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Health and Human Services Committee  
February 11, 2016

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[LB804 LB891 LB985 CONFIRMATION]

The Committee on Health and Human Services met at 1:00 p.m. on Thursday, February 11, 2016, in Room 1510 of the State Capitol, Lincoln, Nebraska, for the purpose of conducting a public hearing on Department of Health and Human Services, Division of Behavioral Health Committee Briefing; confirmation hearing of Sheri Dawson, LB985, LB804, and LB891. Senators present: Kathy Campbell, Chairperson; Sara Howard, Vice Chairperson; Roy Baker; Sue Crawford; and Merv Riepe. Senators absent: Nicole Fox; Mark Kolterman.

SENATOR CAMPBELL: Good afternoon and welcome to the hearings of the Health and Human Services Committee. I'm not going to go through all of the procedures that we usually do because we're starting at 1:00, because we're hearing a report from the Division of Behavioral Health overview, and then we'll have the confirmation hearing for Director Sheri Dawson. And then we will start taking the bills after that. So if you've come to testify on a bill, sit back, relax, you've got a little while. Okay? I'm Kathy Campbell and I serve District 25 which is east Lincoln. And we'll go around this way...

JOSELYN LUEDTKE: Joselyn Luedtke, committee counsel.

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

SENATOR RIEPE: Merv Riepe, District 12, which is Millard, Omaha, and Ralston.

CLERK: I'm Elice Hubbert, I'm committee clerk.

SENATOR CAMPBELL: Okay. And we expect Senator Howard and Senator Baker shortly. Senator Kolterman and Senator Fox will not be here this afternoon. So, Director Dawson, go right ahead. We're glad to have you.

SHERI DAWSON: (Exhibit 1) Okay, well thank you for having me. So I'm going to share with you what's happening with the Division of Behavioral Health. And just a reminder that I really feel like we provide very important and life-sustaining services and help individuals reach their full potential. So we definitely fulfill our mission to help people live better lives. And it is very important in our culture and we are committed, both at DHHS and in the Division of Behavioral Health, to carry out ourselves with trust, with accountability, with competency, and transparency. So I want to talk to you a little bit about what we do in case you don't know about the Division of Behavioral Health. So we very much believe that prevention works, that treatment's effective,

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and that people recover. And what we do is all about those three things. We provide community-based services primarily through the six regional behavioral health authorities, but we also have additional community-based services for individuals that are a member of tribes, for those that are served at Lasting Hope Recovery Center, and a variety of other services such...I think you all are familiar with the Family Helpline and the Family Navigator service as well. And we operate three regional centers. So at the Norfolk Regional Center, we serve Phase I of individuals that are on a commitment for sex offender programming. And we can serve 90 to 95 individuals there. At Hastings Regional Center, we have a psychiatric residential treatment facility that will serve young men that have substance use disorder or co-occurring disorders. And most of them have some connection with the court or Probation. At the Lincoln Regional Center, we have a little more mixed population in that we have 90 individuals that are served under a Mental Health Board commitment. We have individuals that are there for forensic or court reasons, so they're there for competency evaluation, competency restoration, or deemed to be not responsible by reason of insanity. We also have Phase II of the sex offender program at Lincoln where individuals are in a secure residential treatment facility. And then we also have individuals out on the Whitehall Campus. So we serve young men in a psychiatric, residential treatment facility that have sexually harmed, and treatment for that. We also have a Network of Care; and I don't know if you're familiar with that, but that is a Web-based resource that is helpful to individuals to find out information about different illnesses, wellness recovery action plans, provider support groups, just...it's a nice resource for individuals looking for information. Accomplishments, I have a list, so I won't dwell, because I'm a crowd person, but we have accomplished a lot. First of all, I'm very proud that we have a very talented team of our senior leadership team. Have hired Deputy Director Tamara Gavin and Linda Wittmus. And we have our chief clinical officer, Dr. Todd Stull. And I really appreciate Dr. Stull is coming into a new vision of a chief clinical officer role. So it's not just for the Division of Behavioral Health, but is also serving Medicaid. So that Heritage Health integration will be a nice fit under that chief clinical officer role. And we also have Anthony Walters who is now on board as our CEO of the three regional centers. There's one key position that is still yet to be filled. It's posted and it will be the administrator for our Office of Consumer Affairs. So I will be really excited to complete that process and have our full team in place. We have developed and implemented a 2016 strategic action plan. So it guides our work for this year as we move forward, while we're working with the needs assessment in collaboration with the division of...let's see, I've got to get this right...UNMC College of Public Health is doing our needs assessment for the larger behavioral health system. And 2016 is...the plan just guides our work for this year. We've developed and operationalized the children's System of Care plan with key partners. And because it's very important in terms of serving people that you have adequate work force, we're working hard with BHECN, the Behavioral Health Education Center of Nebraska and our other federal agencies that are also have initiatives on developing the behavioral health work force. We developed a data-sharing memorandum of understanding with Medicaid, which was a nice innovation that we used to problem solve and avoid a penalty for a federal grant. Federal grants require a maintenance of effort which is,

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basically, their way of making sure that the state has the non-federal investment in dollars and expenditures. And for a variety of factors with Medicaid and Magellan and the Division of Behavioral Health it looked as though expenditures were less. And so that would have opened us up to the opportunity for a penalty. However, we knew that Medicaid was serving individuals for behavioral health. And so, creatively, we thought, well, if we can share data, we can make our case that we're still serving and spending the same amount in Nebraska. And so we were able to do that and avoid a penalty. We've also initiated an office for facilitation of recovery at the Lincoln Regional Center. We are...have been working with UNL's Public Policy Center to help us identify research models for a peer-bridge program. And peer bridgers are individuals that provide peer support and help transition individuals from hospital into the community. And so we look forward to rolling that out in the next months. Nebraska was selected for a multistate symposium for supported employment in December of 2015, and we were selected because of our work in collaboration with vocational rehabilitation. And we have developed a milestone payment system; so we share different milestones, or pay for different outcomes, so it's a nice example of braided funding. And hopefully, again, with braided funding we can serve more folks. We initiated Norfolk Regional Center and Lincoln Regional Center quality initiative to really look at that sex offender program, those phases I talked about, to raise clinical excellence and really help us, again, continue with patient flow. The Lincoln Regional Center was named the top performer for quality issues by the Joint Commission; and I might say that it was for the third year in a row. And they're the only psychiatric hospital in Nebraska to be honored and the only hospital in Lincoln, and 1 of only 8 of 25 that submitted data. So we're very proud of that and they worked very hard to accomplish that. Hastings Regional Center, with the young men, also doing a clinical excellence in operational quality improvement initiative and looking at costs and how we can continue to provide services there in a cost-effective way. Norfolk Regional Center has a...we updated their safety and security area, which is for individuals that are having some challenges with their behaviors. And so we have a safer and more therapeutic environment for...at the Norfolk Regional Center. Both Lincoln and Norfolk Regional Center host clinical sites for nursing. And we have a nursing shortage, so that's a really helpful opportunity for students to see the work that we do. Also, testing and certification of peer support, wellness specialists, it's really important for us to continue to develop peer support in Nebraska and develop our behavioral health work force. And lastly, we've worked on our Mental Health Board commitment training; that's a responsibility that we have. And it's been updated and the new training will roll out to the Mental Health Board commitment, board members as well as others interested; so that will roll out this spring. And then looking ahead: very excited about having our very own data system for the first time in years. We have always utilized Magellan Data System, and we've appreciated that partnership, but this data system will provide us a couple of advantages. Certainly one is the ability to have clinical and interface with the providers and the region so we can also look at units of service and our outcomes. But the greatest opportunity we have is to be able to do reports for planning. And providers and regions, based on security level, will also have access to their own data to really be able to help that local planning effort as well.

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We've been invited to a national IT conference to talk about our data system because it's kind of unique and so we're anxious to do that in March. Further development of a system of care for children and youth: comprehensive needs assessment--I touched on that earlier through the legislative performance audit. We're going to continue to meet those recommendations and do that larger system, not just the Division of Behavioral Health, but larger system needs assessment. And we're very thrilled with the partnership with the College of Public Health and the resources and the data that they'll really be able to help us with that needs assessment. Behavioral health supported employment: we want to continue to provide opportunities for folks with mental illness to have the opportunity to work. And we need to continue to change the environment in which we work so that folks understand recovery. That the first conversation you don't have when you're a person with mental illness is you need to get on disability. That we really talk to them about the opportunities and goals that they have. Behavioral health supported housing: Of course it's important for all of us to have a home...a place we can call home and stable housing so that will, again, allow us some additional opportunity to help focus on...as we work through recovery issues. And we have engaged a consultant that will be working with us this spring. Peer support and wellness specialist credentialing: I mentioned that in accomplishment. We have a project that we have partnered with Behavioral Health Education Center of Nebraska and now, when we have our new administrator in the Office at (sic: of) Consumer Affairs, will help that credential and that credentialing process, and I think there's opportunities for us to do some things differently and raise the bar on that credential and grow the work force. Lincoln Regional Center capacity: We've had some challenges. And so really looking at that community-based flow from the regional center into the community and really looking at all the opportunities for us to make sure that we're...we have the capacity to serve folks and minimal, hopefully no, wait. But right now we're working on minimizing the wait. And we've partnered with Corey Steel and Judy Beutler and the Court Administrator's Office for those individuals that come to us through court and have...really had some good success in minimizing the wait list for individuals there through the court. And then address the nursing shortage and other work force challenges. The Lincoln Regional Center is experiencing a nursing shortage. And we continue to kind of have a multipronged approach. Behavioral health is challenging and not all nurses are interested in that; and so we're continuing to reach out and figure out ways to help folks be connected and understand behavioral health. And then, lastly, is my contact information for you and I'm always happy to hear from you, constituent issues, questions, and happy to help, or have my team assist you. [DHHS BRIEFING]

SENATOR CAMPBELL: Director, I just want my colleagues to know I really appreciate the openness that we're seeing through the department. My legislative aide followed up from the hearing on the Olmstead Bill and dialed and got the director directly, which is...that's refreshing for us. And we really appreciate your help on the suggestions. You'll see it in the amendment to the bill which took care of that concern. And we really appreciate your help. [DHHS BRIEFING]

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SHERI DAWSON: You're welcome. [DHHS BRIEFING]

SENATOR CAMPBELL: Questions from the senators? Senator Riepe, and then we'll work around here. [DHHS BRIEFING]

SENATOR RIEPE: Thank you, Senator Campbell. And thank you for being with us. As Medicaid integrates physical and mental health, which I think is good, what...and you've had Magellan at your site as we've gone along. There's going to be significant change coming; how will you approach that and what are your expectations? [DHHS BRIEFING]

SHERI DAWSON: Yeah, well, expect to be at the table, because there's no health without behavioral health. And we do understand it will be a challenge, because we have had to carve out and separate conversations. So the chief clinical officer role, as I mentioned, serving as both Medicaid psychiatrist, as well as that for Division of Behavioral Health will help us with that clinical part of any of those discussions. We also will be part of the actual MCO conversations and quality groups and planning groups that will roll out Heritage Health. So we will be at the table. And we definitely don't want behavioral health to get lost amongst all the physical health conversations. And so we will be very, very assertive. [DHHS BRIEFING]

SENATOR RIEPE: Do you have someone who that's going to be finding out what United and Aetna and the new group that's coming in... [DHHS BRIEFING]

SHERI DAWSON: Centene, the Nebraska Total Care. [DHHS BRIEFING]

SENATOR RIEPE: Centene...that what they currently do in other markets? [DHHS BRIEFING]

SHERI DAWSON: You know, I don't have a staff person doing that right at this time. But I know that Medicaid has some information, we'll certainly look at that. [DHHS BRIEFING]

SENATOR RIEPE: The only other thing that I had is this presentation in March, if that's in Jamaica, our chairmen, Senator Campbell, might want to attend it. [DHHS BRIEFING]

SHERI DAWSON: Oh, well, it's not in Jamaica. [DHHS BRIEFING]

SENATOR RIEPE: Okay. [DHHS BRIEFING]

SHERI DAWSON: But we'll share the information anyway. [DHHS BRIEFING]

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SENATOR CAMPBELL: Okay. Senator Crawford, you had a question. [DHHS BRIEFING]

SENATOR CRAWFORD: Thank you. And welcome, Director, I appreciate having you here and the update on what's happening. I just wondered if you...on the accomplishments that you talk about testing and certification of peer support and wellness specialists. So have you created a new certification for people with both of those titles? Is that what has happened? [DHHS BRIEFING]

SHERI DAWSON: No, one of the looks, if you will, or research that we've done, is done a peer support work force survey. And we worked with the University of Nebraska-Lincoln, Public Policy Center. So currently what happens is, the Division of Behavioral Health does the testing; but also, a lot of the training. There is some additional training. And if you think about other credentials, most of them have certain topics that should be included in training, and then the state still does the certification. And so we really looked at that survey to identify what are those opportunities that we have to do that differently. Because if we can only provide training so many times a year, it's going to be more difficult to grow that work force. [DHHS BRIEFING]

SENATOR CRAWFORD: Okay. So you're still...so still the process of figuring that out or you haven't, really, created something now, or someone else does the training? [DHHS BRIEFING]

SHERI DAWSON: We have the results of that survey and we have with BHECN, which was the Behavioral Health Education Center of Nebraska, they started Project Propel which pulled a lot of individuals that are peer support and wellness specialist certified. [DHHS BRIEFING]

SENATOR CRAWFORD: Okay, okay. [DHHS BRIEFING]

SHERI DAWSON: So now they have feedback into the service definition to actually have peer support as a service definition. And to also think of it as an umbrella so that it's not just for adults, but also family peer support, as you're probably familiar with. And also could be transitional age youth. So there's recommendations and the survey results ready to take that next step. [DHHS BRIEFING]

SENATOR CRAWFORD: Okay. [DHHS BRIEFING]

SHERI DAWSON: But the accomplishment was getting that far. [DHHS BRIEFING]

SENATOR CRAWFORD: Okay, thank you. [DHHS BRIEFING]

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SENATOR CAMPBELL: Senator Howard. [DHHS BRIEFING]

SENATOR HOWARD: I also had some questions about the peer support. I had a bill about opioid substance abuse and rehabilitation treatment. And one of the pieces of that type of treatment is peer support. And are you working with the Medicaid Long-term Care Division on the state plan amendment to be able to bill for peer support services? [DHHS BRIEFING]

SHERI DAWSON: We have had conversations about peer support. As you know, there's not all Medicaid divisions across the nation that provide that. But it's been very exciting to hear the conversation about peer support. So we will be there because we have the experience and have the program. [DHHS BRIEFING]

SENATOR HOWARD: And then for peer support specialists and wellness specialists, are they subject to the 407 process the way that most other medical providers are? [DHHS BRIEFING]

SHERI DAWSON: Not yet. But again, you know, when we talk about getting that certification credential, certainly that could be a future...a future step. [DHHS BRIEFING]

SENATOR HOWARD: And that would be part of them being able to bill through Medicaid as well? [DHHS BRIEFING]

SHERI DAWSON: It could be. It depends on what those stipulations are for them to be able to bill. Sometimes it's by supervision level of who might supervise them, that kind of thing. So we'll have to see how that plays out. [DHHS BRIEFING]

SENATOR HOWARD: Okay. Thank you. [DHHS BRIEFING]

SENATOR CAMPBELL: Director, do we have a waiting list for the Hastings facility, that program for adolescent boys, do you know? [DHHS BRIEFING]

SHERI DAWSON: I don't know the answer to that. I can tell you from a couple of weeks ago, we had a couple of individuals that were in detention, ready to come in, so I don't know today what that looks like. But we're not full, and so part of that is just getting all of the paperwork and the processes done to be able to get them in. [DHHS BRIEFING]

SENATOR CAMPBELL: For a while there, we had...it seemed to me we had a number of facilities, residential treatment for adolescents. And then when we went through the whole IMD

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and that whole area between Medicaid and child welfare, how are we doing in terms of residential treatment facilities for adolescents? [DHHS BRIEFING]

SHERI DAWSON: You know, I'm going to have to get the answer for you from Medicaid, because Medicaid has the psychiatric residential treatment facilities... [DHHS BRIEFING]

SENATOR CAMPBELL: Okay. [DHHS BRIEFING]

SHERI DAWSON: ...in terms of numbers and those kinds of things. Our two that we have in the Division of Behavioral Health-Hastings and Whitehall are psychiatric residential treatment facility and those two are the only...in the case of Whitehall, it's the only PRTF that serves that population. And on the Hastings side, I know there's only one other substance use only PRTF. [DHHS BRIEFING]

SENATOR CAMPBELL: Because I would assume as we go along that's going to be an issue in terms of mental health for children and adolescents. We continue to hear questions about that and how should it be handled and what more do we need? So at some point along the way, and I know you're working on a strategic plan for the division, but I'm sure at some point we're probably going to talk more about that. [DHHS BRIEFING]

SHERI DAWSON: Yeah, yeah, and you know, and in the children's System of Care as we look at, again, what services currently exist and how are we spending our money, that will certainly be a part of that, because it's across child-serving agencies, not just Medicaid funding. It would be probation and other child-serving agencies. [DHHS BRIEFING]

SENATOR CAMPBELL: Absolutely. When we did the child welfare, we hired a consultant who looked at the many streams of money that went into children's mental health. And at some point, we may want to replicate that. But it was an eye opener at that point to the Health and Human Services Committee because we had no idea all of the different funnels that were going into child mental health. [DHHS BRIEFING]

SHERI DAWSON: Yes. Yes. We actually have a consultant trying to help...do some of that mapping and data across the system so we'll be, hopefully, ready when children's System of Care is ready. [DHHS BRIEFING]

SENATOR CAMPBELL: Good. [DHHS BRIEFING]

SHERI DAWSON: And we used...we looked at the past information. [DHHS BRIEFING]

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SENATOR CAMPBELL: Well, good. At this point, when do you think you'll be at that point of having the strategic plan done? [DHHS BRIEFING]

SHERI DAWSON: For...on our adult system, we're doing the needs assessment with the College of Public Health, that's targeted to be done June 30. And then the strategic planning will follow and we hope...our target date is to have it done at the end of the calendar year. [DHHS BRIEFING]

SENATOR CAMPBELL: Okay. At any point where you at...finishing and think it would be helpful for us to kind of catch up with you to where you are, feel free to give our office a call and we'll set up a briefing because I do think children and adolescent mental health is going to keep bubbling up, certainly in this committee and the Legislature. We're just seeing it more and more. [DHHS BRIEFING]

SHERI DAWSON: Yes, yes. And we'll be more successful in helping them be healthier the early we intervene. [DHHS BRIEFING]

SENATOR CAMPBELL: Good. One last question, with the adults, has there been any conversation with you about mental health courts? [DHHS BRIEFING]

SHERI DAWSON: I have been asked a couple of questions about it. I honestly have to say I haven't done a lot of research on that, but I have been asked a couple of questions. [DHHS BRIEFING]

SENATOR CAMPBELL: I don't know whether there's a bill going to come forward on that. There was some discussion about it, I know. Senator Williams had a real interest. And I know that would be in the Judiciary Committee, so I don't know whether it's there or coming out...don't know very much about them. Might be calling you up. [DHHS BRIEFING]

SHERI DAWSON: Yeah, okay, and we'll have to do some research as well. [DHHS BRIEFING]

SENATOR CAMPBELL: That is great. [DHHS BRIEFING]

SHERI DAWSON: Know very little at this moment. [DHHS BRIEFING]

SENATOR CAMPBELL: That is great. Okay. Any follow-up questions, Senators, that you want to make? Thank you, Director Dawson. It's always helpful to have an update. We will go directly

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into the confirmation hearing for Sheri Dawson as Director of DHHS, Division of Behavioral Health. And I'm assuming you have an opening statement you want to give us.  
[CONFIRMATION]

SHERI DAWSON: Yes, I do. [CONFIRMATION]

SENATOR CAMPBELL: When you're ready, go right ahead. [CONFIRMATION]

SHERI DAWSON: (Exhibits 1 and 2) Okay. Well, good afternoon, Senator Campbell and members of the Health and Human Services Committee. My name is Sheri Dawson, S-h-e-r-i D-a-w-s-o-n, and I serve as the Director of the Division of Behavioral Health. And I've been privileged to serve in this capacity since August 13, 2015. So I appreciate being here today. And over the past months, I've had the opportunity to meet with consumers of behavioral health services and system partners. I'm grateful for the expression of their ideas and concerns and experiences. In my opinion, there is no health without behavioral health. One in four people are diagnosed with mental illness or substance-use disorder. These illnesses touch our families, our neighbors, and our communities. Twenty-five percent of hospital admissions in Nebraska are related or touched by behavioral health diagnoses. Half of all lifetime mental illness starts at the average age of 14, and 75 percent by age 24. So it's important that we continue to develop a system that provides the opportunity for recovery to those we serve. I'm just going to share a little bit about my background and talk about how I believe we can work together to transition Nebraska system into a national leader. So I'm a registered nurse. I graduated from the Bryan School of Nursing and earned a Bachelor's of Science Degree from Nebraska Wesleyan in Health Sciences for Nurses. I began my career as a staff nurse at the Annie Jeffrey Memorial County Hospital in Osceola, Nebraska. And because of the kinds of experiences there it was the best opportunity for a 21-year-old rookie nurse. My husband and I moved to Texas where I worked as nursing coordinator at Charlton Methodist Hospital in Dallas, and the patients I served there were dealing with chronic illnesses and many struggled with the life change that that disease presented. I found myself focused on assisting individuals with their behavioral health issues and a neurologist with whom I worked had noticed how I had taken the time to listen and talk with patients, give them information. And he told me about a new psychiatric hospital in the area and thought it might be a great fit. So I took my nursing career from the medical arena into behavioral health service provision at Willowbrook Psychiatric Hospital. And here we served adults and young people who were struggling with mental illness and substance-use disorders. My husband and I returned to Nebraska where I worked in the state hospital system as the associate director of nursing for nursing in-service and quality assurance at the Lincoln Regional Center. I loved the opportunity to shape nursing policy and impact patient care through quality improvement. To grow my leadership skills, I moved to Lincoln General Hospital, now Bryan Health, in 1993, and I served as the nurse manager for the child and adolescent psychiatric services. I was a founder of the child advocacy team and at the hospital...and one of eight

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individuals that were founders or developers of the Child Advocacy Center here in Lincoln where they still continue to do very important work with children and families in crisis. While raising two daughters, I returned to public service as a nurse surveyor-consultant, which is now the Division of Public Health Licensing Unit. And I surveyed assisted living facilities, mental health centers, and substance abuse treatment centers. But my passion for behavioral healthcare led me to apply for a program specialist position in the Division of Behavioral Health. And I've served in a variety of roles there: managed care and quality improvement administrator; community-based services; deputy director/acting director. My education and work experiences have proven to be incredibly valuable and have really helped me understand the system from all sides of behavioral health programs. As our DHHS teams, including the Division of Behavioral Health, grow together, I do understand the complexity and challenges ahead. Yet I'm committed and excited about moving the behavioral health system forward. And I cannot recall a better moment in time to be building the public behavioral health system Nebraskans deserve. Where there were barriers to partnerships, there are now discussion and collaboration. To create change, our conversations are now about what we can do, not about what we can't do. Leadership supports and expects our division to be the chief behavioral health authority. So it is top priority to continue to build and improve partnerships with consumers, providers, and system partners. Our DBH team is working to integrate operations and really build a culture of ownership across our organization, in our central office, the Lincoln Regional Center, Norfolk Regional Center, and Hastings Regional Center. Our dedicated employees are busy every year serving 31,000 individuals. We're working with Medicaid on the Heritage Health Initiative to integrate behavioral health and physical health and pharmacy services, as well as working with other divisions since we serve some of the same individuals. We also collaborate with Corrections, Probation, the six regional behavioral health regions, provider organizations, consumer organizations, and individuals and families who have experienced mental illness and substance use disorder. We look forward to carrying out the 2016 Strategic Plan as we conduct that larger behavioral health systems needs assessment. The assessment will provide a data-informed way for us to move forward with our strategic plan for 2017 to 2020. We're excited to lead the implementation of the System of Care that was developed with the voice of over 1,100 Nebraskans. The System of Care is not a program. It is really a framework utilizing the power of partnership. So we ground ourselves with that framework and build and conduct ourselves differently because of the partnership. It involves building state and local collaboration with youth, families, and system partners for the purpose of improving access to a coordinated community-based, culturally-responsive array of services and supports. Over the last months, DBH championed work with public and private partners to build a phased approach for moving that strategic plan to a set of outcomes and activities. We're grateful to the Nebraska Children and Families Foundation who served as a constant companion, supporter, and advocate. And through our public and private partnership, Nebraska will build a system that will make a positive difference in the lives of young people with serious behavioral health challenges in their families. Because when partners and communities are engaged, Nebraskans will be healthier. I'm

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proud to serve with a team of incredibly dedicated and talented professionals within the division, other divisions, our system partners, and most importantly with individuals who face challenges with mental illness and substance use disorders. We're all eager to tackle the opportunities before us. Success is dependent upon relationships and realizing that the process is a journey and not a destination. It's imperative that we do what is necessary to remove the stigma and fear associated with mental illness and substance use disorder. We have to become comfortable with having conversations about these illnesses as we do with physical health illnesses. I approach every day as an opportunity to improve our system and to ensure all Nebraskans have the opportunity to reach their full potential. As director, I'll strive to be an effective partner and advisor and a leader in a system change. I'll continue to work towards our DHHS's mission to help people live better lives. And I'm very happy to answer any other questions you might have. [CONFIRMATION]

SENATOR CAMPBELL: Thank you, Director. Questions, Senators? It must be Friday (inaudible), do you think that? So at this point, just for the record, Director, we did not apply...we ended up not applying for the System of Care grant. And, colleagues, this was an effort that the Children's Commission followed religiously. I mean, it was almost at every meeting there were reports. But we decided not to...and to do it in-house. Would I be saying that right? [CONFIRMATION]

SHERI DAWSON: Well, what happened...just from a timing standpoint, last year, to apply, because Director Lynch was just coming, and Courtney wasn't here yet, and so we decided the timing...and the grant was different than previous years. So we made that decision not to, but what we did was move forward that strategic plan that we had put together to operationalize it to get us to this point. [CONFIRMATION]

SENATOR CAMPBELL: Good. We've been hearing a lot in the Legislature about the work that's being done in Corrections. And one of the concerns, as I've watched what's happening and listened to testimonies is are we...do we have enough programs in place for the people who come out of the Correctional system who will need continued mental health therapy or counseling sessions? Are we ready for that? [CONFIRMATION]

SHERI DAWSON: Um-hum. Well, you know, I think that's a really good question and that's part of the needs assessment that we're going to be working on. And we have monthly collaborations with Corrections. And I think they...between their data and the needs assessment, we'll have a better feel for those individuals. You know, some certainly are discharged in the community and served already in our system. But in terms of what that means for capacity, at this moment, we don't know. We need to have some more information. [CONFIRMATION]

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SENATOR CAMPBELL: And my last question is, does the department, or any other regions, do any kind of workshop or collaboration with county jail facilities? [CONFIRMATION]

SHERI DAWSON: Yes. Each of the regions, actually, although they're different, each region does have connection initiatives, if you will, with the jails. [CONFIRMATION]

SENATOR CAMPBELL: Because that's just critical, because you have a lot of people there. [CONFIRMATION]

SHERI DAWSON: Um-hum. Yes. [CONFIRMATION]

SENATOR CAMPBELL: Any follow-up questions, Senators? Okay. Director Dawson, what we will do is...I'm going to anticipate from the questions is that your confirmation will go forward to the full floor of the Legislature. And I'm doing something a little different this year with the directors as their appointments come, I'm distributing to every senator your opening statement. [CONFIRMATION]

SHERI DAWSON: Oh, okay. [CONFIRMATION]

SENATOR CAMPBELL: So that they can become familiar with what happens in those divisions. And I think that will provide some basis of education, because, yes, we're doing a confirmation hearing, but we should be doing some education on what it does. [CONFIRMATION]

SHERI DAWSON: Yes. [CONFIRMATION]

SENATOR CAMPBELL: Just so you know if you start getting calls from senators, that's probably where it came from. [CONFIRMATION]

SHERI DAWSON: Well, I absolutely appreciate that. [CONFIRMATION]

SENATOR CAMPBELL: But we really appreciate you being here. Are you staying this afternoon or going back? [CONFIRMATION]

SHERI DAWSON: I'm going to stay briefly and then I'm going back. [CONFIRMATION]

SENATOR CAMPBELL: Okay. Well, thank you so much. [CONFIRMATION]

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SHERI DAWSON: Yeah, thank you. [CONFIRMATION]

SENATOR CAMPBELL: And that concludes our confirmation hearing. I should say--is there anyone in the hearing who wishes to make comment? We usually don't and I tend to forget that. Thank you very much. [CONFIRMATION]

SHERI DAWSON: Thank you. [CONFIRMATION]

SENATOR CAMPBELL: All right, we will proceed and we need Senator Schumacher. Okay. You can talk amongst yourselves, loudly if you want to, or whatever and we'll just wait for the senator to come.

BREAK

SENATOR CAMPBELL: Good afternoon.

SENATOR SCHUMACHER: Good afternoon, Senator Campbell.

SENATOR CAMPBELL: I'm going to go ahead with the instructions, so you have a minute to kind of relax. Okay?

SENATOR SCHUMACHER: Okay. All right.

SENATOR CAMPBELL: I want to welcome all of you who have joined us for the hearings for the Health and Humans Services Committee. I'm going to go over some procedures of how we work within the Health and Human Services Committee. First of all, if you have a cell phone or anything that makes noise, please turn it off so you don't disturb anybody. If you're planning to testify today on any of the bills, we need you to complete one of the orange sheets that is on either side, as legibly as you can. When you come forward to testify and you have a handout, it's not necessary, not required here, but if you have a handout, we would like ten copies. And if you need assistance with those copies, one of the pages will be glad to help you with them. You come forward and you can give your orange sheet to Elice, who is the clerk for the committee, over there. And if you have handouts the pages will distribute them for you. As you sit down, we will ask you first to state your name for the record and spell it for us so the transcribers who listen can hear and make sure your name is right as we proceed. I don't think there's...I don't think I've forgotten anything. We'll redo introductions so that the people who have come in know who we all are. Senator Baker.

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SENATOR BAKER: Senator Roy Baker, District 30.

SENATOR HOWARD: Senator Sara Howard, I represent District 9 in midtown Omaha.

SENATOR CAMPBELL: And I'm Kathy Campbell and I represent District 25, east Lincoln.

JOSELYN LUEDTKE: Joselyn Luedtke, committee counsel.

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

ELICE HUBBERT: I'm Elice Hubbert; I'm the committee clerk.

SENATOR CAMPBELL: Okay, and the pages.

CAITLIN WELTY: I'm Caitlin Welty, I'm a political science major at Nebraska Wesleyan University, from Omaha, Nebraska.

SENATOR CAMPBELL: I think we only have one page...one page today?

CAITLIN WELTY: Just me. Well, Jay will be is coming.

SENATOR CAMPBELL: Oh, that's right, Jay comes from class. Senator Crawford stepped out for a minute, she'll be back because she has...I think she has to present in another committee. Senator Kolterman and Senator Fox will not be joining the committee today. So that proceeds to open the hearing on LB985, Senator Schumacher's bill, to provide reporting duties for regional behavioral health authorities. Good afternoon and welcome. [LB985]

SENATOR SCHUMACHER: Thank you, Senator Campbell, members of the Health and Human Services Committee. My name is Paul Schumacher, S-c-h-u-m-a-c-h-e-r, here today to represent...or introduce LB985. I have a compulsive need to ask questions at committee hearings. And I couldn't help myself in the LR34 committee, when a regional administrator was testifying, to ask a question which I honestly wanted to know the answer to. And that is--why do we need these regions? How do they work? And I got what you would expect as a fairly typical answer, and it probably would have went in one ear and out the other except for the fact that right after that I was deluged with a highly defensive--gee, how dare you ask that question, kind of an input from some of the administrative folks in some of the regions. Now in the law there's a thing called "inquiry notice." And inquiry notice is something that stands out that just doesn't look

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right, that if you have a responsibility for oversight, you best look into. And you folks probably know far better than I the history of the regions and how they are supposed to work, but it appears to me that...and some of this I remember from my county attorney days, it appears to me that back in the 1980s or so, counties got together to take care of their mental health needs. And there were groups of them that got together and they had an interlocal agreement and they made for some administrative function and some spending to take care of their needs. Then in the early 1990s, the Legislature stepped in and, basically, passed the law that, at least as I read it, and in some simple terms, set up a director of behavioral services (sic: health) as kind of czar of mental health. And appears to me quite a lot of power under that particular office and they were supposed to ride herd on the regions and try to develop a consistent mental health policy. It almost appears that over the years that czar was not fed well because there's not a heck of a lot of power or guidance seems to come out. But imagine a system in which we decided we were going to run a state roads system. And we were going to divide the state up into five or six regions. And each of those regions were represented by a number of counties...a number of counties in them. And then somebody who knew very little about roads, let's say the county treasurer from each of the counties involved, would come in and sit on a supervisory board for the regional road system. And then they would hire an administrator. And the state would pour some money into it; counties would put a little money into it, and we'd expect a road system to work. We probably wouldn't have much of a road system. And there would probably be a lot of questions that are raised. What this bill intends to do is tries to collect information from the regions that will help the Legislature in its oversight duties to determine whether or not they are doing their job; whether or not they got a plan to do their job. I poked around a bit, and there's contracts that appear pretty much like form contracts and don't obligate the entity on the contracting side to do much, if they don't want to do it, as far as taking on an obligation...a patient. If they do, then there's some rules of how to do it and some reporting requirements, but a whole lot of uncoordinated, at least in the region I looked at, helter-skelter type of contracts that are out there. There is, supposedly, responsibility in the regions to take care of emergency mental health commitments where somebody is really in bad shape and dangerous to themselves or others, and the police are supposed to pick them up and take them to a mental health facility pending either a resolving of the crisis or a Mental Health Board hearing to commit them to an institution. They are not supposed to go to jails. We've heard testimony in the LR34 committee that that's exactly what happens, because in cases there is no place for the police to take the person. And in order to protect the person and the public, they unclassify them from a mental case; classify them as a criminal case, because invariably they punch the officer or resisted arrest or whatever, and they put them in jail. It's, as I read the law, the responsibility of those regions to have a place to put those people. And those integrated services are...and reports are not available. There are really hard to understand accounting practices...books that have funds back and forth and it really very unclear as to how the money traces through. Highly discretionary ways in which money is allotted. One part of the minutes that I read...somebody came in and they wanted money, \$20,000, for a vehicle. Well, the administrator said fine and the board rubber stamped it. And so

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it almost looks like you have this highly discretionary thing that is problematic. And what has kind of egged me on some with this is, in poking around at major mental healthcare, providers tell me--look, we have got a problem with how this thing is being administered. I said--well, good, let's talk about it; come to the hearing. Well, because it's so discretionary in how these funds move back and forth, and because we have some really big contracts with the regions, we really can't. And we're behind you, but we don't want to mess our nest. So I...with that I very much think we have an issue that we have an obligation to begin to poke around in. And that's what this does. And we need to get a handle on how that money is being spent. There's tens of millions of dollars...almost \$100 million over the biennium going into these regions; the counties put a little bit in, but not very much. The county board of supervisors, each county sends a board member to the region board. And in Region IV, for example, I've had a couple of the county board members tell me, look, we meet once a month and it's a good place to discuss "gravel prices." And so we've got a problem. And I introduced this bill, there's not much of a fiscal note on it, for all practical purposes to see if we can get a handle on it. And I'm almost afraid that the problem is involved enough that somebody like me who is only, after this session, got two sessions left, may not have enough time to do it. So if it turns out this does not look right and this is not an efficient way to administer mental health and the job is not getting done, a figure that's been tossed out is, well, gee, in 85 percent of the things we do, we do okay. Well, there's 15, the toughest 15 that aren't being done okay. So it's like the biggest bridges we aren't fixing because we don't...we don't know how to fix them. So I bring this to you for your consideration. I'm not sure what type of a vehicle there is for prioritizing it this year, probably is not a consent calendar. I think somebody will probably talk against it. But I bring it to you for your consideration. I'd be happy to answer any questions. [LB985]

SENATOR CAMPBELL: Questions? Senator Howard. [LB985]

SENATOR HOWARD: Thank you, Senator Campbell. Thank you, Senator Schumacher, for bringing this to our attention. Have you spoken to Director Dawson about this bill? [LB985]

SENATOR SCHUMACHER: I have spoken with her about it. There's some indication that there may be administration interest in looking at how we do it. My own skepticism is that the department needs to gear up if it's going to take on a more czarist role or maybe replace the regions down the road. But I think there's interest. And I think the data that this thing attempts to try to collect may help with spurring that interest on. And so I'm hopeful there that something may generate interest in reforming the delivery system for mental health from DHHS, because as we all know, if for some reason the system needs to be reworked, they will have a major role in picking up the burden and being competent to pick up the burden. If for some reason, that office is not up to...this administration has not been terribly aggressive. [LB985]

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SENATOR HOWARD: I'm just curious if you agree with the \$150,000 in the fiscal note for computer programming. She just reported to us during her appointment hearing that they're going to have a centralized data system operational on February 29. And so had you...have you had a conversation with her about how that centralized system might interact with the bill that you're bringing forward today? [LB985]

SENATOR SCHUMACHER: No, I have not, Senator. [LB985]

SENATOR HOWARD: I could see that eliminating your fiscal note. [LB985]

SENATOR SCHUMACHER: Well, that would be very helpful. And it's very good news that they're going to have a centralized system up and running that covers DHHS because I've got another bill that's going to require those various departments to communicate fairly fast. And that's a followup on our Medicaid recovery thing from last year. [LB985]

SENATOR HOWARD: Thank you, Senator. [LB985]

SENATOR CAMPBELL: Senator Riepe. [LB985]

SENATOR RIEPE: Thank you, Senator Campbell. Thank you for being with us. Being a farm kid, I grew up with the philosophy that when you see one rat you've got 50. And so my concern is that you inadvertently, through your own curiosity, stumbled on to this thing; so I'm interested in how deep is the problem? How long has it been there? Can the people in position truly evaluate, because in some ways they're evaluating their own performance. And we all have a tendency to do things more the way we've always done them. Can you...so do you think this needs to be a clean, whole new fresh look at this? [LB985]

SENATOR SCHUMACHER: I've only been around here five years; I can't remember an examination of the regions taking place on the floor, at least it may be a fault of my memory, or it might have been. But it's not been looked at for a long time. And oddly enough, the original region structure...apparently there was great resistance to disassembling it back in the early '90s. It almost has a political life of its own and a political network of its own. And that may somewhat be fueled by the highly discretionary nature of--here, you got a problem? Here, here, I'll give you a deal here with...and I'll give you a deal here... [LB985]

SENATOR RIEPE: And go away. [LB985]

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SENATOR SCHUMACHER: Well, just to be on my side, you know. And so I think that needs to be looked at. It's time, maybe, to get the BB-gun out when we see those rats. [LB985]

SENATOR RIEPE: I want a BB-gun, but, yes. [LB985]

SENATOR CAMPBELL: Senator Baker. [LB985]

SENATOR BAKER: Thank you, Senator Campbell. Senator Schumacher, you state in here there does appear to be some tension of the regional authorities' procedural effectiveness and lack of accountability. You've already talked some...but talk some more about that--the tension that appears to be there...is that your statement in here? [LB985]

SENATOR SCHUMACHER: I think so, yeah. [LB985]

SENATOR BAKER: Okay. It says: it does appear to be some tension with the regional authorities in a perceived effectiveness and lack of accountability. [LB985]

SENATOR SCHUMACHER: Well, for example, at the LR34 hearing, we had a deputy county attorney just absolutely pulling her hair out over the fact that there are cases in which the hospital which has been contracted with to take somebody who is mentally ill and dangerous on an emergency basis won't do it because their contract doesn't mandate them to do it. Okay, fine; where they supposed to go? Well, big problem--do we park them at the regional center when there's not beds there? And, apparently, they've got to negotiate for beds because a county or region is only allotted so many and they've got to then trade them back and forth like you trade baseball cards. And so that was one tension. We have a regional...federal regional health district who hadn't been...who does a lot of mental health-type work off the federal side until this started being stirred, there was no meaningful contact with the region. Now suddenly there's a little contact. We had the police who were fed up with not...sitting there waiting to drive these EPC cases someplace and were, pretty much, getting the cold shoulder that, hey, it's your problem. Now I've been approached with--why don't we compensate you for your time? It is just one of the things that we need to get a handle on and maybe it's all on the up-and-up, hard to say at this point. But it's enough of a thing that we had...we are an inquiry notice that there may be an issue and the issues with the providers who on the QT will say--there's a problem. But officially say we can't jeopardize our income flow because there's a lot of income moving through this thing in a highly discretionary fashion. [LB985]

SENATOR BAKER: Thank you. [LB985]

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SENATOR CAMPBELL: Senator, as a...at a full disclosure, I have to say, I've served on a regional governing board one, I was a Lancaster County commissioner, so I...I have some familiarity with it. If I remember correctly, too, part of the idea with the regions was that they would be closer to the local level and could account for different needs in different areas of the state. And I think that was part of...part of the intent in terms of the regions rather than having a statewide system. But I have to agree with you, I think it's been a long time since it's been looked at in totality. I think we had a performance audit on the regions in the last couple of years. And I'd have to go back and look. Does anybody recall that? Senator Howard do you? We did. [LB985]

SENATOR SCHUMACHER: There was one. And it was kind of a self-grading thing. And at least the region where I'm from gave themselves very high grades. [LB985]

SENATOR CAMPBELL: Oh, so it was sort of a self-evaluation. [LB985]

SENATOR SCHUMACHER: There was self-evaluation there. [LB985]

SENATOR CAMPBELL: Right now, I believe that the regions do have to provide an annual report of some sort. We collected some of those when we did a followup to the Safe Haven in LB603. And my legislative aid, you know, would try to collect them and sometimes we'd have to call several times to try to get them in. But I don't know how much analysis is done and what's required in terms of what you've got here. My question really has to do with your requiring an annual report and all this is to be put together. Then is your expectation through the bill that the department would analyze the information and provide their own report to this...? [LB985]

SENATOR SCHUMACHER: I think that this report, once available, I would expect if the department...indication that they may be interested in the subject is accurate, they would analyze it. I would expect that we would analyze it too and try to get an idea of whether or not these things are working. And certainly if there's something that I'm requiring or would require in this bill that is redundant to something else that's required somewhere else, you know, that should be stricken out of there, but that was not my intent to be redundant with anything that is being required somewhere else. It just seems like a really loose financial arrangement. And maybe Omaha and Lincoln are a bit of a different flavor than the rural areas, but it seems to be a loose financial arrangement with no cohesive policy, no cohesive list of services. Apparently what's available in one region may not be available in another region. And it...you got to scratch your head and say--is this still the right way to do it? [LB985]

SENATOR CAMPBELL: Okay, Senator Riepe, I'll finish up my questions after you. [LB985]

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SENATOR RIEPE: No, (inaudible) want to finish. [LB985]

SENATOR CAMPBELL: Well, in the bill, I can't...I was trying to quickly find it, but you might remember if it's there, do you require a look at the finances of this? And I'll tell you the reason why the question, and it may be that you would want the Fiscal Office do on an annualized basis, give you some rundown in terms of the money. And they would have that pretty quickly, I'm sure. But the other part of this is that the regions do receive money from the Healthcare Cash Fund also, which is, of course, from the tobacco settlement. And what was interesting, and we talked about this under what...Director Dawson was here, is that when we did the child welfare, we had a consultant who looked at where are all the funding streams to mental health for children, and they're considerable. So the regions are not the only place where we would be spending funds in a mental health. So looking at the totality of the finance picture is something that if it is not here you may want to think about. [LB985]

SENATOR SCHUMACHER: Okay. [LB985]

SENATOR CAMPBELL: Senator Riepe. [LB985]

SENATOR RIEPE: Thank you, Senator Campbell. I guess this concept of sort of a self-evaluation as being...brings a new meaning to the word "audit." And when you talk about the financial implications, you know, I immediately popped to audits. I like outside looks; I like outside audits. Is that a thought of yours that...I don't know whether we're in a position where we can request a specific audit, or should, or...do you have some thoughts on how we...how do you go after this aggressively without you as an individual senator outside of committees or anything else, how do you take on that and carry this burden? Because, as you said, it may be more than two years. [LB985]

SENATOR SCHUMACHER: It likely will be. It is apparently a very deep-rooted kind of system that's out there. I think that when we get start getting some of this information and we put this on the radar screen we will know whether we want to have a deeper audit function or simply rearrange the situation and say, you know, there's no reason...if the Department of Roads can bring in public local input and run a roads department, why do we have to have this screwy thing where you have a county board member from each county show up and supervise an administrator and...I think the board members, at least in the...and I did not talk to Lancaster County, would indicate that their level of supervision is...they can't be expected to be highly detailed. [LB985]

SENATOR CAMPBELL: Just for the record...just for the record, you know, you might want to look at the model of LR37; not necessarily, maybe, in this bill, but in the future. And the reason

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why, the Legislature passed LR37, I mean it was...Speaker Flood helped me set that up. And it was assigned to the Health and Human Services Committee to do an investigative report. Now, that may be on down the line, but I mention that to those of you who are still going to be here because it was a mechanism in which we brought together a lot of different people, including Performance Audit and Budget/Fiscal to analyze what we were seeing in the system. So it goes, somewhat, to Senator Riepe in the fact that you use it internally, not always externally, but external to the regions is the point. It's done in-house in the Legislature and at least gives you a part. The other idea that I want to put in the minds of my colleagues here, and that you ought to remember also, is that the Health and Human Services Committee, out of the Healthcare Cash Fund, does have funding for study or investigative. We are allocated. We don't use it all the time, but it is...been allocated for that. And it may be such that some of the funds from...that are allocated to this committee could be utilized if you have to augment it. We couldn't cover that fiscal note by any stretch, but it's another idea that you may want to keep in mind. I mean, I think you're raising an interesting question because it's been a long time since we've looked at this. And knowing that we have individual needs across the state, how do we make sure that we're getting at those needs of people? Anybody have a followup here? Senator Riepe, did you...I didn't mean to cut you off. [LB985]

SENATOR RIEPE: No, no, thank you. [LB985]

SENATOR CAMPBELL: Okay. Anything else? Senator, will you...well, you'll be staying because you have the next bill. [LB985]

SENATOR SCHUMACHER: Well, we've got some activity over in Revenue Committee today so we can cut your taxes and pay for more services... [LB985]

SENATOR CAMPBELL: Would you like us to send the page over when we're ready? [LB985]

SENATOR SCHUMACHER: I don't think that will be necessary. I've laid the bill out before us, and then we can see what testimony there is, if any. [LB985]

SENATOR CAMPBELL: Okay, but you then have...oh that's right, I'm sorry, you don't have the second bill. [LB985]

SENATOR SCHUMACHER: No, not...I only...I've got another one coming down the road; same topic, I really never intended on getting involved with this committee very much, but this is kind of a vortex that has sucked me in. [LB985]

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SENATOR CAMPBELL: We're one of the best committees there are, Senator. [LB985]

SENATOR SCHUMACHER: That's what I hear. [LB985]

SENATOR RIEPE: You're trying to avoid us. [LB985]

SENATOR SCHUMACHER: That's right. Thank you. [LB985]

SENATOR CAMPBELL: Thank you, Senator Schumacher. We will open up testimony on LB985; our first proponent. While Mr. Johnson is getting settled, how many people would like to testify either...oh, as a proponent or an opponent to the bill or in a neutral position? Mr. Johnson, you may be carrying the whole day here. Nobody else raised their hand. [LB985]

C. J. JOHNSON: You're going to give me the whole day? [LB985]

SENATOR CAMPBELL: Well, no, sir, I will not; you still have five minutes just like everybody else. [LB985]

C. J. JOHNSON: Okay. Well, I'll do my best. [LB985]

SENATOR CAMPBELL: Okay. [LB985]

C. J. JOHNSON: I would like to...I would, maybe, ask for an extra minute or so simply because of some of the information I just heard that as I'm giving my testimony I could... [LB985]

SENATOR CAMPBELL: You just need to state your name for the record and spell it and then we'll start off. [LB985]

C. J. JOHNSON: I'll do that, I'll do that. [LB985]

SENATOR CAMPBELL: Okay. [LB985]

C. J. JOHNSON: (Exhibits 1 - 6) Well, let me just start. Good afternoon, Senator Campbell, and members of the Health and Human Services Committee. My name is C.J. Johnson, C, period, J, period, J-o-h-n-s-o-n, and I serve as the regional administrator for Region V Systems. I appear before you today to testify in support of the basic premise of LB985 on behalf of the Nebraska

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Association of Regional Administrators which is comprised of the administrators of the six regional behavioral health authorities across the state. There are components of LB985 which present challenges that will be shared later in this testimony. It is the responsibility of each of the six regional behavioral health authorities to develop, implement, and coordinate mental health and substance abuse services at the local level for individuals who have no form of insurance or who are underinsured. In addition, each of the regional behavioral health authorities coordinate other recovery support services such as supported housing and supported employment. Prevention activities are also supported throughout each region. A coordination of the emergency psychiatric system is also a key activity of each regional behavioral health authority. I have provided Region V Systems fiscal year '14-15 annual report to illustrate the numerous activities that occur annually in Region V Systems' geographic area. I would like to point out very quickly that the regional behavioral health structure was actually developed and passed by the Legislature first in 1974, specifically to address mental health gaps in the state of Nebraska. And then subsequently in 1976, substance abuse was added to that by the Legislature through interlocal agreements through the various counties in the regions. The regional behavioral health authorities by statute have a behavioral health advisory committee which is made up of stakeholders, including consumers, and a regional governing board made up of an elected county commissioner or a supervisor from each of the counties in the geographic region making up the six behavioral health regions. And I'd also like to point out at this point that, for example, in Region V, the chair of our regional governing board is former Senator Dennis Byars who was very active in mental health, developmental disabilities, and other such bills in the Legislature. The behavioral health advisory committees and the regional governing boards hold regular public meetings subject to the open meetings act with minutes readily available on each Web site. In addition, as public entities regional behavioral health authorities are subject to Nebraska's Public Records Law which generally states that all records and documents created or held by public entities are deemed to be public records and the citizens have the right to the copies of those records. The Public Records Law does provide, however, that certain categories of records may be withheld from the public, unless they are disclosed in open meetings, court proceedings, etcetera. Annually, each regional behavioral health authority submits to the Division of Behavioral Health its regional budget plan for the next fiscal year. The regional budget plan includes information regarding contract providers and the services contracted. The regions also develop a report of actual revenue and expenditures for each fiscal year that includes the revenue and expenditures by that region and all contracted providers for each contracted service. I have attached a sample of the guidelines for the upcoming fiscal year. In addition to the regional budget plan, each regional behavioral health authority prepares a strategic plan, an annual report, a management summary, performance improvement plan, risk management report, and business interruption plan, which are all presented in public meetings throughout the year. Fiscal reports are provided on a regular basis in conjunction with the annual budget as approved by the regional governing board. The Division of Behavioral Health completes an annual compliance audit with each regional behavioral health authority to ensure all required documentation is available

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regarding contractual deliverables both between the division and each regional behavioral health authority, as well as between the regional behavioral health authorities and each contracted provider. Additionally, each regional behavioral health authority has an annual, independent audit of financial statements conducted by certified public accountants. Each regional behavioral health authority is nationally accredited under the Commission of Accreditation of Rehabilitation Facilities' standards for provided services. LB985 directs that an annual report be developed by each Regional Behavioral Health Authority and provided to the Division of Behavioral Health. Many of the elements to be reported in LB985 are already readily available as a matter of public record. In addition, the regions, as individual entities, or as a statewide effort, have responded to specialty report requests from state senators, the Division of Behavioral Health, the Legislative Audit Office, and other stakeholders. As regional behavioral health authorities, we believe that a majority of the information sought in LB985 is available upon request. However, such information is developed in conjunction with different processes to address the specific needs of each report. Some of the information sought in LB985 would not be directly available through the regions and would rely on other entities' reporting. For example, information regarding attempted and completed suicides would need to come from local law enforcement and local hospitals. Some data elements need to be further defined such as unnecessary hospitalizations and again would require reporting from other entities. Finally, to combine all the information directed by LB985 into six annual reports would take a considerable amount of staff time and effort and would, in many ways, be duplicative of efforts already put forth throughout any given fiscal year. There is a possibility that the preparation of such a report would require additional staff, computer programming, and ongoing maintenance. I would like to thank you for this opportunity to share the regional behavioral health authorities' thoughts regarding LB985 and I am willing to answer any questions you might have. [LB985]

SENATOR CAMPBELL: Mr. Johnson, you want to just step us through what's in the packet for the record. [LB985]

C. J. JOHNSON: Oh, sure. [LB985]

SENATOR CAMPBELL: So that we kind of know what you provided to us. [LB985]

C. J. JOHNSON: The first document is simply the annual report prepared by Region V that we prepare annually. And part of the reason is, is if you go through there, you'll see that our fiscal components are reported; the number of people served; who had insurance; who was partially covered. There's also just discussion in our region of how we do our crisis response for emergency protective custody holds; the number of EPCs that happen annually. You'll see some of our other initiatives that we're doing throughout the region. So, that's what you would find in this annual report. And it's specific to Region V; I want to be clear about that. [LB985]

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SENATOR CAMPBELL: Before you go on, and I'm going to let you finish the rest of the packet, but there's not a standardized report requirement though, is there? If I remember reading the reports, some of them were more inclusive or less, you usually provide a lot of information in the ones that I remember, but they're not...there's not a required...all the same. [LB985]

C. J. JOHNSON: Right, the annual report itself is done independently by each region; there's no standard. If you go to the next document, that's all really one document, and this is the guidelines from the Division of Behavioral Health that all regions are required to fill out when they're submitting their regional plan of expenditures, or budget plans as we call them, prior to each fiscal year so that those particular reports and planning efforts follow the same guidelines and have a significant similarity in relation to the format. Obviously, each region many times due to service needs and those things may be different in relations to that. [LB985]

SENATOR CAMPBELL: But I'm correct, am I not, that the regions...that they looked at this as a way to have the region closer to the local and to say, well, what's needed in Region VI, which is in the Omaha area, may not be the same as Region II or Region III? [LB985]

C. J. JOHNSON: Correct. [LB985]

SENATOR CAMPBELL: And so that's why the regions were given some latitude as to the services. [LB985]

C. J. JOHNSON: Correct. And also, you know, just as an example, when you look at, like Region V, Lancaster County being the second largest county in our region then surrounded by 15 rural counties, we...in order to deliver services in that geographic area would be very different than if you went out to, say, Region III where you have Hastings, Grand Island, and Kearney all fairly close to each other, even though there's rural counties. But each of those cities have the capability of certain capacity of services. So as you go to each region, the geographic area and the population size and how they're centralized does make it very different how you're going to deliver services to that entire area. [LB985]

SENATOR CAMPBELL: Questions? Senator Riepe. [LB985]

SENATOR BAKER: Thank you, Senator Campbell. [LB985]

SENATOR CAMPBELL: Oh, I'm sorry. [LB985]

SENATOR RIEPE: I'm sorry. [LB985]

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SENATOR CAMPBELL: Would you like to start with you, Senator Baker? [LB985]

SENATOR BAKER: I would like... [LB985]

SENATOR CAMPBELL: Is it okay, we'll start with Senator Baker and then come around. [LB985]

SENATOR RIEPE: Sure. [LB985]

SENATOR CAMPBELL: Go right ahead. [LB985]

SENATOR RIEPE: As long as he doesn't take my question. [LB985]

SENATOR CAMPBELL: It's a chance we take. [LB985]

SENATOR BAKER: You're a proponent? You're a proponent to...? What do you think would be better if this passes? [LB985]

C. J. JOHNSON: Well, I think one of the things that is quite clear is that I think...I believe the regions...I've been at Region V since 1999 and did consulting prior to that, is we have...we have really always had an attitude of being transparent. I mean, we know we're a public entity; we know we have to perform...my interview for the job was in a public meeting, okay? We're aware of that. And we are very willing, when people request information, to give that. The reason we're a proponent to this is if this is a way to allow that transparency to be better promoted, then we're in support of that. What we're simply saying though is we do believe a lot of the elements of this particular bill are readily available, are in the public eye all the time, and that the...to me, when I look at this, the amount of staff time in computer programming for databases that may have to occur is quite significant when you really look at the historical data...you got to go back five years to develop the historical component. I mean, the first report itself would literally take a full-time person just going through digging all that information up. It's a pretty elaborate report that's desired on an annual basis when somebody could call me and say I need to know how many EPCs and what the average length of stay is on those, what the gender distribution is, how many had substance use issues. I could tell you all that with one phone call I could get all that information. So as you go through this, we can find...the information is there, it's just that it goes through different channels to fulfill different needs. [LB985]

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SENATOR BAKER: You sound like a neutral at best on this bill. You believe the information is already there? I want to know...(baby crying)...I agree. How do you think this is going to make things better? [LB985]

C. J. JOHNSON: Well, again, I think if the issue is that there's not enough transparency within the regional structure, that if this bill and fulfilling some of the requirements of this will promote that as transparency, I think...I definitely know we support that because we as entities have always tried to be as transparent as we'd be allowed to. So that's the way we're looking at this. If it's promoting more transparency, we're totally in support of that. [LB985]

SENATOR BAKER: Thank you. [LB985]

SENATOR CAMPBELL: Senator Riepe. [LB985]

SENATOR RIEPE: Thank you, Senator Campbell. Thank you for being here. Now, you are one of six regional administrators, is that correct? [LB985]

C. J. JOHNSON: Correct. [LB985]

SENATOR RIEPE: And my question is, I'm trying to sort of get a foundation here that says--do you have an administrator over all six, or is this kind of like a first among equals or...I mean, is this kind of a, I hate to use the word, club that...do you have some...I'm looking for some central piece that says, you know, this is our structure; these are our best practices; this is something that we do in all six regions, and yet with balance or allowing other regions to do what fits to the regions, given the variety, within Nebraska. [LB985]

C. J. JOHNSON: So to answer your question, first of all, each of the regions are made up of interlocal agreements between the counties in each geographic area. So in other words, in my region the 16 counties all have interlocal agreements. They all contribute a certain amount of county funds towards the regional structure. Okay? That can be used for administration, it could be used for services. We have a regional governing board made up of an elected official from each of those counties who oversee each of the regions. And I'm appointed to serve at the pleasure of that board. That is the way the language in the statute says. [LB985]

SENATOR RIEPE: And no one else. You don't have a dual reporting. [LB985]

C. J. JOHNSON: Correct. Correct. And the Division of Behavioral Health contracts with us for flow-through money, and then we, subsequently, contract with other providers to provide various

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services. We also do the audits of the providers annually, and a variety of other things. Okay? One of the things that Senator Campbell said was at that...that local level is very important when you're looking at--how do you deliver services...really what are the needs. Because it does vary in those various geographic areas. And under...Nebraska is a large geographic state, but we have very significant population components associated with that, which means we have to deliver services in very different ways in those areas. Did I answer your question, Senator? [LB985]

SENATOR RIEPE: Yes. I was trying to figure out...form follows function to me and I'm trying to figure that out. [LB985]

C. J. JOHNSON: A majority of the...I will say that the majority of the items that the regional governing board approves for expenditures then go to the Division of Behavioral Health for final approval. Because it is pass-through money going through Program 38 (sic: 038). So it's not just the board approves and it's an automatic, you know, on a lot of the things that go on in the regions. [LB985]

SENATOR RIEPE: If there's one thing you could change, what would be that one thing? [LB985]

C. J. JOHNSON: The one thing that could change in the region? [LB985]

SENATOR RIEPE: Yeah. [LB985]

C. J. JOHNSON: Well, right now we're...this is going to...I don't want to talk about money, but we are a capitated system. Okay. And so one of the challenges that happens in a capitated system is whenever you need to develop new services, and when I say new ones, I don't mean, maybe, additional ones, but sometimes you need step-down services. So you have two services and somebody needs to come down a little. Come down to this service is too much for them, so you might need a service in the middle. And because we're a capitated system, it's very hard for us to go out and start that service and move those people out of it because we still this service and we need this service here. And if you look back at LB1083 in 2004, the Legislature had the wisdom, if you will, to start with \$6 million for behavioral health reform so we start the services and then move people. And I thought that was very wise back then. You've heard the discussion, if I could change one thing, is that if at the end of the year if there is funding, for whatever reason, that may be unspent, that that can be carry-over money, just like we did with LB1083 to reinvest in our systems. Because it's very hard in a capitated system to start new things as you see gaps develop. So that would be the one piece that, you know, I think is...it's very difficult for us to do that. [LB985]

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SENATOR RIEPE: May I ask another one? [LB985]

SENATOR CAMPBELL: Go right ahead. [LB985]

SENATOR BAKER: It sounds to me that you have no incentive...you have every incentive to spend it down to zero at the end of the year, much like the military does. Is that fair? [LB985]

C. J. JOHNSON: You have that incentive. But what you're really doing is, and let me share with you for example, I have...one of my providers right now is looking at possibly being about \$100,000 of services that they funded...that they're providing that they are not going to be paid for, if you will, right now based on their contract. So what we do is we move closer to the end of the year is we start looking at those shifts in service needs and we try and move that money so this provider, whatever reason, isn't providing all those contract services. We want to move that money to that provider to pay for those services. Because if we don't, they're going to go under. So our goal at the end of the year is, yeah, draw it all down. But it's not draw it all down just to spend it on chairs or whatever, it's to ensure that our providers who are providing services, but haven't gotten paid for them, get paid for those services. So, yeah, we work very hard at drawing all the money down because we want to ensure those providers are getting paid for what they provide. [LB985]

SENATOR RIEPE: Thank you. [LB985]

SENATOR CAMPBELL: And, Mr. Johnson, just to follow up on Senator Riepe's question, I mean, each of those contracts with those providers is sort of units of service or, I mean, you're contracting for a portion of that. So it's not...that's why at the end if you have to make an adjustment, some providers provide more services than you contracted. [LB985]

C. J. JOHNSON: Correct. [LB985]

SENATOR CAMPBELL: And they only get what you've contracted for. [LB985]

C. J. JOHNSON: And it also depends, sometimes, more individuals who are not covered by Medicaid or other insurance have walked through their door that year than the previous year, so we need...we appreciate the flexibility we have in supporting not only single providers, but a network of providers. [LB985]

SENATOR CAMPBELL: Any other questions, Senators? [LB985]

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SENATOR RIEPE: Sounds like you have kind of a block grant model, is that fair to say? No? [LB985]

SENATOR CAMPBELL: Not really. [LB985]

C. J. JOHNSON: No. [LB985]

SENATOR RIEPE: Okay, okay. [LB985]

SENATOR CAMPBELL: I wouldn't categorize it as that. [LB985]

SENATOR RIEPE: Okay. [LB985]

SENATOR CAMPBELL: Mr. Johnson, I'm looking in the future more than what the system is now, and part of what I see is...and I don't know if you were here for Director Dawson's conversations with us, but they're getting ready to look at a strategic plan and...and any number of bills come to the Legislature about mental health, both adult and children, increasingly about children's mental health, and what...the question that I have is how do we set a program or a plan, a statewide...this is really what we're going after. We've got 30 different ways...or, you know, issues, but our priorities are going to be this. How do we get statewide priorities across with the regions, given the setup that they kind of respond to what is here, not necessarily that broad overview of those five big priorities? [LB985]

C. J. JOHNSON: Well, two quick thoughts: the first is, when we talk about each of the regions being different, there's also components that are the same. In other words, there are certain essential types of services that each of the regions have to provide either directly with a provider in their region or, like, some of the rural regions don't have the capacity, so they have to contract for those. So there's a set number of services that every region ensures that they have available. Okay? So that's some of the consistency. As far as a statewide plan, and I am just...can't...Senator Bolz has introduced a bill, and I can't remember the number, and I don't want to say it, but I want to say LB911, but I don't know if that's correct, that is asking that a statewide assessment actually be done similar to the TriWest one that was done out of Region VI. I strongly support that. I think it will go hand-in-hand with the Division's efforts, if they're strategic planning at this point. I am very impressed with the individuals at the Division of Behavioral Health right now. I think they really have an interest...a true interest in bringing services to individuals and making the system to meet the AAA components of the federal government. I'm a little upset that they did take one of my best employees recently to go in there, but that's okay, she'll be great there.

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But I think along with that assessment in their strategic planning that we can look to see what are some of the gaps and are there some consistent gaps across each region. [LB985]

SENATOR CAMPBELL: Thank you. Any other questions, Senators? Thank you, Mr. Johnson. [LB985]

C. J. JOHNSON: Thank you. [LB985]

SENATOR CAMPBELL: Have you provided a copy of this to Senator Schumacher or do we need to do that? [LB985]

C. J. JOHNSON: I left ten there. I can get a copy to him. [LB985]

SENATOR CAMPBELL: Okay. We should have an extra one, make sure that he gets it. [LB985]

C. J. JOHNSON: I'll do that; I have a couple back here. [LB985]

SENATOR CAMPBELL: Okay, excellent. Thank you. Any other proponents for LB985? Anyone who wishes to testify in opposition? Anyone in a neutral position? Okay, that concludes our hearing on LB985 as Senator Schumacher has waived closing. Elice, are there any letters for the record? [LB985]

ELICE HUBBERT: There are no letters for the record. [LB985]

SENATOR CAMPBELL: Okay. All right. We will proceed...Sentor Hilkemann...do we know anything about Senator Hilkemann? The page is going to call for him. [LB804]

BREAK

SENATOR CAMPBELL: Good afternoon. [LB804]

SENATOR HILKEMANN: Good afternoon. [LB804]

SENATOR CAMPBELL: Are you just running from place to place this afternoon? [LB804]

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SENATOR HILKEMANN: I was in Appropriations today. [LB804]

SENATOR CAMPBELL: All right, we will proceed to the next hearing on our schedule this afternoon, LB804, Senator Hilkeman's bill to adopt the Investigational Drug Use Act. Senator, welcome; glad to have you this afternoon. [LB804]

SENATOR HILKEMANN: (Exhibits 1 and 2) Thank you, Senator Campbell, and members of the Health and Human Services Committee. I am Robert Hilkemann, R-o-b-e-r-t H-i-l-k-e-m-a-n-n, and I represent District 4 and I'm here to introduce LB804. This is a bill to give hope to those Nebraskans suffering from chronic and possibly terminal illnesses. And I want you to be assured that this is not a segue to the use of medical marijuana. Marijuana is not a federally approved drug. The Investigational Drug Use Act is more commonly called Right to Try. It is a movement that began in about 2014 with five states enacting laws. When I was at NCSL in Seattle this year, I was at a conference where they were talking about this. They have now a report that 41 states are considering such legislation in 2015 and this law has been signed and in now 24 states. I have a map there which shows you the status that we have across it and you'll see that a number of our neighbors have also adapted it. So the most recent count is at 24 or 25 states have now adopted this law which allows physicians to access and administer certain drugs in certain situations or certain therapies before they have reached the full FDA approval. The current process for drugs seeking FDA approval can take as long as 10 to 11 years through the Compassionate Care Act. It requires lots of forms to be filled. Now it is interesting as when you research this, you'll find out that the FDA, since these are taking place in a number of states, is suddenly beginning to shorten their process slightly, but it's still a very long process for those individuals. So this will speed up the process and allow terminally ill patients to possibly benefit from experimental drugs, the Right to Try law now uses drugs without federal approval. These laws will allow patients to request drugs that have been passed the first clinical trial stage that that stage where scientists will determine that the drug itself is safe in the sense that it doesn't actually hurt people. The efficacy--over the long-term efficacy--comes as they go down additional trials. So in a nutshell, eligible patients under the act may be treated with any drug, any biological product or device that has successfully completed phase one of the clinical trials, but has not yet been approved for general use by the United States FDA and remains in clinical trials approved by the USFDA. The eligible patient must have an advanced illness when considered all other approved...and have considered all other approved treatment options. It must be recommended by the treating physician, and the patient must give written, informed consent. Health insurers are not obligated to pay for this treatment. The patient is liable for all expenses related to the treatment. A manufacturer of such drugs may offer them without compensation and may not seek reimbursement if the patient were to die while in treatment. A healthcare provider cannot lose his license or Medicare certification due to treating a patient with an investigational drug. The act does not create a private cause of action against a manufacturer of an investigational drug. This act is not to be confused with expanded access or compassionate use.

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These requests go to the FDA and require the physician to go through quite a rigamarole to get that all approved. So this is giving patients a right to try. One of the nice things about it, I hope you looked at the fiscal note. There is no fiscal note. We don't want this as being set up so that this does not create another government bureaucracy. We do not need to have another agency within the Health and Human Services to manage this. I don't know how many patients will take a chance...will take advantage of this. It's a new process. We do know that patients are taking advantages in different states. We do not have a database yet. This is a very new movement that's here. This will be developed. One of the groups that...or the group that actually started this was the Goldwater Institute and so this, again, a new process that's there. But that, basically, is the gist of my formal...and I'm going to end up with two comments in the end. Both of these are...in a former life I was a school teacher down in Table Rock, Nebraska. And one of those students that we had there, we maintained a relationship over the years with, and when she was about 40 years of age she developed a brain tumor. And she was a very good friend of my wife's and they were very close. And she did all the treatment. She had surgery; she had chemo therapy. And there was no cure. She was desperate. She had very little money. What money she had she heard about somebody in Mexico that had some snake oils or whatever else and she went down for those. And of course those snake oils didn't work. But it would have been wonderful if there had been some drug that was available, that could have been available that...and in her situation it was terminal. And all these patients are either chronically or terminal. I've included the news story there of someone who we all know, Tom Tonniges, and I wanted you to note that he was a prominent physician in Omaha and we recently lost him to ALS. I wanted you to note in that news story that appeared in The Omaha World-Herald that Dr. Tonniges went to Israel to try an experimental treatment. I don't know what's coming down the line for Alzheimer's, what's coming down the line for MS, what's coming down the line for ALS, what's coming down for all of these. But as time goes on, if there are...if there are treatments available, I think we should provide hope to these people that if they want to try it, they can try it. That's the nature of this bill. And that's why I bring it for you for your consideration today. And with that I'd answer any questions you may have. [LB804]

SENATOR CAMPBELL: Thank you, Senator Hilkemann. Senator Baker. [LB804]

SENATOR BAKER: Senator Hilkemann, is this model language being used in some other state? [LB804]

SENATOR HILKEMANN: It is, that language is being used by all the states that have adopted it thus far. And that's directly out of the South Dakota bill. [LB804]

SENATOR BAKER: Thank you. [LB804]

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SENATOR CAMPBELL: Other questions? Senator Crawford. [LB804]

SENATOR CRAWFORD: Thank you, Chairman Campbell. And thank you, Senator Hilkemann, for bringing this bill and figuring out ways to try to provide this hope. I'm a little confused about who...I guess...who the information about an eligible patient would be given to...and I see there's no fiscal note, so...but yet we have definitions of what makes someone eligible. But I guess I don't understand...and maybe because I'm thinking about it as if, you know, bureaucratic mindset, (laughter) but it seems to me that you'd have to, like, send that form somewhere so someone knows that you're eligible. I mean, I don't understand where, like, approvals are...come from in terms of making sure I am in this program and I do qualify and the drug company knows I am in this program and I do qualify and I can feel confident to provide this drug to this patient. [LB804]

SENATOR HILKEMANN: Yeah, and I...and that's a good question, Senator. And I think that this is going to be between the patient and their doctor. This has to be recommended by their doctor. And this is...and I would guess, Senator, you know, I would...having been in the medical profession, I would say that a patient may come to me and say--doctor, are you...or have you heard of drug X or have you heard of therapy X? And the doctor is...typically that's not an approved-type drug or whatever else like that. And that doctor may check into that and see if that's an availability. Or more likely what would happen is that a doctor while he's at a seminar at some state, as colleagues will do, he'll say--now I heard about a drug that they're using in England...or that they're using in India or whatever else and it's been showing some success; it's still in drug trials here in the United States but we could try that drug and we can...and so this would give them the right to try without having to go through the whole rigamarole of the Compassionate Care Act. [LB804]

SENATOR CRAWFORD: So it would really be the physician's office that would maintain the records that they're eligible and maintain their informed consent forms. [LB804]

SENATOR HILKEMANN: Exactly. [LB804]

SENATOR CRAWFORD: The physician would be the one taking care of it. [LB804]

SENATOR HILKEMANN: That's correct. That's correct. [LB804]

SENATOR CRAWFORD: Okay, thank you. [LB804]

SENATOR CAMPBELL: Senator Riepe. [LB804]

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SENATOR RIEPE: Thank you, Senator Campbell. Senator Hilkemann, good to see you. Question I have, I think you said the South Dakota bill is your, kind of, model legislation. Is that correct? [LB804]

SENATOR HILKEMANN: That's correct, yes. [LB804]

SENATOR RIEPE: Okay. The other question I had was is there a time line on this? Do they have to have an admission to a hospice center which is generally six months of anticipated remaining life? Or they could do this early on and they might have more time? [LB804]

SENATOR HILKEMANN: The bill reads that they've had to try their...they've had to try other options. In other words, this is just sort of a last option for them so they will have been more in the end stage of their treatment of it. [LB804]

SENATOR RIEPE: Okay. The other question I have is, is because in the state of Nebraska, incarcerated individuals are entitled to probably the best healthcare that we have in the state. Would they be entitled to this option as well? [LB804]

SENATOR HILKEMANN: Well, it's the right to try. And the patient is responsible for the payment of this...if the drug company doesn't provide it. So... [LB804]

SENATOR RIEPE: But if they're incarcerated, that payment comes back to the state because they would have...if they're incarcerated in prison, they're not going to have resources. [LB804]

SENATOR HILKEMANN: Um-hum, um-hum. Well, that...I would have to say they probably would not be eligible for the right to try at that point. [LB804]

SENATOR RIEPE: I'm just curious. Okay, thank you. [LB804]

SENATOR CAMPBELL: Other question? Senator Howard. [LB804]

SENATOR HOWARD: Thank you, Senator Campbell. Thank you, Senator Hilkemann. We've spoken about this bill previously. I wanted to go back to Senator Crawford's question about the documentation. So the physician would keep the documentation on file; do they have to share that with the company who would be releasing the medication in order to prove that the patient is eligible? [LB804]

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SENATOR HILKEMANN: Yes. [LB804]

SENATOR HOWARD: Okay. And then following up on that, what type of training are physicians receiving about the use of these new drugs? [LB804]

SENATOR HILKEMANN: Well, I would have to say that...that a physician would have to feel comfortable in prescribing this drug. They would have to be...if it's a drug or whether it's a treatment plan that they would want to do. That, again, goes back to the physician making that decision and helping the patient make the decision whether this...this is really a good option for them. [LB804]

SENATOR HOWARD: And then to follow up on that, in Section 9 on page 4, you have, sort of, a broad immunity clause. And I brought an immunity clause in a bill my first year and learned quite a lot of valuable lessons. Have you spoken with the trial attorneys about that immunity clause? [LB804]

SENATOR HILKEMANN: I have not spoken with the trial attorneys about this. We did have Health and Human Services review this and they found that...the legal staff there did not find any problems in this bill. [LB804]

SENATOR HOWARD: You may want to follow up with them on the language of the immunity clause to make sure that it aligns with Nebraska statute and that they feel comfortable with it as well. And then the only other question that I have is in Section 8 on page 4, line 16 through 20, you talk about Medicare certification. Did you mean Medicaid certification? [LB804]

SENATOR HILKEMANN: This is written as Medicare certification. That's been the model legislation. [LB804]

SENATOR HOWARD: Are we able to insert ourselves into the Medicare certification process? [LB804]

SENATOR HILKEMANN: The Medicare certification process? [LB804]

SENATOR HOWARD: No, sir; yes, because Medicare is a federal program and Medicaid is provided through the state. And so is it a drafting error? [LB804]

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SENATOR HILKEMANN: Senator, I don't think it's a drafting error. I think this is how the model legislation...this, again, was taken from the South Dakota bill. I can certainly check in and get back to you on that question that you have. [LB804]

SENATOR HOWARD: I...only because I could see us having some challenges inserting ourselves into Medicare certification because we are not the certifying body for that. [LB804]

SENATOR HILKEMANN: Okay. [LB804]

SENATOR HOWARD: Thank you though. [LB804]

SENATOR HILKEMANN: Okay. I'll do that. Additional questions? [LB804]

SENATOR CAMPBELL: Senator Hilkemann, is the physician...could...doesn't have to be a person's regular physician, do they? And by regular, I mean that's who your... [LB804]

SENATOR HILKEMANN: You could...I would say you could...they could be referred to...in other words, they would have to be under the care of a physician. [LB804]

SENATOR CAMPBELL: Right, but it could be that they have a condition and there's a physician in South Dakota who specializes in the condition that the patient has, so it's not...it could be any doctor as long as they are a physician of record, I'm assuming. [LB804]

SENATOR HILKEMANN: That's correct. That's how I understand this. [LB804]

SENATOR CAMPBELL: So that physician would have to hold the records and not their regular physician. [LB804]

SENATOR HILKEMANN: Right. [LB804]

SENATOR CAMPBELL: Okay. Other questions, Senators? We may pick up some additional information as we go along. [LB804]

SENATOR HILKEMANN: Yeah, we're aware of a doctor, for example, that's treating a special form of cancer in Texas who's got 25 of these patients already on record. So I'm sure that in many cases, Senator, what may happen is that they'll say--you may want to...doctor so-and-so is

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a specialist in and has been working with this and been finding good success with that. That may be the option. [LB804]

SENATOR CAMPBELL: Okay. All right. Will you be staying to close? [LB804]

SENATOR HILKEMANN: I will stay to close. [LB804]

SENATOR CAMPBELL: Okay, excellent. We will ask for our first proponent for LB804. Good afternoon. [LB804]

KIM ROBAK: (Exhibit 3) Good afternoon, Senator Campbell, and members of the committee. My name is Kim Robak, R-o-b-a-k. I'm here today on behalf of both the Nebraska Medical Association and the Nebraska Oncology Society in support of LB804 with some caveats. We support the bill for the reason that there are patients who have serious or life-threatening diseases or conditions; they are at end-of-life situations and there is no cure. And there are those individuals who have no other option. And so this bill, LB804, makes some sense in those instances to perhaps provide some alternative when no other alternative exists. However, we need to point out a couple of things. And first of all, that this bill would allow the option for a physician to say this drug exists, but it's the pharmaceutical company who makes the decision whether or not to provide access to the drug. And as a result, some pharmaceutical companies, particularly those that are in clinical trials, may feel that it's inappropriate to provide the drug because it could threaten or somehow harm the clinical trial in which this drug is being utilized. For example, if somebody is harmed by the drug or dies after taking the drug, it may be that the individual died as a result of the illness and not the drug, but the company must report then the outcome of the use of the drug. And so it's not necessarily a given that the company will provide access to the drug. There's also a fear that perhaps this will give some folks an unrealistic expectation that something's there. But again, in those instances, if all of the stars should align and there is that potential that someone could be helped, the NMA and the Nebraska Oncology Society support that opportunity for those individuals with no other choice. And I'd be happy to answer any questions. [LB804]

SENATOR CAMPBELL: Ms. Robak, is there suggested language change? [LB804]

KIM ROBAK: I don't know what language we would provide, Senator, because I don't think you can force a pharmaceutical company to provide access to the drug. And there's also a question about whether or not federal law would have any...some impact on this. I think that the FDA has some federal rules that require certain procedures with regard to how drugs are tested and when they're available to the public and I don't have all of that background. I just know that there is some FDA requirements that also could...need to be met. So my understanding is that while this

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bill has been enacted in other states, I'm not aware of any place that the drugs have actually been dispensed at this point. Doesn't mean they won't be at some point, but it's my understanding that it hasn't happened just yet. [LB804]

SENATOR CAMPBELL: To your knowledge there's not been any federal action... [LB804]

KIM ROBAK: No. [LB804]

SENATOR CAMPBELL: ...or regulation or statement that should be referred to in the bill? I mean, a lot of times we refer to federal legislation or regulation in order to give a framework to the bills. [LB804]

KIM ROBAK: Senator, I will double-check. It is my understanding that Congress has not yet acted on this so there's not something yet to refer to, but I will double-check that and get back to you or to legal counsel. [LB804]

SENATOR CAMPBELL: Okay. Questions? Senator Riepe. [LB804]

SENATOR RIEPE: Thank you, Senator Campbell. Thank you, Ms. Robak, for being here. My question would be with the...this, with all of the states, as we have on our little map over here, that currently have Right to Try, how many...are they all just, for lack of a better term, spitting into the wind, that there's a minimal number of drugs that are available, or what are they doing? [LB804]

KIM ROBAK: Since these are clinical trials, the drugs are not yet publicly available, is my understanding,... [LB804]

SENATOR RIEPE: Um-hum. [LB804]

KIM ROBAK: ...so this would be...if the pharmaceutical company agreed and if the individual could get access to it, then state law would allow that access and state law would hold harmless a physician from prescribing that particular drug, because we don't know what the effects of the drug are yet because they're not finished with their clinical trials. So this would simply allow state law to allow that to occur. [LB804]

SENATOR RIEPE: Are you telling us...and I know you're not representing the pharmaceutical companies, or I don't believe that you are... [LB804]

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KIM ROBAK: No, I'm not. [LB804]

SENATOR RIEPE: ...so they're going to make this judgment call on an individual basis so that they don't have an unfavorable prognosis that makes their...that is reportable and they're going to be pretty cautious about allowing it...is that what I hear? [LB804]

KIM ROBAK: I can let Senator Hilkemann address this in his closing, but my guess is, and this is just a guess, that these drugs would be utilized more toward the end of that process than at the beginning stages of the process. I'm...it's just a guess. And again, it...there's nothing in this bill that would require a pharmaceutical company to give the drug. [LB804]

SENATOR RIEPE: Sure. Okay. [LB804]

KIM ROBAK: It simply says they may. [LB804]

SENATOR RIEPE: There you go. Okay. Thank you. [LB804]

KIM ROBAK: Um-hum. [LB804]

SENATOR CAMPBELL: Any other questions, Senators? Thank you very much. Our next proponent. Anyone who wishes to oppose LB804? Anyone in a neutral position? Senator Hilkemann, do you wish to close? [LB804]

SENATOR HILKEMANN: Thank you for hearing this bill. The...thank you for the questions that you had. I'll try to get the answers for those down the line. I just want you to be aware that this is a new movement; that this is just getting started. And every Legislature thus far has looked at this and has been passing it with quite...with almost unanimous approval as we've gone forward because it gives people that hope, that right to try. And one of the things that has not come out, and you talked about whether the drug companies, this is actually one of those things where the people themselves can pay for it. They don't have to have the drug company that...that gives them the right to pay for that drug if they chose to do that. So with that, I would say let's put Nebraska at the forefront; let's be part of this movement and give people a chance. And with that I'll close. [LB804]

SENATOR CAMPBELL: Questions, Senator? Senator Crawford. [LB804]

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SENATOR CRAWFORD: Thank you, Chairman Campbell; and thank you, Senator Hilkemann. I forgot the question I was supposed to ask you earlier, so I'll ask it now. Can you contrast this with compassionate care options for patients? [LB804]

SENATOR HILKEMANN: Compassionate care goes through the FDA. And as I understand it, for the physicians to go through that whole process it's a very...it's a months-long process. And this shortens up that process. A lot of people, by the time they get the FDA approval for the compassion act, it's too late to have even given it a try. [LB804]

SENATOR CRAWFORD: Thank you. [LB804]

SENATOR CAMPBELL: Senator Hilkemann, as we were listening to the testimony, I just started looking at the map, do you have any idea why Idaho, Kansas, Kentucky, West Virginia, and Georgia, if I'm reading this color right, did not adopt it? Is that correct? Is the gray not adopted? [LB804]

SENATOR HILKEMANN: They're probably in the process at this point. I don't know that they...it...I wasn't aware of any states that didn't adopt it. There was the state of California, the...it was approved in California by the Legislature unanimously, but the Governor vetoed the bill saying that he wanted to give the FDA a chance to work more with the Compassionate Care Act. I have a feeling it's probably a little more politics than that. [LB804]

SENATOR CAMPBELL: Okay. And it could have just been that it was a bill, like what happened in our Legislature, that it was in committee and died at the end of a legislative session without any action. [LB804]

SENATOR HILKEMANN: Right. That's correct. [LB804]

SENATOR CAMPBELL: Because it says, no failed legislative actions. [LB804]

SENATOR HILKEMANN: Okay. [LB804]

SENATOR CAMPBELL: Or listed legislative action, I should say. Okay. Thank you very much, Senator Hilkemann. [LB804]

SENATOR HILKEMANN: Thank you very much for hearing the testimony. [LB804]

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SENATOR CAMPBELL: Items for the record, Elice? [LB804]

ELICE HUBBERT: Nothing for the record. [LB804]

SENATOR CAMPBELL: All right. Senator Brasch, sorry, I didn't see you come in. Thank you. Good afternoon. [LB891]

SENATOR BRASCH: Good afternoon, Madam Chairwoman, and thank you, members of the Health and Human Services Committee. This table seems higher. [LB891]

SENATOR CAMPBELL: I know. We've talked about trying to raise the chair. [LB891]

SENATOR BRASCH: Do you have a phone book for me to sit on? (Laughter) [LB891]

SENATOR CAMPBELL: That's exactly how I feel when I sit in that chair. [LB891]

SENATOR BRASCH: (Exhibit 1) My name is Lydia Brasch, L-y-d-i-a B-r-a-s-c-h, and I represent the 16th District in the Nebraska Legislature. I'm here today and pleased to introduce LB891, which will be known as the Down Syndrome Diagnosis Information and Support Act. The idea for this bill was brought to me last summer by my previous legislative aide. And after considering the issue more closely and noticing that several other states had passed this legislation, which today totals 14 states, we came to the conclusion it would also be good public policy for Nebraska. Down syndrome remains the most common genetic disorder caused by chromosomal abnormalities. Despite that fact, unless a person has a close relationship with an individual with Down syndrome, the general public remain largely uninformed about the condition. The inaccurate information from a bygone era that was widely promulgated occurred when children with Down syndrome were, sadly, often stigmatized. It was commonly believed and, unfortunately, is still assumed by many today that kids with Down syndrome live unhealthy, unproductive, or unfulfilling lives. That's further from the truth. That, however, is something that we would like to make clear, that thanks to advancements in research and medicine and a slowly evolving societal understanding, much has changed in just a generation. Even with this progress, the dissemination of accurate information remains a deficiency in our state. Oftentimes, when parents are given the diagnosis that their child has Down syndrome, not only might they feel scared and alone, but to make matters worse parents are frequently not provided with up-to-date information at the time of also receiving the diagnosis. As such, their unfamiliarity with Down syndrome, coupled with their fear about perceived circumstances for their life and child, causes great anxiety. This, however, need not be the case and it is, therefore, the goal of LB891 is to prevent those situations. LB891 requires that the Health Department and Health...the Department

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of Health and Human Services post on its Web site up-to-date information, including an information sheet about Down syndrome that has been reviewed by medical experts and Down syndrome advocacy groups. The information shall also contain treatment and therapy options, life expectancy, and contact information for nonprofit Down syndrome organizations that provide information and support services for parents and family members. This legislation also requires that healthcare practitioners deliver the information sheet contemporaneously with the diagnosis, so that the parents are immediately given accurate and up-to-date information about Down syndrome and the contact information for those support groups. Following my testimony you will hear stories from parents who, at the time of receiving the diagnosis that their child has Down syndrome, were not given adequate information. It is not an uncommon scenario and, in fact, in many instances they were simply left to rely on their smartphones and Google. You'll also hear testimony from individuals who have Down syndrome about the happy, healthy, and productive lives they are leading and how they are contributing to society and making this world a better place by their presence. Given the prevalence of Down syndrome and the advancements made in medical technology that improve the quality and longevity of life for individuals with Down syndrome, we believe this legislation is good public policy for the state of Nebraska to ensure that parents are equipped with necessary knowledge immediately upon receiving the diagnosis. A day which is supposed to be filled with joy should not be replaced with fear and anxiety about the unknown. Someone sounds happy. (Laugh) This bill helps ensure that. And please note there is no fiscal note on this whatsoever. Thank you for your time and your attention, and we encourage you to pass LB891 out of committee to General File. [LB891]

SENATOR CAMPBELL: Questions, Senators? Senator Brasch, I just had...I mean I looked at the fiscal note and I, too, was surprised just because I'm assuming that the department would have to put this information together in some kind of a pamphlet. Is that what you're thinking? [LB891]

SENATOR BRASCH: They are...they have it electronically... [LB891]

SENATOR CAMPBELL: Oh, okay. [LB891]

SENATOR BRASCH: ...and...but when we tried to access it, my staff tried and others, it's buried several clicks down and it's not easily visible or accessible. And so they are upgrading or working on their Web page, I believe, regardless of this bill, and so the director, I visited with her, and there is no fiscal note. We're very pleased to hear that. [LB891]

SENATOR CAMPBELL: So they are thinking that they would provide it on their Web site, not necessarily in a particular piece of (inaudible)... [LB891]

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SENATOR BRASCH: To publish, yeah. [LB891]

SENATOR CAMPBELL: ...or pamphlet that they would give to the parents. [LB891]

SENATOR BRASCH: And perhaps they have some pamphlets. But they're looking at their program today and improvements that they agreed were...are going to be made on repositioning the information. [LB891]

SENATOR CAMPBELL: One of...the last part of the bill talks about that the Down syndrome organization may request that the department include that information material, their (inaudible). [LB891]

SENATOR BRASCH: Uh-huh. [LB891]

SENATOR CAMPBELL: Do you know whether they're doing that now or...on that? Well, you have been able to access so it's hard to tell but... [LB891]

SENATOR BRASCH: Right. And the information...and from speaking directly, on one of our bad, blustery days of inclement weather, half a dozen people came and they're...some are here today to share with you that the information is just not visible, not viable, not available. And these were for both...from both young and older mothers that...so we're just trying to make a good thing even better. Fourteen other states have seen that. When I went about and got the cosigners, most of the senators had a story to tell about a friend, family, relative, a store clerk. You know, it is very...you know, prevalent as a item that we need to be better at in good, up-to-date information. [LB891]

SENATOR CAMPBELL: I just...and the reason for the questions really is just to ensure that the organizations are not at this point expecting that something truly will be given directly to the parents but that they will be told of a link to a Web site, apparently. Because otherwise the department would have some costs. And I've seen them list costs for publications that they've had to put out. And we just may want to check on that just to make absolutely sure. [LB891]

SENATOR BRASCH: We can check. And there may be information out there... [LB891]

SENATOR CAMPBELL: Right. [LB891]

SENATOR BRASCH: ...they're... [LB891]

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SENATOR CAMPBELL: ...they're already handing out. [LB891]

SENATOR BRASCH: It could. It's possible. I will ask. Good question. [LB891]

SENATOR CAMPBELL: Good. Great. Thank you, Senator. [LB891]

SENATOR BRASCH: Thank you. [LB891]

SENATOR CAMPBELL: Senator Riepe. [LB891]

SENATOR RIEPE: Thank you, Senator Campbell. Senator Brasch, thank you for being here. My question and concern is that this seems like it's not state specific. This is a nationwide issue and it would seem that this information is probably available on the Internet, available through Google. I mean everything is out there and available. I want to just make sure that we're not getting into needless duplication, some redundancy that we create something that we're able to put the stamp of Nebraska on it when it's maybe not that important that it have Nebraska on it. Do you have some thoughts on that? [LB891]

SENATOR BRASCH: Well, my thoughts are from, you know, I'm not the parent of a Down syndrome child, but from the experience that was explained, this is very important to them to have information available. It apparently is happening in other states, because 14 have believed it was necessary to create an act very similar to this; that information that will help them in raising the child, in expectations, support groups is necessary and needed. And that's, I think, kind of scary to rely on just Google for information. I don't know if you've ever had to use Snopes that there's a lot of information on the Internet that may or may not be valid information. You don't know. Even Wikipedia, you know, people add to that. And this is good, solid, sound information that they can rely on and not have to use their smartphone and not have to, you know, to search and find, you know, 15 different sources to work their way through. [LB891]

SENATOR RIEPE: Okay. Thank you. [LB891]

SENATOR CAMPBELL: Senator, just as a follow-up, in the amendment it indicates that the practitioner, whoever, shall deliver a support sheet. And so that's why the question. And then in the next section it talks about a written format. So if you could check that out, because the amendment is going to give the impression that something, I think it gives the impression,... [LB891]

SENATOR BRASCH: Is available. [LB891]

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SENATOR CAMPBELL: ...that something is going to be handed to them. And if the department isn't thinking that, we just may want to double-check. [LB891]

SENATOR BRASCH: I know. [LB891]

SENATOR CAMPBELL: This amendment would require something. [LB891]

SENATOR BRASCH: And I don't know if one of the individuals that did come to visit and meet me for the first time was a physician, and perhaps she's here today and... [LB891]

SENATOR CAMPBELL: Good. [LB891]

SENATOR BRASCH: ...can answer that as well. But if not, then I will find more answers. [LB891]

SENATOR CAMPBELL: Thank you, Senator. Any other questions? Will you be staying to close? [LB891]

SENATOR BRASCH: Yes. [LB891]

SENATOR CAMPBELL: Okay, great. Thanks, Senator Brasch. [LB891]

SENATOR BRASCH: Thank you. [LB891]

SENATOR CAMPBELL: Okay. We will take our first proponent for LB891. You have a proponent. Would you mind very much if we took the proponent that (laughter)...the gentleman in the back is sort of saying, I'd like to go first. You have lots of helpers today. That's good. Good afternoon. [LB891]

JAMES FLYNN: (Exhibit 2) Good afternoon. My name is James Flynn, J-a-m-e-s F-l-y-n-n. And this is Max and that's Pia Flynn, and we're here today to speak on behalf of the bill from the perspective of a family...an adoptive family of Down syndrome. My children both have Down syndrome and both of them are adopted. And the bill makes a provision, when it talks about parents, it makes a provision for parents, natural born parents, but also legal guardians. So I want to talk about our experience as legal guardians, my wife and I. My wife picked a stellar time to go out of town because it meant that Max and Pia got to come here with us. (Laughter) But I want to talk about that experience and then I want to talk about some other people who might

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benefit from the bill. When we...both our children are adopted, both our children have Down syndrome. When we adopted our son, we found out that we would be adopting him a day and a half before we met him and took him home, and so we had a very limited time to understand kind of what Down syndrome was. Like many of us, we hadn't had a relationship with a person with Down syndrome. We'd seen somebody, you know, on the bus or on television or something like that. But we hadn't had a relationship with someone with Down syndrome and so we had to kind of ascertain a lot of facts very quickly and we had to kind of sift through a lot of information very quickly. And the difficult part of that, of course, is that there's a lot of information out there and some of it is good and some of it is not. And even we found, as we talked with physicians, especially, we met them in the NICU and as we met with a P.A., a physician assistant, in the NICU who was going to talk with us about Down syndrome, and that meeting ended up being the three of us--my wife, the P.A., and I--reading the Wikipedia article about Down syndrome to each other. So...and it wasn't, you know, through no fault of his own, it wasn't something that he ordinarily treated, but it also wasn't something that he had experience with. And because of the difficulty of kind of sifting through information, one thing that we would have benefited from tremendously, with a very limited time to research, was something precisely that came with the stamp of approval of the state of Nebraska and, therefore, we were able to trust and have some sense of its credibility, precisely because of the kinds of misinformation that's out there, so for the sake of those kinds of parents. There are children with Down syndrome in foster care. And I have foster care placements which happened very quickly and, again, in a situation where I have to ascertain and make judgments about information very quickly. For the sake of you grandparents, who for various reasons become legal guardians of children with Down syndrome, rapidly enough to kind of get themselves up to speed, having not only the information about Down syndrome but also some connection to the community groups that are supportive of families with Down syndrome would be very helpful. The other group that I want to mention though is not people like us who adopted children with Down syndrome but people who I think would most benefit from this bill and that's people who have, you know, decreased education levels or especially people who are new to this country. Three or four weeks ago my wife and I met a woman who was new to this country. She had been in this country about two years. She had a very limited grasp of English and she had a child with Down syndrome and she had connected with no community resources whatsoever. The child was six or seven months old, and the kinds of things that are available to us--early intervention services and therapeutic services and just very...tests, medical tests and processes that are very common in the United States for children with Down syndrome--she was entirely unaware of. And for a variety of reasons, I think she was apprehensive about approaching anyone to ask for this information, especially approaching the state, city, or county government to ask for this information. And so to have, for people who don't have necessarily the confidence or the education to do research on these things on their own, or especially have a limited grasp of English, to be able to have something that, from the state, gives them some medical information and connects them to groups that have some credibility, because the support and friendship of groups that have

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credibility in a situation similar to yours, of course, is always very helpful. So for folks like that it seems this bill would be particularly valuable. [LB891]

SENATOR CAMPBELL: Thank you, Mr. Flynn. [LB891]

JAMES FLYNN: Sure. [LB891]

SENATOR CAMPBELL: Questions? Senator Crawford. [LB891]

SENATOR CRAWFORD: Thank you, Chairwoman Campbell. And thank you for your testimony. I wondered if adoptive parents, if you would indicate the place or situation where this information is most likely to be helpful. [LB891]

JAMES FLYNN: Sure. [LB891]

SENATOR CRAWFORD: As I read the bill, it looks like it's focused on someone who is having a child or focused on the medical... [LB891]

JAMES FLYNN: Sure, and it talks about... [LB891]

SENATOR CRAWFORD: ...relationships. [LB891]

JAMES FLYNN: ...the bill talks about both the prenatal diagnosis... [LB891]

SENATOR CRAWFORD: Right. [LB891]

JAMES FLYNN: ...and the postnatal diagnosis. [LB891]

SENATOR CRAWFORD: Right. Right. And yours is a very different situation. [LB891]

JAMES FLYNN: Right. You know, for a child who is in the foster care system or who's adopted later, that I couldn't speak to as well. Although very often in the case, and those of you who are involved in foster care know this, that a child who's placed in foster care, the foster parents do get a sort of medical briefing of the child's needs. And that would be a place where this would be appropriate. But we adopted Max when it was 11 days. We adopted Pia when she was five minutes old. [LB891]

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SENATOR CRAWFORD: Okay. [LB891]

JAMES FLYNN: So we and their birth parents were sort of getting this information at the same time. [LB891]

SENATOR CAMPBELL: Senator Riepe. [LB891]

SENATOR RIEPE: Senator Campbell, thank you. Administrator from a pediatric background, was your pediatrician or your general practitioner informative at the time when you received your babies? [LB891]

JAMES FLYNN: Well, that's a great question because, of course, prior to having children we didn't have a pediatrician. So one of the things that... [LB891]

SENATOR RIEPE: Oh, Yeah. Okay. [LB891]

JAMES FLYNN: ...one of the things that made a big difference was talking with the Down syndrome community to find out about pediatricians who had some specialization or expertise in this area, finding pediatricians who knew...who had treated children with Down syndrome before, who knew what some of the common issues were. Our daughter Pia is a cancer survivor twice over. She had...she was diagnosed with leukemia when she was five days old and then again when she was about a year old. And because her pediatrician knew about Down syndrome, she knew the signs to look for in both cases. She caught some early signs. And especially, she knew some very early blood tests that would be typically administered to children with Down syndrome but not other children. Well, we wouldn't have had such a pediatrician if we hadn't been connected with those community groups and got some recommendations and those kinds of things, because we would have gone to a pediatrician who our friends went to and our friends' children didn't have the specialized needs that ours do. [LB891]

SENATOR RIEPE: My guess is, too, you live in an urban area. [LB891]

JAMES FLYNN: Right here in the city of Lincoln. [LB891]

SENATOR RIEPE: Yeah, as opposed to... [LB891]

JAMES FLYNN: Sure. And then... [LB891]

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SENATOR RIEPE: ...a little more western area that might not have a pediatrician with...or primary care doctor with that kind of knowledge or experience. [LB891]

JAMES FLYNN: And in that sense, having especially a connection to groups of parents who have gone through this is particularly more helpful because knowing what questions to ask a pediatrician makes a world of difference. Everybody who's a parent knows that. But in our case, you know, especially with Pia, who's been sick so many times, just kind of knowing what questions to ask, knowing what might be a red flag for her, you know, to relapse into cancer, what might not be, and being able to bring that to the pediatrician has been very helpful to us. So we've gotten all that from other families of children with Down syndrome and resources they've pointed us to and things like that. [LB891]

SENATOR CAMPBELL: Any other questions, Senators? Thank you, Mr. Flynn. And we particularly enjoyed meeting your two children. [LB891]

JAMES FLYNN: Well, thank you very much. Can you say good-bye? Can you wave? [LB891]

SENATOR HOWARD: Bye. [LB891]

SENATOR CAMPBELL: Bye. [LB891]

JAMES FLYNN: Good boy. [LB891]

SENATOR CAMPBELL: We've all been trying to wave at him sort of under the radar. And thank you for being an adoptive family. [LB891]

SENATOR CRAWFORD: Uh-huh. Yes. [LB891]

JAMES FLYNN: Oh, it's our privilege, really. [LB891]

SENATOR CAMPBELL: All right. Our next proponent. That's a hard act to follow, (laughter) very hard. Good afternoon. [LB891]

SHERRI HARNISCH: (Exhibit 3) Hello. Thank you, Chairwoman Campbell, and special thank you to Senator Lydia Brasch for introducing this piece of legislation. And thank you very much to this committee for taking the time to learn more about the bill and why it's important. My

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name is Sherri Harnisch, and I sit before you today as president of Down Syndrome Alliance of the Midlands. [LB891]

SENATOR CAMPBELL: Could you spell your name for us? [LB891]

SHERRI HARNISCH: Yes. Sherri Harnisch, S-h-e-r-r-i, Harnisch, H-a-r-n-i-s-c-h. [LB891]

SENATOR CAMPBELL: Thank you. Go right ahead. [LB891]

SHERRI HARNISCH: Thank you. I'm president of the board for Down Syndrome Alliance of the Midlands and serve as an ambassador for the National Down Syndrome Society. Most importantly, I am here today as a mother to six-year-old Macy who has Down syndrome. After a healthy pregnancy, I arrived at the hospital ready to give birth to our second daughter, expecting this experience to be much like the first. I recall, shortly after her birth, holding Macy in my arms and falling immediately head over heels in love with her. So imagine our surprise a few moments later when we were informed that she has Down syndrome. Time seemed to stand still. We were shocked and surprised, a little confused, and speechless. I remember just staring at her, trying to figure her out. It's incredible to think about how intimidating a five-pound person can be. I was already a mom but at that moment I pretty much threw all my previous parenting experience out the window. This was new. We felt discouraged and a little ill-equipped. And I'm not sure why, but this news was not delivered to us from our doctor himself. Instead, he opted to pass the buck to a nurse practitioner who was also in the room whom we were not familiar with. Perhaps he felt ill-equipped too? I'm not sure. In the moments that followed, several medical providers crowded around my bed and continued to point out several physical characteristics that led them to this diagnosis. While we saw what they saw, we still did not know what to think, what to say, or how we were supposed to feel. They asked if we had any questions. Of course we didn't. Up to this moment, Down syndrome was foreign to us and something that we knew very little about and did not have any previous direct experience with. We felt vulnerable and words couldn't get past the lumps in our throats. Mostly, we just felt alone. In the days following her birth, many relatives and friends visited us at the hospital. And even though Macy was greeted and welcomed with love and joy, we still felt alone. As you can imagine, we did what most parents in our situation would do. We turned to our trusty smartphones and there we were, just Googling away in the darkness of the night in our hospital room, because who sleeps after receiving a life-changing diagnosis such as this? Obviously, most of the information that we came across was outdated and actually pretty offensive. Upon physician recommendation, we were transported to another hospital across town, one that could provide a higher level of care for a suspected heart condition. At three days into our new journey, Macy was boarding an ambulance to Children's Hospital in Omaha, and I was sent on my way with a prescription for antidepressants. I wasn't depressed. I was a new mom receiving a new diagnosis. I was in shock. Needless to say, I didn't

fill that prescription. It wasn't until Macy was five days old that a genetics counselor came to meet us at the hospital. We were presented with binders full of information about Down syndrome, and we were finally made aware of local and national organizations we could reach out to for resources, guidance, and support. We had no idea what the future was going to look like for our daughter, but at least now we had some semblance of what was possible. In my role as president of our Down Syndrome Alliance, an organization committed to connecting those touched by Down syndrome through education, advocacy, and support, I've had the opportunity to meet many other families from across our state who share this common bond. While each diagnosis story is unique, most follow this similar trend. I recognize that doctors and nurses have a lot on their plates. I believe in my heart that each physician is doing the best that they can to do right by their patients. But the fact remains this trend of misinformation or lack thereof still very much exists. Appropriate materials can and should be readily accessible to these medical providers. However, still today, even despite our organization's most robust medical outreach efforts, this information is not being passed on to their patients. There is simply no reason for this. It's unacceptable, irresponsible, and, quite frankly, reckless. The passage of this bill is a vital step forward. It will correct an imbalance and make more consistent the availability, accuracy, and appropriateness of information that is provided to parents regarding Down syndrome. Our daughter Macy--she's in the back of the room with braids--she's six years old. She is fully included in her general education kindergarten classroom and thriving. She is bright and speaks her mind articulately. Macy participates in several community activities, including ballet, tap class, gymnastics, swim lessons, Sunday school, vacation Bible school, summer camps, as well as Special Olympics Young Athletes Program. She has formed true, authentic friendships with kids her age. I continue to be actively involved with our local Down Syndrome Alliance because there's nothing more powerful than surrounding yourself with positive, like-minded individuals who share a collective desire to improve the lives of people with Down syndrome. Today more than ever, people with Down syndrome learn in regular classrooms, participate in community activities, and are employed in a variety of jobs. It is important to note that the landscape of our society as it relates to the acceptance and inclusion of individuals with Down syndrome has come a long way. And it is critical that every professional in the medical community is on par with that. Having been through this experience, I know firsthand how confusing and, at first, lonely receiving a diagnosis such as this can be. And today, with more women receiving prenatal screenings earlier in their pregnancy than ever before, there is even more reason to ensure that they are armed with up-to-date, accurate information immediately at the time of diagnosis by their medical provider. This bill provides for that very basic need, and I'm asking for the passage of LB891. Thank you for your consideration. [LB891]

SENATOR CAMPBELL: Thank you, Ms. Harnisch. Questions, Senators? Senator Riepe?  
[LB891]

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SENATOR RIEPE: Thank you, Senator Campbell. And thank you for being here and sharing your story with us. One of the often-forgotten people are the big sisters in your case, and I think that...I don't know whether you've received any help because at the same time when you're dealing with a newborn this older child who is going to be the big sister, big brother kind of gets, possibly, set aside. I'm not saying in your case it did. But it's almost information on how do you also deal with siblings at the same time when you're dealing with this new situation. Now did you receive any information along that line? [LB891]

SHERRI HARNISCH: You're absolutely correct. In fact, that was one of the first things that crossed my mind when we heard the words "Down syndrome" applied to our second daughter was, what is this going to mean to her, us, our family, most importantly Mackenzie (phonetic), who was two and a half at the time? Mackenzie is eight years old and she is the best friend to Macy that any person could ever have. They're so lucky to have each other. And through our local organizations, as well as national organizations, we have received support that does ensure that siblings just are supported as equally as their sibling who happens to have special needs. And I would say that in our family that they both feel equally loved and supported. And there's a lot of programs and resources out there available to assist siblings as well and just be a good support group for them. [LB891]

SENATOR RIEPE: You sound like a good mom, so that helps a lot too. [LB891]

SHERRI HARNISCH: Well, thank you. [LB891]

SENATOR RIEPE: Thank you. [LB891]

SENATOR CAMPBELL: Other questions, Senators? Ms. Harnisch, I have a question. Does the Down Syndrome Alliance provide written materials? [LB891]

SHERRI HARNISCH: They do, absolutely. In fact, you'll hear in a moment from Beth Gard, who serves on our board as our medical outreach chair, and her primary role on the board is to go out to the community and visit with ob-gyn clinics and pediatrician offices and hospitals. She makes grand rounds presentations. And she delivers materials that are consistent with organizations from across the country. And the Down Syndrome Association of Families here in Lincoln, they present materials from a company called Letter, Lettercase, and they're just very well, well-done materials that have been created by Down syndrome advocates and physicians from national, regional, and local Down syndrome organizations. [LB891]

SENATOR CAMPBELL: Thank you. [LB891]

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SHERRI HARNISCH: Thank you. [LB891]

SENATOR CAMPBELL: Our next proponent. Good afternoon. [LB891]

BETH GARD: Good afternoon, Senator Campbell, members of the committee. Thank you for having me here and taking the time to listen to us support this bill and the importance of it to families who have children with Down syndrome. [LB891]

SENATOR CAMPBELL: And we're going to ask for your name. [LB891]

BETH GARD: Yeah. My name is Beth Gard, that's B-e-t-h G-a-r-d, and I'm a mom to a three-and-a-half-year-old little boy named Elijah (phonetic) who has Down syndrome. And as Sherri Harnisch mentioned, I'm also the medical outreach chairperson for the Down Syndrome Alliance of the Midlands. So my son Elijah decided that it was time for him to enter the world on May 11, 2012. He was five weeks early. While we had one test showing an increased risk of Down syndrome, we had no definitive testing done to determine for sure that he had Down syndrome, and we had a series of ultrasounds that were performed that suggested he did not. So when he was born and our doctor said that the NICU staff saw physical markers of Down syndrome, my husband and I were crushed. So our first surprise with Elijah was that he came so early, and our second surprise was that he had Down syndrome, because we were preparing for a healthy baby. We felt alone and we felt scared. We had so many questions. We wondered if he would go to school, if he would ride a bike, if he would have friends, and, most importantly, if he would be happy. We had no idea what his life would be like and what the life of our family would be like, because he was our second child. We had a three-year-old, or almost three-year-old at the time. His diagnosis was confirmed the following day. The OB on call didn't provide us with any information and very little comfort. We received some information from the pediatrician on call with some kind anecdotal experiences that they had with Down syndrome. We continued to be alone and anxious about our son's future. The best that we could do was search the Internet to find out what we could. During our first visit with our pediatrician, she had set us up with a geneticist. And nearly a month after Elijah was born, we received the entire rundown on Down syndrome from a medical professional. We also learned during this time of a support organization, the Down Syndrome Alliance of the Midlands, also known as DSA. Elijah and our family fell through the cracks and didn't get information that we needed when we needed it. Late in 2013, I was approached by the Down Syndrome Alliance of the Midlands about an open board position that focused on medical outreach. I jumped at the chance to make sure that other families received information about Down syndrome and about support groups right away to try to close the cracks that our family fell through. In medical outreach, we visit local hospitals--their mother...specifically mother and baby, labor and delivery, and NICU staff--to educate them about DSA. We visit local ob-gyn and maternal field medicine offices to put on lunch-and-learn

presentations about delivering a diagnosis and DSA. We leave medically reviewed information to give to patients who receive a prenatal diagnosis. These are the booklets that Sherri had mentioned that come from [Lettercase.org](http://Lettercase.org). They're beautiful booklets. They show kids living with Down syndrome who are interacting like typical kids would. They're coloring, they're writing, they're playing with other friends, they're going to school, they're involved in activities. And these booklets are both in English and Spanish because we're aware that there is a need for outreach in the Hispanic community as well. Our outreach appears to be working because we've been invited to speak at several educational events at local hospitals, and we are contacted by social workers and nurses requesting information and visits from our parents per the new parents' request. At the end of 2015, we launched our pediatric outreach program. The program is very similar to our prenatal outreach program where we are putting on lunch-and-learns and providing booklets, new parent guide booklets so that the pediatricians, if the parents are not getting this information from...initially, once they get their diagnosis, once they see their pediatrician, if they haven't already heard about DSA or gotten information about Down syndrome, then hopefully the pediatricians can take the ball there. We feel that by establishing strong relationships with the medical community, we can better support those families who receive a diagnosis. By passing LB891, we feel that this will only improve upon the work that we do in medical outreach. This act will ensure that accurate information is given to parents at the time of diagnosis, whether that be before or after birth. This is such an important time for a family. While this information can't take away the feelings of anxiety and sadness, it will help them quickly get important facts and make them aware that they are not really as alone as they may feel, closing even more of the cracks that we fell through. Thank you. [LB891]

SENATOR CAMPBELL: Questions, Senators? Senator Riepe. [LB891]

SENATOR RIEPE: I just come back, you know, obviously, people that are having children or young people and, you know, they're so attuned to information on a variety of sources beyond my comprehension. I guess I'm just saying how overwhelmed does a person get by all of the information? [LB891]

BETH GARD: (Laugh) Well, when you're meeting with a geneticist who has been working in the field that he's been in for 30-plus years and he's going over your four-week-old infant with a fine-toothed comb, telling you exactly everything that is going on with him now, what's going to go on with him in six months, what's going to go on in two years, five years, ten years, it's a lot to take in. It was extremely overwhelming. My husband and I, our heads were spinning when we left his office. [LB891]

SENATOR RIEPE: Uh-huh. [LB891]

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BETH GARD: But the one thing that I will say that we took away from that experience was he had told us never to lower our expectations with our son, to give him the same or have the same expectations that we have with our oldest son, keep them the same as with him, never, never give up and never lower them. So that was one thing that we took away from all the information that we got. But, yes, it was. It's very overwhelming. You know, it's a tough time and you know, in my meeting with doctors and nurses over the last couple of years, you know, one thing that I have discovered is that it is difficult for medical providers to provide the diagnosis. It's difficult, a difficult situation. So it's difficult on both parts. But the thing is, it's the most difficult for the parents. And to not really get anything when you find out right away is the hardest thing because it makes you feel that you don't have any support, you know, and that's very difficult. [LB891]

SENATOR RIEPE: My understanding, too, is with parents getting so much serious information, it's not uncommon to get brain freeze as you go through. And so my question would be were you provided with hard copy information or DVDs or any kind of information so after you settle down a little bit you can go home and replay it and kind of say, I didn't hear that the first time around? [LB891]

BETH GARD: We had gotten from the geneticist, we'd gotten a lot of hard copied information. Some of it were...there were journal articles. [LB891]

SENATOR RIEPE: Technical? [LB891]

BETH GARD: Technical. I have a biology background so for me it wasn't something that I couldn't understand. But when you're thinking about all the other medical stuff that's going on and, you know, you have this information in front of you, it's a lot to sit there and try to read a journal article at that time, you know? But so we got a lot of hard copied information, journal articles. We had gotten an outdated copy of the Down Syndrome Alliance's "New Parent Guide." It was under a different...their different name. They had a different name prior to them being the Down Syndrome Alliance. And then we got growth charts and charts on when to check on certain...like to check on their eyes, to check...do dental checks, to check their heart, to check sleeping and from birth to one and then from one and beyond. And you know, getting all of this, it's hard to decipher, well, what's important, what's not important, what do we do with this,, do we need to keep this chart, do we not need to keep this chart. So you know, that...taking that information, then going back to the pediatrician, you know, we had questions that we needed to ask and hopefully that she could answer them. And she did, but it's still...it's overwhelming. [LB891]

SENATOR RIEPE: Uh-huh. [LB891]

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SENATOR CAMPBELL: Any other questions? Thank you for your testimony today. [LB891]

BETH GARD: Thank you. [LB891]

SENATOR CAMPBELL: Our next proponent. Good afternoon. [LB891]

DEB SAFARIK: (Exhibit 4) Good afternoon, Senator Campbell and members of the Health and Human Services Committee. It's very nice of you to be able to hear all of us today. My name is Deb Safarik, that's D-e-b S-a-f-a-r-i-k. I live here in Lincoln and I have four children. My youngest, Paul, who is not so young anymore, he's 23 and he is sitting back in the blue shirt, is here with us and he has the most common type of trisomy 21, usually referred to as Down syndrome. I would like to thank Senator Brasch for introducing this bill and the 43 other senators who are the cosponsors. I started the first Down syndrome parent support group in Lincoln 21 years ago and I've been the past-president. At that time I had never met another family that had a child with Down syndrome. And I thought, doesn't anybody want to get together? Don't they want to talk? Don't we want to share our concerns and our joys? And so that was what started the group. Presently, I'm also part of a new grass-roots group called Down Syndrome Advocates in Action. I created the first medical outreach packet that was provided to hospitals for new parents receiving a diagnosis of Down syndrome in Lincoln. I counseled with families considering whether to continue their pregnancy, and with several other families who were considering the possibility of placing their newborn baby for adoption. I tried to give all these families hopeful, realistic information about what to expect and deliver the information in a nonjudgmental manner. Nearly all the many families that I have met tell stories of receiving inaccurate or outdated information or no information at all about Down syndrome. Support groups in Lincoln and Omaha have medical outreach committees--and you'll hear more about the medical outreach committee here in Lincoln--that provide information to maternal-fetal specialists and obstetricians so that they are aware of accurate information they can give their patients. But in smaller communities across the state, there is not the same access. Families deserve to receive accurate, balanced, nonbiased information from their doctors no matter where they live in Nebraska. Doctors should have easy access to information for their patients, whether they have an active Down syndrome support group available to bring them information like is available in Lincoln and Omaha for sure. All of our Down syndrome organizations strive for a stronger collaboration with healthcare professionals to share best practices for delivering a diagnosis of Down syndrome and supporting new and expectant families. LB891 will help healthcare professionals do that and help with the collaboration that we want to provide between our organizations and the medical physicians. We didn't know for sure that Paul had Down syndrome until he was six months old. He didn't have some of the classic characteristics of Down syndrome and we were dealing with some additional health issues. I had to call in to the physician's office for the report and the office was closed for lunch when they told me to call in. When I finally got the geneticist and was told that he has classic trisomy 21, I said, now what?

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And his only information to me was call Tom somebody in the schools and he will help you. So we were left to our own devices to find information about Down syndrome and how to best support Paul. A few years ago Paul went to the hospital with his dad to visit a new family with a baby with Down syndrome, and I asked him today why he thought it was important for families to get good information about Down syndrome. And he said, so they can know that we...what we can do and it's okay. We appreciate your support of this bill. [LB891]

SENATOR CAMPBELL: Thank you. Questions, Senators? Since you developed the first packet and have been around quite a bit, I've been taking a look at what the department...the department expects that they will develop the Web page, and on that Web page they would have an information sheet, which they would expect the physician to print out. [LB891]

DEB SAFARIK: Right. [LB891]

SENATOR CAMPBELL: And so at that point, you think that's sufficient? [LB891]

DEB SAFARIK: Well, I think, you know, if you go to your doctor's office, they probably have a file there on the desk and it says, you know, for diabetes, for smoking, for heart, for whatever, whatever. So I can even envision that they have, you know, have a sheet about Down syndrome. What I think we haven't maybe said about on the sheet, there will be links that...on the sheet that can go to other Down syndrome organizations in Nebraska. And you know, it's not all...not all groups are nonprofit. Maybe they haven't been able to set that up, they aren't bigger to do that. There's a nice big group in Kearney that is out there for people in the western part of Nebraska, and yet they have...they do nice, nice things with families and families come from quite a distance to be able to do things with them. And so if there's those links for families, even if they get it on a sheet of paper, they can go where to look. Because as other people have said, yeah, you can Google, you could check things out, but sometimes the information isn't good. How do you know? And this would supply some information to links to groups within the state so that you could find that information. [LB891]

SENATOR CAMPBELL: Thank you. Thank you very much. [LB891]

DEB SAFARIK: Thank you. [LB891]

SENATOR CAMPBELL: Our next proponent. Good afternoon. [LB891]

ELISSA FUELBERTH: Good afternoon. [LB891]

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SENATOR CAMPBELL: We can get you another chair. Sir, there's a chair right over here. Can you...oh, thank you, Senator Baker. There we go. We now have more than one extra chair. Okay. Maybe we just need to move...there we go, because we want to make sure that your voice comes through on that microphone there. [LB891]

ELISSA FUELBERTH: (Exhibit 5) Good afternoon. My name is Elissa Fuelberth, E-l-i-s-s-a F-u-e-l-b-e-r-t-h. I am 16 years old and am a sophomore at Southwest High School. My favorite classes are Algebra, Geometry, and Choir. I also love lunch because I have time to talk with my good friends, Greta, Kennedy, Charissa, and Lauren. I am working my hardest to get my homework done on time. I have been a Girl Scout for eight years, sing in a community choir called i2Choir, play YMCA softball, and go to youth group at my church. I like to read and listen to music. I love to travel with my family. We went to California this year and I saw the Rose Parade. The trip was very long, but I didn't fight too much with my brother Hayden. I have a wonderful life. I also happen to have Down syndrome. Someday I want to work as a nurse's assistant in Lincoln. Thank you to Senator Brasch and everyone here for supporting this bill, which will allow other families across the state to gain helpful information. It is critical that families can see a positive picture of what individuals with Down syndrome can accomplish. I am hopeful that this bill will give families a vision for their child's future as valuable contributors to communities in the state of Nebraska. [LB891]

SENATOR CAMPBELL: Elissa, you did a great job. Pretty soon you'll be here all the time testifying. Any questions, Senators? Thank you, Elissa, and enjoy that softball season, okay? [LB891]

DEAN FUELBERTH: I can...I have my orange sheet here. [LB891]

SENATOR CAMPBELL: Okay. [LB891]

DEAN FUELBERTH: I can go next if you want. [LB891]

SENATOR CAMPBELL: Sure. [LB891]

DEAN FUELBERTH: Good afternoon, Senator Brasch, Senators on the committee, Chairwoman Campbell, members of the various Down syndrome organizations that are here, and other attendees. My name is Dean Fuelberth, D-e-a-n F-u-e-l-b-e-r-t-h, and I am the president of the board of directors for the Down Syndrome Association for Families of Nebraska, a Lincoln nonprofit 501(c)(3) organization that provides support for individuals with Down syndrome, their families, friends, educators, and professionals who share in their lives. Our organization has

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been serving the Down syndrome community for over 20 years in Lincoln and throughout the state of Nebraska. Many families expecting a child with Down syndrome may not always have great supports or know much specific information regarding Down syndrome. We pride ourselves on helping provide a picture of what a blessing their child will be in their lives. The DSAF offers an array of programs, events, and resources for our membership and the community. Our largest awareness and fund-raising event is our annual Step Up for Down Syndrome Walk in October, and last year was the 14th annual walk with 77 teams and a record 1,620 day-of participants. We also host an annual multitrack educational conference with national and local speakers, and attendees at our last event came all the way from Scottsbluff, Nebraska. Our flagship committee is our medical outreach committee chaired by Alica Bruning, who you will also hear from this afternoon. This mighty committee timelessly connects with the medical community across Lincoln and surrounding areas to attempt to be a source of positive and current information to families receiving a prenatal diagnosis or families upon the birth of their child who happened to have Down syndrome. I'm also the parent to two wonderful children, with my oldest having trisomy 21 or Down syndrome. In the hospital in Kansas City where she was born, we were lucky enough to receive a packet of information from the local Down syndrome guild. After several days in the hospital, I was able to go across the street to Barnes and Noble and find a plethora of current information and guidebooks into the world that we were just entering because of that packet pointing me to these references. I want to thank everyone for your support of this bill to allow other families, no matter what size city they're located in Nebraska, to gain consistent, current, and accurate information as they enter the Down syndrome community. Thank you. [LB891]

SENATOR CAMPBELL: Thank you for your testimony today. Questions, Senators? Thank you for coming and your work. [LB891]

DEAN FUELBERTH: Thank you. [LB891]

SENATOR CAMPBELL: Our next proponent. Good afternoon. [LB891]

JAMIE ANDREWS: Good afternoon. Sorry, I got it folded up. [LB891]

SENATOR CAMPBELL: You're fine. [LB891]

JAMIE ANDREWS: Okay. So good afternoon, Senators. My name is James Andrews from Lincoln, Nebraska. I'm here in support of Down Syndrome Diagnosis Information and Support Act. I think it's important for parents of babies to receive the most up-to-date information of Down syndrome diagnosis. It's not so bad. Parents need to know about information about good medical care and exercise, and particularly to have high expectations for their child. These

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children can grow up to read, write, use computers, cell phones, graduate from high school, even go to college. Well, look at me. I went to University of Iowa for a year. They need to know that (inaudible) will be able to testify before the Senate someday. Thanks, and please support the bill. [LB891]

SENATOR CAMPBELL: So are you a Hawkeye fan? [LB891]

JAMIE ANDREWS: Yes. (Laughter) [LB891]

SENATOR CAMPBELL: You know it's dangerous to say that. (Laughter) [LB891]

JAMIE ANDRES: Kind of dangerous, but again (inaudible) mind it. [LB891]

SENATOR CAMPBELL: I want you to know that the husband of my legislative aide also went to the University of Iowa and is a big Hawkeye fan. And I have to tell you, I lost a bet this year with him. So are they going to be as good next year as they were...? [LB891]

JAMIE ANDREWS: Yeah. They got good last year, went undefeated and lost to the big... [LB891]

SENATOR CAMPBELL: I know. [LB891]

JAMIE ANDREWS: ...in the Big Ten title game against Michigan State. [LB891]

SENATOR CAMPBELL: I know. [LB891]

JAMIE ANDREWS: So they might do it again this year. They got trashed against Stanford, no offense to my dad. Actually, I'm a huge Hawkeye fan, like I mentioned before, and our friends also with Down syndrome, (inaudible) I see at the library, working. Besides Zoe (phonetic), well, she's the brains of the whole operation. So I don't know. I got support by a lot of teachers up in Iowa City, Derrick Rodgers (phonetic) and others. I'm lost for words right now. [LB891]

SENATOR CAMPBELL: You're doing pretty well, let me tell you. We just appreciate so much you taking time to come and testify for us today and good luck to you. [LB891]

JAMIE ANDREWS: Thanks. [LB891]

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SENATOR CAMPBELL: Thank you very much. [LB891]

JAMIE ANDREWS: Thank you. [LB891]

SENATOR CAMPBELL: Our next proponent. Oh, I'm sorry, Senator Riepe. [LB891]

SENATOR RIEPE: I was only commenting that I, too, am an Iowa grad, so we have a bond going here. [LB891]

SENATOR CAMPBELL: He has a friend here. [LB891]

ALICIA BRUNING: I can't really follow that well. (Laugh) [LB891]

SENATOR CAMPBELL: That's pretty tough. [LB891]

ALICIA BRUNING: It is. Tough act to follow. [LB891]

SENATOR CAMPBELL: Good afternoon. [LB891]

ALICIA BRUNING: (Exhibit 6) Good afternoon. Committee Chairwoman Campbell, thank you for having us. And Health and Human Services Committee, thank you for having all of us here, listening to our testimony. My name is Alicia Bruning, A-l-i-c-i-a B-r-u-n-i-n-g. I am here today representing the Down Syndrome Association for Families of Nebraska as the medical outreach chair, and I'm also a parent. My husband and I have two children. Our oldest son Logan is eight and he was prenatally diagnosed with Down syndrome. I didn't bring him today. He's better off in school. I'm going to talk a little bit less about my personal story and more about what we do as a medical outreach committee, because it's so in line with what this bill is addressing. Our medical outreach program supports physicians, families, and community members. We visit every ob-gyn, maternal-fetal specialist, cardiologist, genetic counselor, the NICU, and the newborn nurseries in Lincoln four times a year. We have it on a quarterly basis. We do everybody actually in one day. It works very well for us. This is done to deliver information to them as a reminder that we are here whenever they need us. And it opens the door for a dialogue that we might not have otherwise. We do presentations to three of these organizations every year, and we ensure that we have current information available and they are coached on better ways to present a diagnosis. In turn, they provide pamphlets, books, and our business cards that we have stocked in their office to give to families that receive a new diagnosis. One of the accomplishments I was most proud of last year was I received a call from a physician seven days after I had done a...had a conversation with him, and he personally called to thank me because he

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had delivered two positive diagnosis in that week and he said he felt more comfortable giving that diagnosis than he ever had in the past. And to me, that was a nice compliment that he was much more capable to present that information to the family and he had packets available to hand to them and to answer some of their questions. With our First Call Parent Program, we partner new parents with trained First Call parents to give them the opportunity to get information about Down syndrome from a parent that has walked in their shoes, supporting families from across the state whenever possible. Last year we mailed letters statewide to ob-gyn offices, to the locations that weren't supported by a local medical outreach group, and gave them information about our group as well as other groups within the area. However, efforts to reach all the providers on a regular basis is difficult for a Lincoln-based group. But our goal with that was to ensure that they knew that if they didn't have a resource locally, there was somebody that could reach out to them. But even with the successful medical outreach committee, we still receive cryptic information that new families have been diagnosed, but frequently not enough information is provided to reach out to the family directly. Within Lincoln, it seems that most people know someone who knows someone with Down syndrome. Instead of contacting the DSAF directly, other parents will offer support to new parents. And while this type of support is always well intended, it may represent inaccurate, outdated, or biased information that may not be the best support for the new parent. The best referrals to our group come directly from the medical professionals. Within the smaller communities, incidence of Down syndrome is naturally going to be lower and there will be fewer people that are able to support families with a new diagnosis. Unless their doctor gives them information about Down syndrome, they are likely going to search for it on the Internet. We've talked a little bit about that today. There are some great Web sites and some great support groups that are very helpful, but there's also an enormous amount of inaccurate information about Down syndrome. And the one thing I hear almost all the time is that 80 to 90 percent of children, your pregnancies that are diagnosed prenatally, that mother will terminate her pregnancy. And that is a statistic that we are always fighting to get to the root of, but it's just an example of the inaccuracies on the Internet. When a doctor provides inaccurate or biased information to a patient and no other information is readily available to them, the patient is likely going to accept this information as the truth. Unfortunately, some doctors will openly suggest to their patients that they should terminate their pregnancies when confirming a prenatal Down syndrome diagnosis. Every patient has a right to learn about Down syndrome, to meet individuals with Down syndrome and speak with their families to understand what life is like. While Down syndrome is the mostly commonly occurring chromosomal abnormality, life raising a child with Down syndrome is still unknown for most people. About five years ago, maternal blood testing became available, evaluating the cell-free DNA that is capable of identifying cells from the placenta. These placental cells usually reflect the chromosomal makeup of the fetus. As early as ten weeks gestation, this screening determines the risk that the mother is carrying a baby with Down syndrome. While this test should be considered a screening test, the marketing for these tests indicate that they are over 99 percent accurate for women of any age and risk category. Without taking into consideration the positive

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predictive values that can range from 45 to 97 percent accuracy, communication of these screening results can be interpreted as diagnostic test results. Without accurate, balanced information about Down syndrome, when these screening results are given to parents, some families will terminate their pregnancies without ever receiving reliable information. Down syndrome groups are unable to meet with every Nebraska medical provider that could deliver a diagnosis. We are in support of this bill to ensure that families will receive the same accurate information about Down syndrome regardless of where they live and whether they receive their diagnosis from the maternal-fetal specialist, the ob-gyn, or a family practitioner. Thank you for your time this afternoon. [LB891]

SENATOR CAMPBELL: Thank you for your testimony. Any questions, Senators? Double-checking, Senator Riepe. Thank you very much for your testimony today. [LB891]

ALICIA BRUNING: Thank you. [LB891]

SENATOR CAMPBELL: Our next proponent. Good afternoon. [LB891]

MARCUS SIKORA: Good afternoon. My name is Marcus Sikora and I wrote the book called Black Day: The Monster Rock Band and (inaudible)...Mother? [LB891]

MARDRA SIKORA: Right here. [LB891]

MARCUS SIKORA: (inaudible) that bill, LB1091 (sic: LB891), (inaudible) is Down syndrome. And that's it. She's my favorite blonde. [LB891]

MARDRA SIKORA: You're his favorite blonde. [LB891]

SENATOR CRAWFORD: Oh. (Laugh) [LB891]

MARDRA SIKORA: (Inaudible) why don't you show them the book. [LB891]

SENATOR CAMPBELL: Ah! [LB891]

SENATOR CRAWFORD: Nice. [LB891]

SENATOR CAMPBELL: That's your favorite book, Marcus? [LB891]

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MARCUS SIKORA: Yes. [LB891]

MARDRA SIKORA: He wrote it. [LB891]

SENATOR CAMPBELL: I'm sorry, who wrote it? [LB891]

MARDRA SIKORA: That's his book. [LB891]

SENATOR CAMPBELL: Oh, that's your book. [LB891]

MARCUS SIKORA: Yeah, I'm the author. [LB891]

SENATOR CRAWFORD: Awesome. [LB891]

SENATOR CAMPBELL: We couldn't read that far enough, or I couldn't anyway. [LB891]

MARCUS SIKORA: I'm a storyteller. [LB891]

SENATOR CAMPBELL: That's very good. Is that your favorite hat too? I like the hat a lot. [LB891]

MARCUS SIKORA: Yes. [LB891]

SENATOR CAMPBELL: Excellent. [LB891]

MARCUS SIKORA: Yeah. [LB891]

SENATOR CAMPBELL: And so did you want Senator Crawford to ask you a question? [LB891]

MARCUS SIKORA: Yeah. [LB891]

SENATOR CRAWFORD: Where did you get the idea for your book? [LB891]

MARCUS SIKORA: The idea (inaudible) in the cabin. [LB891]

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MARDRA SIKORA: He was staying in a cabin. [LB891]

SENATOR CRAWFORD: Oh, nice. Thank you. Thanks for being here today. [LB891]

MARCUS SIKORA: Yeah. Welcome. [LB891]

SENATOR CAMPBELL: Senator Crawford is one of our favorites too. (Laughter) [LB891]

SENATOR BAKER: Used to be. [LB891]

MARCUS SIKORA: My mom is named Mardra. [LB891]

SENATOR CAMPBELL: Thank you for your testimony today. Okay. Our next proponent. Good afternoon. [LB891]

ANGELA WILLEY: (Exhibit 7) Good afternoon, Senator Campbell, Health and Human Services Committee. Thank you for allowing us to speak today. My name is Angela Willey, A-n-g-e-l-a W-i-l-l-e-y. I'm from Elmwood, Nebraska, and I have three sons. My youngest one is seven years old. His name is Ben and he was born with Down syndrome. I submit this testimony today as a parent with an experienced view on the issue. I included a picture of my son instead of bringing him along because he's a seven-year-old boy and seven-year-old boys do not sit in committees very well. We learned of our son's diagnosis of Down syndrome prenatally at 19 weeks after standard blood tests, a high-level ultrasound, and finally an amniocentesis diagnostic test. The diagnosis of Down syndrome was delivered on the phone on a Saturday morning. We knew very little about the condition and we looked to the medical professionals for answers. I was told that since my son had fluid around his heart that there was a good chance that he would miscarry or be stillborn. We made an appointment with a pediatric cardiologist, who said, well, really, his heart was in pretty good shape. So it wasn't really a heart issue and Down syndrome; it was really just Down syndrome. So...but the window to do a termination was quickly closing. In fact, we couldn't do one in Nebraska anymore. We were told we would have to go to Kansas City. So most of the information that we were given was the worst-case medical scenarios and you have to make a decision because your window is closing. So I was a business analyst at the time. It was my nature to research things. So I turned to "Dr. Google," which there was a lot of information out there, but it took quite a while to find some information that we found to be trustworthy and accurate. But one of the things I found that I kept coming back to was a picture. It was a Web site that had a lot of pictures of children with Down syndrome in a collage. They were all smiling. They all had black shirts on. I remember that to this day. In fact, I put it on my wall for a long time. And that picture was a picture that gave us hope and it was such a

difference between what the doctors were telling us and this picture that I kept looking at, and that was kind of what made us make the decision to continue the pregnancy, because all those happy faces were...or I just remember thinking how happy they all seemed. And I included a picture of my son Ben and his happy face on your sheet. But unfortunately, after speaking to many parents of other...other parents who had children with Down syndrome, we learned that many of them receive outdated and biased information when first hearing about their diagnosis. Words like "challenge," "risk," "burden," and "termination," still tend to dominate the conversation. These words are going to be...if these words are going to be used in order to bring the picture into focus, we need to include words like "achievement," "rewarding," "blessing," and "acceptance." Individuals with Down syndrome are breaking stereotypes every day thanks to supportive families, early intervention, and inclusive learning environments. They often have to practice more to learn more skills, but the wait and extra effort for every milestone is a cause for celebration. There are individuals with trisomy 21 who have active social lives, actively participate in the work force, live independently, drive cars, get married and enjoy life. The picture of what life could be like for an individual with Down syndrome, this picture was never shared with us by the medical professionals. As a parent, access to information where my children are concerned is vitally important to me. Families deserve to receive an accurate picture of Down syndrome, and that includes both the risks and the positive rewards. Therefore, it is important LB891 be passed in order to ensure that all parents receive accurate and appropriate information. Please support LB891. Thank you. [LB891]

SENATOR CAMPBELL: Thank you for your testimony. Questions, Senators? Thank you very much. Our next proponent. How many more people wish to testify? Okay. I have to apologize. I realize I am yawning. You're looking at a committee that was in a hearing last night here in this room till 8:00. And so if we seem a little tired, we probably are. We apologize for that. [LB891]

MARDRA SIKORA: Thanks for letting us keep going. My name is Mardra Sikora, that's M-a-r-d-r-a, Sikora, S-i-k-o-r-a. My son was born in 1990 in Kearney, Nebraska, a quick 25 years go. The day after he was born, a social worker approached his father in the hospital hallway while I held Marcus in my arms and his tiny fingers curled around mine. She asked if we would be taking the baby home. Before I had a chance to get to get to know my child at all, let alone the implications of Down syndrome, the first provided option was to walk away from my own child. Today you've already heard plenty of other stories more recent than ours that show the gap between helpful information and quality of information given about Down syndrome. Obviously, this information needs to be concise and current and available to parents, prospective parents, and all the professionals working with these parents. And while the parents are the first folks who need these details, I would like to stress that the child with Down syndrome is whose life is most affected. It's true that children and adults with Down syndrome have certain medical and developmental challenges that need to be addressed and cared for. And it's no surprise or secret that these changes in educational expectations and improvements in medical care and simple

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social acceptance have all played a part in people with Down syndrome reaching their potential and proving this to society by becoming television stars and models and getting married and going to college or, like Marcus, writing children's books. However, there are segments of our community that are still not getting the information and support that these families need to help their children thrive. I support this bill not only for the sake of the parents but also for the sake of the many beautiful people living, newly born or yet to be born, with Down syndrome. I believe that giving families quality information and support at the beginning of life will better equip those parents to help their children with Down syndrome to reach their potential and that we as a community can experience the positive impact of having people with Down syndrome thriving. I'd like to add two other notes. One is to Senator Riepe that there actually is a national law called Prenatally and Postnatally Diagnosed Conditions Act, but it's one of those laws that says we should do this but then there's nothing really to back it up. So there are, as we mentioned before, 14 other states that have made this Diagnosis Information Act law so that they can empower their local states to follow through on the national implications. And I'd also like to mention, since it's come up a few times in the previous things too--I've learned so much today (laugh) that it's somehow important how many states have adopted something beforehand--that when Marcus was born 25 years ago Nebraska was one of only five states in the country to offer education from birth. And I remember being immensely proud to be in a state that was already taking into consideration my son's life and his lifelong potential, and I think that that made a huge difference. And so I hope that Nebraska will follow again and continue that trend. Thank you. [LB891]

SENATOR CAMPBELL: Thank you very much. Senator Riepe. [LB891]

SENATOR RIEPE: Thank you, Senator Campbell. Understanding that most physicians leave the education of parents to the nurses, right or wrong, that's what happens, is there an approach to trying to...and I don't know where schools or colleges of nursing are at particularly during their rotation in ob-gyn. [LB891]

MARDRA SIKORA: Uh-huh. [LB891]

SENATOR RIEPE: Is there some focus being made as well to try to make sure that (a) the nurses understand the importance of it, the sensitivity to it, and have the technical skills, at least if they don't have them, they have someone on their team that does? Is there any of that going on? [LB891]

MARDRA SIKORA: I feel like from the many parents that I have talked to that actually nurses--this won't be too much of a surprise--tend to be the ones to give more information and follow through and certainly are more compassionate along the way. I can't speak for any of the

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organizations here as far as how they handle their outreach to nurses specifically, but I can tell you that I personally have been involved with UNMC when they've asked about giving diagnosis and helping people through that process. I think the important thing with this becoming a law is that it makes it...it shows the medical schools, it shows, the doctors, it shows everyone involved that this is a priority to us as a society. We as the state of Nebraska consider this information to be a top priority right away, in a timely way. And I think that raises the bar for everyone involved. [LB891]

SENATOR RIEPE: Okay. Thank you. [LB891]

SENATOR CAMPBELL: Any other questions, Senators? Thank you much for your testimony. Our next proponent. Good afternoon. [LB891]

TOM VENZOR: (Exhibit 8) Good afternoon. Chairwoman Campbell and members of the Health and Human Services Committee, my name is Tom Venzor, T-o-m V-e-n-z-o-r. I'm the associate director for Pro-Life and Family for the Nebraska Catholic Conference, and I'm here on behalf of the conference in support of LB891. The Nebraska Catholic Conference represents the mutual interests and concerns of the Catholic bishops serving in Nebraska. The Catholic Church has a strong tradition of solidarity with those who experience a disability, whether that involves tending to the spiritual needs, assisting with material needs, accompanying families in need of additional support systems, or advocating on public policy matters. This solidarity is born out of an imitation of Jesus Christ, whose ministry constantly reached out to the least among us, especially those marginalized by society. This service of charity highlights the inherent dignity of each person as created in the image and likeness of God. LB891 provides an opportunity to advocate on behalf of children, born and unborn, with Down syndrome, as well as be of assistance to their families, especially expectant and new mothers and fathers receiving a screening or diagnostic test result for Down syndrome. With regard to our concern for children with Down syndrome, LB891 identifies the important scientific advancements of the last several decades pertaining to Down syndrome. By more adequately communicating these advancements to the general public and in the clinical setting, we draw special attention, respect, and concern for children who deserve to benefit from these scientific developments. As Pope John Paul II once stated, "This is true for every child, but it becomes all the more urgent the smaller the child is and the more it is in need of everything, when it is sick, suffering, or handicapped." With regard to our concern for families, it is particularly true that a family is never really prepared for the birth of a child with a disability and is in need of strong support. LB891 serves expectant and new mothers and fathers receiving a screening or diagnostic test result not only by ensuring they receive up-to-date medical information but by providing information for local support groups who can accompany families during an emotionally filled experience. This support often brings hope into the situation and provides the confidence to raise their children despite the challenges Down syndrome may bring. Overall, LB891 provides an excellent opportunity to provide timely

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knowledge and support to families at a critical time in their life. And I just wanted to go off script now and say I'm the legislative aide that was with Senator Brasch last year so...and this is a bill that I had worked on with her. And I wanted to address one issue you had, Senator Campbell, about, I think, the cost. And I think the reason that there--and I don't want to speak on behalf of DHHS or the Fiscal Office--but I think the reason there is no cost is because there's an understanding that the Down syndrome community is more than willing to work with the department to ensure that they get the appropriate information. And since this has been done in 14 other states, not all of them provide an information sheet, some of them do, but that material is already kind of there. So there's...there won't be any reinventing of the wheel or anything like that. So essentially, the material that will be kind of agreed upon will be given to the department and they'll obviously have, you know, an opportunity to look over it. But then they would be able to post it, which, you know, wouldn't require too much work. So I think that's the reason that the fiscal note is able to be nothing, because they can do that within their own resources, as well as, you know, everything that they're putting is on-line so they don't have to produce a pamphlet or send it out. You know, that would be the duty of the practitioner to, you know, pull that sheet down. And as Deb said earlier, you know, maybe that will be in their office along with all their other information on juvenile diabetes or, you know, any other number of issues. That's kind of the way we've envisioned it. And I know in other states, like Ohio in particular, I heard back from some folks there and they said this was useful and that they were hearing from new practitioners, doctors, genetics counselors, people...(Power Outtage--Testimony Lost. See also Exhibits 9-13.) [LB891]