
[LB71 LB218 LB397 LB505]

The Committee on Banking, Commerce and Insurance met at 1:30 p.m. on Tuesday, February 26, 2013, in Room 1507 of the State Capitol, Lincoln, Nebraska, for the purpose of conducting a public hearing on LB71, LB397, LB218, and LB505. Senators present: Mike Gloor, Chairperson; Mark Christensen, Vice Chairperson; Kathy Campbell; Tom Carlson; Sue Crawford; Sara Howard; Pete Pirsch; and Paul Schumacher. Senators absent: None.

SENATOR GLOOR: Good afternoon and welcome to the Banking, Commerce and Insurance Committee hearing. My name is Mike Gloor, I'm the senator from the 35th District which is Grand Island. The committee will take up the bills in the order posted outside the door and for some of you that may be, if you haven't noticed, a reversal in LB397 and LB218. To better facilitate today's hearing, we have rules and procedures that we follow. They are posted up there on the board, but I will run through them quickly for everybody. The first is, I know you think you turned off your cell phone, but please check to make sure you did or put it on a silent buzz, if you would. The order of testimony for us is the introducer, then proponents, then opponents, then those who would like to speak in a neutral capacity, and finally, we'll allow the introducing senator to close if they would like to do so on their bill. We ask all testifiers to sign in. There are pink sheets or coral sheets or red sheets, you pick the color, that we'd ask that you fill out and be sure and hand in before you testify. We'd ask you to spell your name for the record before you testify even though you've just written it out and handed it in. The transcribers who are going to write this all down aren't with us and do this remotely. And so they need to hear how to spell your name because they can't do it phonetically. Please be concise. We have a light system up here and everyone has five minutes, we give the introducer a little longer than that. But you'll have a green light for the first four minutes. Then you'll have a yellow light that warns you that you have one minute left. And then you get a red light which, as is the case with any red light, asks you to stop or at least wrap up your comments if you would, as quickly as you can. We have a lot of bills to cover today, a lot of testifiers, and we want to make sure that people at the end of the day have as much time and get as much energy out of us as possible. So we'd ask you to be considerate along those lines. If you're not going to be testifying at the microphone, but would like your stand to be known, there are sign-in sheets on either side, white sign-in sheets. And you can sign in there and let us know what your stand is on these bills also. If you've got written material you would like to hand out, we need ten copies. And you can hand that in at the same time you give your testimony; the pages will help with that. And if you don't have ten pages (sic--copies), now would be the time to get the attention of one of the pages so that they can be making those copies for you. To my immediate right is committee counsel, Bill Marienau and at the end of the table is the committee clerk, Jan Foster, and they make sure that we keep things going smoothly. I'm going to ask the senators now to introduce themselves starting with Senator Crawford.

SENATOR CRAWFORD: Thank you. Good afternoon. My name is Sue Crawford and I represent Legislative District 45, which is Bellevue, Offutt, eastern Sarpy County.

SENATOR SCHUMACHER: My name is Paul Schumacher, I represent District 22, which is Platte and parts of Colfax and Stanton Counties.

SENATOR PIRSCH: Hi, I'm Pete Pirsch. I represent Legislative District 4, and so that is Boys Town, parts of west Omaha, and parts of Douglas County.

SENATOR CAMPBELL: I'm Kathy Campbell and I represent District 25, which is east Lincoln and eastern Lancaster County.

SENATOR HOWARD: I'm Sara Howard, I represent District 9, and that's in midtown Omaha.

SENATOR GLOOR: Senator Christensen and Senator Carlson will be with us shortly. As many of you know, there are other bills that have to be introduced and responsibilities some of the senators have that means that they have to come and go. But they will join us shortly so you will see them here. And our pages are Nathan who's here and Will who is already running an errand someplace. And with that, we'll welcome Senator Karpisek to the committee. Senator.

SENATOR KARPISEK: Thank you, Senator Gloor, members of the Banking, Commerce and Insurance Committee. For the record, my name is Russ Karpisek, that's R-u-s-s K-a-r-p-i-s-e-k. And I am from Wilber, W-i-l-b-e-r, for the media here that always get it wrong...to listen to. I am introducing LB71 today which would require insurance coverage for single or bilateral cochlear implants for persons diagnosed with severe to profound hearing impairment. I've brought this bill probably three times in the past, and so I understand all the reasons why it hasn't passed. And looking at the agenda today, I understand some more of the reasons because it's hard to draw the lines. My argument for the cochlear implants is that our state insurance would cover the cochlear implants for state employees. Medicaid would cover the implants. We've heard stories in the past of people almost on purpose going broke so Medicaid would pay for the implants. I think that is just a terrible reason for someone to have to...something to do to try to get cochlear implants for their kids. And we have people behind me that will be able to speak much more eloquently on what the implants do and what it means for their lives. But there is a fiscal note on the bill that is fairly high. The bill doesn't really say anything about new implants, new equipment that comes along. I'm sure that this equipment is much like any other equipment, probably like computers. As soon as you have one, it's obsolete and a new one is out. We can certainly put some language in, I think, that would take the fiscal note out of the bill. Through the years, we have had many more insurance companies come on board and start doing the implants. We're not there yet, we don't have them all on board, and I don't think that some of them will...just won't do it until they're forced. I understand about mandates; I don't care for them. I don't like raising insurance rates, but I don't think that this by itself would raise rates per capita by very much for the great things that can...that it will do for people's lives with profound or severe hearing loss. And with that, I'd be glad to take any questions. [LB71]

SENATOR GLOOR: Thank you, Senator Karpisek. Questions from any of the committee members? Seeing none right now, are you planning to stay around and close? [LB71]

SENATOR KARPISEK: I think so. I have a bill in Transportation, but naturally, it's last so I'll stick around. If it goes that long, then I won't. [LB71]

SENATOR GLOOR: (Exhibits 1 and 2) And I have some letters of support form the Nebraska Hospital Association and from Dave Bell. We'll have staff hand these out. Thank you, Will. With that, we'll now start with proponents, so could I ask those who are in favor of this bill please to start coming forward and testify? Good afternoon. [LB71]

RODNEY LUSK: Good afternoon. Chairman Mike Gloor and the members of the Banking, (Commerce) and Insurance Committee, my name is Dr. Rodney, R-o-d-n-e-y, Lusk, L-u-s-k. I'm the director of the Cochlear Implant Program at Boys Town National Research Hospital. And I'm here to offer testimony on behalf of the legislative bill, LB71, which requires coverage of cochlear implants. Boys Town National Research Hospital has been performing cochlear implants since 1991. We perform unilateral and bilateral cochlear implants in both adults and children. We have a team of more than 12 healthcare professionals that evaluate and continually care for patients that have severe to profound sensorineural hearing loss. In addition, the hospital is deeply committed to research and understanding how cochlear implants work and how we can improve the ability of our patients to understand the spoken language. It's important to note that there are few surgeons and hospitals within the state of Nebraska that can perform cochlear implants. We have skilled audiologists and speech pathologists that are dedicated to this purpose. I have technical papers indicating the cost benefit of cochlear implants to families and societies. If you'd like to read these technical papers, I'd be more than happy to make them available. I have actually brought cochlear implants so you can see what they look like. This is the implantable device that is made through a small incision behind the ear, it goes underneath the scalp. And then there is a long, thin electrode that is actually thread into the cochlear; that's the inner ear. This is not a hearing aid. This is a tool that requires a processor which sits on the outside that converts sounds from the environment into an electrical stimulus that's carried through radio waves across the scalp and into the inner ear. We have children that have been implanted at one year of age or younger that are able to communicate within the hearing world. They do not need to have special help or assistance within school systems; that's a tremendous saving to the school systems. In addition, I have children that are now in college. They are getting college degrees, becoming professionals, and there's no way that they would have been able to accomplish that without early implantation. We have the most affect on children that are implanted early. It is extremely beneficial to adults that have had hearing and have developed speech-language skills and then have gone suddenly deaf or had a progressive hearing loss. Some of my most grateful patients are adults that are now back in the hearing world because of their cochlear implants. We have insurance companies that will not cover this device and, for the life of me, I don't understand why because it would cost literally cents or a few dollars on each one of the different programs that they offer. And the benefit to the family is...it's incalculable, really. It's one of the most miraculous things that we've come up with in medicine. At this point, I'd be happy to answer any questions that you may have. [LB71]

SENATOR GLOOR: Thank you, Dr. Lusk. Are there questions? Senator Crawford. [LB71]

SENATOR CRAWFORD: Thank you, Senator Gloor. And thank you for coming and for your testimony. Our fiscal note information on the bill indicates that the essential benefits package for Nebraska covers two cochlear implants in a five-year period. [LB71]

RODNEY LUSK: Right. [LB71]

SENATOR CRAWFORD: Is that a reasonable level of coverage from your expertise? [LB71]

RODNEY LUSK: Absolutely. We are very pro bilateral cochlear implants. We're created with two ears for a reason. One of the biggest benefits of bilateral cochlear implants is to be able to track voices or speech in noisy environments and then, of course, to be able to localize sound. Children live in very noisy environments in the classroom. And if they can't hear bilaterally or if they cannot track speech, then the work of hearing and the work of concentrating on language is significantly increased. [LB71]

SENATOR CRAWFORD: And I don't know very much about this technology, so is it something that you would get replaced every five years? [LB71]

RODNEY LUSK: No. The implant itself has no working parts, it's all electronic. It is designed to last 70 years. If you look at the data, there are three companies that produce implants worldwide and their failure rate is around 1 percent, which is really pretty good. The reason that they do fail is fluids from around the scalp go through the Silastic and it gets through the hermetic seal and it short circuits. And we can take the implant out and put another implant in with equal success of the first implant. But they are not designed to take out and put back in within a, you know, a finite period of time.

There's no battery in this. The battery is actually in the processor and there are two magnets that line up together and it's the electromagnetic field that actually supplies the power and the coding that goes to the electrodes themselves. [LB71]

SENATOR CRAWFORD: So most people would get one in a lifetime? Or... [LB71]

RODNEY LUSK: Yes, that would be the goal. [LB71]

SENATOR CRAWFORD: Thank you. [LB71]

RODNEY LUSK: And most of the technology advancements is not in the implanted electrode, but in the processor itself, and this can easily be updated. [LB71]

SENATOR CRAWFORD: Thank you. [LB71]

SENATOR GLOOR: Senator Schumacher. [LB71]

SENATOR SCHUMACHER: Thank you, Senator Gloor. Thank you for your testimony today. The little probe that goes inside the ear, does that take the place of the eardrum then? Does that vibrate or how does it transduce to the neurosystem? [LB71]

RODNEY LUSK: Good question. This completely bypasses the tympanic membrane, the ossicles, which are the little bones on the inside in the middle ear, and goes directly to the inner ear. Most of the causes of hearing loss are...that are neural sensory are in the little hair cells that are in the inner ear. So what this does is, it provides a very low current that goes to the next order of neurons, the ones that are in the center of the cochlea. So we're stimulating not the little hair cells that move, but the nerves that are just on the other side of that. And that's where this special expertise in programming comes into. The high frequency in the environment goes to a specific electrode here, and that actually stimulates the nerve itself. That's why this is not a hearing aid, it is an implantable electronic device. Does that make sense to you? [LB71]

SENATOR SCHUMACHER: And that's able to, in an analog fashion, deliver...stimulate that nerve just as though the biological function of the hairs and the eardrum and all that... [LB71]

RODNEY LUSK: That's correct. It bypasses the hair cell because it's no longer functioning. In adults that could be due to a number of different causes as why the hair cells aren't working. And in children, they may have not developed at all, but we can still stimulate the nerves that are just inside the center of the cochlea itself, so it's the inner ear that we're actually stimulating. [LB71]

SENATOR SCHUMACHER: And stimulate them in such a way that you trick the inner ear to thinking it's been done normally? [LB71]

RODNEY LUSK: That's right. [LB71]

SENATOR SCHUMACHER: How much does that device cost? [LB71]

RODNEY LUSK: It depends on the manufacturer to some extent, but the device itself is around $30,000. [LB71]

SENATOR SCHUMACHER: Why so much? [LB71]

RODNEY LUSK: A tremendous amount of research has gone into this to get it to the point where they can actually use it. The price has come down because of competition globally, but there's a lot of support that the companies have had to put into it. The technology is very sophisticated and to get a device that will last a lifetime and the amount of research that's gone into it, takes a lot of resources behind it. I have no relationship with any of the companies, I can't tell you specifically why they feel that they're justified to cost that much, but that's what it is. [LB71]

SENATOR SCHUMACHER: Is that patented technology that they basically own and so what you're paying for is past research rather than present product? [LB71]

RODNEY LUSK: There are patents on multiple of the individual devices. I don't know...I can't answer for you if that's the reason why it's around $25,000, $30,000. [LB71]

SENATOR SCHUMACHER: To the extent everybody that needed one of these had one of these, how many more would be sold to reduce that...the price? Thirty thousand dollars just seems out of this world. [LB71]

RODNEY LUSK: Yeah. [LB71]

SENATOR SCHUMACHER: Do you have any idea...I mean, how many people need this so that if we found somebody in China to make it, we'd get by cheap. [LB71]

RODNEY LUSK: I'll refrain from commenting on your last comment, if I may. [LB71]

SENATOR SCHUMACHER: But are there lot...I mean, you know, sometimes the price of stuff comes down when the volume sold goes up. [LB71]

RODNEY LUSK: Sure it does. Sure it does. Most of the progress is actually within...in processing, and they really do invest a tremendous amount of money in that. The hurdles that you have to go through to get one of these devices through the FDA is very high, very costly. [LB71]

SENATOR SCHUMACHER: So...and that's $30,000 an ear? [LB71]

RODNEY LUSK: Correct. [LB71]

SENATOR SCHUMACHER: Sixty thousand bucks. And now how much does it cost to stick it in the ear? [LB71]

RODNEY LUSK: That depends on the institution and how long it takes and...I don't have a good number for you. [LB71]

SENATOR SCHUMACHER: Boys Town give it away free? [LB71]

RODNEY LUSK: We don't give it away free. [LB71]

SENATOR SCHUMACHER: Okay. So we're...even though the fiscal note... [LB71]

RODNEY LUSK: But we have the best team in the...one of the best teams in the nation. [LB71]

SENATOR SCHUMACHER: So even though the fiscal note talks in terms of $400,000, we're talking about possibly $100,000 a pop here. Is that accurate? [LB71]

RODNEY LUSK: We don't get reimbursed that. [LB71]

SENATOR SCHUMACHER: Okay, well... [LB71]

RODNEY LUSK: You know that. [LB71]

SENATOR SCHUMACHER: ...we're talking between...if it's $30,000 a side, we've got a low end just for the toys of $60,000, so maybe... [LB71]

RODNEY LUSK: Well, compare that to a child that wouldn't be able to go much beyond a grade school education as opposed to a college education and be able to actually contribute to society and to their family in a way that wouldn't be possible otherwise. [LB71]

SENATOR SCHUMACHER: How many people in Nebraska could we anticipate if this was included in the program? Would...how many of those things would be implanted? [LB71]

RODNEY LUSK: That's a great question. I don't have that on the tip of my head. [LB71]

SENATOR SCHUMACHER: Because some way or another, I mean, Santa Claus isn't around and so we've got to figure out how to pay for it. [LB71]

RODNEY LUSK: I think in the long run, you're going to end up saving money when it comes to the point of support that the kids would need within the school systems. In children that did have cochlear implants, you really don't need any additional help within the school systems. [LB71]

SENATOR SCHUMACHER: Is this covered by Medicare now for older people? [LB71]

RODNEY LUSK: It is. [LB71]

SENATOR SCHUMACHER: It is? [LB71]

RODNEY LUSK: Yes, Medicaid covers it as well. Medicaid covers bilateral cochlear implants. [LB71]

SENATOR SCHUMACHER: So we're just dealing with the private insurance sector. [LB71]

RODNEY LUSK: That's correct. And it's kind of unbelievable to me that the private sector doesn't cover what Medicaid does. And the cost benefit, honestly, it's much better than heart bypass. There's been good studies that show the cost benefit of this particular device, particularly in children, is very cost effective. [LB71]

SENATOR SCHUMACHER: Now this is not in our essential health benefits package. Is it in the essential health benefits package of some states? [LB71]

RODNEY LUSK: Yes, definitely. [LB71]

SENATOR SCHUMACHER: So the federal government is helping some states, but not us? [LB71]

RODNEY LUSK: I do not know the answer to that question. [LB71]

SENATOR SCHUMACHER: Okay, thank you. [LB71]

SENATOR GLOOR: Dr. Lusk... [LB71]

RODNEY LUSK: Yes. [LB71]

SENATOR GLOOR: ...along that line of questions, I thought Senator Karpisek in his opening said that there was...he had seen changes that there were private insurers who were, in fact, covering this, just not all... [LB71]

RODNEY LUSK: That is the case. That is the case. And we've seen steady progress towards not only covering one device, but bilateral devices. [LB71]

SENATOR GLOOR: I mean, you've been at this just long enough to give us some judge over this. Has this change been one that's happened over the past two or three years, five years? I mean, I'm sure once upon a time, no private insurer provided that coverage. Has that started to build some momentum in recent years or has it been a longer-term, gradual process? [LB71]

RODNEY LUSK: I've been putting implants in for about 15 years and initially it was a big struggle. I would say that there's been a gradual change in acceptance of the technology with more and more data that's come out from each one of...from multiple investigators around the world, as well as in the United States, that show the benefits. It is the majority of insurance companies now that will cover cochlear implants. The efficacy of the implant is really not in dispute, and the benefit is not in dispute. And really, whether kids get bilateral implants is not in dispute. The dispute is really over whether insurance companies will just not make it available. It doesn't cost very much for an entire company to cover this, and the benefits to the families that end up with a deaf child, but can't afford the device is really very significant. And that's why we're here, we think that it should be a mandate because so many of the insurance companies are covering it. [LB71]

SENATOR GLOOR: You understand this, I know, but decisions that we would make, a mandate we would make isn't going to affect ERISA plans, employer-sponsored plans, which in this state are over 50 percent of the covered lives that are out there. Are you able to discern of the insurers who aren't covering this currently, how many of those are a traditional private insurer as opposed to an ERISA plan? I'm just trying to get an idea of how big a problem it is now and whether it will go... [LB71]

RODNEY LUSK: I don't have that information for you. I will be happy to get it for you. [LB71]

SENATOR GLOOR: Okay. It would be...and maybe somebody who testifies will have that information. Any other questions? Senator Crawford. [LB71]

SENATOR CRAWFORD: Thank you, Senator Gloor. I just wanted to come back to the issue of how long the devices last. You said that the goal was that it would last a lifetime. I did notice, again, the information we have indicates the essential benefits package covers two in a five-year period. And I think I remember other people talking about bills in previous years also had this five-year window. What's the logic of a five-year window? [LB71]

RODNEY LUSK: You know, the only thing that I can think of is to cover bilateral cochlear implants where a family, for whatever reason, would choose to have one implant and then at a later date choose to have the second implant put in. [LB71]

SENATOR CRAWFORD: Okay. [LB71]

RODNEY LUSK: It's just an educated case. [LB71]

SENATOR CRAWFORD: Okay, thank you. [LB71]

RODNEY LUSK: I don't recall specifically. I think I've testified each time it's come up. [LB71]

SENATOR GLOOR: I think you have. [LB71]

RODNEY LUSK: Yeah. [LB71]

SENATOR CRAWFORD: But it's a once in a...it is generally a once in a lifetime operation, generally? [LB71]

RODNEY LUSK: That is correct. That is correct. There is a failure rate; it's higher in children than it is in adults because they end up falling more. But as a general rule, we put it in with the expectation that we're not going to have to take it out. [LB71]

SENATOR CRAWFORD: Thank you. [LB71]

SENATOR GLOOR: Other questions? Seeing none, thank you Dr. Lusk. [LB71]

RODNEY LUSK: Thank you very much, Senator Gloor. [LB71]

SENATOR GLOOR: We appreciate your taking time out of your busy schedule at Boys Town. [LB71]

RODNEY LUSK: You're welcome. [LB71]

SENATOR GLOOR: Can I see a show of hands, please, of those who would like to testify either in favor or opposition or in a neutral capacity on this bill? Raise them high, if you would. I see probably seven or eight hands up there. Thank you. This allows us to do a better job of those folks who are watching who have bills to follow, measuring the time that they may need to be down here, so thank you. Welcome. [LB71]

SUSAN STIBAL: Hi. My name is Susan Stibal, S-t-i-b-a-l. I live in Senator Campbell's district, and I am the parent of a child with bilateral cochlear implants. I also serve as a national parent mentor for the Bionic Ear Association, as an advisory board member for the state's Early Hearing Detection and Intervention Program, and as a member of Amplify, a new parent association in Lincoln. When our daughter, Lily, was born, she was identified with a profound hearing loss by the state-mandated newborn hearing screen. The Infant Hearing Act became state law in Nebraska in 2000 and requires screening of newborns as a standard. It also educates parents about necessary follow-up care. The good thing about this mandate is that when babies are identified early, there are dramatic improvements and outcomes in their eventual listening and language ability and dramatic cost savings for society if they have access to the right technology. At eight weeks old, Lily was fitted with two hearing aids which were not covered by our insurance. While today's bill only discusses cochlear implants, 19 other states have mandated various levels of insurance coverage for hearing aids, especially for children under 18. Three states have mandated cochlear implant coverage. When Lily was nine months old, I wrote my first letter to the Legislature and attended a committee hearing about this very same bill we're discussing today, because I was hopeful for all the families that I knew that had been denied benefits by their insurance companies. That was five years ago. At that same time, we filed for cochlear implant benefits for our daughter and although we had asked about and been assured that we were covered, we were denied benefits three different times. I was deeply devastated. I called everyone, including the chair of this legislative committee. And those days were among the worst of my life. We wondered if we could give our house to the hospital that very same week to allow our baby to hear. The hospital wouldn't schedule anything unless they had a guarantee of payment, and time wasn't on our side. The earlier children are implanted, the better their ultimate listening and spoken language is. Finally, after involving our insurance broker, we received an apology letter from our insurance company that said they've covered cochlear implants for years, they've covered bilateral implants, and they have no age minimums or maximums, and that they hope they didn't cause too much stress in our lives. Since that time, we've had adequate insurance coverage. At ten months old, Lily received bilateral cochlear implants. While cochlear implants allowed children and adults to hear, it's not fixing their hearing; cochlear implant users have to work hard to listen how to hear differently. After Lily was implanted, we had numerous visits to the audiologist to make sure her software was set correctly. And we also started visits with speech-language pathologists and hearing resource teachers. And today we've done approximately 700 hours of therapy with professionals and countless hours ourselves. The results have been nothing less than a miracle. For a kid that could only hear jackhammers and jet airplanes at birth, Lily can now hear a whisper. Today Lily is 5.5 years old and although she couldn't hear for the first ten months of her life, her speech is 100 percent intelligible, her language is at or above her hearing peers, she is a star of her mainstream kindergarten class, she is in advanced math, and reading at a second-grade level. So why should the Legislature care, and why should you take action today and not let this bill disappear or die in this committee like it has every other year? Well, while many insurance carriers cover cochlear implants, those that don't, continue to have a devastating impact on their customers. Nebraska has given the insurance market enough time to cover these proven, incredibly cost-effective practices. It's time for the Legislature to mandate coverage like they've done with breast cancer and colorectal screenings. It's only a small fraction, nationally they say 10 percent, of insurance companies that aren't covering implants. But when you lose your hearing or your child is born with no hearing, you better cross your fingers and hope your policy covers them. Do you know if your policies cover cochlear implants? One year a lobbyist in this hearing suggested that if families didn't have insurance that included cochlear implants, it was their own fault. They should have known that their child would be born with hearing loss. In our family situation, we have no history of hearing loss. Our insurance was through our employer so we didn't have a choice of benefits, and we didn't even know what a cochlear implant was before our child was born. In Nebraska, the total number of children each year that are eligible for an implant is quite small. In 2011, 43 children were born with permanent hearing loss. Of those children, 45 percent or 19 children had a severe or profound loss and may be eligible for a cochlear implant. A handful of other children who might qualify for a cochlear implant include those with a progressive hearing loss, those that acquire meningitis which can cause hearing loss...can result in hearing loss, or those exposed to ototoxic drugs that can save their lives, but can also cause hearing loss. Cochlear implants were developed more than 30 years ago and are proven technology that provides tremendous returns not only in quality of life but also in dramatically reduced public support for those with hearing loss. Senators, if you're wearing hearing aids today, I'd like to encourage you to take them out for any opposition testimony, especially because those...your crucial hearing technology, like implants, is probably not covered by your health insurance. Thank you. I'm open for questions. [LB71]

SENATOR GLOOR: Thank you for your testimony. [LB71]

SUSAN STIBAL: Uh-huh. [LB71]

SENATOR GLOOR: Senator Schumacher. [LB71]

SENATOR SCHUMACHER: Thank you, Senator Gloor. Thank you for your testimony. One quick question. As a child's head gets bigger, do they have to adjust to stick the probe in deeper or is it just once done, done? [LB71]

SUSAN STIBAL: No. Yeah well, like Dr. Lusk said, hopefully you will only have one surgery in your lifetime. The external equipment can be changed, and I think that's what your question was. It's like strapping an iPad or something to your body and running around with it for five years. You're going to see wear and tear, whatnot--five years--but the internal piece should last 70 years. [LB71]

SENATOR SCHUMACHER: Even with the head growing and everything else? [LB71]

SUSAN STIBAL: No, it's put on a bone that doesn't move. [LB71]

SENATOR SCHUMACHER: Reference the... [LB71]

SUSAN STIBAL: Uh-huh, to the cochlea so that wire doesn't get pulled out of the cochlea where they put it back here behind your ear. [LB71]

SENATOR SCHUMACHER: Thank you. [LB71]

SENATOR GLOOR: Senator Campbell. [LB71]

SENATOR CAMPBELL: In the interest of disclosure I should say I used to drive Ms. Stibal to school. That says more about my age than yours. [LB71]

SUSAN STIBAL: Yeah, well, I'm not a young parent. [LB71]

SENATOR GLOOR: Other questions? Senator Carlson. [LB71]

SENATOR CARLSON: Thank you, Senator Gloor. In your testimony I think you said that 10 percent of the companies don't cover it. [LB71]

SUSAN STIBAL: That's a national number, right. Uh-huh. [LB71]

SENATOR CARLSON: That's a national number, but we don't know about Nebraska? [LB71]

SUSAN STIBAL: Right. The Cochlear Implant Centers would be more appropriate to tell you who's not covering them. But in my discussions with them, they see a similar rate at 10 percent denials in the clinics. [LB71]

SENATOR CARLSON: Thank you. [LB71]

SUSAN STIBAL: Uh-huh. [LB71]

SENATOR GLOOR: Other questions? Seeing none, thank you, Ms. Stibal. Next proponent? [LB71]

PETER SEILER (THROUGH INTERPRETER): (Exhibit 3) Good afternoon Senator Gloor and other members of the Banking, Commerce and Insurance Committee, my name is Dr. Peter Seiler, S-e-i-l-e-r. I'm from the Nebraska Commission for the Deaf and Hard of Hearing, and I'm the executive director there. The commission believes in LB71 as the most needed bill this session. The commission itself, as you probably know from frequent meetings with me, is the state agency responsible for advocating for deaf and hard of hearing people throughout the state of Nebraska. Right now, we estimate there's 157,000 people with hearing loss from mild to profound within the state, and that covers people ages birth to almost the grave. If they're in the grave, then they can't hear either. That's my little attempt at humor for the day. We believe that all people should have a choice to find a way to circumvent their hearing loss. They shouldn't have to base their decision on how much something costs. Hearing loss is something that affects many, many different families. You might have someone in your family, your parents, cousins, nieces, nephews, who experience hearing loss. There's...you might have friends, coworkers, who also experience hearing loss. The impact of hearing loss is called far-reaching. People think that it's a simple matter of just paying attention more or learning how to read lips or listening harder. I'm having a hard time wondering how I can listen harder if I don't have any hearing ability at all. But actually, it impacts language development as well. I won't deny that it didn't impact my development growing up. I'm lucky my mom and dad knew how to work with me and to help me learn because I couldn't hear. Really at that time I did learn spoken English, but once we've learned spoken, we realize that people with hearing loss sometimes they lose their job, sometimes people at work...people who are adults and lose their hearing, sometimes they get laid off because it's not fair; they can't hear, but they still get laid off at work. Sometimes social skills aren't as developed because people might not hear the way people use English language, the nuances of language, and so sometimes people are...their social skills aren't as developed, because it's not a person's intelligence that is impacted by their ability to hear. Given these points, there's no reason why people should be denied the chance to keep or develop a way to hear. The cost of something should not be the decision maker. I don't know the number of insurance companies that deny the coverage right now, but I know in the past that people have said that it's not necessary. And what the previous speaker said is also true. You know, 57,000 soldiers that have come back recently from Iraq and Afghanistan have come home with a hearing loss. Who could have predicted that? Parents can't predict a child is going to be born deaf, you can't predict what's going to happen to someone in the military. A lot of those people have a hearing loss from their service...from their military service, and those people have a right to be able to hear. It's not just a cosmic chance, you know. It's definitely...it's a lifesaving issue for many people. I'd be happy to answer any questions that anyone has. [LB71]

SENATOR GLOOR: Thank you, Dr. Seiler, and your efforts at humor are always appreciated when you're before the committee. [LB71]

PETER SEILER (THROUGH INTERPRETER): Thank you. [LB71]

SENATOR GLOOR: Are there questions for Dr. Seiler? Seeing none, thank you again. Thank you for your work with the commission. [LB71]

PETER SEILER (THROUGH INTERPRETER): Thank you. [LB71]

SENATOR GLOOR: Next proponent? [LB71]

MARC BRENNAN: (Exhibits 4 and 5) I have two letters that I want to submit. One is from myself... [LB71]

SENATOR GLOOR: Can I ask you to make sure you get next to the microphone when you say that so... [LB71]

MARC BRENNAN: Okay, I'm sorry. I'll repeat that. My name is Marc, M-a-r-c, not K, Brennan, B-r-e-n-n-a-n. I'm submitting two letters, one is a copy of the testimony that I'm going to give today, and the other comes from Steve Kinkead who is the president of the Nebraska Speech-Language-Hearing Association. I'd like to thank the members of this committee for allowing me the opportunity to address you. And as I mentioned, my name is Marc Brennan. I'm a postdoctoral fellow at Boys Town Research Hospital, and I'm a member of the NSLHA, the Nebraska Speech-Language-Hearing Association executive board, and I'm speaking on their behalf today. I have a hearing loss. I was born with a hearing loss, and it wasn't identified until I was four years of age because at that time we did not have universal hearing screening. My hearing loss is a little bit more mild than the type of hearing loss that we're addressing today, so I would not qualify for a cochlear implant and I, instead, wear hearing aids. And I was fortunate enough that even though insurance doesn't cover hearing aids and did not cover it back then, that my parents had the means to pay for hearing aids. And so I've been afforded the opportunity to have access to sounds throughout my development of speech and language in the early years to the point where I was able to go on and get a Ph.D. in Speech and Hearing Sciences. And so the reason that I'm here today is because I decided to devote my life to helping people have access to sounds. You know, my mom reported that I loved being able to hear as soon as I got hearing aids. And I now have...she's actually a seven-month-old daughter as of today, and it's so important to me to be able to hear her, and also to my wife. There are times where I don't have the hearing aids in and it's very frustrating. So I can certainly sympathize with people who are not able to hear. I can't imagine not having my hearing aids. So I'm here today because I want to make sure that people with a hearing loss that's more severe than my own have access to sounds. And I think that providing access to these sounds will best allow everyone with a severe or profound hearing loss to be productive members of society. I know that some might argue that we should not have individual mandates or that these costs are too high. I would argue that all we're doing is shifting these costs around, and we're increasing the total cost. So if we don't provide this sort of coverage, it's going to come out of other forms of tax bills such as those that fund education. And it also cascades into other ill effects such as unemployment. So I respectfully ask you to consider the proposed bill and to vote in favor of its passage. And I'll take any questions that you may have. [LB71]

SENATOR GLOOR: Thank you, Dr. Brennan. Are there questions? Senator Pirsch. [LB71]

SENATOR PIRSCH: Well, thanks for your testimony here today. And I've actually had the opportunity to, through MOMS--I don't know if you're familiar with it--sit through a cochlear implant, so that certainly opens up a lot of doors. My question is, what is the narrow...for those who have...who can't hear at all--right--profoundly deaf, and in terms of children who are born that way, what is...is there a narrow window through which you have to have this cochlear implant or you will be after you get to a certain childhood age, even if you have the operation it wouldn't be early enough in your mental development to provide you any type of use, you know, utility? [LB71]

MARC BRENNAN: Well, that's a complicated question, but the earlier the better, and so we prefer to implant under two years of age. However, there can still be benefit to implanting after that age, but there's less chance of success. But it's very hard to predict for a certain individual, so if someone comes in and they're ten years old, it's very hard to predict for that individual how well they would do. So does that answer your question? [LB71]

SENATOR PIRSCH: Okay. It does, thank you. [LB71]

SENATOR GLOOR: Other questions? Senator Crawford. [LB71]

SENATOR CRAWFORD: Thank you, Senator Gloor. Can I just ask you a follow-up on that? I guess I don't know what you mean by it's very hard to predict how well they'll do if they are ten years old. [LB71]

MARC BRENNAN: Sure. We know on average that, you know, if we implant a child with a cochlear implant that they will do better with that implant provided that they are not receiving benefit from hearing aids. But occasionally, the implant won't be the wonderful success story that we're expecting. And the risk of that occurring increases the later that we wait to implant them. [LB71]

SENATOR CRAWFORD: Thank you. [LB71]

SENATOR GLOOR: Other questions? Senator Carlson. [LB71]

SENATOR CARLSON: Thank you, Senator Gloor. In your testimony you, not in so many words, but you kind of indicated it's either pay now or pay later in different ways. Go over that a little bit again, would you? [LB71]

MARC BRENNAN: Well, if we don't provide a child with a means to communicate, they will essentially operate at a first-grade level, and so they will not be able to be productive members of society. And once you get past that initial window where they can most effectively develop speech and language, it's too late. So it's not like we can implant them when they're 20 years of age and then they'll just be incorporated within the hearing society, if you will. The same thing happens with adults. If you develop a severe hearing loss, you know, when you're 50 years old and you still have a lot of productive years that you can contribute to society, but you can't hear the...your boss or...you know, on your job, then it's hard for you to be an effective member of the workforce. And so then it's been shown that people who do not wear hearing aids or do not get cochlear implants earn less money and they contribute less. [LB71]

SENATOR CARLSON: All right. Thank you. [LB71]

SENATOR GLOOR: Other questions? Senator Schumacher. [LB71]

SENATOR SCHUMACHER: Thank you, Senator Gloor. Thank you for your testimony today. If an adult has a hearing loss through military service or just something else, at that point does the implant pick up where the old hearing left off? I mean, they've already learned language and they've learned what sounds sound like. Is it successful? [LB71]

MARC BRENNAN: It is successful for adults, uh-huh. [LB71]

SENATOR SCHUMACHER: Okay, thank you. [LB71]

SENATOR GLOOR: Seeing no other questions, thank you Dr. Brennan. And congratulations on that seven-month-old. They are beautiful little girls, but in about 11 years, hang on, speaking from personal experience. [LB71]

MARC BRENNAN: Thank you. [LB71]

SENATOR GLOOR: Other proponents? Good afternoon. [LB71]

NATALIE BRAUER: Good afternoon. My name is Natalie Brauer, N-a-t-a-l-i-e B-r-a-u-e-r. I am the mother of Chloe, who was born with bilateral profound hearing loss. Just weeks before her first birthday, Chloe was blessed with the gift of hearing by receiving two cochlear implants. Chloe was actually Boys Town National Research Hospital's 500th cochlear implant recipient. Chloe's hearing loss was identified through the newborn hearing screening and is caused by a gene mutation which is often called Connexin 26. Having a daughter born deaf with no family members with hearing loss was quite an emotional roller coaster. I like to say the first couple of months were a blur. Prior to receiving the cochlear implants, Chloe had stopped babbling, verbally communicating altogether. Now six months later, she has a strong receptive what she understands and expressive what she says language. In fact, just the other night I decided to count how many words Chloe used during play. I stopped at 24--6 months, 24 words--that's pretty impressive. Without the help of the cochlear implants, that would not have been possible. Our goal for Chloe is to have her attend kindergarten with her peers, without the need of interpreter, and without assistance outside of the classroom. We're from rural Beatrice, a rural community, and we don't have access to the deaf community. So without the assistance of the cochlear implants, Chloe's needs would cost her school district. She would need an interpreter. Because of the length of the day, she would need two interpreters. So by having the cochlear implants implanted right before her first birthday, our hope is to have her in that kindergarten classroom with minimal services. Chloe, even though she's only 18 months old and has been hearing for 6 months, she understands what her cochlear implants provide for her. She does not wear them when she sleeps so upon waking up at nap time or in the morning, she requests her cochlear implants by smiling, pointing, and signing yes. Today I am here to ask for your support for LB71 so that other families and individuals can receive the gift of hearing by regulating coverage for cochlear implants. I'm open for any questions. [LB71]

SENATOR GLOOR: Thank you, Ms. Brauer. Is Chloe your first child? [LB71]

NATALIE BRAUER: She is our second. [LB71]

SENATOR GLOOR: Second. Is this condition one that is a concern for you if you decide to have other children? [LB71]

NATALIE BRAUER: We were done with that decision prior to having this one. But no, my husband and I have a 25 percent chance of having a child with hearing loss upon every pregnancy. [LB71]

SENATOR GLOOR: Is this condition as relates to children born with hearing impairments a common one, do you know? [LB71]

NATALIE BRAUER: I believe the Connexin 26...for those we decided to go on with genetic testing because we had no hearing loss in our family. But I believe that Connexin 26, for those family who are identified, is a common gene mutation. But I don't have the facts on that. [LB71]

SENATOR GLOOR: Okay. Well, I know you're not a clinician, but I also know you have great interest in it. [LB71]

NATALIE BRAUER: No, but it is...right. Yes. [LB71]

SENATOR GLOOR: Thank you. Other questions? Senator Pirsch. [LB71]

SENATOR PIRSCH: Thank you. And so when was it that Chloe stopped babbling then? [LB71]

NATALIE BRAUER: She probably stopped babbling around six to eight months of age. [LB71]

SENATOR PIRSCH: Six to eight months of age. [LB71]

NATALIE BRAUER: Uh-huh. [LB71]

SENATOR PIRSCH: And when...was she screened as required by law then... [LB71]

NATALIE BRAUER: Yes. Yeah, we found out...Chloe was born as a scheduled C-section and so we were first told that it was...her hearing loss...why she failed the newborn hearing screening at the hospital was probably due to fluid in her ears. We did follow-up testing with an ENT in Lincoln and with Boys Town National Research Hospital, and that's when she was diagnosed with a profound hearing loss. [LB71]

SENATOR PIRSCH: When was the...so the screening was...how old was she? [LB71]

NATALIE BRAUER: The initial screening I believe it's within hours, maybe 24 hours of being born. It's before you're discharged from the hospital. [LB71]

SENATOR PIRSCH: Discharged, okay. And she failed that initial one? [LB71]

NATALIE BRAUER: She failed that, uh-huh. [LB71]

SENATOR PIRSCH: And then she had a...you said a follow-up appointment... [LB71]

NATALIE BRAUER: Yes. [LB71]

SENATOR PIRSCH: ...or was it just they looked at their ears and there was fluid and so they assumed it was... [LB71]

NATALIE BRAUER: No. They did both testing. They did an audiogram or a ABR test to see if her hearing nerve would respond, which is similar to what they do at the hospital. And they also tested to see if there was fluid in her ears. They had found there was no fluid in her ears, and so then diagnosed her with the hearing loss. [LB71]

SENATOR PIRSCH: How old was she at that time? [LB71]

NATALIE BRAUER: Just weeks old. [LB71]

SENATOR PIRSCH: Just weeks old? [LB71]

NATALIE BRAUER: Yeah, she was born end of August and it was before Labor Day. [LB71]

SENATOR PIRSCH: Okay, so right from the get-go. Thank you. [LB71]

NATALIE BRAUER: You're welcome. [LB71]

SENATOR GLOOR: Other questions? Seeing none, thank you, Ms. Brauer. [LB71]

NATALIE BRAUER: Thank you for your time. [LB71]

SENATOR GLOOR: Other proponents? [LB71]

ANDREW STITHEM: Good afternoon. [LB71]

SENATOR GLOOR: Good afternoon. [LB71]

ANDREW STITHEM: My name is Andrew Stithem, it's A-n-d-r-e-w S-t-i-t-h-e-m. I am here, of course, to encourage you to support LB71. I, myself, am the father of a wonderful 2.5-year-old daughter named Emerson, who was born with profound hearing loss, bilateral. Naturally, my wife and I were pretty devastated when we first found out the news. We've had no prior history of hearing loss. In addition to Emerson, we actually have a five-year-old, Cameron, who has normal hearing so had no reason to suspect that Emerson would be any different. You know initially finding out, I think you go through a lot of the thoughts. You know, why us, you know? And then once you get past that, maybe the what-ifs, as far as how are we going to make this important decision for our daughter? Is it the best decision? There's a lot of emotion that goes with that. Initially we thought, how on earth is our daughter going to be able to hear us tell her that we love her? She will never be able to hear any music, hear laughter or even the sound of her own voice. It wasn't until we met a family that had two daughters themselves who both have cochlear implants. That's when we realized what these devices and the miracle they truly are and what they can do for your children. These two girls, they were talking, singing, even playing the piano. For finding out just a couple of months ago that our daughter was born deaf, it was truly just amazing to witness. You know, you really would never know that they even had a hearing loss. You know, after an evening filled with many questions and even some hands-on learning--their daughter would let us go up, touch the devices, feel how they worked, they were very generous to welcome us into their home--you know, we left with a huge relief. Ever since she did receive cochlear implants at the age of 13 months of age--and I'm proud to say that she's doing wonderful--she tests above average in speech tests that are given to normal-hearing children. She continues to amaze us, as her parents, as well as the professionals that work with her. You know looking back, we definitely consider ourselves a success story and we, you know, definitely feel that way going forward. The reason why I'm here is I want every family to have that same opportunity. And just today obviously we've heard that, for the most part, it sounds like they would be able to, but there's always that possibility that they won't based on their insurance provider. Emerson was diagnosed through the newborn hearing screening process. She referred twice at the hospital, which we then followed up with the Barkley Center a week later, and then we followed that with Boys Town National Research facility two weeks after that. Really we have to say we have appreciated the guidance that our pediatrician, as well as the professionals at Boys Town, have given us. Thanks to everything, they were able to quickly identify her, determine...and allow us to really determine that cochlear implants were the best option for our daughter. The thing that was tough was initially then, is when we found out this, well, it's possible your insurance company may not cover cochlear implants. Really, again, this is where we felt very fortunate as the professionals and the advice they'd given us, the direction. After contacting my insurance company through my work, did find out that we were covered, but there was a series of very specific steps, as well as specific time lines, that you had to meet. Again, we were on the right direction and we felt very fortunate in that. If it wasn't for going through the new hearing-screening process, which I understand is a requirement...but I like to think of, you know, the ability to, you know, make sure that that's done in rural communities. Again, in thinking of specific time lines that we had to meet, I'm not sure if that's always possible. After we did find out we are covered, the next became how long before we get the approval. Again, nothing that we could get really specifics on. But thanks to the dedication of the professionals at Boys Town, we were able to get our request approved and able to, again, have Emerson implanted at the age of 13 months. You know, we feel very fortunate with our story; we feel it's been a success. But it is difficult to hear the stories of families that have to educate their insurance providers on what cochlear implants are, and then just even endure several months of not knowing if they're going to be covered. I could personally tell you that there's a great amount of emotion that goes through parents at this time, and really it even makes these situations more difficult. This bill would greatly help those families during this time by allowing them to know the coverage is available and that they can focus on which is most important, their child. Appreciate you guys, thank you. Any questions? [LB71]

SENATOR GLOOR: Thank you, Mr. Stithem. Are there questions? Senator Carlson. [LB71]

SENATOR CARLSON: Thank you, Senator Gloor. You talk about going through the hoops and so forth and waiting. Why...if the policy covers, why would that be so difficult and time consuming to make sure that you want one. You wouldn't want one if you didn't need one. [LB71]

ANDREW STITHEM: Right, I agree. I'm sure it's the way that insurance companies cover themselves to make sure that, you know, it is accurate and that it is a need for the child. Obviously, it's not a cheap endeavor so I'm sure they're wanting to make sure that they're...cover their bases, so to speak. [LB71]

SENATOR CARLSON: Thank you. [LB71]

SENATOR GLOOR: Other questions? Seeing none, thank you for your testimony. [LB71]

ANDREW STITHEM: Thank you. [LB71]

SENATOR GLOOR: (Exhibits 6 and 7) Other proponents? Can I see a show of hands of those in opposition or in a neutral capacity? About four, I believe. Okay, we'll start with those in opposition. And while he moves his way up here, I will have the pages hand out a couple of letters of opposition on LB71, one from the National Federation of Independent Business, and one from The Association of Insurance and Financial Advisors. Good afternoon. [LB71]

GALEN ULLSTROM: Thank you. Chairman Gloor, members of the Banking, Commerce and Insurance Committee, for the record, my name is Galen Ullstrom, G-a-l-e-n U-l-l-s-t-r-o-m. I'm appearing today on behalf of the Nebraska Insurance Federation. I'm kind of standing in for Jan McKenzie who is unable to make the hearing today. I'm only testifying on this bill because it's the first bill up. My comments relating to mandated benefits would apply equally to all four bills today. The purpose of my testimony is really to provide an example that if the Legislature would determine to pass one or a number of these mandates, who would be impacted by that mandate. And maybe more importantly, who would not be impacted by it. The language of all four mandates is about the same in that it provides that every individual or group health insurance policy in the state issued after a given time must provide this coverage. It also provides that any self-funded employee benefit plan, to the extent not preempted by federal law, would have to provide this benefit. It's this provision that I want to concentrate on. The law requiring or the law which has the preemption, is known as the Employment Retirement Income Security Act of 1974 known as ERISA. That act was passed by Congress to ensure that employee welfare benefit plans offered by employers were only governed by federal law. And it includes a preemption that states cannot pass laws that interfere with those plans. The only exception is that it recognized that under the McCarran-Ferguson Act insurance is regulated by the states and, therefore, they can regulate insurance plans. In a nutshell, what it comes down to is that if a employer plan is fully insured, it can be regulated by the state, this mandate would apply. If it is a self-funded plan under ERISA then it would not be subject to the mandate and would not apply. Putting this in perspective...I think, Senator Gloor, you asked the question earlier. I think maybe some of the other people behind me can give you current numbers. I know when our company exited the major medical business, which is about five years ago, we had over 70 percent of our plans were self-funded plans that we just administered--we did not underwrite, they were not insured plans. So of those plans, if...unless the employer chose to provide the benefit, they would have been exempted. And I don't have the number of covered lives, but that's a large...certainly more than the majority of plans we had over the last X years. And since '74, a lot more plans have moved to be self-funded, not only for mandated benefits, some for tax reasons, but have moved to that funding as opposed to being fully insured. If you eliminate those large employer plans, and it's mainly large employers, the mandate itself would be most applicable and apply to individual policyholders buying on their own or small employers who don't have the size to self insure. And mainly, I don't think we used to write any self insurance on anybody under 100 lives, so it would apply only to large numbers. There's an additional monkey-wrench I think that got thrown into this by the passage of the Affordable Care Act in 2010. It provides that everybody must have coverage by 2014, both employers providing coverage and individuals buying coverage. It also provides for an essential benefit package. This essential benefit package was originally going to be determined by the federal government. It then got kicked to the states so each state could develop their own benefit package. There were a number of safe harbors in that bill that states could choose from, but basically if they didn't adopt one, they had a default mechanism. And the default was the largest plan of enrollment for small employers in the state, and that was determined as of January 1, 2012. And that would apply to the benefit package being required in 2014 and 2015. So the law also said that states could go beyond that. They could apply additional benefits from the essential benefit package. The problem...they said, but if the state does that, it must provide the funding. That's different from what we had in the past. Before the cost would go...there are no rules or regs regarding that provision. I don't know how it would work. I don't think any state...any state has the same issue, but it's not clear how that would be implemented by the state or otherwise. So it's an additional compounding factor in the mandated-benefit issues that we have. And those are the reasons--I just want to provide that background on all the bills--that before the Affordable Care Act, the main cost for mandated benefits would have gone into individual policies or small groups. Now, assuming those benefits are outside the essential benefit package, they would appear to be placed on the state in order to either reimburse the individual directly or pay the plan directly for the cost of that benefit. How administratively it would work, I have no idea, and I doubt very much if HHS knows how it would work yet either. But I'd be glad to answer any questions. [LB71]

SENATOR GLOOR: Are there any questions for Mr. Ullstrom? Senator Christensen. [LB71]

SENATOR CHRISTENSEN: Thank you, Chairman. Has...when mandates have come from the Legislature, has independent group plans and things that way tended, in the long run, to start adding them also later on or is there a big separation between the independent plans and the mandated from the state? [LB71]

GALEN ULLSTROM: It would depend upon the mandate and the cost of the mandate, Senator. I would say most large plans for competitive reasons in trying to provide a benefit package are trying to provide benefits that everybody uses and needs. So assuming it was a generally accepted benefit, if you look at some that we've passed, screening for breast cancer or colon cancer, those things, I think most employer plans provided those prior to, you know, any mandate. But as far as small employers who are looking at the costs and they don't provide a lot of contribution to the plan, they might have not wanted to provide those plans in the absence of a mandate. [LB71]

SENATOR CHRISTENSEN: Okay. Thank you. [LB71]

SENATOR GLOOR: Other questions? Senator Carlson. [LB71]

SENATOR CARLSON: Thank you, Senator Gloor. Galen, essential benefit plan, tell me again what that is, what's in there. [LB71]

GALEN ULLSTROM: Well, it's...there's a laundry list, Senator, of things that have to be included in it; it was included in the law. And you have to provide minimum benefits, physicians visits, emergency care. It's the kind of the standard benefit package you would have, but it said how to get there. It gave the state some flexibility to say, okay, what is that? It said you can have the state health plan could be the guideline, the largest HMO in the state could be the guideline. It also talked about the small-employer health plan. But then it had a default that said, well, if the state doesn't elect one of those, it will default to the largest covered...plan providing the most coverage to small employers in the state. And I believe that's a Blue Cross and Blue Shield plan, and I'm sure they can provide more information on that. But that's...that would be a plan that is offered now or was offered in 2012 to small employers in Nebraska. And that's the essential benefit package for Nebraska. [LB71]

SENATOR CARLSON: Okay. And under the new healthcare plan from the federal level, self-funded are not held to that? [LB71]

GALEN ULLSTROM: Self-funded are not held to that. [LB71]

SENATOR CARLSON: Or is there a basic benefit package that they have to provide, but then... [LB71]

GALEN ULLSTROM: There is a basic benefit package that they need to provide in order to qualify as providing coverage to their employees. [LB71]

SENATOR CARLSON: Okay. [LB71]

GALEN ULLSTROM: But most of the plans are grandfathered in, and most large employers would be providing a package that would be at least equal to the essential benefit package in Nebraska. [LB71]

SENATOR CARLSON: But because they have leeway...we hear these testimonies, and boy, they tear at you, but that would be a reason that a large employer would decide not to include that in their plan... [LB71]

GALEN ULLSTROM: That's correct. [LB71]

SENATOR CARLSON: ...and, in a sense, then they're just hoping that it doesn't affect a lot of people. [LB71]

GALEN ULLSTROM: That's true. And I think that part of the problem between the self-insured and insured plans is that, for the employee, they probably don't know it. Most employees in larger corporations don't have a clue whether the plan is self-funded or insured. They get a card that they bring and if you really look at the card the only difference is probably it might say, for example, Mutual of Omaha Plan administered by Coventry Health Care, which mine says. But if it is transparent, they don't know whether it's self-funded or not. But as a practical matter, if it is self-funded, any of these mandates passed by the state would not have to be implemented by that plan. [LB71]

SENATOR CARLSON: Okay. And those...the employees of those self-funded plans, they do get a booklet which, understandably, they're not read very often... [LB71]

GALEN ULLSTROM Correct. [LB71]

SENATOR CARLSON: ...but that would indicate what's covered and what's not. [LB71]

GALEN ULLSTROM: Definitely. It would definitely have the same requirements, really, as an insured plan. In fact, the same materials I'm sure that Coventry provides their insured plans, they provide to us through their administration. [LB71]

SENATOR CARLSON: Okay. Thank you. [LB71]

GALEN ULLSTROM: Sure. [LB71]

SENATOR GLOOR: Just a procedural thing. You understand that...your comment was that your comments related to all four of the bills, but your testimony will only show up under this particular bill. [LB71]

GALEN ULLSTROM: Yes, and that's fine, Senator. I think it's...it was mainly for the committee's benefit. Again, it's applicable to all, but it's not...I didn't want to take the committee's time to say the same things four times. [LB71]

SENATOR GLOOR: (Exhibit 8) I would also along those lines, there is a letter of opposition from the City of Omaha for all four of the bills. So I'll ask the pages to hand these out. Were there other questions for Mr. Ullstrom? Senator Schumacher and then Senator Pirsch. [LB71]

SENATOR SCHUMACHER: Thank you, Senator Gloor. Thank you for your testimony. Now, Nebraska's essential benefit plan is this Blue Cross small-business plan. [LB71]

GALEN ULLSTROM: Right. [LB71]

SENATOR SCHUMACHER: And had we not defaulted to that, could we have selected a plan that included implants or these other mandated items? [LB71]

GALEN ULLSTROM: I don't know what those other plans would have been. I mean, I don't know what benefits they provided, but they certainly could have had more benefits than were provided under the small group plan. [LB71]

SENATOR SCHUMACHER: Okay, thank you. [LB71]

SENATOR CHRISTENSEN: Senator Pirsch. [LB71]

SENATOR PIRSCH: Thanks. I just wanted to get a sense in terms of numbers of Nebraskans who are covered under ERISA then and, thus, would not be affected one way or the other by what the state Legislature does in the area. [LB71]

GALEN ULLSTROM: I would say at least 50 percent. I mean, that's the number we used to use. I was surprised the last time I checked on our own plans that on the group side, employer group side, it had gone up to 70 percent that were self-funded. So I would say of the number of covered lives, probably including all group plans and individual, you probably have 50 percent of the people that are covered under self-funded plans. [LB71]

SENATOR PIRSCH: So the Legislature would be preempted by the federal government... [LB71]

GALEN ULLSTROM: Correct. [LB71]

SENATOR PIRSCH: ...from having a voice in the outcome of half... [LB71]

GALEN ULLSTROM: That...those plans would not be required to provide those benefits.

[LB71]

SENATOR PIRSCH: Thank you. [LB71]

SENATOR CHRISTENSEN: Are there any other...yes, Senator Howard. [LB71]

SENATOR HOWARD: Thank you, Senator Christensen. Thank you for your testimony. I actually had a question. This seems like a more of a pediatric issue than an adult issue. In the essential benefits package, aren't pediatric services more comprehensively covered? [LB71]

GALEN ULLSTROM: I believe they are, but I'd defer to somebody who's been working on it, one of the other carriers that's still in that business. But yes, there is a pediatric benefit. There's a pediatric dental benefit I know also, as a specific... [LB71]

SENATOR HOWARD: Uh-huh. Uh-huh. So they have more wraparound services, so there's the potential that they would include this as well? [LB71]

GALEN ULLSTROM: There probably is. It's possible, but I think it is limited to whatever that coverage is now. I mean, I think it's very interesting to see how it works. I'm not sure because it really references the plan of 2012, the plan...the benefit package of 2014 is what was in place January 1, 2012. So mandates passed after that, I'm not sure that they would apply until possibly future years. [LB71]

SENATOR HOWARD: Okay. Thank you. [LB71]

GALEN ULLSTROM: So...you bet. Thanks. [LB71]

SENATOR CHRISTENSEN: Any other questions? Thank you, Mr. Ullstrom. [LB71]

GALEN ULLSTROM: Thank you, Senator. [LB71]

SENATOR CHRISTENSEN: Welcome, Ron. [LB71]

RON SEDLACEK: Good afternoon, Senator Christensen and members of the Banking, Commerce and Insurance Committee. For the record, my name is Ron Sedlacek, R-o-n S-e-d-l-a-c-e-k. I'm here today on behalf of the Nebraska Chamber of Commerce. Mr. Ullstrom explained the general overview of the insurance situation. At this time, we would concur in those remarks and would like to extend our remarks also in order to save the committee time in regard to all four pieces of legislation, although I have signed in for this particular bill only on behalf of the state chamber. Over the years when we had testified in regard to mandated benefits, our concern always was two factors. Essentially, since most of our employers or employer members provide health insurance for their employees, and that was affordability and availability. Well, availability is no longer really on the table, but affordability is to a limited extent. When we talked about the ERISA plans, the last that I remember of those employees who are covered by members is approximately 60 to 65 percent--someplace in there--we figured were under the federal ERISA program. So that leaves...that left, essentially, those who either had individual policies or group health type plans that they were offering to their employees. Right now, we're testifying in a neutral position. That could possibly change over time, but what we're very much concerned about is affordability in regard to insurance. For those who are not under ERISA plans, what's going to happen as we begin to step into this new health insurance world, and particularly next year? Many of our employers...we have the small employers who could be exempt, we've got those employees in the middle or the employers in the middle. What is the reaction going to be? How is affordability going to affect conduct? We don't have that answer yet. We know that passing individual type of mandates...and each one is meritorious. Certainly each group can make their case as to why coverage should be there. However, it's always a matter of affordability. Who's going to pay for it? The question becomes are we encouraging migration then to an exchange? And does the state pick up, we believe, the tab, which it may well do? Our message, essentially, is to exercise a little bit of caution and perhaps we ought to be taking some time to see what the final regulations look like...what...so we have more definitive answers to the many questions we certainly have in trying to figure out how this might affect those remaining employers who do offer health insurance on a nonERISA type basis. And that's the substance of my testimony. Be happy to answer any questions. [LB71]

SENATOR CHRISTENSEN: Are there any questions for...yes, Senator Schumacher. [LB71]

RON SEDLACEK: Yes, Senator. [LB71]

SENATOR SCHUMACHER: Thank you, Senator Christensen. And thank you for your testimony today. Are you getting a sense from your membership whether or not there is any movement toward the discontinuation of employer-based insurance to just pay the fine rather than the insurance bill and then let people go to the exchanges? [LB71]

RON SEDLACEK: Our employer members really aren't sharing that information at this point with us. You certainly can pick up some anecdotal stories and you read the national press as to what's trending, which I'm sure the employers are also doing as well as their consultants in advising them. I think there is some--I wouldn't call it anxiety, that's a little bit too strong of a word there--but a number of employers are anxious to find out what the pricing of insurance is going to be. And there's variations of predictions, and if some of them would come true, I'm sure that there will be rethinking in that regard, Senator. [LB71]

SENATOR SCHUMACHER: Thank you. [LB71]

SENATOR CHRISTENSEN: Senator Carlson. [LB71]

SENATOR CARLSON: Thank you, Senator Christensen. Ron, I think I heard you say, are you testifying neutral? [LB71]

RON SEDLACEK: No, I'm not. I'm testifying in opposition at this time. [LB71]

SENATOR CARLSON: Oh, I heard you say neutral. [LB71]

RON SEDLACEK: I said...no, I said there's a possibility that, you know, over time we could be... [LB71]

SENATOR SCHUMACHER: Okay. [LB71]

RON SEDLACEK: ...potentially neutral. We just don't know the answers to any of the questions that we have in this regard. [LB71]

SENATOR CARLSON: Okay. Thank you. [LB71]

SENATOR CHRISTENSEN: Are there any other...yes, Senator Crawford. [LB71]

SENATOR CRAWFORD: Thank you, Senator Christensen. I just wanted to clarify one of the points that you made where you were concerned about migration to the exchange. So if we require the cochlear implants then people would migrate to the exchange. Just from what we have in front of us indicates that the exchange plans also require cochlear implants, so I don't think that would happen with this bill we have in front of us if anything...the exchange already also requires that. So... [LB71]

RON SEDLACEK: And that's...although...and perhaps there will be testimony that follows. I think that there is a question as to what are the limitations, if any. [LB71]

SENATOR CRAWFORD: Uh-huh. Yes. [LB71]

RON SEDLACEK: And perhaps that's something that ought to be considered in that regard, too. But nonetheless, even if that be the case, and I...and that's the danger of extending your remarks to other bills... [LB71]

SENATOR CRAWFORD: Right. [LB71]

RON SEDLACEK: ...besides this one. The question becomes, who is left then, to pick up the tab? If the ERISA programs are exempt, you've got covered by the exchange, then there's that little middle ground there. What is the effect going to be, and what is the effect on conduct... [LB71]

SENATOR CRAWFORD: Right. [LB71]

RON SEDLACEK: ...in the future event? [LB71]

SENATOR CRAWFORD: Right, point taken. Thank you. [LB71]

RON SEDLACEK: Uh-huh. [LB71]

SENATOR GLOOR: Other questions? Seeing none, thank you. [LB71]

RON SEDLACEK: Thank you, Senator. [LB71]

SENATOR GLOOR: Other opponents? [LB71]

ANDY POLLOCK: Good afternoon, Chairman Gloor, members of the Banking, Commerce and Insurance Committee. My name is Andy Pollock, A-n-d-y P-o-l-l-o-c-k. I am here as registered lobbyist on behalf of UnitedHealthcare, and I have also been asked to speak on behalf of Coventry and Blue Cross Blue Shield, both in Nebraska. I want to first say thank you to Senator Karpisek for spending some time visiting with me about this particular issue. It's an issue that the insurance companies that I'm speaking on behalf of take very serious. And in fact, all three companies today in Nebraska, and I believe elsewhere, too, cover cochlear implants; they cover bilateral cochlear implants. So what Senator Karpisek is seeking to require here is covered by those three insurance companies. I don't have reason to doubt or dispute the figures that were mentioned earlier in terms of 10 percent of plans not covering, but I can say categorically, on behalf of the people and companies I represent here, that we do cover. I think the question, and I mentioned this to Senator Karpisek this morning and it's come up a little bit, has to do with the limitations. This bill really doesn't have any limitations, and you've heard that these implant devices are intended to be lifetime devices. I think the three insurance companies--and I can't speak for the other two on this front--but I think we have different limitations on how many during what period of time. For United, I can say that we require if there's a problem that's been reported by a patient, that there be a manual inspection of the cochlear implant. And before we replace it, we have to have evidence that it's medically necessary for that particular patient. What we're concerned about is that as technology changes we just can't afford to put on our other insurers, the other people who will be helping foot the bill for this, for a change in the implant every time a technology might change and improve. We see that with computers, we'll see it with cochlear implants too. Obviously, this is a much more serious endeavor than computers, but I don't think anybody could realistically expect the other insureds to pick up the tab for a new implant every time technology changes. And, frankly, I don't think you're hearing that from the people who have testified in support of this bill, but that would be one concern that we have. That concern is an issue because of the cost associated with it, as I mentioned. It will create a cost for the state for insurance issued through the exchange, and that shows up in the fiscal note that you see. If there's not some limitation that would create a cost to other plans as well, they will increase...premiums will increase for other people paying that insurance. And this is obviously a concern for us because of the small businesses that we carry plans for. With that, I would conclude and just say, on behalf of United and Coventry and Blue Cross Blue Shield, that we ask you not to advance LB71. [LB71]

SENATOR GLOOR: Thank you, Mr. Pollock. Are there any questions? Senator Campbell. [LB71]

SENATOR CAMPBELL: Thank you, Senator Gloor. Mr. Pollock, when you consider UnitedHealthcare, Blue Cross Blue Shield, and Coventry, and the ERISA programs, that's where you think that 10 percent of the population isn't covered by those or 10 percent of the companies are left? [LB71]

ANDY POLLOCK: I don't...that was referenced by a earlier witness that talked in support of the bill and I don't know where that number came from, Senator Campbell. [LB71]

SENATOR CAMPBELL: Because with the three companies that you're testifying for, I mean, you would cover a large percentage of the population in Nebraska, would you not? [LB71]

ANDY POLLOCK: I would guess that it would be significant. I don't know what percent, but... [LB71]

SENATOR CAMPBELL: At one point, I heard that the three of you covered like 85 percent. [LB71]

ANDY POLLOCK: I don't have any reason to doubt that. We can try to find out the answer to that if you'd like me to. [LB71]

SENATOR CAMPBELL: And I wouldn't be able to tell you exactly where I heard that either, but it just sticks in my mind. [LB71]

ANDY POLLOCK: Okay. [LB71]

SENATOR CAMPBELL: So you've covered a lot of those. In the exchange that's going to be there, I mean, we have to do Blue Cross Blue Shield 5 as that essential. And I can't remember, the insurance committee people are going to remember that a lot better whether that's the...I mean, there's like a gold and a platinum and all the different levels, but there has to be that particular level. But in other levels, there could be additions to the essential benefits, could there not? [LB71]

ANDY POLLOCK: I assume that there could. And just a clarification, I think Senator Carlson asked about this and I think most of the testimony has been consistent on this, but in Nebraska that plan does cover two implants every five years. [LB71]

SENATOR CAMPBELL: Okay. [LB71]

SENATOR GLOOR: Other questions? Senator Crawford. [LB71]

SENATOR CRAWFORD: Thank you, Senator Gloor. And thank you for your testimony. When you're talking about your plans all covering the cochlear implants, I assume you're discussing the plans that are insurance plans, but also, you have...you probably manage many self-insured plans as well. And so, do you have a sense of how many of those are the self-insured, ERISA plans we're talking about? Do you have any sense of whether or not those typically--the ones that you manage--typically cover this as well? [LB71]

ANDY POLLOCK: I don't know the answer to that, Senator Crawford. The insurance department might have a better sense of that. [LB71]

SENATOR CRAWFORD: Uh-huh. [LB71]

ANDY POLLOCK: Those would be plans that we administer, but they would be plans chosen by the employers... [LB71]

SENATOR CRAWFORD: Employers, right. [LB71]

ANDY POLLOCK: ...and I honestly don't have an answer for you. I'd be glad to try to find out. [LB71]

SENATOR CRAWFORD: Thank you. [LB71]

SENATOR GLOOR: Other questions? Seeing none, thank you. [LB71]

ANDY POLLOCK: All right. Thank you. [LB71]

SENATOR GLOOR: Other opponents to the bill? Anyone who would like to speak in a neutral capacity? And while the director comes up here, we have a letter I believe is from the Department of Insurance that's in a neutral capacity. Good afternoon, Director. [LB71]

BRUCE RAMGE: (Exhibit 9) Good afternoon, Senator Gloor and members of the Banking, Commerce and Insurance Committee. My name is Bruce Ramge. For the record, that's spelled B-r-u-c-e R-a-m-g-e. I'm the director of insurance, and I'm here to testify in a neutral capacity. I have provided letters for each of the bills that are coming up before the committee today. But I plan to really only testify on this one because the information very much is repetitive with the exception of the specifics for each of the medical issues that will be discussed today. As you know, the Affordable Care Act has really changed the landscape in the area of mandated benefits. And as was mentioned earlier, one of those specific changes is a regulation or a rule under the Affordable Care Act that the citation is listed in the letter provided. And it will require payment by the state of mandates that are not included in the essential health benefit package. The processes and specifics of this have not yet been given to us in the form of a regulation, so we're learning as we go. We have posed a couple of questions to the HHS, at the U.S. Department of Health and Human Services, and primarily in two areas of questions relate to the scope. And one is whether or not the plans sold outside of the exchange, whether or not the state would have to pick up the extra cost of the mandates for those plans or whether it's just for those sold within the exchange. So that's an area of uncertainty for us. And also, there's some information that's really not clear upon whether they're talking only about specific procedures or whether different sublevels within the policy for those procedures, such as copayments. And, Senator Campbell, earlier I know you had a question about the tier levels of the plans. All the plans will basically cover the same benefits. Where they will differ is through copayments and deductibles. Basically in the case of cochlear implants, the essential health benefit package is going to be modeled after the Blue Cross, Blue Pride Option 5. And that policy has a limitation of two procedures every five years, and so that is what basically the assumption the department used in providing this estimate on the cost. Another issue that will be applicable to all the bills this afternoon is timing. And that's because the plans that are going to be offered to be sold on the exchange have to be basically filed and approved with the Department of Insurance and given to the federal government for inclusion before the end of July of this year. So it would not be possible to get a new benefit onto those plans until January 2015, so there is a timing issue as well that should be taken into consideration when looking at these issues. With that, again, I would encourage you to review the letter. I've just kind of paraphrased parts of it. And if you have any questions, I'd be happy to answer those. [LB71]

SENATOR GLOOR: Thank you, Director Ramge. Senator Christensen. [LB71]

SENATOR CHRISTENSEN: Thank you, Chairman. Did you say the blue level, default level insurance does cover cochlears? [LB71]

BRUCE RAMGE: It provides for two cochlear implants every five years. [LB71]

SENATOR CHRISTENSEN: So it is going to be covered starting when? [LB71]

BRUCE RAMGE: January 1, 2014, for new policies that would be issued...new qualified health policies issued either inside the exchange or outside of the exchange. [LB71]

SENATOR CHRISTENSEN: So what will this bill accomplish if we pass it, unless it gains a few months? [LB71]

BRUCE RAMGE: There may be some types of policies, I suppose, that are not qualified health plans. I suppose it could offer clarity as well. But other than that, we think that because of the federal requirements and the essential health benefit package, that this specific procedure will be covered by those newly-issued plans. [LB71]

SENATOR CHRISTENSEN: Will that affect the independent driven plans? [LB71]

BRUCE RAMGE: No. [LB71]

SENATOR CHRISTENSEN: No. [LB71]

BRUCE RAMGE: No. [LB71]

SENATOR CHRISTENSEN: So still leaves those out. [LB71]

BRUCE RAMGE: It will be those insured plans. [LB71]

SENATOR CHRISTENSEN: Just those that are choosing the... [LB71]

BRUCE RAMGE: Yes. Yes. [LB71]

SENATOR CHRISTENSEN: Okay. That's all I wanted to make sure. Thank you. [LB71]

BRUCE RAMGE: Okay. [LB71]

SENATOR GLOOR: Senator Crawford. [LB71]

SENATOR CRAWFORD: Thank you, Senator Gloor. So just following up on Senator Christensen's questions here, if the essential benefits package is required for plans in the exchange already, then the timing or time line of this bill probably doesn't matter because...I mean, well, if the bill were to adopt the language of two every five so it matched the essential... [LB71]

BRUCE RAMGE: Yeah, yeah. [LB71]

SENATOR CRAWFORD: If it were to do that. [LB71]

BRUCE RAMGE: Yes, if there were an unlimited number. [LB71]

SENATOR CRAWFORD: Right. So my questions are based on...okay. Right. So if it was changed so it was not unlimited but it was two per five... [LB71]

BRUCE RAMGE: Yes. [LB71]

SENATOR CRAWFORD: ...then the two per five is going to happen on the exchange no matter what happens with the bill. But...right. [LB71]

BRUCE RAMGE: Yes, for this particular procedure. But...yes. [LB71]

SENATOR CRAWFORD: For this, but not for the others. So...but, I just...are there still insurance plans that we will be regulating, that will be sold in the state, that are not in the exchange, that this bill would apply to? [LB71]

BRUCE RAMGE: Yes. [LB71]

SENATOR CRAWFORD: Yes. All right, so there are other insurance plans, yes, that it applies to. [LB71]

BRUCE RAMGE: Yeah. It's difficult for me to anticipate how many of those might be sold. I mean, logically... [LB71]

SENATOR CRAWFORD: Right, but there is a pool there. Right. Right. [LB71]

BRUCE RAMGE: ...most...there's that possibility, yes. [LB71]

SENATOR CRAWFORD: And for that pool, it wouldn't matter if it started September 1... [LB71]

BRUCE RAMGE: That's correct. [LB71]

SENATOR CRAWFORD: ...because it doesn't...the ACA doesn't matter for that pool. [LB71]

BRUCE RAMGE: That's correct. [LB71]

SENATOR CRAWFORD: Right? [LB71]

BRUCE RAMGE: Yes. [LB71]

SENATOR CRAWFORD: Okay. So, we wouldn't necessarily have to pass it with an E clause because...if what we wanted was two per five, we wouldn't have to have an E clause because the exchange is taken care of, and the other ones could start September. [LB71]

BRUCE RAMGE: Yes. Yes. And on this date, even though July 31 is the date that they have to be approved by, the date that they have to actually be filed with the Department of Insurance is more like April 1... [LB71]

SENATOR CRAWFORD: Okay. [LB71]

BRUCE RAMGE: ...so timing is very, very tight. [LB71]

SENATOR CRAWFORD: Right, right. But assuming you were doing just this, just two for five, you wouldn't have to do it anyway for the exchange. [LB71]

BRUCE RAMGE: That's right. [LB71]

SENATOR CRAWFORD: It's already there. [LB71]

BRUCE RAMGE: Yes, yes. [LB71]

SENATOR CRAWFORD: So also, assuming that someone was only accomplishing the two for five, am I correct... [LB71]

BRUCE RAMGE: Yes. [LB71]

SENATOR CRAWFORD: ...am I correct as I read the fiscal note, that these costs disappear in that case because we are just going with the essential benefits plan. We are not requiring anything more than that, so we are not picking up this $200,000 to $400,000 cost anymore? [LB71]

BRUCE RAMGE: That's my understanding as well. [LB71]

SENATOR CRAWFORD: Right. So it becomes $0... [LB71]

BRUCE RAMGE: Yes. [LB71]

SENATOR CRAWFORD: ...if we are going... [LB71]

BRUCE RAMGE: Yes. [LB71]

SENATOR CAMPBELL: ...two for five. All right. Thank you. [LB71]

BRUCE RAMGE: You're welcome. [LB71]

SENATOR GLOOR: Senator Christensen. [LB71]

SENATOR CHRISTENSEN: Senator Carlson. [LB71]

SENATOR GLOOR: Oh, Carlson. Sorry. [LB71]

SENATOR CARLSON: Yeah, thank you, Senator Gloor. I'm going to go for two different questions that were asked here, so I get this clarified. Senator Crawford talked about plans that could be sold in the state that are not part of the Affordable Health Care and that will still be possible to have those kinds of policies sold by companies? [LB71]

BRUCE RAMGE: It's possible, but the individuals who buy them would have to understand that they would be subject to a tax penalty for not buying a qualified health plan. [LB71]

SENATOR CARLSON: Oh, okay. [LB71]

BRUCE RAMGE: Okay. So that's why they can exist, but they'll be rare. [LB71]

SENATOR CARLSON: So let's go back to the essential benefit plan that has various things in there that need to be a part of the plan, need to be covered. [LB71]

BRUCE RAMGE: Okay. [LB71]

SENATOR CARLSON: That's true, right? [LB71]

BRUCE RAMGE: Yes. [LB71]

SENATOR CARLSON: But that's going to apply to the state plan or the exchange plan? It's going to apply to plans that are somehow related to the specifications of the federal government. [LB71]

BRUCE RAMGE: Yes, it will apply to policies issued to individuals and small groups. [LB71]

SENATOR CARLSON: But if they don't offer all the benefits of the essential benefit package, then they're subject to a fine? [LB71]

BRUCE RAMGE: Correct. A tax penalty, yes. [LB71]

SENATOR CARLSON: Okay. [LB71]

BRUCE RAMGE: And one other area that would not be covered, and going back to Senator Crawford's question, there could still be fully insured, large group plans that would not have to follow the essential health benefits. [LB71]

SENATOR CARLSON: That was the next question. [LB71]

BRUCE RAMGE: Yes. [LB71]

SENATOR CARLSON: And you're agreeing with what Mr. Ullstrom said, that the self-funded plans are just not...they're not going to be held under this. [LB71]

BRUCE RAMGE: That's correct. [LB71]

SENATOR CARLSON: Okay, good. Thank you. [LB71]

SENATOR GLOOR: Senator Campbell. [LB71]

SENATOR CAMPBELL: One more clarifying point. [LB71]

BRUCE RAMGE: Okay. [LB71]

SENATOR CAMPBELL: Thank you, Senator Gloor. Of those that would be outside...that...we're going back to Senator Crawford's... [LB71]

BRUCE RAMGE: Okay. [LB71]

SENATOR CAMPBELL: Not only would they suffer a penalty, but would the people in...who utilize them could not draw down the federal subsidies either? [LB71]

BRUCE RAMGE: Correct. [LB71]

SENATOR CAMPBELL: Okay. That's an important point for those people who might qualify up to that 400 percent of poverty. [LB71]

BRUCE RAMGE: Yes. [LB71]

SENATOR CAMPBELL: They would not be able to exercise that... [LB71]

BRUCE RAMGE: Yes. [LB71]

SENATOR CAMPBELL: ...subsidy. [LB71]

BRUCE RAMGE: Yes. The subsidy applies to...only to plans purchased inside the exchange. The tax penalty for not buying insurance would apply to policies that are not qualified health plans. So you can buy a qualified health plan outside of the exchange, yes. [LB71]

SENATOR GLOOR: Seeing no further questions, thank you, Mr. Director. [LB71]

BRUCE RAMGE: Thank you. [LB71]

SENATOR GLOOR: Anyone else in a neutral capacity. Did Senator Karpisek... [LB71]

SENATOR CHRISTENSEN: He waived. [LB71]

SENATOR GLOOR: (Exhibit 10) ...waived closing. That will end the hearing on LB71. If you are leaving, I'd ask that you leave very quietly, if you would, so that we can move on with our next hearing which is LB397. Welcome, Senator Conrad. [LB71]

SENATOR CONRAD: Hi, good afternoon. [LB397]

SENATOR GLOOR: Good afternoon. Senator Conrad, if you'd give me just a second. For the benefit of those of you who are here for LB397 and LB218, there may be a little confusion based upon calls that we've got from our office. If you're here to testify on LB218, but think you can testify for (LB)397 and cover both these bills since they're very similar, that is not the case. You're welcome to provide one testimony for one bill or the other that's your favorite, but if you wish to show up on the record in favor or in opposition for one or the other, you really need to testify for both. Also for those of you who have just arrived, we have a light system. And although this doesn't apply to the introducing senator, that light system will give you four minutes of green, one minute of yellow, and then at red, we ask that you wrap it up. You've got five minutes for your testimony. Thank you for your patience on that and consideration of it. And, Senator Conrad, welcome to Banking, Commerce and Insurance. [LB397]

SENATOR CONRAD: Thank you. Thank you, Senator Gloor and members of the committee. My name is Danielle Conrad, that's D-a-n-i-e-l-l-e, Conrad, C-o-n-r-a-d, representing the "Fighting 46" Legislative District of north Lincoln. I'm here today to introduce LB397. LB397 requires insurance companies to provide screening coverage for amino-based elemental formula regardless of the delivery method. This mandate requires a doctor order that this formula is medically necessary and would not pertain to self-insured organizations as per federal law. Let me tell you why I introduced this bill. I introduced this bill because a citizen wrote a letter to me and provided a very well-written packet of information about their family and their child who could only use this type of formula. That citizen is here today and will have an opportunity to describe to you what it is like to have a baby that needs to have this type of formula to survive, yet her frustrations in dealing with her insurance company who would not cover the cost. This family was in a very difficult position as they did not qualify for Medicaid and the formula is very, very expensive. Interestingly enough, the insurance company would pay for an invasive feeding tube, but not for the formula. Again, there are many people here today that you'll have a chance to hear from who will share their experiences from their family about why this bill is so important. And let me just add, as a new parent in reading through this packet of information, there is no question that this issue really hit home. I thought very deeply and carefully about how much time and attention myself, my husband, and our family have devoted to the care and feeding of our new baby, Caroline, which many of you have had a chance to meet. And to think about other families who were spending a similar amount of time, care, and consideration who are running into serious medical problems and really having their hands tied from an insurance coverage perspective, from a cost perspective, I had no choice but to act. And so it's an honor to bring this bill forward. It's been an honor to work with the citizens who are engaged on this topic. I think they've been very active and, hopefully, have contacted many of you already. But I think that you'll be equally persuaded by their powerful testimony. And that being said, it is absolutely no indication of my stress in how important this legislation is, but I do have a 3:30 conflict, a scheduling conflict that I was unable to move. So I may have to reserve my right to close, but I'd be happy to follow up with any of you individually after the hearing if there any additional questions. But, please, don't take that as any indication that this isn't important legislation to me because it is. And it's heartbreaking to me that I might not be able to be here for every minute of the testimony you're about to hear. Thank you. [LB397]

SENATOR GLOOR: Thank you, Senator Conrad. Are there questions for Senator Conrad at this time? Yes, Senator Howard. [LB397]

SENATOR HOWARD: Thank you, Senator Conrad. [LB397]

SENATOR CONRAD: Yes. [LB397]

SENATOR HOWARD: Can you clarify? This bill is just about the screening for the needed formula? [LB397]

SENATOR CONRAD: I think that our hope is that if there's buy-in from the committee in terms of moving forward on this issue, we want to work with you to ensure that it's technically appropriate to cover the tests and the treatment for this particular situation. [LB397]

SENATOR HOWARD: Thank you. [LB397]

SENATOR GLOOR: Other questions? Seeing none, thank you. [LB397]

SENATOR CONRAD: Thank you. [LB397]

SENATOR GLOOR: Could I see a show of hands of those people who are here to testify in support of this bill? And then could I see a show of hands of those who are here in opposition or in a neutral capacity? Okay, thank you. We will start with those in support. Good afternoon. [LB397]

KRISTIN ADKINS: (Exhibit 1) Good afternoon to Senator Gloor and members of the Banking Committee. My name is Kristin Adkins, that's K-r-i-s-t-i-n A-d-k-i-n-s. And thank you for allowing me to testify...to submit written testimony on LB397 regarding elemental formulas. Imagine the happiest day of your life. You welcome a beautiful, healthy baby into your family. All seems well until a few weeks later. Your baby cries for 18 hours a day, has difficulty feeding, diarrhea, severe diaper rash, and bloody stools. After many changes in diet and formula, your baby is diagnosed with MSPI, which is milk/soy protein intolerance. The only way to make the baby well again is to use an elemental formula such as Neocate, Nutramigen AA, or EleCare. These formulas are only sold behind the pharmacy and are not covered by insurance. They run around $50 per can and last just a couple of days. This is the story of my son, Jacob. There are other stories in Nebraska like mine. Although not that common, it is financially devastating. Jacob was allergic to the protein in milk which was the only thing that he can have for the first year of life. My first reaction was relief; finally we had a diagnosis and my baby would be okay. The pain and the misery would end and we were finally on a road to recovery. The financial effects are astounding. There is no generic for this type of elemental formula and it's only available behind the pharmacy, yet insurance does not cover it. Families on Medicaid get this for free. People who are upper class can afford the formula so they don't feel the financial effects. Families like mine who are the middle class and do not qualify for Medicaid are devastated and frustrated. Elemental formulas like Neocate, EleCare, and Nutramigen AA are for the sickest of sick. They are hypoallergenic and so pure there is no generic. He cannot have Alimentum or regular Nutramigen. These formulas still have proteins in them. The only thing that he can have is the elemental formula which has all proteins removed and is only sold behind the pharmacy. Imagine our further shock that our health insurance company at the time, would not cover the cost of the formula unless it was delivered by a feeding tube, not orally with a bottle. Health insurance companies in Nebraska would rather pay for a feeding tube than a can of formula. This defies logic and is actually more expensive. Nothing is more depressing than taking the majority of your paycheck and driving to the pharmacy in tears to buy more. After a few months, due to a recent change of employment and a stroke of luck, we now have different healthcare coverage. We now have Blue Cross Blue Shield of Illinois because my husband's company is based in Illinois. We have gotten lucky because Illinois is one of the states that covers the cost of elemental formulas. There are 14 other states in the U.S. that have recently passed legislation requiring insurance companies to cover the cost of elemental formula delivered orally or by feeding tube. Just because ours is now covered does not change the fact of what is right and wrong for other middle-class families struggling to feed their children in Nebraska. Ladies and gentlemen, I encourage you to support LB397 regarding elemental formulas. We have a responsibility to help families in Nebraska. While I appreciate Senator Avery's efforts regarding LB218, we are striving for full coverage, not just partial coverage, for our families. Our children deserve better. I have included information on how the other 14 states have enacted their legislation for further reading. I would be happy to answer any questions. Thank you. [LB397]

SENATOR GLOOR: Thank you, Ms. Adkins. How old is Jacob now? [LB397]

KRISTIN ADKINS: He will turn one next week and he has outgrown this. [LB397]

SENATOR GLOOR: I was just going to ask. And that's not uncommon, as I understand, is that... [LB397]

KRISTIN ADKINS: Our pediatrician said 80 to 90 percent of them outgrow it by age 1, and he had outgrown it by 9 months. [LB397]

SENATOR GLOOR: Good. Good for you, good for Jacob. [LB397]

KRISTIN ADKINS: Uh-huh. [LB397]

SENATOR GLOOR: Other questions? Senator Schumacher. [LB397]

SENATOR SCHUMACHER: Thank you, Senator Gloor. And thank you for your testimony. This is a little bit of a follow-up on a question that Senator Howard asked. Is there a lot of screening required during this proceeding or are they diagnosed once and they use the formula and that's it? [LB397]

KRISTIN ADKINS: Diagnosed once. That's what we did. [LB397]

SENATOR SCHUMACHER: Okay. Because the bill seems to require screening after the doctor has ordered the formula already and it's almost a catch-22 there. So maybe that needs to be clarified in the bill. But that's none of your concern. Thank you. [LB397]

SENATOR GLOOR: Senator Crawford. [LB397]

SENATOR CRAWFORD: Thank you, Senator Gloor. Could you tell us, you're talking about you're seeing this bill as more comprehensive. Can you tell me a little bit about what the means to you? [LB397]

KRISTIN ADKINS: To me--I appreciate, like I said, Senator Avery's--but the wording in his bill was more limited and only covered kids up to age five and only with a couple of different disorders. They use the elemental formulas for MSPI, which is what my son had, but they also use it for other disorders as well that are more serious. [LB397]

SENATOR CRAWFORD: So it's the list of disorders... [LB397]

KRISTIN ADKINS: Uh-huh. [LB397]

SENATOR CRAWFORD: ...of her bill is more...okay. [LB397]

KRISTIN ADKINS: Yes, uh-huh. [LB397]

SENATOR CRAWFORD: Thank you. [LB397]

SENATOR GLOOR: Other questions? Senator Carlson. [LB397]

SENATOR CARLSON: Thank you, Senator Gloor. In your testimony, you indicate in the second paragraph there that the formula is sold behind the pharmacy, not covered by insurance, and they run $50 per can. [LB397]

KRISTIN ADKINS: Uh-huh. [LB397]

SENATOR CARLSON: But the can lasts a couple of days, is that correct? So you've got to have 3.5 cans a week? [LB397]

KRISTIN ADKINS: At least. This...the two or three days, this...when I wrote this months ago, he was not even six months old then. That's when he was only taking three to four ounces in his bottle; he wasn't even taking a full bottle. If he wouldn't have outgrown it and would be taking the full ten-ounce bottle, we probably would have used a can a day. [LB397]

SENATOR CARLSON: Okay, so that's the way it can get... [LB397]

KRISTIN ADKINS: Uh-huh. [LB397]

SENATOR CARLSON: ...as they grow and want more. [LB397]

KRISTIN ADKINS: Uh-huh. [LB397]

SENATOR CARLSON: Okay, thank you. [LB397]

SENATOR GLOOR: Seeing no further questions, thank you, Ms. Adkins. [LB397]

KRISTIN ADKINS: Thank you. [LB397]

SENATOR GLOOR: The next proponent, please. [LB397]

SARAH AURIT: (Exhibit 2) Thank you, Senator Gloor, and distinguished committee members. My name is Sarah Aurit, S-a-r-a-h A-u-r-i-t, and I'm here today to testify on behalf of my three children. They have all been diagnosed with a rare disease called eosinophilic esophagitis or EoE, an eosinophilic gastrointestinal disorder, EGID. J.P., Gianna, and Elizabeth rely on amino acid-based elemental formula as their primary source of nutrition. Our oldest, J.P., was sick from birth. He initially had severe insomnia, pain, and diarrhea, but by age one, he began to projectile vomit on a regular basis. After years of watching him suffer, specialists became involved and he was diagnosed with EoE after an endoscopy. J.P. was given steroids and we watched him suffer for two more years due to the ineffectiveness of the medication. He did not have energy to learn to ride his bike like other kids his age. And I have memories of him lying down in our hallway because of how tired and sick he was, and also seeing that he tended to pick up every illness that was floating around. We decided to bring him to Cincinnati Children's Hospital and Medical Center. And it was there that we were told that elemental formula as his sole source of nutrition was the best option. He absolutely flourished with this treatment. At the same time our two girls and I were diagnosed with EoE. The girls thrived as well on formula and continue to do so as we pinpoint exactly which foods are causing activation of the disease. There is currently no cure for EoE and it will be a lifelong battle. Reported incidence rates for EGID range from 1 to 5 in 10,000. So with the Nebraska population, approximately 600 people on average are dealing with these diseases. There is also a spectrum of severity for these diseases, so not everyone with an EGID needs formula. Steroids and elimination diets are common treatments here in Nebraska, which we experienced firsthand. And approximately 75 percent of people on a top-six elimination diet taking out milk, egg, nuts, fish, soy, and wheat, will have disease remission according to multiple studies; and another portion will use steroids; and yet another will enter remission with skin testing, allergy testing, and removal of those identified allergic foods. So I think it's appropriate to identify there are about 100 to 150 people in the state that are dealing with these diseases and need formula. The American Partnership for Eosinophilic Disorders released a 2012 study that related approximately two-thirds who need formula require feeding tubes due to the taste. And this means that the aged and disabled waiver portion of Medicaid will pick up the tab for some. And for those who remain, a portion already have commercial formula coverage. So it is apparent that a small number of our overall population and the impact that they will have will be minimal. So it's appropriate to pose a question as well. What happens when these patients who require formula do not receive it? Some will require hospitalization, emergency room visits, additional prescriptions, tests, etcetera. And these costs need to be considered and put into the equation. We also need to think about the missed days from work and school and the impact they have on the state as well. So I welcome any questions. [LB397]

SENATOR GLOOR: Thank you, Ms. Aurit. Do any of your children need feeding tubes? [LB397]

SARAH AURIT: Two of them have feeding tubes. [LB397]

SENATOR GLOOR: Two have feeding tubes. Other questions? Seeing none, thank you for your testimony. [LB397]

SARAH AURIT: Thank you. [LB397]

SCOTT AURIT: (Exhibits 3 and 4) Thank you, Senator Gloor and distinguished committee members. My name is Scott Aurit, A-u-r-i-t. That was my wife, Sarah, that just presented before you. We provided a packet of information that includes letters of support from APFED, the American Partnership for Eosinophilic Disorders. There also is a letter of support from the International Association for Food Protein Enterocolitis, a letter from our doctors in Cincinnati Children's Hospital of support, a letter from our pediatrician at Village Pointe Pediatrics, a letter of support from the Omaha Children's Hospital G.I. group. And then also another parent that was not able to testify today because of work, a letter of support from her as well. In the packet also is letters from the state of Minnesota, health plan coverage letters that show that they are providing coverage in those states, as well as other information from APFED based on some of the statistics that my wife just previously shared for your assistance. This right here is the feeding tube equipment that my children use. My oldest and my youngest have a feeding tube. My middle, eight-year-old daughter, does not. It includes an IV bag, a feeding pump, IV pole. These items are covered by most insurances. Yet the medical food that goes into this bag that needs to get pumped into their body is often not covered, and that's why we wanted to come today to talk about. It's hard enough to tell your children that they are no longer able to eat anything except sugar and ice, but also we need to consider the enormous financial impact of the situation. It really made it unbearable for our family. At the initial diagnosis and commencement of amino acid-based medical foods, insurance for us was not available. We researched options to switch employers and thus insurance companies, but found no opportunities without requiring a feeding tube for delivery. One ingenious insurance company recommended that my wife and I divorce to allow her and the children to qualify for government assistance. We bribed our son for three years with LEGOs to drink the juice boxes or this is the formula in the can here, that you mix with water. We bribed him for three years with LEGOs to try and prevent him from having to have the surgery, and the days in the hospital, the permanent scar, and the side effects of a lifetime with reflux, as your stomach is permanently affixed to the side of your body. Our family is the exception to the exception; we have three kids with this disease. Our bill has peaked at about $3,000 a month, but as our kids grow, more formula may be required to keep up with their growing bodies, depending on how successful we are with the food trials that we are currently undergoing. We were able to negotiate insurance coverage with my employer's group policy that is time limited and running out shortly. Two of my children have had feeding tubes placed due to the inability of consuming enough of this foul-tasting formula. They are now covered by Medicaid, but we feel the constant push out of the program as J.P. has already been dropped once from Medicaid. We are fearful that both insurance and Medicaid will drop out for our family at the same time. There are no guarantees. Elemental formula is accessed through a written prescription and is not a supplement. Our formula is shipped in from a local pharmacy monthly. Pharmacies don't carry it usually because due to the short shelf life and high cost. It is a medical food produced in a laboratory setting. Our shipment was delayed once and we were not able to locate it in Nebraska and had to look out of state for the nearest available supply, which was in Belton, Missouri, a short seven-hour, round-trip drive to a pharmacy there. Eosinophilic diseases are rare and impact a very small number of families. Elemental formula is a preventative treatment for eosinophilic disease that will lower the amount of visits to physicians, hospitals, lab tests, and prescriptions. The financial impact of this bill will be negligible. The positive impact to families are enormous. Ninety-eight percent of those diagnosed with eosinophilic disease will reach remission with this FDA-approved medical food. This is the best treatment option. There are those in our community faced with the impossible medical decisions regarding care. Some choose divorce or bankruptcy to have the state pick up the tab since elemental formula is covered by Medicaid. We can't bear the thought of picking which of our children receives the medical food while watching other children go without. Now is the time for private insurance companies to cover this lifesaving treatment. We request that Nebraska join 14 other states, most recently Texas, in providing coverage for these amino acid-based medical foods. There are currently eight other states that are also moving forward with legislation. We strongly support LB397 and urge you to do so as well. And at this time, I'll be happy to answer any questions. [LB397]

SENATOR GLOOR: Thank you. Are there questions? Senator Campbell. [LB397]

SENATOR CAMPBELL: Thank you, Senator Gloor. In the packet of information that you gave us is a letter that was sent by a number of organizations to Secretary Sebelius with a request to include this in the Affordable Care Act. Do you have any information as to what the Secretary's response was? [LB397]

SCOTT AURIT: No, we do not. It's currently something that we're continuing to push for, both at the federal level as well as at the state level. The same entities that are pushing for it at the federal level are also working with different families at the state level. [LB397]

SENATOR CAMPBELL: Thank you. [LB397]

SENATOR GLOOR: Other questions? Senator Carlson. [LB397]

SENATOR CARLSON: Thank you, Senator Gloor. Thank you for your testimony. But you referred to the bad-tasting stuff. Is it still bad tasting? [LB397]

SCOTT AURIT: It is. [LB397]

SENATOR CARLSON: Okay. So that's not an improvement that's been made? [LB397]

SCOTT AURIT: They have a variety of different flavors, but even some of the best ones taste like a rich--sometimes--wedding cake. And, you know, that's great. I like having wedding cake when I go to weddings every so often, but I can't imagine eating wedding cake seven, eight times a day. You lose the taste. And then the hardest part is then when you get sick and you throw up. A lot of us when we have a food that we get sick on, we really don't want to go back and visit that food again for a long period of time because we'll have a taste aversion. Unfortunately, most kids with this disease have a lot of times that they do throw up. And so it is a strong push from the parents to the kids in a battle that we have to fight with them to continue to try and push this food. So even some of the ones that are flavored and taste better, it isn't a...it's a very difficult thing to understand unless that's what you're faced with all the time. [LB397]

SENATOR CARLSON: Well, this...and this is a very expensive liquid. So do you agree with the price of the $50 a can? [LB397]

SCOTT AURIT: We do. We get it in a can, we also get it in a liquid format. Like I said, our costs...we both have liquid and this formula...the powdered formula that we give our kids. And so we go through...our son is about $1,100 a month, our daughter is about $1,300 a month, and our other daughter who is doing very well without the feeding tube is somewhere around $600 a month and hopefully continuing to go down. But, yes, this is the can that we talk about that is that $50-plus a can whether...this is by Neocate, but EleCare and the other ones are very comparable in price. [LB397]

SENATOR CARLSON: Okay. Well, it seems incredible that somebody that produces something like this that is this expensive and so many people have to have it, they can't make it taste good. [LB397]

SCOTT AURIT: I agree. I would like to say that. I like our insurance company, I really do. They save us thousands of dollars a year when you look at the cost of what it would cost from the hospital and the agreements that they have reached. If I look at our total of our bills, we save about 30 percent because our insurance company is able to negotiate on our behalf for providing that coverage and also the guarantee of the payment which helps many places in the cost. Our insurance company does pay for us to go to Cincinnati Children's four times a year, and so we greatly appreciate the service they provide for us. I think by having insurance companies join us as a partner in going to try and find options to reduce the cost of this by providing for that coverage, I think that we can have a network that will help reduce the cost of this formula as well to the benefit of everybody. [LB397]

SENATOR CARLSON: Okay, thank you. [LB397]

SCOTT AURIT: Thank you. [LB397]

SENATOR GLOOR: Other questions? Senator Pirsch. [LB397]

SENATOR PIRSCH: Just a comment. I've had both Neocate and EleCare. I think you're being very generous to say that it tastes like wedding cake. That's horrible, nasty-tasting stuff. So, thank you. [LB397]

SENATOR GLOOR: Other comments? Seeing none, thank you very much. [LB397]

SCOTT AURIT: Thank you for your time. [LB397]

SENATOR GLOOR: (Exhibit 5) We also have a letter of support from the Nebraska Academy of Nutrition and Dietetics. And so Nathan, if you'd hand these out. Good afternoon. [LB397]

KARI WADE: (Exhibit 6) Good afternoon, Senator Gloor and committee members. My name is Dr. Kari Wade, K-a-r-i W-a-d-e, and I am a registered nurse. I am testifying not only for myself, but the Nebraska Nurses Association. The Nebraska Nurses Association is the voice for approximately 31,000 nurses across Nebraska. We are asking for your support of LB397. Every month infants are born in Nebraska who are unable to process essentially, naturally-occurring nutrients such as proteins in milk and soy. As a result, when milk or soy is consumed, the infants' bodies respond similar to that of an allergic reaction and their immune system mistakenly sees the milk and soy protein as something the body should fight off. When this occurs, the infant becomes excessively fussy, crying up to 18 hours a day due to their extreme discomfort. As the infant's body treats the milk and soy proteins as allergens, gastrointestinal symptoms such as bloody stools, mucousy stools, dehydration, and weight loss occur. In addition, respiratory and skin reactions may also manifest. There is no medication to treat milk and soy protein intolerance. The only treatment is through diet modification, which includes the use of the expensive amino acid-based prescription formulas. This is the only formula these infants can tolerate. During my years as a registered nurse in Nebraska, I have encountered families who have lost their home, had to take out a second mortgage, or even had to seek out desperate and unsafe methods of obtaining the amino acid-based formula in order to provide the medically necessary nutrition to their child. LB397 would ensure children requiring amino acid-based formulas are receiving adequate nutrition to lead a healthy life. Therefore, I urge you to support LB397. Thank you, I'm open for questions. [LB397]

SENATOR GLOOR: Thank you, Dr. Wade. Dr. Wade, what would be a desperate and unsafe method of obtaining? [LB397]

KARI WADE: Some parents have identified that they have obtained it through eBay, also through foreign countries, any means in which they can get it without a prescription in order to supply it to their infant. [LB397]

SENATOR GLOOR: Thank you. Other questions? Senator Schumacher. [LB397]

SENATOR SCHUMACHER: Thank you, Senator Gloor. And thank you, Dr. Wade. Now this is completely different from what they call colic or something like that, is that correct? [LB397]

KARI WADE: This...colic is a symptom as a reaction to the extreme discomfort. Colic is diagnosed as excessive crying more than 3 hours a day more than 3 days a week. And, therefore, as a response to their body and their intestinal lining being affected by this as their body reacts to this intolerance, that produces the colicky behavior of the infant crying. [LB397]

SENATOR SCHUMACHER: Now is this genetic? [LB397]

KARI WADE: It can be genetic, yes. Typically, if a family has one infant who has it, the milk or soy protein intolerance, additional...it is more likely that additional children will also have it from those same parents. [LB397]

SENATOR SCHUMACHER: And they will pass it on to their children, or not? [LB397]

KARI WADE: I don't know the answer to that. [LB397]

SENATOR SCHUMACHER: Thank you. [LB397]

SENATOR GLOOR: Senator Crawford. [LB397]

SENATOR CRAWFORD: Thank you, Senator Gloor. And thank you for your testimony. Other examples of prescribed foods like this that you can think of, is this one of a class of several types of foods or allergies that might fit this situation? [LB397]

KARI WADE: Well, mostly I was speaking to infants. [LB397]

SENATOR CRAWFORD: Uh-huh. [LB397]

KARI WADE: Typically, this is diagnosed six to nine weeks of age as formula is being introduced to the infant. Some infants are able to tolerate what's called extensively hydrolyzed formulas where the protein chains are actually smaller in size than the protein chains that are produced with over-the-counter, typical, infant formulas. However, some infants are not able to tolerate that, and they go to the next level, which is the amino acid-based formulas. These are the prescription-only formulas. These formulas are not chains of proteins. They are single proteins so the infants are able to digest them better. [LB397]

SENATOR GLOOR: Senator Schumacher. [LB397]

SENATOR SCHUMACHER: It's just a follow-up on an earlier question. The folks that buy this over the Internet or from foreign countries, is it good stuff? [LB397]

KARI WADE: I can't speak to that. We do not recommend it unless it is from a reputable source through a pharmacy. [LB397]

SENATOR SCHUMACHER: How cheap is it when they buy it through the other source? [LB397]

KARI WADE: Typically...well, and the scary thing is sometimes those are open containers because an infant may have tried one particular kind and it was not tolerated. And so some families, because of the cost of that can, will try and sell it as a hardly used can of infant formula. I'm sure the range would vary according to whatever the family decided to...that is selling it on eBay would decide to put a price on it. [LB397]

SENATOR SCHUMACHER: Do the manufacturers of the prescription stuff bought in this country...what do they do to make this stuff? I mean, what does it start out with? What food do they start with before they grind it up or do whatever they do to make it into this stuff? [LB397]

KARI WADE: They take...they make it synthetically produced through synthetically-produced amino acids. As far as the exact makeup of the formula, I'm not able to speak to that. [LB397]

SENATOR SCHUMACHER: Okay, thank you. [LB397]

SENATOR GLOOR: Senator Pirsch. [LB397]

SENATOR PIRSCH: Is it the...so this is a lab-produced, synthetic amino acid. So are they perfectly interchangeable with, say, cows' milk--children are able to tolerate--or is there somewhat lesser of a quality in terms of what the baby or child's need in terms...

[LB397]

KARI WADE: Are you asking me about the quality in comparison to cows' milk? [LB397]

SENATOR PIRSCH: Yeah. Well, yeah. I'm saying in terms of what the baby or child needs, is the fact that these...they are synthesized amino acids, are they of...you know, the best we can do, but somewhat you're going to not achieve the same type of effect as if they were not allergic to cow milk or are they perfectly...with this, the same results will come? [LB397]

KARI WADE: I'm sure it's not perfectly, but the caloric intake requirements for...that is produced through cows' milk, the infants that are on this are calculated specifically how many calories that particular infant needs. And so that's how it's determined how much of the formula they will need in order to have the equivalent to what they would consume by cows' milk if they were able to tolerate it. [LB397]

SENATOR GLOOR: Can I ask your involvement in this? Are you a nurse educator or clinician that specializes in this? [LB397]

KARI WADE: I am currently a nurse educator, but my past nursing practice has been within pediatrics. [LB397]

SENATOR GLOOR: Okay. Thank you. Senator Schumacher and then Senator Campbell. [LB397]

SENATOR SCHUMACHER: Thank you, Senator Gloor. Babies that are breast-fed, are they affected by...I mean, is that a cure too? [LB397]

KARI WADE: It's not a cure. The infants that are breast-fed, the mother...if the mother continues or chooses to continue, she must follow what's called a total elimination diet where she completely eliminates all milk and soy from her diet. It's very difficult to follow. If a mother is producing enough milk to be able to have that option, many times they are unable to follow it just because it is such a stringent diet to follow and they switch to the formula. [LB397]

SENATOR SCHUMACHER: Thank you. [LB397]

SENATOR GLOOR: Senator Campbell. [LB397]

SENATOR CAMPBELL: That was my question. Thank you. [LB397]

SENATOR GLOOR: Okay. Seeing no further questions, thank you, Dr. Wade. [LB397]

KARI WADE: Thank you for your time. [LB397]

SENATOR GLOOR: Next proponent, please. [LB397]

SAMANTHA GOERTZEN: (Exhibit 7) Hi. My name is Samantha Goertzen, S-a-m-a-n-t-h-a G-o-e-r-t-z-e-n. And I am here on behalf of my daughter, Shae, who is ten years old. I knew when she was three weeks old that there was something not quite right with her. Through the process of trial and error, her pediatricians discovered that she had a severe allergy to milk. Despite the removal of milk from her diet, she remained lethargic, fussy, difficult, and never had normal bowel habits. I constantly had her at the pediatrician, the G.I., and the allergist's offices. It wasn't until the age of six and because of the diagnosis of another illness that we discovered she had eosinophilic esophagitis. It's the same disease as the Aurits' children. And I can tell you that it was the biggest blessing in her life to have that diagnosis. We spent the next few years trying unsuccessfully to control the illness with various prescriptions and diet modifications. Finally in February of 2009, we had to have a G-tube placed in her stomach and she went strictly to the amino-acid diet. I cannot tell you the quality-of-life impact that this change had on my little girl's life. The child who had been spending hours sitting in front of the TV and had been unable to ride her bike or scooter due to pain, was finally outside with her older brother and the neighborhood kids. We no longer had to carry her from the living room to her bedroom because her legs hurt so bad that she couldn't walk herself. We also discovered that she has a wicked sense of humor and a smile that lights up the room. In the two years since having the tube placed, she has only been able to reintroduce three foods, potatoes, apples, and brown rice, and those are in their simplest forms. We don't get to drive through McDonald's or any of the restaurants and get an order of French fries. We know through allergy testing and failed food trials that she is also allergic to every meat imaginable, beans, tree nuts, legumes, and many other foods. So for her, it's highly unlikely that she will probably ever be able to come off formula just because there's nothing...there's no protein that she can eat. And I just...in an effort of full disclosure here, I need to say right off the...from the beginning that my husband's company is actually headquartered in New Jersey and we have Blue Cross and Blue Shield of New Jersey. And they're one of the few states that actually pay for the coverage of the formula. So our formula has been covered for the last two years. I do know that our insurance company gets billed $2,500 a month. My daughter takes one full can a day of the formula, and she has the same equipment that Scott showed you. She uses it during the day and then she is hooked up to it throughout the night while she is sleeping. Two years ago I was diagnosed with breast cancer in both of my breasts. After multiple surgeries and complications, I lost them. Every year for as long as I can remember, I have gotten a letter from my human resources company stating that reconstructive surgery is covered by my insurance company by law. I think it is shameful that I have the ability to go out there and get a new set of boobs and have them paid for, but I don't have--and the other families here--don't have a guarantee that their children are going to have the food that they need to sustain their lives. I ask today that you support this bill so that those children out there who don't have the luxury of having a company outside of the state of Nebraska to pay for their formula, that they have that option as well. Thank you. [LB397]

SENATOR GLOOR: (Exhibit 8) Thank you, Ms. Goertzen. Questions? Seeing none, thank you for your testimony. Other proponents? We'll now hear from opponents. And we have a letter of opposition from The Association of Insurance and Financial Advisors that we'll hand out. Good afternoon. [LB397]

MICHAELA VALENTIN: (Exhibits 9 and 10) Good afternoon, Senator Gloor, members of the Banking, Commerce and Insurance Committee. My name is Michaela Valentin. I am the director of government affairs and registered lobbyist for Blue Cross Blue Shield of Nebraska. My name is spelled M-i-c-h-a-e-l-a, last name is V-a-l-e-n-t-i-n. And you're going to be receiving some documents. You will note that on the lengthier document, it is labeled LB218. That information that is provided there can also apply to LB397. And I'm also giving you the (LB)397 testimony that refers you back to (LB)218 because it's essentially the same testimony. But I will get up on that bill and testify in opposition as well. So that being said, I would encourage you to take a look at the lengthier, two-page document if you want to follow along for the testimony. Okay? Today I am appearing on behalf of Blue Cross Blue Shield, Coventry, and UnitedHealthcare in order to efficiently present opposition testimony on LB397 and again on (LB)218, which requires insurance coverage for certain food formulas. First, the carriers that I am representing today cover items and services related to formulas, but not the formulas themselves. To varying degrees, Blue Cross Blue Shield of Nebraska, UnitedHealthcare, and Coventry cover pumps, tubes, and other tools necessary to deliver formula, any medical services needed for blockages of the digestive tract, any prescription medications that may be necessary for digestive issues or gastric issues such as vitamins for vitamin deficiency or other prescription medications as needed, and screening for medical conditions that would require certain medical foods such as formula. Historically, the carriers have not covered any type of formula at any price point whether it's your first-line formula, nothing wrong with the "gastro" or digestive tract, all the way up to more expensive formulas such as Vivonex T.E.N. Second, there is complexity regarding the interplay between the Affordable Care Act essential health benefits regulations and the financial impact to the state for mandating this proposed coverage. Although the essential health benefits final regulations were issued last week, there was not further guidance on how to handle the interaction between state mandates and the cost of additional state-mandated coverage. Any health benefit mandate legislation passed after December 31, 2011, that is in excess of the chosen essential health benefit package for the state will have the cost of coverage spread across taxpayers for coverage in the exchange. State mandates continue to apply to coverage outside of exchanges and will be spread across the insureds outside of the exchange. This means that individuals and small businesses outside of the exchange will bear the brunt of the cost of additional coverage mandates while the state taxpayers will pay for additional coverage inside the exchange. States that mandate additional benefits inside exchange must make payments to cover additional costs for such benefits for those that are subsidy eligible, meaning no subsidy amount can go toward the cost of coverage for a state-mandated benefit. State payments for that additional coverage are to be made to individual enrollees or to the health plans in which such individuals are enrolled. For the multi-state plans that OPM is requiring to offer through the state's exchanges, states are allowed to mandate additional benefits but must cover the cost for all enrollees from the state. And that includes those who are not subsidy eligible. And the provisions that I'm referring to will take effect on January 1, 2014. Lastly, I think it's important to mention that any state-mandated coverage is not really a mandate on the insurance companies. It's a mandate on individuals and small businesses that are outside of the exchange and a mandate on taxpayers to cover additional benefits inside of the exchange. So I ask that you please carefully consider these ramifications as you deliberate on both LB218 and (LB)397. Thank you, and I'm happy to take any questions you may have. [LB397]

SENATOR GLOOR: Thank you, Ms. Valentin. Senator Campbell. [LB397]

SENATOR CAMPBELL: Thank you, Senator Gloor. Ms. Valentin, we've heard testimony from several people who were covered by Blue Cross Blue Shield in other states. Under those states' essential benefits, do you know whether the Blue Cross Blue Shield, one of those plans, was selected as their essential benefit? I'm just trying to figure out how different we're going to see in 50 states regarding the payment for this formula. [LB397]

MICHAELA VALENTIN: Right. In full disclosure, I didn't hear a couple of the proponents because I had to run to the restroom. But I did hear one of the ladies that had testified mentioned that her husband was employed through New Jersey and had a New Jersey plan. And the only familiarity I have with that--I don't know what their essential health benefit plan is--but I do know that New Jersey has guaranteed issue of insurance, but without an individual mandate. So there's no penalty for not getting on insurance. You know, if you were to get cancer, you could just jump on. Unfortunately, with that comes the consequence of New Jersey being one of the highest premium states in the nation. So, I mean, that's really all I know. But we...I'd be happy to look into see what other states are doing as far as their essential health benefit package and get that answer to you. [LB397]

SENATOR CAMPBELL: That would be great. [LB397]

MICHAELA VALENTIN: Okay. [LB397]

SENATOR CAMPBELL: The other state that was mentioned in testimony was Blue Cross Blue Shield of Illinois. [LB397]

MICHAELA VALENTIN: Okay. I can definitely get you the information about what...if the information is available, what their packages look like. [LB397]

SENATOR CAMPBELL: And one second question is, will Secretary Sebelius be coming out with additional information about how this is to be paid or is this kind of the final word of paying...you know, you're saying inside the exchange or outside? Is this kind of the final word? [LB397]

MICHAELA VALENTIN: Uh-huh. I hope it's not the final word because I still think we need some clarification. I would have to check with the legislative liaison at the Department of Insurance. I noticed they're not here anymore, but I'm sure they're watching this. And I'm sure I can converse with him to see if he has heard anything from his connections. So hopefully, that's not...one thing I would say about that is the essential health benefits package, I mean, this is something the folks that are in this room that are very concerned, which I understand, they could try to pursue under the habilitative category. I think I've discussed that with some of you that that's an open category where they may have, you know, some chance of getting this covered. And also the essential health benefit package is due to change again in 2016. So if it wasn't covered at this time under the essential benefit package as we know in the state of Nebraska, there may be an opportunity going forward where Kathleen Sebelius might say, okay, we need to cover this. And we're going to put it under habilitative or we're going to, you know, put it under some other area of the ten categories that need to be covered in the essential health benefit package for the entire nation. So I think that's still a possibility. [LB397]

SENATOR CAMPBELL: Thank you. [LB397]

SENATOR GLOOR: (Exhibits 11 and 12) Other questions? Seeing none, thank you. Anyone else in opposition? Anyone in a neutral capacity? We have a letter from the Department of Insurance that I'll ask the pages to hand out. It is, I think, very much similar to the one that was handed out on the last. And I believe Senator Conrad waives closing--that's per Julia. That will end the hearing on LB397. And we will take a ten-minute break before we begin the hearing on LB218 to allow the members up here a chance to stretch their legs. Ten minutes, please. [LB397]

SENATOR CHRISTENSEN: If everybody could take their seats, we'll get started again. Welcome, Senator Avery, and we'll be on LB218. [LB218]

SENATOR AVERY: Thank you, Mr. Vice Chair. I think this might be my first appearance before this committee so welcome me here. Let me just say at the outset that when we were developing LB218 to deal with eosinophilic disorders we did not know that Senator Conrad also was developing a similar bill. So I'm not going to go into the details of this bill except to point out a important difference. We have in this bill a cap on coverage at age five, and after listening to some of the testimony I realize that might be too young.

But we did this with the expectation that by that age, families would have worked out with their child's physician a safe and reliable nutrition plan that might make the coverage no longer necessary. We do recognize that these are serious illnesses and that currently the state of Nebraska does not mandate coverage. I would point out as well that 14 other states do have some kind of requirement for insurance coverage for this condition. Arizona insurance coverage is at 75 percent of the cost of formula and it is capped at $20,000 annually. It covers both oral administration and the feeding tube. Minnesota has a similar plan and, interestingly, the Blue Cross Blue Shield does participate in that plan in Minnesota. That's a reimbursement by the state. New Jersey has a reimbursement plan as well. The fact is that the state of Nebraska has not chosen to cover this, and I think that it's time that we did. It's a tremendous economic burden to the families whose children suffer from these diseases. I received a letter as I was walking into the room in which a representative of a major metropolitan area in this state said their principal objection was that this was not an area where the Legislature needed to do any legal work at all, that this should be left up to the providers. And I would simply point out to this committee, unnecessarily, I'm sure, that we already do that in a number of important areas. I think this is a good bill and I would have no trouble at all in trusting this to your hands to use it as you see fit in combination with the proposal of Senator Conrad. Thank you. [LB218]

SENATOR CHRISTENSEN: Thank you, Senator Avery. Are there questions? Senator Carlson. [LB218]

SENATOR CARLSON: Thank you, Senator Christensen. Senator Avery, I should have asked a question on the other bill, and I didn't. And so somebody from the insurance industry that's going to testify on this, hopefully they'll hear this. I wouldn't expect you to have the answer, but obviously, it would be important if we had some indication of how this was going to affect premiums. [LB218]

SENATOR AVERY: It would. And I cannot answer that, and I don't know if anybody could. But I think there is enough variability in those 14 states that already have some law in this area. I know that in those instances where the state reimburses, it probably has a minimal effect on premiums. In those cases where the state only reimburses a small part of it, I suspect that it would have an impact on premiums, but I can't say how much. [LB218]

SENATOR CARLSON: Okay. Thank you. [LB218]

SENATOR CHRISTENSEN: Are there any other questions? Thank you, Senator Avery. You going to stick around and close? [LB218]

SENATOR AVERY: I cannot. [LB218]

SENATOR CHRISTENSEN: Okay. [LB218]

SENATOR AVERY: I have the learning community to defend. [LB218]

SENATOR CHRISTENSEN: (Exhibits 1 and 2) All right. Okay. Those in support, if they'd move forward. I've got two letters to read in, one from Dr. Stacey Houston, Doctors of Children, and then Jayne McClenahan. So two letters of support, and I'll have them handed out. Are there any...anybody want to testify in support of this bill? Come on forward. [LB218]

KARI WADE: (Exhibit 3) Good afternoon again. Senator Gloor and committee members, my name for the record again is Dr. Kari Wade, spelled K-a-r-i W-a-d-e. And I am a registered nurse. I am testifying not only for myself, but on behalf of the Nebraska Nurses Association. The Nebraska Nurses Association is the voice for approximately 31,000 nurses in Nebraska and we are asking your support for LB218. Now part of my testimony is similar to that that I testified in LB397, but there are some important highlights that I would also like to speak to. Every month children are born in Nebraska, and they are unable to process essentially occurring nutrients such as milk proteins. Now we've also heard of some other additional diagnoses which do require these specialized formula. Parents have to seek the synthetically-made amino acid-based formulas to provide the proper, medically necessary nutrition to their child. Without such treatment, the child would become malnourished, would be hospitalized, and would require further treatments and further costs in order to get them to the point of being a healthy infant again. If they do not receive this kind of formula, they would have a decline in physical health and could potentially lead to even death from malnourishment. Amino acid-based formulas require a prescription from a licensed medical professional. Now I know we've identified that Medicaid does cover in Nebraska. However, no one has mentioned yet that in addition to Medicaid, the Nebraska Women, Infant, and Children program, otherwise known as WIC, also covers the prescription formula. Private insurance companies in Nebraska, however, do not provide coverage. So it's our middle and working class families who are becoming financially devastated as a result. During my years as a registered nurse--I've already identified with the previous bill, but it goes with this one as well, and I want to emphasize--families have lost their homes, they've had to take out a second mortgage, they may seek out means of unsafe or desperate measures to obtain this formula. And based on the other testimonies we've heard, they may be, God forbid, recommended to break up their family in order to qualify for such benefits to pay for this formula. Therefore, I urge you to support LB218. Thank you. [LB218]

SENATOR CHRISTENSEN: Thank you, Dr. Wade. Is there any questions? Senator Carlson. [LB218]

SENATOR CARLSON: Thank you, Senator Christensen. So you've testified on both

LB218 and LB397. If you were to put those in order of preference, which would be first? [LB218]

KARI WADE: (LB)397 is more broad as far as diagnoses go, but also (LB)218 I think is more specific in covering the actual infant formulas. [LB218]

SENATOR CARLSON: Okay. Thank you. [LB218]

SENATOR CHRISTENSEN: Are there other questions? Seeing none, thank you, Dr. Wade. [LB218]

KARI WADE: Thank you. [LB218]

SENATOR CHRISTENSEN: Next proponent? [LB218]

KRISTIN GEIST: Hi. My name is Kristin Geist, K-r-i-s-t-i-n G-e-i-s-t. I'm here to testify in support of LB218 requiring insurance coverage for certain formulas as prescribed. As a pediatric nurse, myself, and the mother of a child with milk/soy protein intolerance of MSPI, it's imperative for children to get the amino acid-based formulas to have adequate growth and development. My daughter, Ruby, has MSPI and she cannot digest milk or soy proteins and it causes her severe abdominal pain and painful stooling. Ruby can cry for hours on end just from the pain alone. The only treatment for Ruby and for children with MSPI is amino acid-based formulas that are expensive. They can range from $35 a can to $50 a can and last my four-month-old daughter four days. That's $262.50 to $375 a month for my family as compared to $112.50 for regular formula. My husband and I are both middle class professional college graduates, and the cost of this is still hard for us to pay. We have healthcare insurance and pay our monthly premiums but Ruby's formula is not covered. Medicaid and WIC patients get this formula covered. Because amino acid-based formulas are the only treatment for MSPI, it should be covered under insurance with a prescription from a healthcare provider to ensure proper growth and development for our children. Thank you. [LB218]

SENATOR CHRISTENSEN: Are there questions? Seeing none, thank you. [LB218]

KRISTIN GEIST: Thank you. [LB218]

SENATOR CHRISTENSEN: Next proponent? Anyone else want to testify as a proponent? How about opponents? [LB218]

MICHAELA VALENTIN: Good afternoon, members of the Banking, Commerce and Insurance Committee. My name is Michaela Valentin, spelled M-i-c-h-a-e-l-a V-a-l-e-n-t-i-n. I am the director of government affairs for Blue Cross Blue Shield of Nebraska and their registered lobbyist. Today I will also be appearing on behalf of

Coventry and UnitedHealthcare in order to officially present opposition testimony to LB218, which requires insurance coverage for certain food formulas. For the reasons that we gave in our prior testimony on LB397, Blue Cross Blue Shield of Nebraska, UnitedHealthcare, and Coventry renew our opposition on LB218, which is similar to LB397. And I would like to answer your question, Senator Carlson. We did a range study on the fiscal impact for a particular group, and all we can do is extrapolate numbers from that. So I believe that I think a fair range for what it might cost would be probably somewhere from .05 percent to .25 percent premium increase. And if you look at your fiscal note, you'll see that I think it was either the university or the state referenced the .25 percent, which I believe was an additional $240,000 that they thought would be allocated to cover. But a range with the information that we have is really about the best we can do, but I would say that's probably the upper end at the .25 percent. Any other questions? [LB218]

SENATOR CHRISTENSEN: Any other questions? Yes, Senator Schumacher. [LB218]

SENATOR SCHUMACHER: Thank you, Senator Christensen. We've heard testimony that in some other states the formula is covered. In those other states, do you know if they have that as part of their essential health benefit? [LB218]

MICHAELA VALENTIN: I don't. And I had actually reached out, based on Senator Campbell's question from our previous hearing on the other formula bill, I've already reached out to the Blue Cross Blue Shield Association in Washington, D.C. And I've asked our policy representative to get back to me with a summary of what the 50 states have for their essential health benefits packages, thus far, so that I can provide that to the committee. [LB218]

SENATOR SCHUMACHER: Had we included it in our essential health benefits, would then we have this issue of the state having to pick up the tab? [LB218]

MICHAELA VALENTIN: No. [LB218]

SENATOR SCHUMACHER: So by defaulting, we kind of got ourselves in this fix? [LB218]

MICHAELA VALENTIN: Well, it was never included. Since none of the carriers ever covered this, it would have never been included in an essential health benefit package. So no matter what package would have been submitted by Governor Heineman to Secretary Sebelius, this coverage would not have been in there. So we, I mean, there's...it's not in there right now. The only way to change that is to either do a mandate like you all are considering today or to wait for Secretary Sebelius to possibly include this coverage in either habilitative coverage in 2016 or issue some sort of regulation that we would not expect to cover something like this. [LB218]

SENATOR SCHUMACHER: But yet, some of the other states might be getting it covered by...how did they do it? [LB218]

MICHAELA VALENTIN: They might. And the reason they might is either because it was initially within that...if you think of essential health benefits package right now as a closed box, it's either in that coverage right now as the coverage stands in that state or it was added as a mandate prior to December 31, 2011. So it automatically becomes part of that closed box. And so they wouldn't have to do anything to add it, it would already be in there. That is not the case in Nebraska. [LB218]

SENATOR SCHUMACHER: Okay. Thank you. [LB218]

SENATOR CHRISTENSEN: Senator Crawford. [LB218]

SENATOR CRAWFORD: Thank you, Senator Christensen. You mentioned that in 2016 Secretary Sebelius could consider habilitative care to include this. Now is the same true for our interpretation of that term and our understanding of our essential benefits packages? [LB218]

MICHAELA VALENTIN: It might be. Since that's so far out in the future, I hate...I would hate to opine on that... [LB218]

SENATOR CRAWFORD: Right. [LB218]

MICHAELA VALENTIN: ...because I could be wrong. And the reason I say that is because originally if you talked to the Department of Insurance and it was known by folks that were, you know, paying attention to the issue as well, the federal government was supposed to define the essential health benefits package. And then they kicked it back to the state with what they said was our choice to do it. Only our choice was limited to four options. [LB218]

SENATOR CRAWFORD: Yeah. [LB218]

MICHAELA VALENTIN: So it wasn't like we had, you know, some great free range. We have four choices to pick from. [LB218]

SENATOR CRAWFORD: Right. If I could just follow-up. I just want to understand the connection... [LB218]

MICHAELA VALENTIN: Sure. [LB218]

SENATOR CRAWFORD: ...between this prescription formula and habilitative care.

[LB218]

MICHAELA VALENTIN: Well, the whole thing about habilitative care is, habilitative care has never been covered under insurance up until this point. Habilitative care means you would take someone and get them to a point of something that they've never done before, like in this case maybe it's a child would eat on their own or without formula. I'm not a medical doctor. I can't, you know, give you articulate facts on that, but I can say that's what I would guess it would be. And that, because it's never been defined before, it's sort of up to the state or the carriers to give valid input on what they think are different things that could qualify under habilitative. So you know, I don't know. This might be one of them that sort of lies more with, I would assume, the medical policy teams of insurers. So it's sort of outside my scope of knowledge, but I'd be happy to look into that for you and get you an answer on maybe what the carriers all think that is... [LB218]

SENATOR CRAWFORD: All right. Thank you. [LB218]

MICHAELA VALENTIN: ...if that's helpful at all for you. [LB218]

SENATOR CRAWFORD: No, that's helpful. [LB218]

MICHAELA VALENTIN: Okay. [LB218]

SENATOR CHRISTENSEN: Senator Carlson. [LB218]

SENATOR CARLSON: Thank you, Senator Christensen. Going back to...you gave a figure that was kind of calculated would be the total cost to the state or I mean, in the state by covered people for this? [LB218]

MICHAELA VALENTIN: Right. [LB218]

SENATOR CARLSON: What was that figure? [LB218]

MICHAELA VALENTIN: The figure that I gave you was what we think a range would be for how it might increase premiums would be .05 percent to .25 percent. And I think you'll see in your fiscal note that the university supplied you with the .25 percent figure. [LB218]

SENATOR CARLSON: Okay. I thought you gave another total that across the state it's going to amount to so much money. You didn't give that? [LB218]

MICHAELA VALENTIN: No, I was referencing the university... [LB218]

SENATOR CARLSON: On the A bill? [LB218]

MICHAELA VALENTIN: ...and the fiscal note that they gave you. [LB218]

SENATOR CARLSON: Okay. [LB218]

MICHAELA VALENTIN: And as an example, I think they said $240,000. I don't have a dollar figure for that. [LB218]

SENATOR CARLSON: All right. I'm going to...I'm trying to put this into a practical figure. And if we have a $1,000 a month premium, you know 1 percent of $1,000 is $10, so .25 would be $2.50 on a $1,000 premium. And I've been away from it long enough, I don't know what would then an average monthly family premium be? More than $1,000 probably. [LB218]

MICHAELA VALENTIN: Yes, I would...I don't know that. I imagine it would be more than $1,000. What I have seen just preliminarily is due to healthcare reform. Some of the groups that I have looked at their premium increases, say if they had a 6 percent premium increase maybe, 3 percent of that already would be attributable to ACA for near term provisions. So that would be anything like preventive care. Maybe a group didn't provide the extensive preventive care under their original benefit package as they now have to under the ACA. So we've seen that, you know, there is, at least in this one case that I saw was a 6 percent increase, 3 percent of that was attributable to the ACA near term and provisions that came after near term, but have still been implemented for close to 6 to 12 months. [LB218]

SENATOR CARLSON: So for the provisions of ACA on a $1,000 premium, that's a $30 a month increase. On a $2,000 premium, it's a $60 a month increase for the affordable care plan. That's what it is, okay. Thank you. [LB218]

SENATOR CHRISTENSEN: Senator Campbell. [LB218]

SENATOR CAMPBELL: My question was covered, thank you. [LB218]

SENATOR CHRISTENSEN: Okay. Anybody else then have a question? Seeing none, thank you. [LB218]

MICHAELA VALENTIN: We're good? All right, thank you. Thanks. [LB218]

SENATOR CHRISTENSEN: (Exhibit 4, 5, and 6) Any other in the opposition? I have a letter to read into the record from The Association of Insurance and Financial Advisors in opposition. No one else in opposition? How about neutral? Seeing none, Senator Avery waived then. That will finish LB218. And I'll ask Senator Coash to come up and introduce LB505. Welcome, Senator Coash. [LB218]

SENATOR COASH: (Exhibit 1) Thank you, Senator Christensen. Well, it's a long day so I'm going to get right...get started here. It's kind of like being in Judiciary. All right. Well, good evening, afternoon to all of you members of the Banking, Commerce and Insurance Committee. For the record, I'm Colby Coash, C-o-l-b-y C-o-a-s-h. I represent District 27 right here in Lincoln, here to introduce LB505. I'm going to start my introduction just walking through what (LB)505 does technically, and then I'll end with why I introduced this bill. LB505 requires nearly all insurance plans in our state to cover all medically necessary care for the screening, diagnosis, and treatment of autism spectrum disorders or ASD. Such treatment includes pharmacy care, psychiatric care, psychological care, therapeutic care, and behavioral health treatment, all of which must be provided by someone licensed in the field or certified in the case of behavioral therapy. The amount of coverage per treatment in the bill is this: $70,000 for the first three years and $20,000 per year for subsequent years until the covered person reaches the age of 21. The higher amount of coverage in the first three years ensures that people with autism receive the front-end, intensive therapy that is critical to their habilitation. The bill also includes a few provisions that address various concerns expressed to me last year when I introduced a nearly identical piece of legislation in LB1129. First, I addressed the concern about the Affordable Care Act by ensuring that benefits prescribed in this bill will not exceed the maximum benefits prescribed in the Affordable Care Act, the ACA health care exchanges. Secondly, I included an opt-out provision for small businesses. That is, a small business may opt out of providing this coverage if they can demonstrate an increase in premium costs of 2.5 percent in one calendar year. Finally, while we do not currently have licensure in Nebraska for behavioral analysts, LB505 via an amendment which I will present, requires that such providers be nationally certified by the Behavior Analyst Certification Board or an equivalent organization. There's 1 out of 88 kids in our country that are diagnosed with this disorder every year, so there's a good...there's a high likelihood that many of you know somebody diagnosed with autism. Given the interim study that was conducted on this bill and previous bills I have introduced in this matter, you understand why I'm bringing this bill yet again. Nebraska families deserve better. Because of the lack of insurance coverage for autism in Nebraska, families faced with an autism diagnosis are left really with three options. They go without treatment and hope that the school system will somehow accommodate and ameliorate their needs, they seek treatment and they go bankrupt in the process, or they leave the state to live and seek treatment elsewhere like in our neighboring states of Iowa, Kansas, Missouri, or Colorado, all of which have coverage for autism in their law. The need is clear. Some of you will also recall an actuarial study that was the result of a bill I introduced last year, LB1129, and we have provided that information to you as well. You will see on that...based on that actuarial study that requiring this coverage here in Nebraska will raise premiums, but very minimally. Based on Nebraska-specific data, costs will rise anywhere between a conservative estimate of .28 percent and a high estimate of .65 percent. Compared to the financial and emotional cost experienced by Nebraska families, this is fairly negligible. I have experience in working with people with autism and I want to paint a picture for you as a committee, if I can. I've worked with adults that have autism. And when they were children, the science wasn't out there to provide that kind of treatment. And those are adults who now live in Nebraska, many of them...most of them, I would say, are highly dependent on specialized services. They are dependent on taxpayer resources in order for them to live and participate in their communities. I've also worked with children who became adults who have had this treatment. They live independently, they participate fully in their communities. The resources that they need because they had this treatment as children is so different. And that's one of the reasons I brought this bill. This bill is lifesaving for people who have family members who need this treatment. And it's not lifesaving in the sense of somebody who is having a heart attack needs CPR. That's not the kind of lifesaving that I'm talking about. This is the kind of lifesaving where people with autism actually get their lives back. Imagine knowing that there was a treatment that allowed a child to tell his parents he loved them. Inside of children with autism there is a life of love, but it's locked away behind this diagnosis. ABA treatment unlocks that door and it removes enormous barriers that people with autism face. That's why I introduced this bill. And I will close by telling you that since this bill last year and the introduction of this bill this year, I've worked with the insurance industry. I've been working in good faith with them and they've been real partners in this effort, and I want to commend them. And they're going to have some testimony that I think is appropriate and I would encourage the committee to listen to that as well. And with that, I want to end and let some of...some people following me tell you a little bit about the science of this treatment that would be covered and how it works. And you'll also hear from some family members that really illustrate those two examples that I shared with you. Family members who have struggled because they can't get this treatment and family members who have seen enormous gains because they can. So I would thank the committee for their indulgence in this and I appreciate your time. [LB505]

SENATOR CHRISTENSEN: Are there questions for Senator Coash? Seeing none, thank you. I'll have a small list of testifiers I'll call up in order before we go to the open proponents. First, Michael Wasmer. [LB505]

MICHAEL WASMER: (Exhibits 2, 3, 4, and 5) Good evening, Vice Chair and members of the committee. My name is Mike Wasmer, M-i-k-e W-a-s-m-e-r, and I am the associate director for state government affairs at Autism Speaks. Autism Speaks is the world's leading autism science and advocacy organization, and our state government affairs team has been directly involved in most of the now 32 states that have passed legislation similar to LB505. I'm also the parent of a child with autism and I'm happy to speak here today in strong support of LB505. Opponents of this legislation may assert that the cost of coverage is unknown or prohibitively high. However, given that there are 32 states now that have enacted similar laws that require state-regulated health plans to cover the diagnosis and treatment of autism, including ABA, we do have actual claims data to present, actual claims data from states which were among the first to enact such legislation. So the average cost of coverage is 31 cents per member per month; less than a can of Diet Coke. This includes claims data recently reported by the Missouri Department of Insurance which also demonstrated that the actual cost of Missouri's autism benefit was less than 0.2 percent of their total healthcare costs. Based on this observation, the Missouri report, which I think some of you have seen, and we can provide that for you if you'd like, their conclusion was that it is very unlikely that such costs would have an appreciable impact on insurance premiums. The cost of not providing appropriate treatment for individuals with autism has been estimated to be $3.2 million per child over their lifetime. Much of that expense is associated with the intensive special education involved, adult disability services, and decreased productivity. The actuarial analysis that Senator Coash referred to, performed on (LB)1129 last year, estimated that the cost of autism insurance reform could be recovered in reductions and savings in special education and medical expenses alone. Failure to enact this bill is the high-cost option. Other arguments against autism insurance reform include the assertion that small business owners will be negatively impacted. However, 12 years after the first autism insurance reform law was enacted, not a single example has been provided to support this claim. The Missouri law includes a provision that allows small employers with group health plans to apply for a waiver to opt out of coverage if it can be demonstrated that the cost of the benefit resulted in premiums increasing by 2.5 percent or more. And the language in LB505 is identical to the language in the Missouri bill which offers similar protection to small business owners. Despite enormous evidence to the contrary, the most common reason that insurers will deny ABA is their assertion that this is experimental. LB505 explicitly requires that all covered treatments be evidence based, and ABA is the most commonly prescribed evidence-based treatment for autism. It's efficacy is supported by over 40 years of research and is endorsed by the U.S. Surgeon General, the American Academy of Pediatrics, and other leading national medical agencies, pediatric, neurologic, and psychological organizations. Another discussion that may arise in hearings is in regard to licensure of ABA providers. It's important to note that licensure of ABA providers is not a prerequisite for enacting this legislation nor is it a prerequisite for ABA providers to be reimbursed by insurers. Of the 32 states that have already enacted similar legislation, only 8 of those require licensure of the ABA providers. The Behavior Analyst Certification Board is an accredited national organization, accredited by the National Commission for Certifying Agencies which is the accreditation arm of the Institute for Credentialing Excellence. And the majority of states with existing autism insurance reform laws allow for reimbursement of ABA providers if they hold this credential from the BACB or if they are appropriately-trained, licensed psychologists. Whereas Autism Speaks doesn't have a position on state licensure, that's something that states decide on a state-by-state basis. It is important to consider a couple of factors in that discussion. One would be the cost of licensure. The second would be assuring that the licensure process doesn't restrict access to services. And finally--and Senator Coash has addressed this provision as well--but the ACA does require states to defray the cost of any benefit that exceeds the essential health benefit. But what's important to note is that that obligation to defray the cost only applies to plans sold inside the exchange, it doesn't apply to plans sold outside the exchange. So the provision that Senator Coash referred to specifically states that if HHS were to interpret proposed benefits as exceeding the essential health benefits, then it would not apply to plans sold inside the exchange; it would only apply to plans sold outside the exchange. The prevalence of autism as reported by the CDC is now 1 in 88, and this represents over and a thousandfold increase in the past 40 years. Autism is an epidemic, it's a public health crisis, and the time to act is now. And I appreciate your consideration of my comments and I'd be happy to answer any questions. [LB505]

SENATOR GLOOR: Thank you, Mr. Wasmer? [LB505]

MICHAEL WASMER: Yes. [LB505]

SENATOR GLOOR: Thank you. Questions? Senator Carlson. [LB505]

SENATOR CARLSON: Thank you, Senator Gloor. My first take on this page is pretty impressive, so are you really familiar with it that I can ask you...I can grill you on it? [LB505]

MICHAEL WASMER: I am very familiar with it. Yes. Drill away. [LB505]

SENATOR CARLSON: That figure in the last column is per member per month? [LB505]

MICHAEL WASMER: That's per covered, per member, per month. That's covered life, that's not per policy. That's per covered life. For example, sometimes figures are reported per policy. Like I have a health insurance policy, but there are four covered lives under my insurance policy, so that's the figure that we're referring to there. [LB505]

SENATOR CARLSON: So in a family of four, it's...that's okay, but it's four times that figure? [LB505]

MICHAEL WASMER: Well, the figure that we have there references all covered lives under the plan, including me and my wife and my two kids. [LB505]

SENATOR CARLSON: Okay. The Missouri figure is 38 cents. [LB505]

MICHAEL WASMER: Right. [LB505]

SENATOR CARLSON: So on a family of four, it'd be four times that? [LB505]

MICHAEL WASMER: Yes, that's correct. [LB505]

SENATOR CARLSON: Okay. Per individual. [LB505]

MICHAEL WASMER: That's correct. [LB505]

SENATOR CARLSON: Now why is the year of coverage two all the way down the line? [LB505]

MICHAEL WASMER: The reason that...we wanted to be consistent with, you know, if it were a newly implemented law versus a law that's been in existence for a while. So to compare apples to apples, the data that you have there represents the second full year of implementation of their law. [LB505]

SENATOR CARLSON: But this is going to be cumulative because we're talking about coverage from 4 to 6, which is the two years and then through age 20. So these figures are only good for two years and as the cumulative effect gets... [LB505]

MICHAEL WASMER: No, sir. I... [LB505]

SENATOR CARLSON: Go ahead. No, go ahead. [LB505]

MICHAEL WASMER: That's incorrect, it's not per two years. What I'm referring to is that the claims data that was collected...say, for example, the Missouri data that is presented there saying the 38 cents per member per month. That is the entire claims data for calendar year 2012. Their law was implemented calendar year 2011, so the data that we have there represents total claims costs for the autism benefit in calendar year 2012. It's not two years of claims data, it's one year of claims data, that year being 2012. [LB505]

SENATOR CARLSON: So there's not an anticipation here of increase other than inflation? [LB505]

MICHAEL WASMER: Really we don't...I mean, we consider this a pretty mature benefit after two years. You know, that first year if you look back at the claims data from Missouri and their first year of coverage, it was 25 cents per member per month. So it has gone up. That was anticipated because there is a period of ramping up providers, getting them approved by the insurers, as well as increasing awareness among the public that this is a benefit. But after two full years we would expect that to represent a pretty mature benefit. [LB505]

SENATOR CARLSON: Okay, I'm going to drive a little bit further here... [LB505]

MICHAEL WASMER: Okay. [LB505]

SENATOR CARLSON: ...because, again, I hope the answer is what I want. Let's go back to the Missouri at 38 cents. And a lot of times with...the employer might pay 50 percent and the employee pays 50. But this is the cost of the entire plan whether the employer pays any part or no part. [LB505]

MICHAEL WASMER: I believe that is correct. [LB505]

SENATOR CARLSON: You believe, you're not real... [LB505]

MICHAEL WASMER: I believe that's correct, yeah. I know for a fact... [LB505]

SENATOR CARLSON: Would you try and verify that? [LB505]

MICHAEL WASMER: Yes. I know for a fact that the Kansas data there represents only the...if you look at those data, the first five states there are all from state employees' health plans. Obviously, there are 32 states that have passed this. We don't have data on all 32 states. I wish we did. One of the reasons we don't, we've addressed...we've contacted insurance companies about this, but they've not been very forthcoming with the information. So what we did initially was to go to states whose autism insurance law included coverage for their state employees. So we went to the administrators of the state employees' health plans in those states and it's of those five states that we were able to get claims data from. And I know for a fact that all of that data represents the total cost to the state. It doesn't represent any of the copays or anything like that. That's just to represent the actual cost to the state by requiring that coverage. [LB505]

SENATOR CARLSON: Okay. I understand that. And I'm going to go one step further because then I'll quit asking. But Kansas, 24 cents. Family of four, that's 96 cents a month. [LB505]

MICHAEL WASMER: Right. Right. Per member per month. [LB505]

SENATOR CARLSON: And that takes care of the entire policy aside from coinsurance and deductibles. [LB505]

MICHAEL WASMER: That's correct. [LB505]

SENATOR CARLSON: And it should take care of these benefits that we're talking about all the way to age 20? [LB505]

MICHAEL WASMER: Well, the terms of coverage are a bit different in each state. You know, for example, in Kansas the terms of coverage only go up to age 19. [LB505]

SENATOR CARLSON: Okay. [LB505]

MICHAEL WASMER: I did provide in there kind of a graph that helps you to kind of relate the terms of coverage proposed in this bill relative to all the other states. [LB505]

SENATOR CARLSON: Okay. All right. Thank you. [LB505]

SENATOR GLOOR: Senator Howard. [LB505]

SENATOR HOWARD: I had one question, but now I have two questions, and I apologize. Just going off Senator Carlson's discussion, can you explain to me...the average cost of 31 cents seems very low. Can you explain to me why that is? [LB505]

MICHAEL WASMER: Right. Right. The...and thank you for asking that because that's something that has come up in other states where we will get a fiscal note, for example, that's very, very high and not consistent with the actual claims data. If you go back--some of the data that we collected from the state employees' health plans--we went back and compared the fiscal notes that were prepared by the state legislatures and the fiscal notes exceeded actual costs anywhere from 300 to 1,200 percent. And the reason that is, is twofold. A common mistake when considering the cost of this is to fail to recognize that autism is a spectrum, meaning that there are some children who are very severely affected. There are others who are very mildly affected. And it's...you know, we'll frequently mention, you know, in testimony that parents often pay out of pocket in excess of $50,000, $60,000 a year. But it's only the most severely affected children who are likely to ever be prescribed treatment that would approach that level of intensity. So one mistake in actually looking at the fiscal notes that were prepared for this bill, whoever prepared that failed to consider that they multiplied the total number of children affected by $75,000 which is the easy way to do it, but it's not the most accurate way to do it because it fails to consider that not every child is equally affected. The second consideration is with regard to utilization of the benefit. Not every child in Nebraska that we estimate has autism will seek treatment for autism. And actually, if you look at the data from multiple states, the utilization rate ranges from anywhere from 20 to 50 percent so that is another area where some of the fiscal preparations are inaccurate. [LB505]

SENATOR HOWARD: And then I had a second question. In your letter here, you talk about your daughter Kate, and she received applied behavior health analysis, the ABA. [LB505]

MICHAEL WASMER: Right. [LB505]

SENATOR HOWARD: Is that an effective treatment method? Did she respond well to it? [LB505]

MICHAEL WASMER: She responded very well, and one of the following conferees is going to speak to more of the science of it. I can speak to the personal aspect of it in that my daughter, Kate, had a regressive form of autism. And that's fairly common, where a child is developing apparently normally and then their development goes backwards. She was developing typically up until two years. She was able to speak, she was interactive with our family, and we didn't have a reason to believe there was a problem. And then gradually she lost her ability to speak, she disengaged from our family, and she would be content just to sit in the corner flapping her hands, not responding to us very well. When she was diagnosed at two and a half, many of her developmental skills were assessed at those of a six-month-old. When most of her peers were speaking in sentences, she was completely nonverbal. Where most of her peers were interacting in play groups and following instructions in Gymboree and playing with the other kids, she was sitting on the mat staring at the clown, flapping her hands and not engaging with the rest of the group. But based on her individual strengths and weaknesses--and that's something that's important to note as well and kind of speaks to the fact that not every child is the same--based on her individual strengths and weaknesses, she was prescribed 30 hours a week of ABA. I live in Kansas, and at the time we didn't...we had insurance, but we didn't have a bill to require insurance coverage, but my wife and I were blessed to be able to provide that out of pocket. At that time it cost us about $35,000 a year and she had...her program lasted three years. We started it shortly after her diagnosis and we were able to stop her--it was a home-based therapy program--we were able to stop it just prior to her starting first grade, halfway through kindergarten, actually. And she has been in regular education without an aide since first grade. She has not been in special education, she is now in eighth grade, she is making straight A's, she has been in the school play, she is the first chair in the violin, and she just joined a swim team. So I have no doubt that she is going to go on. She wants to go to college, she wants to got to K State--sorry about that--but she wants to go to K State. And I have every reason to believe that she will be able to do that. I mean, she still struggles with the disability of autism in that she has some issues with understanding, you know, some of the nonverbal cues, body language, sarcasm, and things like that that she will struggle with, and has gotten into some issues at school. But she is thriving and, you know, it just speaks to the fact that if afforded the appropriate treatment...and she's not the exception. You know, the data shows that almost half of kids will be able to have the same level of success that she did. Another 42 percent will improve to the point where, you know, although they can't mainstream, they will require much less intense special education. And that reflects directly back on cost savings to the state. So, you know, she didn't need special ed and she's not going to be reliant on adult support services funded by the state. I have every reason to believe that she is going to be self-sufficient, and that's what LB505 would provide for children of Nebraska. [LB505]

SENATOR HOWARD: So you feel that ABA was effective, but it wasn't...you didn't need it permanently? [LB505]

MICHAEL WASMER: No. [LB505]

SENATOR HOWARD: Okay. [LB505]

MICHAEL WASMER: No. And that's not...I mean, when we speak about ABA, there's kind of a comprehensive ABA which is what Kate received early on. And when I talk about comprehensive ABA I mean, you know, it is an intense, you know, sometimes up to 40 hours a week of therapy working on multiple aspects of deficits, you know, to improve communication, to improve the social interaction, to minimize the repetitive behaviors. And then there is focused ABA therapy which is the reason why, you know, the majority of states continue the coverage, you know, up through age 21. Some states, you know, have no caps. But it's for the instances...and Kate has required focused ABA therapy, you know, for different behavioral issues that have come up that we needed to work on. And it might...that focused therapy might be the difference between a child like Kate who has, you know, may have persistent inability to interact with peers correctly or interact with the public. It may be that focused ABA therapy that allows her to function in a work setting as opposed to, you know, not being able to get a job and, you know, living at home playing video games when she's 30. So... [LB505]

SENATOR HOWARD: Thank you for your testimony. [LB505]

SENATOR GLOOR: Senator Pirsch. [LB505]

SENATOR PIRSCH: And thank you for your testimony. Just a few questions to clarify things. So is the...and if you don't know the answers, by all means... [LB505]

MICHAEL WASMER: I'll defer. [LB505]

SENATOR PIRSCH: ...one of the questions is just with autism. You know, it's 1 in 88, is currently. Those numbers probably weren't when the medical community and, you know, 30, 40, 50, 60 years ago probably...I don't even know if they recognized autism for what it was or if there was just thought maybe to be some other cause or some other condition. [LB505]

MICHAEL WASMER: It's been recognized since the--I believe--since the '40s. But to...I think what you might be alluding to, you know, is that increased prevalence. Is that due to increased awareness or is it, you know, change in diagnostic criteria? [LB505]

SENATOR PIRSCH: Or some sort of environmental factor, change... [LB505]

MICHAEL WASMER: Right. And that's the cause of autism...the short answer is, we don't know. But we do know that there is a very strong genetic predisposition. But we also know that there is not an epidemic of genetics so that you know, genetics alone, is not going to cause that increased prevalence. So to your point, and that's where the bulk of our research is going into now, is looking at that interaction between some sort of an environmental trigger and a child who is genetically predisposed so that perhaps there's something in the environment, some sort of toxin that that child's non-ability to metabolize well, ultimately leads to the chain of events that leads to autism. And that's the bulk of why that prevalence has gone up. The CDC themselves, you know, when they report those prevalence rates, they do make the comment that, you know, up to that 30 percent of that increase may be due to increased awareness and broadening of the diagnostic criteria, but it doesn't explain all of the increased prevalence. [LB505]

SENATOR PIRSCH: Yeah, and the...in recent years, does it seem to be...has it leveled off or is there still an uptake? [LB505]

MICHAEL WASMER: Unfortunately, it's not leveling off. And, you know, and that 1 in 88 is probably several years behind, you know, the actual current prevalence. [LB505]

SENATOR PIRSCH: Okay. And you had mentioned that you were familiar with the Missouri...you were kind of patterning the future...the what was it, .025 of the... [LB505]

MICHAEL WASMER: Two and a half percent. [LB505]

SENATOR PIRSCH: Two and a half percent that...I think that's on page six of the bill at the bottom. "Two and one-half percent or greater over the period of a calendar year in" the premium was patterned off Missouri, right? Can you relate to us the...did...so, was that often invoked in Missouri or what was the rate of... [LB505]

MICHAEL WASMER: The Missouri report that was...just came out stated that, to date, no small employer has applied for a waiver. So no one has been able to demonstrate or sought to demonstrate that the premiums have increased. And if you look at...I think I mentioned the Missouri Department of Insurance, you know, given that the total cost of their autism benefit was so negligible relative to their total healthcare costs, they didn't feel that it would really have an impact on premiums. [LB505]

SENATOR PIRSCH: Okay. And with respect to then the chart that you handed out, right--and I think Senator Carlson had made some inquiries and I hope I'm not covering territory already...but with respect to your second column, it says number of covered lives. And in some states there were...it lists, like for example, the second from the bottom, Missouri, 1.4 million and Arizona--which is probably, you know, somewhat of a similar type of population both, I think, over 10 million or close--it lists 130,000. I'm just...so the number of covered lives, what does that mean exactly? [LB505]

MICHAEL WASMER: It's the number of lives on the policy that are being afforded health benefits through that policy. And one of the reasons for the disparity in the numbers you might see there is that the number...whereas Missouri's information was from the entire state because as part of their law, it required that the Department of Insurance report back annually their cost experience and their claims data. So theirs is much larger because they're looking at the entire population of Missouri who has health insurance regulated by the state, whereas some of those others--like Kansas and South Carolina--those only represented covered lives in their state's employee health plan. [LB505]

SENATOR PIRSCH: Okay. Thank you for explaining that. [LB505]

SENATOR GLOOR: Senator Campbell. [LB505]

SENATOR CAMPBELL: Thank you, Senator Gloor. Mr. Wasmer, I'm going to look at the last paragraph or the last big topic you have in your letter... [LB505]

MICHAEL WASMER: Okay. [LB505]

SENATOR CAMPBELL: ...to us. And has Secretary Sebelius put out any further definition or included autism in an essential benefits, I mean, you know, that whole topic? [LB505]

MICHAEL WASMER: Yeah. The Secretary hasn't clarified the congressional intent of the ACA with regard to autism, and let me specify what I mean by that. Through the course of hearings in the Affordable Care Act there was an amendment made to one of those ten categories of essential health benefits, that being the category of "mental health and substance abuse disorders." That amendment changed that category to read "mental health and substance abuse disorders, including behavioral health treatment." And Senator Menendez was the one who introduced that amendment and, you know, in his congressional testimony he specifically stated that the purpose of that amendment was so that individuals with autism could receive behavioral health treatment, including ABA. As you're probably well aware, guidance from HHS early on was less than clear and, you know, left much of that up to the states. But to date, they have not clarified that ABA for autism is an essential health benefit. However, of the 32 states that have passed autism insurance reform laws at the state level, 24 of those do include ABA for autism in their essential health benefit package. The reason it's not 32 is because there are some differences from state to state with regard to which markets are covered by the mandate. For example, in South Carolina their law does not apply to small group plans. It applies to large group plans and individual plans. South Carolina defaulted to the benchmark plan, what happens to be the largest small group plan in the state. So although South Carolina has an autism law, since they defaulted to the small group they don't have that in their essential health benefit package. The discussion is not complete. I work in state government affairs. We also have a federal government affairs team who is continuing to speak with HHS about this. The...although they have also given states flexibility to add ABA for autism under that habilitative category...and actually, the state of Ohio just did that. Although they don't have a law, they added that benefit through that mechanism. Minnesota is in the process. Their governor is writing a letter to do that, but that mechanism isn't going to provide for all 50 states to include it in their essential health benefit package which was the intent of the law. So I expect that if HHS doesn't clarify that in the next several months, there's probably going to be litigation to clarify it...to help to clarify it. [LB505]

SENATOR CAMPBELL: And I'd have to say that what your expertise is, is a lot more thorough and a knowledge about what the states...but, you know, we would concur from the work that the legal counsel to the Health Committee has looked at, too. It's still an issue. [LB505]

MICHAEL WASMER: The issue is not so much, I think, the ability for a state to include it. I think the biggest concern comes up, and we deal with this issue in other states moving forward who haven't yet passed a law, and that is the concern about that obligation to defray the costs. And I think where the confusion comes in is that obligation to defray the cost of the benefit that's not included in the essential health benefit package. That obligation specifically only applies to plans that are inside the exchange. And so the provision that Senator Coash mentioned with regard to that clarifies that if ultimately HHS doesn't interpret the law the way it was intended to be, that the benefits we're asking for in LB505 would not apply to those plans. It would only apply to plans outside the exchange and, therefore, you know, taking away any obligation to the state of Nebraska to defray those costs. [LB505]

SENATOR CAMPBELL: And I don't know if you were in the audience when that question was asked of the director of insurance a couple of bills back in the sense that if you're on an outside plan, the converse problem is that the federal subsidies don't apply to that. If you're going to be able to drive down the federal subsidies, you have to be within the exchange. [LB505]

MICHAEL WASMER: Uh-huh. Right. But on the other hand, there's...the...if you look at the fiscal note, the only obligation for the state to pay for is for your state employees. Yeah. [LB505]

SENATOR CAMPBELL: Right. No, I do understand that. Thank you, Mr. Wasmer. [LB505]

MICHAEL WASMER: Sure. [LB505]

SENATOR GLOOR: Other questions? Senator Schumacher. [LB505]

SENATOR SCHUMACHER: Thank you, Senator Gloor. Thank you for your testimony. I'm just trying to get an impression of the cost for a family of four. As I understand it, this is the total number of people covered by the policy, the total claims for a year. [LB505]

MICHAEL WASMER: Correct. [LB505]

SENATOR SCHUMACHER: So your first step, you divide total claims by 12 to get... [LB505]

MICHAEL WASMER: I'm sorry, I don't have a copy of it in front of me here. [LB505]

SENATOR SCHUMACHER: Well, one of them was 11 months. It's the last one. But generally it's by 12. And then divide by number of covered lives to get your... [LB505]

MICHAEL WASMER: Correct. You take the total claims cost, divided by the number of covered lives, divided by 12. Correct. Because it's per month. [LB505]

SENATOR SCHUMACHER: Okay. Right. And if I add up total claims and I add up total covered lives and I do the division and I divide by 12--even though Kansas is by 11--I come up with 36 cents a month instead of 35 because the...apparently--or 31--this 31 is just a simple average of the... [LB505]

MICHAEL WASMER: It's the average of those. [LB505]

SENATOR SCHUMACHER: And it's not weighted by the number of people that were involved. [LB505]

MICHAEL WASMER: That's correct. [LB505]

SENATOR SCHUMACHER: So at 36 cents a month, times a family of four, times twelve months will cost the average family--if a family of four is average--about $17.25 a year. [LB505]

MICHAEL WASMER: I think what you might be referring to--and let me make the distinction between the claims cost and premium increase because that's not the same thing--what we are talking about there is the actual claims cost, the actual cost of covering the services. That table that I presented there does not represent premium increase, so that's not the premium increase to the family. [LB505]

SENATOR SCHUMACHER: Well, but what goes in must come out. And so if that extra money goes out, it's got to come in and it's got to come in from the people who are covered. [LB505]

MICHAEL WASMER: Right. I mean, and as we mentioned, we do expect there to be an increase in premium. And the actuarial analysis that was done on the bill that was filed last year, you know, they looked at a range of intensity of the treatment. And as Senator Coash mentioned, the high end, they expected premiums to increase it was, I think, .65 percent. [LB505]

SENATOR SCHUMACHER: Percentages don't mean anything because you don't write a check in those. But if you...if this is actual experience and assuming that they're given the proper kind of care, I guess my question is are we looking at about $17 a year on a family of four extra contribution to the system? [LB505]

MICHAEL WASMER: Right. That would be the claims cost. Correct. [LB505]

SENATOR SCHUMACHER: Thank you. [LB505]

SENATOR GLOOR: Senator Carlson. [LB505]

SENATOR CARLSON: I got my question answered, thank you. [LB505]

SENATOR GLOOR: Okay, good. Thank you. Any other questions? Seeing none, thank you, very informative. Appreciate it. [LB505]

MICHAEL WASMER: Thanks. [LB505]

SENATOR GLOOR: (Exhibit 6, 8, and 9) Next proponent? Dr. Ellis. And while Dr. Ellis is working her way up here, I have a letter of support from the National Nebraska Association or National Association of Social Workers, from The Arc, and then we also have a letter of support from Brad Meurrens with the Disability Rights Nebraska and a number of handouts that go along with that. And I'll have the staff pass that out as they're able. This includes the report from the Department of Insurance from Missouri, both 2012 and 2013. Thank you. Go right ahead. [LB505]

CYNTHIA ELLIS: (Exhibit 10) Good afternoon. I guess it's almost evening. My name is Cynthia Ellis, C-y-n-t-h-i-a E-l-l-i-s. I'm a pediatrician and director of developmental medicine in the Department of Pediatrics in the Munroe-Meyer Institute at UNMC. I have a large clinical practice and the majority of my patients are children and young adults with autism. I have been working in this field almost 25 years and I've been practicing in Nebraska for the past 14 years. I'm one of four developmental behavioral pediatricians in the state of Nebraska, and the only physician in Nebraska who is board certified in neurodevelopmental disabilities. I am also the leader of the Nebraska Act Early State Autism Team. I also have firsthand experience with autism because I have a nephew living in Omaha who has a diagnosis of autism. I'm testifying today as a private citizen and I don't represent the University of Nebraska. I have three main points that I want to make today. The first is that autism spectrum disorders are biologically-based neurodevelopmental disorders that are pretty common and occur in 1 in 88 children in the United States. It's important to know that these are medical disorders, they're diagnosed by medical professionals using specific DSM-IV criteria. As the name implies, autism spectrum disorders have a spectrum in their presentation of symptoms and severity, and so the disorder looks very different among different people with autism. Medical treatment is frequently indicated to help individuals with autism achieve their optimal functioning. And this brings me to my second point that autism is treatable. For many of the young children with autism, early and appropriate treatment is crucial to a positive outcome. We usually recommend that treatment begin as soon as possible after a diagnosis because the evidence suggests that the sooner that you begin treatment, the better likelihood for a positive outcome. However, it's also important to know that people across the life span will benefit from autism treatment. So we see that older children and adults also benefit from treatment. And there's a number of different treatment approaches that have sound, scientific evidence for benefit in autism. There are two medications, Risperidone and Aripiprazole, that have been approved by the FDA for treatment of children and adolescents with autism. These are specifically indicated to treat the symptoms of irritability. These medications are frequently prescribed for the comorbid psychiatric conditions or to help manage behavioral manifestations of autism. It's important also to realize that these drugs don't change behavior. What they do, is they alter the neuronal activity in the brain by changing neurotransmitter function. So they really change how the brain chemicals work and how they...when those neurons and brain cells are interacting with each other. That's what they do, they just change that brain cell functioning. Furthermore, use of these medications is really limited by the side effects. And there can be a number of potentially severe side effects such as weight gain, sleep problems, endocrine changes, hormone changes, you can have some permanent motor movement abnormalities, and there's even a syndrome with vital sign instability and cardiovascular instability. Behavioral treatment is the other major category of treatments, and these are really the standard of care for autism. And they have the most supportive data. A subsequent testifier is going to talk more about these behavioral treatments. In contrast to medications, these treatments actually target those core symptoms of autism. Parents are sometimes confused about the difference between educational services and medical treatment, and they ask me if the services that their child is provided at school is enough. And I frequently explain to them that it's important for children with autism to have school services, that the goal of the school services is to accommodate the disability and to really facilitate that child's education. But what is provided to children in schools does not treat the autism and doesn't treat the problems associated with autism, but it's not supposed to do that. That's not the intent of school services. In my medical practice I see a large number of children with autism. And their limited access to appropriate treatments is my third point. And parents work hard to provide health insurance for their children and they trust that I--and I'm representing the healthcare system--are going to take care of them when they need it. And I feel good that I can...I know what we have. We have some treatments that will help them. However, when I go to prescribe treatments, if I prescribe medication whether it's FDA approved or not, whether there's good data or not, health insurance will usually pay for that. When I prescribe behavioral treatments, they're rarely covered. Health insurance usually covers medically-necessary, cost-effective, evidence-based treatments if they're prescribed by and provided by a qualified practitioner. Behavioral treatments, that's not the case and these are often denied. And even when I appeal these, I'm told that they're educational services, they're experimental, and they're not medical services. But we know that the data doesn't support that. In my experience, when a child with autism doesn't receive or is unable to access the treatments they need, we often end up relying on medication. And I think the overmedication of children with autism is a real problem. The data shows that the majority of children with autism eventually end up on medication and frequently end up on multiple medications. And I frequently see kids who are on five or six or even more medications, and they still are having a lot of problems. So in summary, the treatment of children and adolescents with autism should be based on matching the individual needs of the child with an evidence-based treatment. Determining which treatments are to be provided, the primary consideration should be the science and the evidence that the treatments that we provide are safe, appropriate, and effective. It shouldn't be the availability of insurance coverage and the access to those treatments. I think this is really an issue of outcome. Providing appropriate treatment that improves outcome is the right thing to do, and the fact that it's cost effective and saves money in the long run also makes it a smart thing to do. [LB505]

SENATOR GLOOR: Thank you, Dr. Ellis. Are there questions? Senator Schumacher. [LB505]

SENATOR SCHUMACHER: Well, thank you, Senator Gloor. Thank you for your testimony. The growth rate on this disease is 10 to 17 percent a year? [LB505]

CYNTHIA ELLIS: Well, you know, it's really hard to make that conclusion because the data...when we look at the data and look at the prevalence rate over recent years, there's been some changes in the criteria that have been used and so we...like Mike was saying, that the number...that we picked up more children. We've picked up a lot of the children that were missed in the past because our diagnostic criteria don't only include those severe children with autism that we used to classify, but now include some of the less severe cases of autism such as Asperger's. So we are picking up more children than there used to be picked up. [LB505]

SENATOR SCHUMACHER: I got the 17...10 to 17 percent off of a letter we were just handed, but if that is anywhere near being accurate, and I think we heard earlier testimony that that's...the growth rate isn't leveling off, then in 5 years the number of autistic kids will double, in 10 years that will double, and the cost goes from $17 a year to $35 dollars a year to $70 a year in 10 years. What's... [LB505]

CYNTHIA ELLIS: Well, I don't think that...go ahead. [LB505]

SENATOR SCHUMACHER: What's...I mean, what's causing this? I mean, is it just a broadening of the definition in order to basically include any behavioral issue? Is that what we're seeing? [LB505]

CYNTHIA ELLIS: Well, I think that a part of it is the broadening of the definition. So now we're calling children autism spectrum disorder that we used to not call autism, so there's a greater pool of children. So they were the same children that they've always been, but now we're calling some of them autism because we can recognize that they fit into that same group. [LB505]

SENATOR SCHUMACHER: And that's a group defined by the DSM? [LB505]

CYNTHIA ELLIS: Correct. That... [LB505]

SENATOR SCHUMACHER: Did that definition change? [LB505]

CYNTHIA ELLIS: That definition does change. It changes every time they revise those criteria. They look at all the scientific evidence, all the prevalence data, all the genetic data, ideologies, treatment effects. And they come up and they say, now the way we used to classify that, does that still fit? And that changes over time. It's going to change again in another...this year. [LB505]

SENATOR SCHUMACHER: So the world of psychology can redefine what autism spectrum disorder is, broadening the market of people who are classified in there to draw down on insurance companies for the basic treatment of whatever behavioral disorder they put into that classification. [LB505]

CYNTHIA ELLIS: Well, I think that...you know, I think it's not just whatever behavioral disorder goes into that classification. They really look at the science, and when they're talking about kids with those core symptoms of autism spectrum disorders, which kids fit together. [LB505]

SENATOR SCHUMACHER: At what point do we draw the line between autism, the disease caused by something screwy going on at the synapse level, to just plain old behavioral disorders? Just plain misbehavior? [LB505]

CYNTHIA ELLIS: I think we draw that line all the time. Every time that we diagnose a child we look at, you know, are these symptoms related to an environmental aspect?

You know, maybe poor parenting. And this child just doesn't follow rules or maybe they never learned social behavior. But if that's the case and they can learn those...they can be taught that, then it's not a deficit in that. It might be just be a lack of exposure. [LB505]

SENATOR SCHUMACHER: Does the DSM, then, have a component that says you need to find this particular physical thing wrong or it's not autistic, it's behavioral? Or it's not biochemical, it's a disease? [LB505]

CYNTHIA ELLIS: Well, we don't know. We don't know what that specific genetic marker is or that specific brain abnormality is. But the DSM will say you need to rule out all these things. You need to make sure that it's not oppositional defiant disorder, that it's not, you know, ADHD, all these other things. You make sure that it's not those before you come up with ADHD. [LB505]

SENATOR SCHUMACHER: But the ruler out is also the psychologist or psychiatrist that is getting...going to get paid from the insurance company if they rule it to be autism. [LB505]

CYNTHIA ELLIS: Well, I think that sometimes that's true. But often the diagnosis isn't...like for myself. I'm a physician, I make that diagnosis and I prescribe these behavioral treatments, but they're nothing that I do, and so I don't make any more money by diagnosing more children with autism. A lot of the treatments that are provided, the people providing the treatments aren't always the same person who is making that medical diagnosis. [LB505]

SENATOR SCHUMACHER: Thank you. [LB505]

CYNTHIA ELLIS: Conflict of interest. I don't think that...I don't see that as a reality. [LB505]

SENATOR SCHUMACHER: Thank you. [LB505]

SENATOR GLOOR: Senator Pirsch. [LB505]

SENATOR PIRSCH: And thanks for providing your testimony here today and for all you do for that matter, but I had a question. You had indicated as part of your testimony that it saves money in the long term. Are you aware of empirical kind of studies that have been published or research in the area that kind of document from, you know, societal viewpoints based upon having access to this type of...the ABA...that, you know, society...the productivity gains or anything of that sort? [LB505]

CYNTHIA ELLIS: Well, there's a number of ways that they look at that. One example is something we already talked about, that providing treatment early on--appropriate early intervention... [LB505]

SENATOR PIRSCH: Right. [LB505]

CYNTHIA ELLIS: ...half of...almost half of those kids will not need special education services. So already you're saving money in special education. Those children then will grow up to need less services from adult rehab, they'll be more productive citizens able to hold down more productive jobs. So there's been a number of studies that have demonstrated that effective treatment does result in long-term savings. [LB505]

SENATOR PIRSCH: Did they say reaching children by what age in that study? Do you remember? [LB505]

CYNTHIA ELLIS: You know, it really varies. But most of the time--this is not my exact field of expertise--I think that most of those studies look at early treatment of children probably when they're less than 8. There kind of becomes this window when some of that early behavioral intervention that is targeting some of those core symptoms of autism isn't as effective anymore. So an older child I would prescribe something different probably than a younger child. [LB505]

SENATOR PIRSCH: But as many as half then wouldn't require the special education. [LB505]

CYNTHIA ELLIS: Right. And up to another, I think, a majority of those kids then that do need special education need less special education if they have received early intervention. [LB505]

SENATOR PIRSCH: Okay. Thank you. [LB505]

SENATOR GLOOR: Senator Crawford. [LB505]

SENATOR CRAWFORD: Thank you, Senator Gloor. And thank you for your testimony. Would you say that the three years of intensive therapy is scientifically appropriate or based on scientific experience? [LB505]

CYNTHIA ELLIS: I think that that...again, that's a guesstimate. [LB505]

SENATOR CRAWFORD: Uh-huh. [LB505]

CYNTHIA ELLIS: And that's not probably my field of expertise, but that that's...to me, seems about right. [LB505]

SENATOR CRAWFORD: Reasonable? [LB505]

CYNTHIA ELLIS: Right. [LB505]

SENATOR CRAWFORD: Thank you. [LB505]

SENATOR GLOOR: Seeing no further questions, thank you, Dr. Ellis. Next testifier. Anytime you're ready. [LB505]

TORRI SMITH TEJRAL: (Exhibit 11) Okay. Thank you so much and good evening. My name is Torri Smith Tejral, T-o-r-r-i S-m-i-t-h T-e-j-r-a-l. I'm a licensed mental health practitioner as well as a board certified behavioral analyst. I work at the Munroe-Meyer Institute at the University of Nebraska Medical Center, but today I am testifying as a private citizen. I have had the privilege to provide services to children with an autism spectrum disorder and their families over the past 13 years. In this time, I have coordinated care for children in a center-based treatment program, I have consulted in home-based services, and conducted outpatient therapy. I have worked with a lot of children with autism of all ages. As a provider, there are several key points I would like to present today in support of LB505. Treatment for children with an autism spectrum disorder: autism spectrum disorders or ASDs are characterized by varying degrees of difficulty in social interaction, verbal and nonverbal communication, and the presence of repetitive behavior or restricted interests. The Centers for Disease Control currently estimates that 1 in every 88 children will be affected by autism. Autism can be a varied and complex diagnosis. It presents differently in each child and has different effects for each family. However, autism is treatable. There are evidence-based treatments that address the deficits associated with ASD. This means that we know what works with children. The National Autism Center completed the largest and most comprehensive review of the literature on interventions with children with autism. This review, known as the National Standards Project, provides us with a knowledge of interventions that are empirically supported. Current literature supports the most evidence-based practices are based upon applied behavior analysis. ABA is the design, implementation, and evaluation of environmental modifications to produce socially significant improvements in human behavior. The field of ABA evolved from the scientific study of the principles of learning and behavior. Applied behavior analysis is a well-developed discipline among helping professionals. We have a mature body of scientific knowledge, established standards for evidence-based practice, distinct methods of service, recognized experience, and educational requirements for practice, and identified sources of education and professional certification. Interventions are individualized to meet each child's unique needs and can be flexible in accommodating the needs of the family. Treatment involves constant progress monitoring and is based upon data. This is how we know how much treatment and how long to continue the treatment. With the extensive research available, providers have the knowledge to treat this diagnosis to produce meaningful and lifelong changes. Outcomes for children: research supports that best outcomes for children occur when services are provided intensively. These services for children vary depending upon their age, severity of symptoms, and responsiveness to treatment. The earlier the child receives intervention the better the outcome. Many factors influence the outcome for each child, but study after study supports that children make gains in multiple areas resulting in more appropriate skills in all domains of daily living. Children receiving intervention are more successful at school, they are better able to develop appropriate peer relationships, and they acquire the skills necessary to be independent adults. Without access to intensive intervention services, long-term outcomes are bleak. One follow-up study of adults with autism found that only 26 percent had one or more friends, 13 percent had independent jobs, and only 4 percent lived independently. We are in a position to change those outcomes. Access to services: providing services to children with autism is difficult not because of the challenges presented with this diagnosis, but rather because these types of services are not covered by insurance in Nebraska, and most families do not have the resources to pay privately. While parents want to provide what is best for a child, most families are unable to provide the most effective interventions. As a provider, this creates an ethical dilemma. It is difficult to work with a child and tell their parents that the best outcome is only available if they can afford it or if they move to a state where the service is provided. I cannot provide the standard of care required to meet the needs of my patients. I know rural access to services is a concern for many members of the committee. Having lived and worked in Lexington, Nebraska, for five years, I understand the challenges for a child to access services in a rural community. However, we have several options available to families if services are covered. Within the Outreach Behavioral Health Program, the Munroe-Meyer Institute's pediatric psychology department has trained professionals in 17 collocated clinics across the state. In addition, there is also expanding services available through the telehealth network. We are able to provide services to families through secured videoconferencing and reach children where they are. Additional trained professionals would be a possibility if we had jobs to keep them here. Currently those who receive specialized training in autism often leave the state in search of employment. If services to children with an ASD become a covered benefit, Nebraska could retain more qualified professionals and access to services would be available to children across the state. I am passionate about working with children with autism, and I am currently unable to provide this service. Nebraska is ready to move forward in providing this much needed service to children. Please support this legislative bill to ensure that children in Nebraska have access to the services that they desperately need. I would welcome any questions. [LB505]

SENATOR GLOOR: Thank you. Are there questions? Senator Schumacher. [LB505]

SENATOR SCHUMACHER: Thank you, Senator Gloor. And thank you for your testimony. [LB505]

TORRI SMITH TEJRAL: Uh-huh. [LB505]

SENATOR SCHUMACHER: What's the difference in definition of autism under the DSM-IV and the DSM-V? We're under V now, right? [LB505]

TORRI SMITH TEJRAL: We are currently under IV. Five will be going into implementation later in the 2013 calendar year. [LB505]

SENATOR SCHUMACHER: Okay. Can you go over then maybe from III to V in what the incremental changes of that definition has been? [LB505]

TORRI SMITH TEJRAL: I feel comfortable speaking about the current diagnostic criteria and then talking about the evolution to DSM-V. DSM-IV currently defines an autism spectrum disorder as having significant delay in three core areas: the first being communication, the second being social interaction, and the third is they present with a repetitive or restrictive pattern of behavior. Within the autism spectrum currently we have diagnoses of autism spectrum disorder, we have the diagnosis of Asperger's disorder, and we have a diagnostic category called PDD-NOS. Those are the big three that exist under the umbrella of autism spectrum disorders. When the DSM-V is implemented, what we will see is that those three diagnostic categories are combined into one diagnostic label called autism spectrum disorders. So it has then proposed that what we will see is instead of autism, Asperger's, or PDD-NOS a child would receive a diagnosis of autism spectrum disorders. [LB505]

SENATOR SCHUMACHER: Okay, and then one other follow-up question. [LB505]

TORRI SMITH TEJRAL: Sure. [LB505]

SENATOR SCHUMACHER: When you talk of ABA, the core of that is basically operant conditioning, is that correct? [LB505]

TORRI SMITH TEJRAL: The basis of ABA began in looking at the principles of operant conditioning, but then those principles of operant conditioning are then applied to a range of skills, and we're looking at applying them in a range of environments. Often ABA has the...has been misinterpreted to be overly restrictive and that we only do treatment in environments that may not be natural to the child. However, that is not the case with ABA. ABA is based upon the principles of basic learning. These principles are applied to specific skill deficits for children with autism. They are taught in a systematic and structured format. Once the skills are acquired, our goal is to then work to make sure those skills are available in multiple environments with multiple people to ensure that that child has the most independence that they can have. So to answer your question, yes, that's where we got some of our initial technology, but it has evolved over the course of the last 50 years to include the ability to work on a number of skills in a number of environments. [LB505]

SENATOR SCHUMACHER: But that's just operant conditioning in a proactive design. So, I mean, what we're basically talking...basic learning theory that applies toward behavior and toward disease situations. And we're asking the insurance mechanism rather than the education and funding mechanism or the parenting mechanism or something else to step in and basically deal with a wide range of behavior and fund that. Now what I'm beginning to feel is we need to find a delineation where we cut off what is--we've heard in past testimony--very legitimate things where something has clearly gone wrong with the kid. It's not a behavioral disorder, something is really shorting out. To these things that could be said are, well, they're behavior--they're really kind of extreme--but they're behavior. And what we're trying to do is fund the treatment and saying, well, the best way to fund the treatment of all this stuff is just lay it on the backs of the insurance system rather than the taxing system or the parental system. Where do we make that line between something clearly shorting out and something that is a behavioral problem that maybe doesn't belong in the medical insurance field? [LB505]

TORRI SMITH TEJRAL: In an attempt to answer your question, I would like to clarify that my experience has been working with children with autism. But I also provided outpatient services to children with a host of behavioral concerns, kiddos that weren't good listeners, had ADHD, potentially had oppositional defiant disorder. And as a provider who sees children, the first thing that we look at is what is going on as a result that creates this behavior. So when we're talking about a child with a behavior disorder, there are concerns present and there is a body of research that supports how we affect and how we treat behavioral concerns. When we're talking about a child with autism, their concerns are pervasive developmental concerns. Do these children have behavioral problems? Yes. They have behavioral problems because they don't have the ability to communicate, they don't have the ability to interact socially, and they tend to engage in patterns of repetitive or ritualistic behavior. Now those are behavioral concerns that we often see, but those aren't the result of poor parenting or having poor structure. That is a result of their neurological disability. So in our approach to treatment, the treatment that we would provide to a child with autism is to address the core deficits that are present in a child with autism. When we are looking at that, their ability to communicate affects their ability to have appropriate behavior because they don't have any way to tell you that they're done with an activity, that they want more juice. So we see problem behaviors in these children, but they're not what we see as a behavior disorder. They have autism that affects their ability to have skills in these arenas. [LB505]

SENATOR SCHUMACHER: Thank you. [LB505]

SENATOR GLOOR: Senator Howard. [LB505]

SENATOR HOWARD: Thank you, Senator Gloor. Thank you for your testimony. You mentioned on the second page telehealth, and we've been having a lot of discussion about telehealth in this body. Can you talk about how telehealth works for an autistic child? [LB505]

TORRI SMITH TEJRAL: Well, telehealth, when we're looking at children with autism, involves providing the training and support to service providers that are available or to their parents where they are located. So the service does look a little different because I'm not able to actually sit down and work with a child with autism. However, we are able to work with the family, and if access to additional services were provided we could then work with additional staff that would provide direct service, and we would provide the training and support to those therapy providers. So the therapy looks a little different, but we would still be able to support the family to address those concerns. [LB505]

SENATOR HOWARD: And do you know, is telehealth a covered service on insurance plans for kids with autism? [LB505]

TORRI SMITH TEJRAL: Well, right now, depending upon your plan--and I'm not an expert in all plans--so to the best of my knowledge, autism is often not a covered diagnosis. So it doesn't really matter if you'd like to do services in person or via telehealth, you don't have access to that as a service option. Outside of that arena, I'm not an expert in what telehealth services are covered or not covered, but I would be more than willing to see if I can find that information for you. [LB505]

SENATOR HOWARD: That would be great. Thank you. [LB505]

TORRI SMITH TEJRAL: Sure. [LB505]

SENATOR GLOOR: Other questions? Seeing none...oh, I'm sorry. [LB505]

SENATOR PIRSCH: I'm sorry. I just had a quick clarification. [LB505]

SENATOR GLOOR: Senator Pirsch. [LB505]

SENATOR PIRSCH: You had said under the existing DSM-IV, I believe, that there are independent categories: autism, Asperger's, and then PDD-NOS. So you did say PDD-NOS, right? [LB505]

TORRI SMITH TEJRAL: Uh-huh. Yes. [LB505]

SENATOR PIRSCH: So NOS, not otherwise specified deficit disorder. What's the P for? [LB505]

TORRI SMITH TEJRAL: PDD-NOS--I'm sorry if I did not clarify--PDD-NOS is pervasive developmental disorder not otherwise specified. What that means is they present with developmental concerns, with delays in several areas, but they don't meet the full criteria for autism. So for example, they may present with a communication delay and they may present with social skill delay, but they may not present with a restrictive pattern of behavior. [LB505]

SENATOR PIRSCH: Okay. [LB505]

TORRI SMITH TEJRAL: However, when looking at these children, we often see that there is a pervasive developmental concern so they would fit the PDD-NOS category. [LB505]

SENATOR PIRSCH: I see. Thank you. [LB505]

TORRI SMITH TEJRAL: Uh-huh. [LB505]

SENATOR GLOOR: Any other questions? Seeing none, thank you, Ms. Smith Tejral. [LB505]

TORRI SMITH TEJRAL: Thank you. [LB505]

SENATOR GLOOR: Next proponent. Good afternoon. [LB505]

COLLEEN JANKOVICH: (Exhibit 12) Good afternoon. My name is Colleen Jankovich and I am here to testify on behalf of my son, Matthew, who is affected with autism spectrum disorder. And I have a couple of pictures to show you because I'm definitely going for the cuteness factor here. This is Matthew when he was about two years old splashing in our backyard. Isn't that a great picture? Cute kid. And then this is him...more recent pictures of him now. He's ten and he's sitting on my lap in our kitchen. He's very dear to me. His name happens to mean gift of God, just for the record. Matthew was born a relatively healthy and happy boy, meeting all of his milestones within a reasonable amount of time although he was slightly delayed. And I think in my gut I always knew something was a little off, although I tried my best to just ignore it because no one really wants to admit there's something wrong with their child. Matthew didn't seem to interact well with other children. He only parallel plays still to this day, and I did notice that his speech was starting to regress at about 18 months of age. He was once able to sing happy birthday. He did that to my father who is here with us today. He would ask for specific toys, he loved to play with airplanes. Anything that had wheels, he would ask for those. Specific food--he loves Cheez-Its. And generally, he seemed interested in the world around him. He was a handful, he was very hyperactive, he is destructive to property. We've had to replace all the flooring in our house; it's awesome. He's very disruptive. I would have loved to have brought him here for you all to meet, but he would have just been too disruptive. But I just thought he was being a boy, you know? I thought he was just kind of a rough-and-tumble boy, but I was wrong. Matthew was diagnosed with pervasive developmental disorder not otherwise specified in January of 2004 at age 2. Millard Public Schools provided some early intervention. They taught me to use PECS cards for communication. They're small little cards and they have pictures on them usually with a word underneath it so that he could show me, I want applesauce, I want Cheez-Its. And they eventually enrolled Matthew in a special education preschool. My hope was that he would catch up. He didn't. It was about this time that I learned about ABA, and I was also disappointed to learn that most insurance companies didn't cover it. Still, we put Matthew on the waiting list at Munroe-Meyer Center for Autism Spectrum Disorders. And during the summer of 2007, a part-time slot opened and we took it and Matthew was enrolled in the program. Because my husband's company was self-insured and they are based in North Carolina, they did pay for his therapy, although for only 6 weeks at 20 hours a week. And it is recommended for children on the spectrum with the degree of disability that my son has, to receive 40 hours a week for much longer than 6 weeks. It's usually years and years. Matthew is now about ten and a half years old. He attends a private school that specifically works with children on the spectrum, as public schools in our community simply do not have the resources to deal with my son. He cannot read, he cannot write, he cannot talk, he can't ride a bicycle, he can't play normally with other children, he's still in diapers, he's hyperactive, he's destructive to property, he's self-injurious, he fecal smears and most of us just call it a code brown in the autism community because we have to keep our sense of humor. He is somewhat aggressive towards myself and his siblings. He has elopement issues so I'm not sure I ever actually sleep. Matthew requires 24-hour supervision. I truly feel that if Matthew had received proper early intervention with a recommended 40-hours per week of ABA, he might be in a different place in life. My entire family might be in a different place. Imagine a life with no vacations, no social life, constantly walking on eggshells because you never know how your son will behave. I've done my best to give my children as normal a life as possible, sacrificing my own ambition and desires. I cannot even begin to state how damaging autism has been to my marriage. No one should have to live the way my family does. No one. So I urge you all to please pass LB505 so that no other family should suffer as mine has. If you have any questions, I'd be happy to answer them. [LB505]

SENATOR GLOOR: Thank you. Are there questions? Seeing none, thank you for your personal testimony. Next testifier, please. Go right ahead. [LB505]

CATHY MARTINEZ: (Exhibit 13) Hello, my name is Cathy Martinez, C-a-t-h-y M-a-r-t-i-n-e-z. I'm going to show you some...my cute pictures here. This is my family and my husband Cesar and our four children. This is a picture of Jacob before he received ABA. He couldn't make eye contact, he couldn't look at a camera, doesn't smile on cue. This is a picture of Jacob six years after ABA. Notice the eye-contact difference, notice the smile. As I stated, my name is Cathy Martinez. My husband, Cesar, and I have four children. We live in Lincoln and we are both full-time employees.

Our oldest two children, Madison and Colton, attend Pius X High School. Our ten-year-old, Alex, attends St. John the Apostle. Our youngest child, Jacob, is nine years old and attends Meadow Lane Elementary. Jacob was born in 2003 and was a healthy baby. He developed normally and hit all of the major milestones. In 2005 his development dramatically changed at approximately 20 months of age. At 24 months, he was diagnosed with moderate to severe autism. He lost all language skills, he could no longer make eye contact, respond to his name, or engage in play activities. Jacob spent the majority of his days sitting in the corner banging his head against the wall. He stopped eating all foods and only wanted foods with a very specific texture. We began private speech and occupational therapy immediately. We also utilized Lincoln Public School's home-based service. These services totalled five hours a week of therapy for the first year after diagnosis. We saw minimal progress, if any at all, that first year. We sought advice from Dr. Lorrie Bryant, the pediatric behavioral psychologist specializing in autism spectrum disorders. She recommended ABA for Jake. The cost would be approximately $62,000 annually. She warned us that insurance would not pay for autism treatment in the state of Nebraska. We left feeling devastated that a treatment existed to help our child but our insurance refused to cover it. The next several months were filled with many difficult decisions for us. We knew our son was at the more severe end of the spectrum and desperately needed help. Time was our enemy and we needed to make a decision. Should we commit to an ABA program and put our family in financial ruins or should we deprive our son of the treatment that he needed to recover and know that one day he'd be institutionalized? If we opted for ABA, how were we supposed to pay for the treatment? We are a middle-class family earning under $100,000 a year with four children. How and where would we find that kind of money? We debated if leaving Nebraska and moving to a state with ABA coverage would be the best option for us. No one should be faced with these decisions, yet hundreds of Nebraskans face the same scenario every day. I was so angry that we were put in this position. We decided in December of 2006 to start an ABA program for Jake. It was the most difficult yet most rewarding decision we have ever made. We privately paid for ABA until October of 2011. The first three years, our cost was over $180,000. Because we had seen so much progress that Jake had made with intensive treatment, we continued to do ABA after school and summers once Jake had started kindergarten. The treatment consisted of fewer hours because of his time in school. We paid nearly $20,000 annually for ABA when Jake had started school. In total, we spent nearly $250,000 on Jake's ABA program from 2006 through 2011. We had to eventually file bankruptcy in August of 2010 on the debt incurred for therapy costs. The benefits for a child and family far outweigh the monetary cost and the embarrassment of filing bankruptcy. Our son who once sat in a corner slamming his head against the wall, now can independently toilet, write his name, eat with utensils, play games with other children, dress himself, add and subtract, brush his teeth, get a haircut, and type sentences and reports at school. Jake can look me in the eye again, and responds when we call his name. He has recently learned how to tell time also. He learned to obey simple commands like "stop" and "wait" to ensure his safety. He learned not to leave the house unattended as he once had done. We can take Jake into public places without worrying about his behavior. Through his ABA program, he has completed a food desensitization program and eats meat, fruits, and vegetables once again. Jake has primary insurance through my husband's employer. We pay $1,036.44 a month for our family premium. Jake now has Nebraska Medicaid from the DD waiver as a secondary insurance. We have a $2,000 individual deductible. Medicaid picks up Jake's $2,000 deductible and all other medical bills that his primary refuses to cover. Most children go without ABA in Nebraska because of inability to pay. But standardly, children with autism receive private speech and occupational therapy. A typical prescription for OT and speech is one hour each, weekly. Private insurance companies will cover 20 visits of OT, 20 visits of PT, and/or 20 visits of speech per calendar year. I've included a small chart to estimate the expense of OT and speech that Nebraska Medicaid pays for, for every child with Medicaid as a secondary. Obviously, deductibles will vary for each individual, but the state of Nebraska will save money if this bill becomes law. On Jake Martinez alone, the state would save a minimum of $12,000 annually on speech and OT costs. [LB505]

SENATOR GLOOR: Cathy, I wonder if I could ask you if you can summarize the last couple of paragraphs that you have. Thank you. We've run out of time and so we just need you to speed that up a little if you could, please. [LB505]

CATHY MARTINEZ: Okay. Well, Jake now has Medicaid through the DD waiver, but that's nearly impossible to achieve that status. We had to fight for several months to get that and hire a private attorney and have our senator advocate on our behalf to get that. So Jake is a minority receiving the DD waiver. [LB505]

SENATOR GLOOR: Okay. Thank you. I have a question. Would you take a moment and walk us through your chart of Jake's expenses? [LB505]

CATHY MARTINEZ: Sure. The average cost of speech and occupational therapy is $160 an hour. And that's 1 hour per week, 52 visits per calendar year for 52 weeks. Our insurance deductible would cover...well, the covered by our primary would be 7.5 hours of speech therapy because the other 12.5 hours would be under his $2,000 deductible. So the covered by Medicaid would be $7,120 for speech, given the $2,000 deductible, plus the 32 additional visits over the 20 visits allowed per calendar year. And the same with occupational therapy, but I didn't include the deductible on that occupational therapy. That's why that cost is lower. [LB505]

SENATOR GLOOR: Okay. Thank you. Other questions? Senator Schumacher. [LB505]

SENATOR SCHUMACHER: Thank you, Senator Gloor. Just looking at the occupational therapy thing for a minute, during that hour how many people are working with him? [LB505]

CATHY MARTINEZ: One. [LB505]

SENATOR SCHUMACHER: One? [LB505]

CATHY MARTINEZ: One person, an occupational therapist. [LB505]

SENATOR SCHUMACHER: And it's $160 an hour? [LB505]

CATHY MARTINEZ: It's a medical service. That would be a standard pediatric visit. Our pediatrician charges us $180. [LB505]

SENATOR SCHUMACHER: Is this occupational therapist a pediatrician? [LB505]

CATHY MARTINEZ: No. [LB505]

SENATOR SCHUMACHER: Does it have a level of education residency of pediatrician? [LB505]

CATHY MARTINEZ: I'm not sure what the educational requirements are for an occupational therapist. [LB505]

SENATOR SCHUMACHER: But Medicaid is paying somebody, one person, $160 an hour? [LB505]

CATHY MARTINEZ: I'm not sure what the...if there...I'm assuming that's what we're being billed for on the explanation of benefits. [LB505]

SENATOR SCHUMACHER: And for one person, if you figure they work...have 30 billable hours a week, that comes to almost $250,000 a year. Can that number be right? [LB505]

AUDIENCE MEMBER: Yes. [LB505]

SENATOR SCHUMACHER: Okay. No further questions. [LB505]

SENATOR GLOOR: Other questions? Senator Carlson. [LB505]

SENATOR CARLSON: Thank you, Senator Gloor. I think what happens here, the $160 is split a lot of ways. And it's not only the speech therapist or the occupational therapists. They're not getting $160. [LB505]

CATHY MARTINEZ: There's an owner of... [LB505]

SENATOR CARLSON: That's split many ways and that's how it adds up and you just scratch your head. [LB505]

CATHY MARTINEZ: The clinic may be charging $160 an hour and I'm not sure how it breaks down. [LB505]

SENATOR GLOOR: I would say we have to be careful. We're not sure what the charge is and what the reimbursement rate is. It may be that this is the reimbursement rate, but the issue of costs and charges get intermixed quite frequently. But that's not your problem, but we appreciate your attempt to try and answer it. [LB505]

CATHY MARTINEZ: And it would...ultimately it would save the state money and Medicaid charge. And DD waiver has a cap on Jake of $70,000 annually. And I don't know if this bill would come into effect if that would cause our Coventry of Nebraska to pay the first $20,000 instead of DD waiver because then you would have that on top of the OT and speech to look at as a savings to the state. [LB505]

SENATOR GLOOR: Other questions? Thank you, Cathy. Other testifiers? [LB505]

ROBERT WOODRUFF: Good afternoon. My name is Robert Woodruff, W-o-o-d-r-u-f-f. I wasn't originally planning on testifying today, but I think the spectrum you've seen from people that haven't had services, and along the way I'm kind of at the lucky end of the spectrum. My son was originally preliminarily diagnosed at about a year and half at Munroe-Meyer, and then a formal diagnosis at age four. We started the program when he was age four, and we ran the program for 40 to 50 hours a week primarily out of our house for 8 years. It ran approximately $1,000 a week during that time, and we had no insurance support whatsoever. At that time, he was ready to enter middle school. We had pretty much graduated through all of the programs that were provided. And he was nonverbal at four and progressed that far. I'll tell you now that he's, with minor accommodations in school, he does have a full-time para provided by the school, he's a high honor roll student, he has a job at Wendy's a couple nights a week, he runs a lawn-mowing operation with my other son, he just competed in the state bowling tournament, he's played piano at different times during that, he's going to be on the golf team this spring, and he's driving. He got his driver's license, went through driver's ed this last summer, and has progressed quite dramatically. And I don't know if you saw the program that 10 and 11 did on the news of our family on Sunday night, but I think...why I wanted to come up is I think we're at the other spectrum. You've seen people that couldn't afford the program that have suffered from it. You've seen some that have maybe been able to kind of go halfway, if you will. And we're on the other end of the spectrum, and I think we've had a phenomenal outcome. We've had...at the time when we started the program, there was about a dozen families in the program and now there's really only a couple because just nobody can afford it. We have a nonprofit group that attempted through fund-raisers and things like that to raise some money during that time to help defer the costs, and a lot of those families are here in the room, but I just felt I wanted to give you a little bit of time. I know it's getting late, but we're kind of on the other end of the spectrum. And this ABA program can work. And I think the cost benefit analysis--I don't have any raw numbers to add it up--but I think you've seen that, you know, the...if you can apply some of that up front and incur some of those costs, I think there will be a lot more productive members to society ongoing. So I'd be happy to answer any questions. [LB505]

SENATOR GLOOR: Thank you, Mr. Woodruff. Questions? Seeing none, thank you for your spontaneous willingness to testify. Other testifiers? Hi. [LB505]

COURTNAY VANDEVELDE: (Exhibit 14) My name is Courtnay VanDeVelde, C-o-u-r-t-n-a-y V-a-n-D-e-V-e-l-d-e, and I'm a policy associate at Voices for Children in Nebraska. Voices for Children strongly supports LB505 because we believe it will increase access to critically necessary services for children who are currently being denied. When services are denied...delayed or denied to children with autism in the early years of life, critical windows to intervene are lost. But when early and intensive intervention is provided, it results in improved language skills and behavior, raised IQ levels, and greater success in school. Mandated private insurance coverage allows children with autism to access treatments that have been proven to be effective. ABA therapy in combination with occupational therapy, speech therapy, physical therapy, have been repeatedly established. Prior to moving to Omaha I worked at an autism therapy center as an ABA therapist in Minnesota. My main duties while there focused on providing one-on-one direct care for children on the autism spectrum. The children ranged as young as 18 months up to 8 years. The families paid for the treatments through insurance payments, so I saw the direct impact that changes or cuts in health insurance plans had on the children and the families even when the absence of therapy was only for a month. Currently 34 states include coverage for autism therapy; 4 have limited coverage, and 9 have a mental health parity. Nebraska and Minnesota are currently among those with mental health parity. However, Minnesota's legislature went forward with a concept similar bill earlier this month to support its children and families who are faced with autism, and they are now in the second engrossment with this bill. All children deserve to have the opportunity to be healthy and productive adults. Voices for Children urges the committee to support LB505 as it is important to provide necessary services to Nebraska's children with autism. And I'd be open to any questions you have. [LB505]

SENATOR GLOOR: Thank you, Ms. VanDeVelde. And I have to say that I've been hearing a lot of testimony in a lot of committees over the past four years, but no one has ever worked second engrossment into their comments. So good for you for knowing your legislative process. Are there questions? Seeing none, thank you for your testimony. Additional testifiers who are proponents? [LB505]

SANDRA LUNDEEN: Good evening... [LB505]

SENATOR GLOOR: Good evening. [LB505]

SANDRA LUNDEEN: ...Senator Gloor and distinguished committee members. My name is Sandra Lundeen, S-a-n-d-r-a L-u-n-d-e-e-n. I also go by the name of Nana, N-a-n-a, and I am Tucker's Nana and Tucker is four and he has been diagnosed with autism. They started therapy...ABA therapy five and a half months ago, and they moved from North Platte to Omaha so that he could get therapy. I've seen changes in him already, it's been unbelievable. Please, please, please pass this bill. Don't let our children fall through the cracks. You have no idea how important this is to these people here. I'm sorry, but it's very personal. And you've got to do this for the children of our state and everyone is affected. Thank you. [LB505]

SENATOR GLOOR: Thank you. Just a second if you would, please. Any...are there any questions for Ms. Lundeen? Sorry to bring you back, but... [LB505]

SANDRA LUNDEEN: Okay. I'm done crying. I'm done crying. [LB505]

SENATOR GLOOR: That's all right, not a problem. I don't see any questions, but thank you for coming, back just in case. [LB505]

SANDRA LUNDEEN: Thank you very much, everybody, for listening to everybody here because we need all of your help. Thank you. [LB505]

SENATOR GLOOR: Thank you. Additional testifiers as proponents? Good evening. [LB505]

KARI KENSINGER: (Exhibit 15) Senator Gloor, members of the committee, I thank you for letting me testify. My name is Kari Kensinger, K-a-r-i K-e-n-s-i-n-g-e-r. I just recently moved back to Nebraska after living in Florida and Michigan for a few years, and I sent you guys an e-mail. And I want to just say I got responses back immediately from you guys which is exciting to see, and I'm glad to be back home. I'm testifying on behalf and representing the Nebraska Recreation and Parks Association, and personally and professionally I support this legislation. I've worked for over 25 years with individuals with autism. When I was in middle school I began volunteering at the Munroe-Meyer Recreation Therapy Program and it launched my career pretty much. I am a certified therapeutic recreation specialist, I'm a certified autism specialist, I earned by Ph.D. from the University of Florida in Therapeutic Recreation. And my bachelor's and master's degree is from UNO. I've worked with individuals with autism in home settings, community settings, schools, and hospital-based settings. Along the whole continuum of care, I see...getting to Senator Schumacher's concerns about healthcare, I have seen what this looks like in the hospital setting as compared to home and community and the continuum of care of when you can't get this stuff under control, what happens when they end up at places like Richard Young. And it is my position after seeing kids with autism benefit from ABA therapy that they can get that under control as a preventative measure. I'm currently president of the Recreational Therapy Foundation and I know there's some concern that recreational therapy does not have evidence-based practice. Our foundation funds research in recreational therapy and we helped kind of establish that. The reason I support LB505 is that it will help individuals with autism and their families receive the services that they need. When I first heard about ABA, I saw a kid...I was working 40 hours a week providing ABA before there was a certification, in their home under the supervision of an ABA specialist. I saw a child increase their vocabulary by over 500 words in less than 3 months, and they were fairly severe at the time. I've seen individuals with autism show decreased agitation through sensory integration by an occupational therapist, and I have witnessed frustration levels decrease when children have the augmentative communication devices, and this legislation will help fund all of that. Recreational therapy is not included in this legislation, and we kind of looked at this under section (h) where there's therapeutic services provided. And we just wanted to get us on the radar a little bit to say that: (a) we support everything that everybody has talked about, but we wanted to try to see what we would need to do to get recreational therapy on the radar. As far as cost effectiveness, I've provided you with a document that shows that we get paid 22 percent less on average than the other therapies, yet CMS, Carter Joint Commission, they all recognize us as a skilled therapy. And we can complement what ABA professionals and the other therapies do as part of a treatment team. And there's a shortage of healthcare professionals, and we would help add to some of that. It's getting kind of late, but I've given you a lot of information here for you to understand what a recreational therapist is. We get at least a bachelor's degree in psychology, health and human services, leisure behavior, human growth and development, anatomy and physiology, pharmacology. We are an allied health discipline, we are an education discipline, we are a corrections discipline so we work in a lot of settings. My personal interest has always been children with autism. And so in getting to that point, three of the diagnostic criteria associated or identified in the DSM are social skills, deficits in communication skills, and those repetitive behaviors include leisure and play skills or, at least, the old versions of the DSM used to say play skills. We teach those three areas in every clinical setting, every community-based setting, every home-based setting. As far as evidence-based practice, the National Professional Development Center for ASD says that there are 24 evidence-based practices. I've provided a list with all of those evidence-based practices that we have been trained to use parts of and have been implemented. And so I just provided you with a lot of resources just on recreational therapy and to let you know that our profession supports this initiative. [LB505]

SENATOR GLOOR: Thank you, Dr. Kensinger. Are there questions? Senator Christensen. [LB505]

SENATOR CHRISTENSEN: Thank you, Chairman. Question. Just reading here what it says, recreational therapy means treatment service designed to restore, remediate, and rehabilitate a person's level of functioning and independence in life's activity and promote health and wellness. What would...that definition would be very similar to physical therapists, wouldn't it? [LB505]

KARI KENSINGER: We work with physical therapists, occupational therapists, and speech pathologists in treatment teams across the country and in different settings. And our approach uses recreational leisure as our primary modality, so we primarily use things that patients like to use. And depending on what setting it is, we complement what they do and we use it more from a strength-based or based on their interests...their leisure interests. [LB505]

SENATOR CHRISTENSEN: Okay. I'm very familiar with it because I have a boy with Down's syndrome that's 15, doesn't walk, doesn't talk, has maybe three or four signs he does. And it's just been a struggle. So that's why I wanted to know if there's something else I could try and drag into my situation. So... [LB505]

KARI KENSINGER: We help teach them whatever skills that they need that maybe one of the other therapies aren't doing or we may complement what they're doing as far as gaining those skills in a more generalized or natural environment. A lot of times, in physical rehab hospitals we will take them out to a general setting. But using the ABA approach, we'll take a child with autism who may be learning these skills at home and using those same skills at the bowling alley or using those same skills so that they're prepared to enter the bowling alley. [LB505]

SENATOR CHRISTENSEN: Thank you. [LB505]

SENATOR GLOOR: Other questions? Seeing none, thank you. And am I correct in that you have an uncle who used to be a fiscal analyst for the Legislature? [LB505]

KARI KENSINGER: Yes, he was here. He passed away five years ago. [LB505]

SENATOR GLOOR: I'm sorry to hear that. [LB505]

KARI KENSINGER: So it was...and his birthday was this week. So thank you very much. [LB505]

SENATOR GLOOR: I'm sorry to hear that. We honor his service to the Legislature. [LB505]

KARI KENSINGER: Thank you. Thank you very much. [LB505]

SENATOR GLOOR: (Exhibits 16 and 17) Thank you. Other testifiers who are proponents? Testifiers who are in opposition? And I have a letter here from The Association of Insurance and Financial Advisors that is in opposition to LB505. Testifiers in a neutral capacity? And while they come forward, we have a letter from the Department of Insurance that is very similar to the other 403 letters I've handed out today that is in a neutral capacity, and we'll hand that out also. Good afternoon, Doctor. [LB505]

DEB ESSER: (Exhibit 18) Good afternoon. Hello again, Senator Gloor and members of the Banking, Commerce and Insurance Committee. My name is Dr. Deb Esser, D-e-b E-s-s-e-r. I'm vice president of medical affairs for CoventryCares of Nebraska. On behalf of Coventry Health Care of Nebraska, Blue Cross and Blue Shield of Nebraska, and UnitedHealthcare we would like to offer neutral testimony for LB505 as introduced in this committee this afternoon. For the tenured members of this committee, you may be surprised to hear that the major insurance carriers of Nebraska are not opposing Senator Coash's bill to provide insurance coverage for autism spectrum disorder in Nebraska, although this is perhaps the first time we have weighed in on a neutral position on a mandate bill of this kind, all three carriers have been involved in meetings over the interim with both Senator Coash and former member of this committee, Senator Beau McCoy, to discuss this exact issue. Over the legislative interim, representatives of all three healthcare insurance companies and other stakeholders met to discuss policy considerations regarding insurance coverage for autism. And our three companies have continued these dialogues, especially as they relate to LB505. And as a result, we will be offering model language from other states for both Senator Coash and this committee's consideration. As we have heard, autism has variations or ranges in delays or impairments, thus the name autism spectrum disorder. As insurers, we agree that early detection and treatment will give the highest benefit. We also agree that coverage for autism has been at the forefront of legislative debate, both nationally and locally, and we are committed to being a part of that discussion in Nebraska. Insurers would like to continue to work with the legislators on coverage language through an organized work group and would commit to strong advocacy for this process to move it forward. We believe a good starting point for these discussions would be age limitations of coverage and possible cap coverages. Thank you. [LB505]

SENATOR GLOOR: Thank you, Dr. Esser. And just to make sure that...and for the record, you are providing this testimony on behalf of Coventry, Blue Cross, and United. This is on Coventry stationery, but the narrative underneath also represents the stand of the other two insurers. [LB505]

DEB ESSER: That is correct. [LB505]

SENATOR GLOOR: Okay. Thank you. Are there other questions for Dr. Esser? Senator

Christensen. [LB505]

SENATOR CHRISTENSEN: Thank you, Chairman Gloor. If you guys aren't in opposition of this and willing to work with the language, why don't you just implement it instead of having us do this? [LB505]

DEB ESSER: We have discussed at length what the major insurers in the past...I can't really speak historically why coverage for autism has not been covered. I can only speak to this point going forward that we have been in discussions and that we do think that it probably is time for this to be brought forward. We're not opposed to a mandate because it evens the playing field across the insurers, and I suppose that's probably one of the reasons why. We are willing to work on this, we have been working and discussing for several months and would like to continue those types of discussions. [LB505]

SENATOR CHRISTENSEN: I appreciate that answer, a level playing field makes sense. Thank you. [LB505]

SENATOR GLOOR: Other questions? Seeing none, thank you, Dr. Esser. [LB505]

DEB ESSER: Thank you. [LB505]

SENATOR GLOOR: Anybody else who would like to provide testimony in a neutral capacity? Senator, you're welcome to close. [LB505]

SENATOR COASH: (Exhibit 7) Well, this should only take about an hour. [LB505]

SENATOR GLOOR: We are at your beck and call. [LB505]

SENATOR COASH: I'm just kidding. I wrote down a quote that I just heard and I just want to repeat it. The last testifier--they're not opposed to a mandate. It's a pretty big deal. It's a big deal and I want to commend them. They've been partners in this. It's been a year of work. Senator McCoy who used to serve on this committee was very helpful, and I appreciate his leadership on this issue even though he's not on the committee anymore. And I want to thank you all for your patience. I know this was a long day. I've told some of the testifiers that your questions show that you care, and that's very much appreciated. Thirty-two states do this, so we'd be 33. So this...we're not charting new territory here. There is a cost to doing this and we've had a lot of discussion on that, but there's a cost of not doing this as well. And the one thing that stood out to me as I listened to all the testifiers, one of the testifiers talked about special ed and how half of the children who get these services early do not find themselves in special ed. Now consider that in our world here where we put almost half of every dollar that the state gives us back into education. And how much of that do we filter into special ed? This prevents the need for special ed, and I think that became clear through the testimony. This works. This treatment works. It's not a newfangled thing that we're trying out. This is a thing, this is a treatment modality that is effective and it works. I was really taken aback by one of the testifiers who said his son was nonverbal, got this treatment, now he works and he drives a car and he's going to go to college. From a kid who couldn't speak to get to that point as a result of this therapy is a pretty special thing. These kids are counting on us and I appreciate your attention to this. This was a good hearing, and it was late, but I do appreciate the attention. [LB505]

SENATOR GLOOR: Senator Coash, I wasn't able to make your opening, but... [LB505]

SENATOR COASH: I got it. You want me to say it again? Just kidding. [LB505]

SENATOR GLOOR: That's right. It's at your own risk, but I'd be glad to stay here. I would listen to you, Senator Coash, you know I would. In your opening, did you mention the fact...did this not start with a legislative resolution this past year, and then some of these discussions then were part of that legislative resolution? [LB505]

SENATOR COASH: Yes. This was a result of a legislative resolution. I introduced a similar bill last year, and what that did was allow for an actuarial study of our own state... [LB505]

SENATOR GLOOR: Okay. [LB505]

SENATOR COASH: ...which has been provided to the committee. That was a really good first step because we were able to use our own state's data to get that study, and that's been provided to the committee. And that's why I feel very confident in the accuracy of the testimony that you all received with regard to the impact on costs of premiums. This wasn't, well, we think it will cost this much. We did a study. And we spent money--the state didn't spend money--but there was significant money spent to try to figure out how much this would actually cost so that I could come back to the committee this year and give you data that would say, this is what we know this treatment will cost. It's not free and premium payers will pay a little more. That is the reality, but it is not a break-the-bank thing, and so I'm happy to report that it's not going to sink anybody if we do this. [LB505]

SENATOR GLOOR: Thanks for taking the time to come up with some hard numbers. That certainly makes the decision process an easier one for the committee. Other questions for Senator Coash? Senator Carlson. [LB505]

SENATOR CARLSON: Thank you, Senator Gloor. Now I'm missing something here and we've got a stack and I don't know where to look in the stack, but somehow, these hard figures you're talking about, make sure I get those. Okay? [LB505]

SENATOR COASH: Okay. [LB505]

SENATOR CARLSON: Because I'm paying attention to costs, and you can't help, but pay attention to costs. And I'd like to...I liked Mr. Wasmer's chart that he gave us, and I think that was zeroing in on actual costs of the benefit. But we know that insurance companies have additional costs because it costs them to process a claim, and I may corner him afterward. But I think that we've got that cost of the benefit plus the cost...and Senator Schumacher brought up some things about...which led me to believe, you know, the diagnosis and determining that it's actually autism and it's not something else, and the insurance company's got to make sure that's what it is before they pay it. I think it's more expensive than most other claims that are treated. But I just need to get my head around that, and so I appreciate your effort on that part and make sure I get the figures. [LB505]

SENATOR COASH: So moved. Done. [LB505]

SENATOR GLOOR: (Exhibit 19) Other questions? Thank you, Senator Coash. And that will end the hearing on LB505. Thank you all for your patience. [LB505]