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Appropriations Committee
January 30, 2012

[LB901 LB952]

The Committee on Appropriations met at 1:30 p.m. on Monday, January 30, 2012, in Room 1524 of the State Capitol, Lincoln, Nebraska, for the purpose of conducting a public hearing on an agency budget, LB901, and LB952. Senators present: Lavon Heidemann, Chairperson; John Harms, Vice Chairperson; Tony Fulton; Tom Hansen; Heath Mello; John Nelson; Jeremy Nordquist; and John Wightman. Senators absent: Danielle Conrad.

SENATOR HEIDEMANN: I think we're going to go ahead and get started. Welcome to the Appropriations Committee. It looks like it's going to be an interesting and, hopefully, informative day. Looks like it's going to be a little bit longer day, so if we can all cooperate and we can get as much information to the committee as possible, that would be a good thing. We're going to start with self-introductions over to my right.

SENATOR NORDQUIST: Jeremy Nordquist, representative of District 7, which is downtown and south Omaha.

SENATOR HANSEN: I'm Tom Hansen, District 42, Lincoln County.

SENATOR WIGHTMAN: John Wightman, District 36, all of Dawson and Custer County, part of Buffalo County.

SENATOR HEIDEMANN: Right next to Senator Wightman is Senator Danielle Conrad from Lincoln. She will not be with us today. I am State Senator Lavon Heidemann, Elk Creek, Nebraska. To my right is fiscal analyst Liz Hruska. To my left is fiscal analyst Sandy Sostad, and to her left is...

SENATOR HARMS: John Harms. I represent the 48th Legislative District, Scotts Bluff County.

SENATOR NELSON: John Nelson, District 6 in Omaha, central Omaha.

SENATOR FULTON: Tony Fulton, District 29 here in Lincoln.

SENATOR MELLO: Heath Mello, District 5, south Omaha.

SENATOR HEIDEMANN: Right to Senator Mello's left is Anne Fargen, the committee clerk. Our pages for today are Christina and Alex. I just want to stress, we always stress they're great resources, but they are a great resource. Is it a busy day today. If you need anything and you think the pages can help, just ask them. They're always more than willing to help. At this time, I do want to say one other thing. We have a full committee today except for Senator Conrad, who's not going to be here. Some of the

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senators have bills in other committees and will be in and out all day long, but what we have before us is very important. I just want you to know that. At this time, as not to be disruptive later on, if you have cell phones either put them on silent or vibrate so they don't disrupt us later on. I also want to remind you that testifier sheets are on the table or near the back doors. You need to fill out completely and put them in the box on the table when you testify. At the beginning of your testimony, we ask that you would please state and spell your name. Nontestifier sheets near the back doors if you do not want to testify but would like to record your support or opposition, you only need to fill this out if you will not be publicly testifying. If you have printed materials to distribute, please give them to the page at the beginning of your testimony. We need 12 copies. We ask, in the matter of time, that you please keep your testimony concise and on topic. Looking today at what we have before us, we are actually going to use the light system. In an effort to be fair to all that want to testify, the Appropriations Committee will be using the light system. The principal introducer or the principal agency representative will not have a time limit. We do urge even those to keep their testimony concise and on topic. All testifiers following will be given three minutes. On the light system sitting on the testifier table, you will notice a green light when you start your testimony. When you have one minute left, the yellow light will turn on. When the red light turns on, we ask that you conclude your testimony. Following the principal introducer on bill hearings, we take testimony first from proponents, then opponents, then neutral. For agency budget hearings, which we have first, we will take general comments, not in opposition, not for, general comments following the principal agency's representative. We are going to open up the public hearing on LB901. Senator Lathrop.

SENATOR LATHROP: Chairman Heidemann and members of the Appropriations Committee, my name is Steve Lathrop, L-a-t-h-r-o-p. I am the state senator from District 12 and I'm here today to introduce LB901. LB901 would direct funds to individuals who are in need of developmental disability services. Currently, most individuals who need services are put on a list and they wait on that list until the state provides an appropriation for the services they need. There are currently over 2,600 individuals who are on the waiting list. Of those on that list, over 1,700 are past their date of need for services. This means that there are about 900 people who are on the list but not yet at their need of service date. In 2008 the Developmental Disabilities Special Committee made recommendations that the waiting list for the individuals with developmental disabilities be eliminated over the next four years. As a result, legislation was introduced to do that in 2009. In 2009 this committee included approximately \$15 million in the budget to begin to address the waiting list. That was \$5 million in the first year and \$10 million in the second year. According to the Division of Developmental Disabilities, approximately 900 individuals are now receiving services as a result of this funding. These are people who would still be in need of services if the committee had not taken that action. In other words, the waiting list would now be around 3,500 people if funding had not been provided in 2009. In state law there's a statute that says the following: The Legislature finds the present state of appropriations on behalf of the community-based

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services to persons with developmental disabilities are inadequate to pay the reasonable costs of providing such services to all Nebraskans who are eligible to receive them. It is the intent of the Legislature the state pursue full funding of community-based developmental disability programs in a reasonable time frame and that the Legislature commit itself and the state to attaining the goal of providing all eligible persons services by July 1, 2010. While we've made some progress, thanks to the action taken in 2009, we need to continue to move forward and follow through on the commitment made by the Legislature to our fellow Nebraskans. I would add this to the remarks that I've prepared. I appreciate what this committee did two years ago. I hear from people who are on the waiting list and sometimes I think the list...when we passed that bill in 2009, I think the list was about 1,700, and it would have been much larger than that but people had just plain given up on the list. We provided services to 900 people and if we are going to make good on our promise to provide services to those in the community-based services to those with developmental disabilities, it needs to start here in the Appropriations Committee. I would encourage the committee to advance the bill with an appropriate amount so that we can make significant progress this year on the waiting list. [LB901]

SENATOR HEIDEMANN: Thank you for testifying and introducing LB901. Are there any questions? Senator Harms. [LB901]

SENATOR HARMS: Senator Lathrop, thank you for your constant interest in this particular subject that we both have. In regard to the services that are provided for folks who are needing help, what level of services are we actually providing? Do you have any idea about how serious some of the clients are that are needing these kind of services? Do we rank those in any form or manner? [LB901]

SENATOR LATHROP: I think you'll hear from Mary Gordon today who can probably tell you or give you a little more statistical information on the level of care required of those who continue to wait for services, Senator Harms. [LB901]

SENATOR HARMS: Okay. [LB901]

SENATOR LATHROP: And I want to take this opportunity to thank you for your leadership on this issue two years ago. [LB901]

SENATOR HEIDEMANN: Are there any...Senator Hansen. [LB901]

SENATOR HANSEN: Thank you. Senator Lathrop, can you kind of summarize what's available for community services that are available now, I mean, for the waiting list? [LB901]

SENATOR LATHROP: Community services is basically everything someone that has a

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family member with a developmental disability needs, and it can range from residential, like putting somebody in a Mosaic home, for example, or a residential facility, to transportation, to respite care. They get on the list and they have varying degrees of needs. [LB901]

SENATOR HANSEN: But my question would be, what is available? That was my question. Can you summarize what's available for community services now? Isn't that the problem, that we're short of...? [LB901]

SENATOR LATHROP: No, I don't think the problem... [LB901]

SENATOR HANSEN: Okay. [LB901]

SENATOR LATHROP: No, I don't think the problem is...it may be with child welfare. We may be...we may be losing a lot of our providers. I don't think having enough providers is an issue. [LB901]

SENATOR HANSEN: Okay. [LB901]

SENATOR LATHROP: I'm not familiar with it, if it is. [LB901]

SENATOR HANSEN: Okay. [LB901]

SENATOR LATHROP: I think the problem is this making a commitment by the state to put the resources into it so that folks can get the services that are available. [LB901]

SENATOR HANSEN: Thank you. [LB901]

SENATOR HEIDEMANN: Are there any other questions? Seeing none, will you be sticking around to close? [LB901]

SENATOR LATHROP: I will. [LB901]

SENATOR HEIDEMANN: All right. Thank you. [LB901]

SENATOR LATHROP: Thanks. [LB901]

SENATOR HEIDEMANN: We will first take proponents and then opponents and then testimony in the neutral position. Are there any proponents on LB901? Welcome. [LB901]

MARLA FISCHER-LEMPKE: (Exhibit 18) Good afternoon. My name is Marla Fischer-Lempke, M-a-r-l-a F-i-s-c-h-e-r-hyphen-L-e-m-p-k-e, and I'm the executive

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director for the Arc of Nebraska. The Arc is a statewide advocacy organization for people with developmental disabilities and their families, and we have 15 local chapters. The Nebraska providers network has also contacted me to join us in supporting LB901. The Arc strongly believes that people with developmental disabilities have the right to a good quality of life and to fully participate in their communities. Unfortunately, a very significant number of Nebraskans with DD have been waiting for far too long for the services which support those rights. They are waiting for services for which they are eligible. They are waiting for services to enable them to remain in their homes and communities. Thanks to the understanding of the importance of funding the waiting list, this committee appropriated significant funds to the list two sessions ago and it is now funded through 2008. Unfortunately, the list still exists and will continue to grow without being fully funded. We are hopeful that this committee continues to recognize the importance of adequately funding systems so that people who need services and supports can contribute as citizens themselves. In examining the fiscal note, we do not believe that funding the waiting list in its entirety will be as costly as proposed. First, we must acknowledge the changes that have taken place within the DD system in Nebraska. The division has amended its Home and Community-Based Waivers and services to make them more person-centered. When implemented correctly, the person's needs and wants will drive the services they access. No longer does it need to be a situation where the person is supposed to fit the system; the system can fit the person. Using the waivers in such a way helps people in services build real relationships and network with people outside of systems in their community. This will actually drive down costs per person. While it will take time to fully maximize the potential of the waivers, we believe that the fiscal note fails to consider these first steps that have been taken. Even though more people may be using services if the waivers are used as they are intended, it seems that the service coordinator intervention would be less and not more as people become better networked with others outside of services and included in their community. We would like to emphasize how maximizing the new options will really benefit all Nebraskans. The ongoing partnership of many entities has the potential to create an outcomes-based system. By considering the person's goals and interests and necessary supports, we can maximize how people interact with their community. People will be able to live where they want and with whom they want. They also will be able to explore and pursue careers just as people without disabilities. They'll use supports and waivers to get the jobs that they want to have. In turn, people will become contributing members of their community and taxpayers. We need to stop thinking of this as a system that fulfills the needs of the needy; instead, as a system that supports people so they can give back. Overall, we believe great strides can be taken to maximize the use of the new waiver options through funding the waiting list. We understand that many people have begun to successfully use the new waivers that have already come off the list. The Arc of Nebraska is glad to offer any assistance that we can toward this effort if the waiting list is further funded. And I'd be glad to answer any questions you might have. [LB901]

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SENATOR HEIDEMANN: Thank you for coming in today. Senator Fulton. [LB901]

SENATOR FULTON: Thank you, Mr. Chairman. Thank you for being here, Marla. [LB901]

MARLA FISCHER-LEMPKE: Sure. [LB901]

SENATOR FULTON: You talk a little bit about the fiscal note. We have to kind of live off those fiscal notes. What...do you have an estimate as to what the fiscal note ought to be? [LB901]

MARLA FISCHER-LEMPKE: I don't have exact numbers. However, I know that when people use some of the nontraditional options that might be available, that are available through the new waivers, those can be offered at less cost than more traditional options. [LB901]

SENATOR FULTON: Is there a percentage? Can you get us in the ball park? [LB901]

MARLA FISCHER-LEMPKE: Yeah, I don't have exact numbers. [LB901]

SENATOR FULTON: Okay. [LB901]

MARLA FISCHER-LEMPKE: I think, if I remember correctly, the division has published what it costs per hour of the different kinds of services that people are able to have, and so again if person-centered planning happens, they can pick and choose what dollar amounts will fit based on what they actually need. [LB901]

SENATOR FULTON: Okay. Thank you. [LB901]

MARLA FISCHER-LEMPKE: Uh-huh. [LB901]

SENATOR HEIDEMANN: Senator Harms. [LB901]

SENATOR HARMS: Well, thank you for coming and testifying. Yeah, one of the concerns I had when we received this a couple years ago was about the community-based programs and do we have enough...do we have the appropriate community-based programs. I think when we look at urban America it's probably fairly good, but as we move out further into rural Nebraska it becomes more difficult. Are you comfortable with the kind of community-based we've been able to put together? Sum up what I am really asking, do we have enough physicians, psychologists, social workers, psychiatrists, whatever we're going to need, do we have enough available to continue to bring this number down and put them in the real world? [LB901]

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MARLA FISCHER-LEMPKE: I think while what I'm hearing you talking about is more medical supports that someone might need and I think we obviously need to be able to facilitate people accessing those within their communities or using telehealth or different things that are available. But what I'm also talking about is we need to kind of think outside of the box with how people have accessed services in the past. And what the new waivers allow is for people to use nontraditional providers to help them. Rather than having to live in a group home necessarily they might live in their own home and have a friend or someone else be paid to assist them with what they need. It just will look very different. Many states have implemented these kinds of things. It's more of a progressive way to look at service provision and we just kind of need to be a little bit more open-minded with it. [LB901]

SENATOR HARMS: Thank you. [LB901]

SENATOR HEIDEMANN: Are there any other questions? Seeing none, thank you for coming in today. [LB901]

MARLA FISCHER-LEMPKE: Thank you. [LB901]

SENATOR HEIDEMANN: Welcome. [LB901]

BRAD MEURRENS: (Exhibit 19) Good afternoon. Good afternoon, Senator Heidemann, members of the committee. For the record, my name is Brad Meurrens, B-r-a-d M-e-u-r-r-e-n-s, and I'm the public policy specialist and lobbyist for Nebraska Advocacy Services Incorporated, The Center for Disability Rights, Law, and Advocacy. We are the designated protection and advocacy organization for citizens with disabilities in Nebraska, and I am here today in support of LB901. First of all, I'd like to also extend my gratitude and thanks to the leadership on this committee and to Senator Lathrop for taking this issue up. For too many years the Legislature in the past has just repeated promises to provide adequate funding for persons who are waiting to receive developmental disability services via the waiting list. Those previous Legislatures, rather than fully funding services for people on the waiting list, they've responded by just pushing back and kicking the can down the road for the dates that they set for themselves to fund the waiting list. As a result, the number of people waiting for services has grown over time and continues to grow. That's notwithstanding the amount of the influx that was given in 2009, but now is the time to fully capture the momentum that was achieved in 2009 and fulfill the promise to persons who are waiting for years to receive developmental disability services through the waiting list. Our position is very simple and very clear. The state has an obligation to fully fund the waiting list. We recommend that adequate funding be appropriated in LB901 to fully meet this obligation and we also would be happy to work with the Legislature in this regard. I'd be happy to answer any questions you may have. [LB901]

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SENATOR HEIDEMANN: Thank you for coming in today. Are there any questions? Seeing none, thank you. Is anyone else wishing to testify in support, as a proponent, on LB901? Welcome. [LB901]

TERRY KRUSE: Good afternoon. My name is Terry, T-e-r-r-y, Kruse, K-r-u-s-e. I'm the father of Brady Kruse. Brady was 1 of the 47 displaced in 2009 and put into hospitals around the state. I'm here today to support LB901. I want you senators to understand I fully agree with the last speaker. I want you senators to understand that you have families in the state that are making critical decisions about placement and to come to that decision is heartrending for a parent to do that. I took a one-year-old baby four hours from home and put him in the arms of strangers by myself. That's how I placed my son. I can't tell you what I went through to make that decision. Now you saw fit to fund some of this problem two years ago. In North Platte, I ran into a man at a support group for those that have lost a child. That man took care of a 27-year-old daughter from the time...by himself, from the time that child was born and she was just like Brady, not as severe as Brady. Now he had her on the list, the waiting list, for eight to nine years and he got a call after you put some of that money in last, two years ago. He was able to put her into an apartment with periodic care during the day and special care once or twice a week, and that was the happiest that she's ever been. Okay? So that's what kind of good we can do with just a little bit of money, but we as a state and a culture make a commitment to take care of these people. And in '97 there wasn't a waiting list...or '94. Now we face this waiting list and it's getting worse. It's time for us to take care of this problem and get something done with it. You've got families on here that are making those decisions. You had a mother last Thursday in a child welfare hearing testify that she had a daughter that she went everywhere she could think of to place her, and she needed to be placed. She says the best place for her is a home for the mentally and physically disabled, and she could not find placement because we don't have any place for them to go. And we don't have it because we don't have the funding. We need the money. We've got caretakers, caregivers that we can get some support in this to take some of these people, that are looking for placement, off this list. It's about priorities. I listened to three senators in the last session that verbally were pounding their fist on their desk saying, we take care of the people in Nebraska. We don't. This list proves it. It's time to do something about this. I have been involved with this for three years now, going on the third year, and I spent three months getting ready to testify at the first hearing for Senator Lathrop's bill for that money two years ago, and in reading the bill that's when I found out that the waiting list existed, and I was so emotionally distraught I could not even testify, and I had spent three months working on that. I couldn't believe that the state of Nebraska could come to the point where we had a waiting list. And I'm telling you, I'm...from experience, I've been there. I've had to make that decision and it is gut-wrenching to make that decision and then to find out that there's no place for them to go. So I ask you, live up to what has been put in bill after bill that we're going to take care of this problem, the state is going to be responsible for these people, because financially, emotionally, physically, spiritually the

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parents can't do it. They can't do it. It will eventually break them. I thank you for your time. [LB901]

SENATOR HEIDEMANN: Thank you for testifying today, Terry. Senator Mello. [LB901]

SENATOR MELLO: Thank you, Senator Heidemann. And thank you, Mr. Kruse, for your testimony. A couple questions: Would it be safe to say that you see the state providing the necessary services for those with developmental disabilities as a core function of government? [LB901]

TERRY KRUSE: Yes. And, quite frankly, time after time, in bill after bill, the Legislature said that. It's stated. I've got copies right here. [LB901]

SENATOR MELLO: I don't disagree with you. I wholeheartedly agree with you. I think it's a core function of government. I guess my second question is, as you may be aware of, there is a proposal that has been introduced in the Legislature, LB970, that provides roughly \$326 million in tax cuts, 55 percent of them going to the wealthiest 20 percent of Nebraskans. To answer I guess the question is, would that be in a counterproposal in regards to what this committee and other senators need to discuss or wrestle with where you... [LB901]

TERRY KRUSE: Absolutely. If you guys can consider that, knowing that this list exists, can you really do that? Can you consider a tax cut like that when you've got a list sitting right in front of you, a waiting list? These are the people of Nebraska that need the most help. These are the people that a culture should take care of. They cannot speak and they cannot do for themselves. This should be number one priority. Look around the room. Go in, if you take a break, go in the overflow room. These are the people that cannot speak for themselves. And to even consider tax cuts, I spoke today to senators and I told them I'd take a tax increase. If you'll do...I'll take a tax increase if you'll do something about this. I'll help you. And I'll tell you I'm in no position for that but I'll do it. Does that answer your question, sir? [LB901]

SENATOR MELLO: It does. Thank you so much, Mr. Kruse. [LB901]

SENATOR HEIDEMANN: Any other questions? Seeing none, thank you. [LB901]

TERRY KRUSE: Thank you. [LB901]

DON WESELY: Mr. Chairman, members of the Appropriations Committee, I'm Don Wesely, D-o-n W-e-s-e-l-y. I am here representing Nebraska Association of Service Providers. We are community-based developmental disability service providers across the state. We're here to answer a few of your questions about the ability to meet the waiting list need, and certainly our answer is that we can. You're not going to turn the

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switch on overnight. It will take some time to get the services in place, but currently there is some excess capacity in the system as it stands. We have providers who have the ability to take on additional developmental disabilities individuals and provide services immediately and then we can grow from there. The thing I would caution you is that you not come into this lightly, that this is an ongoing expense. There was some money and you took the lead. You put it out there to start dealing with the waiting list. It wasn't done. It was turned back over to the committee and part of the reasoning was the administration felt, well, we don't want to have this ongoing commitment. The budget is tight; times are tough. We understand that. So entering into this issue, you've got to have a long-range view that we're going to do something about the waiting list and we're going to do it on an ongoing basis. Well, we did that in the '90s and you just heard the last gentleman testify. There was a commitment from the Governor, from the administration, and from the Legislature that a waiting list was immoral and that we needed to do something about it. We were able to get the waiting list down to just individuals who didn't need services immediately. There was a waiting list but they didn't need services immediately. They just wanted to be in line later when their children got older and needed the services. So we could do it. We did do it in the '90s. Now that list is so long it's daunting and you're not going to get it done overnight. It's going to take step by step with a long-range plan but it can be achieved. And I'm here to tell you that we have service providers in the community ready to help you accomplish that goal. So I'd be happy to answer any questions you have. [LB901]

SENATOR HEIDEMANN: Thank you for coming and testifying today. Are there any questions? Seeing none, thank you. [LB901]

DON WESELY: Thank you. [LB901]

SENATOR HEIDEMANN: Is anyone else wishing to testify in support of LB901? Are there any other proponents? You're in front of it. Welcome. [LB901]

AMY SVOBODA: Hi. My name is Amy Svoboda. I'm representing the Down Syndrome Association for Families here in Lincoln and I also have a son who has an intellectual disability. He's 19 and we're looking at, you know, two years and in that time we're hoping that the waiting list will be clear. I echo--this is the grumpy part--I echo what the earlier gentleman was talking about, about the shame of having such a huge waiting list. And if I'm right, I'm not sure I'm correct, but I think that it's one of the legal responsibilities for the state to give the kind of services to people with developmental disabilities. And you know people pay taxes. They're responsible for doing that. They sign up for the draft. They pay their mortgage. You know, why doesn't Nebraska do the same thing, take on...I mean deal with their own responsibilities? I mean Nebraska, you know, it seemed like a blink of an eye and suddenly there was \$2 million to pay for the XL's responsibility for them to do their own EIS. We seem to have plenty of money to give to programs that support the demand by Kansas for our Nebraska water. That

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doesn't seem to be a problem, so why is this a problem when you're dealing with individuals that are our own citizens here in Nebraska? So on my positive note, I wanted to--I ran in, that's why I'm sounding funny--on a positive note, I want to talk about, you know, what...one of the main things that I know the Down Syndrome organization is looking for is in the services that are given, and sometimes services is so abstract, is the job coaching, and that's really important. And part of it, I want to let you know that I think you're going to get a big bang for your buck supporting this and I think you should tell your other constituents, I mean your other senators that this is really a jobs bill. The kids coming up in the last 15 years are really more capable I think than any other in really our...thank you...than we've seen really in the last, well, number of years, because they've had special education and they've been accepted into the community. So when you're out...I trust that you all will be generous but when you're out talking to your fellow senators, if you can say this is a jobs bill for Nebraskans. Thank you. [LB901]

SENATOR HEIDEMANN: Thank you for coming in and testifying today. Are there any questions or comments from the committee? Seeing none, thank you. [LB901]

AMY SVOBODA: Thank you. [LB901]

SENATOR HEIDEMANN: Welcome. [LB901]

ALAN ZAVODNY: Good afternoon. Thank you for the opportunity. For the record, my name is Alan Zavodny, A-l-a-n Z-a-v-o-d-n-y. I'm the chief executive officer of NorthStar Services. We provide services to people with developmental disabilities in 22 counties in northeastern Nebraska. And Senator Wesely did a very, very fine job, but I thought it's important to at least give you the opportunity to talk to a provider if you had interest. The one thing I wanted to really emphasize is we have a very little window here. We had a capacity and I know us, as a provider, we were serving close to 400 people at one time and we're closer to 300 now just because of our ability to provide services based on a number of factors, one being the methodology that you've looked at, another being the ability for us to meet needs of people coming from BSDC. Senator Lathrop has invested an awful lot of time in his career in the Legislature here and I think it's really important that we support his efforts here, and we know the impact on families of people as they wait for services. So what you're considering here is very, very important and, as a provider, I wanted to give you the opportunity if you had any questions on what the system could handle as far as capacities. [LB901]

SENATOR HEIDEMANN: Thank you for coming in and testifying today. Are there any questions? Seeing none, thank you. Is anyone else wishing to testify in support of LB901? Is anybody wishing to testify in opposition, as an opponent, to LB901? Does anybody wish to testify in the neutral position on LB901? With that, would Senator Lathrop like to close? [LB901]

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SENATOR LATHROP: I would, and thank you for the opportunity, Chairman Heidemann and members. I looked at the fiscal note on this one and maybe I can take a minute to talk about that. One of the reasons that nothing happened to the waiting list before 2009 was every time somebody asked what's it going to take to take care of the waiting list, we'd get some number. And I know that the number that we got in 2009 was...it was maybe \$143 million or something like that. It was an astronomical number. And this committee invested \$15 million over two years and we cleared 900 out of this... [LB901]

SENATOR HEIDEMANN: The Legislature as a whole invested \$15 million. [LB901]

SENATOR LATHROP: Okay. Yeah, but it started here. [LB901]

SENATOR HEIDEMANN: We would like to take all the credit for it but it was a group effort. [LB901]

SENATOR LATHROP: Well, you deserve a lot of the credit because we never get it until you bring it to the floor. But my point is this, that when we put \$15 million into it we cleared 900 names, and I think the hard list was about 1,700 at the time. So we cleared about half the list out. And what we learned in the process of doing that was...is that people, and I don't want to say gamed the list, but people out of desperation, the reputation of the list was nothing is going to happen so some people never bothered to get on it. Some people got on it when their kids were in grade school, even though all the services they needed were provided at the school, and the list didn't reflect the true list. And for the integrity of the list, if we can catch up we'll find that the list will become a real list. I don't think it's going to take \$63 million to provide the services that we need to the people who are in need, and so one thing I hope the committee doesn't do is it's \$63 million, we can't afford it, let's do nothing. Do something. Do something because I think what you'll find is that we'll take care of a good number of people on the list and if we could...well, I'll leave it to your judgment because it's a balancing act. But I am reminded of something one of the people said when we were doing the BSDC special committee. They said that during good times people want to give tax cuts and during bad times we don't have money for things like these. And I think what we need to do this year is to make this a priority, make sure that we properly funded it so that we make good on the commitment by the BSDC committee to eliminate the waiting list, as a practical matter, after four years. [LB901]

SENATOR HEIDEMANN: Thank you. Are there...Senator Mello. [LB901]

SENATOR MELLO: Thank you, Senator Heidemann. I apologize, Senator Lathrop, for missing your introduction on this bill. I was introducing a bill of my own in another committee. But for the record, I guess it's more of a statement, you clarified a little bit of what I was going to ask in your closing. I do appreciate your call of conscience of not

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only this committee but the Legislature in general, similar to what...the testimony we heard from Mr. Kruse of your work of trying to remind us of our core responsibilities of government to provide these services to Nebraska's truly most vulnerable. And I know on behalf of my constituents and myself, I appreciate it. Thank you. [LB901]

SENATOR LATHROP: Thank you, Senator Mello. [LB901]

SENATOR HEIDEMANN: Senator Fulton. [LB901]

SENATOR FULTON: Thank you, Mr. Chairman. Senator, you were starting to touch on the fiscal note a little bit and I'm not going to pin you down on numbers or anything like that, but I'm just...do you have a sense from your vantage, and you have a vantage that's more...well, informed more in a different way probably than us, so there's a real number that will appear on that list and we're not certain what it is, but by putting some money into the system we get a sense because then people start to populate the list. Are we at a point where we have a hard number of what the list is, in your opinion? [LB901]

SENATOR LATHROP: I think we thought we had a hard number at 1,700 the last time. We were somewhere between 1,700 and 2,000 in 2009, and when they sent letters out to people and said we're prepared to provide you with services, a lot of them said, oh, you know what, I've got them somewhere else or we've adjusted or we don't need them or my son or daughter died. And so what we found is a lot of people said, I got on the list before I needed the services, I'm okay for now, and they got off and then went back on so that they can start working their way up. And what happens when you don't take care of that list is that people start getting on it when they don't need the services. What we have now are 1,700 people that are past their date of need. That's the hard number. If you started to provide services like we did the last time, I think you'd find that probably not all 1,700 would take you up on the offer but a good number would. [LB901]

SENATOR FULTON: What's the...can you get a...I mean 80 percent, 50 percent? And this isn't hard and fast. This isn't an analytical endeavor, but you have a sense of it. When I look at this I see a number and, you know, my eyes get big and wide and, gosh, how are we going to do that, but that tends to be the reaction that we have, and you touched on it. And so it would seem that if we could at least settle on a number that's more realistic of reality... [LB901]

SENATOR LATHROP: Right. I thought Mary Gordon was going to be here today, Senator Fulton, and I don't mean to misrepresent that she was going to be here because she obviously isn't. Let me talk to her and see if we can't get her best judgment, she would know better than I, get her best number on the hard number on the waiting list. I know it's no more than 1,700 because that would represent the top end of the list of people, the people who are on the list that are past their date of need. [LB901]

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SENATOR FULTON: Very good. Thank you. [LB901]

SENATOR HEIDEMANN: Senator Nelson. [LB901]

SENATOR NELSON: Thank you, Senator. Thank you, Senator Lathrop. When you say let's at least do something, do you have a figure in mind that would be a good start here as far as funding? [LB901]

SENATOR LATHROP: Well, I can tell you that when we put \$15 million into it in 2009 we saw 900 people go and receive the care and services that they required. And certainly I think if you put \$15 million into it this next time that you would not end up having people...you'd use it all up. You'd use it all up, in my opinion. [LB901]

SENATOR NELSON: Thank you. [LB901]

SENATOR HEIDEMANN: Are there any other questions, comments? I did want to say that we have a letter in support of LB901 from the Nebraska Planning Council on Developmental Disabilities. (Exhibit 20) Anything else from you, Senator Lathrop? [LB901]

SENATOR LATHROP: Not from me. [LB901]

SENATOR HEIDEMANN: Thank you. [LB901]

SENATOR LATHROP: But if you have other questions, I'm happy to track down any information the committee requires. [LB901]

SENATOR HEIDEMANN: Thank you very much. [LB901]

SENATOR LATHROP: Okay. Thank you. [LB901]

SENATOR HEIDEMANN: With that, we are going to close the public hearing on LB901. And we are going to open up the public hearing on LB952. Senator Nordquist. Welcome. [LB901 LB952]

SENATOR NORDQUIST: (Exhibits 21-22) Thank you, Mr. Chairman and members. I'm Jeremy Nordquist; I represent District 7, which covers downtown and south Omaha. I'd like to start by thanking the families and providers who have both reached out to me, to my office, to support this bill and for those that have sat through today to testify on this bill. There are two letters going around, one from Nebraska Appleseed, one from Voices for Children, stating their support. And they asked me to hand those out in the interest of time, to help move the committee process along. I'll do my best to keep my remarks

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short today, as the stories of the individuals and families that follow me will better illustrate the need for the passage of LB952 and for a stronger role to be played by the Legislature in making policy decisions that affect the care of our most vulnerable citizens. My office, I'm sure as many of yours, has been overwhelmed with letters, phone calls, e-mails, and visits from families and individuals who have...whose lives will be turned upside down if these proposed cuts are put into effect. And I hope that we as policymakers listen to them. They certainly are the experts in their situation, and they know how their lives will be impacted should these cuts go forward. There really are three reasons I introduced LB952. First, the importance of these services to the health of our vulnerable citizens and the importance of the Legislature being part of the decision-making process. These cuts, if you add up both pages of the December 1 letter, will impact over 170,000 Nebraskans. That's not a decision that should be made unilaterally by the administration. That is a significant policy decision. And as the Legislature being the policymaking branch of government, that should be our responsibility to make those decisions. These proposed cuts are devastating to families and will result in greater institutionalization and forcing family members to quit their jobs to attempt to provide care for their loved ones. We've heard that testimony already today; I've heard in letters and e-mails and calls. And the cuts proposed by the Medicaid program, as I said, reflect a significant policy change, by eliminating critically important services. From the contacts that have been made to my office, many of these individuals will be forced out of their homes, family members will have to quit their jobs and obtain public assistance to be able to care for their family members' healthcare needs. And third, I don't see a budget justification for these cuts at this time. Spending in Medicaid has been so controlled that the Governor has found \$12 million in savings in our current healthcare safety net, between Medicaid and CHIP, over the next couple years to pay for proposed tax cuts for the wealthy and for corporations. Colleagues, a budget is a moral document. And it's unconscionable for us to pay for tax cuts that benefit largely the wealthy by pulling the healthcare safety net out from vulnerable Nebraskans. You can see in the bill the laundry list of services that will be cut. And by Medicaid's own accounting, as I said, 170,000 clients would be impacted. That's 74 percent of the entire Medicaid population. I believe this makes it one...a decision that the Legislature needs to be actively involved in. But I also think that these cuts are a significant step backwards in the system of care we've created for the children, the disabled, and elderly. I have no doubt that with some of the home health, private duty, personal assistance, and nutritional support services that are currently being provided in the home and proposed to be cut back or eliminated, transition to institutional care will result. In this year's Medicaid annual report, it says, quote: Efforts to encourage home- and community-based alternatives to facility-based care are resulting in a gradual rebalancing of long-term care expenditures. Without enacting this bill, without stopping these cuts, I think we're going to fall backwards into more institutional-based care. The program, the Medicaid program, will probably argue that people who need services will be able to receive them under different programs. I don't know exactly how we would do that and how we're going to save the millions of dollars that are projected. Those dollars

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mean lost services. It means vulnerable citizens will suffer. It means that we will make life more difficult for families who are already in these difficult situations. And I certainly am not willing to put more vulnerable Nebraskans into a fragmented system of case management. We've seen that in other areas of Health and Human Services. I'm not willing to put this population into what's been called a fragmented system of case management. LB952 will protect our most vulnerable citizens. It'll allow the Legislature to affirm that this is our will, and as a policymaking body of our state, to provide high quality of care for the most vulnerable citizens and families. And I urge you to support this legislation. Thank you. [LB952]

SENATOR HEIDEMANN: Are there any questions for Senator Nordquist? And I think it was Kerry Winterer's testimony; he said that there are surrounding states that don't do as much as that we do. Have we looked in to see how that plays out in the surrounding states? [LB952]

SENATOR NORDQUIST: I haven't. But I think we had a little bit of that discussion on our Health and Human Services budget. And at least those experts I asked about that just indicated to the committee that they didn't see that in their experience. But I certainly would be willing to request more data from the department on that. [LB952]

SENATOR HEIDEMANN: Okay. Are there any other questions? Seeing none, thank you. [LB952]

SENATOR NORDQUIST: I will be here to close. [LB952]

SENATOR HEIDEMANN: You will be here to close. [LB952]

SENATOR NORDQUIST: At 9:00. (Laughter) [LB952]

SENATOR HEIDEMANN: We will begin to take proponent testifiers on LB952, and then we will take opponents and then testifiers in the neutral position. At this time we will take proponents. We will be using the light system once again. [LB952]

KEN NELSON: (Inaudible) and everyone. My name is Ken Nelson, K-e-n N-e-l-s-o-n. I am (inaudible). And I support the bill LB952. I have to have Medicaid because they pay for my medication that I take daily. They pay for people to help me get up for the day, (inaudible) eat meals. And they put me to bed. They also pay for people to prepare the meals. They also pay for me to go to the doctor when I am sick, and as you can see, I wear glasses and so I have to go to the eye doctor every year. They pay for transportation for me to go to the doctor and back home. They pay for me to go to the dentist. Home health has made a huge difference in my life, because if it wasn't for home health, I would not be able to volunteer for the community. And if you let Medicaid go, people like myself are not going to be able to do what we do now for the community.

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My question for you all is, do you want to have that happen? And I'd like all of you to know that I (inaudible) I am a human being. I am not a dollar sign. That's it. [LB952]

SENATOR HEIDEMANN: Thank you very much for coming in and testifying today. [LB952]

PAIGE DENMAN: (Exhibits 23-25) Hi. [LB952]

SENATOR HEIDEMANN: Welcome. [LB952]

PAIGE DENMAN: My name is Paige Denman, P-a-i-g-e D-e-n-m-a-n, and I am here and I am passing out testimony from myself and also from my sister and brother-in-law that had to leave. My nephew couldn't wait any longer; he can only go so long. Quite honestly, I came with a written statement, thinking that all I would do was hand in a written statement, unless I got mad enough to stand in line and wait and talk. And I got mad enough to stand in line and wait and talk. I wish that you guys could have heard in the overflow room when Director--I can't say the last name--Chaumont said, maybe people need 24-hour support that receive the in-home nursing care. Holy moly! We just heard a physician testify about her own son and needing support. I can't...my sister and brother-in-law receive that support for my nephew. I want you to imagine for a second what it would be like to have in your home at night when you sleep somebody awake, a person that's not a member of your family awake in your home. And not only are they awake in your home, but they are keeping your child breathing. Now, think about that for a minute. You're parents; you're grandparents. They're keeping your children breathing. The directors talked about having home assistants that could come in and do the care for the nursing staff who only wanted the dollars. Oh, my goodness, if I could yell out and be so offended, I would have. To say that the nursing staff that keep my nephew alive are...it's about money? Are you serious, that they would say that his needs are more than they actually are, because of money? You know, my sister and brother-in-law owe their entire lives, as you'll see by their statement, to having the nursing care. You know, there's 341 families, according to the bill, that would be affected by that. You're seeing some of them here. These are not people who take these situations lightly. They don't want to push their family member with health issues off on someone else. They don't want to give them away and run away; they don't want to drop them at the hospital and leave. They want to keep them at home, and they want to care for them. They don't need a service coordinator that tells them what to do for their own child. They just need some help. And they need nursing care. I've been working with folks with developmental disabilities for more than 26 years. I care for two ladies with disabilities, in my home. I don't feel comfortable taking care of my nephew. I'm not a nurse, and he needs nursing care. It scares the living daylights out of me if I'm in a position where, you know, I might have to take care of his trache. I'm not a nurse. I'm a master's-level therapist, and I'm scared to take care of my nephew. So, I mean, you'll hear it; you'll hear it from a bunch of folks. And I jumped up here to give three people's worth of testimony real quick

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before it turns red. But you just have to know that in my family it's not unusual for Christmas to be spent with Jake (phonetic) at the hospital, in the ER. It's happened...in the 15 years that he's been alive, it's been four times that I can think of off the top of my head, where Christmas Day is: Jake is sick, we better take him in, or he's at the hospital now. Unless you live with that, you have no idea. You're going to hear it again and again. Please don't let those people down. [LB952]

SENATOR HEIDEMANN: Are there any questions? Seeing none, thank you. [LB952]

PAIGE DENMAN: Thanks. [LB952]

SENATOR HEIDEMANN: Welcome. [LB952]

ROXANN HAMILTON: I'm Roxann Hamilton, R-o-x-a-n-n H-a-m-i-l-t-o-n. I live here in Lincoln, Nebraska, and I'm asking the members of this Appropriations Committee to pass LB952, as I believe that an emergency exists if it is not passed. I'm asking that the members of this Appropriations Committee table 100 percent of the proposed short- and long-term Medicaid budget cuts by Ms. Vivianne Chaumont, as they don't conform to LB709, 2005, requiring persons on Medicaid having the responsibility, to the extent that they are able, to contribute to the cost of their healthcare, nor the intent of the Medicaid Act 42 U.S.C. 1396a(a)(19), requiring each state's Medicaid program to be administered in the best interests of the recipients of Medicaid. Ms. Chaumont's proposal does indeed pose an emergency situation in the great state of Nebraska for thousands of elderly and disabled adults who live here, just like me. And this is my impact statement of how Ms. Chaumont's proposed Medicaid cuts would affect me. I would become further seriously ill, require greater and more extensive and expensive healthcare or long-term healthcare placement, or probably, and very well likely, die as a result of the proposed changes to Medicaid. I'm 63 years old. My income is now \$700 per month from Social Security. Medicare is my primary health insurance. Medicaid is my secondary health insurance. I have multiple life-threatening comorbidities, and these include insulin-dependent diabetes, high cholesterol, high blood pressure, Alzheimer's disease, history of strokes, heart disease, history of heart attacks and heart surgeries, precancerous colon polyps, glaucoma, macular degeneration, asthma, chronic and severe mental illnesses, periodontal disease, massive abdominal herniations that are not operable, and as a result my intestines are under my skin, outside my abdominal cavity. I also have a partially blocked bowel, due to adhesions, and morbid obesity. In 2011 it was medically necessary for me to have 280 prescriptions filled, using nine to ten different doctors and specialists, between 1 and 24 visits each, and be hospitalized several times and have surgery two or three times. I was in the ER maybe five or six times. If Ms. Chaumont's current proposed Medicaid cuts were to be approved, I would not be able to afford the copayments or other costs to obtain the medical care that keeps me alive and living independently. My health would rapidly deteriorate to the point of my debilitation and death. The Medicaid proposed cuts by Ms. Chaumont would

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cause an undue endangerment, financial hardship, frustrate and deny access to medically necessary care for the great state of Nebraska's most ill, fragile, and impoverished citizens. At the bottom of Ms. Chaumont's Health and Human Services official letterhead, it is stated: Helping people live better lives. And let this, please, ring true and not allow Ms. Chaumont's Medicaid changes to be a painful death sentence to our most vulnerable and fragile citizens. And if you have any questions that I could answer, I'm more than happy to clarify information. [LB952]

SENATOR HEIDEMANN: Are there any questions for Roxann? Seeing none, thank you. [LB952]

ROXANN HAMILTON: Thank you. [LB952]

STEVE WALLINE: (Exhibit 26) Just a moment to park here. I'll try to get straight with the microphone. Thank you, sir. Mr. Chairman, members of the committee, my name is Steve Walline, S-t-e-v-e W-a-l-l-i-n-e, and it's a pleasure to be able to speak to you today. I have several documents that I've handed out to you, and I'm going to try to paraphrase some of them and speak to others. So I used to be a teacher. I have a degree from the University of Nebraska at Kearney. I'm a proud former resident of Kearney; I live in Lincoln now. What I have to talk to you about in this short time is a little bit ominous. It seems like in the last two years there's been a concerted effort by the long-term care department, under Director Chaumont, to put people that don't necessarily need to live in nursing homes at least out of their normal independent, living-at-home cycle. In 2010 she delivered some five dozen recert notices to residents of the state of Nebraska. During the recert notice it explained what their rights were, it explained the process of appeal. Now, I've been on a lot of services with the state and federal government, and I've read a lot of appeal notices. And I've never read an appeal notice that said: If you choose to appeal and your appeal is turned down, you may have to pay for the hours during the time that your appeal was in process. Now, to me, this is intimidation. My state senator, Ken Haar, and Mrs. Conrad wrote him a letter, and several other senators...I mean, they wrote Director Chaumont a letter, excuse me--several other senators agreed to the letter--asking her a variety of things, asking her about if she had the authority, where did QUALUS get the authority, how did this happen, what was going to happen? Subsequently to them writing that letter, I led a group of wheelchair people around the Governor's Mansion in kind of a march. Maybe some of you folks remember that. I was the one that happened to cook it up, but my friends were there with me, like Kenny and everybody else that you're going to hear today. I think somebody ought to refer it to whoever, that you guys should know that taxpayers are being intimidated by heads of departments so as not to appeal decisions. After Chaumont got the letter from Senator Haar and Senator Conrad, suddenly she retracted the recert letters. She said there was confusion; she said there was misunderstanding. No confusion or misunderstanding on my part. I knew exactly what she was trying to do. I receive home health in Lincoln from one of the best companies in

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the city. Without it...I have been on the PAS program before, in Kearney. I lived in Kearney with my own home-health aides for two and a half years and would still be living there now except for the fact that the system fell through. We couldn't get coverage. The only names were on a list at the courthouse. I heard Director Chaumont say they can deliver that service for half of what it costs to get it from home-health aides. That is not true. The agencies have been cut. In 2010 Director Chaumont redid how they pay. They used to be paid on a visit basis; now they're paid on an hourly and even a quarter-hourly basis. So this idea that she's going to be able to deliver care to us at half the price...it's like that CarMax commercial you see on TV: the guy keeps trying to sell the used car, and the person says, show me the CARFAX, or whatever it is. That's not going to happen. And there are several other things I'd like to talk to you about. I had an analogy there with Senator Callahan, I mean, excuse me... [LB952]

SENATOR FULTON: Wait a minute. [LB952]

STEVE WALLINE: ...Coach Callahan. [LB952]

SENATOR FULTON: Not Senator Callahan. [LB952]

STEVE WALLINE: Not Senator Callahan. (Laughter) Excuse me, Senator Fulton. Coach Callahan, when he was here and he thought he was going to bring in his fast California offense and all this streamlined stuff. And he didn't have "Husker culture," I called it. Here in Nebraska, you know, the signs at our borders say "The Good Life." And as I said in my statement, let's make sure "The Good Life" doesn't say, "If You're Healthy," underneath it. And being a teacher, I would love some questions. [LB952]

SENATOR HEIDEMANN: Are there any questions? Senator Nordquist. [LB952]

SENATOR NORDQUIST: I got an easy one for you. How many years have you lived in Nebraska? [LB952]

STEVE WALLINE: Well, I'm 62, and I lived 8 of those in Houston, so that would be 54. [LB952]

SENATOR NORDQUIST: Okay. Thank you. [LB952]

SENATOR HEIDEMANN: Seeing no other questions, thank you for testifying. [LB952]

STEVE WALLINE: Okay, thank you. Thank you, folks. [LB952]

SENATOR HEIDEMANN: I do ask that, in a matter of time...and your applause is almost a commentary, which is something we don't normally accept in Appropriations. We don't accept booing or applause. So if you could keep that down, I would appreciate it.

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[LB952]

MARTY FATTIG: (Exhibits 27-29) Senator Heidemann and members of the Appropriations Committee, I also...I have testimony, written testimony, that is being passed around. I also have a letter from the Lexington Regional Health Center in Lexington, the CEO there, Leslie Marsh, and also a letter from the Madonna center here in town, Victor Witkowicz. And you'll be receiving copies of those letters as well. And in the interest of time, we will not present those. Senator Heidemann and members of the Appropriations Committee, my name is Marty Fattig, M-a-r-t-y F-a-t-t-i-g, and I'm the administrator and chief executive officer of Nemaha County Hospital in Auburn. And I come here in support of LB952, representing Nemaha County Hospital and the Nebraska Hospital Association. LB952 was introduced in response to one more of DHHS's actions that, if allowed to take place, would significantly and negatively impact the public program beneficiaries. In a letter to the Legislature dated December 1, 2011, that was subsequently amended to a second letter that was dated December 16, 2011, the Director of Medicaid and Long-Term Care outlined the proposed potential cuts of about \$60 million that included things that you're aware of, and I won't read those to you. Continual cuts to Nebraska's benefits programs and those who provide services are counterproductive to the health and productivity of those who desperately need those services. On average, Nebraska's hospitals are currently reimbursed at 28 percent below their costs for taking care of Medicaid patients. And in 2009, unpaid costs of providing Medicaid services in Nebraska hospitals exceeded \$130 million. In addition, the Patient Protection and Affordable Care Act expands Medicaid eligibility in 2014 to 133 percent of the federal poverty level for nonelderly, which includes parents, children, and childless adults. Those financial realities, coupled with more potential Medicaid cuts from the federal level, are exerting enormous pressures on hospitals that evaluate what services they will provide in years to come. Recent headlines across the state have indicated that other providers, especially physicians and dentists, are questioning how much longer they will accept Medicaid patients. And some are considering the same for Medicare. Most hospitals in Nebraska, of course, are rural hospitals--I expressed that to you earlier--and I urge you to think of rural hospitals when you look at supporting this legislation. We have to be able to recruit doctors and dentists to rural communities. And cuts to these providers would definitely be counterproductive there. Continual cuts to the Medicaid payments to providers will unravel the state's healthcare provider network and will adversely impact the availability and quality of healthcare for those who desperately need it. Contrary to the proposed changes, the NHA and I request that the Legislature place a priority on investing in the physical and mental health of Nebraska's low-income individuals. Healthier people make better students, employees, and families. Funding Nebraska's Medicaid program should be viewed as an investment in our state's overall productivity potential. A healthy and prosperous Nebraska will be greatly enhanced if appropriate care is provided at the appropriate time. Taking bold steps in this direction, the NHA and I request that the Legislature oppose the cuts outlined in the December 2011 letter by the Director of Medicaid and Long-Term Care

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by supporting LB952 and advance it to General File. On behalf of Nemaha County Hospital, the Nebraska Hospital Association, and rural hospitals throughout the state, I appreciate your time and attention to this very important issue. Thank you. [LB952]

SENATOR HEIDEMANN: Are there any questions? Senator Mello. [LB952]

SENATOR MELLO: Thank you, Senator Heidemann. And thank you for presenting additional testimony on LB952. It's similar to a question Senator Nordquist asked. Are you seeing--if you can speak about your experience in maybe the Nemaha County Hospital--are you seeing people from outside of Nebraska coming to your hospital requesting to sign up for Medicaid to receive our Medicaid services through your county hospital? [LB952]

MARTY FATTIG: Thank you for asking that question. I think it's important to note for those of you from western Nebraska, where I grew up, Nemaha County Hospital in Auburn, we sit 12 miles from Missouri, about 20 miles from Iowa, and about 30 miles from Kansas. We would be in a perfect position, if this were the case, to see increased numbers of Medicaid beneficiaries from all of those states. And it is not the case. It's just not the case. [LB952]

SENATOR MELLO: Thank you. [LB952]

SENATOR HEIDEMANN: Are there any other questions? Just out of curiosity, following up on his question, and this is more curiosity than anything else, if they actually move here and establish residency, how can you actually tell that? [LB952]

MARTY FATTIG: Then I would not know. Then I would not know. But when we look at their prior history, Senator Heidemann, we're not seeing a prior history of seeing doctors in Kansas or seeing doctors in Missouri or seeing doctors in Iowa. [LB952]

SENATOR HEIDEMANN: Okay. It could happen, though, I mean. [LB952]

MARTY FATTIG: Oh, it could happen. But, like I say, when we look at the prior history, where do you get...you know, bring in your medical records, it's not indicating that that is the case. [LB952]

SENATOR HEIDEMANN: Okay. Thank you. This...any further questions? Thanks, Marty. [LB952]

MARTY FATTIG: Thank you very much. [LB952]

SENATOR HEIDEMANN: Welcome. [LB952]

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SCOTT WOOTEN: (Exhibit 30) Thank you. Senator Heidemann, members of the Appropriations Committee, thank you again for allowing me to testify and spend time with you today. I know it's been a long one. I'm Scott Wooten, senior vice president and chief financial officer of Alegen Health. And I want to thank Senator Nordquist for introducing LB952, which addresses critical issues to the Medicaid program for...which are of significant import to Alegen Health. And we come here today to give support to LB952. We're deeply troubled by the December 1 proposed cuts by the director. We believe these cuts will limit access to very essential, basic preventive healthcare, primary care, and will cause Medicaid patients to wait until their need is so urgent that they'll be forced to access healthcare in a much more costly manner, in the emergency room and at much higher acute levels. We also believe this matter is so important that it should be decided by our elected officials. You'll notice a theme in my comments, and that is a theme of an ounce of prevention. And I would like to just cover four of the items in the proposed cuts with you today, the first one being the proposed increase in copay for nonemergency visits. It's our opinion that this proposal will have little or no incentive to keep individuals, clients, from using the emergency room for nonemergent reasons and will simply increase the costs of Medicaid and cost-shift to providers. Secondly, the proposed limit to behavioral therapy to 60 visits per year. As we visited previously, in prior testimony, we do not support any additional reductions to behavioral health. The needs are tremendous, and the safety net is very thin. Thirdly, the proposed limit to prescription drugs to ten per month for adults. We've heard testimony, very moving, already to that effect and the significant impact that would have on individuals who are critically ill, seriously ill, and particularly the mentally ill. It's one of the top reasons readmissions occur and individuals are required to go into a higher cost of care, is lack of appropriate and adequate medication, largely because of cost. We encourage you and the director to approach this with caution. We believe it's shortsighted and a one-size-fits-all strategy to attempt to eliminate costs, when, in the end, we believe there will be exponential cost increases downstream as a result of this. The last item, the reduction in allowed days to 45 days, we believe that over 42 percent of this will impact the patients at Alegen Health. Of that, approximately 72 percent are behavioral health patients. This is a behavioral health limit in benefit, and it will do nothing more than exacerbate the current process of reducing payments to providers, and it will result in the reduction and the closure of facilities and access points for this critically necessary care in our community. We ask you as a committee to reject the proposed cuts. We support the proposed LB952. As we look for cost savings, we want to propose solutions, and we stand by with you to explore those solutions. We would encourage increasing access to primary care. We would encourage increased transitions of care to decrease the fragmentation of care. We would increase the sharing of information regarding quality and safety of care, which will result in cost savings. Additionally, personal incentives for living healthy and choosing a healthy lifestyle are clear cost-saving mechanisms which we encourage you to consider. The director's proposal does not embrace that, nor does it begin to shift to the import of increasing access of care, as healthcare reform would require all of us to do. Again, very important issue,

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and as our elected officials we appeal to you to champion this cause and make the decision as an elected body. Thank you for your time. And if you would like to visit, I'm at your disposal. [LB952]

SENATOR HEIDEMANN: Are there any questions? Seeing none, thanks... [LB952]

SCOTT WOOTEN: Thank you. [LB952]

SENATOR HEIDEMANN: ...for coming in and testifying. [LB952]

JENNIFER CROMWELL: (Exhibit 31) Good afternoon. [LB952]

SENATOR HEIDEMANN: Welcome. [LB952]

JENNIFER CROMWELL: Thank you. My name is Jennifer Cromwell, J-e-n-n-i-f-e-r C-r-o-m-w-e-l-l. I am here today as a home-health nurse and a taxpayer. I have many concerns regarding the proposed Medicaid budget cuts, but I would like to elaborate on just one of these at this time. It is my understanding that Director Chaumont is proposing private caregivers can replace nurses in the home healthcare setting. Under current Nebraska law, in order to work in any healthcare setting, whether an institution or at home, a Nebraska nursing license is required. Obviously, there is reason this law is in place. We as nurses have a minimum amount of schooling we must undergo. It is because of our experience, knowledge, and training that we are able to handle medical emergencies and implement the proper interventions. It would be detrimental and dangerous to have anyone other than nurses to take care of this disabled population. It would put at risk the most vulnerable in our society. Many of these patients have ventilators, tracheostomies, gastrostomy tubes. These patients are not acutely ill enough to be in an institution but still have complex medical situations that require proper professional, medically trained staff. I've asked a few parents of some of my specific patients the amount of time it took for them to feel that they could safely and comfortably take care of their child, without having any kind of previous medical background. Their answer, unanimously, was several months. Some of them said it took a year; some still are not comfortable completely doing everything it takes to take care of their child. It is my understanding that it's proposed any person can be trained, at most, a few short hours to take care of these people. I adamantly disagree. I have seen emergencies where if a nurse had not been present and educated on how to make the correct intervention, these patients would have lost their lives. One instance comes to mind in particular. A toddler who was ventilator-dependent was fine and stable at the beginning of the shift. Within five minutes, her oxygen saturation dropped from a normal 95 percent to a life-threatening 47 percent. Her color went from a rosy pink to a terrifying bluish gray. It is hard for me to believe that the average, untrained person would know what to do in this situation. As a nurse, this is what we are in the home setting for, to keep these patients stable and bring them back to a, quote unquote,

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normal state of health. I've been told it takes a special kind of person to be a nurse. This person needs to be cool under pressure, focused, have a genuinely compassionate heart. I disagree that any random person can do the tasks included in this job. Whether it's knowing these patients on a personal level in order to meet their individual needs or distinguishing between the various clinical symptoms that could reveal an underlying problem, not just anyone can do this. Professionally educated, experienced, trained people need to be in place in order to provide the quality of care needed by these patients. So in closing, I present to you two questions. Would any of you feel safe or comfortable taking care of these disabled patients with only a couple hours, at most, of training? Or would you want someone with little or no medical training to care for you or your loved ones? I thank you for your time and giving me the chance to voice my concerns. [LB952]

SENATOR HARMS: Thank you very much for your testimony. Do we have any questions? Seeing none, thank you very much. [LB952]

JENNIFER CROMWELL: Thank you. [LB952]

JOLENE KOTSCHWAR: Thank you, Senator Nordquist, for proposing... [LB952]

SENATOR HARMS: Welcome. Welcome. It's okay. [LB952]

JOLENE KOTSCHWAR: ...thank you, Senator. I come before you as a mother, a single mother, as a RN... [LB952]

SENATOR HARMS: Would you spell your name, please? [LB952]

JOLENE KOTSCHWAR: Yes, K-o-t-s-c-h-w-a-r. [LB952]

SENATOR HARMS: Thank you. [LB952]

JOLENE KOTSCHWAR: I come before all of you as a mother of a total-care son; I'm also a single parent; and I'm also a registered nurse; and I'm also a nurse educator. There's many factors here that need to be examined and looked at. And it's not just nurses that can take care of my son, because I also work. They have to be experienced nurses that keep him out of the hospital, and it's averaging less than one time a year, due to this. Reading the letter from the Department of Health and Human Services, it was quite...contraindicates the mission statement. I really am trying to find why this letter came from the Department of Human Services. The mission statement is, and I'm sure you're all aware, but just to remind us: The Department of Health and Human Services is the United States government principal agency to protect health and provide essential human services to Americans, with emphasis on those least able to help themselves. The department provides services that protect and advance the quality of

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life to all Americans. That's why it's kind of ironic that this letter originated from the Department of Health and Human Services. The cuts that have been proposed will set society back at least 150 years, back to Florence Nightingale's era. And in that era, she came across the problems with the laypeople trying to take care of these people. So that's why, with all the many healthcare needs, that's why the first school of nursing was devised, greater than 150 years ago, for this very problem that we're discussing today. Acuity is now higher than ever. I've been a nurse over 30 years, and acuity that is coming into the home is much higher than ever before. Even if you hear me say the impact this would have on my son and my family...and I don't even know; I'd have to stop work. There's much evidence-based practice out there; there's much research out there. There's one from the journal for Healthcare Quarterly, had a large database, 59,000 patients. And they examine better outcomes, more efficient use of resources, and lower costs of healthcare. There's many studies that have proven this already. So it's kind of, in a way, sickening to have to read these cuts and ignoring these quite significant research out there. They examine hospitalizations, the use of emergent care, and improvement in activities of daily living. There's much...also, even the Institute of Medicine also supports research in looking at keeping these patients out of the hospital and with a quality of life that society is now at. Thank you. [LB952]

SENATOR HARMS: Thank you very much for your testimony. Do we have any questions? Thank you very much. [LB952]

THERESA FITZGERALD: (Exhibit 32) Good afternoon, Senators. This has been a long day, and I don't want to be the one that holds everything up so I'm going to be as brief as possible. My name is Theresa Fitzgerald, T-h-e-r-e-s-a F-i-t-z-g-e-r-a-l-d. I'm the founder and CEO of Children's Respite Care Center. CRCC is licensed as a children's day health service. We provide an array of specialized services for children with medical, developmental, and behavioral disorders. We're an independent, small, nonprofit agency. We don't have an association or an alliance or an affiliation; it's just us. And I may be testifying as an organization, but I've been an advocate for the families that we've served for the past 22 years. And I don't think one can have this debate without including both the individuals and the service providers, because there must be providers in order to meet the needs of the individuals. So having cost-effective community-based services such as CRCC really is a win-win for the state and for the people that we serve. We really do support families' abilities--and you've heard it today over and over--to care for and have access to services that maintain the child in the home. It allows parents to maintain meaningful employment, thus being self-sufficient taxpayers. And we really do offer a low-cost alternative to residential or institutional care. If these community-based options are gone and more costly care is needed, state expenditures increase, not the proposed shortsighted savings. And as an organization, we employ 120 people. And we contribute to the economy, just as any operating business would. We were recognized as a needed and valued service by the department 22 years ago when we opened. And because of our unique service mix,

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Medicaid kind of categorized us under private-duty nursing/medical day care and created a billing code specifically for us to use. Only us and one other agency in the state use this billing code, and it's only for children's services. This code is included in the proposed Medicaid cuts. In the recent past, provider rates have been frozen and now reduced 2.5 percent. Eliminating private-duty nursing results, for us, in another 10 percent reduction in revenue. And while all our other expenses tend to increase, that shortfall is going to be very hard to sustain. And speaking for my agency, we're not in it for the money, but we do have to keep the lights on. The one thing I will not do is sacrifice the quality of care. And the department stated quite recently that these kids can get the services through the waiver program. And we are an A&D Waiver provider as well as a straight Medicaid provider. But the process and the eligibility criteria would not result in all these kids being eligible for waiver. And the number of children is limited; it's finite; there's only so many slots available. And that's a control mechanism that the department has and understandably uses. Bottom line, there's not nearly enough slots available for the all the kids that this would affect. And I just wonder, if the criteria truly would allow all these kids to be on waiver and there is an advantage to the department, why hasn't it been done previously? You know, during tough times for our state, providers kind of all took one for the team. But the state budget is in good shape; tax revenue projections are ahead; and we've got a good Cash Reserve. Why are we doing this now? Overall, the proposed cuts would have detrimental effects for children, families, and communities all across the state. It's quite likely some service providers will be forced out of business. And then since choices for services for special-needs kids are limited anyway, this would really reduce the options for quality care and services for the ones who need it the most. You know, I was born and raised in Nebraska; I've lived here all my life. And I tell people I meet from all over the country what a great place to live this is. And they ask me why. And I tell them about the people, about the quality of life, about what a great place this is to raise your kids. What does this say about our state's priorities in caring for the most vulnerable of our citizens? Just let's not go backwards. So I ask that you just show that our state has its priorities in the right order. Thank you for your time and attention. [LB952]

SENATOR HARMS: Thank you for your testimony. Do we have any questions? If not, I thank you. Before we go any further, we have people who would like to testify who are in wheelchairs. And so as the Chairman, I have that prerogative to have them come in and testify. I apologize for that, but it's something we need to do. So thank you much for your kindness, appreciation. Thank you. [LB952]

JONI THOMAS: Good afternoon, Senators. [LB952]

SENATOR HARMS: Welcome. [LB952]

JONI THOMAS: Thank you. I appreciate this time. I come in support of LB952 from the perspective of a professional point of view. [LB952]

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SENATOR HARMS: Excuse me, would you... [LB952]

JONI THOMAS: Oh, I'm sorry. [LB952]

SENATOR HARMS: ...give us your name and spell it for us. We'd appreciate... [LB952]

JONI THOMAS: My name is Joni Thomas, J-o-n-i T-h-o-m-a-s. I was so anxious to get going that, you know... [LB952]

SENATOR HARMS: Thank you for your kindness. Don't worry about that. [LB952]

JONI THOMAS: I come in support of LB952 from the perspective of a professional point of view and a personal point of view, because these cuts outlined in the December 1 Department of Health and Human Services letter would drastically impact consumers served by our agency and myself personally. As the executive director of a center for independent living, we represent consumers throughout a 39-county area, with nine senators representing those consumers. We serve individuals who experience disabilities of all types and across the life span. We provide services and supports to assist them to remain independent in the community or transition from a nursing facility back to the community. We provide information and referral; advocacy, where we assist them in applying for Medicaid, SSI, SSDI, and other public benefits. We provide peer counseling and independent living skills training. These cuts would drive consumers either back to institutions or onto a waiver program, which...then my question is, what happens when the waiver slots are full and there's no more space? Or is the state going to apply for more waiver slots? So many who use personal assistance services would also not qualify for the waiver, but yet they still need those supports in their home. So they would then be forced to go back into institutions, without the daily assistance of that personal assistant. From my personal perspective, let me say that I support LB952 because I am one of those consumers who would be dramatically impacted by those proposed cuts. Just to give you a real-life example, I receive home-health aide service from a local agency, and I also have a PAS provider. It is true that I would most likely be eligible for waiver services; however, again, what happens when they're full, and what if they were full at that time? I work full-time as an executive director. I teach at Grand Island Community College as an adjunct instructor and have a direct-sales business. I own a new home that I built four years ago. I drive my own car that I was able to purchase. I pay taxes. I buy large-ticket items. I support local restaurants way too much (laughter) and provide employment opportunities for those who work for me, for my aides and for the endless...and I tire of the endless need to brag about those accomplishments just to justify my existence and my need for Medicaid. I realize the economy isn't that great; however, taking those supports away from people who are contributing makes little sense to me and those I represent. Our agency would be honored to work with the Department of Health and Human Services on improvements

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to the Medicaid program. And I ask you to move forward LB952. And any questions, I would be happy to answer. [LB952]

SENATOR HARMS: Thank you for your testimony. Do we have any questions? Seeing none, thank you. [LB952]

JONI THOMAS: Thank you. [LB952]

THAYER RADWAY: My name is Thayer Radway. [LB952]

SENATOR HARMS: Welcome. We're happy to have you here. [LB952]

THAYER RADWAY: T-h-a-y-e-r R-a-d-w-a-y. [LB952]

SENATOR HARMS: Thank you. [LB952]

THAYER RADWAY: I have lived in my own home since March of '98. And I have had (inaudible) nursing agency, and I've also had mostly private-duty nurses that take care of me; I have 24-hour care. Sorry, my voice is really raspy. [LB952]

SENATOR HARMS: You're doing fine, just relax. Thank you. [LB952]

THAYER RADWAY: I just really (inaudible) in my own home. And I was at Madonna for two years. Right after my accident and since I was living in my own home, things were really good. And it's good to have my own caregivers, and it's good that, I think, for them, because they get good experience taking care of me. And I know that it's a lot less expensive having me at home than it would be if I was in a facility. (Inaudible.) Yeah, Dad. [LB952]

SENATOR HARMS: Thank you for your testimony. Do we have any questions? If not, thank you. Appreciate it. [LB952]

JOHN RADWAY: Senator Harms, I'm his father; can I just add a couple of comments, please? [LB952]

SENATOR HARMS: You sure may. You sure can. Would you please give us your name and spell it... [LB952]

JOHN RADWAY: Sure. I... [LB952]

SENATOR HARMS: ...spell the name for us, please. [LB952]

JOHN RADWAY: My name is John Radway, J-o-h-n R-a-d-w-a-y. Just a couple other

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points. Also, past retirement age. But one of the challenges we're...we're supportive of the bill, but one of the challenges that we're seeing with the bill is attracting quality caregivers at all right now. The issue has become that, over the last year, their income actually went down to about \$9 an hour. You can flip hamburgers and make more money. How do we hope to attract people into this industry, long-term care, especially since more and more people will be coming on to the caregiving rolls, if we don't do that? Having quality home care keeps Thayer out of the hospital. If once a year he's out of the hospital...or he has one less issue...and he's only been in maybe, max, once a year for some kind of an infection. But the quality of infections, everything, has gone way down. His ability to live independently keeps him healthier; it eliminates pressure sores; it allows quality people, like CNAs, LPNs, and RNs, to care for him and address these issues proactively rather than reactively. One trip to the hospital would provide at least one if not two caregivers a year and pay for their care. So I think we have to look at the large picture, not just the small picture, not just the immediate pieces of that. I thank you for your time, and I thank you for your help. Thank you. [LB952]

SENATOR HARMS: Well, thank you for your willingness to testify. Any questions? If not, thank you very much. [LB952]

JOHN RADWAY: You're welcome. Thank you again. [LB952]

JORDAN ELLER: So I want to jump in real quick. My name is Jordan Eller, E-I-I-e-r. I am a caregiver for Thayer, who just testified. And I'm in support. I have been a caregiver for him for four years now. I am a nursing student at Union College here in Lincoln. I am a senior; I'm going to graduate in December. And just by working for Thayer over these past four years, I've noticed how much more difficult it is for him to find caregivers that can provide good care and everything for him. It's tough enough with me, learning these cares in nursing school; I couldn't imagine somebody coming in as a layperson trying to learn sterile procedures and colostomy care and tracheal suctioning. And it's difficult, but I enjoy the field. And I love doing it. I just can't...it's very difficult for him now, even since I've...I was one of them who was affected by a recent pay cut, and, yeah, it's more difficult. I go to school full-time. I work 32 hours a week some weeks, when I can; otherwise I at least work 24 a week, just to pay the bills. I don't live anyplace fancy; it's...I just try to get by. And that's the way it is being a student as well as working. But I just know with people working the evening shift right now, this is when he has his free time in the day to try to find people to work for him. And we've been looking, and it's very difficult to find good caregivers for him. And a lot of times it's because, you know, they come interview, and they find out what the pay is. And it's not very good. And it is tough; \$9 an hour is tough to live off of, especially with the current economy and everything. But I really...I love...I know working for him that his quality of care is good; his quality of life is good; he's happy. And it's a lot of times keeping away some of those mental illnesses and physical illnesses is, you know, having the joy of freedom and enjoying themselves and just the simple pleasures in life that living in a facility wouldn't

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be able to, you know, keep him in and active in the society each day. So that's all I really have to say. I just want to represent some of our caregivers that we have. [LB952]

SENATOR HARMS: Well, thank you for your testimony. Have any questions? [LB952]

JORDAN ELLER: Thank you. I apologize for my appearance. I forgot this morning when I woke up that we were doing this, so... [LB952]

SENATOR HARMS: You're dressed the way I want to be dressed, (laughter) so thank you very much; I appreciate your... [LB952]

JORDAN ELLER: All right. Thank you all. [LB952]

NANCY PEETZ: Actually, I'm going to speak first, if you want me to go ahead while Jesse gets in position. I am Nancy Peetz, and I am Jesse's mother. And Jesse obviously came with us, and Michelle. [LB952]

SENATOR HARMS: Would you wait, please, till we get things set up and so we get your name, and... [LB952]

NANCY PEETZ: Okay. [LB952]

SENATOR HARMS: ...everything, spelled out. It would be helpful. Thank you very much. First of all, welcome. We appreciate it. Now I think we're ready and... [LB952]

NANCY PEETZ: Thank you very much. I am Nancy Peetz, N-a-n-c-y P-e-e-t-z; and this is my son Jesse; and the star of our show today is Michelle, his home-health nurse. And that is one...we are here today because we are in support of the LB952 and we do not want you to in any way support these Medicaid cuts that have been proposed. I thank everybody that has testified before me, and I will ditto absolutely everything that they said. And we can use Jesse as a visual aid and Michelle as a visual aid to show how sound their reasoning and their comments have been. I believe I e-mailed everybody a letter prior to today, and I sent a picture along for Jesse. And, to be truthful, we didn't think we were going to make it today because we didn't have a home-health nurse. Thank goodness Michelle completely rearranged her schedule today so she could come with us, and so we're very thankful for that. And to my...what I would like to is give you just a short history of Jesse's medical synopsis. He...and I'm not going to go into great detail because, believe me, it would take too long. Jesse was a sophomore at UNL when he was stricken by a virus. This is not a regular spinal cord injury;... [LB952]

SENATOR HARMS: Would you like to sit down? [LB952]

NANCY PEETZ: ...it is a virus. No, I'm fine. [LB952]

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SENATOR HARMS: Okay. [LB952]

NANCY PEETZ: That's okay. I sit way too much. Anyway...and, believe me, we never thought that we would be in this position before, and we are very grateful to the taxpayers. As a taxpayer and as a Medicaid recipient, we are grateful to the taxpayers for what they have done for us. My understanding of the Medicaid cuts that were proposed in that December letter is that the private nursing hours would be cut to such an extent that Jesse would qualify for basically 45 minutes of care a day. Jesse and I have lived together for nearly the entire time that he...since he was stricken by the virus. And during that time we have depended on home-health nursing care. We could not survive with...I can give you examples of where the home-health nurses picked up on things with Jesse. And if these cuts are allowed to go through, in effect, Jesse will have to go to a long-term facility. There are only two long-term facilities in Nebraska. One is in Ambassador and one is Madonna. And I've called at different times to see about their availability. Jesse is also on a chemotherapy drug, which would require a private room. And, in fact, in the summer of 2007 Jesse did try a long-term facility. He was there about ten days, became deathly sick with pneumonia, was in the hospital for two months, got better, went back to the facility, was back in the hospital for another two months, after four or five days. I don't believe Jesse can survive in a long-term facility. Since...when he was discharged in October of 2007, we began living together with the aid of home-health nurses. He has been in the hospital for a week maybe once a year since then. We had a visit with our pulmonologist, a routine visit, just a couple of weeks ago. He is amazed at how well Jesse has done. And he, unsolicited--he didn't know about these cuts--said it's because he's at home with the care. When Jesse was first stricken with the virus, he couldn't swallow. He can swallow now; he can eat; he is registered for classes at UNO. He has thrived with home healthcare, as any disabled person has. And I would just like to make one quick comment. I've heard over and over again: disabled people, disabled people. There's not a disabled person in this room. We are all people; first and foremost, we are people. We are children, every single one of us, we are children of God. We...there are some people that have physical or other disabilities that require them to have aid, and that is the only difference. And we appreciate the taxpayers. And in the long run, not only, as other people have testified, will it create more taxpayer expense to have persons not in the home health, but they just will not thrive. And Jesse is an easy example of how that has worked. Thank you. [LB952]

SENATOR HARMS: I thank you for your testimony. Do we have any questions? Seeing none, thank you. We appreciate it. [LB952]

JESSE PEETZ: Good afternoon, Senators. My name is Jesse Peetz, J-e-s-s-e P-e-e-t-z. And I just wanted to say, like my mom said, I've been stricken for almost six years now, over six years now. (Inaudible) I've lived the majority of the time with my

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mom in an apartment with home healthcare. And without it, I don't think I'd be the person I am today. I'm more motivated to get out, go to school, and go to activities. And in a facility, I don't know that I would be that motivated. I am an active person. I love the outdoors, and I just love to be around people. I guess the real thing about these cuts that are being proposed is it's not about just saving money here or there or whatnot; it's about people, jobs, the economy. Without home healthcare, these nurses wouldn't be here, the agencies wouldn't be here. These people would lose their jobs; it would affect them, you know, as much as me. And I think that's the important thing, because in the economy we're in, we can't afford to do that, cut jobs and leave people hanging. And for me, myself, I have some very high-tech equipment, this wheelchair, for example. I have a mattress that rotates me, by itself, so I don't have to be manually turned. These things are not cheap, by any means. So these cuts would greatly affect what quality of life...my ability to get around and see people or go home, come watch Husker football games. But like I said, I think it all boils down to people and jobs and how that would affect our state's economy and way of thinking. And I just thank God that I've been given the opportunity to live at home with nurses from Maxim Healthcare, and I appreciate everything they've done and everything that everyone has done for me. That's all I have to say. Thank you. [LB952]

SENATOR HARMS: Well, thank you very much for coming and thank you for your testimony. We appreciate that. Do you have any questions, please? Seeing none, thank you very much. [LB952]

JESSE PEETZ: Thank you. [LB952]

MICHELLE BROCHTRUP: Hi. [LB952]

SENATOR HARMS: Hi. [LB952]

MICHELLE BROCHTRUP: You ready? Okay. My name is Michelle Brochtrup, M-i-c-h-e-l-l-e B-r-o-c-h-t-r-u-p. I'm a registered nurse. I work both with Maxim and Creighton Medical Center in Omaha, Nebraska. I work on the trauma unit. I just want two points to make and they're going to be real quick. I'm sorry, I'm going to speak fast because I know I have limited time. Personal care: Jesse is one of my four home healthcare clients. When he has either fevers or temperatures that are normal for you and I, his heart rate would be normal for you and I, it is not normal for him. We have averted him going to the hospital because we've been able to notice these and get him the appropriate treatment. If Jesse goes into the hospital, he goes to the ICU. You can imagine the ICU costs per week or even one day. If we can avoid that, that saves the taxpayers money, that saves him. He goes to the hospital, he's at risk for decubesc, bedsores, decubitus ulcers, pneumonia, blood-borne pathogens, which are immense, and being...seeing how he is on a chemo agent, is actually life-threatening, as he has already demonstrated twice with a home health...with a institution here in Lincoln. All

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right, second thing is when I first became a home-health nurse, I had been 15 years in a hospital. What I thought home-health nurses did was sit at the bedside and just say yes, no, get them a cup of water and make sure to suction them and give them meds; that's it. We don't. We are the social workers, we're the occupational therapist, PT, OT, social work, housekeeping, RT, that would be respiratory therapist. We don't have a respiratory therapist that comes out. We change his trache, his G-tube. On other clients we've changed catheters, suprapubic catheter, straight caths that normally would take quite a bit of time to teach somebody how to do. We change all the vent circuits. We troubleshoot vents. We're also the infectious disease persons. We're patient advocates. We're secretaries. You know, we line up hospital or doctor's appointments, we keep all the meds straight. Thankfully, Nancy is very good and she picks up the meds for us so we don't have to do that. We just make sure that everything is there, we have the adequate meds we need, we have adequate supplies. We do inventories. We don't just sit there and do absolutely nothing, which is what I thought when I first became a home-health nurse: I'm not going to do anything. You know, this will be an easy job, I won't be doing anything other than just minimal basic stuff, which is totally not the case. It has actually turned into an ICU in the home, which is what all my clients have been. So these people would not be in a normal facility. They would be in only I think there's three places: Select, Madonna, Ambassador. And they would be in very high-cost areas. The most important part of my job is patient advocate, which is why I'm here. You know, Jesse has been a challenge at times, but he's been a fun challenge. So thank you for listening to me. Do you have any questions? [LB952]

SENATOR HEIDEMANN: Are there any questions? Just briefly, you work for Maxim. [LB952]

MICHELLE BROCHTRUP: Uh-huh. [LB952]

SENATOR HEIDEMANN: And as somebody in the industry, is there anything that we can do that is just as efficient what you do now and is there any cost savings out there? [LB952]

MICHELLE BROCHTRUP: Right now the cost savings that I see is averting infections. If you put somebody in a hospital, being that I worked at Creighton Medical Center and I have worked at the VA and I've done clinicals in all other hospitals, almost all other hospitals in Omaha, keeping the infection rate down, keeping their nutrition up, keeping them active, keeping them mentally active will help out more than probably anything else that I know about. You know, you have to be able to troubleshoot different things that go on. You know, if his heart rate gets high tonight because he has been out of bed, on a normal person you would ignore that. We will have to push some fluids tonight. He will probably spike a fever, but we're not going to panic over it because...and we're not going to call 911 and have him transported to the hospital, which we would have to call 911 because he is vent-dependent. If he's going to a hospital he has to go,

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and not just for a clinic appointment, he has to go by squad. So, oh, that's the other thing we do is we play paramedic too. One of my other clients, she respiratory arrests twice a night so we have to bag her twice a night and we know the interventions to make sure she stays breathing after we're done with that. So I don't envy you your job. I like mine, thank you. And I don't really know what other cost-saving measures because I don't get into the cost-saving part. I get into the lifesaving, keeping people alive and keeping people out of the hospital part. [LB952]

SENATOR HEIDEMANN: I appreciate what you do, too. Just listening to the description, that would be very nerve-racking for me, just to let you know. [LB952]

MICHELLE BROCHTRUP: Thank you. [LB952]

SENATOR HEIDEMANN: Go ahead. [LB952]

JESSE PEETZ: May I make a quick point? [LB952]

SENATOR HEIDEMANN: Yes. [LB952]

JESSE PEETZ: I was just thinking, and my mom alluded to this a little bit, but if these cuts occur and we have to be institutionalized, I can tell you there is not enough room in all the facilities in Nebraska to hold us all, so that would be a great problem for the industry. So you'd have to build more facilities and train more nurses and I think in the long run it would be more expensive than allowing us to stay at home. [LB952]

SENATOR HEIDEMANN: Thank you very much. [LB952]

JESSE PEETZ: Thank you. [LB952]

NANCY PEETZ: If I might make a comment, when you talk about cost savings, as I've been exploring alternatives, I've been continually being told Medicaid waiver, Medicaid waiver, Medicaid waiver, because Jesse is on straight Medicaid right now. You cannot believe the phone calls I have made, been transferred, got this person, that person. I have never gotten an answer as to whether Jesse would qualify for the Medicaid waiver plan. And you've heard other testimony alluding to whether everybody would be eligible for that. Right now, if those cuts were to be instituted, there's no alternative for Jesse except for a long-term facility. [LB952]

SENATOR HEIDEMANN: You're convinced of that. [LB952]

NANCY PEETZ: Absolutely. Absolutely. I have made phone call and phone call and phone call, and I can get no answer. [LB952]

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SENATOR HEIDEMANN: Thank you very much. [LB952]

MICHELLE BROCHTRUP: (Inaudible) am I getting (inaudible) in the right place?
[LB952]

NANCY PEETZ: I'd love to talk more. [LB952]

MICHELLE BROCHTRUP: All right (inaudible) after you, man. [LB952]

SHELIA WORRELL: Hi. My name is Shelia Worrell, S-h-e-l-i-a W-o-r-r-e-l-l, and this is my daughter Taralynn, T-a-r-a-l-y-n-n. I was kind of nervous about this so I've got it wrote down, and hopefully I don't mess up. Taralynn was born a, quote unquote, normal, healthy child with a clubfoot. Right before her first birthday she got spinal meningitis, which turned into encephalitis of the brain, resulting in about a 40 percent loss of her brain function. She did not, however, lose her intellect. Due to all of the damage she received, she requires 24-hour care. She has to have all of her daily living cares done for her. She has tons of appointments, most of which are in Omaha as there are no such...no services for these things in Lincoln for pediatrics. The appointments require a lot of time and lifting, which most of the nurses, x-ray techs, and other personnel in the offices do not help with. She needs moved, turned, bathed, changed, and many other things for her cares. She has very fragile bones due to the brain damage and they break easily. She needs someone with her almost all of the time. Very seldom is she left alone, even for very few minutes. She doesn't talk verbally but she does communicate with her eyes, her glazes, her facial expressions, her hand movements and such, however, many people have a very hard time with this until they know her well. Also, taking away the nutritional help with the Ensure formulas, the nutritional vitamins and stuff would be devastating for us as many of the other families. It's expensive. We can't afford it. We already use Foodnet for ourself, you know. A six-pack of formula is almost \$9. You multiple that times four for \$36, and she gets six cases a month. It gets pretty expensive. Many parents of these kids need the extra help for different reasons, some of which, but definitely not all, include single parents, working parents that aren't able to be there, parents that have their own health issues and restrictions, spouses that no matter how much they love their child they just don't know how or are too scared to help with the things. This help is vital to us and our children for our families to be together in our homes, which is where my daughter should and will be, so that we can give her/them the best care which they would not...which would not happen in a nursing home or other facilities. I don't even leave my daughter alone in or at the hospital--I'm with her when she's there also--let alone somewhere else where they don't really care about her. You need to remember that this is an issue that will not only...that will not get any better as far as the number of children. Children are living at lower birthweights, through more accidents, illness, diseases because of advanced medical...advances made in the medical field. There is already a shortage of nursing personnel, caregivers and such. Steps need to be taken to help

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parents not make things worse or step back in time and institutionalize people, which seems to me like a very large step back in time. There's a lot of advances that have been made and to go backwards is really sad. [LB952]

SENATOR HEIDEMANN: Thank you for coming in and testifying and telling us your story. Is there anyone wishing to ask any questions? Seeing none, thank you for coming in today. [LB952]

SHELIA WORRELL: Thank you. Taralynn is 16 now so...Taralynn is 16 now so we've been dealing with this since she was almost a year old. [LB952]

SENATOR HEIDEMANN: You've been at it a while. [LB952]

JENNIFER STUHMER: I have a copy. [LB952]

SENATOR HEIDEMANN: Welcome. [LB952]

JENNIFER STUHMER: (Exhibit 33) Thank you. This has been a new experience for me. I'm really kind of impressed with the government system today, so thank you. [LB952]

SENATOR HEIDEMANN: Let's hope you stay that way. (Laughter) [LB952]

JENNIFER STUHMER: Me too. My name is Jennifer Stuhmer, Jennifer, J-e-n-n-i-f-e-r, Stuhmer, S-t-u-h-m-e-r. This is my most adorable son, Damon Stuhmer, and my husband, Ryan Stuhmer, and earlier I had my home-health aide, one of our home-health nurses with us as well. Thank you for sharing your valuable time today. I'm Damon's mom. I'm here to show my support of LB952 with hopes that you will see that my son is worth living and our family is worth saving. Damon is 1 of 60 people in the world with a rare chromosome deletion that led to his severe special needs. Damon has a G-button, a tracheostomy, and is ventilator-dependent at night. These are critical to Damon's survival. We have tried to wean Damon off of the ventilator at night, but his body doesn't tolerate it and he develops pneumonia quickly. A ventilator-dependent patient requires someone to watch and listen for possible lung complications that may occur. Only skilled registered nurses that are trained on Damon's case have the ability to recognize any possible irregularities in breathing. We currently receive Katie Beckett Medicaid funding for medications, durable medical equipment, and private duty nursing. We receive nursing hours so that my husband and I both can work, maintain our jobs, and get sleep at night. These are much needed hours of care for Damon that not just anyone can provide. Damon requires a registered nurse trained on G-buttons, tracheostomies, and how to properly handle Damon's numerous special needs. If these cuts are approved our nursing will be drastically reduced. This will mean that I will be forced to give up my job and lose that income and will not get proper sleep. This all puts

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Damon at a high risk, at a very high risk for developing future illnesses that right now are being prevented by the skilled nurses. Our fear is that if we lose our private duty nursing, Damon will be hospitalized much more often and eventually we would have to find an acute care facility. These registered nurses are not a luxury to our family or to Damon but a necessity. The current proposed budget cuts have made our family feel as if our son is not viewed as a productive member of our community. We love Damon. We love his contribution to our family, to his friends, and to this community. One more sentence: Keep private duty nursing in Nebraska. Please support LB952. [LB952]

SENATOR HEIDEMANN: Thank you for coming in today. You did good. [LB952]

JENNIFER STUHMER: Thank you. Thank you. [LB952]

SENATOR HEIDEMANN: Is there anyone that has any questions? [LB952]

JENNIFER STUHMER: I have lots of answers. [LB952]

SENATOR HEIDEMANN: Thank you. [LB952]

JENNIFER STUHMER: Thank you. [LB952]

SENATOR HEIDEMANN: Welcome. [LB952]

JOAN KELLY: I'm a little nervous. I hope you can hear me. Sorry. [LB952]

SENATOR HEIDEMANN: You're doing good. We got time. [LB952]

JOAN KELLY: (Exhibit 34) This is...well, first of all, my name is Joan Kelly, J-o-a-n K-e-l-l-y, and this is my PAS provider and friend, M.J. Higgins (phonetic), and I'm a client with the PAS program. I'm also eligible for six to eight hours a day of private duty nursing, but since I don't have family members who can care for my needs, the PAS program is essential for my care. I have 24-hour care and so my PAS providers do many things for me. They cook for me, feed me, help me with filling out forms, making phone calls, and paying my bills. They transport me every place I go, which means securing seat belts, operating a lift, and driving my van. They help me with the commode and with bathing. They assist me with breathing treatments, quad coughs, and physical therapy. They operate the ventilator, the PSI and the MIE. They manage the oxygen tanks and all of the supplies. They do sterile suctioning of the trache and change it out when necessary. They clean, clean, and clean some more. They transfer me to and from my wheelchair, which is quite a task since I'm kind of a rag doll, and a very sensitive one too. Throughout the day and night, they reposition me in the wheelchair or bed, and sometimes they have to reposition me a lot. I depend on my PAS providers to be there for me, and depending upon the weather or what's going on

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in their families or their finances or their health, sometimes the pressure is extreme for them and for me. For \$7.68 to \$9.40 per hour, which is a few dollars an hour below the average market rate for nursing assistants in most nursing facilities, the PAS provider does the work of the licensed practical nurse, the registered nurse, the physical therapist, and the respiratory therapist. This is a lot of responsibility for a job with no health insurance, sick leave, workers' compensation, overtime pay, vacation pay, holiday differential pay, or any other benefits common to employees in most nursing facilities, all of which makes PAS providers substantially less costly to the taxpayers. And I should interject that obviously a great deal of testimony has been taken about the need for private duty nursing and this is obvious, but I feel that there is...not much has been said positively about the PAS program, and for me it is very important. All of those factors make it also substantially more difficult for me to find and keep PAS providers who are both willing and able to work for me. The turnover in PAS providers is very high, and I spend a significant amount of time recruiting, training, scheduling, and managing my providers and then having to start all over again. I would rather spend my time pursuing a career that would enable me to be self-supporting, but the fact is that maintaining my staff of PAS providers is for me literally a matter of survival. Having resided briefly in a couple of nursing facilities on a few occasions, I am keenly aware of the fact that nursing facilities are unable to provide the specialized care my needs require. In each instance it was necessary for me to call on my PAS providers, some of whom have still never been paid, just to meet my basic needs. Some of the tasks that my PAS providers are able to do for me cannot be done for me by a nursing facility staff member. Policies and staffing limitations prevent them from being able to transfer me to and from my wheelchair, from repositioning me when needed, and in some instances from even feeding me. In-home care seems to be the only practical solution for my care needs, and I believe that it would still be a good deal for the taxpayers even if the PAS providers were given a much deserved raise. Furthermore, I still have plans to pursue my career and become completely self-supporting. This would be the best deal of all for the taxpayers because I would then become one of them, and then you could all say you knew me when. [LB952]

SENATOR HEIDEMANN: Thank you very much, very good job. Are there any questions? Seeing none, thank you for testifying today. [LB952]

JOAN KELLY: Thank you. [LB952]

M.J. HIGGINS (phonetic): Thank you. [LB952]

ALICE WASHBURN: Hi. My name is Alice Washburn, A-l-i-c-e W-a-s-h-b-u-r-n. If you don't wash clothes, please burn them. I'm a registered nurse and I am here to represent Brianna (phonetic). Brianna, I have been taking care of her for four years. Just so you know, I've been a nurse for 28 years. I've cared for another child in her home for 17 years. Now I've progressed to Brianna for the last four years. I take care of her full-time.

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Brianna can't tell you today that she has a trache and she can't tell you that she has a G-button for her feeding. She can't tell you that she has seizures all the time. She can't tell you when she needs suction. She can't tell you when she needs to go to the bathroom or when she needs to have her diaper changed or when she wants to move or this is just not comfortable. Brianna, the only way you know these things is by learning Brianna. I've learned Brianna and I know these things about her. I know when she's uncomfortable because she gives me a very mad face, and I know when she's unhappy. I also know when she is happy. She recognizes my voice. She recognizes Mom's voice. This is Mom, by the way. And I would have to say I am with her in the home so Mom can work. I take care of Brianna so Mom has respite hours. I have kept Brianna out of the hospital. Before I started on her case, she went to a specialized day care, which is very significant to have in our community, but know that in the year and a half before I started she was in the hospital every four to six weeks with pneumonia from going to this facility. Well, okay, so over four years and every six weeks you're in the hospital, an average \$40,000 to \$50,000 hospital stay because it's...we're talking ten days of IV antibiotics and respiratory therapy and percussion and aerosols and blah-blah-blah-blah-blah, all that expense, I've saved you \$1 million in hospital expenses by me being in the home. Now granted, I don't make \$1 million and, in fact, in the past 17 years of taking care of a child in her home, I've received two pay raises, both of those have been in the last two years and they were a quarter each year. I guarantee you my cost of milk and the cost of gas for my car to go to work have gone up more than a quarter in the last two years. I don't do it for the money. I do it because I care for Brianna and I care that her mother has the ability to go to work and take care of her other children, and she'll tell you all that. But I care for Brianna. I care for these children that I've cared for in the home and I would really hate to see her go...have to go or not be able to be somewhere where she couldn't even tell anybody, hey, does anybody know I need my diaper changed, does anybody care? Because when you go to a facility that rounds every three hours, she could cough out her trache and be dead in that length of time. She has coughed out her trache, and if I wasn't there to put it back in she'd be blue. If somebody was there who only had a high school diploma and was required to suction her...would any of you like to suction her, because I'm sure you all have high school diplomas. And anyway, she would turn blue and die. She has done that, she's turned blue without her trache. So I'd like you to keep nurses in their homes and let these children grow up and do the...have...you know, be the best that God has enabled them to be. [LB952]

SENATOR HEIDEMANN: Thank you. [LB952]

MARIBEL FUENTES: Thank you. My name is Maribel Fuentes, M-a-r-i-b-e-l F-u-e-n-t-e-s. I come from Omaha, Nebraska. I'm a single mother of four children. I work full-time so I could provide for my family. I have personal insurance for myself and my three children through my job. Brianna needs care at home because she has cerebral palsy, seizures, a G-button, a trache as a newborn. Nurses care for Brianna so I have

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freedom to work. If Brianna coughs out her trache, she would be...she would turn blue and die. By the time the nontrained person calls 911, she'll be dead. If I don't have no nurses, I can't work. I have to go on ADC. I will need Medicaid for me and my children. I would probably lose my house. But you guys should also put yourselves in my place. You do also have children. Someday you will maybe, you know, go through what I'm going through. So please don't let this happen. Thank you. [LB952]

SENATOR HEIDEMANN: Thank you. Are there any questions? Seeing none, thank you for coming in today. [LB952]

MARIBEL FUENTES: Thank you. [LB952]

ALICE WASHBURN: Thank you. Did any of you want to suction Brianna? (Laughter) She's ready. Okay, thanks. [LB952]

CONTESSA EAGLE ELK: Hi. My name is Contessa Eagle Elk, C-o-n-t-e-s-s-a E-a-g-l-e E-l-k. I'm a CNA from Omaha. I have no license, only a certificate. And all I have to say is if the patient dies in my care, who's responsible? And I'm not allowed by the state to change the trache or suction her, and I don't want to be responsible for any of the patients' death, so please keep the nurses in the home. Thank you. [LB952]

SENATOR HEIDEMANN: Thank you. Are there any questions? Seeing none, thank you. [LB952]

JESSICA OCKER: I am Jessica Ocker, J-e-s-s-i-c-a O-c-k-e-r. This is my sister, McKenzie. Do you want her name as well? [LB952]

SENATOR HEIDEMANN: You can if you want, yes. [LB952]

JESSICA OCKER: McKenzie Ocker, M-c-K-e-n-z-i-e O-c-k-e-r. McKenzie wanted me to come here today with her just to put the thought in your head, what if she was your child, what about your children's quality of life and their dignity? And is 16 hours a month in respite care enough for her to be a normal teenager? Is that enough for her to do her homework? Is that enough for the family to get a break? My mother and my father are in their fifties and their health is declining as well, and that leaves me to be her guardian and we can't do it without you guys' help. That's what we wanted to say today. Keep the nurses in our homes. We need them. [LB952]

SENATOR HEIDEMANN: That's what you wanted to say and you did a good job doing it, so thank you. Are there any questions? Thank you very much for coming in. Welcome. [LB952]

SUSAN OTTE: (Exhibits 35-36) Hello. I'm Susan Otte, S-u-s-a-n O-t-t-e. This is my

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daughter, Quinn Otte, Q-u-i-n-n O-t-t-e. I did good until I heard that last one. Woo, I should have gone before her. I am an elementary art teacher and this is my amazing daughter, Quinn. She is vibrant, smart, amazing. She has a great sense of humor. She is a five-year-old who is at Lincoln Public Schools in preschool. I want to focus on what most other people are focusing on, nursing in homes with kids with severe disabilities, as well as giving these kids opportunities to continue therapy. A nurse, who is educated and understands the issues that my daughter and all kids with disabilities have, is what we need. Nurses or medically educated people that come into our homes teach us, the parents. When we get a child with a disability, we don't get the magic power of knowing how to deal with them at all times. We need somebody to educate us as well as they take care of her. And if I didn't have the education that I've had from all the nurses and the medically able people that we've had, she would not be doing as good as she is doing. Having a personal assistance provider who simply has to be 19 years old and pass a background check does not make me comfortable having a person like that in my house that I have to train when I do not have a medical certificate. I've had wonderful caregivers, not nurses, in the past. They were amazing people. One person in particular didn't understand the medical issues my daughter had and how to care for her. We found that it was not good for the caregiver, it was not good for my daughter, and it was not good for me. Our caregiver did her best and was an amazing person, but she finally had to stop because she was too worried that something would happen in her care with my daughter and she knew she could not live with that kind of guilt. I have many friends and family who agree with that same sentiment. They do not want to watch my daughter simply because they are scared of what's going to happen if she is in their care and something happens to her. We currently have a nurse for Quinn at school, as her school requires a nurse with any child with respiratory issues, like a trache. She keeps Quinn safe and protects her airway, whether she needs to be suctioned, if her trache would get pulled out, and if she has a cold or is under stress her respiratory and breathing will change and she knows how to deal with that. If some of these issues would happen without a nurse present, an ambulance would be called, I would have to take off work, meet the ambulance with my daughter at the hospital for the nurses there to work with Quinn through her respiratory issues, not knowing her or her needs, while a trained professional who knows Quinn would have known how to deal with it in a calm manner, keeping her safe at home or school and preventing a trip to the emergency room, along with those bills. Financially, having medically trained caregivers such as nurses taking care of Quinn saves Nebraska taxpayers money. In the year before we got our medically educated caregiver, Quinn was in the hospital over 26 times. After being with our medically educated caregiver for over a year, she's only been in the hospital for three times. If we simply use the cost of a hospital room, before being with her medically educated caregiver the room alone is over \$46,000, while in this last year it was less than about \$6,000. That's a difference of over \$40,000 that educated caregivers such as nurses have saved Nebraska taxpayers with just my daughter alone. In conclusion, I'm terrified that a personal assistant will not have the correct knowledge or skill or just know-how of how to care for our daughter. Without

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nursing care for her, we'll be back in the hospital numerous times because we will not know what is medically okay. On the other hand, keeping nurses and therapists will continue to help our kids with disabilities survive in our homes while improving and gaining skills, saving many trips to the hospitals. Our kids with disabilities, no matter what their age, deserve to feel safe and secure, and we can save taxpayers money by staying in our homes safely with nursing rather than spending time in the hospitals. Thank you. [LB952]

SENATOR HEIDEMANN: Thank you for coming in and testifying today. Are there any questions? Seeing none, thank you. [LB952]

MICHAEL BAUER: (Exhibit 37) My name is Michael Bauer, B-a-u-e-r. My daughter, Madison, and my wife, TyLynne, are both here as well. Been here I think about as long as you guys have and heard a lot of stories; mine is the same. My wife put together a pamphlet on my daughter. A lot of the stories you heard already apply to Madison as well. I don't think you can sit through these hearings without getting what's being said here. My wife is a registered nurse, she is advanced practice. She goes to work every day, 8:00 to 5:00, just like I do. I'm a police sergeant for the Norfolk Police Division. We both work 40 hours a week and we both have the private duty nursing come in that allow us to do just like what you're hearing here with all these other parents, go to work and support the rest of our families. There's many important issues that are associated with these proposed changes and in this bill, including nursing, psychiatric, dental, hearing, and sight just to name a few. These have been labeled by someone as optional. I think these are optional Medicaid services that can, don't have to be...have to be provided, but can be. Now I think that we as Nebraskans, as proud people that we are, I don't know that we want to do the minimum or be known as doing the minimum. I know when I've heard testimony about other...what are other states doing, well, that's great, we can learn from them, but we shouldn't take their lead. Nebraska took the lead. Nebraska's Legislature took great strides in leading the nation in defining what life was and protection of newborn children. This shows our commitment to life. That commitment has to be carried on, not just life itself but the quality of life that our kids, our brothers, our sisters are living through. Like Steve said earlier, it's even put into our state motto, Nebraska, the good life, for some. The proposed changes to Medicaid would be devastating on our family. Madison has the nation's leading private insurance along with Medicaid as a secondary insurance. Medicaid is the insurance authority that authorizes the private duty nursing services while we're at work. Without it, our life is going to drastically change. LB952 is going to be a bill that will define who we are as a state or who we ought to have been if it doesn't pass. I strongly believe that the children, such as Maddie and other children here today, and the citizens of Nebraska represented here today deserve this protection. Governor Heineman said it in his 2012 State of the State Address, "Nebraska has what hardworking American families want--safe communities, good jobs, great schools, affordable neighborhoods, and an unmatched quality of life." Folks, we're not there yet, not if these proposals go through.

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We need LB952 to pass. Thank you. [LB952]

SENATOR HEIDEMANN: Thank you. Are there any questions? Seeing none, thank you for testifying. Welcome. [LB952]

MAURA FARRUGGIA: (Exhibit 38) Good evening. Thank you so much for all your time and attention. I know it's been a long day. My name is Maura Farruggia, M-a-u-r-a F-a-r-r-u-g-g-i-a. I'm here with my husband, Nicholas, and we are legal guardians and grandparents of Kareaden Farruggia, and together we submit this testimony in response to the proposed Medicaid cuts that will take effect July 1, 2012, if not stopped by LB952. Our granddaughter, Kareaden, was born on December 10, 2005. She was born 29 weeks premature and was cared for in a neonatal intensive care unit for approximately one to one and a half months. She was diagnosed with a brain bleed and would require neurological follow-up and in-home therapies. Legal guardianship of our granddaughter was awarded to us when she was ten months old in October of 2006. She is now six years old with several disabilities that prevent her from being able to function as a normal six-year-old. She has cerebral palsy and a feeding button. She has been tested legally blind due to the damage in her brain and this condition cannot be corrected with surgery or glasses. Kareaden is unable to sit up on her own, hold her head up for more than short lengths of time. She has minimal ability to use her right arm, some limitation with her left arm. She requires a wheelchair and supportive orthotics for her legs. When we took guardianship of Kareaden, we made a decision for me not to return to work. It was the right thing to do even though it reduced our family income by a third, but we wanted Kareaden with us. We have done our best to provide what Kareaden has needed in order for her to thrive, grow, and have quality of life. We provide as much as we can through our own primary insurance and our own means. I can testify to the fact though that the quality of life Kareaden has today would not have been possible without the support of Medicaid. After she had her surgery to receive her feeding button, we saw a marked turning point in her health and development. When she started receiving the nutrition she needed, which she could get no other way than through a feeding tube, she started growing and developing physically and mentally in ways we'd only hoped for. She strengthened physically, was sick a lot less often, started putting on needed weight, and most notably her cognitive abilities improved immensely. She went from screaming and crying in frustration, because she couldn't communicate her own needs, to talking and singing and learning. For a long time I thought that I would never hear her say grandma. Now she says she loves me. Medicaid supplemented our insurance to meet this critical need of nutritional supplements. One thing I'm afraid I have never understood, however, is how something so critical to the life of a child like Kareaden could fall under durable medical equipment. To us, her nutritional supplements are not her equipment. Her wheelchair is her equipment. Her nutritional supplements are her life. Kareaden also receives therapy weekly. Her therapies include physical, occupational, speech, vision, and until last week feeding. Due to changes with Medicaid already, she has lost her feeding therapy. However, we are appealing that decision with

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Medicaid and following up with her primary insurance to remedy this situation. Her therapies have been crucial in getting her to progress as well as she has. I didn't have a clue how to help her. I didn't know things like if she's not up on her feet enough, weight bearing, it will really hurt her joints and hips as she grows and will cause her a lot of pain and complications when she's older. I didn't know how to stretch her leg muscles properly. I didn't know how to help her learn how to use her tongue to move food to her teeth so she could chew. There are all these little functions that I've always taken for granted because they just came naturally, but how do you teach a child that can't do them naturally? I didn't know. There is so much more I'm learning every day that I don't know but her therapists do. They teach me as much, if not more, than Kareaden. They have been key to our ability to care for her and keep her. Medicaid has helped us afford this very important, life-changing service as well. Another way Medicaid has assisted us is with Kareaden's durable medical equipment. The durable medical equipment purchased by our insurance and Medicaid has had tremendous impact on her physical development and provided us with the means to care for her in our home and do our part for her continued care and therapy. We can bathe her. We can lift her and move her to her wheelchair or her protective bed. We can help her take steps in her KidWalk. We can have a life with her in our home. We can have a safe environment for her and for us long term because of her medical equipment. Her special equipment enables us to manage her care where we want to manage it, at home with us. However, as wonderful as she is and as much as we love her, taking care of Kareaden has been hard. For the longest time, I couldn't be out of her sight without her having an anxiety attack, which usually ended up with her vomiting. I couldn't even go to the bathroom without expecting an episode. This problem was compounded when my husband had to travel for work, which required me to provide round-the-clock care with no means of a break. We also have had to keep Kareaden on a monitor constantly, especially at night, due to vomiting and choking issues, which of course greatly affected our being to get a good night's sleep. Before we were able to find Children's Respite Care Center, my health and well-being were deteriorating and Kareaden's constant care was becoming draining on both myself and my husband. Medicaid and CRCC made it possible for us to take Kareaden to a place where nurses, therapists, and trained paraprofessionals meet her complex medical and physical needs while we have some much needed recuperation time. The CRCC team helped us build up social interactions for Kareaden too. She had grown very dependent on us and this was a very difficult time for us. We could hear her on the other side of the building when we left and again when we came back. I don't believe she ever took much of a break in between. They helped us get her ready for her next big step, which was preschool, and she was ready and she was happy to go. CRCC gave me some time to myself. I felt like I had a life again. If I needed to just come home and get a nap or read a book, I could. I had time with just my husband again. We were able to spend some time on our own relationship, which is critical when living with such challenges. Our home for Kareaden will only be as good as we are together. Having a dependable, knowledgeable place like CRCC to rely on has established us to catch our breath...has enabled us, I'm sorry, to catch our breath and

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reaffirm that we can do this. The staff at Children's Respite Care Center, like so many other of our service providers, have also helped us understand and access what was available to Kareaden through Medicaid. If weren't for their assistance, we would have been lost. Medicaid has helped us immensely. But if there is anything I would like to see changed, it would be our ability to talk with someone with Medicaid in a timely manner that could give us the information we needed to make informed decisions concerning her care. Many of the items that will be eliminated from Medicaid, if the proposed cuts go through, have directly improved Kareaden's quality of life and ours. They've allowed us to keep her at home and keep her healthy and keep us sane. We are requesting, before these cuts are approved, that more consideration be given to children like Kareaden and their families. There is so much more work for this little girl that she has to do in her life and I feel the reduction in Medicaid services will greatly impact her future. If you look at the following picture, it's a picture of Kareaden's first field trip with the CRCC. The following picture was Kareaden's first steps with her KidWalk at age three. The next picture is Kareaden at six years old on her first day of kindergarten, being picked up by the bus. It was her first bus ride to school and this achievement was made possible by approximately three years of therapy, nutritional support, medical equipment, and a lot of love. Without all the work of many others this picture would not have been possible. We want Kareaden to have many more firsts in her life. Thank you. [LB952]

SENATOR HEIDEMANN: Thank you for telling your story. Are there any questions? Seeing none, thank you. Welcome. [LB952]

AUBREY PAULSEN: (Exhibit 39) Good evening, Senators. My name is Aubrey Paulsen, A-u-b-r-e-y P-a-u-l-s-e-n. I am a wife, a full-time professional, and mother of two beautiful sons, ages three years old and six months old. Both of my children were born with conditions that caused them to be medically fragile. I want to talk about my son, Christian, who is six months old. He was born at the University of Nebraska Medical Center where he was hospitalized for 11 weeks in the neonatal intensive care unit; 3 of those 11 weeks he spent on life support. I also spent 11 weeks, unsure if my baby was ever going to come home. By the grace of God, with the support of family, friends, and my community, I was able to bring him home; however, he came home so very fragile and with lots of medical equipment. My husband and I were required to take infant CPR in the event Christian stopped breathing due to his compromised lung capacity. To this day we have CPR posters placed strategically around our home in case he stops breathing. We live in Friend, Nebraska, more than 60 miles from the nearest facility equipped to handle him. My husband and I both work full-time. We have full health insurance benefits through my employer. Christian became eligible for Medicaid because of his severe medical condition upon birth. Medicaid has allowed me to return to work and provides for a registered nurse to care for him while we are at work. My insurance does not cover home health nursing. If I were to choose the option...if I had to choose the option to quit my job, we would lose our family benefits.

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My husband is self-employed, and looking at benefits for us, it would be upwards of \$1,500 a month and I don't believe that Christian would be...would qualify anyway, given his history. I've been fortunate that I have not had to make this decision whether to return to work or care for my critically ill child. No mother should have to make this decision. A personal assistant is not appropriate in my circumstance. Christian must have a medically trained professional who is trained to save his life should he stop breathing. As I mentioned, I'm unique in that both of my children were born with rare congenital anomalies and were provided nursing care under the Medicaid program. My three-year-old son, Owen (phonetic), is now a happy, healthy toddler attending a typical day care, no longer requiring services under Medicaid, and is covered fully by my health insurance. We just needed a nurse and a little extra help to get him to this point. I urge you to look at families like mine when considering Medicaid cuts. Please don't make me or anyone else choose between providing insurance for my family and keeping my children alive. What I do know is that my family is surviving emotionally and financially due to Medicaid-provided nursing. Thank you. [LB952]

SENATOR HEIDEMANN: Thank you for coming in today. Are there any questions? Seeing none, thank you. Welcome. [LB952]

JENNIFER SMITH: Welcome. Thank you guys for listening to us. My name is Jennifer Smith, J-e-n-n-i-f-e-r S-m-i-t-h. I am actually one of the nurses, like in the case you just heard, that would come in and bridge the gap for kids. A lot of my children that I have taken care of in the past 20 years only needed services for a short amount of time. Some of them needed services for a length of time. My presence in the home has allowed families to remain employed as they don't have to choose between their career and quality care for their loved one. I care for patients with very high skill levels, such as those with tracheotomies and ventilators. If my patient pulls out their trache or airway, I'm right there to reinsert it immediately. Many patients with traches don't have the time to wait for an ambulance to arrive to reinsert, as their airway collapses when the tube is removed, meaning they can't breathe until it is reinserted. When the ventilator alarms, I take action according to my assessments immediately. My experience and knowledge allows me to perform these functions. These are very real scenarios that I encounter in my work every day. I am both liable and responsible for my patients' lives and I maintain a license to support this, yet we are moving to have laypeople with no license at all take on these responsibilities. I have also had the privilege of caring for infants and children in hospice at home. Without the funding, these children would be seeing their final days in a hospital or institution. They would be in the care of strangers or whoever the staff nurse is for that shift. While there are fantastic staff nurses in hospitals, I would absolutely prefer to bring my child home. They can live their last days enjoying their siblings, their family pet, their own bed, while looking at their own bright blue walls. They are in the care of the nurses who come to the house, who the family knows and trusts, in this most personal and private time. I ask you, what happens to these patients? What would you want for your daughter or son? Almost every one of my patients that goes to

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the hospital for short periods of time end up returning home with either wounds or secondary infections. For my patients, that can be either a death sentence or a significant setback that may reduce their ability to function. Additionally, this requires a higher level of care and increased expense. What happens to them? How do we explain those costs? Quality of life is really the larger picture here, independence, pride, and dignity. Living at home allows my patients to direct their own cares and, therefore, take charge of their own lives. They are not on some schedule set by a facility for the convenience of the staff. They can get out of bed at noon and stay up till midnight. They take showers at any time of the day, play on the computer for hours, go out to eat with friends or attend sporting events. They can choose to eat popcorn and cookies for lunch, not some predetermined menu with foods they don't like. They go to work or school, or they work from home. They receive quality one-on-one care by trained staff. They get to make choices in their lives, the same as you and I. Tomorrow this could be any of you. I had been asked to come and speak by my patients and they have all asked me to tell you that if there's any question about a layperson coming in instead of me, as a licensed professional, you are invited to come into their homes any day and just take a look. As several parents have said here, can you really handle changing out a trache tube? Do you want that responsibility of somebody's airway? I wouldn't think so. Thank you very much for your time. [LB952]

SENATOR HEIDEMANN: Thank you for testifying. [LB952]

MILLIE DEMUTH: Hi. [LB952]

SENATOR HEIDEMANN: Welcome. [LB952]

MILLIE DEMUTH: (Exhibit 40) I brought a picture because she couldn't come along with us today. My name is Millie Demuth, M-i-l-l-i-e D-e-m-u-t-h. I am a little nervous. I apologize if I seem like I'm reading. I don't want to forget anything. I am the mother of a severely disabled child. Alissa was born September 30, 2009, eight weeks premature and weighing in at 2 pounds 1/2 ounce. Alissa has spent many weeks of her 12 years of life in the University of Nebraska Medical Center. During these many and sometimes extended hospitalizations, we have discovered that Alissa has a neuromuscular disease called Stiff Man Syndrome, cerebral palsy, severe seizure disorder, and is respiratory compromised, including asthma and severe allergies. Alissa can do nothing for herself and has a tracheostomy tube and a G-button. My daughter uses a CPAP at night to help her breathe deeply. She receives five breathing treatments per day, seizure and muscular medications every eight hours, and her oxygen...I'm sorry, and is fed by a feeding pump every four hours. Alissa is on heated, humidified oxygen and her oxygen saturation must be monitored while sleeping and every hour when awake. Alissa is a medically fragile child who can become critically ill very quickly. My daughter is also a 6th grader at Culler Middle School, is a Barney the Dinosaur fan, very loving, and has a great sense of humor. Because Alissa has home nursing care, she is able to remain in

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her home with a family that loves her very much. Without nursing care, I would be unable to work to support my family or sleep for any length of time at night. My day consists of work and home. I have a nurse at 11:00 p.m. for sleep time. After giving report to the nurse, I get to bed around 11:30. I am back up and getting report from the nurse before she leaves at 7:00 a.m. I use 45 minutes of my weekly respite time each morning so I can shower and get ready for work. After my eight-hour workday, I am back home to care for Alissa until 11:00 p.m. I am in for the evening. Weekend respite time is used to run errands, get haircuts, and get groceries for the week. On a good week, I will get out to dinner and perhaps a movie. On Sunday, Alissa is in my care from 7:00 a.m. until the nurse arrives at 11:00 p.m. that night, and then my week starts over. My husband died April 13, 2009, after a two-year battle with colon cancer. I have been caring for Alissa by myself since his death. Even during my husband's hospice, Medicaid was unwilling to extend extra nursing hours. My great fear was that my husband would die between the end of my work hours and the beginning of my 11:00 p.m. sleep time and I would not be at his side because I was caring for our daughter. If these cuts are passed, my daughter will have to be moved to an institution. I pray that you will consider some of the tragic past events related to moving medically fragile children from their known life and the people who love them. All I want is to keep my family together and continue the life we have. I already lost my husband and now I fear losing my daughter. I appreciate your taking the time to listen to me and hear about my daughter and how her nursing care is important for her to remain at home. My name and address is here if you need to contact me. [LB952]

SENATOR HEIDEMANN: Thank you very much for sharing your story. Might want to take your picture. [LB952]

MILLIE DEMUTH: I know you'd like to keep that. [LB952]

SENATOR HEIDEMANN: Thank you. Welcome. [LB952]

SEAMUS KELLY: (Exhibits 41-42) Good evening. My name is Seamus Kelly, S-e-a-m-u-s K-e-l-l-y. I represent parents on the Nebraska Planning Council for Developmental Disabilities, and I have submitted a letter of support on behalf of the DD Council. I also just prepared some remarks just as a dad. I'm the father of a child with multiple disabilities. I also am a foster parent of children with developmental disabilities. My daughter, Molly, has several needs, all caused by polymicrogyria, which is a congenital brain malformation. She has epilepsy, cognitive impairments, cerebral palsy. She's not able to sit without a lot of support. She's chronically cute. She's not able to eat solid food so she gets food through a feeding tube. She's blind and she's got a lot of other health issues. We currently benefit some from the programs that are proposed to be cut. My children attend CRCC so they get some private duty nursing, or that falls in there. My wife and I provide the care for our daughter at home. We've considered private duty nursing, especially as she gets older and bigger and her needs get a little

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higher. That's my daughter's, not my wife. Without these sorts of services, as I don't need to tell my story, I guess a lot of people have done a good job, but just...see, I get all nervous. I'm new at this too. Well, like I said, a lot has been talked about the private duty nursing so I'm not going to say anything more about that. One thing that hasn't been brought up I think is some of those other later proposals for...in Director Chaumont's letter for if budgets are reduced further. You know, imagine, as I have here, people wouldn't have teeth, wouldn't be able to eat because they didn't have teeth because the dental care was removed. Then you wouldn't be able to have liquid nutritional supplements because they've already been removed. With no glasses you're not able to see; no hearing aid, you can't hear; no speech therapy so you can't communicate; physical therapy, muscles will get tight and you can't move; no occupational therapy so you can't perform the daily functions for yourself. This seems a little extreme but that describes my daughter. She gets all of those services now. She already is on more than ten meds per month now. I don't know how we would decide which ones were the ones that weren't necessary. And she's been hospitalized I think over 30 times in the seven years, the longest time being 90 days, so that's well in advance of both the 45 days for children or 30 for adults. So mostly I just wanted to voice some support for LB952 and I thank you for your time. I'll get out of here so we can leave. [LB952]

SENATOR HEIDEMANN: Thank you for testifying today. [LB952]

SEAMUS KELLY: Thanks. [LB952]

SENATOR HEIDEMANN: Welcome. [LB952]

TAMMY WESTFALL: (Exhibit 43) Thank you. Chairman Heidemann and members of the committee, my name is Tammy Westfall, T-a-m-m-y W-e-s-t-f-a-l-l, and I am the regional vice president for Mosaic and here this evening on behalf of the Nebraska Intellectual Disability Service Providers. We are here to support LB952 and commend Senator Nordquist on its introduction. For the Legislature to fully discharge its role under their original Medicaid reform legislation, it truly has to actively consider a proposal as far-reaching and consequential as the Medicaid reductions proposed by Director Chaumont's letter of December 1, 2011. We are especially disturbed at the so-called optional services that would be curtailed in the case of federal budget crisis. How and when would we know if indeed one occurred? As providers of largely residential services, we bear the final responsibility for the overall well-being of our clients who very commonly utilize vision, dental, therapy, and pharmacy services. Virtually every one of our clients is a Medicaid client who have limited incomes, many only receiving \$698 per month to cover room and board, personal needs, copays, and any other needs that are not covered by Medicaid. Based on past history, we are not very confident, if these services were no longer Medicaid reimbursed, that the Department of Health and Human Services, Developmental Disabilities Division would build these additional costs

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into their rates. Would the expectation be for the medical needs to come from the existing rates being given to providers? Again, based on our past experience, we would not expect that denying Medicaid for these services would in any way relieve us of the obligation to see that they are provided. Given the depth of these proposed reductions, they will have a severe impact on a person's health and quality of life. Our hope is that you will advance LB952 and that the full Legislature will enact it. If not, if that's the case, it seems to us that you can add to the issue inherent in LB952 by defining what exactly is a federal budget crisis, a term which so much is riding on. If this array of services, critical to the well-being of so many vulnerable Nebraskans, is to be one day eliminated, all of us should be aware of exactly what event or events will create the instability of medical care for the people that we support. And I thank you for the long day today and taking this into consideration. [LB952]

SENATOR HEIDEMANN: Thank you for testifying today. Appreciate it. [LB952]

TAMMY WESTFALL: Thank you. [LB952]

SENATOR HEIDEMANN: Welcome. [LB952]

MEGHAN CASSEL: (Exhibit 44) Thank you. Mr. Gimm (phonetic), he's going to be my easel. (Laugh) My name is Meghan Cassel, M-e-g-h-a-n C-a-s-s-e-l. I'm a registered nurse and I'm the administrator for Craig HomeCare. I'm very glad that you asked the question about what the neighboring states provide, because that's actually what I'd like to testify about today. Director Chaumont spoke at our Home Care Association conference on January 19 and she presented the information, the same information that Mr. Winterer provided you earlier today, and so that's what I'd like to speak about, specifically relating to the private duty nursing in the surrounding states. I was able to do some research and in Mrs. Chaumont's presentation she said that 28 states do not cover PDN, including 5 of the states surrounding Nebraska. And the second page of your handout there is a visual aid that we put together that shows all of the states surrounding Nebraska and what is provided or allotted in those states. Craig HomeCare provides care in Kansas, Nebraska, and Missouri. In Nebraska, private duty nursing services are covered under the Technology Assistance Waiver Program. In Missouri, private duty nursing is covered under the Healthy Children and Youth Program, and the Medically Fragile Adult Waivers. There's a company that's very similar to ours, provides the same type of nursing services that we do, that operates in South Dakota, North Dakota, Minnesota, Iowa, and Wisconsin. I was able to touch base with their compliance officer and she assured me that private duty nursing is covered in all of those states, up to 24 hours a day, with the exception of Iowa which is 16 hours a day, all with some sort of prior approval. In Colorado, I touched based with a budget analyst that said that private duty nursing is approved up to 16 hours a day for children and adults, up to 24 hours a day temporarily based on medical need for children. In Montana, the program officer for the Montana Department of Health stated that private

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duty nursing is covered for 21 years of age and under, up to 24 hours a day. The only state that had limits on the private duty nursing services that surrounded Nebraska was Wyoming, and when I talked to the caseworker there in Wyoming it was more actually because of the limitations that were written into the Nurse Practice Act that limited nurses' ability or nurses' scope to practice in the home setting. There it's written into the state budget and they have the capability to do it, but there's just an overall lack of DME providers. So as you can see, all of the states surrounding Nebraska do approve private duty nursing services with no limitations more than what Nebraska already provides. So as you can see the third bullet on Director Chaumont's slide that said the alternate services or home health waiver and PAS, I think you've heard a lot of testimony about how those are really not viable options for home care. Really, the only alternative for these patients, the less acute could go to a long-term care facility, but really for the majority of patients it would require acute care, which would come at a much greater cost to the state. So that's what I have. Any questions? [LB952]

SENATOR HEIDEMANN: You did a good job of covering it, Meghan, and the rest of the story, so I appreciate that. We don't ask questions to try to get our side of the story. We actually are trying to get information here to make a good decision down the road. So I appreciate you testifying. Is there anyone else have any questions? Thank you. [LB952]

TOM McBRIDE: (Exhibits 45-46) Good evening, Senators. My name is Tom McBride, T-o-m M-c-B-r-i-d-e, and I'm here this evening representing Epworth Village and the Children and Family Coalition of Nebraska. Most of the testimony you've heard so far has dealt with home healthcare and related industry topics. I think it's important to remember that behavioral healthcare has taken its share of cuts and limitations as well over the past several years, and I want to thank Senator Nordquist for sponsoring LB952. You know, whether it be home healthcare, whether it be behavioral healthcare, we're dealing with quality of life of people in Nebraska, and in our instance specifically children and young people. I don't want to go over a lot of things. I think everything that has been said before me tonight would...you know, anything I would say would pale in comparison. I did want to address one item though as well when it was talked about the neighboring states and, you know, if they saw Nebraska as where they wanted to come to get services. We have not seen that at any time in our agency, in our services. However, I can tell you that in November of 2011 six youngsters from Nebraska, in that month alone, were sent to Colorado because they could not get approved for services in Nebraska. I guess I would just like to end my testimony with a, you know, from the Bible in the 25th Chapter of Matthew when Christ was talking to the multitudes and He said, when He was talking about the poor, the infirm, you know, those diseased and He said: When you do the least for these, you also do to Me. And I think that's the prevailing attitude that you've heard here today is that we are working with those people who definitely need our help and need our services. And once again, I'd like to thank the senator for LB952 and we would offer our support for that. [LB952]

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SENATOR HEIDEMANN: Thanks, Tom, for coming in and testifying. Senator Nordquist has a question. [LB952]

SENATOR NORDQUIST: Yeah, thank you, Tom. I think it's just important to reiterate the point, maybe ask Director Winterer. On these services that we're capping at 60 visits are already...I mean this is...Magellan already approving them saying, yes, you should go past 60 visits and... [LB952]

TOM McBRIDE: Right. [LB952]

SENATOR NORDQUIST: ...and now we're just putting an arbitrary number on it. And they've already determined that to be medically necessary, right? [LB952]

TOM McBRIDE: Right. [LB952]

SENATOR NORDQUIST: Yeah. Thank you. [LB952]

SENATOR HEIDEMANN: Thank you. Welcome. [LB952]

KASEY GONSIOR: (Exhibit 47) Chairman Heidemann and members of the committee, my name is Kasey Gonsior, K-a-s-e-y G-o-n-s-i-o-r, and I am a director of clinical services for the Omaha branch office of Maxim Healthcare Services. Today I'm representing 58 home-care agencies who are members of the Nebraska Association of Home and Community Health Agencies, also known as NAHCHA. Together we provide home-care services to over 1,000 Medicaid patients across the state. I sincerely appreciate the opportunity to speak with you today on behalf of the patients, family members, nurses, and referral sources we service throughout the state of Nebraska regarding LB952. We are asking for your support of this bill. As you are aware, the Division of Medicaid and Long-Term Care has previously acknowledged the cost savings of home care versus institutionalization, while at the same time the department has proposed the care for these patients to be provided by nonlicensed professionals. I won't repeat what's already been demonstrated here I think today. The high acuity that these patients need, the skill level that these patients need has already been demonstrated in everybody's testimonies. I just stress the importance that nonlicensed professionals just don't have the knowledge and the training that licensed professionals do to provide care for these patients, and a person's inability to recognize and respond to the potential complications appropriately could result in increased hospitalizations and, worse yet, death. In my testimony that I provided for you I included a story about a family who receives private duty nursing in their home in Falls City, Nebraska, and how these services have impacted them. I have also included a letter from NAHCHA about the long-term impact of proposed Medicaid cuts to Nebraskans receiving home care, as well as a letter from Dr. Andresen and Dr. Jeffrey Nelson, who are physicians for several of our pediatric clients. Their letters address their professional opinions on

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providing a nonlicensed professional. And I'd just like to leave you with one last thought that I think has already been stated previously. Who would be more qualified to care for your parent, your child, your grandchild or yourself when skilled services are critical to their health and safety, a nonlicensed professional or a person who is fully trained, licensed, and experienced in providing the level of care? Thank you for your time. [LB952]

SENATOR HEIDEMANN: Thank you. Are there any questions? Seeing none, thank you. [LB952]

KASEY GONSIOR: Thank you. [LB952]

STEPHANIE WIESE: Hello. [LB952]

SENATOR HEIDEMANN: Good evening. [LB952]

STEPHANIE WIESE: (Exhibit 48) My name is Stephanie Wiese, S-t-e-p-h-a-n-i-e W-i-e-s-e. I am the director of finances at a Nebraska home-care agency. It has been stated that home-health agencies are supporting LB952 because we stand to lose money. While the threat of losing money if these cuts take place is very real to many agencies, it is offensive that it was stated that this is our sole or main concern as home-health providers. We have been providing cares for many of our clients for years. It should not be hard for anyone to understand how close our providers become to these clients and their families. We actually love them and will continue to fight for them to receive the safest and highest quality of cares possible. If the budget cuts go through, we as a smaller agency will not be able to survive. We currently have 100 employees and we would look to layoff at least 50 employees for lack of work, who will then ultimately apply for unemployment through the state. Until September 2010, home-health agencies were able to bill multiple visits per day, which is defined by the department as two hours or less of uninterrupted direct client care in the home. As an example, some patients in 2010 had up to two hours in the morning and one hour in the evening of home-health aide care on a per-visit fee. This fee was \$51.50 per visit, to total \$103.14 a day, \$37,646.10 a year. In September of 2010 the way agencies could bill and authorize was changed to any person being seen more than two hours per day is now required to bill at the extended hours rate. Now said client with a two-hour visit in the morning and a one-hour visit in the evening is being billed at \$21.10 an hour, \$63.30 a day, or \$23,104.50 a year, saving \$14,541.60 for the state per one individual, while agencies lose this money per one individual. Home-health agencies also received a 2.5 percent cut on their provider rates in 2011. While these cuts are taking place, agencies are still required to do nonbillable supervisions on the home-health aides and LPNs, as well as nonbillable RN assessment visits with the patients. According to state regulations, agencies must also provide orientations, training, in-services, and drive time to our employees, all of which are nonbillable. The department states that the cost

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of supervision is included in the payment for the LPN or aide service. Agencies barely make enough money to cover the cost of employees, let alone to cover these additional required services. These cuts have made it difficult for home-health agencies to compete with hospitals or inpatient facilities when hiring staff members, as we are unable to provide employees with comparable benefit packages. With \$19,146,172 of the proposed cuts coming from home-health services, and the last two years of rate cuts and changes in authorization and billing processes, these budget cuts make it feel as though there is an attack against home healthcare. As home-health providers, we spend 2.1 percent of the total annual Medicaid budget. We save the state of Nebraska money in decreasing the use of hospital and inpatient facility stays. Please support LB952 for the clients who depend on it, for the families who rely so much on agencies, for the healthcare employees who work every day to improve the lives of Nebraskans with disabilities, and for the agencies who wish to stay in business and continue to serve the clients that we love and support. On the next page is one of our patients. He was not able to make it here, he's a quad, but he e-mailed over. He just came home from Madonna Rehab and that is his bill summary, so I quickly this morning did the calculations on what we take care of him per day for a home-health agency and it's broke down. So basically, in one month we will bill the state \$11,873.88 for home healthcare, while at Madonna for a one-month stay it was \$82,390.32, so quite a difference. And then also one last thing, Senator Fulton had asked if anybody had waiver rates. We have contracts with the League of Human Dignity, the LIFE Office, and A&D Waiver, that's the children's waiver. Our home-health aide rates are...we have a contract set up with them, it is \$22.43 for a home-health aide visit, RNs are \$33.15, and LPNs are \$29.25. So it is a little bit more than what we bill to the state for direct Medicaid. [LB952]

SENATOR HEIDEMANN: Thank you for that information though, appreciate that. Are there any questions? Seeing none, thank you. [LB952]

STEPHANIE WIESE: Thank you. [LB952]

SENATOR HEIDEMANN: Welcome. [LB952]

KELLY HANEY: (Exhibit 49) Hi. My name is Kelly Haney, K-e-l-l-y H-a-n-e-y, and as our representatives I would really like you to know a few facts regarding nursing care. As home healthcare agencies, we hire both LPNs and RN staff members. Agencies are regulated closely by the state of Nebraska surveyors to ensure that these nursing staff members are providing adequate cares to our clients and remaining within the scope of their practice while doing so. It has been mentioned by Director Chaumont that it does not require an LPN or an RN to work with a ventilator-dependent individual. I have great concerns with that statement, as do many of my clients' physicians, and I have attached a physician's letter with my packet that you already have. New nurses are not allowed to begin running these cases. These nurses are actually high-tech trained to run a vent

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and care for a vent-dependent client. This is an extra education and training above and beyond. The level of potential adverse effects are very real. To my knowledge, when a vent-dependent client enters a local hospital, they're placed, at a minimum, on a progressive care unit and are never placed on a general care unit. This is due to the high-tech training that's involved in these persons' delivery of care. Of course, when the client is a child and the parents want their child to live in the home-care setting, the hospitals and rehab centers are training those parents to be able to assist in running the vent so that their child can remain in the home safely without the need for 24-hour care. This allows the state to save money, while parents, loved ones, guardians, etcetera, are present in the home with this client. This does not mean that these persons go into this training easily or lightly. They essentially become a nurse to their children. They still require backup nurses as high-tech medically trained professionals. There is a reason the state of Nebraska, the Board of Nursing, and the licensure unit has a scope of practice to specify what type of nurse can provide what type of cares. There is a reason physicians order the home care that can be provided by these nurses. There is a reason that we have nurses. There's a reason that the nurses are high-tech trained. It is not done just so that the healthcare providers can personally benefit. In-home cares provided to these clients is even more vulnerable as there is not direct access to a physician or backup nurses, etcetera. Most importantly that you may not understand if you are not a medically trained individual is that running a vent case is not just sitting and watching the client while the machine does the work. There is critical thinking involved. Some of our clients that are vent-dependent have up to 12 different machines in their rooms. There are assessments that take place throughout the shift to include lung sounds, vitals, monitoring of oxygen saturations to ensure the ventilator's delivery of breaths and oxygen is adequate, answering alarms and determining why they are being set off, monitoring of apnea alarms to ensure that the client has not stopped taking in these breaths delivered by the vent, suctioning through a tracheostomy to keep the client's airway clear so that they can continue to breathe on their own ventilator, breathing treatments, delivery of medications through a tube, feedings through these tubes, positioning so that bedsores are not developed, changing of the tracheostomy itself if the airway cannot be cleared, providing breaths with an "Ambu bag" until the client can recover from a respiratory setback. I can go on and on. These cares are done throughout every shift in these clients' homes. I would especially like to thank you for your time today. I know that it's been a really long day. Attached with the packets that you also have is a testimony from a parent. She is a single mother who could not be here today and asked that I deliver that to you as well. [LB952]

SENATOR HEIDEMANN: Thank you for testifying today. Are there any questions? Seeing none, thank you. [LB952]

KELLY HANEY: Thank you. [LB952]

AMBER HAFER: (Exhibit 50) My name is Amber Hafer, A-m-b-e-r, last name H-a-f-e-r.

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I'm here today to be the voice for my eight-year-old son Taylor. Taylor falls on the autism spectrum, is nonverbal, and does not comprehend language. He functions at the level of an 18- to 24-month-old. He still wears diapers. He also suffers from treatment-resistant epilepsy and has regular uncontrolled seizures. Fortunately, our son currently receives services through the Medicaid waiver program, but as you've heard before, these services are in danger and he has to be recertified every single month, and there's usually a delay jeopardizing our ability to send him to day care. The Medicaid program allows us to provide two of Taylor's most basic and necessary needs: adequate day-care services and adequate healthcare. Taylor has attended Children's Respite Care Center in Omaha for several years. It is vital he is in an environment where full-time nursing staff is available to help administer medications, monitor and treat seizures, and keep him safe. If Medicaid cuts are allowed to go through, this care would no longer be available to us. Because Taylor's needs are so intensive, regular day-care centers are not an option. I would be left with no choice but to quit my job of ten years in order to stay home and care for him. This would devastate our family. We would lose our home and, likely, a vehicle. I'm not sure how we would get by. Medically, the expenses to care for Taylor are incredibly high. He has suffered countless injuries, including broken bones, teeth, and head contusions as a result of violent grand mal seizures. Currently, he's on eight different prescriptions--so getting above ten is not that far off--including a nutritional supplement to help maintain his body mass. He regularly sees several specialists. We're attempting to gain some ground nutritionally through the use of supplements to stabilize his weight. The proposed cuts would eliminate the coverage for his supplements and potentially the drugs he currently needs or may need in the future. This would cause even greater concern for our family. These supplements and drugs are not affordable even after our primary insurance covers a portion. Being forced into the position of deciding which drugs we can afford to give him is unfathomable and potentially life threatening. We do not know what the future holds for Taylor. It is certain he will need skilled services and ongoing medical care throughout adulthood. Should these cuts occur, the effect on Taylor in adulthood could be severe. It's difficult to comprehend now as we live day by day, sometimes hour-by-hour, trying to keep him as safe and healthy as possible. As a parent, many dream of providing a wonderful life full of opportunities, health, and happiness for their children. For my family and many others in a similar situation, that dream is long lost in a sea of constant worry and struggle. The services we receive through the Medicaid program help alleviate a piece of that struggle. They allow us to go to work, be productive citizens, and give our children the care that they need. If we do not have these services, we lose a large portion of the comforts and dignity we have knowing we can care for our children. And I'm begging you in support of LB952, please don't take away from these people who do not and will not have the ability to provide for themselves. Any questions? [LB952]

SENATOR HEIDEMANN: Thank you very much. Senator Mello. [LB952]

SENATOR MELLO: Thank you, Senator Heidemann, and thank you, Ms. Hafer, for your

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testimony. I just have a quick question because you discussed it extensively in your testimony. The director or the CEO of the Department of Health and Human Services, in his testimony today said, quote unquote, Medicaid is not a food program. And it sounds, from your testimony with Taylor's conditions of epilepsy primarily, as well as in multiple prescriptions and on, that these nutritional supplements, it would be almost impossible for him to survive without them. Can you provide any explanation? Or, I mean, is this something that he could possibly go without or? [LB952]

AMBER HAFER: Well, I'm glad you brought that up because when the director of Medicaid services said that, I thought back to one of our visits with his GI doc, and that long term if he does not maintain a healthy body mass, long term a GI tube might be a possibility. So you can allow me to use the oral supplements now and potentially prevent this more expensive level of care. And really what's the difference? I mean, if I'm supplementing it orally or I'm supplementing it through a tube, what's the difference? If they need it, they need it. I would think a healthy body mass wouldn't be just a food program. It's medically necessary for a healthy child. [LB952]

SENATOR MELLO: I would agree with you. Thank you so much. [LB952]

AMBER HAFER: Um-hum. [LB952]

SENATOR HEIDEMANN: Seeing no further questions, thank you. [LB952]

AMBER HAFER: Thank you. [LB952]

SENATOR HEIDEMANN: Welcome. [LB952]

KASEL YAUSSEI KUNATH: Hi. My name is Kasel Yaussi Kunath. It's K-a-s-e-l Y-a-u-s-s-i K-u-n-a-t-h. And forgive me if I'm random. I don't like public speaking at all. I'm not going to bore you with a bunch of details on my daughter other than she had a growth on her brain stem. As a single mom, she has needs mostly at night hooked up to machines. And I just want to let you know she had waiver services for years, the kind that they're wanting to move people to where private people come in, the parent hires then, finds them, hires them, trains them. And that didn't work out very well for me because I was a single mom up until a few months ago. I got married to a wonderful man that wanted to walk in on all this. I lost my job. I'm an RN. I took care of pediatric patients in their homes, the same patients you were seeing today. I got fired because I missed so many shifts because these private people that are working for what they said, \$9 an hour, don't take the job seriously. I had went through eight to ten people in a year, some of them administering oxygen when my daughter didn't need it; some of them not; some of them turning down alarms because they didn't want to be bothered by them. Some of them I found sleeping. They don't understand the ramifications. They don't understand...they just don't have the medical knowledge. You can teach anyone to run

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a machine; you can teach anyone to do that. You can teach people to suction some of these people. But you can't teach them to assess and you can't teach them the importance of the alarms and watching for them and watching for potential problems. And there was two times in the last year and a half where she ended up in the hospital when I came home from a shift because untrained people took care of her and let it go too far, and it probably could have been stopped had she had treatments during the night or something more than what they provided. So basically to me, having untrained people that aren't nurses is the same thing as sending your kid to school and not having a teacher teach them; paying somebody \$9 an hour off the street to teach them and not training them to be a teacher. I compromised...I did something I said I would never do because I had to have a job and compromised my child's care and left her with people that I wouldn't have had I been looking for day care for a normal child. And the last thing is just that again I want to tell you that I'm an example of I lost my job because people were no-showing, they weren't trained, and I was going through too many people. People were scared of her. I was going to lose my house. I still might. I was very excited because she finally got to where she could have way more hours than what the waiver would provide, just found that out in the last couple weeks, and now it might be pulled. And that leaves me back to I don't know if I can have a job and save my house. And I think that puts a lot of people in the same position. So that's it. [LB952]

SENATOR HEIDEMANN: Thank you for telling your story. Are there any questions? Seeing none, thank you. Welcome. [LB952]

MARK INTERMILL: (Exhibits 51-52) Hello, Senator, members of the 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; also have a statement circulating from The Arc of Nebraska. I'm here to speak for the old people. A lot of...almost all of the things you've heard today apply to older people who are needing long-term care and receiving that service in their home. I'm also kind of feeling a little bit old today because I can remember back when, in 1990, when I came to Nebraska to work as the long-term care unit manager in the Nebraska Department on Aging and we had 20 percent growth rates in Medicaid. It was kind of a typical thing. A double-digit year was not uncommon. In 1997, we put together a long-term care plan, because we saw that one of the drivers of Medicaid costs back then was long-term care costs specifically for older people. So in 1997 we started the plan. At that time we had 17,000 people living in nursing homes in Nebraska, and as of about 2008 we're down to 13,000, and our costs have gotten under control. What we appear to be doing in this proposal of cutting private duty nursing, home-health services, nutritional supplements, personal assistance services, is going back to where we were when I came to Nebraska and not having the type of in-home supports that will allow people to stay home and stay out of a nursing home at a much lesser cost to the state of Nebraska. I have a few case studies in my testimony I've attached. I've had several people contact me when they've heard about these proposed cuts with concerns and wanting to share some of the challenges that they're seeing that people would have if they didn't receive the

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supportive services that are provided through those four services. So that's just basically what I wanted to say, and be happy to try to answer any questions. [LB952]

SENATOR HEIDEMANN: Are there any questions? Seeing none, thank you. [LB952]

MARK INTERMILL: Thank you. [LB952]

LAVONE MEAD: Hello. [LB952]

SENATOR HEIDEMANN: Welcome. [LB952]

LAVONE MEAD: Thank you. My name is Lavone Mead, L-a-v-o-n-e M-e-a-d. I work as a home healthcare here in Lincoln. Sorry, I'm a little nervous. I'm here to support the bill. I don't believe you should allow just anybody without the proper schooling and training to take care of some of these children and adults. I take care of Taralynn who was here earlier. I'm sorry, I can't read this...(crying). [LB952]

TALENA PUMEL: Hi. My name is Talena Pumel. I am here in support of LB952. [LB952]

SENATOR HEIDEMANN: Could you spell your name for us? [LB952]

TALENA PUMEL: T-a-l-e-n-a P-u-m-e-l. I am here in support of this bill. I am a sister of a handicapped person. If it wasn't for this, the Medicaid and everything, my sister would not be able to stay at home, enjoy her family and life. As a kid, I remember playing kickball with her. Even though she was in a wheelchair, I would kick the ball and I'd take her around the bases. If we do not have this for these children or the disabled people around or the elderly, they would not be able to stay at home with their loved ones and live a long life that they want. I remember taking care of my grandmother at home when she was bedridden and tube-feeding her. And this is part of the reason why I wanted to get into the healthcare profession. I am in SCC college right now to become an RN to work with these special needs children, and soon to bring home my sister when my mother can no longer take care of her. And I'm also here representing Taralynn. She goes to therapy twice a week and gets botox every three months, which helps out with relaxing her muscles to help healthcare providers take care of her and physical therapists to do her physical therapy that she needs of the stretching of the muscles. If she does not get this stuff and isn't able to be at home, she will be institutionalized or imprisoned, as I feel, in an institution. And by doing that, is taking her life away from her and the loved ones that love her, and the same with my sister. They have every right to live a life just as we do. If they are not provided this life, I feel that they will come to their demise and no longer be living a happy life and soon die. So please do not cut the costs or take Medicaid away from these people. They have the right just as much as we do. [LB952]

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SENATOR HEIDEMANN: (Exhibits 53-60 and 62-71) Thank you for testifying. Are there any questions? Seeing none, thank you. Is anyone else wishing to testify in support of LB952? Seeing none at this time, I want to state that there are letters in support from the Nebraska Physical Therapy Association, the National Association of Social Workers, the Nebraska Association of Area Agencies on Aging, the Nebraska Pharmacists Association, the Brain Injury Association of Nebraska (inaudible), two other individuals, Nebraska Nurses Association, the Children's Hospital and Medical Center, and also a whole bunch more that we got that are also in support. With that, we are going to close the support side of it as proponents. Are there any opponents to LB952? Welcome back. [LB952]

VIVIANNE CHAUMONT: (Exhibit 61) Thanks. Well, we'll change good afternoon to good evening. Senator Heidemann and members of the Appropriations Committee, my name is Vivianne Chaumont, V-i-v-a-n-n-e C-h-a-u-m-o-n-t, director of the Division of Medicaid and Long-Term Care with the Nebraska Department of Health and Human Services, and I'm here to testify in opposition. Nebraska State Statute 68-905 states that the Medicaid program shall be appropriately managed and fiscally sustainable. I believe we, as a state, have made a concerted effort to bend the cost curve of the Medicaid program to ensure the program is sustainable. However, this has required difficult decisions particularly in light of federal mandates. In fiscal year 2011, the Nebraska and CHIP program spent more than \$1.57 billion meeting the needs of vulnerable Nebraskans. These numbers represent the ongoing needs of more than 235,000 individuals and the very real solutions we provide as a state. It's important to note that between fiscal year 2010 and 2011 there was an increase of 10,894 Nebraskans served by Medicaid and CHIP, and the total increase in average monthly eligible individuals was 4.9 percent. Medicaid eligibility is projected to increase by an additional 4.2 percent in fiscal year 2012. In December of 2011, eligibles had increased to more than 237,000. Managing the growth of the Medicaid program requires difficult decisions and impacts real people. However, the program must be sustainable for the 237,000-plus individuals that rely on the program every day. The proposals included in my December 1, 2011, letter, and included in LB952, are in keeping with our mandate to manage the growth of the Medicaid program. I am not going to read, in the interest of time, the things that Kerry talked about, but your testimony has that. Let's talk about emergency room overuse. The overuse of emergency department use for nonemergency diagnoses is well documented through the current Patient Center Medical Home Pilot Program. Both practices in the pilot have implemented programs within their clinics to track emergency department misuse and to work to improve appropriate utilization. In the August 2, 2011, Medical Home Council meeting, physicians from both practices brought examples of inappropriate use of the emergency departments and asked for assistance in finding solutions. In one clinic, nearly 100 patients were identified as misusing emergency departments in a three-month period. In another clinic, 274 clients were identified in a six-month period. The clients stated various reasons for choosing to use the emergency department for nonemergency care: client wait time, after clinic hours, outstanding

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charges with the clinic. Numerous clients presented at the clinic office and when told the wait time was 30 minutes, left the clinic to walk across the street to the emergency department. The physicians within the clinic are then pulled out of the clinic to provide services to the emergency department to the client that had just walked over to the hospital. As far as the reduction to home health to 2040 hours, we talked about some of the things Kerry talked about. I want to reemphasize that the Nurse Practice Act allows personal assistance services and waiver providers to be reimbursed by Medicaid for any task that an individual can be trained to do for a family member. These tasks include ostomy, wound, skin, and ventilator care such as suctioning; provision and application of medication; injections into veins, muscles, or skin; insertion and care of catheters. The variety of these services, along with home-health services up to 240 hours per year, provide options for people to continue to live in the community. I want to give you some examples. Person A is a man in his thirties...these are current clients. He is a man in his thirties with quadriplegia as a result of a spinal cord injury. He has a tracheostomy and requires the assistance of a ventilator 24 hours per day. He requires assistance with ventilator care and monitoring, catheter care, and all activities of daily living. Almost two years ago, this client chose to transition from home-health services to the Aged and Disabled Waiver. He continues to receive waiver chore services in his home. One of his chore providers is a home-health agency. The current cost of his waiver services is approximately \$16,500 per month, 27 percent less than the charge for nursing facility care and substantially less than what the services would cost if provided only by home health. Person B is a man in his forties with quadriplegia who requires 24-hour-a-day assistance from a ventilator as a result of a spinal cord injury. He requires assistance with all activities of daily living. He lives in his own apartment and self-directs his own care. He has managed his own care successfully for a number of years. His current care is provided by a combination of RNs, LPNs, home-health aides, and personal assistance service providers. He currently has 14 individual personal assistance providers he has trained to safely provide his care. If he chose to transition to the Aged and Disabled Waiver, he could continue to receive services from his current providers, schedule his caregivers, and direct his own care. He would also have the availability of a services coordinator should he need or want this assistance. The cost of his care would decrease. Person C is a woman in her forties with quadriplegia as a result of a spinal cord injury. She does not require ventilator assistance or have a tracheostomy, but does require physical assistance with her nonmedical activities of daily living. She is able to assist with her catheter care. She currently receives a combination of RN, LPN, and home-health aide services through a home-health agency. Should she choose to transition to the Aged and Disabled Waiver, her care needs would continue to be met and she would have a services coordinator available to assist in managing her care rather than having it managed by her paid service provider. The cost of her care would decrease. Person D is a woman in her fifties with muscular dystrophy. She has a tracheostomy and needs assistance with all activities of daily living. She currently has 15 personal assistance providers trained to provide her care. She arranges her schedule, self-directs her care. She uses a

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home-health agency as backup support in case of an emergency. Children who would be impacted by the limitations on extended hours of nursing care and PDN could also choose to receive waiver childcare or respite services. The Aged and Disabled Waiver program currently enrolls individual providers, home-health agencies, and independent nurses as childcare and respite providers. Children with high medical needs are currently authorized for RN or LPN services up to 20 hours per day to allow the parent or caregiver to work, attend school, or sleep. Additional hours are authorized as respite for the parent or caregiver. This means that parents are responsible for providing their child's care for four to eight hours per day. I just want to note that most parents are not trained medical professionals, and yet they're watching these children and taking care of these children for four to eight hours a day. The remaining 16 to 20 hours are covered by RNs or LPNs who provide one-to-one care. As a comparison, an individual receiving 24-hour care in a nursing facility or a hospital would typically receive services provided by an aide, with occasional services, assessment, and monitoring provided by an LPN. It would be rare for a nursing facility or a hospital staff to staff a patient one-to-one with a nurse 24 hours a day. If an individual has a family member who needs care, they are often trained to provide this care by a nurse or the physician. This can include ventilator and ostomy care, injections, wound care. Family members are taught to monitor the individual and respond in specific ways should a problem arise. An amendment to Nebraska's Nurse Practice Act allows nonnurses to provide the same care as a family member and allows those individuals to be reimbursed by Medicaid. Some examples: person E is a young boy with a tracheostomy who uses a ventilator for assistance with breathing 24 hours a day. He has multiple medical needs. He is currently authorized for 48 hours per week while his parents are at work, 56 hours to allow them to sleep, and 16 hours for respite. His parents are responsible for providing 48 hours of his care each week, approximately 7 hours per day. His care needs could be met by waiver services. Person F is a young woman who experienced an injury at birth resulting in severe brain damage. She has a tracheostomy, seizures, and other medical conditions. She is currently authorized for 16 hours a day of nursing care while her parents work, sleep, and have a respite from providing her care. Currently, her parents are responsible for providing eight hours a day for her care. When she turns 21, in a few months, her family will need to look at other options for her care. Her needs could be met through waiver services. When faced with cost limitations on skilled nursing care, families sometimes choose to provide more of the child's care themselves. Sometimes they rely on a combination of RNs, LPNs, and trained individual providers to provide the care, and sometimes they consider facility care. If the family chose to consider waiver services, a service coordinator could explore options for meeting the child's needs in the community within the cost limitations of comparable facility care prior to her 21st birthday. I want to share with you some highlights about a few of our clients who receive services through the waiver. Person G is a married man in his sixties who lives in rural Nebraska. His hometown has a population of under 1,500. He has a neuromuscular disease which has caused him to use a wheelchair and also depend on a ventilator to survive. He requires complete physical assistance with all basic activities--dressing, bathing, eating--as he

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cannot move his arms, legs, hands, or toes. He lives at home, which has undergone some modifications, like a ramp. He has trained providers on how to assist him, and they are paid under \$4,000 per month. This is far under what Medicaid would pay to a nursing facility for services. He has friends; he is active in the community; he is home. Person H is in his late thirties and lives in Lincoln with his family. He too has a neuromuscular disease, has quadriplegia, and is on a vent. He is assisted by another person to eat, get dressed, brush his teeth, and shave. Two people generally help on shower days. He and his family are committed to life at home. Various family members provide assistance, as well as other individual providers who have been trained on his specialized care. He is rarely hospitalized, which indicates quality services are provided to him. We have a little six-year-old girl, person I, who lives in western Nebraska. She uses a wheelchair due to her disabilities. Respite providers have learned how to care for her, as she needs someone to help her eat, get dressed, transfer out of the wheelchair. They have been trained on how to use a urinary catheter. She goes to school and other activities, but most importantly, she is at home with her mom and dad. It has been stated that waiver services are not a viable option for clients subject to the limits in home health and private duty nursing because of the waiver cap. This is simply not true. Currently, if the cost of the individual's care exceeds the waiver cap, then a request can be submitted to central office for an exception to that cap. To determine the cap exception amount, the individual's care needs are compared to the cost of providing his or her care in a nursing facility. If necessary, Nebraska can also request to amend the current Medicaid waiver to accommodate the needs of specific populations, including adding private duty nursing services for a individual with high medical needs. Lastly, I'm going to talk about the behavioral health services. The department proposes to limit behavioral health services to 60 outpatient therapy visits per year. This limit would provide parity with the current limit of 60 outpatient physical health therapies per year. The vast majority of Medicaid clients do not currently exceed the limit of 60 mental health therapy visits per year. Person J is an adult living in assisted living and diagnosed with bipolar disorder, who had a frequent amount of individual psychotherapy with and without medication management across the entire year. Under the proposed limit, this person would be reduced from having therapy once every five days to once every six days, which is still more than one therapy visit session per week all year long. Medicaid management would still be covered without any limitations per year. Someone testified that Medicaid management and therapies were combined. They're not. Person K is an adult who did not receive routine therapy sessions but instead had nearly daily individual psychotherapy with medication management for two months. It would be highly unlikely from a clinical perspective that a person could benefit from that intensive level of psychotherapy. Person L is a youth who has received up to eight family therapy sessions per month, though the client was only four years old. It isn't clear how much intensive psychotherapy a client of this age would benefit from. I know it's been a long evening for you and I want to thank you all for the opportunity to testify. I'd be happy to answer any questions. [LB952]

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SENATOR HEIDEMANN: Senator Mello. [LB952]

SENATOR MELLO: Thank you, Senator Heidemann, and thank you, Director Chaumont, for your testimony. I didn't notice and looked at the clock, it's roughly 8:00 or almost. We've been here for roughly four hours on LB952, and it's unfortunate...I guess this is more of a statement than anything. Over the past four hours, we've heard testimony in support LB952. Not once have we been graced by the presence of our Governor who spent four hours on his tax bill last week, LB970, which he spent the entire hearing, support and opposition, to push his tax bill forward, but was unable to join us today as we heard from I think a good number of Nebraskans who have concerns about your proposals put in your December 1 letter. Two questions I have. One, we did just hear testimony from an individual who explained her family's situation as a Medicaid recipient in regards for her son taking oral nutritional supplements. And in your testimony I saw you did not read it but it is part of the similar testimony that Director Winterer mentioned. Your testimony does, quote unquote, says Medicaid should not be treated as a food program. In cases such as we heard earlier where families do not view this as a food program but more of an oral supplemental nutritional program that helps them and their child possibly to not have to get a G-tube, ultimately, the department's efforts on this, is it safe to say we're being pennywise and pound-foolish to try to limit oral supplements where the likely result would be is that families would have to get G-tubes for their children? [LB952]

VIVIANNE CHAUMONT: Well, you know, the testimony is that. No physician came over and said that. I don't...I don't...you know, I think the issue is one of drawing the line somewhere. You know, Medicaid is not about food, okay? I think if a child needs it and a doctor is willing to certify that under EPSDT, we might be willing to pay for it if it's required for us to pay for it under EPSDT. But, you know, the issue is where do you draw the line? A healthy four-year-old needs food. Is Medicaid going to pay for a healthy four-year-old's food? Where do you draw the line? And I think that what we're trying to do here is we're trying to draw the line at providing necessary medical services for needy Nebraskans. [LB952]

SENATOR MELLO: It is safe, though, that an apple and an orange is different than oral nutritional supplements. It's safe to say that, correct? [LB952]

VIVIANNE CHAUMONT: It is safe to say that a child... [LB952]

SENATOR MELLO: That doctors are not... [LB952]

VIVIANNE CHAUMONT: Right. [LB952]

SENATOR MELLO: ...prescribing apples and oranges to Medicaid patients. [LB952]

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VIVIANNE CHAUMONT: No. And they are not prescribing nutritional supplements either. These are...these can be had without a doctor's prescription. [LB952]

SENATOR MELLO: Okay. I guess one last question I have, and it's something else that wasn't...specifically you didn't mention in your spoken testimony but it was part of your written testimony, which said according to 2008 data, 28 states do not cover this service. This service is private duty nursing, an optional service under federal law. Your written testimony says 28 states do not cover this service, including 5 of the surrounding states. We also heard testimony from someone else who provided I think a fairly detailed chart showing that pretty much every state around surrounding Nebraska does provide this service, with the exception of Wyoming, which theirs was dealing with more of a scope of practice issue in regards to nursing. Is that just old data? Are you essentially...I'm giving you the ability just to explain this as...are you just using old four-year-old data or...? [LB952]

VIVIANNE CHAUMONT: Right. And we also called surrounding states and were given the testimony. Our data comes from the Kaiser Family Foundation report, and perhaps one of the issues is that perhaps a discrepancy. So, I mean, we called folks as well. Perhaps a discrepancy is that some states, those states, some of the testimony that I heard--Colorado, for instance--covers it as a waiver service. It does not cover it as a state plan service. So as a waiver service it is subject to a cap and restrictions to a specific population. [LB952]

SENATOR MELLO: Okay. Thank you. [LB952]

VIVIANNE CHAUMONT: Um-hum. [LB952]

SENATOR HEIDEMANN: Are there any other questions? Senator Nelson. [LB952]

SENATOR NELSON: Thank you, Senator Heidemann. Thank you, Vivianne. I'm interested, and, you know, I think we covered this well. If necessary, Nebraska can also request to amend the current Medicaid waiver to accommodate the needs of specific populations, including adding private duty nursing services for individuals with high medical needs. We saw a number of people with high medical needs here. Is what you're proposing going to preclude 24-hour-a-day private duty nursing for individuals like that? How are those evaluated and how are they accommodated? [LB952]

VIVIANNE CHAUMONT: We don't pay 24 hours a day for anybody. [LB952]

SENATOR NELSON: Okay. [LB952]

VIVIANNE CHAUMONT: If kids are at home, as everyone testified, they are watching the kid, the child, you know, some of the time. So like somebody testified, I'm familiar

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with Colorado, which limits it I believe to 16 hours a day, meaning that a parent has to be responsible, someone else has to be responsible for 8 hours. I don't know that we have cases where we provide 24 hours a day of nursing care to anyone. [LB952]

SENATOR NELSON: When you mention parents providing four to eight hours, are those...can those be separated into two different segments? I mean, when are the parents available if both are working? [LB952]

VIVIANNE CHAUMONT: That's in the morning before they go to work; they go to work; in the evening when they come home before the person comes to provide them nursing hours so that they can sleep. [LB952]

SENATOR NELSON: All right. Thank you. [LB952]

SENATOR HEIDEMANN: Are there any other questions? Senator Mello for one more. [LB952]

SENATOR MELLO: I just had one question, and if you don't have this data, if you could help us maybe find this data that would be helpful. [LB952]

VIVIANNE CHAUMONT: Uh-huh. [LB952]

SENATOR MELLO: One of the testimony, essentially part of the underlying focus of what we heard a lot, was the change that the department is making in regards to moving towards private care providers instead of nurses or home-health nurses. Who is one of the largest companies who are private care providers who would be able to now do these services that these home-health nurses currently provide? [LB952]

VIVIANNE CHAUMONT: Several of the...they wouldn't be done by nurses necessarily. That's the whole point. [LB952]

SENATOR MELLO: I understand that. [LB952]

VIVIANNE CHAUMONT: Right, but... [LB952]

SENATOR MELLO: But what are some of the... [LB952]

VIVIANNE CHAUMONT: I believe that some of the larger providers also do waiver services: Maxim, Elite. [LB952]

SENATOR MELLO: Okay. [LB952]

VIVIANNE CHAUMONT: I don't know. I would have to check, but... [LB952]

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SENATOR MELLO: Okay. [LB952]

VIVIANNE CHAUMONT: ...a lot of the big waiver provide...the big home-health agencies also do waiver. [LB952]

SENATOR MELLO: Okay. [LB952]

SENATOR HEIDEMANN: Anyone else have any questions? Seeing none, thank you. [LB952]

VIVIANNE CHAUMONT: Thank you. [LB952]

SENATOR HEIDEMANN: Is anyone else wishing to testify on LB952? Anybody in opposition? Seeing none, does anybody want to testify in the neutral position on LB952? Seeing none, would Senator Nordquist like to close? [LB952]

SENATOR NORDQUIST: Thank you, Mr. Chair and members, for your attention all day to this issue. We...and I want to thank all the testifiers. We heard from Nebraskans who need these services for their families, who are coming before their government to ask for these services to be maintained, and their voices were heard loud and clear today. I understand Director Chaumont's concerns about the sustainability of Medicaid. I have full confidence in her ability to maintain a sustainable growth rate in Medicaid. She has shown a...she has quite the track record when it comes to that, doing that, while including these services. So I think it just goes back to the initial point that I made about a budget being a moral document and how as we make decisions I don't know any priorities in this body that should rise above meeting the healthcare needs of the most vulnerable in our state. So with that, that's all I've got. [LB952]

SENATOR HEIDEMANN: Thank you. Are there any questions for Senator Nordquist? Seeing none, we will close the public hearing on LB952. [LB952]