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Health and Human Services Committee
January 25, 2018

[LB685 LB793 LB800]

The Committee on Health and Human Services met at 1:30 p.m. on Thursday, January 25, 2018, in Room 1510 of the State Capitol, Lincoln, Nebraska, for the purpose of conducting a public hearing on LB800, LB685, and LB793. Senators present: Merv Riepe, Chairperson; Sue Crawford; Sara Howard; Mark Kolterman; Lou Ann Linehan; and Matt Williams. Senators absent: Steve Erdman, Vice Chairperson.

SENATOR RIEPE: We will now...we're going to open on the Health and Human Services Committee. I am the...Merv Riepe...I'm the chairman of the Health and Human Services Committee. I represent District 12, which is Omaha, Millard, and Ralston. And I would ask...I want our panel members--our committee members--to introduce themselves, if they will, starting to my far right over here. Senator.

SENATOR KOLTERMAN: Senator Mark Kolterman, District 24: Seward, York, and Polk Counties.

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

KRISTEN STIFFLER: Kristen Stiffler, legal counsel.

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

SENATOR WILLIAMS: Matt Williams, District 36: Dawson, Custer, and the north part of Buffalo Counties.

SENATOR LINEHAN: Hi. Lou Ann Linehan, District 39: western Douglas County.

TYLER MAHOOD: Tyler Mahood, committee clerk.

SENATOR RIEPE: We also have our two pages that are routinely with us, and we appreciate all the work that they do, as well. So they may come to your assistance as we go along. The committee will take up bills in the order posted. Our hearing today is your public opportunity to participate in the legislative process. We ask you to express your position on the proposed legislation before us today. Committee members will come and go during the hearing. They may have to introduce bills in other committees or get called away. It is not an indication of any lack

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of interest in your bill, and it's just part of the process. You will also see that they may be using laptops, and that's part of our new process as we proceed forward into the 21st century. Some of the rules of engagement include my asking you to please silent or turn off your cell phones. If you plan on testifying, we would ask you to move up towards the front row as best you can, just to expedite the process. The process, or the order of testimony, will be first the introducer of the bill, followed by proponents, then opponents, then anyone testifying in a neutral capacity. We will ask Tyler for any letters or other correspondence that's been submitted, and then the introducing senator is afforded the opportunity to close on his, or her, bill. If the...when the testifiers are signing in, we'll ask you to hand in your orange sheet to the committee clerk and, from there, you'll be asked to go to the table. We're working on a five-minute clock, which means: four minutes on the green, one on the amber, and then the red light will come on and we will ask you to try to conclude your remarks. If you have something that's pertinent beyond that, you may get a question from a committee member that will afford you an opportunity to proceed on, or I will try to at sometimes, if you're in the middle of a thought, let you try to finish that thought up. When you come up to testify, please state your name, spell your name, and state your...the organization that you represent, so that we can have that for the record. If you will not be testifying at the microphone, but want to go on record as having a position on a bill being heard today, there are white sign-in sheets at each entrance where you may leave your name and other pertinent information. These sign-in sheets will become exhibits in the permanent record at the end of today's hearings. Written materials may be distributed to the committee members as exhibits only while testimony is being offered. Hand them to the page for distribution to the committee and staff when you come up to testify. We will need ten copies. If it happens that you do not have ten copies, our pages are fast of foot, and they will run and get copies made and then distribute them. With that, I would like to open today's hearings with LB800, which is Senator Walz. So if you would, Senator, your name and introduce yourself. [LB800]

SENATOR WALZ: Sure. [LB800]

SENATOR RIEPE: And then proceed forward. [LB800]

SENATOR WALZ: (Exhibit 1) It's a low chair. Thank you. Good afternoon, Chairman Riepe and my colleagues on the Health and Human Services Committee. My name is Lynne Walz, L-y-n-n-e W-a-l-z, and I proudly represent District 15. I'm here to introduce LB800, which would allow Nebraska to meet federal guidelines of treatment for those with disabilities. Currently state statute 81-6,112 was introduced by Senator Kathy Campbell and passed into law in 2016, by LB1033. And it is falling short to ensure that Nebraskans with disabilities are receiving the quality care that they deserve. LB800 would amend the statute to include and develop a comprehensive Olmstead Plan under the Americans with Disabilities Act, pursuant to the Supreme Court ruling in Olmstead v. L.C.. Under this ruling, persons with disabilities are required to be provided services in the most integrated setting possible, as to prevent

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discrimination and segregation. The U.S. Supreme Court strongly encouraged the development of Olmstead Plans in 1999, and the U.S. Department of Justice has since intervened in the states that are failing to meet this requirement. First, the bill adds specific language to outline what shall be in an Olmstead Plan, in order to meet requirements outlined by the federal government and court cases decided across the U.S. Second, it requires the Department of Health and Human Services to hire a consultant. Groups I have been working with think this is necessary because an Olmstead Plan deals with more than just living facilities and healthcare. It also deals with transportation issues, education, and more--something that the Department of Health and Human Services would not be able to complete on their own. Finally, the bill changes the required completion date from December 15, 2018, to December 15, 2019. We changed this date to ensure the Department of Health and Human Services has enough time to hire a consultant, and the consultant has enough time to complete this plan. I introduce this bill for a few reasons: First, I think it's good public policy. I've worked as a direct care staff member and an administrator, as well as in management, for agencies that support people with developmental disabilities. I've listened to the dreams and goals of people who want the opportunity to live a normal life, to live in a home, to be part of a community, and to have access to everyday activities and everyday rights that we so often take for granted. Advocating for people with disabilities is something that is near and dear to my heart. Because of my experience working with people who have disabilities, and their families, I fully understand that community living is not always going to be the best choice for every person. There are many people who choose to live in a more structured environment because they are not comfortable in a community-based home. However, we should always make strides to allow those who want to live in the community the ability to do so. Second, this is something that is required by law. Based on events that have occurred in the past, I don't want the state to pay for a lawsuit, get federal funding taken away, or have the federal government write the plan for us, and it to be out of our control. It is essential that we do this right the first time. And hiring a consultant to help, while being an immediate expense, would likely save the state money in the long run. While instituting federal guidelines in our state is extremely important, we also have the responsibility to defend the right of Nebraskans with disabilities to be treated fairly and with compassion. The findings of recent investigations into mental health and long-term care facilities have shocked me. I want to share a story that I think allows us to look at the problem when putting everyone in an institutional setting. On September 3, a U.S. military veteran died at Life Quest as a result of the facility's complete disregard for her health and, at the same facility, staff locked themselves in a room when an individual became aggressive. All residents were left to fend for themselves. This is not just the case of one mismanaged facility. Across Nebraska, facilities practicing neglect or segregation are the norm, not the exception. Residents are being rotated from one terrible facility to another, and are not given the right to live in a more integrated setting with community-based care. As one former resident of Hotel Pawnee assisted living facility said of the conditions there: I felt like a rat trapped in a cage. It's degrading to your spirit to live here. Little action is being taken to change this issue. Small fines from DHHS do not match the abuses committed. While the investigations

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into these facilities are thorough, current legislation does not create an urgency for change. It is time for our state to stop allowing the segregation and mistreatment of those with disabilities, and match other states in developing a plan to combat the issue. This bill has the ability to guarantee that an essential quality of life, filled with dignity and respect, is readily available for many Nebraskans. I have other bills to examine the facilities that I feel need more oversight, but I think this bill is essential in actually creating the change that we need. Finally, I've passed out an amendment, at the request of the department. It would change existing statutory language from six to five divisions, as the Division of Veteran Affairs was moved to the Department of Health and Human Services--moved from the Department of Human Services. I'm happy to work with the committee, the department, stakeholders, and anybody with an interest in this bill. I hope you will advance this bill to General File so the full body can debate. I'd be happy to answer any questions that I can and, if I can't, there will be people following me that will be able to answer questions I may not be able to. Thank you for your consideration. [LB800]

SENATOR RIEPE: Thank you. Are there questions of the committee members? Senator Williams. [LB800]

SENATOR WILLIAMS: Thank you, Chairman Riepe. And thank you, Senator Walz, for being here today and your interest in this important topic. I'll ask this question of you but, if someone is better qualified to answer this...and it's actually in the wording of the insert that you have, on the first page of the bill at line 9. I'm just interested, in my mind, of trying to get my head around item (b) in the list that is here, which is "concrete and reliable commitments to expand integrated opportunities for services to qualified persons with disabilities." I'm interested from the legal perspective of what is...what would be measured as concrete and reliable commitments? [LB800]

SENATOR WALZ: Um-hum. [LB800]

SENATOR WILLIAMS: And if you have any examples, or if that would be something that somebody following you or... [LB800]

SENATOR WALZ: I think somebody who's following me... [LB800]

SENATOR WILLIAMS: That'd be great. If someone who would be...if you would address that in your testimony, I would appreciate it. Thank you. [LB800]

SENATOR RIEPE: Are there other questions? I have a couple of questions. Would you help us with the fiscal note, because that's always a question in this session? [LB800]

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SENATOR WALZ: Do you have a copy of it? [LB800]

SENATOR RIEPE: I do have. [LB800]

SENATOR WALZ: Okay. So you're asking what the... [LB800]

SENATOR RIEPE: It looks like there's.. [LB800]

SENATOR WALZ: ...what it--the funds--will be for? To hire the... [LB800]

SENATOR RIEPE: ...it's where the funds from General Funds are what? [LB800]

SENATOR WALZ: General funds... [LB800]

SENATOR RIEPE: \$75,000. [LB800]

SENATOR WALZ: Um-hum. And federal funds \$75,000? [LB800]

SENATOR RIEPE: I'm just...whether the...Appropriations will find the \$75,000...I'm just...is that...that seems like that could be a challenge. Could it? [LB800]

SENATOR WALZ: Well, I don't know if it... [LB800]

SENATOR RIEPE: Okay. [LB800]

SENATOR WALZ: You know it depends upon where you want to spend your money... [LB800]

SENATOR RIEPE: Okay. [LB800]

SENATOR WALZ: ...today or down the road. [LB800]

SENATOR RIEPE: Okay. The other question I have is, do you have someone that's going to prioritize this, or is this going to be your priority bill? Or do you know? [LB800]

SENATOR WALZ: I don't know yet. [LB800]

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SENATOR RIEPE: Okay. That's all I had. Chairman...or sure. [LB800]

SENATOR HOWARD: What are the consequences of us not following Olmstead? [LB800]

SENATOR WALZ: Well, first and foremost, just the fact that there are people in very vulnerable situations. So above anything else, the consequences are people continue to be abused and neglected and rights taken away. Secondly, there's a consequence that our state could be sued. [LB800]

SENATOR HOWARD: Thank you. [LB800]

SENATOR RIEPE: Senator Linehan, please. [LB800]

SENATOR LINEHAN: Thank you very much for bringing this. This is not an area I'm very deep into. How many people do we have in these facilities statewide...do you know? [LB800]

SENATOR WALZ: I think I have somebody who can answer question. [LB800]

SENATOR LINEHAN: Okay. [LB800]

SENATOR WALZ: I don't have that information. [LB800]

SENATOR LINEHAN: That's okay. But that'd be something I'd be interested...the magnitude of what we're talking about and the number of facilities, because (inaudible). [LB800]

SENATOR WALZ: Um-hum. I think...and again, somebody's going to be able to correct me. [LB800]

SENATOR LINEHAN: That's okay. [LB800]

SENATOR WALZ: But as far as mental health facilities, I think there are 12... [LB800]

SENATOR LINEHAN: Okay. [LB800]

SENATOR WALZ: ...across the state, but I'm not sure. [LB800]

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SENATOR RIEPE: Okay. [LB800]

SENATOR LINEHAN: But is this mostly mental health facilities, or is it... [LB800]

SENATOR WALZ: This has to do with mental health facilities, it has to do with agencies who serve people with developmental disabilities. It's the Division of Disabilities (sic--Division of Developmental Disabilities). [LB800]

SENATOR LINEHAN: Okay. So it's across the board. [LB800]

SENATOR WALZ: Yes. [LB800]

SENATOR LINEHAN: It's not just mental. Okay. All right, thank you very much. [LB800]

SENATOR WALZ: Um-hum. [LB800]

SENATOR RIEPE: Okay. Thank you very much. [LB800]

SENATOR WALZ: Thank you. [LB800]

SENATOR RIEPE: I assume you'll be staying around for closing? [LB800]

SENATOR WALZ: Yep. [LB800]

SENATOR RIEPE: Okay, thank you. We will ask for proponents and, if we have anyone that needs some individual accommodation on the lights, we will accommodate that, if we need to have the lights turned off. So with that, if you'd be kind enough to state your name, spell it, and your organization, and then proceed forward. [LB800]

DIANNE DeLAIR: (Exhibit 2) Good afternoon, Senator Riepe and members of the Health and Human Services Committee. For the record, my name is Dianne DeLair, spelled D-i-a-n-n-e DeLair, D-e-L-a-i-r. I'm the senior staff attorney at Disability Rights Nebraska, and that's our state's private protection and advocacy system in our state. I'm here to provide testimony in support of LB800, but I think, in order to really understand the implications of what an Olmstead Plan is, we need to go back and look at some historical context, as well as a little bit of legal history, just to bring this into full picture about why this is so important for our state. So as we know, in 1990 a bipartisan Congress passed the Americans with Disabilities Act. And

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George...President George H.W. Bush signed that into law. We know that the ADA has a universal ban on discrimination of people with disabilities, and today we're really going to focus on Title II. And Title II specifically prohibits state and local government agencies, along with other public entities, from discriminating against people with disabilities, not only in their programs, their services, their activities, and also facilities. So who enforces the ADA? Within the federal government that's charged to the Department of Justice, and they've promulgated rules that interpret that statute. So these rules and regulations that have been implemented require states--and the language used is public entity--to administer these programs in the most integrated setting appropriate to the needs of qualified individuals with disabilities. Now the most integrated setting is something we'll talk about, but that has been defined as a setting that enables individuals with disabilities to interact with nondisabled persons in the fullest extent possible. Now this integration mandate was at the central core of the U.S. Supreme Court lawsuit Olmstead v. L.C., and this was a major court case that interpreted the ADA, which is still good law today. And the court made clear that the integration mandate...it requires public entities to ensure services to...services provided to people with disabilities are administered in that most-integrated setting. So what does that mean? So Olmstead extends not only to those who are institutionalized, but also to persons who are at risk of being institutionalized. It applies to individuals who are waiting for services, and one not need wait until one is actually institutionalized. What was the other part of that case that's important today? The Court said: Look, states, this case was in 1999. This isn't going to happen overnight for you to show us that you're administering your programs, for all people with disabilities, in the most integrated setting. One way you can avoid liability is to develop a comprehensive Olmstead Plan. And I believe there was a question about concrete goals within LB800, and I'll talk about that in just a minute. So as I mentioned, in light of the Olmstead decision, President George W. Bush made it a high priority for his administration to tear down barriers to equality, and to expend...and to expand opportunities available to Americans living with disabilities. And in 2001 he launched the New Freedom Initiative. In 2009 President Barack Obama not only pushed this issue but, through an executive order, he created an enforcement mechanism called the Olmstead enforcement division (sic) within the Department of Justice. So in the years since Olmstead has been decided, it's been expanded to cover not just people leaving institutions but also the services and programs that a state provides. Now what I want to talk about today is why we're back here again, because I was here in 2016 to testify in support of LB1033. To this day, we still do not have an Olmstead Plan. The Department of Justice was in our state in 2008, and they clearly stated in their letter Nebraska does not have a written Olmstead Plan. This is 2008. 2014: The Division of Behavioral Health consulted with the Technical Assistance Collaborative to look at community integration in our state. They issued a report and said that: Look, community integration--and I'm quoting--and more specifically the civil rights of individuals to live in the most integrated setting possible is the law. In order for Nebraska to meet its requirements under the ADA and Olmstead, and minimize litigation risks, it will need to initiate an actionable planning process that results in an effectively working plan. Now in fact, "Nebraska"--and I'm

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quoting--"does not have an Olmstead Plan that addresses any disability group."--2014. 2016: The division brought the Technical Assistance Collaborative back again. What was their first strategic goal outlined in that report? Implement and get the Olmstead Plan going; this is important. It did recognize the passage of LB1033. What is most concerning to me is the lack of urgency on the part of the administration, part of the Legislature. You know, the impact for people is direct and, as a part of my job, I go out to these facilities and services all across the state, and I monitor them, I talk to people, and I see where people are living. And the delay in this planning process has a direct impact on vulnerable people in our state, and we need to approach this with a sense of urgency. And it's not when this, you know, if we don't develop this plan, the state will be liable. We're in a unique opportunity to do this ourselves, and I strongly support LB800 so that we can further get this process completed and implemented. And again, it's 2018 and we're still planning to plan. I'll take any questions, if you have them. Thank you. [LB800]

SENATOR RIEPE: Senator Linehan. [LB800]

SENATOR LINEHAN: So are you familiar with the numbers? [LB800]

DIANNE DeLAIR: Let me be clear with...this doesn't just apply to facilities, so... [LB800]

SENATOR LINEHAN: I actually...yeah, I get that. Then you did a great job of explaining that; that's wonderful. So but I would like, because I cannot remember this. I remember 90 only had huge facilities, and I know they have dwindled. So I'm just trying to get a scope of the situation. So if you don't, that's fine because somebody else might. I don't want to...I don't want to put you on the spot. [LB800]

DIANNE DeLAIR: So if you're talking...sure. If you're talking about the mental health centers and assisted living facilities that Senator Walz mentioned, I would say that there are probably between 15-18 identified facilities where 99 percent of the people living there are diagnosed with a severe and persistent mental illness. [LB800]

SENATOR LINEHAN: But isn't this first...okay. So the one I'm familiar, because I grew up by it--Beatrice Developmental Home. That's not...is that mental...that's all mental illness now? Because when I was a kid, they were...it was much different than it is today. [LB800]

DIANNE DeLAIR: Absolutely. So the Beatrice State Developmental Center is licensed. It's a state facility. It's licensed as an intermediate care facility for individuals with developmental disabilities. So your primary diagnosis is going to be an intellectual disability or a developmental disability. [LB800]

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SENATOR LINEHAN: Right. And the population there has dwindled significantly since 1990, right? [LB800]

DIANNE DeLAIR: Absolutely. [LB800]

SENATOR LINEHAN: So is what you and Senator Walz were saying, some places we made progress but, with mental health issues, we're still in the ditch. If that what you're saying? [LB800]

DIANNE DeLAIR: I would say that...I would caution. I think it's a little bit more complex than that... [LB800]

SENATOR LINEHAN: Okay. [LB800]

DIANNE DeLAIR: ...only because with Olmstead planning, it's not just about facilities. We need to get the Department of Transportation involved, housing authorities, education. It covers any service that the state provides to people with disabilities. And we need to show that we're doing it in the most integrated way possible. And that's just good planning. [LB800]

SENATOR LINEHAN: Okay. All right, thank you very much. [LB800]

SENATOR RIEPE: Thank you. Other questions. Senator Williams, please. [LB800]

SENATOR WILLIAMS: Thank you, Chairman Riepe. And thank you for being here. In your testimony--and hopefully you can clear this up for me--in your written testimony it says: Nebraska has been afforded opportunities, time and time again, to develop an Olmstead Plan, and has been told to do so. Nebraska has said, time and time again, that it is doing things that are in compliance with Olmstead. Can you explain to me the difference between what you're saying that we don't have a plan and, evidently the state is saying we maybe do? [LB800]

DIANNE DeLAIR: Well, say if we go back, in the behavioral health context, to behavioral health reform, which is in 2004, you know there were...there was some language about Olmstead in there, but it might help further clarify what other states have done. And this goes back to, I think, your question about concrete and measurable goals. So let's take, for example, we have, let's say, 2,500 people on the waiting list to receive developmental disability services. As part of this plan, each year the state would have to figure out how, exactly how many people they plan to get off of that wait list and provide services for. It cannot be a general statement that we are really committed to providing community integration to people. It has to be a goal that's

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measurable and, in many states, it does come down to that--the number. In the behavioral health context, North Carolina...they had to enter into a settlement agreement with the Department of Justice... [LB800]

SENATOR WILLIAMS: Okay. Is that in...is that in the legal interpretation of Olmstead, or is that in statute, somewhere, of what is required in the actual plan? [LB800]

DIANNE DeLAIR: That's through legal interpretation. [LB800]

SENATOR WILLIAMS: Okay. And then I want to go back to the question that I asked Senator Walz. Where it says concrete and reliable commitments to expand. Can you describe what that means to me? [LB800]

DIANNE DeLAIR: Well, I think...yeah. I think the court wanted to try to say, as forcefully as possible, that look, in a way to achieve this, you can move resources around. You can look for other funding to support these programs. But you also might have to add more resources, more, you know, financing money to this issue. And the state will not escape liability from that. [LB800]

SENATOR WILLIAMS: Okay, I'm still mystified in what is actually a concrete and reliable commitment. But...so this whole area is subject to legal interpretation. Is that a fair statement? [LB800]

DIANNE DeLAIR: Well, I would say that there's been 17 years of legal interpretation of this through...all across the U.S., so yes. [LB800]

SENATOR WILLIAMS: Thank you. [LB800]

SENATOR RIEPE: Are there other questions? Senator Linehan, please. [LB800]

SENATOR LINEHAN: Just one more because, when you said 2004, is that when we closed the facility in Norfolk? [LB800]

DIANNE DeLAIR: Correct. That was the downsizing of the regional centers. [LB800]

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SENATOR LINEHAN: Okay. So that was in 2004. So is part of what you're saying here is we did that--we did step one, downsized the regional centers, but we never did the other steps of making sure that people were still okay? [LB800]

DIANNE DeLAIR: That's one component, so I would argue that... [LB800]

SENATOR LINEHAN: I'm not trying to argue; I'm just... [LB800]

DIANNE DeLAIR: Or...well, that I think there's questions about where that money went, when we closed those facilities down. And did they, in fact, make them...did that money actually get to community programs and placements for folks? There's a question. [LB800]

SENATOR LINEHAN: Okay, so that's...this helps a lot. Is there any other big things that happened, in this continuum from 1990 to now, that there's been actions taken but it's not...the follow through is what you're concerned about? I mean attention span is not huge here, but I'm trying to kind of... [LB800]

DIANNE DeLAIR: Sure, sure. [LB800]

SENATOR LINEHAN: Is that kind of what...were there any other big closures or where we've...because I mean there are...I've heard concerns, since I've gotten down here, that we closed Norfolk but we didn't do the follow-up. So the regional centers...are there any other--and I know there's been a push down in Beatrice. But is there other institutions that I'm not thinking of right now to ask you about? [LB800]

DIANNE DeLAIR: Well, that's a good point, Senator. With the decrease in population at Beatrice State Developmental Center, you know, we still have sheltered workshops in our state with...we've been advised by the federal government and through new regulations, that we really need to have options for, you know, integrated employment and real opportunities for people that are not in segregated, congregated settings. [LB800]

SENATOR LINEHAN: Okay, thank you. [LB800]

DIANNE DeLAIR: So that would be another example. [LB800]

SENATOR LINEHAN: Okay, thank you very much. You've been very helpful. [LB800]

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SENATOR RIEPE: Senator Crawford. [LB800]

SENATOR CRAWFORD: Thank you, Chairman Riepe. And thank you, Ms. DeLair, for being here. I appreciate it very much. Could you speak to the concern that Senator Walz raised about the quality of care in some of the facilities? And how does that relate to an Olmstead Plan? [LB800]

DIANNE DeLAIR: So...absolutely. So I had mentioned that the Technical Assistance Collaborative--and they're experts in this area--they're brought in to states, not only when they're in settlement agreements or lawsuits, but they really are experts in the field of community integration and Olmstead and working with states. So the Division of Behavioral Health brought in the consultant, and they issued a report in 2016 that I mentioned, and they gave a whole list of short-term and long-term recommendations to improve services for people so they wouldn't have...so their only choice wouldn't be an assisted-living facility or a mental health center. And so that's really the big picture--the big view here--and they did mention that, look, this report that we've issued this would be a really good groundwork and framework to put into your Olmstead Plan. So that would be incorporated. And I know the division is...they do have a housing plan but, you know, from my perspective, when I go to facilities and I see people who've lived there from year after year after year, and they have no one...no one is going in to advocate for them, you know that piece of the puzzle would be incorporated into Olmstead planning. So for example, how many people need community-integrated, supportive housing in our state? We'd have to figure out the data on that and then plan for it. So the people who would like to actually receive some services that would be helpful to them, living independently, would have them. And right now, what's going on is the state is relying on these private facilities so that they are not doing what they need to do with bolstering and improving access to community services. Now I ask anybody to go to these facilities that I'm talking about and see if not only you would want to live there and receive services, or want a loved one. And I guarantee you the answer will be no. So I hope that answers your question. [LB800]

SENATOR CRAWFORD: Thank you. Well, so again, a major part of Olmstead is making sure people have options in the community, and then some individuals may still need some kind of assisted living. Is part of the plan also, evaluation or quality control of those facilities that may remain? [LB800]

DIANNE DeLAIR: Well, from our perspective, people should not be living in facilities like this, where they're not receiving what they need. That's not going to change overnight; we realize that. There should be some movement on the part of HHS, the Division of Public Health, to get in there and do assessments like they did at Palmer, for the facilities in question. As far as changes to keep them open, what we're suggesting is that, if you look into what permanent supportive

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housing is--and that's really kind of the best practice in the field--is that it's not just finding an apartment or house for someone to live in. There a whole array of services that need to be provided in order for that individual to live independently. So...and we have a few of those types of services kind of scattered throughout the state. However, it's not consistent from region to region. So you know, long term I don't think these facilities would exist if they were required to be certified by a national organization like JCAHO... [LB800]

SENATOR CRAWFORD: Um-hum. [LB800]

DIANNE DeLAIR: ...or other such bodies...they would never pass. So in the short term, I definitely think there are things that the department could be doing to make sure people are safe and are getting at least the medical care they need. [LB800]

SENATOR CRAWFORD: Um-hum. Thank you. [LB800]

SENATOR RIEPE: Is it fair to say that the Olmstead Plan is highly recommended but not mandatory? [LB800]

DIANNE DeLAIR: It's highly recommended because that can be a defense to litigation. [LB800]

SENATOR RIEPE: But not mandated. [LB800]

DIANNE DeLAIR: Pardon? [LB800]

SENATOR RIEPE: Not mandated. [LB800]

DIANNE DeLAIR: I suppose it would be how you interpret that. [LB800]

SENATOR RIEPE: Well, what we...is there a penalty for not having a plan? [LB800]

DIANNE DeLAIR: No. [LB800]

SENATOR RIEPE: Thank you. That's it. Senator Kolterman. [LB800]

SENATOR KOLTERMAN: Yeah, thank you, Senator Riepe. How many states have enacted the Olmstead Plans? [LB800]

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DIANNE DeLAIR: Not all states have enacted them, and I don't have the exact numbers. But what I can say is that states that have plans that have passed legal muster have really just shown leadership in the area. Like you know, this is hard and it's going to take some reorganization. It may take additional funding. But where states show leadership, they've really got movement. So for example in New York, they've elevated Olmstead planning to a cabinet position. Minnesota...while their first Olmstead Plan had to be amended because it was...they were taken to federal court and the court found it did not meet the requirements of Olmstead, you know, eventually they are getting closer to a plan. So you know, we're not probably the only state in this position, but what I'm saying is that our...Nebraska's own consultants are telling us, you know, this is something to do; you're, you know, you're at risk of litigation. [LB800]

SENATOR RIEPE: Okay. Other questions? Seeing none, thank you very much. [LB800]

DIANNE DeLAIR: You're welcome. [LB800]

SENATOR RIEPE: Thank you for being here and thanks for your knowledge. Additional proponents? I know you've testified in front of us before, and we will suspend the lights for you. [LB800]

KATHY HOELL: Okay. I really appreciate that. Could you give that to him, please? Okay, I have also brought some... [LB800]

SENATOR RIEPE: Would you be kind enough to spell your name and say it? [LB800]

KATHY HOELL: (Exhibits 3, 4, and 5) Oh yes, okay. Just a second. See it's that one, this one, and this one. Okay. My name is Kathy Hoell, K-a-t-h-y H-o-e-l-l, and I am the executive director for the Nebraska Statewide Independent Living Council. The council is a nonprofit organization that is mandated to exist in all 50 states and territories, and our role is to develop, with our partners, the State Plan on (sic--for) Independent Living and to promote a philosophy of independent living in all aspects throughout life for individuals with disabilities. First of all, we would like to thank Senator Walz for introducing this really important piece of legislation. Previously when Senator Campbell introduced LB1033, which set the basic framework for Olmstead, we found that the department needs further direction. They have refused to call this an Olmstead Plan. It's being referred to as the LB1033 committee. We know what it is; call it what it is...don't play games with it. The department has not...you've been able to have the committee meet on a regular basis. In the past year I think we've only met a couple times. They just say they don't have the money for it, which is fine, but we need to figure out a way to make this happen. Olmstead does not just include DHHS; it includes anything that provides services to people with disabilities. So we're talking Corrections, we're talking Department of Education. We need to get

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all those people involved, and we need to have a viable plan because, without the plan, the state of Nebraska is pushing their luck big time, and they're leaving themselves open for a lawsuit. Personally, I have talked to--I don't know how many--governors and other people in Nebraska since '99, about developing an Olmstead Plan. And the response I've always gotten is: we developed an Olmstead Plan; we're admitting we're not doing something right; we don't want to do that. As far as Senator Linehan's question about localities, for me I know about nursing homes; I know lots about nursing homes. And the fact that we now have nursing homes that have pediatric wings where they're discharged...they've discharged people from Beatrice, or they've...they're not providing family support, and these families are putting their kids into a nursing home. I mean I find something really wrong with this system that allows...that has approximately 200 two-year-olds in a nursing home; that is just totally unacceptable. We need to find a better way to do this, and I hope that the committee will pass this bill forward to General File so that it can be debated on the floor. If you have any questions, I'd be... [LB800]

SENATOR RIEPE: You don't think... [LB800]

KATHY HOELL: ...glad to answer them. [LB800]

SENATOR RIEPE: We'll see. Any members of the committee have any questions? Apparently not. Thank you so much for being here. [LB800]

KATHY HOELL: Oh... [LB800]

SENATOR RIEPE: We appreciate it. I...we know that you make a special effort. [LB800]

KATHY HOELL: Okay, thank you. [LB800]

SENATOR RIEPE: Thank you. Additional proponents, please. Okay, we have two contenders here. Okay. Welcome, Sir. If you'd be kind enough to state your name, spell it, and who you represent. And then proceed on. [LB800]

ALAN ZAVODNY: (Exhibit 6) Okay. Good afternoon, Chairman Riepe and members of the Health and Human Services Committee. For the record, my name is Alan Zavodny, A-l-a-n Z-a-v-o-d-n-y. I'm the chief executive officer of NorthStar Services, an agency that provides supports to people of intellectual disabilities, primarily in 22 counties in northeast Nebraska. This is my 37th year in this field, and I'm also privileged to serve as mayor of David City, Nebraska, a community of 2,906. Technology is a great thing--and I'll be way under my time, but I thought I'd share with you some questions--and Courtney Miller is awesome--the director of the Division

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of Developmental Disabilities. To answer some questions, there are approximately 5,000 people receiving supports, and she also went on to say that there are 1,857 on the waiting list with 663 of that 1,857 on another waiver, waiting for DD residential services. So technology is an amazing thing. And I'm glad you're not going to ask me about concrete, because if it doesn't deal with cement, water, and sand, I can't help you. Okay. Thank you, Senator Walz, for introducing LB800. Frankly, it is a good idea that comes at a good time. I'd like to use a weather analogy to make my point. If you can imagine that the Developmental Disabilities system's current status in Nebraska is like a tornado watch...the conditions are ripe for a tornado but there isn't one yet. Obviously we have an advantage here. We can't prevent tornadoes from happening, but we can prevent the Developmental Disabilities system from having a tornado. So what does that mean? Specialized providers that have been the backbone of the Developmental Disabilities system are in an epic struggle. We face rising costs and ever-increasing expectations on rules, regulations, etcetera. We are facing unprecedented difficulties in hiring and retaining direct support staff. Every one of these factors affect the quality of supports that are provided to one of our most vulnerable populations. We have seen a proliferation of community supports. Currently this approach does not have the rules and scrutiny that is required of specialized providers. It is most appropriate at this time to study this system and to make recommendations to the Legislature. In our current reality, we have term limits. We simply do not have the institutional memory that once existed. With eight years of service in this body at best, we understand that Senators are not afforded the time to learn the complexities and nuances of every facet of state government. The findings of the work that this legislation provides for will be a beneficial tool for the current Legislature and the new senators that will be sworn in next January. We need to evaluate our compliance with Olmstead. We need to have a strategic plan to address the issues outlined in LB800. We encourage you to vote LB800 out of committee and advance it to the floor. And that's it. [LB800]

SENATOR RIEPE: Thank you. Are there questions from the committee members? seeing none, thank you very much for your testimony. [LB800]

ALAN ZAVODNY: Thank you. [LB800]

SENATOR RIEPE: We continue on with proponents; it looks like we have two. [LB800]

ERIN PHILLIPS: Hello. [LB800]

SENATOR RIEPE: If you'd be kind enough, please, to state your name and spell it. [LB800]

ERIN PHILLIPS: Erin Phillips, E-r-i-n P-h-i-l-l-i-p-s. [LB800]

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SENATOR RIEPE: Okay. [LB800]

ERIN PHILLIPS: (Exhibit 7) And dear Senator Riepe and the members of the HHS Committee, I am requesting an accommodation, under the Americans with Disabilities Act. Because of my disability, I am asking you not to use the timer. Hello. My name is Erin Phillips. I am a disability specialist for the People First of Nebraska. People First of Nebraska is an organization that is made up of self-advocates throughout Nebraska. Our mission is to empower, train, and advance advocacy so People First and all people with disabilities are able to speak up for themselves. I have cerebral palsy. Under the Disability Act, I cannot be timed due to my disability with my speech. I'm here to speak on the LB800 Olmstead introduced by Senator Walz. I don't know about you; I want to live on my own with my dreams. I cannot do that if I live in an institution. But if you don't segregate, people with disabilities want to be part of an entire community. We can learn to live like you or Senator Walz, on our own, by the proper supports in the community. At first, when we leave the shelter of our families' homes, most of us have no clue how to, or what to, spend for groceries, room, or board. Disabilities people don't have much idea how to save or spend wisely towards important stuff like groceries, room, or rent. As summary, if you put me in an institution and not let me learn to be an independent adult of society, I cannot reach the dream of living in a loft apartment with a service animal. I cannot do what I need to be independent as I can. All this is what Senator Walz's LB800 is designed to do. Thank you very much...People First of Nebraska. [LB800]

SENATOR RIEPE: Thank you very much for testifying. Are there questions from the committee? Senator Kolterman. [LB800]

SENATOR KOLTERMAN: Thank you, Senator Riepe. Erin, thank you for coming today. We visited a little bit before in my office. Can you tell us a little bit about...do you have a job? [LB800]

ERIN PHILLIPS: Yes, I do. [LB800]

SENATOR KOLTERMAN: And where do you work? [LB800]

ERIN PHILLIPS: Besides just...besides specialist of... [LB800]

SENATOR KOLTERMAN: Of Nebraska? [LB800]

ERIN PHILLIPS: Specialist of People First of Nebraska. I work at Super Saver. [LB800]

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SENATOR KOLTERMAN: Okay. And do you live alone? [LB800]

ERIN PHILLIPS: No, I don't. I live in an assisted family home. [LB800]

SENATOR KOLTERMAN: Okay. Thank you very much. [LB800]

ERIN PHILLIPS: Welcome. [LB800]

SENATOR KOLTERMAN: I appreciate you coming today. It takes a lot of courage to come. [LB800]

ERIN PHILLIPS: Thank you. [LB800]

SENATOR KOLTERMAN: Thank you. [LB800]

SENATOR RIEPE: Okay. Any other questions? Seeing none, thank you very much. [LB800]

ERIN PHILLIPS: Thank you. [LB800]

SENATOR RIEPE: We will now take additional proponents. [LB800]

MARK SMITH: Good afternoon. [LB800]

SENATOR RIEPE: If you'd be kind enough, Sir, to give us your name, and spell it. [LB800]

MARK SMITH: (Exhibit 8) Absolutely. My name is Mark Smith; that's Mark with a K and Smith with an S-m-i-t-h. Chairman Riepe and Senators, again my name is Mark Smith. I want to let you know that, while I work at the Munroe-Meyer Institute in Omaha at the University of Nebraska Medical Center, my testimony represents my own personal and professional opinions, knowledge and experience. I'm not here speaking for the University; I'm here on my own time. I've had the opportunity to work on disability service policy and practice at the local, state, and national level throughout my career. In addition, in due diligence, I want to make you aware that I'm also the parent of a young man who receives state community-based developmental disability services. I can say that I share the opinions of all that have testified so far, in that the Olmstead v. L.C. decision represents a legal requirement to the state to ensure access to home- and community-based services as a guaranteed option to individuals receiving disability-related, long-term care, and that the development and implementation of a state Olmstead Plan is clearly

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in Nebraska's best interest in ensuring the requirements of the ADA are met to an acceptable level in our state. As a function of my career experience, I'm familiar with the tenets of the Americans with Disabilities Act, its subsequent amendments, with the Olmstead decision, etcetera. But I'm...and I'm, as you've heard much more on the details, in any case, I have supported the passage of LB1033, as written and introduced by Senator Campbell. However, since the finding of the...the finding of Olmstead v. L.C. in 1999 was handed down, Nebraska has been relatively slow by comparison in the oversight, development, and implementation of an Olmstead Plan, as compared to many other states. That observation serves as the basis for my support of LB800, as introduced by Senator Walz. It's my belief that the development and implementation of a Nebraska Olmstead Plan can only benefit from introducing additional expert guidance into the process. Ensuring that home- and community-based service options have the adequate means to provide those services to quality is critical to an effective plan. Public law 106-402, the Developmental Disabilities Assistance and Bill of Rights Act of 2000, otherwise known as the DD Act--either are the same--initially states that its first finding is that Congress finds that: disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their lives, and to fully participate and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society. The act also authorizes a national network of protection and advocacy agencies, councils on developmental disabilities, and university centers for excellence in developmental and related disabilities. I know that my fellow colleagues in these programs, along with my fellow family members, in addition to individuals with disabilities, stand ready to support a robust Olmstead process, and we've said so--stated so--for coming on 20 years now. With adequate resources and supports, individuals with disabilities have been shown to enjoy a better quality of life and higher satisfaction with their lives when afforded supportive community living opportunities, in countless studies. Without the necessary planning, however, this task, in my experience, can become exceptionally more difficult. A well-developed and implemented plan would go far in ensuring that the choice of community living, the standard of accepted practice in developmental disability services, and a right afforded by the federal statute is afforded to Nebraska citizens in need of, and desiring, these services. Many are aware the Monroe-Meyer Institute is the University Center for Excellence in Developmental and Related Disabilities, otherwise known as the UCEDD, which is not my favorite term. But for Nebraska...every state and territory has a designated UCEDD. The primary role is to build capacity of services for the state it serves. And by capacity, I'm referring to, primarily, trained personnel in addition to working to improve systems, providing technical assistance, community education, and service provision. As many are also aware, Munroe-Meyer has this history of promoting services primarily to children with disabilities, in terms of training professionals for the state. What I think is germane to the bill at this juncture is that there is, under new leadership, we're making great strides towards building training systems to serve adults with disabilities across the state.

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As these efforts proceed, I believe it will position the institute to directly support a robust and efficacious Olmstead Plan for Nebraska. And I'm happy to answer any questions. [LB800]

SENATOR RIEPE: Thank you, Mr. Smith. [LB800]

MARK SMITH: You're welcome. [LB800]

SENATOR RIEPE: We appreciate you being here. Let's see if we have some questions from the committee. Senator Williams. [LB800]

SENATOR WILLIAMS: Thank you, Chairman Riepe. And thank you, Mr. Smith, for being here. [LB800]

MARK SMITH: You're welcome. [LB800]

SENATOR WILLIAMS: The proposed legislation talks about hiring a consultant. [LB800]

MARK SMITH: Um-hum. [LB800]

SENATOR WILLIAMS: Do you have any experience with who could be a qualified consultant for a project like this? [LB800]

MARK SMITH: I do. There are probably numerous agencies, programs, individuals across the country that can serve in that role. [LB800]

SENATOR WILLIAMS: Previous testimony by Ms. Hoell mentioned that she has repeatedly been told that we do not have an Olmstead Plan because it would be admitting that we are not doing what we should do. Do you have some response to that? Or... [LB800]

MARK SMITH: Well, I don't disagree with Kathy on that. But from my perspective, it's a matter of, not as much that we're not doing something that we're not...we're doing something wrong, it's that we need to start moving in the direction of doing things better. The field that we're in is not a field that you can just kind of tread water. You have to take steps forward in order to make things work and have them work out the best for the people that we serve. I...in my mind, having an Olmstead Plan just basically kind of catches us up with the other states in the country that are making an effort to do, if not the best they can, an acceptable and reasonable level of effort towards the services of people that are eligible. [LB800]

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SENATOR WILLIAMS: In your judgment as an expert in these issues, what do you think has stopped Nebraska from doing...moving forward on this? [LB800]

MARK SMITH: That I...that would be of...I wish I had a clear answer for you on that. I'm a little puzzled. The movement at the passage of the bill was clearly in the direction that states would develop plans and make movement towards ensuring that community-based options were available. And, as you've heard from several of the other testifiers, this is not just a simple...let's just open a place where someone can go. I mean there's, you know, all aspects of community living fall into that, so it's a complex task. As to why there has not been movement in the direction of actually kind of embracing this as being the right thing to do on behalf of our citizens, I'm hard pressed. [LB800]

SENATOR WILLIAMS: Seems disappointing that we're here today having to pass, or look at, legislation to do what maybe should have been done already. [LB800]

SENATOR CRAWFORD: Yes. [LB800]

SENATOR WILLIAMS: I'm not asking you for a comment on that. Thank you, Mr. Smith. [LB800]

MARK SMITH: I appreciate that. [LB800]

SENATOR RIEPE: My sense is sometimes that people that know what's going on, or what could benefit the state, are inside, not necessarily requiring an external consultant, if you will. [LB800]

MARK SMITH: Um-hum. [LB800]

SENATOR RIEPE: It's just maybe a realignment of task. Is that a possibility to get the plan with, and therefore, avoiding the fiscal note because you have an inside talent that can write the plan. And I'm assuming the plan doesn't have some mandatory number of pages. [LB800]

MARK SMITH: Well, that's a...that amount...I would be on the fence, in terms of being able to respond to that, Senator. We do have very qualified professionals in the state who are working on behalf of people with disabilities across the spectrum of disabilities. But it's also been my experience that sometimes it's the best to bring in a fresh set of eyes, someone who's had experience in writing these plans. Given that we haven't had a plan, we...this effort would be starting fresh. [LB800]

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SENATOR RIEPE: Um-hum. [LB800]

MARK SMITH: We're aware of what's in, you know, what the legal signings were but, in terms of actually developing this to the extent that we would have, I think, a reasonable confidence and success, I would be concerned because we just haven't gotten there. I mean, that's what I see. [LB800]

SENATOR RIEPE: I only can think that there must be some Ph.D. candidate who's looking for something that they could do for their dissertation, and this might fit into that bill. [LB800]

MARK SMITH: Um-hum. That would be quite a...that would be quite a dissertation; that would be more like a set of books. It's a complex issue, and again, there are people outside the state who have done this repeatedly and done it well. And it never hurts to have someone, who has been down that road before, guiding the process, from my perspective. I mean I work with a lot of people that (inaudible)... [LB800]

SENATOR RIEPE: I'm just looking for what you can get done as opposed to... [LB800]

MARK SMITH: I'm sorry... [LB800]

SENATOR RIEPE: some of the obstacles that exist, but okay. Are there other questions? Seeing none, thank you very much for being here. [LB800]

MARK SMITH: Thank you. [LB800]

SENATOR RIEPE: We're still on proponents. Thank you for being here. If you'd be kind enough to state your name and spell it, and then we'll go. [LB800]

DEA HENKE: (Exhibit 9) Ah, yes. My name is Dea Henke, D-e-a H-e-n-k-e. I am a board member of the Nebraska Statewide Independent Living Council; however, I am here today just as a private citizen. I'm testifying in support of LB800. I do have a significant disability, a form of muscular dystrophy. I am also the mother of a daughter who has the same disability and, because of this, I know how important it is to have services provided in the least restrictive environment possible. It's important to our health, but also our dignity and our quality of life, to be able to live in the community rather than an institution or a nursing home. The Olmstead Plan that Nebraska needs to have would provide these things that we need--the community living with the supports that we need. The ADA would provide for this. However, currently in Nebraska there is no plan, with any clear parameters or guidelines to guide it, to ensure that the Olmstead

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Plan could be enforced. The benefits of LB800, I feel, are twofold: First, it would provide clear guidelines so that there is no gray areas, no various interpretations of how it needs to be administered, no discrepancies in that. And secondly, as many people have stated, it would save Nebraska money because, without these clear guidelines, without an Olmstead Plan, we are open to litigation and that would cost money, not only to proceed with the lawsuit, but also the settlements that we would have to pay out to people that were not being serviced. So for those two reasons, I ask that you support LB800 and pass it into law. Thank you. [LB800]

SENATOR RIEPE: Thank you very much. Are there questions from the committee members? Seeing none, thank you so much for being here; we appreciate it. [LB800]

DEA HENKE: Thank you. [LB800]

SENATOR RIEPE: Additional proponents? [LB800]

CODY LEMMER: My name is Cody... [LB800]

SENATOR RIEPE: Would you...yeah, get seated so you're right in front of the mic, Sir, please. [LB800]

CODY LEMMER: Thank you. [LB800]

SENATOR RIEPE: Thank you. [LB800]

CODY LEMMER: My name is Cody Lemmer, C-o-d-y L-e-m-m-e-r, and I work through the Mental Health Association of Nebraska. And I've come to the table today. I've had regional center stays in the past, and I've had the opportunity to work with an adult day service for five years, managing that at the end of my stay there. And a lady spoke before about looking into the homes themselves. Managing the homes and working at one of the care facilities, you can see that people are told that this is a way of life, this is what you're going to do with a certain majority of the time that you're going to spend at the home. The consensus is, when I found about two years into being into...I had my own apartment, but it was only for back pay, back pay reasons are the reason that I could have stepped out of the group home that I was in--the facility--and get my own apartment. Two years into that, I was told that this is just transitional living...like we want you to further yourself, gain employment, work outside of the...going to a mental health center group once a week. So that was my thought but, every time I asked about volunteering or employment, the organization, as a whole, told me that well, you could lose everything that you have if you go back to work. Your disability--your mental illness--could stop

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you from actually achieving your goals. And working through the adult day center, I started seeing that people were told the same thing: you don't really want to strive for anything because you could fail and fall back into the situation that's much worse than what it is. Well, the organization, as a whole, is set up a three and a half-year trial work program, where you can go out there and you can obtain employment and, if it doesn't work, you go right back into the system where you were before. There's not a huge motivating factor, and I think that the system has kind of worked itself to the point of where, if you stay where you are, you generate the people that are above you--your doctors or caseworkers, your healthcare providers--you generate the money by doing so. So if you step away from an organization, you're actually placing them without a potential person to generate money from. And I think the consensus is, as a whole, that if we have the idea that we want to shut these group homes down--these facilities down--that's not it at all; that would cause chaos. The state would have to step in, from my understanding, and find housing for people. But the only thing I really want to state today is, I found out early, with my own recovery process, that the idea is to have everybody that is part of a group home--a group facility--the developmentally-disabled side, the people-with-mental-issues side--have their own apartment and have somebody come in, if they need so, to help them. That's what we're looking for. But if you look into our group homes in Lincoln now, you will see three or four people to a room. Some people say it's squalor. I wouldn't say it's squalor, but that drive of independence is taken away when things are done for you. Too many things are done for the people that are living in these facilities and it takes away that stress that causes us to press forward in our lives. So I would just like the senators, the representatives as a whole, to look deeper into the actual facilities themselves and see how people are living. Thank you. [LB800]

SENATOR RIEPE: Okay, and let's see if we have any questions. Any questions? Seeing none, thank you very much for your time. Thanks for being here. [LB800]

CODY LEMMER: Thank you. [LB800]

SENATOR RIEPE: Additional proponents? If we have more proponents, I'd ask you to come up to the front to get staged. Sir, if you would, give us your name, spell it. [LB800]

EDISON McDONALD: Hello. My name is Edison McDonald, E-d-i-s-o-n M-c-D-o-n-a-l-d. I am the executive director for The Arc of Nebraska. We have...we're a nonprofit with 1,500 members, nine chapters covering the state. We're advocates for the most integrated lives possible for folks with intellectual and developmental disabilities. We focus on community inclusion because it ensures that we are cost-effective, focus on the best treatment possible, and help to integrate people in a society--helps to support our community. We strongly support LB800 because it ensures a path to that most integrated life. The bill addresses the federal Olmstead case, as we have discussed, and I won't go into a bunch of detail, as I think a lot of that has

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already been covered. The two biggest things that I can really speak to on this bill are: number one, that importance of having those community supports. In my office, you know, we have those nine chapters that I can regularly go and refer folks to, but then we also have a broad state beyond that, where there is a tremendous limit of supports. And trying to go and help find that in between is just a huge struggle and, for family members, that is really such a detriment. They don't know what to do, they don't know where to go, they don't know how to react. This would help to put into place a plan that would at least kind of begin to give us a little more solid direction. Then the other piece I'd really like to address is the potential cost. Although, you know, the \$75,000 was indicated in the fiscal note, the cost, if we don't do anything...let me see, Missouri. We looked at \$1.72 million that the court case in Missouri ended up costing. I don't know about you. I'm sitting out on a meter. If I were to go and have that meter start to run out and say, well, I can go and drop in another quarter to make sure that we won't have...that I won't have to get a bill, then, you know, I would rather go and plug that meter than take the \$10 or \$25 charge. Right now the state is sitting in that position. We know that our meter is up, and we fail to take action. We're failing to go and pay that meter; we're failing to go and make sure that we properly care for people, and we fail to make sure that there's a solid direction forward. Also in addressing one of the earlier questions about other states that do have plans, I can tell you for sure there are 28 states, as of 2012, that had solid Olmstead Plans, and I'm not sure beyond that. But yeah, again I would urge you, for the sake of human dignity, to further Nebraska values and act as fiscally wise caretakers of state funds, please pass LB800. Thank you. [LB800]

SENATOR RIEPE: Okay, thank you very much. Are there questions from the committee members? Seeing none, again, thank you for your testimony. Are there additional proponents? Seeing none, are there opponents, those in opposition? Okay. I saw a movement, but it was out the door. Any opponents? Seeing none, are there anyone that wish to testify in the neutral capacity? Please come forward, Sir. [LB800]

DAVID MOHLMAN: My name is David Mohlman. I'm from Red Cloud, Nebraska. I do have a lot of handouts, but maybe I should drop these off at your offices. Would that be better than doing it right now? It's information about the Olmstead. [LB800]

SENATOR RIEPE: If you have them, let's distribute them now. [LB800]

DAVID MOHLMAN: (Exhibits 10, 11, and 12) This is...they're all itemized here. Okay, and we have a mission statement. I represent IDAN, which it's kind of hard to say. It's the Intellectual Disabilities Advocates of Nebraska, and the mission is advocacy for the developmentally disabled. I believe I met you and talked to you in Beatrice, Senator Riepe. Do you remember that? [LB800]

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SENATOR RIEPE: That's right. That's right, I do. [LB800]

DAVID MOHLMAN: So... [LB800]

SENATOR RIEPE: You had a son that was there, and no longer there. [LB800]

DAVID MOHLMAN: Yes, Sir. He's still there. [LB800]

SENATOR RIEPE: He came from Kansas. [LB800]

DAVID MOHLMAN: Yes. Yes, Sir. [LB800]

SENATOR RIEPE: Yes, Sir. [LB800]

DAVID MOHLMAN: And that's what I wanted to talk about today, is I'm neutral because I'm not sure about the consultant. Because it seems to me last year there was the talk of a consultant, and it had to do a lot with Beatrice. And the reason there wasn't one is because of funding. Funding was a big issue, and they couldn't find a senator that wanted to sponsor the bill. And the "they" I'm talking of is the disability rights people and Arc, okay. And, you know, I'm thankful to Edison McDonald because he's the one who informed me that this hearing was going on. I didn't know about it, so I must thank Edison. And I've known him previously, and I was really surprised that he's got that job. But that's another detail. Unless you ask me about it, I'm not going to tell you about it. So anyway, I'm here to defend Beatrice, because I'm worried that this could be an end run around to get Beatrice closed, because where will the consultant come from? Well, I imagine he's going to come from one of those agencies that their number one priority is to close Beatrice, and their second priority is to keep people from coming into Beatrice. And you wonder, how do they do that? How can they keep people from Beatrice? Well, it's called a waiver. Now my experience is that you have a handicapped child or a brother or a sister or something, and you're taking care of them, and you're desperate. You are desperate, terribly desperate. You don't know where to turn; you don't know what to do. So you go to help with Health and Human Services. Well, they're loaded down. They've got...they've got a lot of responsibility, as your committee does, too. And you try to help, but you don't know what to do. So the priority is we don't really want them to go to Beatrice, because it's going to cost more money and it's going to be more complicated--get more complex. Well, Beatrice has the worst of the worst, okay? That's why they're there. My son has a triple diagnosis of handicaps; that's how we got there. So they sit you down and they say: well, we'll help you, but you've got to sign this waiver. And the waiver states: we don't want to go to Beatrice; that's what the waiver states. And I'm not making this up. And so if they don't sign that...if they sign the waiver, they get some help

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of some sort. Now you think: Where did you come up with that? Well, I came up with that on the advisory committee, the Governor's advisory committee. It was at a meeting they had, and I got to asking questions. And that is exactly what happens. They wouldn't lie to me about it. Because I asked them: Is that what happens? Yes. Okay. So what does this have to do with the consultant today? You know, I'm neutral, but I am concerned about who's coming in because the first thing they might do is say: Well, we've got to get rid of that. Well, Beatrice has got a three-year plan, and it's a good plan. And it's going back to the day when my son got in there. Now don't get me wrong. It was tough getting my son in there. He had to become a ward of the state. And it was real tough. But they had an intensive treatment center there. They call it a different name now, but it's the same thing. They have experts there. The worst of the worst come in. They help them out, they straighten them up, they turn them around, and they get them out into the community if they can. Some people do not respond to community-based resources. Some people need a lot of structure and they need a lot of help. And the help is there at Beatrice. And I think that we could make that an example to the rest of the states that have lost their state-based ICFs and the MRs, because I just took a little tour and I wasn't on a special trip to check out the handicapped people out in the world. But I went to several cities on the west coast: California, Arizona, and the homeless everywhere...obviously there are mentally hurt people out there. But the strangest one was in Arizona--in Phoenix--where they actually have homeless camps and they send out people from Health and Human Services to give the folks meds, make sure they get their meds in the homeless camps. [LB800]

SENATOR RIEPE: Okay. [LB800]

DAVID MOHLMAN: That's their plan. [LB800]

SENATOR RIEPE: Are you able to kind of pull it together and finish up? [LB800]

DAVID MOHLMAN: Well, that's good enough. I made my point, I hope. [LB800]

SENATOR RIEPE: Well, and I... [LB800]

DAVID MOHLMAN: If you have any questions, just let me know. [LB800]

SENATOR RIEPE: Stay there a second. We'll see if we have some questions. I appreciate your enthusiasm and I think that, in our conversation at Beatrice, you talked about the strength of the Beatrice program so much so that you relocated from Kansas to participate in the Beatrice program. [LB800]

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DAVID MOHLMAN: Exactly, yeah. [LB800]

SENATOR RIEPE: Okay. I thought I'd remembered that right. Senator Williams. [LB800]

DAVID MOHLMAN: To close up... [LB800]

SENATOR RIEPE: You're going to get a question here. [LB800]

SENATOR WILLIAMS: Thank you, Chairman Riepe. And thank you for being here. One of the previous testifiers, I specifically asked the question about the availability of consultants. And I believe his answer was there were a number of people that could do that. From your experience and your judgment, is there a way to determine in advance that that consultant would not have a preconceived motive--I'll use that term to be a little stronger--that that was on their agenda, to close Beatrice? [LB800]

DAVID MOHLMAN: I think that would be a pertinent question within the interview with the man or the woman... [LB800]

SENATOR WILLIAMS: Thank you. [LB800]

DAVID MOHLMAN: ...that would have that job. [LB800]

SENATOR WILLIAMS: Thank you. [LB800]

DAVID MOHLMAN: Thank you. [LB800]

SENATOR RIEPE: Any other questions? Thank you for making the trip. Good to see you again. [LB800]

DAVID MOHLMAN: Okay. Thank you, Senator Riepe. [LB800]

SENATOR RIEPE: Are there others that want to testify in a neutral position? Okay. Senator Walz, we would ask you if you'd like to close, and then we will go through any letters that we may have. [LB800]

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SENATOR WALZ: First of all, I just want to make sure that I address the gentlemen who was just here. I have worked extensively as a direct-care staff person in residential facilities with people who have developmental disabilities, and their families. And I do understand that there are times when the choice is not a community-based facility. And because of that experience, again I just fully understand that the community living is always not going to be the best choice for every person and there are going to be plenty of people choose to live in a more structured environment. So I understand your concern, Sir. I want to clarify that this is for all people with disabilities. Senator Williams, I do have a Minnesota Olmstead Plan that I think you might find helpful and would give you examples of concrete and reliable commitments. So I'll follow up with you, and I'm glad to clarify some of the language in the bill. Senator Linehan isn't here right now, but I'll be happy to follow up with her on how many people, the disabilities that this would affect. Senator Riepe, I just have to say that I am a little disappointed in the questions regarding the importance of securing a consultation group to provide a quality plan for people with disabilities. Suggesting that maybe we can get a student who needs a dissertation makes me feel as though, maybe, you don't feel like this is an important issue. And I feel it's a very important issue; I feel like we cannot brush this under the rug again. I feel that LB800 is a good bill. I'm happy to work with all of you to get this passed. I will stress that the \$75,000 is not much when this could cost hundreds of thousands of dollars, maybe even millions over the next few years. But more so, I don't think that \$75,000 is that much to make sure that people with disabilities and people who are vulnerable get the assistance and the services that they need to be safe and free from abuse and neglect. This is an example today...or Senator Blood told a story today, actually on the floor, that really resonated with me. It was a story regarding the difference between justice and just us. I don't know if you heard the story. And I feel that this is an example of people who do not see experience...do not see or experience justice every day. I've witnessed this in the past, and again today, with the people who are here. And I feel that they certainly understand that this is a just-us situation. I think it's time for us, as legislators, to take action and do what's right for people. I think that's all I have to say. [LB800]

SENATOR RIEPE: Thank you. I would like to respond at, you know, the use of students. They are, in fact, one degree away from being a consultant, if you will. I know Senator Crawford and my son are both Ph.D.s and they are, neither one of them, slumps so that, you know, you can get quality work because they do have oversight. So there's a lot of very talented people. [LB800]

SENATOR WALZ: There is, but I would also have to say that I would think that the experience would...should be taken into consideration, as well. [LB800]

SENATOR RIEPE: Fair enough. I am going to read something--a piece here--and I'm going to ask you to respond. So I just want to give you a heads-up, as we go into it. It's from the Division of Developmental Disabilities--The Strategic Plan Report, which is dated December 15, 2017, so it's very current. And I...I'm going to pick parts of this, only in the interest of time. And the first

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one in it starts, and I quote, "The Department of Health and Human Services, in collaboration with the Disability Services Stakeholder Olmstead Planning Advisory Committee, drafted a Request for Information," an RFI. It goes on to say, in a later paragraph, "The RFI was released October 19, 2017, with the opening December 5, 2017. The Department received one response to the RFI from Technical Assistance Collaborative," that's TAC. "TAC indicated the time to facilitate the planning process and prepare a written plan for Nebraska to adopt would cost approximately \$125,000-\$150,000" for a 6-month process engagement. So that even challenges the existing \$75,000 fiscal note. I'm just telling you what they're telling us, so... [LB800]

SENATOR WALZ: Okay. [LB800]

SENATOR RIEPE: Okay. You don't have any response to that? Okay. [LB800]

SENATOR WALZ: I guess I just feel that the second report...you know, when I read what they were asking for and what they received, I would have just hoped that there would a little bit more... [LB800]

SENATOR RIEPE: Oh, you have it. [LB800]

SENATOR WALZ: I certainly do, yeah. I would have hoped that there would have been a little bit more to their progress report that what was just asked of them. I don't feel...you know, this is an important issue. We have people who need help; they need help. They don't have somebody. They don't have family members. Their guardians are not very active in their lives. So they're all alone; they need some help. And to me, this...the couple paragraphs that are on this just aren't...it's not justice. [LB800]

SENATOR RIEPE: There is some final report out there, and I'm not exactly sure about it, but it's due the 15th of 2018. So there is some work going on. I don't know enough about it. [LB800]

SENATOR WALZ: Right. [LB800]

SENATOR RIEPE: But you probably do, or will. Okay. [LB800]

SENATOR WALZ: Thank you. [LB800]

SENATOR RIEPE: Thank you very much. Is there...Tyler, do we have any letters to add in? [LB800]

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TYLER MAHOOD: (Exhibits 13, 14, and 15) Yes, I have...all of the following letters are in support: a letter signed by members of the Nebraska Association of Service Providers; a letter signed by Kristin Mayleben-Flott of the Nebraska Planning Council on Developmental Disabilities; and Mark Matulka of Mosaic. [LB800]

SENATOR RIEPE: Okay. Okay, thank you very much. That's it. I declare LB800 has received a full and fair public hearing. And this concludes this hearing. Thank you very much, all, for...that came in. We're going to take a little bit of a break here, because we're expecting Senator Blood to appear momentarily. [LB800]

BRANDON BAYER: She's here.

SENATOR RIEPE: She is here? Okay. Do we still need to take a five-minute break? Okay, let's do that. Thanks, guys.

BREAK

SENATOR RIEPE: (Inaudible) Health and Human Services Committee. We started out with a quorum and we have them coming back, but we are within our legitimate right to start. And so with that, Senator Blood on LB685, please. [LB685]

SENATOR BLOOD: Thank you, Chairman Riepe and members of the committee. My name is Senator Carol Blood; that is spelled C-a-r-o-l B-l-o-o-d, and I represent District 3, which encompasses western Bellevue and southeastern Papillion, Nebraska. I'm very happy to be able to bring you LB685 today, as it can have a major positive effect on my constituents and others who transfer into our state as a result of a new duty assignment from the military. As you may know, since 1992 Offutt Air Force Base has, literally, been in my backyard since moving to Bellevue. And because of this, I've become very aware of the needs of the people who live and work in my community. These are people that have to pack up and move at a moment's notice, and they generally do so without complaint. I always like to remind those not exposed to this community that the families also serve. You are all aware that I am on a mission to make the move into Nebraska as easy and painless as possible for our military families through numerous bills I brought last year and yet more that I've introduced this session. I will continue to do this throughout my time in the Legislature. The majority of those bills are about making sure that the spouses of our active duty service members are able to get a job in his or her licensed or certified field and begin work as soon as possible, by cutting red tape the state has had...has or had in place. This is not one of those bills, at least not exactly. Though it does cut down on the red tape these military families run into when they first get into the state, LB6085 (sic--LB685) is my way of trying to make sure that dependents of active duty military, who suffer from severe

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disabilities, are getting adequate and timely care. I know some of you, such as Senator Crawford and Linehan, who aren't here, are aware that when a child in a military family has severe disabilities that requires extra medical care, TRICARE does not cover that help. So imagine if your family must move every two to three years and a state does not offer a way to help expedite services for that child. Do you pay out of your own pocket? Do you allow that child to suffer? Do you quit your job and try to become the caregiver? What do you do? In most military-friendly states, such as Texas, you're offered a Medicaid waiver that helps to expedite the process. In Nebraska, we utilize a five-tiered system as to how we prioritize those in need, the first tier being those most in need and the last tier being, basically, everyone else needing services. In order to do this, my bill would insert "active duty military dependents who have severe developmental disabilities" into the priority listing for the Department of Health and Human Services that is already in Nebraska state statute. As mentioned, currently there are five funding priorities for the department in statute. Current priorities are: number 1) persons with developmental disabilities in immediate crisis due to caregiver death, homelessness, or a threat to the life and safety of the person; tier number 2) persons with developmental disabilities that have resided in an institutional setting for a period of at least 12 consecutive months and who are requesting community-based services; tier number 3) persons with developmental disabilities that are wards of HHS or persons placed under the supervision of Probation administration who are transitioning upon age 19, with no other alternatives, as determined by Health and Human Services, to support residential services necessary to pursue economic self-sufficiency; and tier number 4) persons with developmental disabilities transitioning from the education system upon attaining 15 years (sic--21 years) of age, to maintain skills and receive the day services necessary to pursue economic self-sufficiency; the priority listing after that incurred statute, which is number 5) all other persons by date of application. Our bill makes that last priority, which was the fifth priority, the sixth. By doing this, I feel we're making sure that we aren't jumping the line when it comes to Nebraska residents with severe developmental disabilities, but it does make sure that those military dependents who do really need the time and attention of Health and Human Services will receive it. Now I want to point out two factors: First is that, not only do we want to make sure we're getting these people the services they need, but putting language like this into statute helps get Nebraska designated as military-friendly. This is a real designation that could have far-reaching effects. When the federal government starts looking at bases they might consider closing, by having it in statute, our intent to serve the military is clear. Nebraska simply cannot afford to see Offutt closed. It would not only kill the community surrounding the base, but would have a huge negative impact on the state's economy as a whole. I'll also point out that we worked closely with the Department of Health and Human Services in order to come up with this approach. At the time we crafted the legislation, we were told they couldn't tell us whether or not they supported it, but this was language that they could work with, should it be made law. We've also had people reach out to us, concerned that we'll be taking money from other deserving cases. I don't believe that this is the case, considering we're talking about truly severe cases being pulled from a very specific population. I think you would be hard pressed to find

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more than a handful of cases in a calendar year. I believe my fiscal note demonstrates that. Additionally we have worked closely with the Liaison Office in the Department of Defense, as we do in all bills that affect military families. With that, I would ask for your support of LB685, and I hope you will vote it to the full Legislature for debate. [LB685]

SENATOR RIEPE: Thank you very much. [LB685]

SENATOR BLOOD: My pleasure. [LB685]

SENATOR RIEPE: Are there comments or questions from the committee? Senator Crawford. [LB685]

SENATOR CRAWFORD: Thank you. And thank you (inaudible). [LB685]

SENATOR BLOOD: I'm not repeating the whole thing. [LB685]

SENATOR CRAWFORD: Yes. No, I apologize. [LB685]

SENATOR HOWARD: Start at the beginning. [LB685]

SENATOR WILLIAMS: You're right. [LB685]

SENATOR CRAWFORD: I was listening in the room and trying to get back as soon as possible. I apologize for that. [LB685]

SENATOR BLOOD: That's all right. [LB685]

SENATOR CRAWFORD: I just want to thank you for working with the liaison. I think that's a very important part of the process is working with them and looking at these bills that help our state accommodate and work with the special situations they would have with our military families. So thank you for doing that and bringing this bill; I appreciate it. [LB685]

SENATOR BLOOD: You're welcome. [LB685]

SENATOR RIEPE: Additional questions? Seeing none, will you stay around for closing? [LB685]

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SENATOR BLOOD: I will stay around for closing. [LB685]

SENATOR RIEPE: Wonderful. Thank you. We would like to have proponents and supporters. Please come forward if you're there. Okay. Any opponents? Any neutrals? Seeing none, Senator, would you like to close? And then we'll ask Tyler to read in any letters he might have. [LB685]

SENATOR BLOOD: I would. [LB685]

SENATOR RIEPE: That was quick. [LB685]

SENATOR BLOOD: We try and make it simple. But this is what I always like to call a no-brainer piece of statute. The intent is clear, what we want to do is possible, there is no fiscal note. But the power that it's going to have, when it comes to solidifying the fact that we are, indeed, a military-friendly state, is huge. And so I ask that you consider all of those things, and I pray that you vote it out. [LB685]

SENATOR RIEPE: Okay. Are there questions? Do we have...oh, Senator Williams. [LB685]

SENATOR WILLIAMS: Thank you, Chairman Riepe. And thank you, Senator Blood, for bringing this. I want to be sure I understand one thing. [LB685]

SENATOR BLOOD: Yes, Sir. [LB685]

SENATOR WILLIAMS: You think there would be maybe a handful of people that would potentially qualify? [LB685]

SENATOR BLOOD: Based on my conversations with Health and Human Services, yes, there are. [LB685]

SENATOR WILLIAMS: Something like that. If they do qualify for services, how are those services paid for? [LB685]

SENATOR BLOOD: I'm not sure what you mean. You mean through Medicaid? [LB685]

SENATOR WILLIAMS: They're paid for through... [LB685]

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SENATOR BLOOD: Yes. [LB685]

SENATOR WILLIAMS: Medicaid, correctly. [LB685]

SENATOR BLOOD: Right. [LB685]

SENATOR WILLIAMS: So they are... [LB685]

SENATOR BLOOD: Up to... [LB685]

SENATOR RIEPE: I've never heard that before. [LB685]

SENATOR BLOOD: Excuse me...beyond what TRICARE has already paid for. So they're not going to be solely dependent on Medicaid. [LB685]

SENATOR WILLIAMS: Right. [LB685]

SENATOR BLOOD: TRICARE will pay up to a certain point but, when the care is...when the disability is severe and they might need constant care, then that's when Medicaid has to kick in. [LB685]

SENATOR WILLIAMS: Yeah. I wanted to be sure I understood that correctly. [LB685]

SENATOR BLOOD: Yes, Sir. [LB685]

SENATOR WILLIAMS: Thank you. [LB685]

SENATOR BLOOD: It's my pleasure. [LB685]

SENATOR RIEPE: Okay. Are there other questions? Okay. Seeing none, Tyler, do we have letters? [LB685]

TYLER MAHOOD: (Exhibits 1 and 2) Yes. I have a letter signed by members of the Nebraska Association of Service Providers, in support; and a letter signed by David Brown of the Greater Omaha Chamber of Commerce, in support. [LB685]

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SENATOR RIEPE: Okay. Thank you very much. I declare LB685 has received a full and fair public hearing, and that concludes this hearing today. [LB685]

SENATOR BLOOD: Thank you. [LB685]

SENATOR RIEPE: Thank you very much. We will now proceed on to LB793, which happens to be my bill. And in the absence of Vice Chair Erdman, I've asked Senator Crawford, to my left here, if she would be willing to facilitate and manage and run the committee meeting, and she said, yes, that she would. So thank you. And I will go to the chair. [LB793]

SENATOR CRAWFORD: Welcome. [LB793]

SENATOR RIEPE: Thank you. Would you like me to proceed? [LB793]

SENATOR CRAWFORD: Yes, please proceed. [LB793]

SENATOR RIEPE: Thank you, Chair... [LB793]

SENATOR CRAWFORD: We'll now proceed with the hearing for LB793 and, introducer, Senator Riepe, you're welcome to begin. [LB793]

SENATOR RIEPE: Thank you, Chairman Crawford. My name is Merv Riepe. It's Merv, M-e-r-v, my last name is Riepe, R-i-e-p-e. I represent District 12, which includes portions of Millard, Omaha, and Ralston. Last session, the Legislature passed LB333 to establish the five prioritizations of funding within the Medicaid home and community-based services waiver for individuals with developmental disabilities, which include the first funding priority is for individuals with developmental disabilities in immediate crisis due to caregiver death, homelessness, or threat to the life and safety of the person. The second funding priority is for individuals with developmental disabilities that have resided in an institutional setting for a period of at least 12 consecutive months and who are requesting community-based services. The third funding priority is for individuals with developmental disabilities who are wards of the department or individuals under the supervision of the Office of Probation Administration. The fourth funding priority is for individuals with developmental disabilities transitioning from the educational system, upon attaining 21 years of age, to maintain skills and receive the day services necessary to pursue economic self-sufficiency. The fifth funding priority addresses the wait list. LB333 also, and I quote, kicked the can down the road regarding the conflict in state statutes regarding prioritization of funding to July 1, 2019. During the debate for LB333, I stated I would bring a bill to address the conflict in statutes regarding service for individuals with

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developmental disabilities. LB793 is that bill. On July 1 of 2019, the state will again have a conflict on how to spend General Fund dollars. The language in LB333 states the funds spent should maximize federal dollars and should be spent first on individuals in immediate crisis due to caregiver death, homelessness, or a threat to the life and safety of the person. But in 2019, the state will have to fund the high school entitlement with 100 percent General Funds rather than coming within the umbrella of the Medicaid waiver where the state can maximize the federal funding and provide more services for more individuals, including the high school graduates. I appreciate all advocates. They continue to express concern regarding funding services for individuals with developmental disabilities. And I do not see LB793 as a policy issue but an appropriations issue. It is the Legislature's wish to fund services for individuals with developmental disabilities then that the state should do and in a way that is fiscally responsible and allows to provide services for the most Nebraskans as possible. As Chairman of the Health and Human Services Committee, I want to see that the state is providing services to as many individuals as possible with the funding we have available. I ask you, colleagues, is continuing to fund the high school entitlement with 100 percent General Funds a fiscally responsible way to use taxpayers' dollars when the state could maximize the dollars to support more individuals with developmental disabilities through the waiver with federal and state funds? Director Miller will testify in support of LB793. I thank you and I would take questions if you have them that I am able to address. Thank you, Madam Chairman. [LB793]

SENATOR CRAWFORD: Thank you, Senator Riepe. Questions from senators? I just have a question. [LB793]

SENATOR RIEPE: You say no or you do? [LB793]

SENATOR CRAWFORD: I have a question, yes. [LB793]

SENATOR RIEPE: Okay. [LB793]

SENATOR CRAWFORD: (Inaudible). [LB793]

SENATOR RIEPE: I will try. We'll see. [LB793]

SENATOR CRAWFORD: So one of the important reasons of putting...leaving the language in the statute was it was, again, an important state priority to make sure we're addressing services for these children and to then identify, make sure, that when we are doing...serving them through the waiver that we're indeed making sure that we're meeting the needs of all those students. And so to strike the language now would mean we just have sort of one year of seeing if that need is

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being met. So to allow...to allow the 2019 to be shifted to 2021 would give us a chance to see, make sure that waiver is working in terms of making sure we don't need to pay attention to if there is additional funding that's needed to make sure we're serving these important students in our state. So are you amenable to changing the date to 2021? [LB793]

SENATOR RIEPE: We are certainly open to anything that makes sense. The original...the intent here is to try to, first of all, to prioritize to make sure that the most vulnerable are the ones that we make sure that we take care of, and hopefully we can take care of more. I think Director Miller will talk about what she's been able to do with the wait list. And it's a matter of trying to get this thing on a more definable basis than we've had it. But we would have to take a look. I'm not sure of the implications. Director Miller might have more insight about the possibility of that going from 2019 up to 2021. [LB793]

SENATOR CRAWFORD: Thank you, Sir. Any other questions? [LB793]

SENATOR RIEPE: Because it's not something I personally thought about. [LB793]

SENATOR CRAWFORD: Right. Senator Howard. [LB793]

SENATOR HOWARD: Just for the record, how long is our waiver good for, for DD? [LB793]

SENATOR RIEPE: I will have to ask Director Miller... [LB793]

SENATOR HOWARD: Okay. [LB793]

SENATOR RIEPE: ...to get the date right or I might give you the wrong one. [LB793]

SENATOR HOWARD: And then are the graduates that we're talking about, are they on the wait list as well? [LB793]

SENATOR RIEPE: I believe that they are, but we will let her either confirm. Or some of them, I know she's made some progress in terms of shortening that wait list. And so who remains on that wait list I do not know. [LB793]

SENATOR HOWARD: Okay. Thank you. [LB793]

SENATOR RIEPE: Okay. Thank you. [LB793]

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SENATOR CRAWFORD: Thank you. Any other questions? [LB793]

SENATOR RIEPE: Okay. [LB793]

SENATOR CRAWFORD: Thank you, Senator Riepe. [LB793]

SENATOR RIEPE: Thank you, Chairman. [LB793]

SENATOR CRAWFORD: So now we are...the hearing is now open for proponents of LB793. Welcome. [LB793]

COURTNEY MILLER: (Exhibit 1) Thank you. Good afternoon, members of the Health and Human Services Committee. My name is Courtney Miller, C-o-u-r-t-n-e-y, Miller, M-i-l-l-e-r, and I am the director of the Division of Developmental Disabilities in the Department of Health and Human Services. I am here to testify in support of LB793. Thank you, Senator Riepe, for introducing this bill to ensure we align our funding priorities to meet the needs of individuals eligible for developmental disability services. The current law requires those who are high school graduates, age 21 and older, to receive services as of July 1 of 2019. LB793 will remove this entitlement language to allow for clear direction of funding priorities for the Developmental Disabilities Services Act. Last year the Centers for Medicare and Medicaid Services, CMS, advised that prioritization of participants to receive state entitlement services as the first priority would not be approved within our Medicaid-funded home and community-based services waiver application. DHHS worked collaboratively with you last year to update Nebraska law to outline the priorities for serving individuals on the Medicaid waivers. The department is committed to prioritization based upon the severity of the participant's need and other qualifying circumstances, which includes providing services for individuals transitioning from the education system to maintain skills and receive the supports necessary to pursue economic self-sufficiency. Slots were reserved for capacity within the approved Medicaid waiver application specifically for this population. DHHS has made Medicaid waiver funding offers to the 2017 graduates and will make funding offers for the 2018 graduates prior to their 21st birthday. If the entitlement language is not removed, the law will prioritize funding entitlement services for graduates over all other categories of eligible applicants, including priority one applicants who have demonstrated health and safety needs. Entitlement services would require full state General Funds until the participant receives a funding offer to participate in the Medicaid waiver program based on prioritization criteria in Nebraska law. That kind of redirection of state General Funds would have fewer individuals on the wait list being served. I had the opportunity to travel the state on several occasions, but most recently in October of 2017, to engage stakeholders in the delivery of developmental disability services. I had honest and candid conversations with participants, their families, friends, providers, and advocates---critical voices associated with the

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programs that serve Nebraskans with developmental disabilities. A concern I continue to hear year after year is how the department is going to serve individuals on the wait list with aging parents or caregivers that are unable to care for themselves. If the entitlement language is not removed, it will prioritize funding for a current graduate over the highest priority group defined in Nebraska law. These individuals are also waiting for funding, while an entitled high school graduate receives services whose needs may be met by other DHHS programs, community resources, or natural supports at that point in time. The health and safety of all individuals must be the primary concern, especially when there are funding constraints. By prioritizing services for a select group of high school graduates over others that do not (sic) meet the emergency criteria, a threat to the health and safety to an individual on the wait list could occur. The negative fiscal impact amounts in the DHHS fiscal note do not represent amounts available for reduction if the bill passes. The amounts represent estimates of General Funds that may be needed to be added to the budget for fiscal year '19 to finance the entitlement services for graduates in 2019, if LB793 does not become law. DHHS worked with Governor Ricketts and his team on the proposed budget adjustments on funding for developmental disability services. Funding to align our budget priorities remains as previously proposed--to serve eligible individuals with developmental disabilities in crisis situations and on the wait list. Any redirection to utilize 100 percent General Fund appropriation again translates to a reduction in funding offers that can receive the federal matching funds. Thank you for the opportunity to testify before you today. I believe LB793 will help DHHS continue in our mission of helping people live better lives. I'm happy to answer any questions you may have. [LB793]

SENATOR CRAWFORD: Thank you. Questions? I'll just ask if you can just, for the record, talk about the way in which the waiver has served these people in need of services in our state... [LB793]

COURTNEY MILLER: Uh-huh. [LB793]

SENATOR CRAWFORD: ...in this window that we've seen so far. [LB793]

COURTNEY MILLER: So for 2017, our adult day waiver was approved September 30 of 2017. And so with that...I'm sorry, May 1 of 2017. And with that approval, we established the funding priorities with reserve capacities. And the fourth funding priority that's reserved for those graduates is we have reserved 200 slots per year of the waiver, which is a five-year approved waiver, and we have made 120 offers that have been accepted to be served on the waiver this year. We have estimated, as these individuals are also on the wait list, known to us, we have another 32 remaining offers for this fiscal year for graduates. And then for fiscal year '19 we have 135 graduates that are known to us at this time and the funding is available and set aside to fund them as well. [LB793]

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SENATOR CRAWFORD: Excellent. Thank you. Any other questions? Senator Howard. [LB793]

SENATOR HOWARD: How long does the waiver last for? [LB793]

COURTNEY MILLER: The waiver is approved for five years. [LB793]

SENATOR HOWARD: So we put it in 2017, so it's good until... [LB793]

COURTNEY MILLER: '22. [LB793]

SENATOR HOWARD: ...2022? [LB793]

COURTNEY MILLER: 2022. [LB793]

SENATOR HOWARD: So would you consider an amendment to extend the deadline to 2021? [LB793]

COURTNEY MILLER: I think my position remains the same in that we're looking at a situation where, regardless of the year, I am still going to be in a position where with \$1 available with the division to serve someone, what that top priority is. [LB793]

SENATOR HOWARD: How long has LB333 been in effect? [LB793]

COURTNEY MILLER: I believe that was passed last year in the 2017 Session. [LB793]

SENATOR HOWARD: So when we discussed and made the agreement for 2019,... [LB793]

COURTNEY MILLER: Uh-huh. [LB793]

SENATOR HOWARD: ...I think my understanding was that we wouldn't hear a bill like this until next year because July...we pushed it to July 2019. Was that your understanding? [LB793]

COURTNEY MILLER: I'm not aware there was a specific understanding of when a bill would be introduced. No. [LB793]

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SENATOR HOWARD: Okay. Thank you. [LB793]

SENATOR CRAWFORD: Thank you, Senator Howard. Other questions? Yes, Senator Linehan. [LB793]

SENATOR LINEHAN: Thank you, Senator Crawford. Thank you for being here. Okay, I remember this from last year and I remember...so the high school kids, the way we've done it in Nebraska, we put them at the front of the list. [LB793]

COURTNEY MILLER: Yes. [LB793]

SENATOR LINEHAN: So who goes behind them when we do that? [LB793]

COURTNEY MILLER: On the current...on...to receive services through the Medicaid home and community-based waiver, above them, they are fourth priority, the first priority is those in crisis with health and safety, abuse and neglect concerns. The second priority is those that have resided in an institution, whether that would be a intermediate-care facility like the Beatrice State Developmental Center or a mental health hospital such as our behavioral health regional centers or a hospital setting or a rehabilitation acute hospital. That would be the second funding priority. The third priority is those that are wards of the department or those that are under the supervision of the Office of Probation Administration. So those are all vulnerable youth. And then the fourth priority is those graduates. [LB793]

SENATOR LINEHAN: But right now we've put the graduates ahead of the rest of them. [LB793]

COURTNEY MILLER: Not today. The graduate... [LB793]

SENATOR LINEHAN: I mean with this. [LB793]

COURTNEY MILLER: ...the entitlement program is suspended. So we have served them. We have successfully served them this fiscal year through the fourth funding priority as we've met the needs of priorities one through four and made additional offers from the fifth priority, which is the first come, first served off the wait list. [LB793]

SENATOR LINEHAN: Okay. So but what you're trying to do here legally is just make sure that the people from one to three that you just listed get taken care of, because that's what the federal government has requested us to do, right? (Inaudible). [LB793]

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COURTNEY MILLER: The federal government has indicated that our first priority, and I think that we're in agreement, that that is those in a crisis situation, that they are served first. [LB793]

SENATOR LINEHAN: Okay. [LB793]

COURTNEY MILLER: And then we have established our second, third, fourth, and fifth in statute for Nebraska. [LB793]

SENATOR LINEHAN: And you established that because you just think it's the most urgent. It's like from crisis to almost crisis to not quite a crisis to it will be a crisis? [LB793]

COURTNEY MILLER: It's a level of severity. Uh-huh. [LB793]

SENATOR LINEHAN: Okay. Thank you very much. [LB793]

SENATOR CRAWFORD: Other questions? Do you know if there are other states or mechanisms that states have to just ensure continuity of services? I think that's one of the concerns that is often raised is just to make sure that we have some attention to continuity and preventive services to keep someone from falling into crisis. [LB793]

COURTNEY MILLER: I think with other states, you've seen one state, you've seen one state. I think they all do it very differently with their programs and their array of services. I am not aware of any state that has an entitlement program like this with 100 percent state General Funds. [LB793]

SENATOR CRAWFORD: Thank you. Other questions? All right. Thank you, Director Miller. [LB793]

COURTNEY MILLER: Thank you. [LB793]

SENATOR CRAWFORD: Other proponents of LB793. Proponents. Are there any opponents of LB793? Step forward and give your orange sheet to the clerk or the page. And if you would, yes, sit and state and spell your name, appreciate that. [LB793]

PHIL GRAY: Thank you. My name is Phil Gray, P-h-i-l G-r-a-y. I'm here representing myself and some volunteer parents that we've organized into a parents group. We have about 100 people on our mailing list now who have volunteered to take part in our activities. We've gotten big

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enough we can no longer call ourselves a volunteer parents group, so now we call ourselves parents for...or Persons, because we have more than parents, Persons for Appropriate Special Services, PASS. So if you hear from PASS, that's us. I'm here today to oppose this bill for some of the reasons that Senator Howard had mentioned and for reading the bill. When the bill...by the way, I'm a parent of a handicapped son, an adult son. We're not affected by this bill. My son is in services actually in your district. My provider is in your district. I'm in Senator Hilkemann's district, so pretty typical nowadays. My son was...contacted (sic) viral encephalitis at age six weeks from a mosquito bite. That bite changed his life and ours forever, not in a positive way. But we've been involved in all of this stuff, with these activities, for a number of years, although the last 10 or 15, I have not been actively involved. But now it's clear to me, after we lost the bill on LB333 that parents are not involved, parents are not informed. They're interested. They want to be involved. And so we started this group with another fellow and myself and we've grown from 2 people to 100. We've sponsored an ICAP training session. We've sponsored a town hall meeting with three senators. We have an active survey going on for parents who can't...on our list who want to tell us how their ICAP process went. We're sending parents to the stakeholders' meetings and we're all becoming more informed. We realize it's a complicated process and I'd like to add I wish your constituents could see how much time and energy and work and seriousness you take with this effort. It's...if you're not here all the time, you don't realize exactly what's involved and what you have to do. I'm opposed to this bill because the bill eliminates the one shred of stability in the life of a family with a handicapped son that--or daughter--when they come out of school there is some services going to be available for them. That's the one shred of stability when you're raising a handicapped son or daughter. Everything is under flux. Everything changes. I would like this bill...LB333 was passed with a sunset clause for 2019 to see if it worked. It hasn't had any opportunity to work. It hasn't had any opportunity to test it. I think that what we should propose is that the sunshine settlement be extended two years. Let's see how it works. Let's see what can happen as we go forward, how the funding works. I don't see any reason, from what I've heard, that you can't do that. I'm also a little confused why you can't put some of those top priorities, the kids in crisis. We all...nobody wants to stop services for kids in crisis. But I don't know why you can't write an entitlement bill that includes kids getting out of school and kids in crisis. The Social Security Act has multiple entitlements in its bill without any problem. I don't know why we can't have multiple entitlements in a bill. I've been told we can't but I think that seems a little unusual. Other than that, as a parent who I've been active in the past, I don't know if you need my resume, but I have been involved with our parents group. Now we send people to the stakeholders' meetings. It's been very educational. We get a good idea, a better sense of the issues facing the department and the Legislature and the efforts that are being made. We, you know, really do appreciate that. But I think this is a wrong way to go. I think this entitlement should be at least only suspended for a couple years. Let's see how this bill works. Priorities are not mandated. Priorities are subject to the whim of the Legislature or the whim of the Governor. You don't have to fund a priority. You can; you can't. An entitlement gives some

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parents at least a leg to stand on. Thank you. Appreciate your time. I'll be glad to take questions. [LB793]

SENATOR CRAWFORD: Thank you, Mr. Gray, and we appreciate you being here and sharing your perspective. I appreciate that very much. Are there... [LB793]

PHIL GRAY: And I think we have another parent from our group who's going to testify... [LB793]

SENATOR CRAWFORD: Sure. [LB793]

PHIL GRAY: ...and we have a couple other parents here that will come up to testify. [LB793]

SENATOR CRAWFORD: Great. Great. We'll have plenty of time. If you'll hold on one second, see if there are any questions from committee members. No. Thank you, Mr. Gray. [LB793]

SENATOR LINEHAN: I actually have a question. [LB793]

SENATOR CRAWFORD: Oh, oh, oh. [LB793]

PHIL GRAY: Yeah. [LB793]

SENATOR LINEHAN: Thank you very much. [LB793]

SENATOR CRAWFORD: Senator Linehan, yes. [LB793]

SENATOR LINEHAN: Thank you very much. [LB793]

PHIL GRAY: Sorry. [LB793]

SENATOR LINEHAN: Thank you very much for all your efforts on behalf of all the kids and the parents. It takes a lot of time and a lot of energy, so thank you very much. [LB793]

PHIL GRAY: I'm a little hard of hearing what you said. [LB793]

SENATOR LINEHAN: I'm saying thank you very much for being here... [LB793]

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PHIL GRAY: Oh. [LB793]

SENATOR LINEHAN: ...and for all your efforts, volunteering and organizing people, which is sometimes thankless. I think it was Senator Howard, asked if there other states that did this better. Do you know if there's other states that do this better or differently? [LB793]

PHIL GRAY: You know, I don't. And my experience, though, is even though I object to this particular bill, my experience is that Nebraska probably does it almost as well as other states. I've had friends move out of state and go on a long waiting list. Nebraska has a long waiting list. My son is in his early 40s. There have been waiting lists since I've become involved with it. I was involved on the Millard LB889 interim committee, you know, to move kids. My son was in the first LB889 class that gave us the right to free access of public education. I was on the committee from Millard that worked on that. I've had parents move out of state whose kids are on two- and three-year waiting lists also. I don't know that we're quite in that shape. The waiting list has been here forever. I was involved in the effort with Governor Nelson when the state changed the funding method so that kids in service on December 31 were served in January. And we ended up not having all those great, dramatic hearings with (laugh) the Appropriations Committee. I remember parents coming and leaving and bringing their kids and saying, well, if you cut the services for my provider I'm leaving my kid with you. I mean they were not good. I think Nebraska works real hard at doing what they're trying to do but this is the one stable thing in our environment at this point. And the waiting list is just something everybody deals with. [LB793]

SENATOR LINEHAN: Okay. Thank you very, very much. [LB793]

PHIL GRAY: Yeah. [LB793]

SENATOR CRAWFORD: Thank you, Mr. Gray. Other proponents of LB793. [LB793]

SENATOR HOWARD: Opponents. [LB793]

SENATOR CRAWFORD: Opponents, thank you. Other opponents of LB793. [LB793]

BRENDA HOFFMAN: I'm sorry; his nickname is Bamm-Bamm. [LB793]

SENATOR CRAWFORD: Welcome. [LB793]

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BRENDA HOFFMAN: (Exhibit 2) My name is Brenda Hoffman. [LB793]

SENATOR CRAWFORD: Welcome. Yes. Would you...let's make sure you get a chair here also. [LB793]

BRENDA HOFFMAN: Okay. Thank you. [LB793]

SENATOR CRAWFORD: Yes, please, go ahead and state and spell your name. Thank you. [LB793]

BRENDA HOFFMAN: My name is Brenda Hoffman. That's B-r-e-n-d-a, Hoffman, H-o-f-f-m-a-n. This is my son Nicholas Hoffman, N-i-c-h-o-l-a-s. Nicholas is graduating in May of this year. We've been on that list since he was age four; currently waiting for DD. We're wiggling the way through these services. And everything I wrote this morning to make sure, I'm going to go completely off key. We've been on this list. It's been a long struggle to find out who's going to have services. The parents are confused. They don't know, is there a list? What list am I supposed to be on? So some of us parents are trying to stay well-informed and we will get on that group of the parents so that we can be better informed. And the parents that are not here are not just not concerned. They're working. They're struggling. They're taking their kids to doctor appointments. They just cannot get here. They're tired, taking care of their medical needs. Thank you for listening to him. He was very good here. But I just want to tell you that as far as a parent, we want our kids to grow up. We want them to have all the dreams that others (inaudible). Our dreams are different. We want to have our kids out there at graduation. We want them to be able to have the services available that all these years we've been waiting for. And now it's like, wow, wait a minute, they might not be there. And we understand the importance of the priorities and that. We just want you to not forget that they're seniors. They're not going to college. They're not finding jobs. He's at the 11th or 11-month-old thing. He's not going to even wipe a table at McDonald's, because I'd be excited if my son could do that job. But he needs day care, day care services. I went part time. I've got a 22-year job. My husband has got a 35-year job. We don't want to have to quit our jobs to be able to stay at home. I want to keep him home because I am afraid of all the horrible stories we hear about the people that are abused. He's nonverbal. He wears diapers. He's got all...he can't run away from people--the terrors that we have. I want him to be out in the community, making friends, meeting people so that advocates like the ones that have talked will know him, meet him, and be here when I'm dead and gone to support his needs. So, please, let these kids have some dreams to find friends in the communities and let them have the day services so he can go out in the community. And I just beg for that support. He's 100 percent hands-on and it allows us to keep our part-time jobs. It allows me to take my mom, who's...and we think she's got dementia. And when she has to go to the hospital, I'm dragging two wheelchairs and trying to...I can't do it without day services. And then I know that this isn't

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in regards to day services but respite three days a month is sometimes really tough. And if you've got other kids, it allows me to pay, if I'm working, I can send my girl to college. She's the first one on both sides of the family that could go to college. And we wouldn't be able, she wouldn't get the grants and scholarships and things like that, but she was able to go. Amen, we were able to work through the child waivers that you have to have in process. So we appreciate all that. We want to pay our taxes. We'd love for him to be able to do the other, but we need those day services. [LB793]

SENATOR CRAWFORD: All right. Thank you, Ms. Hoffman. [LB793]

BRENDA HOFFMAN: Thank you. [LB793]

SENATOR CRAWFORD: And thank you, Nicholas, for being here today. Any questions from committee members? And we thank you for your taking the time to be here today and we thank you for... [LB793]

BRENDA HOFFMAN: Thank you. [LB793]

SENATOR CRAWFORD: ...your witness. Thank you. Any other opponents to LB793? Welcome. [LB793]

ALAN ZAVODNY: (Exhibits 3 and 4) Good afternoon, Senator Crawford, members of the Health and Human Services Committee. For the record my name is still Alan Zavodny, A-l-a-n Z-a-v-o-d-n-y, and I am still the chief executive officer of NorthStar Services, at least no one has told me I'm not yet this afternoon. I'm also privileged to serve as the mayor of David City, Nebraska, a community of 2,906. I'm also asking and requesting that we set into the record a letter from the Nebraska Association of Service Providers, which you're receiving. And it's never fun to oppose the Chair. I've had to do that once or twice in my career, and usually I'm having to stare at them when I'm telling them I don't like what they're doing. (Laughter) So I appreciate the fact that Senator Riepe is behind me right now. And it's not fun to have to oppose the department, but that's where we find ourselves today. I want to begin by saying that I fully understand the concern of the Division of Developmental Disabilities about not eliminating the prioritization of graduates. None of us benefit from the state of Nebraska getting sideways with CMS. That being said, the potential risk to young people experiencing an intellectual disability is significant. The entitlement for graduates goes back to circa 1996 and Governor Nelson's blueprint. And I was in the Capitol that day. We know that these young people lose vital skills if there are disruptions in supports. And it didn't occur to me necessarily earlier but Senator Crawford said something that sparked something that I can't imagine that it won't cost more, because people are going to need a higher level of supports if there is that disruption in services

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because there will be lost skills. I would respectfully suggest that the Division of Developmental Disabilities find a way to not prioritize graduates but does provide for enough slots for every graduate in a given year. To not do so would be a monumental mistake, in my humble opinion. The consequences of not supporting graduates in this instance are pretty clear and the risks outweigh the benefits. And that may be something that we will need to address through appropriations if we're going to fund slots. Additionally, the waiting list for services will continue to swell and families with a loved one with an intellectual disability will continue to not receive services while other Nebraska taxpaying families do. How do we reconcile that fact? We are picking winners and losers. That is very poor public policy. Thank you for allowing me to testify and for your consideration. [LB793]

SENATOR CRAWFORD: Thank you. Thank you for your testimony. Do we have any questions from committee members? Thank you. Do we have other opponents of LB793? Welcome. [LB793]

DOUG ROBERTS: (Exhibit 5) I'm Doug Roberts, D-o-u-g R-o-b-e-r-t-s. I'm a father of a special needs person and his power of attorney. I want to thank the state agencies that have helped him to get to where he is now. The support that we have experienced has been very helpful. He is largely independent now. He's a taxpaying citizen of our state and that's due to the fact that you partnered with us, as parents, to see that he could develop his full potential. After he finished high school, there were programs there that enabled him to find housing, appropriate housing, to be involved in social activities, and to find employment. But I'm getting older. I won't always be there or able to do the things that he can't do for himself. He does much. He is...I am very lucky, as a special needs parent, at the high rate in which he is able to function. But there are crucial areas and, if we lose those basic entitlements, he won't even know how to access the priorities. That is beyond his ability. You can say, okay, here are the priorities, but who is going to even know about him or to service him to get those priorities if I'm gone? So I oppose this bill, LB793, because what it does, it sets fine priorities. I agree with those priorities. They have many good things about them. But if you don't have a basic level of service, as you've heard some of the people that are waiting lists talk about not being there, then there is no safety net. There is nothing. When he lost employment for a short period a few years ago, I was living out of state working. I did everything I could to access the services to help him find a job. If I hadn't had agencies that were funded like Mosaic and their employment specialties, he may have not been able to return to employment. He has now returned to full-time competitive employment. That would not have happened if those people hadn't been here. I moved back, in part, to the state of Nebraska to see that those services would be there for him because I would be his advocate. But as I age, I won't always be here. I'm sorry. Usually I'm not a very emotional person, but... [LB793]

SENATOR CRAWFORD: It's fine. [LB793]

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DOUG ROBERTS: My experience with Nebraska has now spanned some...a good third of my life. I have found Nebraskans to be very considerate, good people. Most of them would identify them as Christians. But I have seen a change in the environment of concern for special needs decrease. I have seen the political leadership of not only our state, but elsewhere, have less concern for those in need and instead of seeking funding I see them wanting to give tax cuts to people, even like myself that don't need it. And that tightens up the financial pool for those that do need it. And so I oppose this bill because if we set those and there is no basic line of advocacy, if there's no entitlement to somebody to step in there, he's toast. He won't know how to access that priority. He will have no one to go to. I guess that's something. And first, I guess there's a last concern of what I hope, as a good Christian. I don't think anybody that reads the New Testament, and particularly things like Matthew 25, can believe that Jesus didn't set as a priority those who were in the most need. And so I encourage you at least to delay the implementation of what is currently being done until we have a chance to test the funding. But we also know the economy goes up and down and has always done so and we can expect it to do so again. If it goes down, will there be anybody if there isn't a basic entitlement? And we thank you for your listening. [LB793]

SENATOR CRAWFORD: Thank you, Mr. Roberts. I appreciate your testimony. Thank you. Are there any questions for Mr. Roberts? Thank you. Thank you for being here today. [LB793]

DON WESELY: Senator Crawford, members of the Health and Human Services Committee, for the record my name is Don Wesely, D-o-n W-e-s-e-l-y. I'm here representing Nebraskans for Rate Equity. These are some community-based providers of developmental disability services. And Alan Zavodny does a great job of giving you some background. I was...I carried the legislation that you're discussing right now, the Developmental Disabilities Services Act. So I can tell you that we did this purposely and with good intent and I think also for good reason. Our thinking was that there's so much money spent in high school special education services that are required by the federal government, it made no sense to us that upon graduation or reaching the age of 21 that they would fall off the edge and lose whatever advances they made with their abilities and their skills. And it seemed like an investment. And I guess the question I'd ask, and I don't know the number but it's got to be a lot of money spent on those services in our school system. We spend a lot of money, federal and state money, to do that. So here we are, we've spent that money, we've worked with these individuals and those families, and then just to have them wait for months, years, maybe never getting services made no sense. So we put this in place with the idea that we made an investment, let's continue to take advantage of the benefits of that investment. So that's number one. The second thing was we actually had the goal at that time, in the 1990s, to end the waiting list that...and we actually came very close. And maybe, technically, didn't achieve that--there was a small waiting list--but we actually didn't have anybody that actually needed services not getting services. And that all changed in the last 20 or so years. And that gets back to the question before you. There are five priorities, and if Senator

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Blood's bill is passed there would be six. So if you look at it, nobody can argue with some of those first priorities: crises and, you know, wards and what have you. So we're not arguing that. The question is how far down does the state of Nebraska want to fund, in cooperation with the federal government, the services that these people need? And we're talking now about level four priority I think, but we were actually past that, saying we need to get into level five, that everybody who needed services, we should find a way to provide them. And now we're talking, we're like giving up on that ideal that everybody should have services and now we're talking about how much of this level four are we going to take care of. And I say we should just assume and work together to find the funding to take care of those folks to that fourth level and then what we can...I'm giving up on the idea we can ever end that waiting list. It's just gotten too long. But it was really long when we...before we got started too. But at least we should do this. We should get back to the idea that these individuals deserve, when they graduate, services awaiting them that they can count on. Now one of the interesting things about the fiscal note--I looked at that--and they have down here from the department that having an entitlement will encourage people to relocate to Nebraska and take advantage of that entitlement. But we've had that entitlement. We've had it for 20-some years. Do they have any examples of anybody who moved here because of that entitlement? I think the answer is...if they have any examples I'd like to see that, and if they do, you know, I understand that. We can deal with that. But I just don't think that's been the case. So that's my testimony. Again, we oppose this bill. We believe that we could delay the implementation date, see how this works out, but I see this as the chance to talk once again about the ideal of what do we want to accomplish with developmental disability services. That entitlement forces that issue. And then we talked about what we want to fund and the priorities and everything. We wouldn't be having this discussion if that wasn't still in the law to be reinstated. So I believe keeping it in the law is important. [LB793]

SENATOR CRAWFORD: Thank you, Mr. Wesely. Questions by committee members? Yes, Senator Linehan. [LB793]

SENATOR LINEHAN: Thank you, Senator Crawford. Thank you for being here, Senator Wesely. [LB793]

DON WESELY: Uh-huh. Senator. [LB793]

SENATOR LINEHAN: I call you Senator Wesely. I don't know what your right title is. (Laugh) I'm really happy you're here because this is very hard for me to kind of figure out. Do you know how long the waiting list is? [LB793]

DON WESELY: I don't. I don't know what it is anymore. It was... [LB793]

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SENATOR LINEHAN: And how long it is and...because somebody, and you can help, obviously if you have a special needs child and they're in high school or even in, as somebody said earlier, since they were five, you put them on the waiting list as soon as you know you're going to hit that mark. So is there any...who could you go to, to figure out, okay, we've got a list that's this long, but how many of them are on there because they need help in ten years or five years or two years, and how many of them are like in a holding pattern that's very bad? [LB793]

DON WESELY: That's an excellent question because that's what we found out. That's why I said we thought we took care of the waiting list but there was still a waiting list. [LB793]

SENATOR LINEHAN: Right, because if you're five, you're staying home with your folks. [LB793]

DON WESELY: They were on it, yeah. [LB793]

SENATOR LINEHAN: Right. [LB793]

DON WESELY: So what we thought is, well, we'll get to them that actually need it now, and we took care of them. But there was still a waiting list for people, like you said, for... [LB793]

SENATOR LINEHAN: Right. [LB793]

DON WESELY: And I don't know the answer to that. I don't know what the actual immediate waiting list is versus the long-term waiting list. I do not know. [LB793]

SENATOR LINEHAN: That would be really helpful in this conversation, I think. [LB793]

DON WESELY: Yes, it would. [LB793]

SENATOR LINEHAN: And do you know if anybody...because part of the reason we're in this, as I understand it, we're in this crunch, is because the federal government has said you need to do this. So I don't know if the department has or anybody in the administration has. Do you know of any of the providers who reached out to our federal officials and said, can you help us with this, can you make this go away? [LB793]

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DON WESELY: You know, you make an excellent point, because I think we could go back to the Legislature and the department. And Courtney Miller is doing a great job, and the providers and the parents. Boy, I thought the parents' testimony... [LB793]

SENATOR LINEHAN: Right. [LB793]

SENATOR CRAWFORD: Right. [LB793]

DON WESELY: ...was outstanding. Get together and say what can we do together to make sure there's enough federal funding to take care of this. And, no, we haven't found the information to be able to know if we can help or not, but we want to. [LB793]

SENATOR LINEHAN: Okay. Thank you very much for being here. [LB793]

DON WESELY: Uh-huh. Yeah. Thank you. [LB793]

SENATOR CRAWFORD: Thank you. Other questions or...? Thank you. [LB793]

DON WESELY: Thank you. [LB793]

SENATOR CRAWFORD: Any other opponents of LB793? Welcome. [LB793]

EDISON McDONALD: Hello there again. Okay. Hello again. My name is Edison McDonald, E-d-i-s-o-n M-c-D-o-n-a-l-d, and I am the executive director for The Arc of Nebraska: again, 1,500 members, nine chapters across the state, and a key focus on community inclusion. We're strongly opposed to LB793 because it removes the guarantee for transitional care. We understand what the department and Senator Riepe are trying to accomplish here, however, what I would urge is that we wait on this and try and determine a better path forward in the future. I have a constant stream of calls from parents, allies, providers, and self-advocates who are concerned about a great many issues. But this time period is one of the highest volumes of calls because people are kind of getting away from the school and figuring out, well, okay, what's the next step in their life. How do things look? Things really kind of change up. And so trying to figure out exactly where they're going to go, how they're going to live, how they're going to react is a huge issue, so really focusing on making sure that we have a little bit better understanding. I think also with transition services, it's not just this issue; there's a much broader piece of the puzzle that needs to be addressed. And I think to go and remove this entitlement, after we've only had one year following LB333, is premature. I think that it would be better if, instead, we were to wait, give it some opportunity so we can see how it plays out. The other thing is I want to make sure that we

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have the opportunity to work a little bit more on this. I'll tell you that this is an issue that has really caught my attention in my new role here at The Arc and I think it's one that we need to look more into. So I've started to take some steps for us to kind of begin to dig more into that conversation. And I know our chapters and some of our typical allies have said that they are very interested in engaging in further dialogue on this. But we need more time. So let me have some more time to go and talk with people, figure out a better direction forward on this. I hope to engage in some dialogue with all of you. Particularly coming to mind, Senator Linehan, I've got an event on transition services coming up in your district that I'll get you an invite to shortly that I'd love to have you there. And my hope is that we can go and look forward to having a better overarching direction and we can figure out a way to take into consideration the focus on the highest need and simultaneously look at ensuring that we're still protecting transition services. Thank you. [LB793]

SENATOR CRAWFORD: Thank you, Mr. McDonald. Any questions? Yes, Senator Linehan. [LB793]

SENATOR LINEHAN: Thank you very much... [LB793]

EDISON McDONALD: Uh-huh. [LB793]

SENATOR LINEHAN: ...for being here. Doing great. When...because one of the parents that testified... [LB793]

EDISON McDONALD: Uh-huh. [LB793]

SENATOR LINEHAN: ...(inaudible), so once you get enrolled, you graduate from high school, you go into the program. And he's right. He's a parent. We all worry about what happens to our kids when we're not here anymore. [LB793]

EDISON McDONALD: Uh-huh. [LB793]

SENATOR LINEHAN: Even because you, you know, you worry. So once someone with developmental disabilities that needs these services, once they're enrolled, they're enrolled for life, right? Or do they (inaudible), I mean how does that work? Because he is concerned I think (inaudible) like what happens, and that's a legitimate concern, so... [LB793]

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EDISON McDONALD: Yeah, it's...I mean it's a continuing battle and it's a continuing discussion. And I think that, you know, we need to...there's always further need. So I don't see it as just kind of a, like, once and done. I see it as... [LB793]

SENATOR LINEHAN: In a perfect world, there's always an advocate there, right? Is that what you're saying? [LB793]

EDISON McDONALD: In the perfect world, there's always an advocate there. And trying to, you know, figure that out is hard, you know? And it's just like if you were to change a job. At different points there are different times when everybody has a different need. So this time period, just like with any other young person, is a period of significant transition in their life. And so I see this as kind of a key piece to say, well, we have this high area of need, let's focus on this for now so that we can go and make sure that we provide some stability. And as Mr. Wesely indicated, you know, that focus of continuing the investment that we've put into them in our schools and saying this is a good start, let's go and make sure that we continue to get them into a more integrated life. [LB793]

SENATOR LINEHAN: Thank you. [LB793]

SENATOR CRAWFORD: Thank you. [LB793]

EDISON McDONALD: Also on the waiting list, I think the last number I had was 1,857 people. [LB793]

SENATOR LINEHAN: But do you know how many...I'm sorry. [LB793]

SENATOR CRAWFORD: No, go ahead, Senator Linehan. [LB793]

SENATOR LINEHAN: One thousand eight hundred fifty people, but some of those are still in school. That's...the breakdown I'm looking for is... [LB793]

EDISON McDONALD: Yeah, I don't have the specific breakdown that you were looking for,... [LB793]

SENATOR LINEHAN: Okay. But that's very nice you have that number. [LB793]

EDISON McDONALD: ...just the top line. [LB793]

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SENATOR LINEHAN: Thank you very much. [LB793]

SENATOR CRAWFORD: Thank you, Mr. McDonald. Are there any others here wishing to speak in opposition to LB793? Anyone wishing to speak in a neutral capacity on LB793? Tyler, do we have letters to enter into the record? [LB793]

TYLER MAHOOD: (Exhibit 6) Yes, I have a letter signed by Mark Matulka--I apologize for the mispronunciation--Matulka from Mosaic in opposition. [LB793]

SENATOR CRAWFORD: That's the only letter? [LB793]

TYLER MAHOOD: Well, we did have the letter from Nebraska Association of Service Providers but I entered it as part of an exhibit of a previous testifier. [LB793]

SENATOR CRAWFORD: Okay. Excellent. All right. All right. Thank you. With that, I will end the hearing on LB793. We thank you all for...oh, no, excuse me...okay, Senator, and with...Senator Riepe has waived closing. And so with that, we will end the hearing on LB793. Thank you. [LB793]