## [LB236 LB397 LB482 LB523 LB555]

The Committee on Health and Human Services met at 1:30 p.m. on Wednesday, February 14, 2007, in Room 1510 of the State Capitol, Lincoln, Nebraska, for the purpose of conducting a public hearing on LB482, LB523, LB555, LB236, and LB397. Senators present: Joel Johnson, Chairperson; Tim Gay, Vice Chairperson; Philip Erdman; Tom Hansen; Gwen Howard; Dave Pankonin; and Arnie Stuthman. Senators absent: None. []

SENATOR JOHNSON: (Recorder malfunction)...if we do have an overflow crowd. This is the Health and Human Services Committee for the Nebraska Legislature. Let me introduce the people around the room. On my far right is Senator Pankonin from Louisville; Senator Phil Erdman from Bayard; Tim Gay from Papillion; Jeff Santema is to my immediate right, our legal counsel; Senator Gwen Howard has had to step out for just a minute and that doesn't mean that that is a lack of interest in what is going on here. It probably means that she is testifying at another committee. Next is Senator Tom Hansen from North Platte; and Senator Arnie Stuthman from Platte Center; and Erin Mack is our committee clerk. I did hear a couple of cell phones going off in the last little bit and usually we shoot people, but (laughter) today being Valentine's Day, we will just use a bow and arrow. (Laughter) Now the way we operate is this; is that a senator will introduce the bill and then there will be proponents and opponents and then neutral testimony. We've got a lot of people here today. Chances are it's going to take us a long time. What I'd like you to do is please be brief. We often let the first person talk a little bit longer than the others, but even there we want you to kind of be careful how long you talk because what can happen is this; is that towards the end of the day we really shortchange those people because one of the things that happens is not only is there just the lack of time, but when you've been sitting up here for three or four hours there's a lack of interest. We can't help it. And so you're just not fair to the last people if the first ones use up a lot of the time. Now let me see. So I guess what I'd say is, by and large, hold it down to three minutes and try and make what you say something new. And one of the things that we don't like at all is for somebody to come up with six written pages and think that they're going to read their report. It will not happen. All right. And now there may be many of you that want to officially make your position known and so there are sign-in sheets of support or opposition or whatever for each of the bills. And for those of you that do testify, give us your name and then spell it. These are recorded and transcribed. If you have literature to pass around, please have 12 copies. If you don't have that many, why, the pages will make more and will pass them around. I think that about takes care of anything. Jeff, I didn't leave anything out, did I? All right. So with that, let's start out and we'll delegate the responsibility here to our Vice Chair Senator Gay and we will open the hearing on LB482, provide for the coverage of qualifying autism services under the Medical Assistance Act. [LB482]

SENATOR GAY: Thank you, Senator Johnson. [LB482]

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SENATOR JOHNSON: Senator Gay, members of the committee, I am Senator Joel Johnson, J-o-h-n-s-o-n, representing the 37th Legislative District. Let me begin today with some background. The subject is autism. In Nebraska, approximately 1,400 to maybe as many as 1,500 children are...under the age of nine have been diagnosed with autism. Last week the Center for Disease Control released new numbers on the incidence of autism. It is now thought that it occurs in every 1 in 150. The last number I saw on that was 1 in 160. Autism, we think, is an urgent health concern and one of the things about it is I don't think that Nebraska has what we could interpret in any way, shape, or form a stellar record. It's almost been one of neglect. The diagnosis is growing at the rate of perhaps more than 10 percent a year. No one knows why. Autism is more prevalent than juvenile diabetes, muscular dystrophy, leukemia, cystic fibrosis combined. Autism is receiving national attention. Many magazines have featured this recently and the last weekend's USA Today also had that as their feature article. Autism...here's kind of an interesting thing, it is the eighth most common word "googled" in Google News for 2006. I think it's a pretty good indication of the interest in this and I think, more importantly, the desperation felt by these families. Here's what this legislation does. LB482 requires the Department of Health and Human Services to apply for a Medicaid waiver to cover medical assistance for intensive early intervention services based on the behavioral principles for children with autism. This language is identical, except for the dates, to the committee amendment, LB101 during 2005, which is advanced by the Health and Human Services Committee. The Medicaid waiver is but one piece of this puzzle. For those of you who are new to the committee, a Medicaid waiver will cover about 60 percent of the funding for treatment and help us leverage public and private dollars so that we can begin to get help for those children and their families. I am proposing an amendment to LB483, the A bill, that would appropriate additional funds from the Nebraska Health Care Cash Fund for a demonstration project for children with the autism spectrum disorders. I think it's important that we stress that we are not trying to note there that I'm not asking for General Fund dollars for this project at this time. I think maybe the best thing that we might even say about this is, with this being such a huge problem and the potential as well as the actual dollars that are spent on this...because what we do now basically is transfer the medical responsibility to our schools--probably isn't the most satisfactory solution. So what we're trying to do here, basically, is look for guidance by putting in this program. What am I asking for the Appropriations Committee is to set aside an additional \$1 million from the Nebraska Health Care Cash Fund to a newly created category entitled public-private partnerships for long-term healthcare issues. Appropriations for the new category would be designated for programs with: one, contractual, private sector willingness to commit to match public funds on a not less than a two-for-one basis; and the opportunity to bring about early intervention with children who would otherwise require significant public costs for care as adults because the early intervention was lacking. Let me just repeat that. I think it's worthwhile. This is for those children who would otherwise require significant public costs for their care as adults if we don't do something with early

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intervention. It is intended that the research and demonstration project for children with autism disorders would qualify as the initial program for this category with the intent that there would be \$1 million per year for five years. I'm very excited that we do have a partner to introduce for this process. It is a partner of the best kind, that is the private sector. It has been my experience and the experience of most people that the best outcomes involving government resources are those where public-private partnerships were established. We're also very fortunate to have a partner to help us take on this very monumental task, and you'll hear more about this from the people that will follow me. My friends, we have many heavy issues to come before this committee. I know I speak for those that share this tremendous pressure, but there are also much to be gained by what we do. There's no secret the resources are limited. It's really kind of frightening task, it's...the task is so big. However, I think we have to find direction from this committee through programs like this so that we know which direction to go in the future. The proposal I bring before you, I think, fits these goals. If we invest in children with autism early on, provide, and I might see...say not only provide for the intensive therapy but study the direction that we should go down the road, we will be well-served. It does work with these programs now. Their...vastly improve IQs and other things like that do go up, and they can return to virtually a normal existence without state assistance as adults. Another 30 or 40 percent will be markedly improved and have a much better, reduced cost to the state in their adult lives. So with that, I will pass on to two people here really that I want to make special mention of. One is Matt McNair, who many of you know in our own Attorney General's Office, and his wife Chrissy, who have a son with autism; and the other person is Gail Werner-Robertson, who is committed, and we'll let her talk about that more, to...she has already started a foundation called the Sunshine Foundation for autism, and so on, and would be a very helpful person in this. One other thing that many of you got to meet, and if you haven't, Senator (sic) Wayne Fisher has come to the University of Nebraska and they have already established an autism program up there and at the Munroe-Meyer Institute, and it's really worth the trip and I'm sure they'll be glad to show you around up there as to what they're doing. So there's many things here that we need to do. I think there's one statistic that shows how hard this is on families and what it is, is this; is that couples with an autistic child, 70 percent of them will become divorced. It's that hard on families. So I think there's both the personal cost, as we can see by that statistic, but there's the immense cost as we look down the road for this and we've got to find the best direction that we can for doing this. So I've talked for awhile; hope that explains what we're trying to do, and there will be people behind me that probably won't talk as long as I have (laugh), but did want to give you an overview for this. [LB482]

SENATOR GAY: Thank you, Senator Johnson. Are there any questions from the committee? Senator Stuthman. [LB482]

SENATOR STUTHMAN: Thank you, Senator Gay. Senator Johnson, when you talk about the private money and the federal money or state money, two for one, is that two

private, one...? [LB482]

SENATOR JOHNSON: Well, the minimum amount would be that, Senator Stuthman, and we would hope to leverage things better than that. But what we're saying, I guess, and Ms. Robertson will, I think, go through this, but, you know, we're talking from a family that is willing to make a significant contribution to this public-private partnership and she will tell you what her inspiration is for doing that as well. [LB482]

SENATOR STUTHMAN: Okay. Thank you. [LB482]

SENATOR GAY: Thank you. Any other questions? I see none. Again, Senator Johnson was being nice. As the introducer, he gets a little longer time (laughter) to visit. So... [LB482]

SENATOR PANKONIN: You mean a lot. [LB482]

SENATOR GAY: ...but...yeah, a lot longer, but it's an important issue. We understand that we do have five different bills today. We don't want to limit you in any way. You know, we're not going to hold you right to the three minutes, but it will be a long day if we don't, for everybody. So with that, I'd like to ask for proponents to come forward, and if you could state your name, spell it out for the clerk here that's always helpful too. [LB482]

CHRISSY McNAIR: In this box? [LB482]

SENATOR GAY: Yep, and then put your testimony sheet in the box. Thank you. [LB482]

CHRISSY McNAIR: Okay. My name is Chrissy McNair, M-c-N-a-i-r. First of all I want to thank all the senators, members of the committee for allowing me this opportunity to testify. Most of you I've actually spoken with in person already, and had the pleasure of talking with you and talking with you about this issue, so I will try not to be repetitious for what we've already mentioned. But five years ago my husband Matt and I, our two-year-old son Luke was diagnosed with autism, which began an adventure that we never thought we would embark upon. We immediately started researching what does this mean, what do we do. All we knew is we had a child who was breaking windows with his head and wasn't talking, so we knew we had to do something to help him. The more we started researching the more realized that there is treatment out there, and what we found is a program called a behavior therapy program that would help our son and help many other kids with autism. So I was so excited that I found something that was going to work, and over and over I read, you know, articles, statements from the Surgeon General, from the American Academy of Pediatrics. Everywhere I went I was hearing about this behavior therapy program, and became excited because I knew I

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could do something to help my son. Well, when we looked into it, we...our little balloon guickly deflated, realizing that we're talking about \$50,000 to \$70,000 cost. And so we knew we had to do something different. You may recall that a couple years ago we were here, for the members that are returning on the committee. This is not the first time the autism community has been in front of you and I want to thank all of you for passing unanimously last...two years ago our other initiative that's very similar to the one we're doing now. I want to start off a little bit by talking about autism. Senator Johnson had mentioned that the incidence has grown to 1 in 150. What's interesting is that my son is in 1st grade now and he has about 63 kids in his class; 4 boys in his 1st grade have autism. So it's all over the place and it's something that affects everyone. Autism is a spectrum disorder. A lot of people ask me, what does that mean, to be austistic. It looks different in different people. Some kids are very, very high functioning, and some have...struggle with everything and it's a lot harder for them to integrate into society. So it's a spectrum disorder and it looks very different in every child. Fifty percent of kids with autism have very severe behavior disorders, meaning they break windows with their heads like my son does (laugh) and those are the kids that are really going to need a lot of intervention. They all need a lot of intervention, but those kids are the ones that end up costing the state a lot of money as well because those severe behavior disorders, if not attended to by the time that child is, you know, 12 years old and weighs 110 pounds, his mom can no longer handle him anymore, and it becomes a real issue by the time, of course, you can imagine, by the time you're 21 years old. So that's a little bit about what autism is. Briefly, what is behavior therapy, because that's really what we're asking you to be an advocate for, so it's important, I think, that you understand behavior therapy really is, and you'll hear more about that from Dr. Fisher, but what behavior therapy does from the parents' perspective is it teaches your child how to talk, how to learn, how to play, how to connect with other kids, how to connect with adults, how to ask for what he wants. It teaches them how to initiate a conversation with another child and how to respond when another child initiates toward them. It teaches them to learn by watching others, which is something that we all do naturally, but to a child with autism that's the last thing they want to do. They don't really want to tune in to what other people are doing and learn from that, so they're taught to do that. And that's what behavior therapy does. It teaches all this by working with the family and I think every parent in this room would probably second this notion that none of us are asking for a free ride, and none of us are not willing to step up to the challenge of having a special needs child, but you don't know what you don't know. I mean, Senator Stuthman, if I asked you to teach me Chinese, maybe you could, I don't know (laugh), it's one of those things, if you don't know how to speak Chinese, how can you teach someone else how to speak Chinese? So it's the same thing. It's the same concept. We don't know how to teach our children and so we're asking that the experts who do know how to teacher our children, that we are allowed to interface with those people and be taught with them how to work with our own kids. You know, I think we can all imagine how these parents feel when their child is diagnosed and how desperate you feel and how sad you feel, but then how excited you feel to find that there is an intervention that

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can help. But it's only available to those who can afford it, and that's a tragedy. So what we're asking for you to do is to support this pilot program. The way that the bill is written is in more of a general sense, and we are working with members of the education community, members from the state, parents, interested parties. We're all coming together to work out this bill so that it will become something that will work for everyone who's interested in this issue. The main thing that we want to really iterate is that this is about controlling costs, it really is. It's about investing in these children now and saving paying for them a lot later. And it truly is... I hate to sound sensational, but it truly is a pay now or pay a heck of a lot more later situation. We're talking about saving between \$1.6 million and about \$2.2 million per child over that child's lifetime if they're invested in early. And what we're looking for is an intensive early intervention program, and I think "intensive" is the operative word because there are early intervention programs out there, but intensive is not what's being regularly offered and it's not being offered in the families' homes as well. So that's something that we would like for you to consider. You know, there truly are two issues here. It's kind of a moral issue and it's a fiscal issue. And I know, just from speaking with all of you individually, that you are understanding of the moral issue and so we appreciate so much your time and dedication, and certainly appreciate Senator Johnson's stepping up and sponsoring this bill and just really becoming a champion for us. You know, autism knows no boundaries. It will affect any child, rich or poor, regardless of where that child comes from, and the treatment should know no boundaries either. Thank you. I'll be happy to answer any questions that you have. [LB482]

SENATOR GAY: Thank you. Are there any questions? Senator Stuthman. [LB482]

SENATOR STUTHMAN: Thank you, Senator Gay. Thank you, Chrissy, for your testimony. The thing that always concerns me with the cost of doing this, it's, you know, it's a large amount, \$50,000, \$60,000, like you stated, is that because of the intensity of it, or is that because of the knowledge that is needed to have this care for these children? That price seems terrible high to me. [LB482]

CHRISSY McNAIR: It's both. It is...it's the knowledge. The individuals that work intensively with behavior therapy, it takes a lot of expertise, and so you're working with people who have a high level of training. And so, yes, you're paying for the knowledge, but you're also paying for the time. Because what...when you're developing an intensive program--let's say it's a 40-hour-a-week program--typically, your staff really can't be expected to work more than about 3 hours at a time with your child, because you can imagine the burnout rate. The research has shown that they need three hours to be effective. Less than that you don't really get a whole lot accomplished, especially if you're dealing with a lot of behaviors. Four hours is a really high burnout rate. So if you have three-hour intervals, you have to employ more people. So it's an intensity issue and it's an expertise issue. [LB482]

SENATOR STUTHMAN: Thank you, Chrissy. [LB482]

CHRISSY McNAIR: Sure. [LB482]

SENATOR GAY: Thank you. Senator Erdman. [LB482]

SENATOR ERDMAN: Chrissy, good to see you again. I was hoping maybe you'd ask Senator Stuthman to show you how to part your hair, but...(laughter) he actually did know that at one time. (Laughter) He actually just got too tall for his hair. Let me ask you a couple quick questions. As we debated or discussed LB101 in 2005, we were talking about the ABA type of treatment, the applied behavioral analysis, and I'm assuming that others will be here to speak specifically to the programming. Is that a similar model that we're looking at when you talk about the intensive treatment, or they're more advanced or better programs out there, just for clarification of the type of treatment that we're talking about? [LB482]

CHRISSY McNAIR: Sure. It is basically the same treatment. ABA is a very umbrella term and there's some...a little bit of misconception about what actually applied behavioral analysis is. It used to be, years ago, that it was just what they would call discrete trial training, where you'd sit across the table and work with that child in one setting, and it has expanded into so much more than that. So we changed the language from ABA to behavior principles, which opens up all different types of therapies that actually do fall under the ABA umbrella. But I think for the community to really understand what it is that we're advocating for, that change in language was necessary. [LB482]

SENATOR ERDMAN: Okay. Thanks. [LB482]

CHRISSY McNAIR: Sure. [LB482]

SENATOR GAY: Thank you. Are there any other questions? I see none. Thank you. [LB482]

CHRISSY McNAIR: You know, I forgot to do something. (Exhibit 1) I do have, if I can do that now,... [LB482]

SENATOR GAY: Sure, just hand them out. [LB482]

CHRISSY McNAIR: ... I have about 50 letters from parents and grandparents and family members. [LB482]

SENATOR GAY: Okay, we will make sure those get distributed and put in the...placed in the record, okay? [LB482]

CHRISSY McNAIR: Okay. Great. [LB482]

SENATOR GAY: Thank you very much. [LB482]

CHRISSY McNAIR: Thank you. [LB482]

SENATOR GAY: Thank you. Other proponents, please come forward. And while we're getting other proponents up, we do have other letters of support from Lorrie Bryant of Behavioral Pediatric and Family Therapy Program, Patrick and Jeanne McClure, Laura Burkard and her family. So those will also be entered into the record. (Exhibits 5, 7, and 8) Go ahead. [LB482]

CONNIE SHOCKLEY: (Exhibit 2) Thank you for seeing us today here. Mr. Chairman, members of the committee, my name is Connie Shockley, spelled C-o-n-n-i-e S-h-o-c-k-l-e-y. I'm here today representing the Autism Society of Nebraska and as a parent and proponent of LB482. Thank you for allowing me to testify. And I have a letter that I'd like to have entered in for the record. Thank you. I speak to you today as a parent of two children with autism, as a therapist experienced in behavioral therapy, and as the vice president of the Austism Society of Nebraska. As a parent of two children with autism, one 17 and one 10, my experience with gaining assistance has varied throughout the years. The crucial first few years for my son was missed when I was advised by a local developmental pediatrician that the local school district would take care of dealing with him and his issues. It wasn't that the school didn't have good intentions; it's just that they didn't have the education in how to actually teach him. And it was noted in his documentation that the first two years that they had him he made no significant language gains. When my youngest daughter was also showing signs of autism, the local school district had a little more information on autism; however, homebound services were limited to one hour a week due to funding issues, and that is a far cry from what anyone might term intensive. Our financial situation was tight and we could not afford the huge bill that came with running with a home program, so I took it upon myself, after work and through conferences and networking with parents, to educate myself on autism and the various therapies. We were lucky that we did qualify for some Medicaid services, but Medicaid in Nebraska does not cover autism services. What advancements my children did make through...I'm sorry, my advancements my children did make was through the tireless efforts of teachers who had a good understanding of autism and behavioral therapies, and what I could implement myself at home. Our limited budget has gone towards the therapies we could access and very basic living necessities. Vacations are a rarity in my household. Then tend to come in the form of autism conferences. The harsh reality is that many things most people consider necessities, such as health and dental checks or tune-ups and oil changes, are luxuries for those dealing with autism due to the huge costs involved in the crucial therapies needed. As an advocate and, for the last two years, as the vice president of

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the Autism Society of Nebraska, I've spoken with many parents. The sad fact that faces these families is that unless they have the financial ability to start an in-home program, there are few services in this state. Schools try, but even today it's hard to find an appropriate program with a teacher who has any training on autism or behavioral therapy. Parents of a child with autism have to learn to advocate, to be detectives in searching out those few providers who do exist in the state, to educate themselves on autism, and often be the main therapist for their child. It's a daunting task for even the most determined person to start down on that long road. I was fortunate enough to work for Project Best Case at Munroe-Meyer for three years, under the direction of Dr. Susan Wilczynski. Using a variety of behavioral therapy strategies, I saw the children we treated flourish and grow in the short time that they were in our program. As a therapist and as a parent, it was the best training I have ever received. I stated many times during my time there that I thought it was the place that parents needed to go. They needed to work there, to do the things that I was doing so that they would know how to work with their children. As a parent, I could understand the relief and the hope, as the parents who came through our program, that they had finally found something that was working for them, that was working for their child. The fact is that children with autism can improve with the right therapy. They can be taught to talk, they can be taught to interact with others, and they can and do show us every day the miracles of each step they master in the process. My son lost the first few years of his early education in a program that didn't know how to teach him. When we finally got him in a program with a teacher well-versed in behavioral therapies, the turnaround that first year was amazing. When he was five, shortly after he started his new program, we had drilled him extensively the first few months on how to answer questions appropriately, and one of those questions was, what is your name? We had gone to the park that fall and he had played with the children, when one turned and asked him the fateful question, what is your name? I was halfway out of my seat to help prompt him to answer the question when, for the first time, my son looked directly at that boy and said, my name is Chris. I wanted to dance. I wanted to scream. I wanted to point to the miracle that was my baby boy and shout out to the other parents, look what he did! Look at the miracle that happened right in front of you! Parents of typically developing children take for granted those developmental steps that happen throughout their child's live. Parents of a child with autism know them for the miraculous events that they are. As a parent, as a therapist, and as the vice president of the Autism Society of America (sic), I am happy to give my full support to this bill and hope that you will offer your support as well. Thank you very much for listening to me. I'll be happy to answer any questions. [LB482]

SENATOR GAY: Thank you, Connie. Are there any questions from the committee? Senator Stuthman. [LB482]

SENATOR STUTHMAN: Thank you, Senator Gay. Connie, in our public schools we have special needs students that,... [LB482]

CONNIE SHOCKLEY: Uh-huh. [LB482]

SENATOR STUTHMAN: ...you know, require--sometimes it's a one-on-one individual--attention by a teacher. But the schools do not have anything for autism, do they? But that is a special need, isn't it? [LB482]

CONNIE SHOCKLEY: It is a special need, but any special education program, if you go...if you were to go to UNO, the maximum amount of time a teacher would receive on information on how to work with a child with autism is maybe half a day, and that is just to cover the basics, autism 101. It doesn't really cover autism therapy strategies or anything of that nature. So really, special ed teachers are on their own and with their local school districts to find resources on learning what these therapies are and how to implement them in their schools. [LB482]

SENATOR STUTHMAN: Okay. Thank you. [LB482]

CONNIE SHOCKLEY: Uh-huh. [LB482]

SENATOR GAY: Connie, I have a question for you. Many times we hear problems because of no parental supervision and it promotes problems. In this case, it's almost, as a parent, you're just...I commend you and all the other parents coming today. But the question I want to know--you're getting involved and you're putting your whole life into your children, which is great--how many, you know, I don't know if you know this from...but how many other kids out there that, you know, maybe we talk a lot about foster care and they don't have parents and they may have be "strucken" with this or that won't get any early intervention probably, but do you have any numbers of kids out there that maybe don't have good parents like yourself work in this problem? Because I think they would just be in deep, deep trouble then with nobody trying to help them. [LB482]

CONNIE SHOCKLEY: I don't have access to that kind of information. [LB482]

SENATOR GAY: No figures like that? [LB482]

CONNIE SHOCKLEY: No, I'm sorry. I couldn't... [LB482]

SENATOR GAY: It would be interesting to find out because if we don't get to those then your two-thirds...because in the letter here, costs can be reduced by two-thirds with early diagnosis and intervention. Well, if we can't find them we'll miss the boat. That would be an interesting thing to find out, I think, down the road. [LB482]

CONNIE SHOCKLEY: Uh-huh. [LB482]

SENATOR GAY: So thank you. [LB482]

CONNIE SHOCKLEY: Thank you. [LB482]

SENATOR GAY: Any other proponents? [LB482]

WAYNE FISHER: (Exhibit 3) Good afternoon, Senator Gay, members of the committee. My name is Wayne Fisher, F-i-s-h-e-r, and I am the director for the Center for Autism Spectrum Disorders at the Munroe-Meyer Institute at the University of Nebraska Medical Center. Although I work at the university and have expertise on autism, I am expressing my personal opinions today and not speaking for the university. As others have said, autism is a serious and lifelong condition that impacts multiple areas of development and has significant and lasting consequences for the affected individuals. Autism is ten times more common than juvenile diabetes, muscular dystrophy, childhood leukemia, and cystic fibrosis, yet a hundred times more dollars are spent per case on those other conditions than are spent on autism. The potential devastating effects of autism are evidenced by the fact that only a small minority of children graduate with a regular high school diploma. The vast majority of adults do not become self-sufficient. Children with autism are more likely to display destructive behavior, like self-injury and aggression, and are more likely to be segregated from their peers and even institutionalized. And the overwhelming effects of autism extend beyond the individual. The divorce rate has been said it's over 75 percent in some parts of the country, and siblings and parents of children with autism are much more likely to experience stress-related mental health problems. The funding we are requesting through LB482 and LB483 will make available effective treatment that will help, over the next five years, approximately 420 children attain their fullest potential. That treatment is called early intensive behavioral intervention and, when implemented by well-trained professionals and peer professionals, children with autism show marked gains in IQ, language, social skills, and reductions in aberrant behavior. Nearly half of the children who receive this treatment improve to a level where they can be educated in regular classrooms with minimal assistance. Early intervention is based on the principles of behavioral analysis and is well-rounded in both basic and applied research on learning and behavior. As stated by the Surgeon General's report in 2000 related to autism, 30 years of research has demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and increasing communication, learning, and appropriate social behavior. Early intervention based on the principles of behavior analysis has also been endorsed by a research review panel of the New York State Department of Health, the National Research Council, and the Association for Science in Autism Treatment. In fact, it was the only treatment found to have strong evidence supporting its use for treating the major symptoms of autism by the New York study group. Behavioral treatment is highly effective for children with autism for a number of reasons. First, it uses highly refined empirical methods for identifying items and events that will motivate children with autism to learn new skills and behave in more socially

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appropriate ways. Second, behavioral interventions follow a very data-driven approach in which the goals and objectives of the treatment are clearly specified and measured on an ongoing basis. In contrast to traditional approaches where progress is monitored once or a few times a year, the effectiveness of behavioral interventions are monitored on a daily basis and this ongoing feedback informs the therapist as to when appropriate progress is being made and when refinements to the treatment are needed. Third, behavioral treatments for autism are comprehensive and include a specific set of research-based treatment protocols that target a wide variety of skill deficits and aberrant behaviors that are not typically addressed through other approaches. It is important to note that the effectiveness of behavioral treatment is not just due to the number of hours of individualized therapy involved in the treatment. In two recently published studies, behavioral treatment was compared with a more eclectic approaches, but both groups received approximately the same intensity of services. Behavioral treatments resulted in statistically significantly higher scores in all domains of development except motor skills. IQ scores were 22 to 27 points higher in the behavioral treatment group than in the comparison groups. Providing effective, research-based interventions for children with autism and their families benefits not only those families but also local school systems and the state...entire state of Nebraska. According to the report of the General Accounting Office, the cost of educating a child with autism is about three times higher than for a typical child. In Nebraska, this means that it costs about \$400,000 to educate a child with autism until that child reaches the age of 21. Add to this the fact that the majority of adults with autism become wards of the state when their parents are no longer able to care for them, and the average lifetime cost of an individual with autism is over \$4 million. Researchers have used this data, along with data on the effectiveness of behavioral treatment of austism, to model the lifetime costs of autism with and without effective intervention. the results indicate that the lifetime cost savings associated with behavioral treatment range from approximately \$1.6 million to \$2.7 million for each individual treated. Finally, because we are proposing to support this program through a combination of private, state, and federal dollars, the program will bring into the state of Nebraska private and federal dollars that would otherwise be spent elsewhere. Our goals are that for every \$2 of state money will be matched by \$1 of private money, and that these...the combined \$3 will be matched by \$4.5 of federal money through a Medicaid waiver. Thus, \$2 of state money would result in \$7.5 of service for children and their families with autism. In addition, if we conservatively estimate that 25 percent of the \$7.5, or approximately \$1.88, will be recouped by the state of Nebraska in property, sales, and income tax, then the net cost to the state would be just 12 cents of state money for every \$7.5 of service to children with autism and their families. Thank you for your valuable time, and I'll be happy to answer any questions that I can. [LB482]

SENATOR GAY: Thank you, Doctor. Are there any questions from the committee? I don't see any. Thank you. [LB482]

# WAYNE FISHER: Thank you. [LB482]

SENATOR GAY: Other proponents? [LB482]

GAIL WERNER-ROBERTSON: (Exhibit 8) Good afternoon, members of the Health and Human Services Committee. My name is Gail Werner-Robertson, it's W-e-r-n-e-r-dash-R-o-b-e-r-t-s-o-n. I'm president of the GWR Companies. GWR helps clients in financial matters. My husband Scott and I cofounded the GWR Sunshine Foundation about ten years ago, and I also serve on the Nebraska Investment Council and have served as the chairman for such for the past two years, and I'm here to testify in support of LB482. Thank you for allowing me this opportunity to do so. I would also like to thank Senator Joel Jensen...Johnson for his commitment to autism, for introducing this legislation. And I'd also like to take the opportunity to thank each of you for your willingness to serve in the Nebraska Legislature. As a fiscal conservative, this is a first for me to come to the Legislature in search of funding. I do so because I truly believe, as the Center for Disease Control stated, autism is an urgent public concern. I also believe that the outlined approach today is a good investment for Nebraska, and to stay on the current course will cost the state millions of dollars long term, and the very growth that you are trying to slow down will continue to escalate at an even more alarming rate. In addition to the escalating costs, it causes families to leave our state in search of resources for their autistic children. So today I'm going to share with you my personal story, but more importantly I've really come to seek your support and ask you to help the many families across this state who are feeling helpless and alone, and many whose children are at risk for becoming long-term dependents of the state. So we come with a proposal that provides a public-private approach, an approach that I am so confident will yield good results, I'm committed to raising the funds to make it happen. So let me begin with my personal story. My experience with autism started 19 years ago as my oldest son was nearing his second birthday. He had been a very happy, good natured little baby, but as he started to edge toward age two odd behaviors started to develop. He enjoyed watching toys being thrown up into the air and falling down. He picked at the carpet. He liked to watch the fan spin. He didn't like to play with other kids very much. But most disturbing of all was his odd language which developed where he used incorrect pronouns, saying "I" for "you," and "you" for "I." You can only imagine the disjunction for Jared and the temper tantrums that came out of this when he couldn't communicate. He could not communicate his most basic needs and wants. When he was age three, we had a doctor tell us that he most likely would be institutionalized and he would never be able to live on his own. Well, we just did not accept that prognosis and we continued to search for answers. We had so much difficulty getting him to adjust to a school that we unschooled him for 1st grade, and it was that year, when he was almost seven, that we finally got the diagnosis of autism, and we had lost so much time. The days were long, the decisions were agonizing, and yet we had other children at home to take care of. When our third child, who is a boy as well, started showing similar symptoms of delayed language and development, we did not waste time. We got Cleigh

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immediate, intensive help at home. And while Jared ended up spending his first five years of school in a special education room, Cleigh has always managed to be in a regular classroom. If you met Cleigh, who's 13 right now, you would think, well, he's kind of shy, he doesn't look you in the eye, but he looks like a pretty normal kid. So I'm really proud of the accomplishments that both the boys have made. Jared is almost 21. He currently lives on his own with minimal supports. He drives. He attends classes at Metro Tech, and he works at the Henry Doorly Zoo Aquarium, where he can tell you everything you wanted to know about sharks, fish, and other sea life. He's a certified diver and wants to be a marine biologist. He loves to be around people, which is a common misperception about autistic individuals, and he especially enjoys sharing his math skills. He still has a hard time understanding why we neurotypicals cannot do 82 to the 4th power, or the cube root of 35,937 in our head, but he doesn't hold it against us. I truly believe that these outstanding outcomes for our boys are due to the fact that we had resources to deal with autism. Although there were no programs specifically developed at the time, we were able to build our own. And however, even with the resources, there were days that I didn't know that I would be able to keep going on. I thought at times we were losing the war. And I still have difficulty sleeping, wondering if my boys will be self-sufficient enough to take care of themselves by the time I'm no longer here. I understand the stress, the pain, the heartbreak that thousands of other parents are experiencing as they try to raise their autistic children, but I feel blessed. I was blessed with resources, I was blessed with tough-mindedness to keep searching for answers even when things look glum, and I was blessed with wonderful professionals who helped our boys reach for the sky. I needed, though, to do more to help the other parents experience that joy that I have experienced watching my sons pull themselves from the depths of the affliction we call autism. So about ten years ago the Sunshine Foundation was formed and it was formed to be a catalyst for providing assistance to parties that are interested in the autism spectrum disorders and the challenges of individual diagnosed with ASD and other special needs, and our ultimate goal of the foundation is to remind society and reaffirm to the individual with special needs that there are inherently valuable. We started by giving grants to other organizations who were working on autism issues, like the Munroe-Meyer Institute, which is connected to the Med Center. the current social skills program for high school students and young adults was borne out of a grant from the Sunshine Foundation to MMI. We've grown into doing specific programs, like copartnering with Easter Seals to provide an overnight camp for those with ASD. Prior to this time there was no place in the state of Nebraska where a ASD individual could have an overnight camping experience. We also provide educational opportunities to both parents and educators, and we just held our second autism summit last weekend where we addressed a crowd of over 200 individuals, both Friday and Saturday, giving them up-to-date information on medical treatments, behavioral treatments, teaching strategies, as well as parenting strategies. And probably one of our most important items, we helped recruit Dr. Fisher to Nebraska, who's been a great addition to the talented staff at MMI. MMI and the Med Center do an outstanding job in their treatment of ASD patients, and there's a great deal

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of confidence that the private sector holds for the Med Center and for MMI. The Durham Research facility is a great example of how well public and private partnerships can work and the leverage that's gained by pairing these two powerful resources together. I'm confident that teaming up with the Med Center will produce an excellent return on the investment for all parties involved. So why do we need to do anything? Well, because the current numbers of those being diagnosed is now currently 1 out of 150. If we can use early intervention to curb the likelihood that those individuals will end up being institutionalized, we save both lives and dollars. Well, so why this approach? Because autism is a huge problem. It will take many sources of talent and resources to address this ever-growing population. I've been knocking on many doors in Omaha, seeking the advice of some of the world's best investors, and one particular advisor said to me, Gail, this is bigger than all of us, and it was then that I knew we must do more, we must have the state's help. So here is the pledge. You heard from Senator Johnson, the parents, and an expert, Dr. Fisher, who's outlined a plan. I pledge to bring to you today a private sector match. For every \$2 the state commits, the private sector will commit \$1. The Medicaid waiver is but one piece. The state committing \$1 million per year for five years from the Health Care Endowment Fund is another important piece. The private sector matching that, the \$500,000 against the \$1 million from the Health Care Fund, represents a strong approach to yield good outcomes. Private dollars demand accountability, as well as a quick return on investment. I believe we will be able to show both and we will show savings to the state over the long term. If we don't do something about this soon, we will be facing a cataclysmic funding crisis related to the long-term care for these children when they reach adulthood. I've studied the sustainability of the Health Care Endowment Fund and the distributions from it. The suggestion that a total of \$55 million be transferred from the Health Care Endowment Fund, which is currently \$52 million with the suggestion that \$1 million of the increase be targeted for public-private partnership for long-term health issues, is a reasonable distribution amount, and it would not endanger the long-term viability of the fund. This would be a good source of state funding, instead of using General Funds for the project. I thin, in the end, this plan is about leverage. It's about partnering. It's about results, and it is about children and families. We ask for your help. And I would be very happy to try to answer any questions you might have. [LB482]

SENATOR GAY: Any questions from the committee? Senator Pankonin. [LB482]

SENATOR PANKONIN: Thanks, Senator Gay. Ms. Werner-Robertson, and all the testifiers, thank you for coming today and I think the committee is very friendly to these proposals. My curiosity, my question, is besides this initial step, do you think there's more...if we can do more of this partnering there would be more private money to come if there's proven results? [LB482]

GAIL WERNER-ROBERTSON: Yes, absolutely. [LB482]

SENATOR PANKONIN: And you're interested in working on that. [LB482]

GAIL WERNER-ROBERTSON: Absolutely. We're in this for the long haul, to make Nebraska a better place to live and for these children. [LB482]

SENATOR PANKONIN: That's good to hear, because obviously I thought your comment about leverage is so important and, you know, our funds are limited as well, and... [LB482]

GAIL WERNER-ROBERTSON: That's right. [LB482]

SENATOR PANKONIN: ...thank you for that commitment. [LB482]

GAIL WERNER-ROBERTSON: You're welcome. [LB482]

SENATOR GAY: Senator Hansen. [LB482]

SENATOR HANSEN: Thank you, Senator Gay. Would some of the private money be money from the parents themselves? [LB482]

GAIL WERNER-ROBERTSON: Well, yes, they would certainly be a funding source. Our foundation would be a source, so I do think there would be parents that would be definitely investing, and grandparents. [LB482]

SENATOR HANSEN: Yes, very good. [LB482]

GAIL WERNER-ROBERTSON: Uh-huh. [LB482]

SENATOR HANSEN: Thank you. [LB482]

SENATOR GAY: Senator Stuthman. [LB482]

SENATOR STUTHMAN: Thank you, Senator Gay. In listening to your testimony, you're willing to invest \$500,000... [LB482]

GAIL WERNER-ROBERTSON: Uh-huh. [LB482]

SENATOR STUTHMAN: ...and have the department invest \$1 million... [LB482]

GAIL WERNER-ROBERTSON: Uh-huh. [LB482]

SENATOR STUTHMAN: ...for this program. In the statement earlier by Mr. Fisher, he stated that if we don't do anything for these kids, it could cost \$1.5 million per child...

[LB482]

GAIL WERNER-ROBERTSON: Uh-huh. [LB482]

SENATOR STUTHMAN: ...in long-term expense to the state. So this little partnership here that you're trying to do will help quite a number of kids and it's going to be the same cost as if we just let one kid, you know, not get any attention and it's going to cost the state that \$1.5 million. Taking that into consideration with the 400 kids that you're looking at of trying to assist with, you know, that's \$600 million, \$700 million if we don't do anything. [LB482]

GAIL WERNER-ROBERTSON: Exactly. And as Dr. Fisher testified, if you take the economic development portion of the investment into the state, it really is very...you know, it's less than that, as far as the impact net to the state. But you are exactly right. It is astronomical when you add up these numbers over a long period of time, by the numbers that are coming. [LB482]

SENATOR STUTHMAN: Yes. And, you know, I really respect the fact that you're willing to try to gather up the \$500,000, you know, to try to help with this. [LB482]

GAIL WERNER-ROBERTSON: Yep, that's my commitment. [LB482]

SENATOR STUTHMAN: And I think we should be very serious, you know, as to, you know, your willingness and then we can add some more to it. [LB482]

GAIL WERNER-ROBERTSON: That's right. [LB482]

SENATOR STUTHMAN: I really appreciate that. [LB482]

GAIL WERNER-ROBERTSON: It's huge leverage. [LB482]

SENATOR STUTHMAN: Yes. [LB482]

GAIL WERNER-ROBERTSON: It's an investment I wouldn't pass up. [LB482]

SENATOR STUTHMAN: Yes. Thank you. [LB482]

SENATOR GAY: Gail, I have a question for you. You talk about Nebraska Health Care Cash Fund. From your experience on the Investment...Nebraska Investment Council, just for...and keep it to a layperson, but how would you...how do you see that fund, because it's through Appropriations,... [LB482]

GAIL WERNER-ROBERTSON: Uh-huh, that's right. [LB482]

SENATOR GAY: ...not this committee, how do you see that fund and why do you say sustainability? So if we see a colleague on Appropriations and we want to ask them, explain that. [LB482]

GAIL WERNER-ROBERTSON: Right. Actually, Nebraska has been very conservative in what they have distributed out of the Health Care Fund, and if you look at the corpus of the fund, it has been continuing to grow substantially over, you know, the last four or five years. If you look at it, I think I have the numbers out to 2017, the numbers grow almost \$100 million in that period of time. So even taking several million more dollars out, it still is going to continue to grow at a very nice level. So I don't think it's...it will not engender...you know, jeopardize the fund at all. [LB482]

SENATOR GAY: Okay. Is that still getting inflows though annually? [LB482]

GAIL WERNER-ROBERTSON: Some...for a couple years; then some of the inflows stop. So, yes, it does take into account where some of the inflows stop. [LB482]

SENATOR GAY: Okay. Okay, thank you. Are there any other questions from the committee? I don't see any. Thank you very much. [LB482]

GAIL WERNER-ROBERTSON: Okay. You're welcome. [LB482]

SENATOR GAY: Other proponents. No other proponents. Any opponents? Okay, we have one opponent, or neutral? Opponent. Come on up. [LB482]

MARY STEINER: (Exhibit 4) Good afternoon, Senator Gay and members of the Health and Human Services Committee. My name is Mary Steiner, S-t-e-i-n-e-r, and I'm the Medicaid director for the Health and Human Services Department of Finance and Support. I'm here to testify in opposition to LB482. HHSS is opposed to this bill as it is an expansion to the Medicaid program that is in conflict with the fundamentals of Medicaid reform. The Medicaid program's growth rate has an impact on the total dollars available to Nebraska. In 1982, the state General Fund expenditures for Nebraska Medicaid were \$38.4 million, or 5.3 percent of the state spending. For fiscal year 2006 the General Fund expenditures had grown to \$505 million and accounted for 17.3 percent of total state spending. LB482 is an expansion of the Nebraska Medicaid program. The bill seeks coverage of services not currently paid by Medicaid for children, many of whom are not currently eligible for Medicaid. The expansion is both in service and population. Private insurance provided by employer-sponsored plans do not cover these services. Most state Medicaid programs do not cover these services. The Medicaid program in Nebraska would be shouldering the financial responsibility for this specific treatment at the exclusion of the private sector. When HHSS applies for a home- and community-based waiver, the number to be served can be specified.

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Therefore, the cost would vary based on the number to be covered. The cost for additional youth receiving this service is estimated at \$11 million, or \$4.6 million General Fund per year per 100 children. While the bill might imply that services could be funded at a cost-neutral manner with reference to a waiver, the department's analysis is that these services are not currently covered and that no offset from current expenditures exists. And I'm happy to answer any questions. And I probably should also offer, after listening to some of the testimony, the way the Medicaid program works. There are limits to what can apply to...apply as state match in order to earn the federal share, so some private sector funding might have to go through some scrutiny. Might have to be put into a fund that then would be under the direction of the state or something like that. Otherwise, not just any dollar qualifies for federal match, if that's the intent. [LB482]

SENATOR GAY: Thanks, Mary. Questions from the committee? Senator Stuthman. [LB482]

SENATOR STUTHMAN: Thank you, Senator Gay. Mary, thank you for your testimony. The thing that really concerns me is, you know, the Medicaid dollars that we're spending. You know, in 2006, it was 17 percent of the total. If...if...and we've got something here where people are willing to step up to the plate and assist, and that should affect the long term. If we do nothing here today and say we can't do anything because dollars won't fit under certain programs, this 17 percent is going to get greater as we continue. Because, you know, we've got 1 child out of 166 that have a possibility of having autism and you know...and if something isn't done where we can get these people to become an asset to the community instead of a liability, and that liability, in my opinion, would escalate this Medicaid cost to...in the 20-30 percent in ten years from now. That's a concern that I have. Would you agree with that? [LB482]

MARY STEINER: The dollars that are predicted to be spent on a child, or a person through the rest of their life, I'm not sure that that would all be Medicaid funds, but you're right that, you know, it would...it could offset future costs... [LB482]

SENATOR STUTHMAN: Okay, thank you. [LB482]

MARY STEINER: ... of some program. [LB482]

SENATOR STUTHMAN: Yeah. [LB482]

SENATOR GAY: Thank you. Senator Pankonin. [LB482]

SENATOR PANKONIN: Thank you, Senator Gay. Mary, thanks for coming today. You've been here for the entire hearing, for the testimony. You've heard the numbers. So, you know, and I understand what this is about as well, but so what would you do? I mean, hearing what we heard today, tell me what your plan is. That's the question.

(Laughter) [LB482]

MARY STEINER: I'm not authorized...I don't think I'm authorized to say that. (Laughter) But, yeah, you know, I think this would have to be weighed. I think there's a number of different populations that would like to get services for their family members. [LB482]

SENATOR PANKONIN: Okay. Well, I think, like Senator Stuthman said, that when we have an opportunity to have people step up and maybe try to save, you know, not only for their interest for their own children but also I think knowing what this problem is going to be down the road and knowing that...don't you agree that the state is going to have a big liability down the road? [LB482]

MARY STEINER: Yeah, somebody has a liability for those costs. And if it can be funded, you know, that takes away a lot of our concerns, if the private sector can raise those funds. [LB482]

SENATOR PANKONIN: Well, I would hope that things could be worked out and we could take advantage of this offer and the thinking behind it, because I think it's the type of long-term thinking that we need to be looking at very closely. Thank you. [LB482]

SENATOR GAY: Senator Hansen. [LB482]

SENATOR HANSEN: Thank you, Senator Gay. I would suggest to HHS that they relook, relook the program over. After you heard what you heard today, and then kind of look down the road because, you know, in 20 years we might have spent way more than what we spend in the next five years. So I would just suggest that you look it over and get back to us soon. [LB482]

MARY STEINER: Okay. [LB482]

SENATOR HANSEN: Thank you. [LB482]

SENATOR GAY: Are there any other questions? I have one for you, Mary. [LB482]

MARY STEINER: Okay. [LB482]

SENATOR GAY: This is the tough part of your job. [LB482]

MARY STEINER: (Laugh) [LB482]

SENATOR GAY: The question I have is you, in your test...it says most state Medicaids do not cover these services, but let's say we did proceed with our own program or we started looking into this more and moving forward. If we create this program, do we

have...and you'd want to provide these services to everybody, does that mean we have to do it their way, or could we be more creative our own way? Because what I'm looking...can we create our own cost-effective delivery system, or would this be...you know, these schools get asked to do an awful lot. Would every school have to have somebody, or could we... [LB482]

MARY STEINER: Well, that's...yeah. [LB482]

SENATOR GAY: I mean, could we make it cost-effective, is what I'm saying? [LB482]

MARY STEINER: I think under the waiver, you know, there would be some criteria to get the waiver granted from CMS in order to...or in the federal Medicaid funds, but under a waiver you are trying to design services that wouldn't normally be paid in a regular Medicaid program. You can limit the number of persons. You can limit some statewideness. You could narrow up the service definition. So you would have more flexibility under a waiver. A waiver, there's several different kinds of waivers. Probably this would be a home- and community-based waiver, which would mean not all of the children would qualify under this. It would be an alternative for institutional care. But this would be the way to design services that would allow the most expenditure on those services. In another demonstration type situation or HIFA waiver, you would have to contract your expenditures on one side in order to expand your expenditures in another area to show that you wouldn't be spending any more federal money than you would be today. So there's some restrictions on how...on, you know, whether you can get a waiver or not, but the idea behind a waiver is that you would design your own program. [LB482]

SENATOR GAY: Okay. Thank you. Any other questions? I see none. Thank you very much. Is there anyone who'd like...thank you, Mary. Is there anyone who'd like to in neutral on this issue? Okay, we have one. Come forward. [LB482]

SARA FARRAND: Mr. Vice Chairman, members of the Health and Human Services Committee, my name is Sara Farrand, Sara spelled with no H, Farrand spelled F-a-r-r-a-n-d, and I'm here on behalf of the State Board of Education and the Nebraska Department of Education. The State Board of Education is appearing in a neutral position on LB482. We feel that continued research is important in the area of autism and autism spectrum disorders, and we agree that more minds put together will help in this effort. It is our hope, however, that these services would be coordinated with the existing Autism Spectrum Disorder Networks, ASD, whose goal is to provide support to children with autism spectrum disorders and their families, as well as provide training and technical support to educators and school systems. And with that, I'd take any questions. [LB482]

SENATOR GAY: Thank you, Sara. Any questions from the committee? I don't see any.

Thank you. [LB482]

SARA FARRAND: Thank you. [LB482]

SENATOR GAY: Senator Johnson, would you like to close? [LB482]

SENATOR JOHNSON: Senator Gay, members of the committee, I think what we have here is this; we have what I think is a disaster that has become one of neglect as well. I think what we're talking about here is a project to find the direction that we should go in the future and hopefully save significant funds. One of the things that I think that we have to do is this coordination that the last speaker mentioned and that there are funds in the school system that are in existence now. I think what a project like what we're talking about here to give us direction where we go, that then that tells, working with our school system, how to best use these funds as well, rather than in what may become just a caretaker situation later in life with these children. So I think we've got lots of work to do, being inventive of how best to find the funding, and but hopefully that will give us the best direction in the future for a very significant problem in Nebraska. Thank you. (See also Exhibit 7) [LB482]

SENATOR GAY: Thank you, Senator. Thank you. With that, we will close the public hearing on LB482. Thank you, all. [LB482]

SENATOR JOHNSON: We'll open the hearing with Senator Aguilar on LB523. Senator, Welcome. [LB523]

SENATOR AGUILAR: Thank you, Senator Johnson. Members of the Health and Human Services Committee, my name is Ray Aguilar, spelled A-g-u-i-l-a-r. I represent District 35 in the Nebraska Legislature, the city of Grand Island, the "City of Love." This bill, LB523, this bill is about saving future state and federal Medicaid dollars while ensuring Nebraskans have quality access to in-home care that will allow them to live at home independently. This bill is also about providing appropriate services for our senior citizens and family members with disabilities, and neighbors with disabilities, in-home services that enable them to remain at home and independent as long as they are able to and as long as they wish to. And we know that most of us prefer staying at home and be as independent as possible. The third portion of this bill is about a group of workers who provide in-home services. This work force fluctuates in number and varies in qualifications. Many of these people in Nebraska work as independent contractors, whether they are connected to clients through family, through an agency, or through a governmental entity, such as the Area Agencies on Aging. These workers are in a unique situation of being employed by the consumer, but being paid through the state. The situation alone creates somewhat of a disconnect. These workers care very much about the people they care for. Their pay is low and there is no benefits, but they do the work because they want to help people. Home-care workers also want to know how to

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do their job better. They realize that many of the people they care for are in a fragile health situation. But working as an independent contractor, paying for their own gas and their own tax on \$6 to \$10 an hour doesn't leave a budget for training or taking a day off work to get training. The stress level is high for these workers and they can't always afford to stay in the work force. These factors lead to high work force turnover. These factors lead to a fragmented system that leaves consumers with few choices. These factors lead to frustrated case coordinators looking for a worker to serve the needs of consumers and wishing they could pay the providers a decent wage. Add the baby boomers reaching age 60 and more, age 70 and more, age 80 and more, and we have a huge demand for in-home services that we currently could not meet and that will cost the state of Nebraska a small fortune. LB523 provides a solution for the challenges consumers of home care the work force and the state are facing. It establishes an entity called the Quality Home Care Council. Now although I'm very creative and original, I have to admit that the idea is one copied from other states, Michigan, Oregon, Washington, Wisconsin, and Illinois to name a few, so we have their experience to draw upon. For instance, Michigan expects to save \$276 million in the next six years alone because of the work of their Quality Home Care Council. Washington has connected 7,400 workers and consumers through their referral registry. Quality Home Care Councils in other states have been successful in meeting their goals. The goals of the Quality Home Care Council and LB523 are: to meet the growing needs for services that allow senior citizens and people with disabilities to stay in their homes and become independent; to create a referral registry of workers to connect consumers and service providers statewide; to provide for background checks for workers to ensure the safety of vulnerable consumers; to provide workers and consumers a voice in the process; to stabilize the work force, providing in-home care service through recruitment, training and retention efforts; to improve the quality of services provided; and to slow the growth of future state spending on long-term care needs, an issue near and dear to all of our hearts. LB523 takes aim at these goals by doing the following: establishing the Quality Home Care Council setting out the structure of the nine-member council appointed by the Governor, to include consumers of home care services, advocates of senior citizens and people with disabilities, a representative from HHSS, a representative of the statewide independent living council, and a representative from an Area Aging...Agency on Aging--that's easy for me to say; establishing the consumer's right to hire, direct or fire an in-home care worker and gives the consumer a mechanism for voicing concerns to the council; authorizing a council to establish gualifications and reasonable standards of accountability for home care workers; to recruit gualified home-care workers; to provide for training home care workers; to establish a referral registry; to set economic benefits for publicly paid home care workers in consultation with the department; requiring home care workers paid through the department to participate in the referral registry; establishing the council as employer of publicly paid home care workers for purposes of collective bargaining only and...only and places a relationship between worker and council under the Industrial Relations Act, giving the workers a right to organize if in the future they choose to, but denies they a right to strike--this is a very

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stabilizing factor for this work force; requiring one- and three-year budgets be submitted to the department detailing the plan of action and expected costs; requiring a performance audit every three years; providing staffing of the council under Nebraska Health and Human Services System. Some things LB523 does not do and is not intended to do: it does not license in-home workers; it does not make the publicly paid worker state employees; it does not automatically raise wages for workers; and it does not create a union. Workers would have the choice to unite through a democratic election, if they so chose. In working with others on this bill a lot of excitement has been created from consumers of in-home services, advocates, and the workers. All these folks see better, more stable service providers for consumers to choose from. All see the voice provided through the council as a positive step toward solving problems for consumers and workers in ensuring seniors and people with disabilities can live at home. These councils work well in other states, saving states money and improving guality of care delivered to consumers. If we need to adjust this structure to fit Nebraska, I'm very willing to work with the committee and others to do so, but I'm very hopeful that we can make this investment for the long-term benefit it provides to people and the long-term savings to the state budget. I hope that my testimony today is a positive step in communicating the concept of Quality Home Care Council to you. To the department and to others, let me just reiterate that I believe, I really believe, Quality Home Care Council would reap large benefits in Nebraska in terms of quality home care and in terms of the state Medicaid spending. I want to thank you for your time and attention to this matter, and I ask that you support this bill and advance it to General File. I'll be happy to answer any questions that I'm able to, and there's more experts to follow me that can answer the really difficult ones. [LB523]

SENATOR JOHNSON: Any question of Senator Aguilar? Ray, I see none. Will you be able to stick around for... [LB523]

SENATOR AGUILAR: I'll stick around for awhile and see if I'm needed to close, Senator. [LB523]

SENATOR JOHNSON: Okay, good. [LB523]

SENATOR AGUILAR: Thank you. [LB523]

SENATOR JOHNSON: Let me say that there is a letter of support from Mark Intermil of AARP, and a neutral letter from Carlos Castillo, the director of Administrative Services for the state of Nebraska. (Exhibits 6, 7) Now, how many people do we have that want to testify in support of this? One, two...oh boy, we've got about eight or ten or so. You know, if you take three minutes apiece, it's going to be quite awhile right there, so again, if you would respect the people that are going to be testifying later in the day, be brief and try not to overlap or say the same thing as what your predecessor. But let's go ahead and go with proponents. [LB523]

TERESA STITCHER FRITZ: (Exhibit 1) Good afternoon, senators. My name is Teresa, T-e-r-e-s-a, Stitcher, S-t-i-t-c-h-e-r, Fritz, F-r-i-t-z. That's the hardest part, just getting all that out. I'm program director of the Alzheimer's Association of the Great Plains, and the Alzheimer's Association of the Great Plains and the Midlands Chapter, which serves the Omaha area, both support LB523. It assists in meeting the growing need for services that allow elderly and disabled persons to stay in their homes as long as possible and live independently. It creates a registry and the necessary checks and balances and training for these workers, paid for with public funds. This bill assists those individuals with Alzheimer's disease and related disorders who are eligible for care through Medicaid to stay in their homes and save the costs of having to move into a skilled nursing facility, which costs the state Medicaid plan much more than creating this safe system of providing home care. We ask that the committee support LB523 and move it to General File. [LB523]

SENATOR JOHNSON: Thank you very much. Any questions? Senator Howard. [LB523]

SENATOR HOWARD: Thank you, Mr. Chairman. Do you find that many of the people that you work with can remain in their own homes? I know that disease is pretty disabling and... [LB523]

TERESA STITCHER FRITZ: Right. In the early and middle stages, we find that having in-home supports can be very effective and families are oftentimes looking for these in-home service providers to allow them to have a necessary break. And, yes, oftentimes in the latter stages, they do need to move into a skilled nursing facility, a nursing home facility, but in the earlier stages and even into the middle stages with these supports they can remain in their home. [LB523]

SENATOR HOWARD: And I would anticipate that being in a familiar environment would be much less stressful than... [LB523]

TERESA STITCHER FRITZ: Yes. [LB523]

SENATOR HOWARD: ...than having to face the possibility of basically altering your life. [LB523]

TERESA STITCHER FRITZ: Exactly, Senator Howard, that's...usually the move, it can be very traumatic and having home care can be a real reinforcing and beneficial approach. [LB523]

SENATOR HOWARD: Thank you. Thank you. [LB523]

TERESA STITCHER FRITZ: Thank you. [LB523]

SENATOR JOHNSON: Any other questions? I see none. Thank you very much. [LB523]

TERESA STITCHER FRITZ: Thank you. Thank you, Senator. [LB523]

SENATOR JOHNSON: You did a very nice, brief job. Hey, who's coming here? (Laugh) [LB523]

KATHY HOELL: And of course I'm not going to be brief. [LB523]

SENATOR JOHNSON: Well, you've got a special reason why you have to be brief today, because it's about 60 degrees on this side of the table and we're all sitting up here shivering. [LB523]

KATHY HOELL: Well, that's life. [LB523]

SENATOR JOHNSON: Welcome, young lady. Go ahead. [LB523]

KATHY HOELL: (Exhibit 2) Members of the committee, Senator Johnson, I'm Kathy Hoell with the Statewide Independent Living Council. The Statewide Independent Living Council is a nonprofit 501(c)(3) organization as defined under the Internal Revenue Code. The purpose of our organization is to support independent living for citizens with disabilities as defined by the Rehabilitation Act of 1973, as amended through 1993. I am here in support of LB523, the Quality Home Care Act. Rather than read my testimony, this act makes sense. We need to stabilize this work force. We have a work force that is paid very low. They have no benefits. They have no weekends off. They have no days off. If for some reason somebody can't show up, the person has no care. And with Medicaid reform last year the state applied for approximately 230 additional aides and disabled waiver slots. As from your previous speaker, you found out Nebraska was the recipient of the Money Follows the Person Demonstration Project. This is an enhanced match that we'll be getting, approximately 90/10. But you get these 900 individuals out of institutions. If these services are...if these programs are going to succeed, it is going to because we have the supports and services that people need. And at the current job market, this current work force is not stable enough to handle this. I would...a friend of mine who is also disabled was planning on being here, but because of the weather he couldn't be here, but he asked me to relay a little bit of his story, which is this man was in a nursing home and he got out. He as out for three years. He spent the entire three years looking for quality staff, never finding it. Now he's back in a nursing home and now the state is paying \$500 a day for his support. It would have been a whole lot cheaper for him to stay in his apartment, but he was not able to do that because there were not people available. I think one aspect about LB523 that makes it so easy to

support is that there is a focus on quality, quality service; this for people who use the system to be involved is a really good thing. One of the basic tenets of the disability community is "Nothing about us, without us." We've had a program that has operated for years not very well, without any input from the disability community, and we've seen where that's gotten us. So maybe it's time to try something different rather than repeating the same mistakes over and over and over again. Thank you. Do you have any questions? [LB523]

SENATOR JOHNSON: Any questions. I don't see any questions, Kathy, but we certainly appreciate your coming out on a day like today. It shows your commitment and... [LB523]

KATHY HOELL: Well, I know a number of people with disabilities that were planning on being here didn't come out because of the weather, and so there will be some other people providing testimony for people that couldn't come because of the weather. [LB523]

SENATOR JOHNSON: Great. Well, thank you for coming, and I think that you should know that when you're hearing from the potential receivers of the care it makes quite a bit of difference. So thank you. [LB523]

KATHY HOELL: It does. [LB523]

SENATOR JOHNSON: Next, please. Welcome. [LB523]

MARY ANGUS: Thank you, Senator Johnson, members of the committee. My name is Mary Angus, M-a-r-y A-n-g-u-s, kind of like the cow. I have just a real brief statement because some of what I was going to say was already said. The first statement I am going to make is an apology. It was my cell phone that went off but I had placed it on silent that I could turn it off. (Laughter) That was the sound that you heard. I'm a member of ADAPT Nebraska and I'm speaking on their behalf. Many of our members utilize personal care and home care and have had concerns expressed to me about their inability to get and keep guality healthcare. I was a member of the coalition which encouraged the state to apply for money follows the person. As you've already heard, we were awarded a \$27.5 million project over the course of five years so that we can remove, we can discharge, we can transition 900 people out of nursing homes and other facilities of that sort. So rather than reiterate everything, I do believe that we need to have a stable workforce. I too am a person who might benefit from home healthcare at some point or another as a person with severe and persistent mental health issues. So I would ask that you...I am supporting the passage of LB523 and ask you to move it forward out of committee so that we can have a full floor vote on that. Are there any questions? [LB523]

SENATOR JOHNSON: Senator Hansen. [LB523]

SENATOR HANSEN: Thank you, Senator Johnson. Mary, appreciate you coming down today, too. Is this a statewide program? [LB523]

MARY ANGUS: Yes. We have members across the state, yes. [LB523]

SENATOR HANSEN: Okay. Because I'm three hours west of here and we have a problem with healthcare providers out there in the home. [LB523]

MARY ANGUS: Oh, I'm talking about the ADAPT Nebraska is... [LB523]

SENATOR HANSEN: ADAPT, okay. [LB523]

MARY ANGUS: ...a, yes, it's a statewide... [LB523]

SENATOR HANSEN: Do you see this bill as a statewide bill? [LB523]

MARY ANGUS: Yes. Oh, definitely. I think it actually would probably be even more of an impact on rural Nebraska because of the even greater difficulty. What happens right now oftentimes is that you get a healthcare provider and then something happens in the instance of some of the folks that have a little higher medical need. They end up going into the hospital for a period of time, during which time that healthcare worker can't afford to be unemployed. So that would be, I think, a greater impact on the rural parts where there aren't very many workers already and so they would be unemployed at that point. [LB523]

SENATOR HANSEN: Could you tell me real quick what ADAPT means? [LB523]

MARY ANGUS: Well, ADAPT originally was... [LB523]

SENATOR HANSEN: Is it an acronym? [LB523]

MARY ANGUS: Well, not anymore. It originally was American Disabled for Accessible Public Transportation. It has evolved into an organization of people who would like to have adaptations in their environment and their community to allow for community living. We are very strongly in favor of community and independent living so that people with disabilities can live in their communities and fully participate, be productive citizens within that community. [LB523]

SENATOR HANSEN: Thank you. [LB523]

MARY ANGUS: Thank you for your questions, Senator Hansen. [LB523]

SENATOR JOHNSON: Other questions? Okay, I see none. Thank you very much. [LB523]

MARY ANGUS: Thirty-five seconds? [LB523]

SENATOR JOHNSON: You did well. [LB523]

MARY ANGUS: Thank you. [LB523]

SENATOR JOHNSON: (Exhibit 5) I do have a letter here that's signed by Eric Ostergaard and Bill Crawford in support as well. Any other proponents? [LB523]

RANITA McCOY: Hello, my name is Ranita McCoy, it's M-c-C-o-y, and I come here today from Crawford, which is in the northwest corner of the state. Nice ten-hour drive yesterday. I'm here to speak to you today about home caregivers and ask that you please support LB523, the Quality Home Care Act. The act would create a home care council to help address the problems facing home caregivers and the people that we assist. Caregivers are a unique sort of people. They're not watchers, they're hands-on. They're not observers, they're right in the mix. And they do exactly what the name says, they give care. I started in home care in 1994 with a woman who was confined in a wheelchair. She was a great lady and I really, really enjoyed working and talking with her. I cooked, cleaned, helped her with her shopping, provided her with transportation and help, her other daily tasks. And then back in '94, that was like 15 years ago almost, a job that paid \$6 an hour was, for a single mom of five, was not that bad in Crawford. I mean, if you knew the rural area. After that, I continued with an elderly couple that I had known all my life. They were like grandparents to me and it was a real pleasure for me to go and help them get by with their...provide them with the assistance that they needed to live at home in their own surroundings. When I showed up, the older gentleman's eyes would light up because I could drive and he couldn't. So when I showed up, that meant we could go for a cruise. So once we spent three hours at the cemetery on Memorial Day picking weeds around their grandson's and his wife's mother's grave. And it was only three hours for me but it was afternoon out filled with love and a sense of independence to connect with their family for them. This is an example of the kind of freedom and sense of a normal life that home caregivers provide to seniors and people with disabilities across Nebraska. Currently I care for a 12-year-old boy named Linden (phonetic). He has been diagnosed with severe cerebral palsy. The doctors say he'll never walk, he'll never talk. But he is the sweetest, most loving kid in the world you'll ever meet. And his grandmother and I talk a lot and she says that without the care and the help with the daily tasks that I do provide for Linden (phonetic) on my own, she doesn't know what she would do. And when I started working for Linden (phonetic) four years ago, I was paid \$7 an hour. Four years later, I'm still at \$7 an hour. It's just a dollar from where I started 15 years ago in '94. But there's a cap

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on my hours now for my wages when it comes to hours. I love caring for Linden (phonetic). He is like one of my own children. But what I used to think was a good paying job in '94 today is less appealing than a fast food job at McDonald's or Burger King. And it's no wonder that it's very hard to attract more of us into this field. The problems that drive many of my fellow caregivers or keep them from pursuing a career altogether is the low pay, the lack of benefits--especially health insurance--and not having a voice to improve the system for the people we care for and for ourselves. I know with the baby boomers aging, we're going to need a lot more home caregivers, people like me and others here in this room today who give the people that they care about what they need to live at home instead of in an expensive nursing home. We also need safety nets like a backup system for days when a caregiver gets sick or can't make it to work. And that's why I ask for your support on LB523, to make sure that people like Linden (phonetic), like the elderly couple that I've cared for have access to quality home care and home caregivers like me have good home caring paying jobs. Thank you. I'll take any questions. [LB523]

SENATOR JOHNSON: Thank you. Senator Stuthman. [LB523]

SENATOR STUTHMAN: Thank you, Senator Johnson. Thank you for coming this distance down here today. How many people do you assist in a day's time? [LB523]

RANITA McCOY: Me? I'm basically...Linden's (phonetic) grandmother works full-time at Fort Robinson State Park. So at this moment, I have Linden full time for her two, her full-time job and her part-time job, which sometimes involves 18 to 20 hours a day. [LB523]

SENATOR STUTHMAN: And that's the only person that you're giving care to, then? [LB523]

RANITA McCOY: That I have at this moment, yes. [LB523]

SENATOR STUTHMAN: Okay. [LB523]

RANITA McCOY: I also do respite for my mother who lives with my grandmother and gets paid for watching her, \$65 a day, I believe, for 24 day care, 7 days a week. So I give my mom respite when she needs it. [LB523]

SENATOR STUTHMAN: Are there other people in the community that should be getting care that are not getting care? [LB523]

RANITA McCOY: I believe so. I honestly do believe so. [LB523]

SENATOR STUTHMAN: Okay, thank you. [LB523]

RANITA McCOY: You're welcome. [LB523]

SENATOR JOHNSON: Senator Howard. [LB523]

SENATOR HOWARD: Thank you, Mr. Chairman. Did I understand you to say you came in yesterday? [LB523]

RANITA McCOY: Yeah. [LB523]

SENATOR HOWARD: Gosh. And so you've given up time that you could be working and getting paid. [LB523]

RANITA McCOY: Yeah. [LB523]

SENATOR HOWARD: I really appreciate that you made...I mean, that is an effort to do that, to come this far... [LB523]

RANITA McCOY: Thank you. [LB523]

SENATOR HOWARD: ...to come here to give us information. And I think it's easy to forget what you lose when you get older. Or if you have a healthy child, how it could be. Thank you so much. [LB523]

RANITA McCOY: Thank you. [LB523]

SENATOR JOHNSON: Any other questions? See none, but let me compliment you as well. And for those of you that don't know where Crawford is (laughter) it's closer than Duluth, Minnesota. (Laughter) [LB523]

RANITA McCOY: It is as rural as you can get in Nebraska. [LB523]

SENATOR JOHNSON: I sent us the wrong way. Duluth is closer than Crawford is... [LB523]

RANITA McCOY: Yeah, it's a ten-hour drive. [LB523]

SENATOR JOHNSON: Go to Crawford. It's one of the most beautiful spots in Nebraska. [LB523]

RANITA McCOY: It is the most beautiful area. It is very pretty. [LB523]

SENATOR JOHNSON: Thank you very much. [LB523]

RANITA McCOY: Thank you. [LB523]

SENATOR JOHNSON: Next, please? All you people coming up with the signs on your chest, I first thought that they were Chicago Cubs shirts that you got on. (Laughter) [LB523]

KORRINE TANNER: Hi, my name is Korrine Tanner, it's K-o-r-r-i-n-e T-a-n-n-e-r, and I am from Hastings. I'm also a home care worker and I appreciate you allowing me to come in here and voice my support for LB523. I also take care of people in their home. I've done it for about six years. I love the work I do because I get to see the pride in these people's faces that they get to remain in their own home and they get to be a part of the community. I take them out into the community just like I would anyone. They enjoy the camaraderie. You get very close to the people that you serve. I currently take care of a lady who is, she's had several hip surgeries. She has a son that has some mental disabilities. And without my care, she would be in a nursing home and he would be in foster care. I currently work with them from 8:00 in the morning to 7:00 at night, Monday through Friday. They have a horrible time trying to find caregivers to come in and be able to deal with her son because he does have some high behaviors. They've gone through several caregivers and it's just a very difficult task to get someone to come in and stay with them. Besides the fact that the pay is low, they have no benefits, if I call in sick--which I don't do, because otherwise they'd be stuck there alone and obviously they can't be doing that because they just have no one to come in and take my place. So I really would appreciate it if you guys would support this bill. I'm not going to keep saying the same thing over and over but I really think that we need this bill to go into effect because these people deserve the best care that they can get. [LB523]

SENATOR JOHNSON: All right, thank you. Any questions? Senator Hansen. [LB523]

SENATOR HANSEN: Thank you. Somewhere along the line, I wanted to ask one of the caregivers--and I don't know how many there will be--but what do you do for medications for the people you care for? Are you a medical...what do they call them, a medical reminder? [LB523]

KORRINE TANNER: I have had my med aide certificate, yes. [LB523]

SENATOR HANSEN: Oh, you have... [LB523]

KORRINE TANNER: And if you go into a facility that they are, pretty much they're capable of doing their own medications. And we just basically monitor them as to how their medications are taken. The mother is capable of...she explains to me what needs to be done and I oversee them taking their medications. I couldn't tell you if everyone has a med aide certificate or not. But I've also worked in other facilities where I have

had to have that. [LB523]

SENATOR HANSEN: And you keep that certificate up? [LB523]

KORRINE TANNER: I'm thinking I might be due. (Laugh) So yeah, and that's another thing. I don't have time to be able to go, you know, I can't take time off because we don't get paid and because these people would be by themselves. So we need to have somebody that can come in and teach us, you know, and give us the testing for our med aide certificate. I don't even know where I would go to do that, you know, so... [LB523]

SENATOR HANSEN: Thank you. [LB523]

SENATOR JOHNSON: Okay. Any other questions? I see none. Thank you very much. [LB523]

KORRINE TANNER: Thank you. [LB523]

SENATOR JOHNSON: How many more proponents do we have? One? Why don't you come up, sir? [LB523]

JIM KEEF: Hi, everyone. [LB523]

SENATOR JOHNSON: Well, welcome. Watch that guy behind you there holding the chair. (Laughter) [LB523]

JIM KEEF: In just a second I'll get my...there. Now you could just a little...thank you. [LB523]

SENATOR JOHNSON: There, great. [LB523]

JIM KEEF: Thanks everyone for listening to us about LB523. As many of you may know, my personal care aide is blind. Let's see, I know two of you on this committee. (Laugh) I guess I forget that a lot of the old-timers are gone now. (Laughter) Three, there are three of you that I know on this committee now. [LB523]

SENATOR JOHNSON: But, young man, we don't know you and I can tell you that the person listening on the microphone can't tell who you are either. So could you tell us your name and spell it? [LB523]

JIM KEEF: (Laugh) Sure. My name is Jim Keef, K-e-e-f. I live at 9906 Evans Street in Omaha, Nebraska. My personal care aide was the first blind personal care aide ever hired by the state of Nebraska to take care of a handicapped person like myself. She's been doing it since January 17 of 1997 to now. And I hope to keep her forever but we'll

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just have to see about that. What we like about this particular bill is it gives them a coalition that they can join if they want to, to help with collective bargaining. But they don't have to, that's the neat thing. My personal care aide took a home-bound healthcare aide course that was offered by the American Red Cross many years ago to be able to learn how to take care of me. She has never missed a day for any reason since she started. We only had one little mishap. I'll tell you about that real quick. Some older person, they didn't mean to, I was pulling her from getting her haircut in my electric wheelchair, which the state of Nebraska bought me, down Maple Street. And what happened was the old man, he accidently didn't see us, not on purpose. He hit us and it broke C7 in Becky's (phonetic) neck. She went flying over the top of my electric wheelchair and it broke C7 in her neck. Well, that night, by the time all the X-rays and everything were done, there was nobody who I could call to say that Becky (phonetic) was not going to be able to take care of me because, you know, HHS, the League of Human Dignity, all these places were closed. And so what we ended up doing, my doctor, he's pretty creative. He says, I don't know if this is exactly (laugh) what we're supposed to do but I'm going to put both of you in the hospital even though you don't really need to be here, Jim, but we don't have any choice. So he put me in the hospital and Becky (phonetic) and we shared the same room. Becky (phonetic) just took care of me that night just like normal with the nurse's help. And then the physical therapy students that I have came in until Becky (phonetic) got out of the hospital. And they did what Becky (phonetic) did while Becky (phonetic) was in the hospital and that worked really great. And so I wanted to tell you that I sure hope this bill passes and thank you for being so very nice to us. [LB523]

SENATOR JOHNSON: Thank you. Any questions? Seeing none, Jim, thank you very much for making the effort today. [LB523]

JIM KEEF: Cool, thank you. [LB523]

SENATOR JOHNSON: I think that that was the last proponent. Do I see others? Do we have any opponents? I see one coming up over here. You got someone behind you there, right? [LB523]

RICHARD SKERBITZ: Do I get overtime for this? [LB523]

SENATOR JOHNSON: Well, we'll see. (Laughter) [LB523]

SENATOR ERDMAN: You can negotiate that later. [LB523]

SENATOR JOHNSON: Do you have anything to hand out? Page, when you have a second, why, good enough. Welcome. [LB523]

RICHARD SKERBITZ: (Exhibit 3) Thank you. My name is Richard Skerbitz,

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R-i-c-h-a-r-d S-k-e-r-b-i-t-z. Senator Aguilar, Senator Johnson, and members of the Health and Human Services Committee, I am the systems change coordinator for the League of Human Dignity. I'm testifying on behalf of the League of Human Dignity in opposition to LB523. This year, the league is celebrating 35 years of providing quality, cross-disability, consumer-controlled services to people throughout 54 counties in Nebraska. Our mission is to assist people with disabilities to be fully integrated into our society. We believe that everyone should expect the right to equal opportunities of guality, independent lives. One of the services provided by the League of Human Dignity is in the area of personal assistance services. We work with and provide training to people with disabilities so they may be able to manage their personal assistance services and recruit, hire, train, schedule, and if necessary, terminate their personal assistance. We wholeheartedly believe there is a need for an increased and consistent supply of personal assistance and chore service workers. These personal assistance and chore service workers provide services invaluable to the dignity, independence, well-being, quality of life for individuals with disabilities and older adults who depend on these services to live independent lives as they choose. Yet these workers are paid lower than almost all other occupations, including fast food restaurant workers. There needs to be a greater regard for these providers. We need to increase their pay and provide access to benefits in order for them to continue providing services to people with disabilities and older adults to live independent self-directed lives. Having stated the above, the consumers' rights to choice and control must first be protected. Senator Aguilar already stated the intent of the bill so I will pass that one. But people with disabilities and older adults must control the options of selection, hiring, scheduling, supervision, training, and termination of the individual providers. Personal assistance and chore services must be provided on a regular ongoing basis without any interruption, interference, or slow down which would jeopardize consumer safety or sense of independence in their own homes. In the current systems, consumers may decide to hire their neighbors, friends, or relatives who they already know, they trust, and they have an established relationship with. To change a system to require workers to be listed on a registry of the Quality Home Care Council prior to continuing service provision or to force the consumer to choose a provider they don't know from a registry disrupts the consumers' sense of security, choice, and the ongoing quality of and pace of service provision. Though LB523 states home care workers cannot strike, there is no stipulation that home care workers shall not induce, encourage, or condone any strike, work stoppage, slow down, or withholding of services. We are very concerned that there will be an interference by this union in the bill that's referred to as the collective bargaining unit, council, or both when a consumer attempts to terminate a home care worker. The league's 35 years of experience clearly tells us that on a regular basis some providers attempt to control consumers' lives by attempting to control consumers' choices. This must not be allowed and consumers' complete rights to full management of home care workers must be protected. We don't believe that this bill goes far enough in protecting consumers' rights. The league urges you to indefinitely postpone LB523. We know there is a need for increased, consistent, and quality personal assistance and

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chore service providers and we are not against change. But it must not hinder, interrupt, slow down the services already being provided to people with disabilities and older adults in any way. These services are a vital part of consumers' sense of dignity, safety, and independence and these factors should motivate all of us to weigh other options for maintaining dignity, safety, and independence rather than jumping on board the first bill that is proposed. As identified by the University of Nebraska Public Policy Center in their June 2003 report on this issue, there are other successful consumer-directed models of service provision throughout the country with the similar intent of those stated in this bill. This bill will impact the quality of thousands of lives and it is imperative that we consider the impact of this bill and study these other service provision models before finalizing any legislation. Thank you for your time and your consideration. [LB523]

SENATOR JOHNSON: Any questions? Richard, I see none. You might want to be on the radio. (Laughter) You've got a good voice for it. Any other opponents? [LB523]

BRENDON POLT: (Exhibit 8) Good afternoon, Senator Johnson and members of the committee. My name is Brendon Polt. That's spelled B-r-e-n-d-o-n P-o-l-t. I'm the assistant executive director of the Nebraska Health Care Association, a trade association with a membership of 400 nursing homes and assisted living facilities. Our membership strongly supports what we understand to be the goals of LB523, if those are improving the guality of home-based care and increasing payments for these services. However, we believe that this bill is not the right vehicle, similar to the prior testifier. This is not the proper vehicle to bring about those goals. A considerable percentage of our membership, almost half, provide home-based services. They also provide, as dual licensed, home health agency type skill services in people's homes. Assisted living, I would like to remind the committee, too, is a home- and community-based service under the Medicaid waiver. In order for Nebraskans to have statewide access to home- and community-based services, existing healthcare providers must continue to expand in this area, serving as hubs, being able to send their staff into the communities in rural parts of the state to provide services. This is recognized in the Governor's Medicaid reform plan and our association highly supports that plan and our members serve on the Rural Task Force charged with identifying ways to expand home- and community-based services in the community. So I want to make it very clear, we support home-based care and quality home-based care and expanding payments for those services so that it's cost-feasible for these services to be provided. That having been said, I do have a list of technical problems in the bill and some substantive issues that I've e-mailed to Jeff and I've made notations on this. So I would like to run through just a couple of those key issues for the committee's attention. [LB523]

SENATOR JOHNSON: Go ahead. You're usually pretty good at those technical things. [LB523]

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BRENDON POLT: (Laugh) Thanks. In Section 2, the legislative findings. I just want to make it clear that nursing home services are not always the least cost-effective services. It really depends on the level of care and the needs of an individual. The need for skilled care and the level of monitoring needed to care for an individual will determine what is the most cost-effective care. So in some of these findings, there are broad statements that say that facility-based care is carte blanche the most cost-ineffective and that's simply not true. Skip a couple here, less important...well, important, but not necessarily to discuss right now. Section 3 is a very troublesome section of this bill because, and I won't list each technical flaw. But what I will say is that the definitions that are provided for home care worker are simply, it simply says look to the various regulations applicable for personal care services for a whole host of...children with disabilities, chore services, home chore services, homemaker services, personal assistance services, respite care services. The problem is, depending on which section of the regulations you go into, each one is 100 pages long, they provide different definitions. So when this says a home care worker is providing personal aide services, well, it depends on what section, what chapter of the regulations you go into to see what are those services. So we believe that this Section 3 would need to be retooled significantly to provide clarification on what is the scope of services provided under the act. Next, problems with the council...well, to have a nine-member council with a majority of seniors or disabled persons and then five of those representatives are from specific entities, that would mean you would have to make hiring decisions based on age or disability. The agency would operate outside healthcare facilities licensure and outside the Uniform Credentialing Act, which was a committee bill to make uniformity in licensure and credentialing. This operates outside that. There's no healthcare or facility-based providers on the council and they're oftentimes the providers in rural parts of the state. And then there's other technical problems. Why are they operating outside the Department of Administrative Services. If they have a director, are they part of Health and Human Services? There's some guestions about the makeup of the council that make it confusing exactly how it operates. Probably the most significant issue in this bill is that providers of home-based services by private entities, by facilities, are not exempted. So is a private business' employees that provide services that seem to be regulated under this bill, are there employees now subject to collective bargaining? Because the way I read the green copy of the bill, they would be which clearly is troublesome. Also this council advises on policies of home health. Well, that would seem to then also mean, home health means home health agencies which is a skilled level of care. And they have their own section of licensure under healthcare facilities licensure. And so presumably those laws and regulations would govern and would be more appropriate than the new council created. Like I said, I've submitted Jeff a copy of my technical issues in the bill and I'd be happy to address any questions or afterwards deal directly with committee counsel. [LB523]

SENATOR JOHNSON: Any questions for him at this time? I don't see any. Thank you very much. [LB523]

BRENDON POLT: Thank you. [LB523]

SENATOR JOHNSON: Any other opponents? Are you a neutral? Let's proceed to neutrals. Welcome. [LB523]

CHRIS PETERSON: (Exhibit 4) Good afternoon, Senator Johnson and members of the Health and Human Services Committee. My name is Chris Peterson. I'm the chief administrative officer of the HHS System and I'm here to testify in a neutral capacity on LB523. LB523 creates a collective bargaining structure by establishing the Quality Home Care Council with its own executive director, staff, and budget funded by Health and Human Services Finance and Support. The council is given the authority to set wages and establish economic benefits for home care workers. Home care workers are defined in LB523 as a person selected by a consumer or the consumer's guardian or agent to provide home care for compensations including, but not limited to, childcare for children with disabilities, chore services, home care chore services, homemaker services, personal assistance services, or respite services. Within the HHS System, programs do not have separate authority to promulgate rules and regulations, report to the Legislature, develop a separate budget, or engage in activities related to collective bargaining. LB523 appears to set up an independent council within the Department of Health and Human Services Finance and Support. Staff for the council are within the department but they are under the direction of the council. Having department employees that are working under the direction of the council would be contrary to any current structure and the coordination that currently exists within the HHS System. LB523 also gives the council the ability to do such activities as lease, acquire, sell, and dispose of personal property. As a part of the HHS System or any state agency, these activities are governed by overall statutes, such as those that deal with the purchase and disposing of assets bought with state funds. Again, this issue could be resolved by clarifying whether or not the council is a state agency. Section 9 creates a budgeting cycle of one year and a three-year budget. All other state budgets are on a biennium schedule and we recommend that the two-year cycle be used in order to harmonize with the Legislature's budgeting process. During the last few years, a strong partnership consisting of the Governor, Legislature, and the Health and Human Services System has been instrumental in developing Medicaid reform plans to redirect Nebraska's costly reliance on institutional care. Long-term care rebalancing efforts center on a shift to less costly community services. This shift is heavily dependent on the network of independent contractors that currently provide respite services, personal assistance, chore services, homemaker services, and other in-home services. As the committee is aware, our agency has estimated that \$121 million can be saved by 2015 resulting from existing efforts under Medicaid reform related to long-term care. In this context, we agree with the premise of the introducers of the bill that a shift to community-based care in other Medicaid service areas that now rely on services being provided in institutional settings is worthy of further study. Our agency cannot, however, be proponents of this

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bill in its current form due to confusing relating to the structure of the bill. And I appreciate having the opportunity to set forth these issues. Based on information provided by the Nebraska Home Caregivers Association, wages increased from 19 percent to 210 percent, averaging 99 percent when home care workers are organized. Therefore it is estimated that expenditures would increase by approximately \$7.5 million at a minimum and possible \$3.9 million, using the average, due to rate increases resulting from collective bargaining. This increase will reduce savings anticipated to be realized, as compared to early estimates of Medicaid reform impact, that assumed lower payments to in-home care providers. I'll be available for questions. [LB523]

SENATOR JOHNSON: Any questions? [LB523]

SENATOR HANSEN: One quick one, Senator Johnson. [LB523]

SENATOR JOHNSON: You bet. Senator Hansen. [LB523]

SENATOR HANSEN: Director Peterson, on your testimony, second page, you said that it could increase by \$7.5 million to a minimum to possibly, and it says \$39 million. [LB523]

CHRIS PETERSON: Yes. [LB523]

SENATOR HANSEN: But you said \$3.9 million. [LB523]

CHRIS PETERSON: Oh, I'm sorry. [LB523]

SENATOR HANSEN: Thirty-nine? [LB523]

CHRIS PETERSON: Yes. And the reason we, the way we based it is, in the information that we received on how much wages went up, the floor was 19 percent and the highest was 210 percent. Looking at an average of those, it can be an increase of up to \$39 million on top of the wages we're already paying those 5,500 workers. I believe the Fiscal Office put it at the floor which was, the lowest was a 19 percent increase under this type of bill and that was the \$7.5 million. [LB523]

SENATOR JOHNSON: Any other questions? I see none. Thank you very much. Any other neutral testifiers? I see none. Would you like to close, sir? [LB523]

SENATOR AGUILAR: Thank you. First let me address that last statement, the \$7.5 million is a lot more realistic. As you know, when the Governor and the Fiscal Office tries to put their fiscal notes together, they look at the worst case scenarios every possible and that's what they base their opinion on. At the same time, it's necessary that I point out, to look at the figures from the other states and estimated savings, which

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brings me to point of the opposition from the representative of the Nursing Home Association. Is that a surprise to anyone? We're talking about some serious bucks they might lose out on that we're going to save as a state. That's the whole point of that. The other gentleman had a very good concern that testified ahead of him in regard to not being able to hire and fire whoever they choose. That is completely false. The consumer has the last say on who they employ. Nobody else has any say so in that matter. They make that choice themselves. But we don't want to take any decisions or choices away from them. That is not the point of this bill. You had a concern, Senator Hansen, a little bit earlier about western Nebraska. Western Nebraska has some of the biggest issues of shortage of these kinds of workers there is. And that's one of the main reasons we're doing this, to eliminate that shortage of workers, to have a base that the overstressed, overworked people in the system right now have because they can't a day off, they can't walk away from the job. You know, they're just stuck with it and that's why there's so much burnout in this. We want to create a registry so that we have people to draw from. There's a lot of technical things that people have problems with. There's nothing in here that technically we can't adjust. We're willing to work with the committee, with the consumers, with the Health and Human Service Department, anything we can do to make this bill perfect. It's no doubt still a work in progress but I think it's the right idea, I think it's something you should pursue. Thank you very much. I'll take any questions. [LB523]

SENATOR GAY: Thank you, Senator Aguilar. Are there any other final questions from the committee? Thank you for bringing this important issue up. It's a looming problem. Thank you very much. With that, we will close the public hearing on LB523 and open the public hearing on LB555. Senator Ashford. [LB523 LB555]

SENATOR ASHFORD: (Exhibit 1) Good afternoon, members of the Health and Human Services Committee. My name is Brad Ashford, and I represent Nebraska's District 20. I am here today to introduce LB555, a bill that I believe will increase the ability of Nebraska seniors to stay in their homes for as long as possible, and possibly have a benefit to the state's taxpayers, as well. I have handed out copies of an article that I...from earlier this year...last year, from The Wall Street Journal concerning a program that was started in Vermont and has had positive results. The idea is very simple. The state of Nebraska would pay family members to provide home healthcare for seniors that otherwise would likely end up in a nursing home. This would increase the number, potentially, of home healthcare workers available and could be beneficial to all parts of Nebraska by keeping families closer together and increasing the number of jobs available. The screening process would take place upon a person's discharge from a hospital or rehabilitation facility, which is the usual departure point of a senior from their home into a nursing home facility. If appropriated, a determination of the number of hours of home healthcare and the rate of pay would be negotiated by the Department of Health and Human Services, at least that was protocol in Vermont. The level of care needed to keep many seniors in their homes does not have to be very involved or

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necessarily require medical training. It often does not require 24-hours-a-day care. It is often a matter of assistance in cleaning, cooking, and simple household tasks. That is a population that my bill would intend to help. Obviously, the appeal of remaining in one's own home as long as possible has great appeal to Nebraska seniors. All of us that campaigned...had campaigned last year and prior to that, know that it's a big issue with our constituents across the board. The growth of Medicaid during the past 20 years and its future costs to the state is of great concern to all of us. I would just ask the committee to consider this proposal as a proposal for a...somewhat of a limited application in a rural county and in an urban county, to see whether it would work; in effect, to try it out in a rural and an urban setting, to see what...how it is received and what the costs would be. Obviously, there would be start-up costs involved, which would have a...could have an up-front significance, but over time, there would be, obviously, a reduction in costs, if the person was not required to go into a nursing home. This was an idea that just caught my eye from The Wall Street Journal article. We've had conversations with the Vermont people, and it has worked quite well. It's very simple, it seems straightforward. There's not a...hopefully, would not be a lot of red tape in trying this out, and I would just ask that you consider it as a possible option, as you look at all the other options you're looking at in the...you're considering in the Medicaid area. Thank you, Mr. Chairman. [LB555]

SENATOR JOHNSON: Thank you, Senator. We have a question from Senator Erdman. [LB555]

SENATOR ERDMAN: Senator Ashford,... [LB555]

SENATOR ASHFORD: Yes, sir. [LB555]

SENATOR ERDMAN: ...welcome to the Health Committee. [LB555]

SENATOR ASHFORD: Glad to be here. [LB555]

SENATOR ERDMAN: As a rural senator, I'm always interested to hear what an urban senator would call a rural county, and so I would imagine an urban county would be Lancaster, Douglas, Sarpy. [LB555]

SENATOR ASHFORD: Um-hum. [LB555]

SENATOR ERDMAN: What would be a rural county--everything but those three? Or... [LB555]

SENATOR ASHFORD: Possibly. [LB555]

SENATOR ERDMAN: I mean, is it...is there a guidance that you can give us that we

could go to determine that standard, or is it just up to the department? [LB555]

SENATOR ASHFORD: Oh, I don't think there's any...I don't...it's up to you. [LB555]

SENATOR ERDMAN: Probably be up to the department. [LB555]

SENATOR ASHFORD: Why not...I'd rather leave it up to you, actually (laugh), if you want...(Laughter) [LB555]

SENATOR ERDMAN: But your bill doesn't say that, and so... [LB555]

SENATOR ASHFORD: It doesn't say that, so I...but I'd be happy to work... [LB555]

SENATOR ERDMAN: You want to leave it up to me personally, or do you... [LB555]

SENATOR ASHFORD: I'd leave it up to you personally. [LB555]

SENATOR ERDMAN: Very well. [LB555]

SENATOR ASHFORD: I have all the faith in the world, Senator Erdman, in your ability to do that. [LB555]

SENATOR ERDMAN: Fantastic. We'll have Scotts Bluff County and Morrill. Those will be our two counties. [LB555]

SENATOR ASHFORD: That's fine. I don't...I really don't care what counties you choose. I just...it just seemed like a kind of idea that was...made a lot of sense and would save money in the long run, though there would be an up-front cost. But it would be something that could work. [LB555]

SENATOR JOHNSON: Senator Pankonin. [LB555]

SENATOR PANKONIN: Thank you, Senator Johnson. Senator Ashford, I remember reading that exact same article during the campaign. This is an idea that needs to be tried, so I appreciate you taking the time to look into it, and actually the fiscal note enclosed is fairly modest to start with. [LB555]

SENATOR ASHFORD: Right, right. [LB555]

SENATOR PANKONIN: It isn't...so how, when you're talking about a pilot program, how many people would be involved, then, do you think? [LB555]

SENATOR ASHFORD: I think that's the issue in determining the fiscal note, is how

many people would participate. We all went door to door, and we all talked to a lot of elderly people that were living as spouses, or with children. And to me, it was one of the most glaringly obvious points, and that was, they don't want to leave their home, and they have problems, issues. They're elderly or whatever, and they want to stay in their...this is very, very straightforward and simple. They want to stay in their homes, and their spouses or a child or a relative could provide some of the service--not all--but some of the services that this person needs and keep them out of a nursing home setting. And I was just struck by the article, as you were, and it's that basic. [LB555]

SENATOR PANKONIN: Thank you. [LB555]

SENATOR ASHFORD: Thank you. [LB555]

SENATOR JOHNSON: Thank you. Any other questions? I see none. Sir, will you be able to stick around... [LB555]

SENATOR ASHFORD: You know, I'm going to...we have a real hot hearing going back in Judiciary... [LB555]

SENATOR JOHNSON: All right, fine. [LB555]

SENATOR ASHFORD: ...and if I do waive, I don't want it to be assumed that I don't care deeply about the bill, but I think I should go back and take care of that. [LB555]

SENATOR JOHNSON: Fine, thank you. Thank you very much. [LB555]

SENATOR ASHFORD: Thank you very much. [LB555]

SENATOR JOHNSON: How many testifiers do we have for the next...for this bill? [LB555]

\_\_\_\_\_: Proponents? [LB555]

SENATOR JOHNSON: Both. Okay. Any...okay, let's just go right ahead. And let me...why don't you come along first, young lady. Let me say that LB555 is...there are letters of support from the Nebraska Hospital Association, AARP, and the Alzheimer's Association. (Exhibits 4, 5, and 6) Welcome to our committee. [LB555]

JUNE PEDERSON: (Exhibit 2) Thank you, Senator Johnson. My name is June Pederson, P-e-d-e-r-s-o-n. I'm the director of the Lincoln Area Agency on Aging. I'm not going to read the testimony that I brought to you, but I'm going to talk to you a bit about how this bill came to be. Senator Ashford's office called my office and said, we've read this article. And I said, interestingly enough, Senator Pankonin, so have I. And he said,

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we'd really like to think about how this option might be used, and he said, it would pay a family member to care for another family member. And I said, well, we already do that under some circumstances, and so we met with him and his staff and explained what those circumstances were. For a person who is on Medicaid waiver--and that's a program where you are low-income, and you have enough disruptions in your life; they call them activities of daily living, that you can't do alone. You have enough of those that you qualify for a nursing home, but you could live at home if you had some help. So the department asked for and received a waiver from the Medicaid department, the federal, to allow services to be provided in a person's home. Part of that waiver allows a family member, now not what we refer to as non-legal...someone who has a legal obligation would be your wife, my husband, my daughter, perhaps, or my son. Those are people who are expected to take care of you. But what if those people were not available, but you had a niece or a nephew or a cousin who could, lived close, wanted to. Under that...and if they were qualified. Our case managers look at that kind of an option, determine if that person is a good person to do that service, and if so, then sometimes that's arranged for that person to do that, under the Medicaid waiver program. But we can't do it under any other programs. So that's what this bill is about. We are looking at a serious shortage of providers, and I will tell you that in Lincoln, it's not difficult to find people to care for others. But I serve Butler County, Polk, many others, and for some of those people who live in the country, it's difficult to find a provider who will drive out, do the service, and be paid what the going rate is. But there might be a family member that lives in the farmhouse down the road that would be willing to do that. And I think that it's an opportunity for us to look at those services. In my view, this would not replace...this person would already be getting services. In this particular situation, we would allow a family member to provide services at a lesser cost. So I don't see it as being a high expense, but I see it as being an opportunity for us to find providers who truly care for these individuals at a time when they need it. So I'll answer any questions you might have. [LB555]

SENATOR JOHNSON: Any questions? Yes, Senator Stuthman. [LB555]

SENATOR STUTHMAN: Thank you, Senator Johnson. Thank you, June, for your comments. Realistically, in listening to your comments, this could really be a savings and in my opinion, could be a family member that would really know how to care for the individual, and would really be a good working situation. [LB555]

JUNE PEDERSON: I think so. I think so. I'm not sure that we can at this point consider it a cost savings, but it certainly does allow for persons to be get care who may not get it now. [LB555]

SENATOR STUTHMAN: Okay. Thank you. [LB555]

JUNE PEDERSON: Yeah. [LB555]

SENATOR JOHNSON: Any other questions? June, I see none. Thank you very much. [LB555]

JUNE PEDERSON: Thank you. [LB555]

SENATOR JOHNSON: Next, please. [LB555]

JOE KOHOUT: Mr. Chairman, members of the committee, my name is Joe Kohout, K-o-h-o-u-t, registered lobbyist, appearing on behalf of the Eastern Nebraska Human Services Agency, which is an interlocal agreement between the...which includes the Eastern Nebraska Office on Aging, for the reasons--the hour is late--for the same reasons as Ms. Peterson illuminated the committee on. We would also offer our support for this bill, as well. I'll happily answer any questions you might have. [LB555]

SENATOR JOHNSON: Thank you very much, sir. Any questions? I see none. Thank you very much. Any other proponents? Any opponents? Here she comes, Ms. Bad News. (Laughter) [LB555]

MARY STEINER: (Exhibit 3) Good afternoon, Senator Johnson and members of the Health and Human Services Committee. My name is Mary Steiner, S-t-e-i-n-e-r, and I'm the Medicaid director for the Department of Health and Human Services, Finance and Support. I'm here to testify in opposition to LB555. LB555 directs the Department of Health and Human Services, Finance and Support, to apply for a waiver from the Centers or Medicare and Medicaid Services, to pay caregivers providing home and community-based services to persons 65 or older who meet nursing facility or intermediate care facility levels of care. The payments would be made under the Nebraska Medicaid program. LB555 directs HHSS to promulgate regulations and to develop a pilot program to take place between September, 2007, and June, 2008, in one rural and one urban county. We believe the intent of LB555 is already enacted into HHSS regulation under NAC, Chapter 480, Home and Community-Based Waiver Services for Aged Persons, and persons with disabilities. This is an approved waiver under the authority of 1915(c) of the Social Security Act. The current waiver covers services to person aged 65 or older who meet nursing facility level of care and authorizes payment for services provided by nonlegally responsible relatives and caregivers. This includes a provider who has the power of attorney or is the guardian. The term "caregiver" is not defined in LB555 and would be open to many different interpretations, and may have the unintended consequence of paying individuals not being in compliance with federal Medicaid regulations governing such payments. At least 1.0 FTE would be required to complete requirements outlined in LB555, including applying for a federal waiver, promulgating regulations, and developing and maintaining the pilot program. There is a possible negative impact to the client and spouse if the income received for provision of these services would make them ineligible for some or

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all programs, due to increased household income. This would be a duplication and unnecessary cost to the taxpayers of Nebraska. If the intent of LB555 is to expand service payment to caregivers who are legally responsible for persons aged 65 or older, such as caregivers would be the spouses. It is a typical situation that the spouse of an eligible person would also be aged 65 or older and be the beneficiary of federal and state financial, medical, and social assistance programs. Any earned income paid to such spouse may reduce their monthly Social Security or other unearned income payment, and negatively impact eligibility for other services or programs which contribute to their ability to maintain a home. Of equal concern are the physical and emotional effects that LB555 would have on a spouse. Persons who require institutional level of care need assistance with their activities of daily living, primarily with bathing, ambulating in and out of the home environment, and moving from a seated or lying position to being on their feet and mobile. Clients' records of the Home and Community-Based Waiver Services, Services for Aged Persons, or Adults or Children with Disabilities indicate that most clients are referred to the waiver because their care needs have increased, and those already providing the care, their caregiver spouses and other relatives, need additional assistance in order to avoid institutional placement. In these cases, payments to the caregiver, if defined as spouse, would provide no solution. It could be detrimental to the caregiver spouse if they continued to care for their nursing facility-eligible spouse and became injured or caused an injury by providing care beyond their physical capacity. Instead of living at home, both spouses could end up in the facility. Nebraska's emphasis on respite care services for caregivers has gained national and international attention. The Lifespan Respite Care Act of 2007 passed by Congress and signed by President Bush was modeled after Nebraska's 1999 legislation which established the Lifespan Respite Network. LB555 may diminish the importance of respite to caregivers and may discourage paid spousal caregivers to seek respite, out of concern that their payment may be reduced if they access respite. They would not have the breaks that they now get from having another paid provider come into the home to provide those respite services. This could attribute to faster burnout and placement of the family member in a nursing facility. In conclusion, HHSS opposes LB555, because home and community-based services to the population described in the bill, and payment to caregivers, is already included in the Medicaid waiver. Passage of LB555 would increase HHS staff workload, by requiring the application for another federal waiver, promulgation of regulations, and the development of a pilot program for services which would duplicate those already allowed under an existing waiver and existing policy. I'd be happy to answer any questions. [LB555]

SENATOR JOHNSON: Senator Gay. No? [LB555]

SENATOR GAY: I'll find the other (inaudible). [LB555]

SENATOR JOHNSON: Anyone else? There's always unintended consequences, aren't there? Any other questions? Thank you, Mary. [LB555]

MARY STEINER: Okay. Thanks. [LB555]

SENATOR JOHNSON: There he is! Brendon. [LB555]

BRENDON POLT: For the record, my name is Brendon Polt. I'm here on behalf of the Nebraska Health Care Association. Very briefly, the healthcare association is very supportive of the Medicaid reform process that was started by Senator Erdman two years ago in LB709. That process undertook input from broad-based groups of people, met over a year period, developed a comprehensive Medicaid reform plan, which Jeff was instrumental in, with the Department of Health and Human Services. And we believe that that plan can work, it's currently working, and we would just advise--please let that process work, and let's not pick it apart, because then we start undoing what that public process accomplished, which we think was very positive. Thank you. [LB555]

SENATOR JOHNSON: Thank you. Any questions of Brendon? I see none. Thank you. Any neutral testimony? I see none. That being the case, we'll proceed...or let's close first on LB555. I don't believe Senator Ashford was able to stay. And we'll proceed with LB236, and I did have a note here that we better pay attention to. It's addressed to June Pederson. It says here, she said she would answer any questions, and one of our panel members wants to know who will be the Nebraska fullback this next fall. (Laughter) [LB555]

JUNE PEDERSON: I don't know. Ask Matthew. [LB555]

SENATOR JOHNSON: Senator Gay, would you take over, please? [LB236]

SENATOR GAY: You bet. All right, we'll open the public hearing on LB236. Senator Johnson and Hansen are on this one. Senator, you'll do the opening? [LB236]

SENATOR JOHNSON: Senator Gay, members of the committee, I'm Senator Joel Johnson, representing the 37th District. Anyone who has a senior family member living alone knows the difficulty, as we've heard about in the last two people, or two bills that have been brought up for discussion. It becomes more and more complicated to find ways for these seniors who wish to live at home as long as they can. And obviously, the longer they can stay at home rather than in a facility, the cheaper it becomes. LB236 is an important step to allow an individual to remain self-sufficient in his or her own residence, and do it for as long as possible. There are a number of services that can be provided to these seniors that are not medical in nature, and do not reach the level of care that is meant to be governed by our present home health agency laws. That's the key statement--do not reach the level of care that is meant to be governed by the home health agency laws. It makes it clear the statutory requirements for home health related to home health aide services do not apply to specific, nonmedical in-home services.

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This does not apply to specific, nonmedical in-home services. Those services of daily living--attendant services, companion services, homemaker services--are what are defined in this bill. By making it clear the fact that the requirements of the home health statutes do not apply to in-home services, agencies that do provide these services can do so without having to hire nurses or a physician to supervise their work, and thereby cutting down on the cost. What the idea here is to reduce the cost of in-home services that will free up nurses and doctors, which particularly in rural areas, are in short supply. In general nurses, particularly, are in short supply in many places. In the long run, we hope to keep our senior citizens home for a longer period of time. Let me just advise you of one particular entity, and the people behind me will address this, and that's this: It does not in any way affect change or affect the "Tim Kolb" exception to home health services or to individuals unaffiliated with an agency who provides services to seniors in their homes. The people behind me will explain that more. There's no sense doing it twice at this late hour. Also, this does not affect respite care that we just heard about, habilitation services, or personal assistant services under the aged and disabled regulations or Medicaid waivers in the Department of Health and Human Services. There is an amendment regarding this that will be presented by the people to follow me. So with that,... [LB236]

SENATOR GAY: Thank you, Senator Johnson. Are there any questions for Senator Johnson from the committee? I don't...Senator Erdman. [LB236]

SENATOR JOHNSON: He must really want to ask it, at this time of the day. (Laugh) [LB236]

SENATOR ERDMAN: I...he didn't really want me to ask it, Senator. [LB236]

SENATOR JOHNSON: Whatever. [LB236]

SENATOR ERDMAN: The only question I have is, as I look through some of the requirements here, one of the things that kind of caught my eye was in addition to doing a...what I would call a background check, you have them do a driving record check. [LB236]

SENATOR JOHNSON: Right. [LB236]

SENATOR ERDMAN: Is that found elsewhere in statute, or is there a specific reason? And then, I guess, what are they looking for? Because it doesn't require them to take any action, based on what they find. [LB236]

SENATOR JOHNSON: No, but I believe what we're looking for is this, is just the overall record of the individual. One of the things, Senator, that we want to guard here or is protect these really quite vulnerable people, is that someone comes into their home,

and we want to make sure that they're dealing with a person who is, shall we say, of good character. And the check for their driver's license would be just another way of ensuring that. [LB236]

SENATOR ERDMAN: And I'm assuming, I mean, it doesn't really specify in the act, it doesn't say the limitations on who has access. I'm assuming it would be the department that would have access to that record, or would they be open to anybody to come in and... [LB236]

SENATOR JOHNSON: I believe that the intent is to run that through the state of Nebraska, but also the employing agency would deal with the state of Nebraska, so that it...you wouldn't have 500 individuals each going to the state, but you know, if there were five agencies, they would collect all the information and then pass it on. [LB236]

SENATOR ERDMAN: Super. [LB236]

#### SENATOR GAY: Thank you. Other proponents? [LB236]

KIM ROBAK: (Exhibit 1) Senator Gay and members of the Health and Human Services Committee, my name is Kim Robak, R-o-b-a-k, and I am here today on behalf of the Eastern Nebraska Chapter of the National Private Duty Association, in support of LB236. I have some... I actually have a diagram to point out to you. I have the amendment that Senator Johnson referred to, and I also have a letter in support of the bill from Rosalee Yeaworth, who is the dean emeritus of the University of Nebraska College of Nursing, who is supporting the legislation. What I want to do, and can I get a copy of the diagram back from you? I gave it away. What I want to do is start out with this diagram, because we've had a number of bills today that have dealt with the same subject, and that is, keeping people in their homes. But they're all going about it in a real different way, and what we're attempting to do here is to deal with private agencies that deal with in-home care, who provide a level of care that is non-nursing...that require non-nursing or medical judgment. If you look at the diagram here, we talk about hospital care, and nursing home care, and assisted living. All of these are facility care, and then you get down to home-based care. What you've had in the first couple of bills today is home-based care that is individually directed. These are individuals who are not associated with any type of an entity or organization or agency, but they provide services to people in their homes, and they were talking about the fact that they have difficulty finding some of these folks, or that they're low pay. These are people who can do any home-based care here. Above the line you see in-home care that is home health. Home healthcare is licensed by the Department of Health and Human Services. So if you are an entity or an agency, you get a home health agency or a home health license, then you can do medical types of services in someone's home. If you don't have that home health license, then you can't do any services in the home. The Department of Health and Human Services has taken the position that in order for an

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agency to be able to perform any services--that includes driving someone to church. that includes sitting, playing cards with them, that includes combing their hair, that includes reminding them that it's time to take their medication, that includes the list of items that we have set forth in the statute--that if you're going to provide those care, that care in the home as an entity such as Home Instead or Guardian Angels, that you have to have a home health license. And if you have the home health license, then you have to have nursing supervision and physician supervision, as Dr. Johnson stated. And what that does is, it causes the cost of care for home-based care to go up. And we want to ensure that if you're going to give in-home services, and only in-home services--those services that do not require medical or nursing judgment--that you be able to do that without having to get a home health license. So Section 5 of the green copy of the bill specifically states that we're exempting out from home health--it says Section 71-...let me get the section. Section 5 of the green copy of the bill says Section 71-6601 to 71-6612 do not apply to, and then you get to the end, to in-home personal care service agencies or to in-home personal care service workers. So we define in the statute what an in-home personal service agency and an in-home personal service worker is. They would not have to get an in-home license; therefore, the work that they do, which would be limited to items that don't have nursing or medical judgment--combing hair, giving a bath, playing cards, cooking meals, etcetera--they would not have to get that license. It would save them money. Now it does allow for one other item in the bill. The bill allows an in-home services worker to be able to give medication reminders without having to be a medication...to get a medication aide license. The rationale for that is that if you're there, Gladys needs to take her meds, you can say, Gladys, it's 2 o'clock. It's time to take your meds. They don't give the medication, they don't give the shot, they just simply say, Gladys, it's time to do this. They would also be allowed to give nonmedical ointments or lotions; for example, after a bath if they wanted to put lotion on somebody. Right now, the department has taken the position, it's my understanding, that they can't do that because that would be the application of a medication, and therefore, they would need to be a medication aide. So the bill does two things: It separates out in-home services, and then it says you can also give medication reminders. What you have in front of you also is an amendment, and we want to make it very clear that as we were figuring out that we wanted to take these agencies like Home Instead and Guardian Angels and all of the other entities that exist out there and allow them to operate without having to get home health licenses, we discovered--in fact, all of the people there know this anyway--that in this home care arena, if you hire somebody...if you hire your next door neighbor, if you hire an individual that's not associated with an agency, they can do anything. They can give baths, they can give medication, they can do all of the level of care without having to be licensed, because they are individuals. So individuals are not licensed. Only agencies and entities are licensed to have to give this care. So we're trying to drop down to this lowest level of care, make sure that we're not in any way harming seniors or individuals, and requiring that they allow them the opportunity to give medication reminders. There is a fiscal note to this bill. The fiscal note says that the cost is going to be \$11 million. The reason it says that there will be a \$11 million fiscal note is

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because at the time that the bill was drafted, we had two provisions in here that indicated that perhaps we were also going to affect all of those individuals that get to do this, when they hire an individual outside of an agency. As Senator Johnson mentioned, there's a Tim Kolb exception to the law, that a gentleman who fought long and hard for the ability to have self-directed care. And I remember when Tim Kolb got the amendment passed. What the Tim Kolb amendment says, as we already discussed, the ability to do this in home. So we have in the amendment some language that says that we exempt out anything that deals with hospice care, with health maintenance activities performed by designated care aides pursuant to Section 71-1,132.30. We are attempting to exempt out any of those individuals who are in any way...that currently perform those services outside of an agency. I hope I'm making sense. What the fiscal note says is, if we required those individuals to have to have nursing and doctor supervision, that it would probably cost some place in the neighborhood of \$11 million. So it gives you some idea, if you take that requirement off of doctor and nursing supervision in that base level of care, of simply in-home services, that there would be a vast amount of savings. Those savings would go to the public, the public would then be able to stay in their home longer, and they would not, then, need to go to nursing homes or to get Medicaid coverage at some point. I should say one last thing: This bill does not deal with Medicaid, as such. We are not asking for money from Medicaid. We are not asking to be covered by Medicaid. We are only asking that the services that we provide, the private care services that we provide, not fall under home health, so that we can continue to provide those services at the lowest possible cost. And with that, I hope I haven't confused you more than clarified, and I'd be happy to answer any questions. [LB236]

SENATOR GAY: Senator Stuthman. [LB236]

SENATOR STUTHMAN: Thank you, Senator Gay. Kim, in other words, what you're trying to accomplish here is the group of people that are not hired by an agency, that are doing an in-home service to keep these people in their homes for a longer period of time. [LB236]

KIM ROBAK: Actually no, Senator. We don't touch the people who are not affiliated with an agency. They operate on their own. They will continue to operate on their own. They're not regulated. It's my understanding--but I'm sure HHS is here; if I'm wrong, they'll correct me. I don't believe that they are regulated by Health and Human Services. They can do whatever they want, and we don't want to affect them. We want to deal with the agencies, and we want to allow agencies to be able to perform a level of care without nursing or medical judgment, without being licensed. [LB236]

SENATOR STUTHMAN: Oh, so...that was my misunderstanding, then, that it is an agency that you're trying to work with, and...but you want that agency, not at the expense of the Medicare. [LB236]

KIM ROBAK: Right. We don't want them to... [LB236]

SENATOR STUTHMAN: That \$11 million. [LB236]

KIM ROBAK: We don't want them to have to get a home health license to be able to do care that doesn't require nursing or medical judgment. [LB236]

SENATOR STUTHMAN: Okay, thank you for explaining that. [LB236]

SENATOR GAY: Any other questions? I've got one. When it talks about good moral character, in Section 2 it goes through all these requirements that has to be in here. Why wouldn't a private company, a decent company, do this anyway? [LB236]

KIM ROBAK: They would do it anyway, Senator. It's in there for...there is a companion bill to this, the next bill up. The next bill up is the next stage in the process, and that would be that these groups would be eventually licensed. We would like there to be consumer protection and consumer safety. The reason that's in there is because there may be an entity out there that creates a company, and we want to have the most basic level of care possible. [LB236]

SENATOR GAY: So this puts teeth in the license, is what you're saying. [LB236]

KIM ROBAK: It just puts a little bit. There's no license, but it puts... [LB236]

SENATOR GAY: Well, okay, no license. But it puts... [LB236]

KIM ROBAK: But it gives a requirement for anybody who's going to provide these services as an agency to have to do a minimal level of background check, a minimum level that those workers who work for that private company, have the obligation to have at least a minimum level of care. Now these companies are going to do this on their own, Senator, and they do right now. They exist today and do that. But today they also have to have nurses, when they're not performing any nursing services. [LB236]

SENATOR GAY: Okay. I mean, I could see some of these you would want to do, because we just heard...you hear horror stories prior, on the people they weren't checking out. So...but I guess some of these, I look...shall have good moral character. How do you enforce? And then the English language thing. I mean, that would make sense, if...I don't know. [LB236]

KIM ROBAK: It is common sense. There are aspects that probably any...and actually, these companies go much further than that, and that's part of what they stand for. And they believe that if an individual does their homework, they'll check out what the

company is, and they'll know that they do this. [LB236]

SENATOR GAY: Their reputation is with it. [LB236]

KIM ROBAK: Their reputation. [LB236]

SENATOR GAY: Okay, thank you. [LB236]

KIM ROBAK: If I may say, Senator Erdman asked a question earlier about the driver's license checks. Part of the amendment says that you only have to do a background check if the person is going to be driving...a driver's license check if they're going to be driving, to clarify that that's when you do it. [LB236]

SENATOR GAY: Thank you. I see no other questions. Thank you. [LB236]

KIM ROBAK: Thank you. [LB236]

SENATOR GAY: Other proponents? [LB236]

PAUL HOGAN : Good afternoon, members. Thank you for your service. My name is Paul Hogan, H-o-g-a-n, and I'm the founder and current CEO of Home Instead Senior Care. In 1994, my wife and I started Home Instead Senior Care, based on the experience we had with my own grandmother, who was 88, lived in her own one-bedroom apartment down the street from where I grew up, and she got so weak she couldn't even get out of her chair anymore. So the family had the meeting, and we were committed--no nursing home was going to be in her future. My mom brought my grandmother into her home, and we all chipped in to do the basics; you know, meal preparation--not just making the meal, but encouraging them...her to eat. We would help her with her laundry. We would stimulate her, get her up out of her chair, you know, once in awhile. She, you know, a reminder--hey, it's 6 o'clock. Grandma, it's time to take your medication, and then just witnessing that it happened. Well, she got stronger and stronger. We thought she had one year to live when we brought her into the home. She lived another 11 years, and she got so strong she was walking herself to church everyday, and it was a real every everyday, and it was a real every everyday and it was a real every every to us that you didn't have to be a doctor or a nurse to turn someone's life around. So we started Home Instead Senior Care and designed our service after exactly what we were doing for my grandmother. And we started in Omaha, and then our first franchise, because I worked with Merry Maids before Home Instead Senior Care and learned that method of expansion, was my wife's uncle here in Lincoln, and then on to Atlanta to my brother-in-law, then two college roommates. Now we have 715 franchises, 520 are in the U.S., and the rest of them are in 9 other countries. So this is the service we're talking about--companionship, light housekeeping, meal preparation. We do incidental transportation; you know, reminding them what time it is so they can take their medications, and so on--all nonmedical, and

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now they're referred to, in this bill, as in-home personal services. Well, the growth of this Home Instead Senior Care is just a reflection of the demand for staying in the home, as we've heard all day today, but it's also a reflection that we've been able to blend a quality service with some, you know, affordable...in an affordable way. And now...well, and not only has Home Instead grown--now we have ten here in Nebraska, and as I mentioned, 700...when I started in 1994, there might have been maybe 20 or 40 or so in the U.S. Now there's over 6,000, so the industry has evolved, as well, over the last 12 years, and that's where this industry association you're hearing about...it was just established in 2002, and we have a chapter here in Nebraska, which is this Nebraska Chapter of the NPDA, which is bringing forth this. So that's a reflection of how much sense this makes, and this industry association, it advocates for quality, training, screening, supervision; advocates for consumer protection. So there is a measurement by consumers--hey, are these folks members of the NPDA, because that's what they all stand behind. So the ... today, the regulation in Nebraska is very unusual, as we see it from across the country. It's very unusual to be feeling the pressure of having to get a full-fledged home health license to do nonmedical services. But that's the position we're in today, based on some of the interpretations, some of the confusion involved with how the rules are written, and so on, and if we comply with those, our prices will go from--well, example right here in Lincoln--from \$16 an hour to \$21.25 per hour, a 30...almost a 32 percent increase, to incur all the overheads it would take to comply with this regulation, that really doesn't apply to us; you know, to have nurses and all the supervisory...you know, and all the stuff that goes along with a full-fledged home health license. So as you can see, that really drives up the cost of our services unnecessarily. So our whole position with the chapter of the NPDA--well, actually the national chapter and the Nebraska chapter--is affordability, because we've all been hearing it all day. We need to keep home care more affordable so people can stay in their home longer. But see, families are no different than government. We have limited resources, and the faster a family goes through their resources, the sooner they become, you know, a burden to the state--Medicaid system. So our whole goal is affordability, with some reasonable guality, and to start that process, we just want to, with LB236, we'd like to make it clear, you know, this is what kind of business we are, and this is the degree to which we can serve people, and there's a clear definition of what we can do, and without having to incur these kind of overheads. So I'm here to urge you to, you know, to support LB236, and I'd be happy to answer any questions. [LB236]

SENATOR GAY: Thank you, Paul. Are there any questions from the committee? Senator Stuthman. [LB236]

SENATOR STUTHMAN: Thank you, Senator Gay. Thank you for your comments. So realistically, with...your experience with a good diet and a little TLC, it makes a lot of difference. (Laughter) [LB236]

PAUL HOGAN : Yes, a square meal is very important. It all starts with nutrition. (Laugh)

Thank you, Senator. [LB236]

SENATOR STUTHMAN: Yeah. Thank you. [LB236]

SENATOR GAY: Senator Hansen. [LB236]

SENATOR HANSEN: Thank you, Senator Gay. Paul, someone would question, a business being here for that long, would really question, has your scope of practice--and that's what we talk about all the time--has that changed in the time that you've...since you're started? And how do you contain your scope of practice to remain at the level you are? [LB236]

PAUL HOGAN: Good question, Senator. Our scope of practice has not changed since 1994. We don't...there are clear lines that we draw as a business, and we always have. It's just that...like in 1998, we had a surprise inspection by the Department of Health and Human Services. They came in, they looked over our files, and they even met with a few of our clients, and they said, oh, you're fine. And now, for some reason, the last couple years it's become this big issue, and there's a lot of people looking at exactly what the law says and it's squeezing us into this, you know, into this regulation that really was never an issue before. So this has caused us...okay, let's get some clarity here, you know. It wasn't a problem five years ago; now it is. But we don't do lifting over...our personal business is, we don't do lifting over a certain weight limit, 25 pounds. We don't do a full bath; we assist in the bathing process. We don't administer medications, and we don't do monitoring of vital signs. We don't give injections. We draw some really clear lines where skilled care really needs to come into play, and then we inform the family, this need is surfacing, and we'll even recommend, here's some companies that can do that for you. So that's how we manage our scope. [LB236]

SENATOR HANSEN: Thank you. [LB236]

PAUL HOGAN: Um-hum. [LB236]

SENATOR GAY: You got something? You looked like you had a question. I do, Paul. On some of the scope of practice, as Senator Hansen was saying, would you limit that because of your own liability, where you don't want to get into that? [LB236]

PAUL HOGAN: Oh, absolutely. [LB236]

SENATOR GAY: Or you do it on your own, too? [LB236]

PAUL HOGAN: Well, there...in many states...yeah, in many states where we operate, it's very liberal. But we draw the line from a risk management standpoint, and that's...and so do the members of the NPDA. They believe that it's incumbent upon

themselves, as a business, to manage their risk. [LB236]

SENATOR GAY: All right, thank you. I don't see any other questions. Thank you. [LB236]

PAUL HOGAN : Um-hum. Thank you very much. [LB236]

SENATOR GAY: Thank you. Other proponents? Go ahead. [LB236]

CONNIE MICH: Time for you to go home, isn't it? (Laughter) [LB236]

SENATOR GAY: I'm going to be here as long as you are. (Laugh) [LB236]

CONNIE MICH: My name is Connie Mich, M-i-c-h. I'm here as a senior citizen. I'm 81 years old, and I representing myself, my husband, a lot of elderly neighbors that live around my house, and I hope I'm going to be speaking also for some of the elderly in the state of Nebraska. I need help. I have a fair amount of arthritis--the hip joint, knee, hands--and I need help sometime with a bath. I need help getting my hair fixed and brushed. Somebody spoke of lotion--that's just wonderful to have somebody give you a back rub with some lotion that you can't reach because your arms are stiff, you can't get back and do that by yourself, so that would be just wonderful to have. Also, medication--you know, when you start getting older you like your reclining chair and you like to sit in that, and you kind of fall asleep, and you should be in bed. You forget to take your medication in the evening, and it would be wonderful to have somebody remind you--the medication is all dished up--but to remind you to take it. Taking medication at two, three in the morning when it should be taken...I mean...in the morning, yes, when it should be taken a nine or ten at night can cause a lot of other things, like falls or some other kind of problems because you're not taking the medication when you should be taking it. The caregivers are capable and nurturing people. They are supervised; the office comes in and checks to make sure they're doing what they should be doing, and as far as care, you couldn't ask for anything better. And I want this service because I need it, not because a doctor is telling me or a nurse is telling me, you need with a bath, you need help with your hair, you need help with whatever, putting on T.E.D. hose or whatever it might be. Our resources are limited; we're elderly and they're very limited, and LB236 would help us to be on our own. We wouldn't have to go into a nursing home, and we haven't got the resources for that, to begin with, and we wouldn't have to depend on the Medicaid waiver to...from the state to support us. The state needs to think of these senior citizens that do not have a lot of money but that need help, and can get the help that they need without spending a great deal of money. And I think we would be saving...or you would be saving a lot of money for the state if we could...and you would be supporting this bill of LB236. And I'd like to thank Senator Johnson for supporting this bill. Thank you. [LB236]

SENATOR GAY: Thank you. Senator Stuthman. [LB236]

SENATOR STUTHMAN: Thank you, Senator Gay. Connie, would you like this service to be daily, or so many hours a day, or what? [LB236]

CONNIE MICH: So many hours a day, probably, just when needed. Some...I don't drive very much any more. I'm not supposed to. I...sometime I need to have somebody to take me to the doctor's appointment, and if I could call on somebody to do that, it would be helpful. [LB236]

SENATOR STUTHMAN: Okay, thank you. [LB236]

CONNIE MICH: Um-hum. [LB236]

SENATOR GAY: Thank you. Any other questions? I don't see any, Connie. [LB236]

CONNIE MICH: Um-hum. [LB236]

SENATOR GAY: Other proponents? [LB236]

LAURA PLOFCHAN: Hi. My name is Laura Plofchan. I'm from Papillion, Nebraska, and that's where my business is. It's called Kind Hearts. We've had our business for four-and-a-half years, and like Paul, I started the business because we were taking care of some family members, and I know Tim and his wife pretty well. I started...the reason why I'm here is just because I, like a lot of the other agencies here in the room, received the same letter saying that we could not perform any sort of medication reminders, and it was listed as one of our services when we first started the business. Because of that, I just wanted to share a quick story. We had a family that we were doing that for before we received the note. We stopped doing that service. The son lived in Florida; the daughter lived in Grand Island. They didn't get to see their mother very often. She was there...we were there every day. We had a medical agency that was there setting up the meds. We also had a medical agency that was doing a bath for her. So all we were doing was providing meals, doing her cleaning, making sure that she took her meds. Well, after this came down from the Health and Human Services, we stopped doing that. Very guickly after, the family could not afford...the two options was to get a neighbor to come by, which was extremely unreliable--this neighbor never showed up--to get her her meds. The other option was to have the home health agency that was there to set up the meds, come three times a day, because that's how often she needed those med reminders. That was unaffordable for this son. He chose to put her in a home. She lasted two weeks. Now I don't think that's going to happen in every situation, but I just, from the heart I just want you to know that when you do take these people out of their home, because of a cost issue, which, that's what happened with this family...they could afford us nonmedically, but they couldn't afford that much medical

service. That's what tends to happen. So, any questions? [LB236]

SENATOR GAY: Thank you, Laura. Are there any questions from the committee? Senator Hansen. [LB236]

SENATOR HANSEN: Thank you, Senator Gay. What's the name of your business? [LB236]

LAURA PLOFCHAN: Kind Hearts. [LB236]

SENATOR HANSEN: Kind Hearts. And I don't know if you spelled your name for the record, so. [LB236]

SENATOR GAY: Oh yeah, Laura, can you...oh, thank you. [LB236]

LAURA PLOFCHAN: P, as in Paul, I-o-f-c-h-a-n, and we have clients in Sarpy, Douglas, Cass counties. We also have clients in Pottawattamie, Lancaster, and Saunders counties, and we've not a franchise. It's just my business. [LB236]

SENATOR GAY: Laura, I have...Senator Stuthman. Then I have a question, as well. [LB236]

SENATOR STUTHMAN: Thank you, Senator Gay. First of all, I want to thank you for your comments and bringing that issue,... [LB236]

LAURA PLOFCHAN: It's just a personal story. [LB236]

SENATOR STUTHMAN: ...surfacing it, because you know, I always say, you know, we're a creature of habit, and when you change the normal habit of a person, it changes their...the way they do things, and it just moves them closer to their last stop. [LB236]

LAURA PLOFCHAN: Absolutely. [LB236]

SENATOR STUTHMAN: Thank you. [LB236]

LAURA PLOFCHAN: Thank you. [LB236]

SENATOR GAY: Laura, I have a question. When you talk about medical reminder, is that a personal, hey, take your medicine, or is it a phone call at a certain time, or how do you do that? [LB236]

LAURA PLOFCHAN: The way we do it is, we're actually in person; we were in person doing this. She was actually...she spoke Lithuanian, so that son had actually written the

instructions in Lithuanian for us. We tried to understand that, and as well...we translated it, and that's what we said. I mean, we...it was all through Lithuanian, so my caregivers got out Lithuanian dictionaries and read Lithuanian to her. So yeah, it was a written note, and we just basically had to read that to her. She was able to take them on her own--no problem. We, you know, have diabetic clients that need to check their blood sugar. It's just a matter of making sure that they're doing what they need to do, as well as get dressed for the day, you know, get to their doctor's appointments, that sort of thing. [LB236]

SENATOR GAY: Okay. Thank you. I don't see any other questions. Thank you. [LB236]

LAURA PLOFCHAN: Thanks. [LB236]

SENATOR GAY: Other proponents? I see none. Any opponents who would like to speak? [LB236]

STEVE MORRIS: (Exhibit 2) My name is Steve Morris. I'm here with my wife, Susan, on behalf of our son, Jeff. Steve Morris, M-o-r-r-i-s. And we're here to testify today on behalf of our son Jeff, and perhaps many hundreds of other people in like circumstances around the state, and also Tim Kolb. Tim has called me this morning and said that he wasn't going to be able to make this hearing today because of the weather and the distance to travel and all that, and I thought that was a wise move on his part. Now it sounds like some of our concerns and some of Tim's concerns have been addressed by, as I understood, the amendment that Kim Robak talked about earlier, and so we'd probably have to temper our opposition to this legislation because of some of the considerations and concerns that Tim had. And when...I've known Tim, he's been a dear friend of ours for a number of years, and helped us a great deal with our son. And when Tim is concerned about things, we tend to get concerned, too, because he studies this all very closely. I do have copies of Tim's testimony, as well as a copy of the Kolb amendment, also, and since I promised Tim that I would give his testimony, I will do that now, and hopefully we'll get this done in just a few minutes. Mr. Chairman, and members of the committee, I am hereby testifying against LB236. In my opinion, LB236 is potentially threatening to Section 71-1,132.30 of Nebraska's Revised Statutes (also known as the Tim Kolb Amendment to the Nurse Practices Act). The Tim Kolb amendment was written to permit competent persons with disabilities to direct their own care that might include invasive procedures (referred to as health maintenance activities) in home and community settings. Prior to the passage of this amendment, only licensed medical professionals such as nurses could perform such procedures. This meant that the cost to the state was prohibitively high if medical professionals had to be hired frequently or for extended periods of time to provide these health maintenance activities in a community environment. Therefore, people with more severe disabilities who had regular need for these procedures were placed in nursing homes and other medical facilities. However, even that solution was costly. As of about three

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vears ago; that is, 2004, almost 30 percent of the Medicaid expenditures were for nursing home placements. It became clear that the way to reduce these costs and increase the quality of life for persons with severe disabilities was to allow people who were not medical professionals to be trained to do the health maintenance activities under the direction of a competent client. The amendment not only enabled persons with severe disabilities to remain in their own home and community, but permitted them to engage in competitive employment, as Tim is right now. Tim has been employed for the last couple years, and much of that has been a direct result of his ability to do these kinds of things that were outlined in the Tim Kolb amendment. The proponents of LB236 insist that it is not their intent to nullify or diminish the Tim Kolb amendment, but the language used in the bill is full of terms so similar to terms typically used to described hired caregivers that work under the Tim Kolb amendment, that there is a real risk of misinterpretation and misapplication. For example page 2 of LB236, line 4 states, "Attendant services means hands-on assistance with activities of daily living and transfer, exercise, grooming, self administering medication and similar activities..." The phrases "attendant services," hands-on assistance with activities of daily living," etcetera, are terms commonly applied to people who provide personal assistance services for persons with disabilities under the Tim Kolb amendment. Also, line 10 of page 2 says, "Homemaker services means assistance with household tasks, including. but not limited to housekeeping, personal laundry, shopping, incidental transportation and meals..." These terms are commonly applied to workers who provide "chore services" under the Medicaid waiver program. It would be easy for HHSS caseworkers, who are already besieged with myriads of regulations they have a hard time understanding and applying, to confuse the regulatory apparatus described in LB236 with what caregivers and chore service providers are now doing under the Tim Kolb amendment, and the Medicaid waiver. Their interpretation might be to have such workers become licensed before they are allowed to work. If they would become licensed, the kinds of care they could perform would be limited as they were prior to the Tim Kolb amendment, and the whole cost spiral upward would happen all over again. I've provided a copy of the relevant legislation that is handed out to you, the Tim Kolb amendment, for you to study and compare with the recommendations in LB236. Once you've made the comparison, I think you will easily understand how misinterpretation and misapplication could occur, and all to the detriment of persons with severe disabilities, and to the state's budget. Please do not pass LB236. And I guess I would add, parenthetically at this point in time, if Tim were here, I'm sure he would understand that given some of the comments from Senator Johnson and Kim Robak, based upon the intention not to affect that, I'm sure that that will be something that Tim will be very happy to hear about. Thank you for your attention on this issue. Now are there any questions that any of you have for Tim that I could relay back to him? [LB236]

SENATOR GAY: (Laugh) You're pushing it, Steve. Be quick. Senator Stuthman. [LB236]

SENATOR STUTHMAN: Thank you, Senator Gay. Steve, the question that I would have, and we've listened to the proponents, and we've listened to an individual that started a business, and he's got many, many businesses in this nation and abroad, is he doing something wrong? [LB236]

STEVE MORRIS: Quite frankly, I don't know anything about that side of the business, and as I listened to most of the testimony prior to mine here, it became clear to me that much of the thrust of this legislation was not along the lines that we were concerned about. And so I really don't have an answer to your question. I certainly don't know anything they're doing wrong. I think Tim was concerned, and when he relaved that to us, we got a little concerned, too, because we knew how hard he had fought for those changes in the law, was that based upon some of the language he was seeing in this legislation, that it could have a potential adverse impact on the ability for him to remain in his home, and for many other like individuals, including our son. Our son Jeff, who will be 34 next month, he was born with Duchenne muscular dystrophy, and as he has gotten older, he got progressively worse and he went into a wheelchair when he was about 12, and he had a respiratory crisis in his late teens. And after he came out of the hospital, he was on a ventilator, and he has been on a ventilator ever since. We in the early going looked into placement for our son at Madonna, one of the local rehabilitation hospitals and just decided at that point in time that we wanted to care for Jeff at home, and we just knew his quality of life and everything would be much better. My wife and I always remember a conversation we had with a physician at Madonna in the early going, too, that related to his prospects for his life, his longevity. And you know, we had been told when Jeff was very young that they didn't...kids with muscular dystrophy didn't live much past their teens, and here Jeff was 19 at the time, but he was on a ventilator, and this individual told us that his life expectancy was probably about 25. Well, as I told you earlier, Jeff is now 33; he'll be 34 next month, and I think a large part of the explanation for that is that we've been able to care for him in his home instead of in an institutional setting, and at far less cost. You've probably heard some of that before, but you know, we do it at our home for a little bit more than one-third of what it would cost in a place like Madonna or the Ambassador or a place like that, which are really the only facilities that have long-term capabilities for handling people who are ventilator dependent. [LB236]

SENATOR STUTHMAN: Okay. Thank you. [LB236]

SENATOR GAY: Thank you, Steve. Any other questions? I see none. [LB236]

STEVE MORRIS: No questions for me to take to Tim, huh? [LB236]

SENATOR GAY: No. [LB236]

STEVE MORRIS: Okay. Thank you. [LB236]

# SENATOR GAY: Thank you. Other opponents? [LB236]

JEANNE SNYDER: (Exhibit 3) Senator Gay, members of Health and Human Services, thank you for having me. My name is Jeanne Snyder, it's spelled J-e-a-n-n-e, and the last name is S-n-y-d-e-r. I, like the previous testifier, was somewhat maybe confused about LB236. The proposed amendments to that tend to look like there's going...that it's different than what we thought. But I'm going to give you my testimony, because I've lived in Nebraska a long time and I've seen things change, and I've seen things come across that look one way and then become another way. I've seen things interpreted differently by people in Health and Human Services and by legislative people and by businesses, so I want you to know what I have to say. I am the mother, guardian, and primary caregiver for my 24-year-old developmentally disabled son, Lee. We live in Bellevue, and this has been his home since he was a year old. Lee has mental retardation and in simplified terms, he is about the age of a three year old. He also has juvenile arthritis, a form of rheumatoid arthritis. It's crippling to him. He has trouble walking and standing from a seated position. My opposition is not only to this bill but the one after it, but I'll speak mainly to this one. I'm not pleased with these bills. We live in a time when the focus on person-centered and consumer-directed services should be broadened and enhanced, not limited by new laws. Just over three years ago the state initiated the Real Choice project. It was successful, and many services coordinators and caseworkers have been trained to work towards the same goals that Real Choice outlined. The goals cited by the primary committee included choice, consumer satisfaction, and improved quality of life. I believe that the passing of this bill could severely limit the ability to accomplish these outcomes. I moved to Nebraska when Lee was a year old. At that time I had to learn about having a child with disabilities. He received a wonderful education through the Bellevue Public Schools, and at the age of 21, he left the school system to become a part of the adult disabled community. Today he attends a day program and workshop operated by Mosaic in Omaha. He loves this place--it's wonderful--but more than that, he loves to come home. I didn't know this system when I moved here. No one taught me anything or everything--I had to learn it along the way. I learned about IEPs, IPPs, service coordination, behavior programs, and community programs. It was difficult, mainly because it was very fragmented and very frustrating, but I did it. My husband and I had an income that excluded Lee from most services, so I did everything. I paid for everything. Everything that happened, I did, and I learned it. I used respite one time a long time ago, and I wasn't happy with it, because it was chosen for me. It was decided by a service coordinator who my respite provider would be. Lee moved to a group home when he was 13 years old. It was not an easy decision, and I really felt I was forced into it. The service coordinator told me when my son was four years old to put him on a list for a group home, and that if I did not do this, I would be sorry one day. I followed her directions, and I put him there when his name came to the top of the list, because I was told I would be sorry if I didn't, and I would lose any opportunity of ever having that again. I was told that I would be missing

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out on my own life by caring for my son, and she convinced me to do it. I put him there, I took him out when he was 20--it was 7 years. I did everything I could to work with that group home, to make his life good. But staff turnover was high, supervision was substandard, training was poor, and there was a great lack of caring and dedication that I thought to be important. Because Lee was on a waiver program, the cost for the group home was soaked up by the state of Nebraska, and it was a cost that was way too high for the services he received. I brought him home and I promised myself that I would do everything possible to make his life wonderful and joyful. I did not want him ever to experience any of the problems he encountered in that group home. I set out to do the right thing for my son. When I read LB236, I truly, truly believed that these private agency companies backing the two bills wanted you to think that I am incapable of understanding the meaning of hiring a person to provide care for my son. That's can't be further from the truth. I want the Nebraska lawmakers to understand that I know what is best for my son, and therefore, I am able to successfully hire a person. It is insulting for anyone to think that I can do otherwise. When Lee returned home in 2003, he was beginning his journey outside the school system, and I began my journey of learning about adult services. I was working a day job. I couldn't give up my job. I needed the money. I needed someone to be home to get Lee off his van. I needed someone to help me care for him, and I needed respite care, and I need my social breaks. I found my relief in the services with the Medicaid personal assistant services and through the Lifespan Respite subsidy program. I'm not going to repeat the Tim Kolb law. I mention it in here, too. But I will tell you this: When I first read it, I was disturbed. I am a registered nurse. I thought it was scary. But then I thought, wait a minute, I can teach these things to somebody. I know how to do this. I can do this, and I felt comfortable doing it. And I found out it was the right thing, it was the very right thing, that I as the primary caregiver could teach someone how to care for my son, and that it didn't have to be a licensed person. I taught people how to do the day-to-day living activities, and I also taught them to do the prescribed physical therapy exercises, how to do intermittent catheterization on my son when he couldn't urinate. I taught them how to give him his medication in a special way. He couldn't take a reminder; he's a three year old almost. You'd have to put it in his mouth. I don't hold the state of Nebraska responsible for my son's well-being--I'm responsible for that. Not only am I able to choose appropriately for son because I'm his mother, but I have the court's backing--I am his legal guardian. This gives me the right to make choices for him, and I'm accountable for those decisions. My care providers receive payment through the Medicaid PAS and from the Lifespan subsidy grant. They are independent contractors, and I like that. Because of that condition, I get to set additional provisions. It's almost like I can have almost a private contract between myself and my providers. I do think that there is a possibility that LB236 could limit my ability to make choices for my son. The two programs I use work because I choose who cares for my son. I do not want any agency making choices for me. An agency may screen staff and only hire trained persons, but they're not going to allow me to choose the rules that have been in my house, or the hands-on type of care. My son likes who works with him. I was very picky. I interviewed many people. I found

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that when I was able to teach these people what to do, that it got done right. There's something else I want to address in this bill, and it has to do with the qualifications of caregivers. I find these to be actually quite vague and substandard. It says a person has to have good moral character. What is good moral character, and who defines that? I want to define it. I want to define what good moral character is when it comes in my house. I don't want an agency to define that moral character. I also find that it says that a person must not be convicted of a crime that has a penalty of one year or more, and which is rationally related to the person's fitness to act as a personal care worker. That's lenient, guys; that's very lenient. I give you the example...Douglas County, if a person is guilty of possession of one ounce or less of marijuana, all they have to do is plead guilty. They pay a \$100 fine, and they do no jail time. I don't want that person in my house, but that person could be hired, according to this bill. The other thing that it addresses that makes me uncomfortable is that a person for whom the care is being provided. My... [LB236]

SENATOR GAY: Ms. Snyder,... [LB236]

JEANNE SNYDER: Yeah. [LB236]

SENATOR GAY: Can you...I hate to cut you off, but some of these things we can always add later, or...so can you kind of summarize what you're doing here? We've got other people who want to testify. Thank you. [LB236]

JEANNE SNYDER: Okay. Okay. I'm just not happy with the idea that an agency might not have what I need, when I know what I need. I think that as lawmakers you need to look at, the current laws are working and they work for a lot of us. And I don't think that we need to be looking at change. I think we need to be looking at making sure that our service coordinators and our caseworkers are trained to teach us family members and caregivers. I'm just asking you to stop LB236 and not let it go forward. Thank you. [LB236]

SENATOR GAY: Thank you. [LB236]

JEANNE SNYDER: Do you have any questions? [LB236]

SENATOR GAY: Are there any questions? I don't see any. Thank you. [LB236]

JEANNE SNYDER: Um-hum. [LB236]

SENATOR GAY: Oh, Senator Stuthman has a question. I'm sorry. [LB236]

SENATOR STUTHMAN: Thank you, Senator Gay. In looking at this here,... [LB236]

JEANNE SNYDER: Um-hum. [LB236]

SENATOR STUTHMAN: ...what was outlined for us, you know, the in-home service, but that's what you're doing,... [LB236]

JEANNE SNYDER: Right. [LB236]

SENATOR STUTHMAN: ...but you don't want to have an agency doing that. [LB236]

JEANNE SNYDER: I want choices, right. I don't find anything wrong with an agency. Some people choose that. I don't choose it, and I don't want to be limited to having an agency. [LB236]

SENATOR STUTHMAN: And that would be your only option, is having an agency to do it? [LB236]

JEANNE SNYDER: If it were to go the way that it was originally written, it seems to appear that way,... [LB236]

SENATOR STUTHMAN: Okay. [LB236]

JEANNE SNYDER: ...that a caregiver would be listed as an agency. [LB236]

SENATOR STUTHMAN: Okay. Thank you. [LB236]

SENATOR GAY: Thank you. Any other questions? I don't see any. Thank you. [LB236]

JEANNE SNYDER: Um-hum. [LB236]

SENATOR GAY: Other opponents? [LB236]

BRENDON POLT: For the record, my name is Brendon Polt, that's P-o-I-t. Before Senator Johnson or Stuthman throws eggs at me, I do want to just reiterate that we're testifying in opposition to the green copy of the bill. We do thank very much the sponsors of the bill for working with us, after that was three-parted. I just want to make sure that...Kim Robak did refer to a couple of the amendments that were suggested pursuant to the drafting of the initial bill. Specifically, what we would ask is that the definition of attendant services, as it says, defined as assistance with self-administering medication and similar activities--we think that means reminders, but that's not what it says, so we'd ask that that might be included in the amendment. Furthermore, as Kim did indicate, there are...we want to make sure that all existing healthcare providers, licensed under the Health Care Facilities Act to be excluded, and we think that that's in

the amendment. I haven't seen a draft of that. But with that, I would close my testimony. [LB236]

SENATOR GAY: Thank you, Brendon. Any questions from the committee? I don't see any. Other opponents? Any other opponents? [LB236]

MICHAELA MYERS: (Exhibit 4) Hello. I know it's been a long day. Thank you, council. My name is Michaela Myers, that's M-i-c-h-a-e-l-a, Myers, M-y-e-r-s, and I have my testimony here, too. I have a copy of it. I'll be brief, it's been long, everyone is tired. I understand that. The main issue I have with this is interpretation. No one has mentioned my company, the one that I'm representing. What we are is we are a home care registry, and that little chart that you got passed out before, we were not mentioned. You cannot ignore us--we help too many people. We are needed. I define it in the letter. I won't go into a lot of detail. The main thing is, we screen and schedule caregivers that are independent contractors. They work directly for the family. In the definition in this proposed bill, Section 1, part 6, it contradicts itself. It's saying that the agency--the terms that they say--that a nurse aide registry is not considered an in-home personal care service agency, but then it also says that an in-home personal care service agency is anyone who...sorry, I need to read it word for word, because it's very specific. But a nurse aide registry does offer in-home personal care service in an individual's residence for compensation through independent contractors. The clients pay us. We make money. Does that put us in this definition? If it does, we cannot be defined the same way as a nonmedical, home care company, because we do not employ the caregivers--the clients do. I am in support of nonmedical companies being able to do medication reminders for their clients. That is needed. If you hire a caregiver, you need to know that they can get their meds, and that someone is there, that you're paying, can say, yes, I saw them take their meds. What is illegal about that? That is "misinterpretated." And I'm for that, but I also have been told that I am not welcomed in meetings to help legislation of this matter, by the NPDA. That concerns me; it makes me...I'm concerned with why I cannot have a voice, and so that's why I'm here, and that's why I'm speaking so strongly, because I'm the only one out here representing the home care registry and it's a needed option, and it is very...there's a lot of home care registries on the East and West Coasts. We just don't have a lot of them here in the Midwest. But Nebraska is good about using unique options to help people, and we have such a unique state. We have a lot of people in Omaha and Lincoln. There's no one in the rest of Nebraska. So you're trying to do legislation that's going to affect the whole state, so I'm just pleading with you to be realistic about it. Read my letter, read my concerns, and look at that. Yesterday I did see some of the amendments that I think were introduced today. I never saw the official copy. What they did was, instead of addressing a nurse aide registry, they just crossed us out. So that means since we are making money, we have to comply by these same standards, which we cannot realistically do, because we do not hire the caregivers. [LB236]

SENATOR GAY: Thank you. Well, we'll definitely...I appreciate you coming. We'll definitely look into it,... [LB236]

MICHAELA MYERS: Yeah, and I'm sorry for my emotion. [LB236]

SENATOR GAY: ...and I know it's important. No, it's important to you. It's important, definitely. [LB236]

MICHAELA MYERS: But it's important, and like I said, if they close us down, no one can handle what we offer people, and there's not the caregivers out there to do it. So realistically look at it, call me if you have questions. My number is on here. I will help you, and that's why I'm here. [LB236]

SENATOR GAY: All right. Let's see if we have any questions right now. Senator Stuthman. [LB236]

MICHAELA MYERS: Yes. [LB236]

SENATOR STUTHMAN: Thank you, Senator. Listening to your testimony and listening to just the previous testimony from Jeanne,... [LB236]

MICHAELA MYERS: Uh-huh. [LB236]

SENATOR STUTHMAN: ...would your agency be of benefit to her? [LB236]

MICHAELA MYERS: It could be, yes. Yes, if she did not want to look for the caregivers herself, and did not want to schedule the caregivers herself, she could hire my company that does that for her, for a fee. We charge anywhere from a \$1.90 to \$2.90 per hour. Do the math--we don't charge a lot (Laugh). And I work a lot of hours to help people, and so I'm irritated...why I'm here. (Laugh) [LB236]

SENATOR STUTHMAN: Okay. I was trying to, you know,... [LB236]

MICHAELA MYERS: Yeah. [LB236]

SENATOR STUTHMAN: ...fit one with the other, that... [LB236]

MICHAELA MYERS: You bet. You bet. [LB236]

SENATOR STUTHMAN: ...there would be a possibility. [LB236]

MICHAELA MYERS: It's an option. It is a needed and used option by a lot of people. [LB236]

SENATOR STUTHMAN: Okay, thank you. [LB236]

MICHAELA MYERS: Um-hum. [LB236]

SENATOR GAY: Thank you. Any other questions? I don't see any. Thank you. [LB236]

MICHAELA MYERS: Thank you. [LB236]

SENATOR GAY: You bet. Any other opponents? [LB236]

RICHARD SKERBITZ: (Exhibit 5) Senator Johnson, Senator Gay, members of the Health and Human Services Committee, I'm going to distribute to you the testimony that I prepared based on the original copy of this bill. We have not had a chance to look over the amendments. [LB236]

SENATOR GAY: Oh, can you state your name? Can you state your name again and spell it, for the record, because we're on the record. [LB236]

RICHARD SKERBITZ: Oh, I'm sorry. My name is Richard Skerbitz; last name is spelled S-k-e-r-b-i-t-z. When we have a chance to look through the amendments, this may change our position. With the original bill, we're in opposition. Thank you for your time. [LB236]

SENATOR GAY: Thank you for your brevity, Richard, appreciate it. Any other opponents who would like to speak right now? [LB236]

TERRI HOLMAN: (Exhibit 6) I'm Terri Holman, H-o-I-m-a-n, with the Development Disabilities Planning Council, and I really don't need to go through this. It's already been said several times, so if I could just hand this in, is all I really need to do. [LB236]

SENATOR GAY: Sure. You bet. Thank you. Okay. [LB236]

SENATOR ERDMAN: Our page, Senator Johnson, would be happy to distribute that for you. (Laughter) [LB236]

TERRI HOLMAN: Okay, thank you. [LB236]

SENATOR GAY: They're busy. All right, any other opponents? Just for the record, we do have three letters of support--Nebraska Hospital Association, AARP with some suggested amendments that they put in, and the Alzheimer's Association with some suggested amendments. (Exhibits 10, 11, and 12) Anybody would like to speak in the neutral capacity? [LB236]

HELEN MEEKS: Yes. [LB236]

SENATOR GAY: Come forward. Do you have written? Do you have written testimony? [LB236]

HELEN MEEKS: Yes. [LB236]

SENATOR GAY: Are you going to summarize it? We will read it. [LB236]

HELEN MEEKS: (Exhibit 7) Good afternoon, senators. My name is Helen Meeks, and I'm the administrator with the Credentialing Division, which is a part of the Department of Health and Human Services, Regulation and Licensure. We're not going to go through the entirety of our testimony. We have written copies for the committee. I only will mention a couple of things that have not been mentioned, in terms of technical concerns. We too had several technical concerns, and we are asking that you give consideration to those as we pointed out in the written testimony that's going around. Primarily, when you are looking at the terms, how the terms are defined in this bill, look at the terms in existing statutes. For instance, "care" and we're glad to see that that amendment is removing care, because what this bill does is create a definition for care that is different than a definition for the same term that already exists in statute, and so that was one of our concerns. Medication reminders, we'd ask you to look at what we pointed to you. We agree with the one of the amendments to make certain that the Tim Kolb amendment is not being inadvertently repealed. The other thing that I would mention, the final technical point that we'd like to make, to call your attention to, and one of you asked about the moral character. We are proposing that in addition to those registries that are listed in the bill, that the sponsors consider adding the nurse aide registry, the medication aide registry, the sex offender registry to the list, because all of those registries contain information that could speak to the moral character of the person. If there's been an adverse finding entered on that registry, it would make sense to us that those would also be checked, so that hopefully, the agencies that are going to be deploying these individuals would have the full...a better picture of any adverse findings that had been entered, that may be indicative of their moral character. So with that, we won't belabor you with all of the details of our written testimony. We think that it is clear. [LB236]

SENATOR GAY: Okay. Hold on one minute, Helen. We'll see if there's any questions for you. Any questions from the committee? We've got two for you. Senator Erdman. [LB236]

SENATOR ERDMAN: Helen, good to see you again. Quickly, on the sex offender registry, would that show up on a traditional background check or not? [LB236]

HELEN MEEKS: Well, I'm not sure. I would think that it would, if the person had been convicted of a crime, you know, yes, I would think it would show up on a criminal background check. [LB236]

SENATOR ERDMAN: Okay, and I can see the need for doing the nurse aide registry, medication, because there may be administrative issues there. [LB236]

HELEN MEEKS: Right. There might be, right. [LB236]

SENATOR ERDMAN: But I was just curious if there was a reason why, and you may not know, but... [LB236]

HELEN MEEKS: And we just added that one, just in the event, you know, that something... [LB236]

SENATOR ERDMAN: Just to be (inaudible). [LB236]

HELEN MEEKS: ...just as a safeguard, because I wouldn't think an agency would want to send a person into the home of an individual who had been convicted of... [LB236]

SENATOR ERDMAN: Okay. Yeah. It would seem contrary to the intent here. [LB236]

HELEN MEEKS: ...who was on that registry. Thank you, Senator. [LB236]

SENATOR GAY: I don't see any others. Thank you, Helen, appreciate your input. Come on. [LB236]

ROBBIE NATHAN: (Exhibit 8) Senator Johnson and members of the Health and Human Services, I'm Robbie Nathan and I'm a branch manager with Care Consultants for the Aging here in Lincoln. It's R-o-b-b-i-e, N-a-t-h-a-n. I work with the emotional Michaela. (Laughter) We have been offering...well, we've been offering healthcare choices to Nebraskans for over 15 years. I am here today representing and advocating for healthcare consumers and the independent providers listed on our registry. We work hand in hand daily with licensed registries, hospices, respite providers and programs, as well as many, many private individuals who wish to direct their own care. We provide nonmedical and medical cares for individuals, both in facilities and at home. We feel the intent of this bill, allowing an in-home personal service worker to provide reminders to clients to self administer medications and the nontherapeutic topical applications is a very valid goal. Please keep in mind the previous conversation about the Tim Kolb amendment, about competent adults directing their own care. However, our support for this bill can only be given if in Section 1, part 6, it is stated that an in-home personal service agency does not include a nurse aide registry, as was originally stated in the bill. We looked at the amendments yesterday, and that part was omitted. We strongly feel

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that the existence of a nurse aide registry should be acknowledged. Omission of this recognition, even though an exemption in the bill, could lead to misinterpretation by other entities that may deny home health choice to the home healthcare...or to the healthcare consumer. Nurse/nurse aide registries provide a valuable, affordable choice to Nebraskans and should be recognized as a source of home health care. It's my understanding, from one of my clients, that Medicaid reimbursement averages over \$20 an hour for licensed agencies. Registry rates in the area approximate to be around \$12 an hour. Last year Care Consultants for the Aging served over 317,000 hours of healthcare in Omaha and Lincoln alone. Our support would be enhanced if the bill were amended in Section 6 to also read, the act does apply to medication administered in the home, when provided through a licensed home agency, or under client or client representative direction. I thank you for the opportunity to speak to you today, and offer support of LB236, should nurse/nurse aide registries and the rights of individuals to choose their own care be recognized. Thank you. Did you have any questions? [LB236]

SENATOR GAY: Thank you, Robbie. Any questions? I don't see any. Thank you. [LB236]

ROBBIE NATHAN: Oh, thank you! (Laughter) [LB236]

SENATOR GAY: Anyone else neutral? Senator Johnson, would you like to close? Senator Johnson is going to waive his closing on LB236. (Laughter) And, you ready on LB397? [LB236]

SENATOR JOHNSON: Sure. [LB236 LB397]

SENATOR GAY: And then I will open the public hearing on LB397. Senator Johnson get his file (inaudible). [LB397]

SENATOR JOHNSON: Senator Gay and members of the committee, make sure that I read the last line here, because it is very important, and because it will shorten the proceedings considerably. (Laughter) I'm Senator Joel Johnson, representing the 37th District. LB397 goes through the types and numbers of home health services that have increased exponentially over the past decade. A number of businesses and organizations now provide these services, some without any statutory supervision or review. LB397 is a first attempt to identify the industry that provides in-home services and to license their activities. This is the difference between this bill and the one that we just finished. These are services that enable a senior to remain safely and comfortably in his own residence as long as possible. They are also services which do not require the exercise of medical or nursing judgment. In order to give the consumer a reference point and a level of comfort in the in-house services, LB397 would create a license for in-home service providers. It is consumer protection legislation, as well as quality control for in-home care. LB397--and this is another important line right here--is a work

in progress. There is a need for in-depth discussion with the Department of Health and Human Services and those caregivers that provide both medical and nursing care, as well as rehabilitation services, personal assistant services, aged and disabled. What we are going to recommend here with the people who have asked me to carry this bill, that further discussions take place with the Department of Health and Human Services and all interested parties before we continue any further with this concept of licensing in-home services. Therefore, I would ask that this measure, although it appears on the calendar today, be indefinitely postponed until such time has occurred. (Laughter) [LB397]

SENATOR ERDMAN: So moved! (Laughter) [LB397]

SENATOR JOHNSON: I think that you might have a few comments for people to follow me. [LB397]

SENATOR GAY: All right. With that being said, thank you, Senator Johnson. I'm going to go through, I guess, for proponents, opponents, and neutral. Proponents, then. Let's go ahead. [LB397]

KIM ROBAK: Senator Gay and members of the committee, my name is Kim Robak, R-o-b-a-k. I'm here in support of LB495 (sic). And I'm here in support of IPPing LB495 (sic). The only reason I came forward is to let you know that the Eastern Nebraska Chapter of the NPDA, the National Private Duty Association, is committed to working with the department and other interested organizations in the future, to see about licensing in-home services, because we want to make sure that the public is protected and that it's provided the least expensive form of care possible. And with that said, I would answer any questions. [LB397]

SENATOR GAY: Thank you, Kim. All right, thank you. Any questions? I don't see any. Thank you. And then also for the record, we have a letter from Nebraska Hospital Association in support, and the Alzheimer's Association in opposition. (Exhibits 7 and 8) Other proponents? Opponents? Anybody... [LB397]

HELEN MEEKS: (Exhibit 1) For the record again, I'm Helen Meeks with the Department of Health and Human Services, Regulation and Licensure, and we have testimony...many of our concerns are the technical concerns that we offered on LB236. We are offering those on LB397 and we laid them out in the written testimony that's going to be passed around to you. Thank you. [LB397]

SENATOR GAY: Thanks, Helen. No questions? Thank you. Any other opponents? [LB397]

TERRI HOLMAN: (Exhibit 2) Again, I guess I'll just go on the record and hand this in.

I'm Terri Holman, H-o-I-m-a-n, with the Developmental Disabilities Planning Council. [LB397]

SENATOR GAY: (Exhibits 3 and 4) Thanks, Terri. And then we have a letter, opponents, this would be the Nebraska Health Care Association and the League of Human Dignity. I have the letters they printed. Anybody neutral? Senator Johnson waives close, and we'll close the public hearing on LB397. Thank you for your patience, everyone. (See also Exhibits 5, 6, and 9) [LB397]

Disposition of Bills:

- LB236 Advanced to General File, as amended.
- LB397 Indefinitely postponed.
- LB482 Advanced to General File, as amended.
- LB523 Indefinitely postponed.
- LB555 Indefinitely postponed.

Chairperson

Committee Clerk