[LR143 LR300]

The Committee on Health and Human Services and the Developmental Disabilities Special Investigative Committee met at 9:00 a.m. on Monday, December 9, 2013, in Room 1524 of the State Capitol, Lincoln, Nebraska for the purpose of conducting a public hearing on LR300 and LR143. Health and Human Services Committee senators present: Kathy Campbell, Chairperson; Bob Krist, Vice Chairperson; Sue Crawford, Mike Gloor, and Dan Watermeier. Senators absent: Tanya Cook, and Sara Howard. Developmental Disabilities Special Investigative Committee senators present: Steve Lathrop, Chairperson; John Harms, Vice Chairperson; Kate Bolz; Bob Krist; and Norm Wallman. Senators absent: Colby Coash, and Russ Karpisek.

SENATOR LATHROP: (Recorder malfunction)...late. My name is Steve Lathrop. I chair the Special Investigative Committee. And we have tried today to combine, essentially, three things in one day's worth of hearings, if you will, and I think they are related. We are going to, since I chair the Special Investigative Committee, we're going to start the day and the morning with hearing from Jodi Fenner, and have Jodi talk to us about a number of things we've asked her to come down here and address. That's addressed primarily to the issues related to the Special Investigative Committee. We're also going to, and perhaps at the same time in some sense, take up Senator Campbell's LR300, and we may do that and have that introduced after we hear from Jodi Fenner. That deals with what's generally regarded as a gap between the people who are trying to get DD services and people with behavioral health issues. And then at some point this afternoon probably we'll take up Senator Krist's, I think it's LR143. My thought is that after we have listened to the invited guests, okay, and maybe "invited" guests gives the wrong impression. We're going to try to hear from the people who we want to hear from so that we're educated and we get some answers. And then I know that some of you are family members who came down here to talk to us today about your family's circumstance. And so what we'll try to do, at the end of the day or after we've had the invited guests testify, is sort of open the mike up so that people have an opportunity to come up, share their account, share their concerns with the committee. This is a joint committee. You'll see an awful lot of people here and we'll have everybody introduce themselves in a moment. This is a joint committee or a joint hearing with the Special Investigative Committee and the Health Committee, which is chaired by Senator Campbell. I will sort of have Jodi come up and then that will be sort of where I turn it over to Senator Campbell and ultimately to Senator Krist, if that works. And I guess that's the way we'll proceed. And maybe we can start by having everybody introduce themselves, beginning with Senator Watermeier.

SENATOR WATERMEIER: Dan Watermeier from District 1, which is southeast Nebraska.

SENATOR BOLZ: Senator Kate Bolz. I represent south-central Lincoln in District 29.

SENATOR KRIST: Bob Krist, District 10, northwest Omaha, Bennington, and unincorporated parts of Douglas County.

SENATOR GLOOR: Mike Gloor, District 35, which is Grand Island.

SENATOR HARMS: John Harms, 48th District, which is Scotts Bluff County.

SENATOR LATHROP: And I'm Steve Lathrop, District 12, which is Ralston and Millard in the Douglas County area.

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

MICHELLE CHAFFEE: I'm Michelle Chaffee. I serve as legal counsel to the Health and Human Services Committee.

SENATOR WALLMAN: I'm Senator Wallman, District 30. I have Mosaic and BSDC in my district.

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

BRENNEN MILLER: I'm Brennen Miller. I'm committee clerk.

SENATOR LATHROP: Okay. With that, I think we'll start with Jodi Fenner.

JODI FENNER: (Exhibit 1) Good morning, Senator Campbell, Senator Lathrop, and members of the Health and Human Services Committee, and the Developmental Disabilities Special Investigative Committee. My name is Jodi Fenner, J-o-d-i F-e-n-n-e-r. I am the director of the Division of Developmental Disabilities. I was asked to present information to the committee today on the status of BSDC and the Department of Justice settlement agreement; an update on the Bridges Program; an update on the LB195 funding and the cost to serve individuals on the waiting list or the Registry of Needs; an update on the implementation of rate methodology and the Objective Assessment Process, funded effective July 2014; an update on community-based services; and information relevant to LR300. The BSDC DOJ status: With regard to BSDC, the independent expert's team performed their last on-site survey the week of May 20, 2013. The results of that survey were received by the division and shared with these committees on September 27, 2013. Subsequent to the last survey, the Department of Justice indicated its agreement to reduce the independent expert's on-site monitoring to only one survey for the 2013-14 fiscal year. That survey is scheduled for the week of April 7, 2014. Efforts at BSDC and in the community related to the settlement agreement continue to occur, with an emphasis on the following: upgrades to the electronic medical record at BSDC; implementation of additional components of the Therap case management system at BSDC and in the community; continued enhancements to our investigation and quality assurance processes at BSDC and in the community; continued enhancements to service oversight in the community, including additional service coordinator training and monitoring revisions. In addition to obtaining and maintaining full certification for BSDC, the division has also moved the Bridges Program to its new location and obtained full certification for the program, allowing the program to access federal funds for the first time since its inception. The residents now live in three rural community-based homes in Hastings and attend day vocational services in Grand Island. They volunteer, work, and recreate in their local communities with the support of qualified, trained staff who provide proper habilitation and ensure their safety and security needs are met. The program has experienced overwhelming success and is an integral part of the division's array of services for people with significant behavioral challenges. A pamphlet from the Bridges open house is being provided to you in your packets today. LB195 funding and estimated cost to fund the registry: With regard to the Registry of Needs, the division has worked diligently over the past year to move the registry information into a new database. This will allow the division to better collect and analyze the needs for people on the registry to provide for better long-term planning. This change also allows for added transparency. Now individuals may contact our central telephone number and staff can determine quickly where an individual is on the registry, whereas previously this information was not available. The division received $1.9 million for fiscal year 2014 and $3.9 million for fiscal year 2015, pursuant to LB195, to provide funding to individuals on the Registry of Needs for this biennial budget period. The division has extended offers to 150 individuals. To date, 32 have accepted offers and only 5 have declined their offers. The remainder of the offers are still in process of consideration. Many individuals are also working with disability service specialists to provide necessary documentation for eligibility purposes. At this time, it is premature to estimate the cost of services for the current offers. Based on historical data, the division believes it will be able to fund new services for at least 200 people through June 30, 2015. With regard to the Registry of Needs, the current database indicates the following. There are 1,787 total individuals whose requested dates of need are prior to November 30, 2013. This is up 12 individuals from 1,775 on January 18, 2013. Of these individuals, 574 are receiving some level of habilitation service from DHHS and 443 were previously offered services, for a total of 1,017 people, 57 percent, who are either receiving partial services or who have been offered services in the past. The estimated cost to fund services to all individuals whose dates of need are on or before November 30, 2013, is $47 million. This is up from an estimated cost of $38.5 million, primarily due to an increase in the current average cost of DD services. Forgive me, I've been traveling all weekend; I'm losing my voice a bit. Of all the people on the Registry of Needs with requested dates of needs going through 2025, there are 2,124 total individuals. This is actually down 83 individuals from 2,207 on January 28, 2013. Of these individuals, 609 are receiving some level of habilitation services from DHHS and 505 were previously offered services, for a total of 1,114 people, 52 percent, who are either receiving partial services or have been offered services in the past. The estimated cost to fund all services to all individuals on the registry is $56 million. A copy of the Registry of Needs data summary as of November 30, 2013, is also included in your packets. Rate methodology: With regard to full implementation of rate methodology and the Objective Assessment Process which the Legislature funded effective July 1, 2014, the division has the following implementation activities in process. We've performed an analysis of the individual impact of the OAP on each individual and summarized that information by provider in March 2013. This analysis predicted the impact on each provider, with only five providers expecting any reduction in income. Based on this data, the division has been collaborating with providers to proactively review individual assessments, with priority being given to the five providers experiencing reductions and then for individuals who are projected to experience more than a 5 percent to 10 percent change in their individualized budgets. Our disability service specialists have been performing updated assessments where necessary. After fully auditing the assessment scores and budget projections, the division intends to send written notice in January 2014 to all individuals in services that detail how the rate methodology/OAP changes will impact them. The division continues to work with DHHS Information Systems and Technology staff to incorporate the necessary changes to our systems to accommodate the new rate methodology structures. The division is also working with our Therap case management software vendor to incorporate these changes into our electronic billing system which is also underway. The division fully expects to be ready to implement rate methodology and the OAP on July 1, 2014. With regard to community-based services, the division began preparing an annual update in 2010. The next update will cover the 2013 calendar year and should be ready in late January 2014. Since the last update, a few highlights that you might be interested in are: The Legislature has dedicated significant new funding to community-based services over the past several years. Not only does every Nebraska graduate with developmental disabilities have access to day vocational and habilitation services, but the division has also received significant funding to address individuals on the Registry of Needs. From 2008 through 2015, the state-funded portion of the DD aid budget has increased from $64 million to $126 million, for an increase of over 80 percent. A summary of the DD historical expenditures by fiscal year is included in your packet. The division has continued to recruit new specialized providers and encourage existing providers to expand their service array and geographic coverage. Currently, there are 37 specialized providers certified to provide services. This is up from 35 in 2012 and 25 in 2009. The purpose of this effort is to ensure that people across Nebraska have access to adequate quality services and do not have to leave their local communities to obtain the services that they need. The division has continued to implement its electronic case management system at BSDC and in the community. The division's expansion of service array options and emphasis on integrated employment and recreational service supports has resulted in positive changes for people through Nebraska. A copy of our "2013 Service Coordination Survey of Integrated Activities" is included in your packets. With the additional service coordinators funded over the past several years, the division has been able to reduce caseloads so that all service coordinators have a maximum caseload of 28 individuals, and coordinators with targeted caseloads, who support individuals with enhanced needs, have fewer than 20 individuals on their caseloads. The division has continued to evaluate and expand its technical assistance efforts. In addition to the existing Team Behavioral Consultation services, we've also began providing Targeted Behavioral Assessments and support consultations, targeted medical/clinical and behavioral reviews and consultations, developed health supports curriculum that is available for all providers to utilize, and have been collaborating with various entities to provide community education related to developmental disability services. Based upon our internal quality assurance data and our annual review of the Team Behavioral Consultation data, the division has identified and collaborated with OMNI Behavioral Health, our TBC contractor, to provide five different areas of training across Nebraska to address targeted areas of need. The division is also preparing to hold our 2014 statewide DD conference, which will provide training to state staff, providers, families, and individuals, and community members from nationally recognized professionals in the industry. Announcements for these two activities are included in your packets for review as well. Finally, the division is in the midst of our state plan process to prepare for renewal of our adult comprehensive waiver in 2015. We've expanded our community outreach from the traditional 5 urban settings to 22 community forums throughout Nebraska. We've also expanded our efforts to include all individuals on the registry and not just those that are currently in services. In addition to our community forums, the division will send surveys to individuals, providers, and service coordinators to collect information that will help us develop our next comprehensive plan that will carry through 2020. With regard to LR300, relating to people with both developmental disabilities and co-occurring mental illness, division-funded developmental disability services are available to individuals with co-occurring mental illness. In fact, over 70 percent of the residents of the Beatrice State Developmental Center have a co-occurring mental illness, as does a large percentage of the individuals in community-based services. We have collaborated with the Division of Behavioral Health and successfully transitioned individuals with co-occurring conditions into the community from BSDC, the regional behavioral health facilities, and from the correctional system. While DD services are habilitative in nature, providing teaching, training, and maintaining skills, and are not medical, individuals in our services can utilize Medicaid or the behavioral health system to obtain medically necessary behavioral health services. We require behavioral support and safety plans for individuals that need them, and we also provide Team Behavioral Consultation services and Targeted Behavioral Assessment services where needed.

The division has also developed a Behavioral Risk Service for individuals with significant behavioral needs, and almost all of the individuals that receive those services have a co-occurring mental illness. There have only been a few cases where the division has not been able to serve an individual found eligible for developmental disability services in the community. Those cases have primarily involved individuals whose professional evaluations indicate a need for a locked facility or other aversive treatments that are not allowable in a community-based developmental disability services setting. In those instances, the DD Division has offered its professional resources, including TBC consultations and transition planning, to work with the Division of Behavioral Health towards transition planning in the event that these individuals become amenable to a community setting. As indicated in the department's 2012 LB1160 report, I think that was an LR1160 report, the Division of Behavioral Health also provides services to over 300 individuals who are documented as eligible for developmental disability services. LR300 also references the Affordable Care Act. While it is clear that the Affordable Care Act will result in expanded coverage for behavioral health services for people with developmental disabilities, it does not address the limited access to qualified professionals in the medical community willing and able to provide those services for people with co-occurring disabilities. Serving individuals with co-occurring disabilities can be quite difficult, and many medical professionals are simply not equipped to provide those services. The department is working towards addressing this issue in a couple of ways. We provide interdivisional consultations: DD psychiatrists and psychologists have provided case reviews and consultations for individuals served by the regional centers and the veterans' homes, and their clinicians are available to provide similar support to the DD division if needed. We provide consultative services through our DD Medical Unit and Team Behavioral Consultation resources to medical and clinical professionals in the community who are struggling with providing services to individuals with developmental disabilities. BSDC continues to offer internships, clinical rotations, and practica opportunities for students through affiliations with Nebraska's universities, colleges, and technical schools. In the past few years, several interns from the Behavioral Support Team have gone on to employment with the intended goal of serving people with co-occurring conditions. Both the Division of Developmental Disabilities and the Division of Behavioral Health have provided training opportunities for medical and clinical professionals related to supporting people with co-occurring disabilities. Several of the workshops planned for 2014 that I referenced earlier are targeted at people with significant behavioral challenges, which often experience co-occurring disabilities. I understand that Director Scot Adams will offer additional testimony on this issue. He will address the other issues referenced in the resolution. Since his testimony may address many of your questions related to LR300, I will remain and be available for questions then as well. Thank you for the opportunity to testify today and for your continued support of people with developmental disabilities in Nebraska. [LR300]

SENATOR LATHROP: Thank you for your prepared remarks, Jodi. We'll see if there's any questions or concerns, thoughts. Senator Crawford. [LR300]

SENATOR CRAWFORD: Thank you, Senator Lathrop. And thank you for being here today. [LR300]

JODI FENNER: Thank you. [LR300]

SENATOR CRAWFORD: I just wondered if you could provide some insight into what happens between 150 individuals getting an offer and then only 32 accepting. What are some of the barriers that happen between receiving the offer and being accepted? [LR300]

JODI FENNER: Yeah. There's a couple of things there. In 2010, we changed the eligibility processes in central office. We made them electronic so that we never lose a piece of paper. Everything related to the eligibility process is scanned into an electronic document system. That ensures that we can maintain eligibility documentation for Medicaid purposes, because we are audited on that. So for a group of individuals who were offered services, whose eligibility was determined prior to 2010, takes a little extra work to make sure that we have the proper documentation in order to substantiate that Medicaid eligibility and the DD eligibility. Also, some individuals aren't always expecting that offer when it comes. Under the prior system, they didn't necessarily know where they were on the registry. [LR300]

SENATOR CRAWFORD: Uh-huh. [LR300]

JODI FENNER: They just knew their date of need, which didn't exactly tell you where--like, are you number 10 or are you number 2010. And so some people, it takes a little time for them to look at what are the options, is this something that I want to do. It's also the holidays. Obviously, we started making these offers and the offers ended up going out in about August. We waited until we could hire the service coordinators that were intended to serve this population. And so sometimes it just takes families a little bit of time. Families of people with developmental disabilities have a lot on their plate and we have to be patient with that, that process. [LR300]

SENATOR CRAWFORD: Thank you. [LR300]

SENATOR LATHROP: Senator Campbell. [LR300]

SENATOR CAMPBELL: Thank you, Senator Lathrop. Director Fenner, I'm going to ask this question probably of Director Adams also. [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR CAMPBELL: It seems to me that what we struggle with is when...and I think you all do a great job with the people who meet the definitions and as you try to work with them. Where we seem to be having difficulty is--and it's not a...perhaps it's not a great number--is people who don't quite fit in the definition and don't quite fit in the other definition. I mean it's...and it seems like they then cannot access services. And what do we need to do as a state to try to begin addressing that pool of individuals? [LR300]

JODI FENNER: If I knew the answer to that, I would have your job, Senator Campbell. (Laughter) But, no, with all due respect, you're right. There are a group of individuals who don't meet the definition of developmental disability but do have intellectual impairments. Sometimes that relates to something that happened after the developmental phase, at age 22 or older. Sometimes it can be the result of long-term untreated mental illness or a physical illness as well. Realistically, the developmental disability definition is fairly targeted. It's consistent with what CMS and other states are using for the Division of Developmental Disability and the clinical standards. As far as what to do for the rest of the population, I really do wish I knew that answer. I think that the expanded behavioral health coverage available in the ACA, maybe that is part of the answer. I'm just not sure. I think the other struggle is, on top of individuals seeing challenges with the economy in the last decade, we're also seeing families who face other external challenges who may not be able to support those people like maybe they did a decade ago or two decades ago. And so that can be a challenge as well. [LR300]

SENATOR CAMPBELL: Or the parents get to a point which they feel that they are aging... [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR CAMPBELL: ...and they want to ensure that their son or daughter have services that are available when they cannot care for them, at least that's some of the examples. [LR300]

JODI FENNER: Well, and I think it's more than just looking at the Health and Human Services System. I think you have to look at the educational system, the vocational rehabilitation system. For individuals who can and are able, are we giving them and equipping them to work and live in the community? And that starts before age 22. That starts at a very young age. [LR300]

SENATOR CAMPBELL: This discussion about the aging parents... [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR CAMPBELL: ...who have sons and daughters surfaced when Senator Gloor and I were working on LR22 and was, in fact, a pretty prolonged discussion at one of the last meetings of the work group because we're worried about how, how do we begin to help those parents aging, what facilities do they need along with their son or daughter. So I bring that up because we have identified that as an issue that we need to address. [LR300]

JODI FENNER: One of the great things we've done with DD services, though, is we've really made them flexible when we did the 2010 revisions. And so we actually can support individuals in their family...individuals in their family home. And sometimes that's a good transition to supporting an individual outside the family home. You can develop that relationship with a provider if you're living with an aging parent, instead of having to move suddenly out of the family home. And we have found that to be very effective. It's...obviously, there is no perfect solution, but we do think that some of the changes we made in 2010 have made that a lot easier for people with developmental disabilities. [LR300]

SENATOR CAMPBELL: Thank you, Director. [LR300]

SENATOR LATHROP: I have a few questions for you. [LR300]

JODI FENNER: Yeah. [LR300]

SENATOR LATHROP: And I think I'll go through the topics, the questions that I have in the topics that you provided, beginning with the BSDC DOJ status. [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR LATHROP: In your remarks, you suggest that they...the expert team performed their last on-site evaluation May 20 of 2013. Actually, during that evaluation, they did not go to BSDC or do an assessment there, but it was in the community. [LR300]

JODI FENNER: They did both, sir. [LR300]

SENATOR LATHROP: I read that report and it suggested that their focus was on the community. [LR300]

JODI FENNER: Their focus was on the community. They spent two days at BSDC and three in the community. [LR300]

SENATOR LATHROP: Okay. [LR300]

JODI FENNER: And the team kind of splits up. There's five of them and they have their own... [LR300]

SENATOR LATHROP: You read the report,... [LR300]

JODI FENNER: Yeah. [LR300]

SENATOR LATHROP: ...however,... [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR LATHROP: ...and the report was focused on the community-based services. [LR300]

JODI FENNER: I would agree. [LR300]

SENATOR LATHROP: Would you agree with that much? [LR300]

JODI FENNER: I would agree with that. [LR300]

SENATOR LATHROP: Okay. Let me ask about BSDC,... [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR LATHROP: ...because some of the concerns that DOJ had when they came in to BSDC, 2007,... [LR300]

JODI FENNER: Seven. [LR300]

SENATOR LATHROP: ...whenever they were here that many years ago, one of them was overtime. Can you share with us how we're doing with overtime? That clearly, from the DOJ's point of view, was regarded as sort of a central problem to the overall problems at BSDC. [LR300]

JODI FENNER: Yeah. [LR300]

SENATOR LATHROP: Where are we at relative to the problems we had when you entered into the settlement? [LR300]

JODI FENNER: We're certainly far better off than we were in 2007, Senator. We're not where we'd like to be. Recruitment is always a challenge. We are working with the Department of Administrative Services on additional recruitments and retention ideas and measures. We're constantly looking at that. But we do have overtime. It's certainly not anywhere where it was in '07. But again, our goal would be to have overtime below 10 percent to 12 percent consistently, and we're several percentage points above that right now. Obviously, the holidays play into that. Our biggest challenge with regard to recruitment and retention is that second-shift schedule. First and third shift are almost completely full as far as staffing, and so that is good news, but second shift continues to be a challenge. [LR300]

SENATOR LATHROP: Can you tell us, though, where we're at relative to a year ago? Are we experiencing more overtime, less overtime? Can you tell us what the trend lines look like? [LR300]

JODI FENNER: Just a hair less, but it's not much less. [LR300]

SENATOR LATHROP: Okay. [LR300]

JODI FENNER: We're holding steady, unfortunately. We've tried a couple of measures to improve that. We've had small intermittent successes with that and so we continue to look at ways to...it's very difficult in a small community to recruit and retain employees. And my fear is we may be at our maximum capacity as far as employee...our employee rolls. Yeah. [LR300]

SENATOR LATHROP: Has CMS done a survey of BSDC in the last year? [LR300]

JODI FENNER: Through their subcontract with Public Health, CMS generally relays that duty to the local public health officials and Public Health has been on campus at least five times a year because we do a survey. [LR300]

SENATOR LATHROP: Can you tell us generally what their findings are in the last year? [LR300]

JODI FENNER: We haven't had any issues out of condition, any major citations. Generally, our citations have been relatively small. I think there was a medication error on one. There was a...they're pretty minor, something to do with a habilitation component. We can get you copies... [LR300]

SENATOR LATHROP: But nothing that would suggest a slipping of the quality... [LR300]

JODI FENNER: No, absolutely not. [LR300]

SENATOR LATHROP: ...of care at BSDC. [LR300]

JODI FENNER: Absolutely not. Generally, minor issues that are readily corrected and often corrected before they've even shown up. [LR300]

SENATOR LATHROP: Okay. And I want to go back then to the DOJ,... [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR LATHROP: ...because we entered into a settlement, and I think that was in 2009, or four and a half years ago. So it was longer than that. [LR300]

JODI FENNER: Yeah. [LR300]

SENATOR LATHROP: What year was it? [LR300]

JODI FENNER: I believe it was '08. [LR300]

SENATOR LATHROP: '08. [LR300]

JODI FENNER: The summer of '08. [LR300]

SENATOR LATHROP: And it's been four and a half years... [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR LATHROP: ...since we entered into the settlement. And the DOJ, just for people not familiar, we entered...they came in and made certain findings about BSDC and the community-based care, and we entered into a settlement where we promised to do a number of things. [LR300]

JODI FENNER: The DOJ findings letter only related to BSDC. They actually weren't in the community at that time at all. [LR300]

SENATOR LATHROP: Well, they certainly expressed concerns about, and the settlement was directed at, how to make transitions... [LR300]

JODI FENNER: Yeah. [LR300]

SENATOR LATHROP: ...to the community. And as a consequence, they've been following how people are doing transitioning from BSDC into the community. [LR300]

JODI FENNER: Yes. [LR300]

SENATOR LATHROP: Okay. And in fact the report that was just authored by the independent expert addresses many of the issues people are experiencing as they transition from BSDC to the community. [LR300]

JODI FENNER: That's correct. [LR300]

SENATOR LATHROP: I guess the first concern I have, and as I read the report, it looked to me like some of it's paperwork stuff, right? Somebody didn't document something, not necessarily suggestive of poor care, but sometimes it was a documentation issue. Would that be true? [LR300]

JODI FENNER: That's correct. Traditionally standard practices, clinical and support areas document by exception. When you go in a nursing home, they don't document everything a person does. They document when something doesn't happen. [LR300]

SENATOR LATHROP: Right. [LR300]

JODI FENNER: The DOJ expects everything to be documented affirmatively, so it is a different standard. [LR300]

SENATOR LATHROP: So there were some documentation issues. [LR300]

JODI FENNER: Yes. [LR300]

SENATOR LATHROP: But as I read it, there are concerns that they continue to express four and a half years later about the quality of care. [LR300]

JODI FENNER: There are some areas that they would still like to see changes made. [LR300]

SENATOR LATHROP: And they relate to the quality of care the people who left BSDC are receiving in their community-based placements. Would that be true? [LR300]

JODI FENNER: Some of those do, yes. [LR300]

SENATOR LATHROP: Jodi, I want to ask you just sort of the big-picture question. It's been four and a half years since that settlement agreement was entered into. I know that we've had testimony where the expectation was that we'd meet most of those criteria within a year and a half. Tell us how come we're not there and when do you expect that to happen. [LR300]

JODI FENNER: Yeah. Well, I believe we are meeting all the expectations documented in the agreement. I will say that since we entered into our agreement in '08, DOJ has entered into several agreements with other states that really focus on community-based services and what they expect to happen there, which is, quite frankly, not in our agreement. We're trying to meet some of those expectations because they're good for the people we support. But having, for example, having the physical nutritional management comprehensive supports in the community, where in many communities we don't even have a speech pathologist, is not going to be possible. They essentially would like to see the same level of medical/clinical support that you have at BSDC occur in the community. Well, when you live in the community, you don't necessarily have the option of going to a physical therapist or a water therapist or a recreational therapist three to four times a week. In the same breath, they... [LR300]

SENATOR LATHROP: You know, as I've read...not to interrupt,... [LR300]

JODI FENNER: Yeah. [LR300]

SENATOR LATHROP: ...but as I've read the report,... [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR LATHROP: ...it sounds today like you're saying we're never going to meet these things that they're asking us for because, you know, you can't do that out in North Platte like you can if you were in Beatrice or you were in Omaha or you were in Lincoln. But the reason we are still trying to comply and the reason they still come back here is because we haven't satisfied the terms of the settlement. [LR300]

JODI FENNER: I think that would be a...I think we would disagree with that. I can say, Senator, I believe that if they don't dismiss when they come back this next time, I think that we needed to bring that up with a judge. I think that the DOJ expectations in some of the recommendations exceed the letter and terms of our agreements. Again, we're trying to make them happy, in the spirit of cooperation, but we didn't enter into the same agreement that Georgia and Massachusetts did. And to hold us... [LR300]

SENATOR LATHROP: They... [LR300]

JODI FENNER: ...to that same legal standard isn't necessarily appropriate. [LR300]

SENATOR LATHROP: Okay. And I don't want to turn...or take up all this time to argue with you about it. But as I read it, the report by the independent investigator, they would put a provision or a paragraph from the settlement, and then talk about how we're doing. In some cases they would say we're doing well and we can taper back off or back off some of the oversight. In other areas, they expressed a good deal of concern. And those aren't terms from Georgia. They're terms from our settlement, are they not? [LR300]

JODI FENNER: Well, again, it's their interpretation of the language in the settlement agreement. And things that come out of that interpretation are things like having some of the comprehensive clinical supports. They also want everybody in the community to work more than 20 hours a week, and we all know that isn't going to happen. And that is one of the standards that they're now trying to reach. [LR300]

SENATOR LATHROP: But, I get that, except that some of those things are basic care, psychiatric services and the assessments. [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR LATHROP: The medications these folks are receiving as they're being cared for, they have concerns about that, and the documentation of the diagnosis and the care, and the reason for the care, and the drugs they're receiving. And that's not from a Georgia provision; that's from ours. [LR300]

JODI FENNER: And those are things that are outside of my control. We work very hard with the local clinicians and psychiatrists, but individuals who live in the community get to choose their doctors. The division doesn't get to do that. And we don't get to tell...I don't get to tell those doctors what to do. When the Department of Justice or when our staff find that they're not necessarily treating someone properly, we report that to Public Health for review. But I can't tell them how to document and diagnose. [LR300]

SENATOR LATHROP: At some point the settlement agreement will be satisfied, and that's not been done yet,... [LR300]

JODI FENNER: Well,... [LR300]

SENATOR LATHROP: ...and dismissed at that point. [LR300]

JODI FENNER: ...we're in a year of a sustainability review, so I would...I would not necessarily agree with that. [LR300]

SENATOR LATHROP: At some point the case will be dismissed... [LR300]

JODI FENNER: Yes. [LR300]

SENATOR LATHROP: ...because we've satisfied the terms of the settlement. Yes? [LR300]

JODI FENNER: Yes. Well, they... [LR300]

SENATOR LATHROP: And that hasn't happened. [LR300]

JODI FENNER: ...they expect a year of sustainability after the settle...after they reach compliance, and that's the period that we're in. [LR300]

SENATOR LATHROP: Okay. Does the DOJ think we've reached compliance? [LR300]

JODI FENNER: They won't put it in writing, but in our conversations they seem to be very happy where we are as long as we sustain the progress that we have in place. [LR300]

SENATOR LATHROP: When do you anticipate that you will be in compliance and the lawsuit filed by the Department of Justice will be dismissed? [LR300]

JODI FENNER: I believe we're in compliance and I believe that our sustainability review will show that all of the efforts that are underway will continue to either be completed or in progress when they come this summer. And I expect them to dismiss the case at that time. [LR300]

SENATOR LATHROP: So what date? [LR300]

JODI FENNER: Depending upon when the report comes. Again, our review is in April. I would expect that to occur sometime this summer. [LR300]

SENATOR LATHROP: Okay. In the Registry of Needs, this is commonly referred to as the waiting list? [LR300]

JODI FENNER: It is. [LR300]

SENATOR LATHROP: And you said there are...your testimony was there's 1,787 individuals who are on the registry. [LR300]

JODI FENNER: Yes. [LR300]

SENATOR LATHROP: You in the past year have gone through and tried to I'll say clean up or... [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR LATHROP: ...look into further. Can you tell us generally what you've done to try to clean up the waiting list? [LR300]

JODI FENNER: Certainly. We moved all the data from the N-FOCUS system into a database, and then we went through and we did an audit of almost every single person on there. There were individuals on the registry who were waiting for day services who were entitled graduates, for example. And so technically, they are never waiting for services because you guarantee those services. But there are adults there who are not and so we pulled those apart. So, for example, you'll see there are only 203 individuals who are waiting for...actually waiting for day services on the registry. Those are people who are not Nebraska graduates, typically individuals who are older, who graduated subsequent to 1996, or who moved into the state. So we basically went through and did various comparisons. For example, there were people on the registry who actually were on the adult comprehensive waiver, which means they're getting all the services that were there but at some point in time their name just didn't get removed from the registry.

We spent about six months going through the data and cleaning it up. [LR300]

SENATOR LATHROP: Okay. And I know that at one point we had an appropriation, it was probably three years ago,... [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR LATHROP: ...for two years. I think it was $5 million and $10 million. [LR300]

JODI FENNER: Yes. [LR300]

SENATOR LATHROP: And when...I think the waiting list was about 2,000 then,... [LR300]

JODI FENNER: Yes. [LR300]

SENATOR LATHROP: ...you offered services to a lot of people... [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR LATHROP: ...and realized that they were on the waiting list but not interested in services... [LR300]

JODI FENNER: Yes. [LR300]

SENATOR LATHROP: ...because perhaps the person died, moved out of the state, or they just decided to stay at home with Mom and Dad and not take services. Is that right? [LR300]

JODI FENNER: That's correct. [LR300]

SENATOR LATHROP: So we had the gross number, which was 2,000, and sort of a net number, which is the people after we identify those who really don't want services. They're just on there because they think they need to be. [LR300]

JODI FENNER: Well, I wouldn't say they don't want services. I would say they weren't prepared to accept services at the time... [LR300]

SENATOR LATHROP: Okay. [LR300]

JODI FENNER: ...we made the offer. [LR300]

SENATOR LATHROP: Have you distilled the list in this process you've just described so that the 1,700 people that you've testified to, 1,787 individuals that are waiting, are actually waiting for services and want them? [LR300]

JODI FENNER: Well, I haven't spoke to each of them individually, so I don't know if I offered them all services today if they would accept. What we do know is they have requested to be on the registry, so I presume they want DD services to... [LR300]

SENATOR LATHROP: But our experience was, if I can, our experience the last time we tried to offer them services is many people were on the list in anticipation of wanting services that they didn't actually need at the time. [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR LATHROP: And when we offered services, a number, a good number, a significant number of them said, no, thanks. [LR300]

JODI FENNER: And that's why I provided that information to you. Four hundred and forty-three of those individuals declined services when offered before. [LR300]

SENATOR LATHROP: Right. But the 1,787... [LR300]

JODI FENNER: But I can't take them off the registry. [LR300]

SENATOR LATHROP: We don't know how many of those people will decline services when and if it's ever offered to them. [LR300]

JODI FENNER: We don't know. [LR300]

SENATOR LATHROP: But your estimate on the cost of providing services to those individuals assumes that they will all take advantage or accept. [LR300]

JODI FENNER: Yes, it does. [LR300]

SENATOR LATHROP: Okay. [LR300]

SENATOR CAMPBELL: May I ask a follow-up question, Senator Lathrop? [LR300]

SENATOR LATHROP: Oh sure, Senator Campbell. [LR300]

SENATOR CAMPBELL: While Senator Lathrop is looking at the figures, on the chart that we had in our packet, thank you, on this chart, Director Fenner, so how many times...but it says "Individuals Previously Offered Services." How many times would that be that we would go back and they'd say, well, we're not quite ready, or, we'll need day services but it...? So it's like they were offered, but how many times where they offered? [LR300]

JODI FENNER: A couple of them may have been offered multiple times, but 443 individuals were offered services. A couple of them, under the old registry, it was done by service codes, which isn't really consistent with what our Medicaid waivers require. You really should be offered to be on a waiver program, so we've changed that a little bit so we won't have those duplicate offers. But today, if an individual declined services, they can be put back on the registry as long as their date of need is after today, and that's typically what happens. [LR300]

SENATOR CAMPBELL: Oh, okay. So they would...those numbers would go back on the list to come up in the queue again? [LR300]

JODI FENNER: They could, yes. [LR300]

SENATOR CAMPBELL: Okay. So would they have to wait for their queue for those to come back? [LR300]

JODI FENNER: Yes. [LR300]

SENATOR CAMPBELL: Okay. So it's like you work your way up, depending on the service that you're looking for. Would that be accurate? [LR300]

JODI FENNER: Well, we offer based on date of need. And so when the date of need comes up, then they're offered. And then whatever service they're eligible for is what they get. [LR300]

SENATOR CAMPBELL: Okay. [LR300]

JODI FENNER: We don't do a date of need by service. We do...there's one registry. [LR300]

SENATOR CAMPBELL: Oh, okay. Got it. [LR300]

JODI FENNER: Yeah. [LR300]

SENATOR CAMPBELL: So then they come back up again. [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR CAMPBELL: But probably not very many people would turn that down multiple times. Would that be accurate? That that large number...that that number of people who are offered services,... [LR300]

JODI FENNER: Yeah. [LR300]

SENATOR CAMPBELL: ...they don't perpetually turn them down, is my point. [LR300]

JODI FENNER: No, not typically. Typically, there's something going on in someone's life. We spoke to a family. We've been doing these public forums. We spoke to a family a few weeks ago and when they got their offer in 2010 their son was in the hospital with brain cancer. DD services were the least of their worries, and so they just rejected the offer. And now they're actually probably going to get an offer this year and they're ready. I mean they are at a point in their life where they really...they are aging parents and they need some additional support. We are also experiencing, I believe, fewer rejections because we've changed the services to better meet individual's need. There used to be a concept of if you wanted DD residential services you have to move into a group home. Well, if you live on a ranch in Gering, Nebraska, you don't want to move into a group home. You want to be supported on the ranch so you can live with your family, just like the rest of your family does. And so because of the way we've allowed people to mix the nonspecialized and specialized services, that does make that a lot more amenable for people to live in their home, in their community, if that's what they choose. And so we're seeing fewer rejections. Last week we were in western Nebraska and that's what we heard a lot about. Parents: You mean I can actually...my son can go to work and then get his residential supports in-home? And that was a big part of many of the conversations we're having. [LR300]

SENATOR CAMPBELL: Can I follow up, Senator Lathrop? [LR300]

SENATOR LATHROP: Sure. [LR300]

SENATOR CAMPBELL: Director Fenner, and I'm going to take a little different topic. The last time that this group was together and convened, we spent a great amount of time talking about Mosaic and the positions that they had available in their facilities. What percentage of capacity are they at, at this point? [LR300]

JODI FENNER: I think they may have had a death a little bit...a month ago, and so...but I believe they're full, other than that. And that may actually be full. They've been full pretty consistently. Obviously, people come and go for various reasons, but... [LR300]

SENATOR CAMPBELL: Sure. Sure. But all the facilities that they have available really are almost at capacity. One would say that. [LR300]

JODI FENNER: I believe they're at full capacity. [LR300]

SENATOR CAMPBELL: Do we need more facilities like that? [LR300]

JODI FENNER: Not from what we're hearing from families. Families don't want to go to a facility. They want to be supported in their community. People outside of Omaha don't want to have to come to Omaha to get medical support services. [LR300]

SENATOR CAMPBELL: Sure. Okay. [LR300]

JODI FENNER: So... [LR300]

SENATOR CAMPBELL: So you think at this point, that problem that we spent a lot of time on at this last hearing, we've really kind of evened out and we have the right composition of services there. [LR300]

JODI FENNER: We address the immediate need at the time. What we still are challenged with is for community providers to have access to nurses and clinicians who will provide supports to people with disabilities. We talked about physical nutritional management. But standard nursing supports, I don't think there's a provider in this room who would tell you if they needed a nurse tomorrow they could go hire one that would meet their needs. And that's a challenge and that's one of the things the Department of Justice has said, is for people with developmental disabilities moving into the community, they need those comprehensive supports: access to psychiatrists, psychologist, other clinicians, clinical services. And they're not always readily available and it's very hard to meet an individual's preference for being with...being near family and in their local community but also having all of those professional needs met. So we do work with the university on recruitment and the providers have done a lot of outreach with various clinicians, but that is a challenge. Facilities are covered; supports maybe not so much. [LR300]

SENATOR CAMPBELL: In the communities. [LR300]

JODI FENNER: Yes. [LR300]

SENATOR CAMPBELL: Thank you, Director. [LR300]

SENATOR LATHROP: Senator Krist. [LR300]

SENATOR KRIST: I'm not sure where to start and I guess this will wrap into this afternoon and may be more appropriate there. But to dovetail on to Senator Campbell's concerns with aging parents and their concerns, you're told from a very young age when you have a child with DD that you need to get on the registry. So you do that. And then your number comes up and it's not what you need at the time. And then your number comes up and it's not what you need at the time. It seems to me that when you say they've declined services, you're speaking more in terms of the category of LB195 in terms of residential services along with the services that might become available within the community. So it's kind of a, not to use that word, but mosaic of treating the individual in terms of their needs when they come up. [LR300]

JODI FENNER: Well, I would say, based upon the old system where you got on the registry for a specific service, I would say you're absolutely correct, and that's why we changed that system. First of all, that isn't really consistent with our Medicaid requirements. You should be on the waiting list for a waiver. Once you get on that waiver program, whether it's the children's waiver or the adult comprehensive waiver, then you're entitled to the array of services in the DD system as you age and your needs change. That wasn't necessarily true prior to 2010. We actually had to make some waiver changes and we've done that. So you're absolutely correct and that's why I respectfully disagreed that...with Senator Lathrop that those individuals, just because they've declined services, doesn't mean we shouldn't expect that they'll decline again, because I don't necessarily think that will be true. I think our system is a little different if you're offered services today. Primarily the reasons some individuals decline is we're not Medicaid eligible and so we don't necessarily want to pay the ability to pay now. When you balance that with the current family needs, that doesn't fit. [LR300]

SENATOR KRIST: Okay. [LR300]

JODI FENNER: But that's really the only main reason we're seeing people decline. [LR300]

SENATOR KRIST: So you're making my point, I guess,... [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR KRIST: ...to some extent. We have changed the way we do business. And yet, on the Medicaid side, we continue to see reductions at the state level on what the state wants to pay for, an example, respite, those out-of-home care situations. It seems to me we're doing this backwards. It seems to me that the transition that we've made in the last few years is a step in the right direction. But when this individual is born without a piece of a chromosome and has a...some kind of disablement or disability or something happens to them during those developmental years, they're not going to change. They're not going to get any better. So why aren't we bundling that person and saying what can we do for you, and moving forward and saying, little--I'm not going to use Andy Campbell, I'm going to use Courtney Krist today--little Courtney Krist was born this way; she will continue to be this way? When you call me and say, do you want to do residential treatment, no, because Bob and Peggy can do what they need to do. Now that doesn't mean I don't want her on that list, because at some point I may not be able to. But all those other things are all part of the process. You made a statement to...I think to Senator Lathrop about that's not...I can't make them do that, that's not in my control. It may be in Behavioral Health's control. It may be someplace else. We still have these silos where we're offering services to individuals. I would contend that throughout the rest of today I will try to support that the individual is the important mechanism to support with the services that the individual needs. And if they present themselves at that time in life or the parents' times in life for needs, we're better serving the community by not necessarily keeping a list of people that we think need things but tracking the individuals and their needs. Go ahead and comment to that, if you want to. [LR300]

JODI FENNER: I think I actually agree with you, Senator. I mean I do think that we have had to change the way we do business. And you used the example of Courtney. And if we came to you and offered you service because you came up on the list, I think the comprehension of what that offer is, is what we're trying to clarify. Maybe you don't want her to go into residential services or you don't need full-time supports. You have an individual budget that she would get if she came into services, but you only use what you need at the time. But it's there so when your needs as a family change and you can't necessarily support her, then you can transition her into other services. But you don't, under the new DD system since 2010, the new waivers, you don't have to change systems for that to occur. And we do provide respite to every individual in DD services if they choose to. That's one of our state plan services if they take service coordination. [LR300]

SENATOR KRIST: And I would contend that most parents that have an issue... [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR KRIST: ...like this don't understand all of those services that are available, and I think we could do a better job of bundling for that individual and looking forward to their growth into adulthood and into old age. So you did great because you're going to make my point for this afternoon. The other question I would ask in terms of Senator Campbell's question was how many times would they turn you down and where would you fall back into the list? Just touch, if you will, on if Courtney is offered a position in a residential setting and we say no, where does she go on that list? [LR300]

JODI FENNER: Well, we never off you a position. We offer you the array of services. So then you, as a family, decide do we want to get supports, so... [LR300]

SENATOR KRIST: Wait. I think that's...understand my question first. She has services. [LR300]

JODI FENNER: Okay. [LR300]

SENATOR KRIST: She's qualified for services but she's on that residential list. [LR300]

JODI FENNER: Yes. [LR300]

SENATOR KRIST: Now she's popped up to the point where again you're going to offer her residential along with the other services and we say no. Now what happens to her on that residential list? [LR300]

JODI FENNER: If she said no, first of all, we would want to reinitiate that conversation because, you're right, a lot of parents don't understand what they're saying no to. So that, you're absolutely right and we realize that that's why we've gone from 5 public forums to 22. But if she did, after that conversation with service coordinators clarifying that you're actually turning away comprehensive services that you can pick and choose how much you need to use right now, then she would change her date of need to the date of that decision, if she wanted to, or she could move that date of need to some date in the future. [LR300]

SENATOR KRIST: And finally, how many actual service providers can provide respite and therapy and other services in one central location? How many service providers do we have like that around the state? [LR300]

JODI FENNER: I'm not sure exactly what you're...I mean... [LR300]

SENATOR KRIST: Well, you talk about the need to service an individual... [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR KRIST: ...on multiple levels. Okay? [LR300]

JODI FENNER: Yes, absolutely. [LR300]

SENATOR KRIST: Part of that might be respite. Part of it might be medical, might be psychological, might be...are there institutions in the state that you can come to one place and actually get those services? And how many of them are there? [LR300]

JODI FENNER: We don't fund any institutions with community-based services, but we do have a lot of providers who have access to various clinical and medical supports. But it really depends upon who that provider is and what their mission is. Not every provider provides all types of support. [LR300]

SENATOR KRIST: So I'll make the point that because of the way we've changed procedures, policies, and implementation, Children's Hospital, that had an all stop, one-stop kind of operation, is no longer in business. And that bothers me because if a family from outstate Nebraska--and this happens, it happened before they closed their doors--would come to Children's Hospital in that respite care environment, they could also be there for two or three days and receive those other treatments, because they're available at Children's. So you talk about providers in the community not being maybe up to speed in Chadron or Scottsbluff or wherever, yet we had a provider that we lost because of policies, procedures, and economics. [LR300]

JODI FENNER: Well, but, sir, I cannot fund facility-based services. And so we've never funded services at Children's Hospital. What we do in DD, though, is if an individual needs to go to the hospital, we will pay their specialized or nonspecialized DD provider to go with them. [LR300]

SENATOR KRIST: Okay. Children's was an outpatient clinic situation where those services were provided. [LR300]

JODI FENNER: But if it's facility-based, I'm prohibited by federal law from funding that service. [LR300]

SENATOR KRIST: So we're not really looking at the needs of the individual. We're looking at the needs of residence-based versus other. And that goes back, I think, to Senator Lathrop's point. We had BSDC and our response to what Justice wanted us to do was contract with Mosaic and build it and they will come. And our first response to that was they're not going to fill up those facilities because they don't want to do that. So once again, we're looking at brick and mortar versus community-based. And I think that there's a different approach where an individual can receive services where they need services, and if that happens to be Children's or the hospital system here in Lincoln, that's where they would receive the services and then go home, because our alternative is what are they getting in Butte? I mean it really is...I think it's a question of servicing the individual. So anyway, thank you. [LR300]

SENATOR LATHROP: Senator Harms has a question for you. [LR300]

SENATOR HARMS: Thank you very much for coming, Jodi. As you know, Jodi, you came into a very difficult setting. We were in the midst of this whole review and investigation of Beatrice. When we...not we, when you finally decided that we were going to go to basically to a community-based program, my concern was, at that very beginning, I don't know whether we can really do this. I don't know whether you can actually bundle the services, almost what Senator Krist was talking about, being able to go deep into rural Nebraska where services are really badly needed, and find the kind of services that a child or a person may need. How many programs or how many people are receiving services deep into rural Nebraska, outside of this urban setting? [LR300]

JODI FENNER: Well, quite a few of them are, Senator. I don't have exact numbers. I wasn't prepared for that. But particularly with behavioral supports, we have the ability to go into any community throughout Nebraska through our Team Behavioral Consultation. So even if there isn't proper or adequate psychology and psychiatric supports in those local communities, our contract with OMNI allows us to basically send specialists out throughout the state to provide those individual teens and families that support. When we get to the medical side of things, things get a bit more challenging. We just don't have an array of doctors and nurses we can send out. We do provide supports through the BSDC medical unit, and we also have two nurses in central office who do frequently case reviews with providers across the state. And then in those cases sometimes we have to reach out to local community providers to see if we can make those connections. I was in...I can't remember the town. Is it Sidney? No, it wasn't Sidney. It was...sorry, I've been all across western Nebraska this last weekend, so my brain is a little mush. But one of the providers, a great example, it's office, it's OHD, it's Region I, Chadron I believe, yes, Chadron, so the provider is here. There's another vacant store here, and then there's a physical therapy office. And then there's our service coordination office right next to it. When we were there a few years ago, we were able to talk to OHD and actually we went into the physical therapy office while we were right there visiting and said, would you consider providing more routine therapies to the individuals if we could share through BSDC what might be helpful? And we find typically when we can make those connections, clinicians even in small-town Nebraska are willing to do that. Sometimes, though, there aren't those things there. So you're right. We...but we can't...we don't have enough medical clinicians to make that happen in every town in Nebraska. We're doing our very best to support people where they live when we can. But I cannot completely make that happen. [LR300]

SENATOR HARMS: It would be much better for us, or at least for me, to have a better understanding about how many individuals we're unable to provide in rural Nebraska that kind of bundle the services that we need, just the very things you were talking about. [LR300]

JODI FENNER: Yeah. [LR300]

SENATOR HARMS: Is there any kind of database available that could help us better understand that we cannot meet all those services? Because, see, I think that comes back then to our responsibility on the legislative side and on the budget side, appropriations side, to start to have this discussion. Are we limited to the people that are closer to urban versus rural Nebraska? And I just was wondering if you have any kind of data or information that would help us better understand the places that we are short, the kinds of services we are short, and the need that we might have, because I think we need to have a better understanding about that. [LR300]

JODI FENNER: Yeah. We have our incident report data, and that's really what we have on DD services, and that's related to incidents with the individuals we support. If somebody experiences medical crisis or in their...or aren't getting the supports they need, those are recorded as incidences and we do keep those in our electronic case management system. And we do review those routinely and oftentimes that's how we decide when we need to send one of the nurses out to do a case review. As far as where medical and clinical providers are, I think Public Health probably has a database of that, but... [LR300]

SENATOR HARMS: But wouldn't you want to know that? [LR300]

JODI FENNER: Well, we do reach out to Public Health when we have an individual who's in need of supports. We oftentimes look at their Web site and say, well, who are the providers in that area that we can help the individual, and the provider contacted to pull in that support. But as far as doing a comprehensive coverage plan, with all due respect, I don't even know how I would do that. But I do think that, again, we're very good at...on a case-by-case basis. If we have an individual in Sidney or McCook or Chadron or Scottsbluff who's experiencing a situation where their needs aren't being met, our service coordinators should be catching that through their monitoring tool. We should be able to loop in our professional staff, either at BSDC or in our central office, and we should be able to provide those providers out west some supports in addressing that need. [LR300]

SENATOR HARMS: All right. Thank you. [LR300]

SENATOR LATHROP: Senator Gloor. [LR300]

SENATOR GLOOR: Thank you, Senator Lathrop. And thank you for being here today, Jodi. [LR300]

JODI FENNER: Thanks. [LR300]

SENATOR GLOOR: I've got kind of a technical question that relates to the coordination of services, and before I do that, a compliment. I had a chance to visit the vocational site out in Grand Island this past summer and had an enjoyable experience. I was not surprised that the clients were in good humor. They're always in good humor and excited when they have visitors. And I know a number of them pretty well. But I was especially pleased that the staff were in good humor and good spirits and were respectful, seemed to be enjoying the job they did. And I say this, maybe it's a sign of my age, but a lot of the clients...a lot of the staff were younger and I thought that the fact that they were clearly respectful and seemed to be enjoying what they were doing was a good sign,... [LR300]

JODI FENNER: Thank you. [LR300]

SENATOR GLOOR: ...a good sign for the care that was being provided there. So I left feeling good about the visit overall, just a comment. Since you hear a lot of other comments during times, I thought you should hear something that was a positive experience. [LR300]

JODI FENNER: Thank you. [LR300]

SENATOR GLOOR: You made reference to the fact that there's an electronic case management system,... [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR GLOOR: ...and I'm not sure what that means and I want an explanation, since obviously case management relates to a lot of the discussions we're having about coordination of services. I'm going to assume it's more than just electronic versus paper and pencil, and relates to an electronic record. But I'd like some explanation of what this electronic case management system is. Is it new? Is it upgraded? Certainly if it operates correctly, it ought to be of help to the department when it comes to some of this issue of making sure that we have the appropriate services, have connections to the appropriate services, or that hand-off from one service provider to another goes pretty seamlessly. So help me with an explanation if you would. [LR300]

JODI FENNER: Certainly. Yes, we actually use the Therap program for our case management system throughout Nebraska and it's fairly comprehensive. Essentially, our providers have full access. They can...they are required to do incident reporting, which is the information that I referenced earlier. There's an array of things that we've defined in regulations, if these things occur, you need to...they're required to put that into Therap. And that feeds into our data system. We've always required that information to be collected, but it used to be on paper and fax machines. And then somebody had to put it into databases for searching, and that was very time-consuming and the data wasn't necessarily readily available, complete, or easy to review, and that was a big issue with the Department of Justice. So we've completely revamped our incident management system and that's in our case management system. The other part of that, and we use Therap completely at our Bridges Program and we're implementing the complete, like, what any other community provider would do at BSDC: daily statistical information on the individual, what are their habilitation programs, their behavioral support plans. Pretty much everything about that person that used to be kept on paper now can be kept in the system, which means if an individual moves from one provider to another, that information can go with them. Quality assurance data can be pulled. It allows us to identify, for example, we can set a system if somebody has more than three falls in a month, we can have it flag that, because that can be an indication that somebody needs clinical supports or at least we need to do a spine/gait assessment. So it really is, it is data and it allows the service coordinators to really focus on the human aspect of what they do so that when they put that information in, they have access to it from here on forward. We also have the ability to scan all of our documents that can be referenced in conjunction with our Therap system. So it isn't just...I mean it's a lot of data that we do track and we look at quarterly, we evaluate it. When I talked earlier about the five areas we're focusing training, we got that from looking at our data, looking at what those needs might be, so. [LR300]

SENATOR GLOOR: You've finally gotten to the point I'm looking for, which is we not only do a lot of data, adding to databases; we have somebody that mines that data. [LR300]

JODI FENNER: Yeah. We do. That's... [LR300]

SENATOR GLOOR: We have quarterly reports that take a look at incidents so that if there are...if somebody has had three falls during a quarter, there's somebody who's assigned the responsibility to look and monitor the number of falls, as an example,... [LR300]

JODI FENNER: Yes. [LR300]

SENATOR GLOOR: ...within incident reports and put together correction plans or whatever the appropriate stand is. And so you're telling me, we don't just enter data; we also have a process in place to make sure we mine it and do something with the data we have. [LR300]

JODI FENNER: Yes. We use it to make our decisions. [LR300]

SENATOR GLOOR: Okay. Thank you. [LR300]

JODI FENNER: Thanks. [LR300]

SENATOR LATHROP: I do have a couple questions. Maybe want to give you a fair opportunity to talk about LR300, because I think we're going to shift to that. As soon as you get out of that chair, we're going to start talking about that a little bit more than some of the developmental disability issues. And maybe I can frame the question as I understand it. And I have to say that I understand the question only by virtue of having spent time with a few families that have expressed frustration. And there seems to be a common thread, so I want to give you a chance to talk about it. If I understand the LR300 issue, we have people who come to the state, they have a son or a daughter who has a challenge, and we look at them and do an evaluation and say, for whatever reason, you're close but you don't meet the definition of a developmentally disabled person. But they have significant behavioral problems. And they come to us probably everyone on this committee, and say, I've fallen through the cracks and I can't get any help. What's the...tell us what's your take on...and maybe the problem is what you've set out in your remarks, which is the Affordable Care Act does not address the limited access to qualified professionals in the medical community willing and able to provide services to people with co-occurring disabilities. In the end, is it a "we don't have the people to provide the care," or is it a "we're not equipped to take somebody who has a foot in either of two silos," or "both feet aren't in my silo so run over to the Behavioral Health guys for services"? [LR300]

JODI FENNER: Well, I believe... [LR300]

SENATOR LATHROP: That's my...that's as good as I understand LR300 and I'm looking forward to understanding it better after today. [LR300]

JODI FENNER: Sure. [LR300]

SENATOR LATHROP: But before you got away, I thought we'd give you a chance to talk about that or your take on it. [LR300]

JODI FENNER: Well, yeah. I think for people who do meet our definition of developmental disability, which is consistent with the Medicaid and national definitions, the generally accepted clinical definition, for those people I think we've made extraordinary...we've had extraordinary successes in developing programs and recruiting new providers into the state, supporting existing providers. So I think if you do meet the definition, even if you have a co-occurring mental illness, I think we do a very good job of supporting that population. And then when we do have challenges, we have our Team Behavioral Consultations and our Targeted Behavior Assessments to come in and help look at those issues. It's for the individuals who don't necessarily meet the definition and they're not eligible that we see those individuals struggling. And we don't just say, you don't meet our definition, take a flying leap. I mean we don't do that. We actually are one system in Health and Human Services. We do try to connect them to our Behavioral Health partners or our Medicaid partners, where feasible. We have to be kind of careful because we can only charge service coordination for people who are eligible. But we do try to give families ideas of places they can go if they're not eligible. We've also tried to be very transparent with school psychologists and programs so that...because oftentimes what we find is that people come to us and initially we have to find them noneligible because the assessments aren't appropriate or things like that, and our DD psychologist in central office I think has done a really good job of reaching out to those clinical providers in the school districts and educational service units so that we're able to more accurately identify individuals who are eligible when they're coming out of the school system. But you're absolutely correct and I think it's not a Nebraska problem, it's a national problem. We have...I don't know if it's because now we recognize things as mental health issues, but the reality is there aren't enough clinicians in the United States to serve all the people who are documented to need services. And I don't know what the answer to that is. I think the universities have to play a role in that. We do, again, we have an internship, several internship programs at BSDC, so we're trying to do our part to grow people in that profession and in...not just the psychology profession but also in some of the clinical support areas. [LR300]

SENATOR LATHROP: But to sort of drill down a little bit,... [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR LATHROP: ...the definition of developmental disabilities is in statute and it...I'm going to try to paraphrase it. You either have an IQ below 70 or you have a...some level of intellectual disability that causes problems in two of seven areas of your life, or limitations. [LR300]

JODI FENNER: Depending on the age, two of seven if you're young and child of five, three to five, yeah. [LR300]

SENATOR LATHROP: Provided it's not mental illness. If it's mental illness as the cause... [LR300]

JODI FENNER: Provided it's not solely mental illness. [LR300]

SENATOR LATHROP: Solely on mental illness. [LR300]

JODI FENNER: You can have a mental illness and that doesn't disqualify you. It's only if your issues are... [LR300]

SENATOR LATHROP: And so when they come to you and they say, gosh, my son or daughter is really struggling, I think she's or he has intellectual disabilities, they don't meet the criteria but they clearly have behavioral or mental health issues, your answer is to send them or point them in what direction? To the regions or to Scot Adams' office? Where do they go? [LR300]

JODI FENNER: Oftentimes we'll give them the DHHS Help Line because the individuals on that Help Line are generally... [LR300]

SENATOR LATHROP: Is that like ACCESSNebraska? [LR300]

JODI FENNER: No, there's (laugh)...I think it's the Help Line you guys actually funded several years ago. [LR300]

SENATOR LATHROP: Okay. [LR300]

JODI FENNER: And I really hate to tell you what all they do... [LR300]

SENATOR LATHROP: Okay. [LR300]

JODI FENNER: ...because Scot is really in a better position to tell you. But if we are declining services... [LR300]

SENATOR LATHROP: But that's where the hand-off happens. [LR300]

JODI FENNER: We do try to make a hand-off,... [LR300]

SENATOR LATHROP: Okay. [LR300]

JODI FENNER: ...yes, because we don't want to leave people out there struggling. [LR300]

SENATOR LATHROP: And that kind of...that's a segue into Scot Adams. [LR300]

JODI FENNER: Yeah. [LR300]

SENATOR LATHROP: Jodi, I want to recognize the work you did at BSDC. I know that I was there when we started the investigation, so was Senator Harms and Senator Wallman, and we watched that place go from, you know, where the CMS and the Department of Justice were chronicling some horrible things. And there has been great improvement. And the purpose of our committee is to continue its oversight, not to bring you down here and dress you down and be critical but to try to get to where...what do we got left to get across the goal line. [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR LATHROP: And I keep thinking we can disband this committee, and every year we're not quite there. And so I remain concerned about complying with the DOJ and satisfying them. But in some sense I look at the DOJ, and just so people understand, the DOJ is only looking at the people that went into community from BSDC, right? So somebody who's in getting community-based services that never started out at BSDC isn't necessarily going to be the subject of their review. And so in some sense, the people that left BSDC and went into the community are sort of our sample of what's going on in the community. And there are some things, it looks like, we need to improve on still and that's the purpose of our hearing today and not to be critical, because I certainly appreciate an awful lot of what you've done in your tenure. [LR300]

JODI FENNER: Thank you. [LR300]

SENATOR LATHROP: So with that, unless anybody has any other questions. Senator Bolz. [LR300]

SENATOR BOLZ: Just a question before we transition, Jodi. I'm just curious to hear your perspective on the recent change to Magellan Medicaid managed care for behavioral health. And I realize that that's new,... [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR BOLZ: ...but I know that there are a significant number of folks with developmental disabilities who are also engaging with that system. And I'm just curious what your initial reaction to that change has been. [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR BOLZ: Are things going smoothly? What can you highlight for us in terms of that change? [LR300]

JODI FENNER: Sure. I think to date it's actually been quite positive. From day one, Magellan has reached out to the division and I believe they've even visited with several of our providers to identify what those specialized needs and challenges might be. And so we have an open conversation, so to speak. We haven't had any incidences that have risen to my level of somebody is not getting what they need, and so that's a very good sign. Service coordinators have been following the situation with individuals because that is part of what we do. It's really been a pretty smooth transition. I'm not saying there won't be bumps in the road and certain individuals may have individualized challenges, but we'll work with them on that as we go. But I can actually say I'm very, very impressed with how open Magellan has been in being proactive and going forward in that process. So it's... [LR300]

SENATOR BOLZ: Great. [LR300]

JODI FENNER: ...been very positive. [LR300]

SENATOR BOLZ: Great. Do we have time for one more question? [LR300]

SENATOR LATHROP: Sure. [LR300]

SENATOR BOLZ: Okay. And forgive me, you've sort of set up a beautiful transition to LR300, but I have a question a little bit off that topic. And the question is, the Appropriations Committee implemented the new rate methodology,... [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR BOLZ: ...and my understanding of that, from an Appropriations perspective, was that it was intended to rightsize the system and kind of rightsize the services that folks are getting. Could you just give me a bit of an update in terms of providers and individuals. Is that rightsizing happening smoothly? Are there any challenges that you can highlight for us now that would help us prepare for the upcoming session? [LR300]

JODI FENNER: Well, the money doesn't come in until July, so individuals don't actually have their budget allocations yet. But the majority of the individuals who are underfunded are people who live outside of Lincoln and Omaha. In fact, I think 40 percent of the money is going to go west of Grand Island. [LR300]

SENATOR BOLZ: Uh-huh. [LR300]

JODI FENNER: And in those small communities where people are significantly funded below their objectively assessed budget, you know, that's where you see some of the negative challenges that we face. So we haven't implemented it yet, so we don't have... [LR300]

SENATOR BOLZ: Uh-huh. [LR300]

JODI FENNER: ...any real good news stories, but we do have teams who already know that that money is coming. And they're looking at how can we better support this person now that we have that adequate funding. [LR300]

SENATOR BOLZ: Uh-huh. Uh-huh. [LR300]

JODI FENNER: So we're really excited to see that occur. [LR300]

SENATOR BOLZ: Uh-huh. Thank you. Thank you. [LR300]

SENATOR LATHROP: Jodi, we're going to call, we have a number of people that are... [LR300]

JODI FENNER: Uh-huh. [LR300]

SENATOR LATHROP: ...that are going to come up after you, but we're going to call up LeRoy Hansen and David Kathol. I think they have something to say. They're folks, Nebraskans. And if you want, we'll give you an opportunity to speak after they're done if you choose to. Otherwise, that will be the next people that we call up if you want to wait around, see what they have to say. [LR300]

JODI FENNER: Certainly. [LR300]

SENATOR LATHROP: Maybe it's the lawyer in me that wants to afford somebody an opportunity for rebuttal. I have no idea what they're going to say, but they're going to share their concerns or their experience. Okay? [LR300]

JODI FENNER: Sure. I'll be here all day, sir. [LR300]

SENATOR LATHROP: Okay. Thank you. And with that, we'll bring up LeRoy Hansen. Are you here? Mr. Hansen, just because we have so many people that are going to testify today and we have so much ground to cover, we'll just ask you to kind of...can you do this in five minutes you think? [LR300]

LEROY HANSEN: I think I can. [LR300]

SENATOR LATHROP: Very good. Well, welcome to the committee. [LR300]

LEROY HANSEN: Thank you for having us here. My name is LeRoy Hansen, L-e-R-o-y H-a-n-s-e-n. We have a daughter that is in the program NorthStar in Wayne, Nebraska. And one of our concerns or our main concern is the ICAP and the cutbacks on services. And that's our daughter is a high maintenance. She has cerebral palsy and she has what they call hypsarrhythmia, which is the rarest form of epilepsy, so she is high maintenance. She is wheelchair-bound. She cannot feed herself and...but what the people in Wayne and NorthStar do for her is amazing. They have done things with her that we were told, by doctors, wouldn't happen, you know, so. But in the cutback of hours that Health and Human Services is talking about, she will regress, and this is a concern that we have. She's been in the program for 38, 39 years. She's 43 years old. She was in the day care part of it to start with. We picked her up, you know. But now, of course, as an adult, she's in the program full time. They do an excellent job. But the cutback in hours is going to be a big issue because she will not...you know, as we grow older, we actually need more assistance. And what we're hearing from Health and Human Services is they want to cut back her hourly or her units, they call it. [LR300]

SENATOR LATHROP: Mr. Hansen,... [LR300]

LEROY HANSEN: Yes. [LR300]

SENATOR LATHROP: ...was that as a result of a new assessment done by a different criteria or the rate methodology? Can you tell us when things changed and what you understand to be behind the change? [LR300]

LEROY HANSEN: Okay. We were first notified--and I have it in my notes but I don't want to take the time to look for it--I believe at the end of 2011, beginning of 2012 that this was coming. And we really didn't know what was coming. We were just told that, you know, there was an ICAP. I do have a problem with the way the interview was done. I don't think I'm alone on that. I think...and Health and Human Services can correct me if I'm wrong. I think there was an individual that sat in their office and did this analysis over the telephone. Now in my opinion, every one of these clients is different. They're individuals. And you can't sit on a phone and ask questions and know how to evaluate a client, in my opinion. You know, you have to meet the client. You have to know who you're talking about and what you're talking about, because these clients are not alike. They're all individuals. [LR300]

SENATOR LATHROP: Right. [LR300]

LEROY HANSEN: And that's one of the problems that we had. We went to the...we've been through the process with them on the informal dispute resolution. We did that, I believe, on October 21, 2012; was a good meeting, very good meeting with them. But since that time, things have pretty much been put on hold and we haven't heard much from that. Now the last thing we heard at our last IPP is that these cutbacks will probably be in place by July of 2014. I don't know, you know, that's what we're hearing now. But, yeah, if there's any questions. [LR300]

SENATOR LATHROP: Is a percent of the services that you're getting now, can you tell us what the cutback looks like? Are they cutting you back ten units or 10 percent of the units or... [LR300]

LEROY HANSEN: They're cutting back 36.9 percent of her units. [LR300]

SENATOR LATHROP: Okay. Senator Krist has a question for you, Mr. Hansen. [LR300]

LEROY HANSEN: Yes. [LR300]

SENATOR KRIST: I again thank you for being respectful of time, but I'd like to see the data, if you could make that available to us, in terms of what happened. And then when you talk about the cutback in the number of units, your daughter is living with you? [LR300]

LEROY HANSEN: No. She is a resident of NorthStar. [LR300]

SENATOR KRIST: Okay. And the units are the units that are available for a particular kind of therapy or treatment? [LR300]

LEROY HANSEN: She has day units and she has residential units. [LR300]

SENATOR KRIST: Okay. [LR300]

LEROY HANSEN: Yes. [LR300]

SENATOR KRIST: And their assessment of her no longer needing those units, was there at all a...you say it happened over the phone or at somebody's desk. Was there ever a session with you and your wife or with you and the family about...or do you know if that happened at NorthStar? Did they have that? [LR300]

LEROY HANSEN: They interviewed two of the people that worked with her. We were never interviewed, my wife and I. We were never called. [LR300]

SENATOR KRIST: And you're still legal guardians? [LR300]

LEROY HANSEN: Pardon? [LR300]

SENATOR KRIST: You're still legal guardians? [LR300]

LEROY HANSEN: Yes, we are. [LR300]

SENATOR KRIST: Okay. [LR300]

LEROY HANSEN: We are now legal guardians, yes. [LR300]

SENATOR KRIST: Thank you. [LR300]

LEROY HANSEN: You're welcome. [LR300]

SENATOR LATHROP: I see no other questions. Mr. Hansen, thanks for coming down here today. [LR300]

LEROY HANSEN: You're welcome. I'll try to get some data to you or to Senator Lathrop, okay? [LR300]

SENATOR KRIST: Thank you. [LR300]

SENATOR LATHROP: If you have not filled out an orange sheet, we'll ask you to do that. [LR300]

LEROY HANSEN: Sure. [LR300]

SENATOR LATHROP: And if you're going to testify, we'll ask you to fill an orange sheet out. That's important to us. Actually, it's important to the clerk so we make a good record and we have everybody's name and we spell it right in the record. So if you wouldn't mind doing that, that would be great. And next we'll hear from Mr. Kathol, if you're still here. Welcome. [LR300]

DAVID KATHOL: Thank you. My name is David Kathol, K-a-t-h-o-l. I've known LeRoy for quite a while. We both worked for power companies till we retired. As he pretty much went over what I was going to say, but to go a little further, the ICAP and the OAP, as I understand it, is a measuring tool and as Mr. Hansen described, you're measuring human beings. And I know, Doug, did you...did these senators get the copy of the letter? [LR300]

SENATOR LATHROP: The letter? [LR300]

DAVID KATHOL: From me? [LR300]

SENATOR LATHROP: Yes. [LR300]

DAVID KATHOL: Okay. Describe what I guess my thoughts on the measuring part of it. My daughter is 39 years old. She functions at a nine-month-old level. She's in the hands of NorthStar also in Norfolk, and what we have found, by having her in Norfolk, is that pretty much all the services we need medically and physically, physical therapy and all that, are available in Norfolk. So we can...different vendors and stuff. But we're scheduled for a 41 percent cut in funding and have gone through a process. I hired an attorney to help me with that just to...because I was lost how to do this. And so on January 6 is a hearing and it will be a phone hearing and will be at our attorney's office for some results of this. It's been a back and forth thing and my last offer to Health and Human Services was let's try a 5 percent cut for three to six months, see what happens. My fear is Angie's mother and I are not kids anymore and Angie has no brothers or sisters or any close relatives close. So we're looking at this Mom and Dad aging thing, so. And she has lupus also, and because of the close relationship she has with the people at NorthStar, and it's the same people constantly, they detect when that lupus starts to flare up. Now if it flares way up, she's going to go to the hospital and...but in helping her walk and just being around her and knowing her, they know that. They can get a doctor and get the prednisone medication upped a little bit for a while and then bring it back to keep that in check. That's sort of a big thing with her because it can be really devastating. So I guess and the other part of it is like for me, why did we stay in Norfolk? I had opportunities. I worked for Nebraska Public Power so I had opportunities to move around the state of Nebraska, which we decided not to do because of Angie. So we could find the things we need between...in Norfolk and we're close enough to Omaha for serious things that we bring her down here for, to Omaha, for serious medical stuff, so. Which also, by looking at these deductions, what's going to happen, and there's a economic development part of what goes on for the tax dollars that are used to take care of anybody that's disabled and keep them in their community. The people stay there. They work there. And in Angie's case she and two other ladies her age rent a duplex, a three-bedroom duplex. NorthStar takes care of them in this duplex. Well, a guy owns it so...and it just transcends itself into different things, that the money stays in Nebraska. You know, one of the things by me saying I didn't get promoted is also if you have people moving into this state and you want that expertise that that family is going to bring for something, they're going to look at, well, what about my son or daughter? I got something good going where I'm at; is it going to be as good where I'm going? I'd like to move, but that's a big...always a big concern for families in this situation, so. Like I said, our...Angie's mother and my fear is that we lose this level of funding in one big chunk, NorthStar is going to have to cut back. And it's people. That's what they get cut back. That's what their cutback will be is people and experience. So then wages have to be lowered or whatever and you're not going to have the quality you need to take care of these people, so. [LR300]

SENATOR LATHROP: Mr. Kathol, is the cut of...there's really two concerns. One is having a cut at all and the other is having a 41 percent cut imposed in one year. Am I right? [LR300]

DAVID KATHOL: That is correct. [LR300]

SENATOR LATHROP: So one concern you have is the belief, and I think you might have shared this with Doug and Doug shared it with me, that your cuts should be limited to 10 percent or 5 percent, something like that, so that you're stepped down or graduated down if, in fact, that's an appropriate cut in the first place. Would that be... [LR300]

DAVID KATHOL Yes. [LR300]

SENATOR LATHROP ...one of your concerns? Tell us about the 41 percent cut, if you would. Is that a function of a new assessment process or do you understand why you were cut 41 percent? [LR300]

DAVID KATHOL: As I understand it, it's the function of a new ICAP and a OAP thing, and it was done over the phone when my daughter...(Recorder malfunction)...questions, so. [LR300]

SENATOR LATHROP: The assessment was posed to the person.

DAVID KATHOL: The assessment was a (inaudible), yeah. And she was the right person to be talking to, but under the conditions she was in, I really question that, but...and like Mr. Hansen said, we weren't involved in it and didn't know it was going on until after the fact, so.

SENATOR LATHROP: Okay. Senator Krist.

SENATOR KRIST: Thanks for coming. Are you legal guardians for your daughter?

DAVID KATHOL: Yes.

SENATOR KRIST: And you weren't involved in the process at all?

DAVID KATHOL: No.

SENATOR KRIST: You were just told that you were going to get a 41 percent cut. Your point is well taken and should be emphasized as public information. When we cut 41 percent here and 20 percent here and 31 percent there and 22 percent there, and all of the...the two names actually this morning have come up with NorthStar. NorthStar is going to have a decision to make, like Children's Hospital had to make, when the money and the funding and the process came down. It's not, now again, about the individual and the services that are required; it's about how much we can save money doing one or two or three different things. But the cumulative effect is those services will not be available in the community if we continue to kill the infrastructure that's there. Thank you for what you said and for coming. And my hope is again that...in your letter you're very specific. But my hope is that you will get a reassessment and I think it's very reasonable, sir, that you should see no more than a certain percentage of the decrease. That's at least a manageable process for both you, your daughter, and the facility that's treating here.

DAVID KATHOL: Yeah. I think probably this ICAP and OAP, you've got to have a start of a measure, you know. But then you have to throw the human factor into it and go from there. So there's got to be some flexibility, so.

SENATOR LATHROP: Okay.

SENATOR KRIST: Thank you.

DAVID KATHOL: Thank you.

SENATOR LATHROP: I think Senator Bolz has a question for you.

SENATOR BOLZ: Briefly, I'm curious, the information we received from the division this morning says that they plan to proactively review individuals who are projected to experience a significant change in their individualized budget. And I'm just curious, have you experienced that? Have you heard plans of that? I'm just want to understand your personal experience.

DAVID KATHOL: I am assuming...that letter that I sent out, went out before I got notice of a January 6 hearing, so I'm assuming at the January 6 at the hearing for Angie that that would be discussed.

SENATOR BOLZ: Okay, thank you.

SENATOR LATHROP: I don't see any other questions. Thanks for coming down and sharing your concerns.

DAVID KATHOL: Thank you.

SENATOR LATHROP: And I think those are the families that we intended to call up, at least as it relates to the special investigative part of the hearing. Jodi, do you want to come up and respond at all? Or I'll give you the opportunity to pass, too, if you'd like.

JODI FENNER: I really can't speak about cases pending appeal (inaudible).

SENATOR LATHROP: And I appreciate that. There are concerns and it wouldn't be appropriate to have you come up here and talk about their case. How about the concerns that they have expressed to the extent that there's a common denominator? If you can talk about them generally in terms of the assessment process and the percentage of changes or cuts in the services.

JODI FENNER: Sure. First of all, no reductions evaluations in any individual's budgets are occurring...no budget changes are occurring at all at this point in time relating to the OAP and rate methodology process. That won't happen until July. That being said, there were many years where individuals' budgets were set upon the personal whim of an administrator in my office. And we can't do that. That violates the statute that you gave, that's in the books, that says we have to use an objective assessment process; and ICAP is a nationally recognized assessment tool and we do use that. And when we have people who the tools shows are significantly over their budget we have a statutory obligation to address that. We do address that in a variety of ways. Typically, we do a step-down process when we have providers who are working with us, and we do do that through a step-down process. But we have an obligation to address that. With regards to Senator Krist's concern about NorthStar going out of business, I believe...I'll have to get those numbers for you but I believe their increases in revenue are...do we have that yet Tricia? I believe it's several million dollars. So most providers, when they see small reductions in individual budgets what they see is the over $30 million that's going into the system in the next year, and they're all getting significant increases with again only five exceptions, NorthStar not being one of those exceptions. And so I don't think that a few situations are going to drive a provider out of business. But we do have...the division has a statutory obligation to use that objective assessment process.

SENATOR LATHROP: Is there anything in rules, regulations, or in statute that limits the extent to which you can cut the funding or the services to, say, a 5 percent or 10 percent a year, as opposed to just going...

JODI FENNER: No, no.

SENATOR LATHROP: ...it's 41 percent.

JODI FENNER: No, there is not, but we also don't...yeah. And typically...

SENATOR LATHROP: Okay. But, well, go ahead and finish your sentence because...

JODI FENNER: Well, and also if there was a plan, typically if we have an individual who has...who is...who needs to be adjusted, we typically work with providers to put a plan in place for that to happen in a step-down process when the provider comes to the table and is willing to have that conversation in a way that we can substantiate this is what you're going to do with the additional funding during the time period of that step down. Without talking about a specific situation, we commonly have that conversation with the providers when this type of situation occurs. And in most cases the providers are really a part of that conversation and process.

SENATOR LATHROP: Is that an informal process or is that an appeal hearing not unlike what Mr. Kathol just learned he's going to have in January?

JODI FENNER: It can be either. That depends upon what the individual requests.

SENATOR LATHROP: Okay. Senator Harms has a question for you.

SENATOR HARMS: Thank you, Jodi. Jodi, the only question I have, and I guess the concern I have out of this beyond just the cutting is that the legal guardian was not involved. The legal guardian received no notification. That really bothers me. Because in the condition that their children are in, their son or their daughter, or both daughters in this case, they should have been involved in this process and should have been involved in the discussion. And not only that, why would you do it over the telephone?

JODI FENNER: Senator Harms, I can't really speak about the individual situations because they are pending appeal. What I can tell you is when we do the interviews, we interview the individuals who care for them on a day-to-day basis. And if the individual isn't living with their parents, then according to the ICAP, the instructions, the clinical instructions, they would not be the proper people to interview. And we do involve guardians and individuals in the process to...

SENATOR HARMS: But don't you think, just the courtesy, that the parent or the legal guardian should have been involved in this discussion? Because that's what bothers me a little bit in regard to this particular issue. I think they should have been notified that they were going to have this conversation and that potentially a cut was coming, and they were going to evaluate his son or daughter.

JODI FENNER: I can't talk about a specific situation but our general process is the guardian and the provider are involved.

SENATOR HARMS: Well, it doesn't make me any happier. I'm just telling you that, that I don't think that's the right thing to do.

JODI FENNER: And if that was the situation, I wouldn't be happy either.

SENATOR HARMS: Thank you.

SENATOR LATHROP: Senator Krist.

SENATOR KRIST: My comment about North...my comment about any in particular business does not mean I want you to go back and find out what their bottom line is. My comment is how they would be affected, in general, across Nebraska as an individual care provider. That could be a psychiatrist, a psychologist, a doctor who now is finding that that care or that managed care program that he is looking at is going to be cut. So...and if NorthStar is a 501 and they do independent fund-raising, that also leads to their bottom line. So, Jodi, don't misinterpret. My concern is not about the viability of the institution as much as it is how the institution is affected on a business plan taking care of the people who really we should be paying attention to. Second, being a guardian, I'm appalled--I'm not just I'm not happy, I'm appalled--that the guardian isn't told and isn't involved in the process. ICAP is a widely accepted and nationally accepted; that doesn't mean that's the Nebraska way of doing business. And if we can't get the guardians involved with it, every time to make sure that they know, I'm disappointed. And I'm not speaking specifically in reference to you or your capability. I understand you're making strides and I agree with Senator Lathrop. But that's unacceptable.

JODI FENNER: I would agree that's not acceptable, but I would also disagree that that's what occurs. I would like to speak about the business issue, Senator Krist, because I do think it's important as we implement rate methodology, because when we implement OAP there are individuals in the process that will decrease. And I do think it's important that we look at the impact on each individual provider, because we don't want providers to go out of business. And, in fact, we actually did that. We did an analysis on the full OAP process by every individual and provider in the state to say this would be the financial impact on each provider so that we could prioritize the five providers who are seeing decreases, because we don't want to lose the resources that are out there supporting people. So I appreciate that's your perspective. I think that's something we had to look at when we did the rate methodology implementation, because what we don't want to do is to see that result in a reduction of services to individuals or individuals being...losing their current placement, so.

SENATOR KRIST: Thank you.

JODI FENNER: Thank you.

SENATOR LATHROP: Senator Crawford.

SENATOR CRAWFORD: Thank you, Senator Lathrop, and thank you, Director. I just want to clarify your comment, and we're talking about working with the providers and working with the legal guardians and parents, you said we have a statutory obligation to use an objective tool. Then you said, but we typically put a plan in place with providers to have some kind of step-down process when there's a high cut, like a 41 percent...you know, a high-percentage cut. So is that...so I'm just trying to understand what this process looks like for the provider or for the parents. So they get some notification that services are going to be cut, say, 40 percent; and then they contact you to try to make other arrangements? Or are guardians allowed to contact and be involved in negotiations for other arrangements?

JODI FENNER: Yes. And actually it's very rare. We're talking about this like it's a very common process. It's actually very rare that anybody has a reduction in services. Usually it's when we come across an individual who has been overfunded for a very long time. But typically, when we find a situation like that, we do; we go to the provider and the family and everybody is a part of that conversation. We can't just pay somebody, a provider, an amount without substantiating the services they're going to provide with those dollars. And so when I talk a step-down process, we would have the provider identify what the need for that service was and then how he was going to meet that need, like the hours that the staff would be providing and that sort of thing, so.

SENATOR CRAWFORD: Is that initiated by providers or parents or you?

JODI FENNER: Typically, the department initiates that conversation. And it just depends, I mean. It is...we have a very flexible, informal dispute resolution. And so sometimes we have to issue that letter, the notice of decision, but then I don't think there's a provider out there that's certified that isn't comfortable picking up the phone and calling us. But again, our intention is to initiate that conversation where possible.

SENATOR CRAWFORD: So parents or providers who are concerned can contact your department to have that discussion.

JODI FENNER: Yes.

SENATOR CRAWFORD: Thank you.

SENATOR LATHROP: I see no other questions or concerns. So thank you for your testimony, Jodi. [LR300]

JODI FENNER: Thank you. [LR300]

SENATOR LATHROP: And I'll turn it over to Senator Campbell who can start us down the LR300 road. [LR300]

SENATOR CAMPBELL: Thank you, Senator Lathrop. We have a number of invited testifiers this morning, and I'm going to give that list so that you know what order you are in. We will start out this morning with Director Scot Adams. And Director Adams, if you want to make your way to the table that would probably help. And then we will move to Claudia Sherman, Janine Brooks, Marla Fischer-Lempke, Eric Evans, Bill Reay, Will Spaulding, and Beth Reynolds. Now I'm looking at the clock, thinking we're not going to get all those people in between now and 12 noon. So most likely, at 1:30 we'll finish up on LR300 before we go to Senator Krist's LR143. Of the people that I read, is there anyone there who has an appointment this afternoon that could not stay till 1:30? Okay. We will proceed with our list. And Director Adams, welcome, and go right ahead. At your time, you may want to identify yourself and spell your name just so that the transcribers have it. [LR300]

SCOT ADAMS: (Exhibit 2) All that stuff. Yeah, great. Thank you very much. Good morning, Senator Campbell and Senator Lathrop, members of the HHS and DD Special Investigative Committees and your staff members. My name is Scot Adams, S-c-o-t A-d-a-m-s, and I serve as the director of the Division of Behavioral Health in the Department of Health and Human Services. First of all, let me offer everybody a happy holiday season in your work and in your families. I'm here today to provide information about the state's public behavioral health system and its response to people who have a dual diagnosis of intellectual or developmental disabilities and a mental illness. Nationally, about 1 in 10 with a substance abuse disorder receive treatment at all. About 65 percent of those with a severe and persistent mental illness receive treatment; and about 35 percent, or about a third of all persons with any mental illness, receive treatment. According to state statute 71-803, the Division of Behavioral Health is responsible to ensure public safety and the health and safety of persons with behavioral health disorders, statewide access to behavioral health services, high-quality services, cost-effective behavioral health services. And as you know, Nebraska services are provided through a structure of six behavioral health regions with the Division of Behavioral Health providing funding, oversight, and technical assistance to them. A board made up of county commissioners from each county in the region then governs these regions. My point here is that this is a different kind of system substantively than the DD system who employs their own persons. Also I want to make a distinction between us and the Medicaid system. The regions are responsible to determine services that will be provided in their region. Those decisions are sometimes difficult to make and are based on the available funding and the needs present in the various regions. They contract with local service providers for public inpatient, outpatient, and emergency services, as well as community mental health and substance abuse services. Based on regionally identified needs and decisions, not all services are available across the state. The division, through the regions, pays for services for people who have little or no ability to pay; are not covered by third-party insurance, which includes Medicaid, unless the service is not part of the Medicaid service array; meet clinical eligibility designated in the service requested; and/or are mentally ill and dangerous to themselves or others; or are publicly intoxicated or under the influence and dangerous to themselves or others. This differs significantly from other systems of care which pay for services. Financial eligibility for behavioral health is defined in the division's financial eligibility policy, and a copy of that is included. Clinical eligibility is based on the 90-page "Division of Behavioral Health and the Division of Medicaid and

Long-Term Care Adult Behavioral Health Services Definition," commonly known as the Yellowbook. And it's available on the Web site and I give that URL. I won't read that into the record at present. The National Association for Dually Diagnosed has estimated about 30-35 percent of all individuals with intellectual or developmental disabilities also have a psychiatric disorder of any degree. How does this compare in Nebraska? Well, in Nebraska, for the two state fiscal years '11 and '12, 8,181 individuals were eligible for services through the Division of Developmental Disabilities. Of these, 55 percent accessed behavioral health services through Medicaid; and 4 percent, or 325 people, accessed behavioral health services through the Division of Behavioral Health, for a total of about 59 percent of the total population. As mentioned, the Division of Behavioral Health does not pay for services that are eligible under the Medicaid system. The breakout is shown in the following two charts, and so you have a picture there in front of you with regard to, of the population, which ones go to Medicaid, which one don't have a behavioral health disorder, and which one--the red--that the Division of Behavioral Health pays. In the next chart, we flip that around. It shows again the 30,600 people that were served by the Division of Behavioral Health, and approximately 1 percent of those also were then eligible for services within the Division of Developmental Disabilities. So it's not a large part of our system's focus and concern. The array of services provided through the Division of Behavioral Health and the regions has continued to expand. And the attached array of services list begins with the services provided prior to the fiscal year 2004 and shows the additions in each consecutive year to implement LB1083, which was kind of our landmark from institutions to the community legislation. And so this development of services and this attachment within your packet shows how incrementally, over time, services have developed on the behavioral health side to be responsive to changes as people moved from institutions to the community and that kind of thing. I think it's illustrative of a growing, evolving, and responsive system. I want to note that there will be no new services in FY '14 as a result of the LB195 language; and that's in there. But the intent I believe of LB195 was to limit services changes as they are sought to be a discussion about the impact of the Affordable Care Act in looking at the impact on region-funded services. Of the services funded through the Division of Behavioral Health, the top five for those with a dual diagnosis of intellectual or developmental disabilities and mental illness include: emergency protective custody hold, that's never been funded by Medicaid, and that's about 131 of those 325 people; community support mental health, which is a very flexible service that can help fill in around the cracks, if you will, in terms of supportive services or different things to help make somebody stay stable in the community; outpatient mental health, 71 people; day rehab, full day, for 63 people; and medication management services for 56 people. Regardless of eligibility, an individual may present in the behavioral health emergency system, including involvement through law enforcement, when a person has been determined to be dangerous to themselves or others, as indicated in the EPC numbers above. As I mentioned earlier, the regions contract with local service providers for services. They also have directors of network services; emergency system coordinators and youth system coordinators who are available to help problem solve with individuals with complex needs, such as a person with a developmental disability and a mental illness. And so those kinds of consultations are available through regions. The regional centers--and I want to make sure we make the switch here, because it's easy to get confused--the regional centers are three institutions run by the state of Nebraska in Hastings, Norfolk, and Lincoln. These also serve people who were previously found eligible for services through the Division of Developmental Disabilities, who may be found eligible in the future, and people who are low functioning but do not meet specific criteria for developmental disabilities. There are 22 people at the Norfolk Regional Center who may fit these descriptions; 3 of those 22 previously received DD services, and 19 may or may not be eligible, but they have not previously received DD services in Nebraska; but we've identified them as potentially close to the line. There are 16 people at the Lincoln Regional Center who may fit these descriptions, and 2 people, 2 of the 16, previously received DD services; and 14 may or may not meet specific DD eligibility but have not previously received DD services in Nebraska. As you can see, the DHHS Divisions of Behavioral Health, Developmental Disabilities, and Medicaid and Long-Term Care provide and pay for a significant number and a variety of services to meet the needs of individuals who have both developmental disabilities and co-occurring behavioral health needs, and who meet the requirements of each division for those services. Another current example of how the divisions are working together is in the federal System of Care grant that is working to develop a particular plan for children's mental health, in particular, that is involving all of the divisions, providers, the Department of Education, and others. DD will be a particular focus of that planning effort. It's also important to recognize that while the department is the largest source of payment for behavioral health services, at least six other systems of care exist in the state, including the federal Veterans Administration, federally qualified health centers, private insurance companies, the four tribal authorities, and public and private hospital and healthcare systems. There are more; there's about 12 systems in the state of Nebraska. As Jodi mentioned in her testimony, our divisions work together on systems issues; and there are also times and circumstances when we collaborate across divisions to find solutions to particular individual needs as well. That said, we must follow legislative mandates and program missions. That means that while our system has currently served nearly 5,000 Nebraskans who have both a developmental disability and a behavioral health diagnosis, there are some people who may be low functioning but don't quite meet the DD criteria, have behavior issues but not a behavioral health diagnosis, who are not eligible for Medicaid or other state-level behavioral health systems. Despite this, we make every effort to work on an individual basis, case by case, to find options that may best help those we are aware of. I'm happy to respond to any particular questions you may have. [LR300]

SENATOR CAMPBELL: Questions from the senators? I'll start off. Director Adams, you have had a long time to think about my question, and the question was that we seem to have a group of people who don't quite fit in either of the divisions, and in my estimation we're failing to try to figure out how to get services for those people. You and Director Fenner and I met with CEO Winterer, and we worked on one in particular, and I think we're going to hear from that parent today. But any comment you want to make about that we're still...have a population we're not serving well? [LR300]

SCOT ADAMS: Well, you know, I think there are two or three things I might. Any time that a line is drawn, there are folks near that line that are close but not quite, whether the numbers...and Senator Lathrop mentioned 70. If it's 75, if it's 65, if it's 80, there's folks going to be right at 81, 76, whatever. And so I don't mean to say that in any harshness but there may always be some point at when a line is drawn--it's a tough job that you folks face--when you draw that line, that there's somebody just on the other side of that line. The second issue I think rests with the issue of the nature of giving a charge to fix something. And so in each of the state's divisions and in each of the state's departments across the state, there is a particular charge to go, for instance, in the case of the state Roads Department, to fix state roads, not the county ones. And so at that nexus of state and county, you have whose crevice is that when it's close. In this case you have a situation where the Division of Behavioral Health was charged with moving people with serious and persistent mental illness out of state institutions and into the community-based care. That's been our primary mission and we have folks who are close to the line of that who sometimes come into state institutional care and who ought to, deserve to, and should live in the community. We do our best to move into that, but there are particular supports that are unique to another part of government. My point is about boundaries and accountabilities. Let me offer you a suggestion or two with regard to possible solutions, because what you need in there is that flexible stuff that goes in between blocks that you see in the street that kind of has a permeability to it that helps blocks of cement stay flexible and not crack during cold weather like we're having. I mentioned community support as an example of a service, and it's on your list, that is highly flexible in its ability to provide service. The downside, and this occurred in Georgia, is that some people think that going too far with flexibility is not an accountable kind of thing. The federal government disagreed with how the state of Georgia thought a flexible service should go. So you always have got this tension between accountability who thinks it's in the box, and people who want to be outside the box. Another example is Ohio where the divisions of developmental disabilities and the divisions of behavioral health are a single unit. They are integrated and so they are chosen, and they have chosen and also structured a particular task force within those major divisions to focus on the co-occurring kinds of issue. They've been given that particular mission. [LR300]

SENATOR CAMPBELL: That's a very interesting idea, sort of like...it's sort of like a SWAT team effort. And in terms of a team of people coming together, saying...and we will use my usual example, as Senator Krist said, if Andy Campbell needs the services but doesn't quite fit anywhere, people come to the table and say, how do we make this happen; how do we braid this funding to ensure that that person gets the funding? The Ohio example, Director Adams, may be the most interesting one where they bring together a single unit and a particular task force. [LR300]

SCOT ADAMS: I think there are other options, as well, in terms of possibilities. Somebody spoke earlier about the Magellan and managed care situation. And I agree that...pretty new with regard to that, but some states have placed all services within a managed care framework. That is another example of something that could be done. And so there are a variety of...there are a variety of options. There are a variety of costs and problems and challenges and opportunities that come with each of those decisions. [LR300]

SENATOR CAMPBELL: Questions? Senator Crawford. [LR300]

SENATOR CRAWFORD: Thank you, Senator Campbell. And thank you, Director. I wonder, since we're trying to probe into where the cracks are, I'm wondering how much of that has to do with habilitative services and the fact that current statute or regulation restricts behavioral health in terms of funding habilitative services; and if you'd comment on that. [LR300]

SCOT ADAMS: You know, that's a great point, because I think oftentimes when an organization is given a particular charge, whether statutory or mission or otherwise, things like that are at the basis of the original conversation that set the mission in motion. And that is, I think, one of the core values and culture differences, if you might say, with regard to things. At one level you might think of this as all people in need; just go help them. You know, you drill down a little bit and now you're separating out into two or three nominal categories of habilitative or rehabilitative, and those two worlds meet sometimes and you have a group of folks right on the edge, but they're in one or the other. They're not in both. They don't have one leg in both at the same time. Our group is a group of people for whom we have great hope of moving forward in life beyond point X today, to a point that is restorative or regains status. I think that's easiest seen perhaps in the substance abuse field where folks oftentimes have gone through jail situations and terrible stuff and come back to be taxpaying citizens and that kind of thing. So I think that evidences a rehabilitation, a coming back to that. Many times in other divisions of the departments of the world's other conditions, that opportunity to come back from is not present; it will be a "let's make the best of" kind of thing going forward. [LR300]

SENATOR CRAWFORD: So just to clarify, the possible silo is that the people that you would serve are people who were healthy or had some status, fell back and need help getting back to a status. But, say, an autistic child would not be covered because they are in a process to get somewhere. They're habilitative as opposed to rehabilitative, and your division focuses on rehabilitive. Is that statute or regulation that really draws that line? [LR300]

SCOT ADAMS: You know, I think it's a little bit of statute,... [LR300]

SENATOR CRAWFORD: Or federal regulation. [LR300]

SCOT ADAMS: ...regulation, feds. I also think it is training and culture. For instance, many of the folks who work in the behavioral health network of providers are not trained, steeped in, and understand many of the dynamics that relate to developmental disabilities and intellectual challenges, many of the things that...there are from time to time folks who just...it's just not a good fit with a particular provider. It's a training issue largely; largely, a culture issue, in terms of being able to move things around and that kind of stuff. So there are a host of challenges in both systems that are trying to do the best they can with what they've got. But it also includes some of those other things that you mentioned as well, Senator. [LR300]

SENATOR CRAWFORD: Just to clarify, are there statutory or regulatory restrictions that also pose an obstacle there? [LR300]

SCOT ADAMS: You know, our mission and our statute speaks to serious and persistent mental illness. And so it doesn't say you can't come if you have developmental disabilities with regard to that. The truth is that most of the folks who have both are Medicaid eligible. And so most of those folks end up over in the Medicaid-funded system. We have a small number that come to us for a variety of different reasons. [LR300]

SENATOR CRAWFORD: Thank you. [LR300]

SENATOR CAMPBELL: Thank you. Senator Lathrop. [LR300]

SENATOR LATHROP: I do have a couple questions. Being the non-Health Committee member here, I don't understand the mental health issues as maybe readily as some of the other folks here, so I'm going to ask a couple questions. We passed LB1083 some years ago and it closed some regional centers; is that the case? [LR300]

SCOT ADAMS: Um, that was close. We passed LB1083 in '04, and we closed behavioral health services at Norfolk but transformed it into a sex offender treatment program. [LR300]

SENATOR LATHROP: Right, right. [LR300]

SCOT ADAMS: So it changed its mission. Hastings... [LR300]

SENATOR LATHROP: But LB1083 was intended to take money that we formerly spent on institutions and spend it on community-based services. Would that be true? [LR300]

SCOT ADAMS: Yes, sir, that would be true. [LR300]

SENATOR LATHROP: And what year would that have been done? [LR300]

SCOT ADAMS: 2004. And it took until about 2007 to get all of the funds into the community. [LR300]

SENATOR LATHROP: Okay. And the way we do that is not for you to write checks from your office but to send the money out to the regions for them to provide this care. Is that true? [LR300]

SCOT ADAMS: There's about $100 million that is appropriated for community-based care; about $76 million of that goes to the behavioral health regions. [LR300]

SENATOR LATHROP: Okay. So the largest share goes to behavioral health. [LR300]

SCOT ADAMS: Yes, sir. [LR300]

SENATOR LATHROP: Where's the rest of it? Do you administer that other $25-or-so million? [LR300]

SCOT ADAMS: The other...the rest of it goes to Magellan to help monitor the services in terms of that. It goes to tribal services as well. [LR300]

SENATOR LATHROP: Okay. [LR300]

SCOT ADAMS: So other community-based services, not through the regions. [LR300]

SENATOR LATHROP: So the point is that unlike DD, behavioral health sends the money out to other places to be done. [LR300]

SCOT ADAMS: Yes, sir. [LR300]

SENATOR LATHROP: And do you send that out with some criteria for what kind of programs they need to have in place? [LR300]

SCOT ADAMS: You know, we have...in fact, you can...on that list of services, you'll see the result of that dialectic process over time. Every year, starting in January, sometimes December, we have conversations with the regions about what are the hot topics, what are the hot issues. There are a number of services. For example, with TAY, that's transitional age youth. So we have brought up new services in response to the conversations going on here with regions. So we ask regions to pay special attention, for instance, to transitional age youth. [LR300]

SENATOR LATHROP: Do you mandate any of it? [LR300]

SCOT ADAMS: You know, we... [LR300]

SENATOR LATHROP: Or are the regions free to offer or not offer services to people at their own whim? [LR300]

SCOT ADAMS: You know, it depends a little bit on the nature of the issue. With regard to transitional age youth, we said that's going to be our priority. And in another year we said emergency services were going to be the priority. But we leave it to the region to say what that's going to look like and need. [LR300]

SENATOR LATHROP: Okay, so you don't mandate it. You might have meetings where you suggest that you have an idea about what you think should be a priority, but ultimately it's up to the regions about what services they want to offer or not offer with the money that you dole out from Lincoln. Would that be true? [LR300]

SCOT ADAMS: Ultimately, it's the regions' responsibility to have their particular array of services in place, yes. [LR300]

SENATOR LATHROP: And you don't mandate that array of services; you leave it to the regions. [LR300]

SCOT ADAMS: We might mandate a category above the particular service. For instance, we might mandate that there be services for transition age youth. [LR300]

SENATOR LATHROP: Okay. [LR300]

SCOT ADAMS: We do mandate... [LR300]

SENATOR LATHROP: You said that there is a program where a flexible approach happens. People come to the table for this flexible approach so that we are looking at the individual and not the two silos that might be involved. Where's that table at? Is that in your office or is that in the regions where the care is provided? [LR300]

SCOT ADAMS: Each of the six regions has a community support, an emergency community support both for mental health and substance abuse, so that there are funds and personnel trained and being able to sort of help a family or an individual in those circumstances that don't quite fit the square box. [LR300]

SENATOR LATHROP: Okay. And that's going to be whether they can offer that service, it's going to be a function of the funding that they have or don't have, is that true? [LR300]

SCOT ADAMS: There will be a budgeted amount based on the total amount that we're going to give to regions, the six regions. The regions then will budget their amount for inpatient hospital care and this and that. [LR300]

SENATOR LATHROP: But again you are not doing that; the regions are. [LR300]

SCOT ADAMS: Yes, sir. [LR300]

SENATOR LATHROP: And they're free to set their budget any way they want? [LR300]

SCOT ADAMS: Ahhh, you know, we approve their budget. [LR300]

SENATOR LATHROP: Well, let me ask you, since LB1083 passed do you have regulations that regulate the regions and tell them what they have to do with the money you give them or are they free to do as they please? [LR300]

SCOT ADAMS: The 206 regulations are coming to a conclusion currently. And so we... [LR300]

SENATOR LATHROP: But we've never got regulations implementing LB1083, is that right? [LR300]

SCOT ADAMS: That's a true statement. [LR300]

SENATOR LATHROP: Okay. And so I think part of the struggle that we have...part of the struggle I'm having with this is that people come to me from different parts of the state and then they tell me their story. And you talk about the table where the flexible approach happens, and I don't think it's happening everywhere. And then your testimony makes it sound like there's this place where somebody can go get equity and where they can talk about how their son or daughter doesn't quite fit into a particular category, and somebody is going to put their arm around them and help them. But that isn't necessarily happening in every region, if it's happening in any of the regions; and that's what I think LR300 is about. So do we need to regulate or insist that the regions put money aside for this process? Are the providers there to help these people who fit the category, a person described in LR300? [LR300]

SCOT ADAMS: Well, you have a couple questions in there. I think there are a small number of providers who are capable and skilled in both DD and mental illness and substance use disorders. I don't think it is the entire cadre of licensed providers in the state of Nebraska. Number two, working backwards, do we need to mandate that a certain number goes toward this population? That certainly is within your prerogative. It will come in current funding appropriations at somebody else's expense. Can't fund it all. [LR300]

SENATOR LATHROP: Okay. And that would explain why some of these people remain in the crack. [LR300]

SCOT ADAMS: It certainly could. [LR300]

SENATOR LATHROP: Okay. That's all the questions I have. Thank you, Senator Campbell. [LR300]

SCOT ADAMS: Thank you, sir. Yes, ma'am. [LR300]

SENATOR CAMPBELL: I'm going to follow up, real quick, Senator Krist. But we do not have in place in the state of Nebraska where there is this task force that comes together, as you described in Ohio, on the state level; not in your...I mean, it's not like we mandate that a task force pulls together when people don't fit in any particular...we don't have that in place. It may...you're saying it may exist in the regions but not at the state level. Is that right? [LR300]

SCOT ADAMS: Well, actually I would say this: There is not a department or division or unit of government that is institutionalized that does that now. Number two, I do believe that the Divisions of Behavioral Health and Developmental Disabilities come together, like we did in your office over some specific and particular situations, quite frequently. Number three, there are some work groups that we have chartered to begin to take a look at some of these. One exists at the Lincoln Regional Center that we called a system enhancement initiative--kind of a goofy name---but looking at 36 particular individuals at LRC; some of which, but not all of whom, have a co-occurring dual diagnosis with mental illness and developmental disability. And I mentioned the System of Care planning grant that is bringing a variety of folks together in those things. So I can point to several state-level kinds of things. I know also, for example, that Region VI, the Behavioral Health Region VI, Omaha area, has brought in persons and expertise to help them become better able to be responsive to this dual diagnosis population. But that has not happened in every region across the state. [LR300]

SENATOR CAMPBELL: But in the case that we had, I mean, it's not like it's routinely done. I wouldn't say that sitting down in a state senator's office is a routine way to approach it. That's my point, Director Adams, is that maybe we need to look... [LR300]

SCOT ADAMS: Yes, it is exceptional. [LR300]

SENATOR CAMPBELL: ...at a more structured, because, you know, not every parent is going to be able to pick up a phone and say, would you pull together this group of people? They may not feel comfortable. I'm looking for those states that routinely develop a way to cross silos, cross funding, and make it happen for folks. And you're just saying I need to look at Ohio. Senator Krist has been very patient. Thank you.

[LR300]

SENATOR KRIST: Well, thank you, Senator Campbell. And to Senator Lathrop, that table should not be in a senator's office. That table should be someone who can--I'm glad somebody else used the word "silo" first today--someone who can sit down and have an individual and have a case plan for that individual and can take care of that individual no matter where they are, and reach into silos of money and take care of the individual, or admit that that individual is on their own. And in the case of not having enough money, there are some of those issues out there. I don't think there are as many as...there are too many of them, I'll put it that way. But I think that by looking at the individual, we would do much better. And to Senator Crawford's point: Are there regulations, are there restrictions? If we had a Medicaid state plan that used more Medicaid dollars to do what we needed to do, which would be in line with another 12 or 13 states out there that are doing things differently, we might have more money to provide those services. And to your point, once a person is incarcerated there's a bunch of money that's cut off for services. And it comes back within the JDAI, the juvenile detention alternative initiative, to how do we get those kids treated? Because there is substance abuse, there is mental issues, there are other issues involved. But the money can't come from that pot, and don't take it from that pot. So there has to be that table, I would agree, and we have to be able to analyze where some states potentially have done things better, some states have a different kind of Medicaid state plan that allows flexibility. I'm a believer that we have too many of those people that are slipping between the crack. We can make some systematic or programmatic changes that could facilitate a better outcome. Thank you. [LR300]

SENATOR CAMPBELL: Senator Bolz. [LR300]

SENATOR BOLZ: Good afternoon. I have a particular interest in children's behavioral and mental health needs. I know a lot of people at this table share that interest. And when I look at the statistics and the reports about kids in our child welfare system, I see some pretty dramatic needs for complex cases, kids who might be falling in the gap, falling in the crack. And at the same time, the last statistics I saw, and you can correct me if I'm wrong, say that we're only spending about 10 percent of our regional funding dollars on kids, on kids' behavioral health services. So when you talk about the different regions prioritizing issues, I'm having a hard time reconciling their dramatic needs that I see in the child welfare system with that relatively low level of children's behavioral and mental health services funding in the regions. Can you speak to that and help me understand how we might be able to increase the prioritization of serving kids? [LR300]

SCOT ADAMS: Surely. Legislatively, is the short answer to that. The public behavioral health system is largely an adult behavioral health system. It's focused...it has largely been moving folks out of the regional centers into the community and keeping adults out of the state hospitals, in the community. We have also picked up some responsibilities over time with regard to children and young adults, and your number is, yeah, close; it's about 10-15 percent of dollars spent go to support children. The large number is, of course, Medicaid, which pays for many children who are poor in this state for behavioral health services; and they spend many more times than what we have in the Division of Behavioral Health. The other large system that pays for children, of course, would be the Division of Children and Family Services. Whether through letter of agreement or through other supports, they pay for a great amount of children's behavioral health services in the state of Nebraska. A third system, of course, is private insurance that families have that pay for that. All three of those systems of care pay for more services for children than do the Division of Behavioral Health. [LR300]

SENATOR BOLZ: Certainly. Do you think that the Division of Behavioral Health is well positioned to engage more deeply on the preventative side? I think the ideal would be that we prevent kids from entering the child welfare system. [LR300]

SCOT ADAMS: I appreciate the question very much, and I think that the Division of Behavioral Health is one of the uniquely situated and qualified divisions to work with the issue of prevention. For decades now, the federal government has required the Division of Behavioral Health to spend money on substance abuse prevention across the state. Twenty percent of our federal block grant has to go to fund substance abuse prevention. So we know that worked pretty well. In the last couple of years, the federal government is requiring us to develop mental health resiliency or mental illness prevention. There's still some freshness in all of this on the mental health side. And so I think we have a charter, a mandate, a knowledge base of assets; we have community-based groups with which we work on that topic. We have been working with the Division of Children and Family Services, as their numbers have come down for wards, to develop additional preventative services cooperatively with that division. You may be aware of the recent IV-E waiver activity. That will result I think in a closer working relationship between the Division of Children and Family Services and Behavioral Health and its regions and providers going forward as well. So I think we are about to embark on a pretty neat new moment with regard to the prevention side of all of this. [LR300]

SENATOR BOLZ: Thank you. [LR300]

SCOT ADAMS: Um-hum. [LR300]

SENATOR CAMPBELL: Questions from here, this side? Senator Harms. [LR300]

SENATOR HARMS: Thank you, Senator Campbell. Dr. Adams, in your testimony you indicated we have six behavioral health regions and they're governed by...I think it was the regions, by the county commissioners. Do the county commissioners set their budgets? [LR300]

SCOT ADAMS: The county commissioners approve the budgets. The budgets are typically developed by staff. As I was mentioning earlier, we oftentimes put out sort of priorities for regions to be responsive to, the staff develop the plans. But in each case those budgets are approved by the regional governing board. [LR300]

SENATOR HARMS: Do you think that structure works well? [LR300]

SCOT ADAMS: You know, it has pluses and it has minuses. I think it has developed a great ability to be flexible to the particular needs, resources, and assets of the local area. I think...because I visit each of the regional governing boards at least annually to talk eyeball to eyeball with the person who is signing the contract with me; and so I have those conversations with the county commissioners. And I think I can pretty uniformly report that the county commissioners love this arrangement. [LR300]

SENATOR HARMS: Well, I guess as I look at it, they probably love it because they can control the cost. And my concern is, and I'm not sure that's the best structure to use. My experience is just, where I live in rural Nebraska, looking at the district, sometimes county commissioners are only concerned about the bottom line and they're not concerned about the services. And I would surely urge us to take a good hard look at that because I think that is where part of the problem lies. I listened to...they'll hear the staff, but when it comes down to actually providing the services that I think are, quite frankly, needed for the public, I don't think they do it. Now they might at some but I'm just guessing (inaudible) that governance structure needs to be reviewed because I don't think it works real well. That's my own observations. Thank you. [LR300]

SENATOR CAMPBELL: Other questions or comments for the director? Thank you, Director. (Inaudible) know if you are going to stay around for a while. [LR300]

SCOT ADAMS: Yeah. [LR300]

SENATOR CAMPBELL: And now I lost my list of who's next. I believe it's Claudia Sherman. Good morning, Mrs. Sherman. [LR300]

CLAUDIA SHERMAN: Good morning, Senator Campbell. My name... [LR300]

SENATOR CAMPBELL: We need to have you state your name for the record and to spell it for us, if you could, please. [LR300]

CLAUDIA SHERMAN: Okay. My name is Claudia Sherman, C-l-a-u-d-i-a S-h-e-r-m-a-n. Thank you for this opportunity to testify. I am the mother of 34-year-old Jill Sherman who was first diagnosed with auditory processing deficits and learning disabilities when she was in kindergarten. We had her repeat kindergarten, and then Jill remained in special education through her high school graduation. I sat with her five nights a week at the kitchen table to make sure she understood her homework and to keep her on task. We hired a tutor to work with Jill, one on one. I regret that now. If I had let Jill fail, she would have had much lower scores and might have received services from DHHS when she graduated. Every time I requested services from DHHS for Jill, I was turned down. Jill meets the statutory criteria for services. She was born with developmental disabilities. They will continue throughout her life and she has substantial limitations in self-care, receptive and expressive language, learning, self-direction, capacity for independent living, and economic self-sufficiency. But I was told by the Department of Developmental Disabilities that although Jill's IQ fell below 70 when tested in 2009, it was too late. Jill's disabilities and IQ had to be below 70 before she was 22. She was 30 in 2009. Her disabilities did exist before she was 22 as evidenced by reports of the psychologists and psychiatrists who tested her. Jill's IQ deteriorated after she left high school. After being turned down by the Department of Developmental Disabilities, I was directed to the Department of Behavioral Health, because in addition to her developmental disabilities Jill has some mental illnesses, including bipolar disorder. I was told that Behavioral Health would accept Jill for services, but they had nothing to offer as evidenced by more than a dozen phone calls and visits I made this year to agencies suggested to me by Mr. Adams and Ms. Fenner. So the Department of Developmental Disabilities has the appropriate services but insists that Jill doesn't qualify for them, although they refuse to tell me why in a written document. The Department of Behavioral Health says Jill does qualify but they have no options for services suitable for Jill. That's the dilemma. What they do not take into consideration is that mental illnesses are even more difficult to manage when someone also has developmental disabilities; and developmental disabilities are exacerbated by mental illnesses. Jill could be a contributing member of society, feel good about herself, and perhaps become a taxpayer, if we could access services from agencies such as the Ollie Webb Center, Career Solutions, VODEC, Youth Care and Beyond, Angel Guardians, Developmental Services of Nebraska, and others, rather than face a future of homelessness, becoming prey for human trafficking, or ending up in prison, if the funding mechanisms would collaborate, if DHHS would think outside the box. Perhaps a pilot program that is designed around the person instead of trying to fit the person into the existing services that don't really help would avoid the waste of time, money, and lives. [LR300]

SENATOR CAMPBELL: Mrs. Sherman, and you and I have had an occasion to talk and you were at the meeting that we had in my office, and I know that you followed up on all the suggestions but none of the suggestions worked for Jill. Is that correct? [LR300]

CLAUDIA SHERMAN: None of them worked, right. [LR300]

SENATOR CAMPBELL: Was the primary problem residential or vocational? [LR300]

CLAUDIA SHERMAN: It was pretty much a combination of both. [LR300]

SENATOR CAMPBELL: Okay. And what was lacking in the residential area for you? [LR300]

CLAUDIA SHERMAN: Well, she has to go under behavioral health, and they recommended Community Alliance, and my husband and Jill and I all went to visit Community Alliance. First of all, Jill did not like living with men she didn't know, and they are coed. Second of all, there are people who smoke that live there. They can't smoke in the group home but they can smoke around the outside, and then when they come in they have the odor of cigarettes. And she...that gives her headaches, plus she has an 85 percent chance, because she is BRCA positive, of cancer. And the other problem was some of the people that live there, you know, God bless them, they're trying to get off of drugs, but they may not be completely off or they may relapse. That's one problem we haven't had, and since she's so naive and gullible I don't want her to live around people who may have a relapse and addictive drugs, so. And that was basically the only place in behavioral health that could help us. There were some in developmental disabilities who said they could work with her...work with both the developmental disabilities and the behavioral health, but we weren't eligible for that. [LR300]

SENATOR CAMPBELL: Right. Senator Krist. [LR300]

SENATOR KRIST: Where do you live? [LR300]

CLAUDIA SHERMAN: Omaha. [LR300]

SENATOR KRIST: So the availability of the both sheltered and other workshops, if she qualified for DD programs, is that something that you would be interested in? [LR300]

CLAUDIA SHERMAN: Yes, they are out there and staffing is out there. We pay for as much as we can but, you know, funds only go so far. She needs more than we can afford in order to live more independently. She lives with us now, my husband and me. [LR300]

SENATOR KRIST: So for a common understanding, what we're talking about here is if she qualified for programs under DD, which her IQ is at a point we're talking about her being diagnosed as 30, as opposed to 22, if the plan was revolved around your daughter and she qualified for DD and she went to someplace like VODEC or a sheltered workshop environment, she could be productive; she could be engaged...

[LR300]

CLAUDIA SHERMAN: I think so. [LR300]

SENATOR KRIST: ...she could be trained to do a job. [LR300]

CLAUDIA SHERMAN: I believe so. [LR300]

SENATOR KRIST: Okay, thank you. I just wanted to make everybody understand that that's...you're not being unreasonable in terms of expectation, but you have a person that needs something different. She might be the square peg trying to be put into the round hole. Thank you for coming forward. [LR300]

SENATOR CAMPBELL: Other questions? Just an observation, as I said to Senator Lathrop, however at that point perhaps Jill Sherman would be on a waiting list, because we...I mean, that's sort of the...what's very helpful for all of us at this table today that we're not only hearing the report of the special committee but LR300 and your bill. So to some extent we're getting a broader picture of what families face. [LR300]

SENATOR KRIST: So if we brought her to the table and found a way to do it, our next step would be to try to find the money to do it. But we'd be making progress moving. [LR300]

SENATOR CAMPBELL: We would have to face the fact that there may be a waiting list there. Thank you, Mrs. Sherman. [LR300]

CLAUDIA SHERMAN: You're welcome. Thank you. [LR300]

SENATOR CAMPBELL: Senator Lathrop just said: And we are probably all sitting around this table, other than Senator Bolz and Senator Crawford, term-limited and gone before we can get to that solution. All right. Our next testifier is Janine Brooks. Good morning. We do need to have you state your name and spell it for the record, please. [LR300]

JANINE BROOKS: (Exhibit 3) Thank you. Good morning. My name is Janine Brooks, Miss Janine Brooke, J-a-n-i-n-e B-r-o-o-k-s. I am the legal guardian and parent to Aleene Esther Brooks, a 27-year-old person who has resided in Nebraska since birth. She's also been on ADC since birth, so she's been involved in DHHS all of her life. July 2008, when the safe haven law originally passed in Nebraska, Allye was 21 years old. If I could have legally dropped her off at a hospital, I would have done so out of love, as I've been unable to provide for my daughter's disability needs. Instead, earlier in that year, I filed for legal guardianship, which I was granted. I have since been Allye's legal guardian and conservator. Twice, adult protective services has tried to find an appropriate replacement but each time the arrangement has failed to happen. Allye, aged 27, is unable to obtain appropriate services through DHHS that would allow for her to live as independently as possible with her disabilities. She is confined to the home for a living environment. Her daily aspirations are to clean the house, plays long hours of Xbox, and ride her moped around town. She has attempted to work with no success, she is a failure in academics, and she is extremely bored. Allye has a current diagnosis of Asperger's disorder, ADHD combined, bipolar disorder, and dysthymic disorder. She has verified memory impairments that greatly affect her thought processing, especially when she is agitated or taking in a lot of information. Allye has been this way pretty much all since birth. For benefits, Allye receives SSI, something she has been collecting since August 1994, at age 8. She also receives SNAP of about $150 a month food stamps. She is on the Medicaid waiver program which provides her a couple of chore attendants and respite hours. Ken Munsell, not associated with any agency, is her personal attendant. He comes out to the house every day for anywhere between 4-6 hours, even though he is only paid for 24-25 hours a week. This man will also come out to the house when I call him desperate for help during one of Allye's meltdowns. An agency called Special Sitters comes out on Saturdays to help by taking her out to do an activity of 4-5 hours. Allye receives respite hours--she either goes out geocaching with Ken or she attends activities on a Friday or Saturday night at the VSP Club. Twice a week Allye is transported to Lincoln for therapy with Dr. Diane Marti, a psychologist who specializes in the treatment of females with autism. While in Lincoln, on Wednesdays, Allye will stay after her therapy session to participate in group therapy, something that I pay for. Medicaid pays for the transportation of Allye back and forth to Lincoln. I have attempted to find suitable psychologists in the Omaha area, but have had little success. Allye sees a nurse practitioner approximately every six weeks. She takes medications but not on a consistent basis. I cannot get her to understand the concept of a pill tray. Often officers from the Omaha Police Department come to the house, usually on a weekly basis, sometimes three to four times during the week. They've tried many times to have her placed in the mental health hospitals, but these places refuse to treat her, claiming her level of care needs are too high for them to address. My neighbors will tell you they have tried multiple times to have her arrested, but the police refuse to do so. My one neighbor now films her behavioral meltdowns and rages, claiming that he plans to take us to court to force us to move out of our home. He perceives us as a disturbance to his right of quiet enjoyment. Allye and I tap into community resources as much as possible. In Omaha, she attends a social peer group called Transitions at UNO. She also participates in the Miss Amazing Pageant and its periodic side events, where she learns things like public speaking and interview skills and how to advocate for herself. And in the summer, she goes to Easter Seals camp. She also participates in a sheep shearing program at Luv-a-Lamb. These are the things that I've been able to find for her. Allye also volunteers a good deal of time at the Community Bike Shop and at Good Karma Dog. These are, for the most part, her benefits. Now a few insights or complaints. On the note of transportation, Allye uses AMR/Access2Care, as required through the Medicaid waiver program. Originally, we arranged all of our rides through them, but found the agency to be extremely unreliable in getting Allye to her appointments. Because of the distance--Omaha to Lincoln--AMR often cited the difficulty of locating a driver. AMR ended up hiring my father, Duane Brooks, as a personal driver for Allye. There is a note on file that allows me to arrange for Allye to go back and forth to Lincoln twice a week. I understand that's called an ICAP. Sometimes that note disappears because of some computer difficulty, and then I am treated extremely rudely and disbelieved, even though I have routinely set rides up with them once a month. They usually deny all those rides and I am forced to have to call down to the Medicaid waiver folks, usually League of Human Dignity, and then the folks down in Lincoln, DHHS transportation, to resolve these issues. This has happened four or five times that I recall since AMR was selected to provide transportation. The Medicaid waiver does not allow for me to contact someone to talk about care issues. I cannot explain it enough, but I have to call at the state level to get answers or to complain about problems in an effort to find alternative solutions or care routes. Allye is not eligible for a case manager to handle her affairs, so I have to call many of the organizations themselves to determine if Allye might be able to tap into their services. Most of these end up with "no's." You should be aware that I am currently in my second appeal with Developmental Disabilities. Recently, I was in an informal dispute resolution, and members are present here for that. I understand it cannot be talked much about. I will also tell you I have a formal complaint filed with the Office of Civil Rights, claiming discrimination against Aleene, that is presently being investigated. I have filed a complaint also with Adult Protective Services against DD. And although in the past they have found me at fault, telling me that I cannot even leave my home for my own protection, they will not investigate their own agencies. So the summer of 2006, when my daughter tried to kill herself four times, I was put on the registry for that, because I left the home. But they didn't do anything to investigate Developmental Disabilities, who was partially the cause of Allye's depression at that time. My first appeal to DD services ended in failure. I was bulldozed over in a court that I had not realized was so formal. My evidence was not allowed to be considered because I did not submit it in a timely manner, nor was I able to locate an attorney willing to help me in court. I went through Nebraska Advocacy but they never had been through a DD appeal; so we were all unaware of how important it was to file in state district court when we lost the formal appeal. It's been ten years that I've been fighting for DD services. It took me forever to get this second attempt for consideration of services.

Each time I saw a different psychologist trying to bring in new information for DD to consider, but the information has constantly been rejected with no right of appeal. Senator Campbell has copies of all of my rejection letters. I can tell you each denial varies greatly from the previous as to why Allye does not qualify for services. And all of the rejections skirt around the problem in trying to wedge Allye into their pegged holes, instead of trying to find an alternate solution. The latest letter cites a neglectful home as a plausible reason Allye is the way she is. Yet, for proof of a bad home environment, I received a hospital placement for pneumonia when Allye aspirated vomit the day after having her tonsils removed. Several years ago, in 2012, Dr. Scot Adams of Behavioral Health requested that a psychological exam be performed by Dr. James Madison. Senator Campbell has a copy of that report as well. It is the most recent report completed in January 2013. On the last pages are recommendations which I will go over that lean toward the need for developmental disability services. We believe that Allye meets five of the seven requirements for services, but she was not diagnosed with autism until age 19. [LR300]

SENATOR CAMPBELL: Ms. Brooks, and I'm watching the clock and I want to leave some time for questions. [LR300]

JANINE BROOKS: Okay, I'm sorry. [LR300]

SENATOR CAMPBELL: So if you could kind of wrap up so we have time for any questions for you. [LR300]

JANINE BROOKS: Okay. I just want to explain one incident real quick. The problem that we're at right now, Allye can't live. She wants to go to Metropolitan Community College to be a culinary chef. She can only take one class a quarter due to her memory issues. In order for her to qualify for adaptive technology, she needs to take 12 credit hours. She can't do that. She's failed multiple times at Metropolitan, so she's no longer eligible to go because she can't qualify for financial assistance anymore. So I have to pay for that. We went to voc rehab and voc rehab won't allow her to participate in their program. She has to have a job first to do that. We cannot access a day program in Omaha very similar to what Mrs. Crawford said. Community Alliance and Friendship program are designed for drug issues and mental health. They do not know how to deal with anybody who has autism. And it's despicable. That's all I have to say. [LR300]

SENATOR CAMPBELL: Ms. Brooks, are you currently receiving any services under Region VI? [LR300]

JANINE BROOKS: No. Allye aged out at 25. [LR300]

SENATOR CAMPBELL: Okay. So there...you...but you did use them. [LR300]

JANINE BROOKS: We used Region VI multiple times, their Professional Partners Program. They were involved in the first appeal. We've had several meetings during the time we were with them where we brought people in, but nobody could help us. [LR300]

SENATOR CAMPBELL: Okay, thank you. Follow-up questions from the senators? Okay. Ms. Brooks, if you wouldn't mind leaving a copy of your full testimony in my office and we'll make sure everybody gets a copy of it. [LR300]

JANINE BROOKS: Thank you. Thank you for hearing me. [LR300]

SENATOR CAMPBELL: Thank you very much. Mr. Evans. Eric Evans. Mr. Evans will be our last testifier this morning and then we will resume after lunch. While Mr. Evans is getting seated, we will then, after lunch, have Mr. Reay, Mr. Spaulding, and Ms. Reynolds. Are there any other people who have come to testify for LR300? Okay, one. Well...oh, I'm sorry, Marla. I skipped over you. If you don't mind, I'll pick you up at 1:30. Anyone else that I might have missed? Okay. All right. We will pick up that extra testifier; and when Senator Krist comes back we'll let him know how many people we have left. Mr. Evans, go right ahead. State your name for the record and spell it, please. [LR300]

ERIC EVANS: (Exhibit 4) Good afternoon. Thank you, Senator Campbell, members of the Special Investigative Committee and the Health and Human Services Committee. My name is Eric Evans. That's E-r-i-c E-v-a-n-s. And I'm the chief operating officer at Disability Rights Nebraska, a federally funded protection and advocacy system for Nebraska. I'm not going to read through my entire testimony. I obviously don't have the time even if I would attempt to do that unless I could really do that kind of speed talking kind of thing. [LR300]

SENATOR CAMPBELL: We appreciate that. [LR300]

ERIC EVANS: In 1975 I was asked to develop a program at the Lincoln Regional Center for people with developmental disabilities and mental illness. And that was conditioned, in part, because of a passage of the Medicaid act which allowed for the establishment of intermediate care facilities for the mentally retarded...or now, for the developmentally disabled. We had a 30-bed unit there and we accepted people from community settings, and one of the things that we found, frequently, is that once we accepted folks and we worked with them and our professional treatment team had determined they were ready to return to the community, the providers really didn't want to take them back because they were very challenging folks to serve. That was very frustrating. I'm sure that similar things are happening at this time. In fact, Director Adams mentioned some instances in which those individuals are still finding difficulty in being placed in community settings. So this isn't a new thing. In fact, in the early 1970s, or in the 1960s, '70s, and '80s at the University of Nebraska Medical Center we had individuals who had considerable expertise in this matter; in fact, they were nationally recognized: Dr. Frank Menolascino, in particular. That program is no longer robust. I do believe there is an individual or a few individuals at the Medical Center who still have some interest in this area. But during the interim there's also been the rise of the National Association for Dually

Diagnosed, so there is a national group now who has considerable expertise in serving this particular population. Recently, we've had some work done in Nebraska. The state plan for developmental disabilities services, that was I think put out in 2007, had a specific goal and objectives around serving this particular population, or at least trying to figure out how we can better serve this particular population, even though there were no real substantive outcome measures in that plan in terms of how we will know when we have gotten to the point that we are being able to effectively serve individuals who are dually diagnosed. The strategic plan for behavioral health was issued I believe in 2011 or so, although it does not have any particular focus on this particular population. So there is a little bit of discrepancy in the planning activities between the Division of Behavioral Health and the Division of Developmental Disabilities in regard to this population. The Governor's Planning Council on Developmental Disabilities in 2008, I believe, funded a three-year grant with the Region VI Behavioral Health Services. And as a result of that, they brought together people within the Region VI region to have discussions about this particular issue and how they could better address this population. And a number of barriers and limitations were identified in that report, and, you know, that report is available from the Developmental Disabilities Planning Council or through Region VI; and I would urge that you look at that report to get a sense of, at least in that particular area, the kinds of issues that are being raised. Director Adams and Director Fenner, I believe, both mentioned a study that was done in, I think, 2011, which again focused on this particular population. So it isn't that we haven't been here a number of times in the past to deal with this population. It isn't that over the last 40 years...it is a fact that over the last 40 years we have not been able to successfully resolve how to provide services to this challenging population. One would hope over the course of 40 years we have made some significant inroads, and listening to Director Fenner's behavior...testimony, and Director Adams' testimony today, it seems like there is movement in that area. We still aren't done with the work. Now both the national associations for mental health program directors and for developmental disabilities services directors have identified a number of recommendations and I've included links to those documents in my testimony. The National Association of State Developmental

Disabilities Directors, for example, identified a number of particular recommendations. The first that I want to highlight your attention to is the lack of established public policies to support model collaborative programs for this population. And if we don't have that kind of policy framework, there's a high degree of likelihood that the programs for this population will be at risk. The second recommendation talks about fostering interagency collaboration. Now again, we've had opportunities for meetings between the two divisions, but we haven't really moved to the place where you have formal or even informal interagency agreements. Again this problem has existed for 40 years and we haven't really conducted a systematic evaluation of the nature of the services that are available to this population and what needs to happen. One of the big issues that I heard today was the absence of any, or very few, cross-training opportunities so that we can develop collaborative expertise in serving these individuals and improve our systems of care. And finally, state funding schemas should require interdepartmental training and collaboration. When we look at the National Association of State Mental Health Program Directors report, of the states responding, 36 percent had a written interagency agreement between the various parties; 74 percent had a task force to address issues in serving this population. And this is the task force at the state level, not just the task forces that are going on locally, which are equally important. Sixty-eight percent had an interagency agreement regarding payment and services coordination; 63 percent offered some kind of cross-training or technical assistance. And again, it seems like we're moving in that direction but we need to be doing more and we need to be being more thoughtful and "planful" as we move forward; and 63 percent collaborate across agencies for discharge planning from state-operated facilities. Again these are things that we're seeing here but we need to do more. As a state we are hampered by a lack of technical expertise in identifying and serving individuals with dual diagnosis. Despite the efforts to try to attract individuals to work with this population, we have not really been successful in developing the cadre of professionals and support staff that are necessary to ensure that these individuals are served in the least restrictive settings possible. Another thing that we should be thinking about is the change at the national level from mental retardation to intellectual disability. This change is starting to be reflected in federal law. The Individuals with Disabilities Education Act has now removed "mental retardation" and replaced it with "intellectual disability." I give you some links to the American Association for Intellectual and Developmental Disabilities and the DSM-V, because both of these entities have developed a definitional framework for intellectual disability as opposed to mental retardation. One of the things about this particular framework is that that IQ issue about, right now, mental retardation, you have to be below 70; so 69 or below is the...that's the cutoff for mental retardation. With intellectual disability, we're seeing a higher cutoff point: 75. And there's even some question whether the IQ criteria is even something that we should be giving so much attention to. Also when we look at the data from the report, we see the high number of individuals in DD services, people who are eligible for services and are receiving services, or are eligible and not yet receiving services, we see a large proportion of people who have mental health and substance abuse service needs as well. So, you know, that again should cause us to think and say, what's going on with this population? Are the services that they're receiving appropriate? Are we adequately monitoring those services to make sure things like "poly-pharmacy" isn't occurring? And finally, we have to work hard to eliminate the silo effect. And you've already talked about the silo effect today; you're real clear on what it is and the problems that it creates. And this population is one that it really creates some significant problems for. [LR300]

SENATOR CAMPBELL: Dr. Evans, you probably...I think you're almost done. I've been following you. [LR300]

ERIC EVANS: Yeah, I'm going to make one more comment and then I'll finish, and that comment is the work that you're doing and have done as a special DD investigative committee is remarkable, and we are so appreciative of your willingness to tackle this issue, of your commitment to try to understand the complexities of all these various systems. But the last six years hasn't been stellar for the department. There's been a lot of things that have come out. Most recently, we've had the issue with the State Auditor's report around the AABD programs and the issue with state guardianships. And, in fact, the department has been instrumental in securing the services of corporate guardians for individuals: corporate guardians like Judith Widener. We also are very concerned about assisted living facilities in Nebraska in which people with developmental disabilities and people with mental illness find themselves placed. In many cases these are isolated and congregated facilities in very small communities, frequently or in some cases where the residents of the facility total more than the regular population of the community. Given these issues, we would ask that you give consideration to expanding the scope of the Special Investigative Committee to include health and human services in general. The issues with the guardians, the issues with assisted living facilities, these are just the tip of the iceberg that we're starting to uncover. And we need your oversight to ensure that the most vulnerable people of Nebraska are protected. We can't do this alone as a protection and advocacy system or as other advocacy organizations. You have and are uniquely situated to undertake that oversight. Thank you. [LR300]

SENATOR CAMPBELL: Thank you, Dr. Evans. Questions or comments from the senators? Dr. Evans, I...oh, I'm sorry. Senator Wallman, I apologize. [LR300]

SENATOR WALLMAN: Thank you, Chairman. And what really bothers me about the, you know, the state agencies, 62 percent offer some kind...or 63 percent collaborates across. Man, you'd think that would be 80-90 percent, wouldn't you? [LR300]

ERIC EVANS: If we lived in an ideal world, it would be 100 percent. But, you know, the reality is we don't live in an ideal world. And for politics...political regions, economic reasons, personal reasons, there's all kinds of reasons that can diminish that ability to meet that more desirable target that you suggest. [LR300]

SENATOR WALLMAN: Thank you for coming. [LR300]

ERIC EVANS: You're welcome. [LR300]

SENATOR CAMPBELL: Any other comments? Dr. Evans, thank you for very thorough testimony. I appreciate that you didn't read every word of it, and I apologize for sort of wrapping up. But you have a lot of wonderful information in there, and I hope we are comfortable to call upon you if we have questions. [LR300]

ERIC EVANS: I'm at your service any time. [LR300]

SENATOR CAMPBELL: Okay, thank you. [LR300]

ERIC EVANS: Thank you very much. [LR300]

SENATOR CAMPBELL: We will recess the LR300 hearing until 1:30 here in Room 1524. Thank you. [LR300]

RECESS

SENATOR KRIST: Good afternoon. Sorry for the delay. My name is Bob Krist and I'm the Vice Chair for the Health and Human Services Committee. And Senator Campbell had to leave unexpectedly, so I will be trying to orchestrate this afternoon, with the help of Senator Lathrop. And we are going to start this afternoon with Mr. Reay, Bill Reay. If you would please, state your name and spell it for the record. [LR300]

BILL REAY: Sure. My name is Dr. Bill Reay, B-i-l-l R-e-a-y. I'm the president and chief executive of OMNI Behavioral Health, the president of the Coalition for Behavioral Health Research to Practice, which is a cross university-research institute aimed at assisting the service community with the latest research results to improve practice. I'm also the executive director of International Academic Program Development for Northcentral University, and the current treasurer of the American Orthopsychiatric Association. In Nebraska, I have been a service provider for more than 25 years. I have worked very closely with every HHS director since Governor Bob Kerrey. I have survived the calamitous results of the state's attempts to reduce costs, privatize child welfare services, and shift responsibilities from one state agency to another. I actually began my career when the counties in Nebraska turned over their responsibility for child welfare services to the state. Over the years, I've been appointed by various Governors to chair and lead child welfare, behavioral health, and intellectual disability movements, including the development of the 1184 investigative and treatment teams, behavioral health reform efforts during the '80s and '90s, and death review teams associated with individuals with intellectual disabilities. I have represented Nebraska in many federal-state partnerships, including being one of the early developers of a child and adolescent service system program system of care, a founding member of the National Federation of Families for Children's Mental Health, and been a member of the United States Department of Education's evaluation team regarding the implementation of the system of care around the country. Consequently, I believe I'm uniquely qualified to provide you with perspective on this issue. The challenges associated with this population, a population most frequently referred to as those with dual disorders, mental health and intellectual disabilities, are really those individuals with multidisorders. Most of these individuals also have serious physical complications: diabetes, heart disease, chronic issues related to diabetes. So these are the most complicated people that the state has to serve. The challenges associated with serving this population are complex, and to adequately address them will require a concerted effort across disciplines, state and local government agencies, universities, and communities. Although the ultimate response of these demands eventually lands on the executive branch of state government, the tools necessary for that branch to adequately plan and execute that response are going to be forged by you, the leaders of our universities and college system, and the quality of the reciprocal relationships created by county governments and government interlocal organizations, like the regional behavioral health and offices of developmental and intellectual disabilities. It is absolutely important that this committee recognize the vast majority of direct-line employees who provide mental health services to the intellectually challenged are high school graduates, people with two-year degrees, some with bachelor's degrees, and it's very rare that you're going to find anybody with a master's degree. Some have the master's degree, but it's rare. The turnover rates associated with the work force are shocking, which prohibits creating a well-trained and stable work force. The work force for the most seriously challenged, most complicated patients in this state are not the high-trained psychiatrists or the psychologists. They are the grunt trench workers that don't have advanced degrees or high training. In close to 30 years of providing behavioral health organizations and organizations for services to intellectual disabilities, I have never been approached by any director of curriculum and instruction by any university or college in this state asking me what they can do to prepare students for the demands of the community. Attempts to engage various academic programs at several of the larger university programs across Nebraska to change their curriculum to one that is more relevant has been met with objections. For example, there is no standard undergraduate or graduate class in the use of electronic database management, one of the fundamental things that you listened to from Jodi Fenner. We're not being...the people that are implementing this aren't being trained at the university level at all, so they come in, they have to be retooled. Ladies and gentlemen, I don't know if you'd be shocked, but I was, to learn that it takes 14 years for a research result to get to an end user therapist in Nebraska, 14 years. And what is more pathetic is that the technology necessary for that therapist to get those results is unavailable to 90 percent of the providers. And if it were available, most of them would not know how to use the technology because they're not being trained. Clearly, the colleges and universities of Nebraska need to step up and assist in educating our next generation of both paraprofessionals and professionals. It is time to recognize that the workhorses of this industry include the lowest paid, least understood, and most untrained. They do not lobby you. They do not have a professional organization. And they are very unlikely to sit down with you and visit with you and tell you the problems of the system. They are regular citizens that want to help but really don't know how, and the organizations that employ them can't do it. Willing it to be better and legislating it to be better is a virtually hollow expectation without providing the work force with the skills that are necessary for high performance. I see that I have a yellow light, so I'm going to have to move quickly. The biggest problem that I see at this point is that there is no systematic evaluation of any behavioral health provider in Nebraska. Money is given out not by what is produced. There is a system of favoritism, cronyism, and folklore at the regional system...at the regional level. It's not an open system. They dole out money to their friends--absolutely no evaluation whatsoever. The behavioral health system in Nebraska is in serious disrepair. Do you know that the regional systems have taxing authority? They have an ability to tax at the local level. Since 1972, they have never done it, ever. In stark contrast to the Behavioral Health Division, Jodi Fenner's division, the Division of Developmental Disabilities, has been cutting new ground in services. Although not perfect, has clearly stepped up to develop services for very, very complicated patients. Under her leadership, the agency has repeatedly responded to the needs of individuals in which they can, those people that are actually qualified. Consequently, many consumers and advocates believe that they'd like to see any initiative that comes out to be managed by the DD division. Although I believe doing so would provide some short-term benefit, it would set up the very unfortunate expectation for this division to do more than it is currently authorized by statute to do, while simultaneously allowing the behavioral health system to slip into even more disrepair, inefficiency, while marginalizing the real problems of seriously mentally ill folks. Want to thank you for your time. I have a few minutes for any specific questions. [LR300]

SENATOR KRIST: Thank you so much. And I failed to mention before we started we are on a light system this afternoon, so you'll see a green light, to be the first four minutes of your talk. When the yellow light comes on, there will be one minute left, and that takes you to five. And at the five-minute point, if you haven't already wrapped it up, please do so. Thank you for being conscious of the time. Are there any questions for Mr. Reay? Senator Harms. [LR300]

SENATOR HARMS: Dr. Reay, thank you very much for coming. [LR300]

BILL REAY: Sure. [LR300]

SENATOR HARMS: Your discussion about the regional commissions or regional areas have taxing authority, that was my very point I was trying to make earlier and I didn't bring that part of it up, that many times in those district areas are made up of county commissioners. They're not going to...they're only interested in the bottom line and that's the reason why a lot of them will not tax. We could resolve some of this issue a little bit by bringing the private and the public together... [LR300]

BILL REAY: Yes. [LR300]

SENATOR HARMS: ...in a much better way to do this. And I really always have felt that that's a big factor with that. They may listen to people who have the background and training in those regional areas, but they just don't implement it. [LR300]

BILL REAY: Yes. [LR300]

SENATOR HARMS: And I think that's a tragedy for the people we're trying to serve. The other thing I wanted to comment, I know that when we went into Beatrice and took a good look at the issues that were there, which were numerous, the one thing that came out really very loud and clear is, one, the technology system was inadequate and, two, they couldn't use the inadequate system to start with because they didn't have the background. The whole system had never been addressed and dealt with in an appropriate manner. And secondly, they lacked staff development. They brought people in, put them in positions, and nothing ever happened. They just lacked that. I don't know whether they've gone through the staff development and made a difference now and whether they've increased that or improved it, but it just literally was lacking. And those are my concerns and I think you're right on target with what you said. I think the biggest issue is going to be, for this Legislature, is going to be how are we going to attack this problem, because it's not going to go away. It hasn't gone away and it's going to get worse. And I think we're going to have to decide how do you want to...how do you want to dissect that issue or do you want to wait and see what a new Governor might do? I don't know what that answer to this is. But I don't think we can go on any longer. [LR300]

BILL REAY: Right. [LR300]

SENATOR HARMS: That's my own personal views. Thank you. [LR300]

SENATOR KRIST: Would you like to comment? [LR300]

BILL REAY: I agree with you 100 percent. Forty years, as Eric Evans was referring to, something that lasts and festers for forty years is a massive cultural problem in the state of Nebraska. I see Nebraska as kind of an aircraft carrier. Not a lot of people coming; not a lot of people going. So you have to work with what you got, and we're not doing anything to develop a work force or a bench of people that are ready to move forward for the next 40 years. It concerns me as a citizen very much. [LR300]

SENATOR KRIST: Any other questions? Senator Lathrop. [LR300]

SENATOR LATHROP: Tell me what type of people do we need to...what professions do we need to turn out from the university to be equipped to do the work that you're talking about. [LR300]

BILL REAY: We need... [LR300]

SENATOR LATHROP: Are we talking about psychologists or licensed social workers? [LR300]

BILL REAY: Well, the whole group, the whole group, counselors, psychologists. Eighty percent of behavioral healthcare in the United States is produced by master's level people and below, right? Now I know that you get a lot of lobbying from the guilds, the large guilds--psychiatry, psychology--which is all fine. But they don't...they're not the workhorses of the profession. The workhorses of the profession are the least trained, least monitored, and the ones that provide the most care to the most seriously involved. A lot of psychiatrists won't... [LR300]

SENATOR LATHROP: That's true...that's true in hospitals though too. [LR300]

BILL REAY: That's true everywhere. [LR300]

SENATOR LATHROP: I mean we delegate everything down to the... [LR300]

BILL REAY: That's absolutely right. You push it down as far as you possibly can so you can walk away from it. So...and this is not sexy work. [LR300]

SENATOR LATHROP: No, I'm... [LR300]

BILL REAY: All of these people are highly lethal. They die, right? People don't want to jump in and work with them because they're complicated. And so when parents say they're desperate, right, I can line up multiple providers that go into the parents' shoes every day and say, yes, it's desperate. I don't have the techniques, I don't have the technology, I don't have the support. And when I get a bad outcome, I'm blamed. Right? It's the same...it's the same thing. It's all the professions. It's all the schools that are trying to churn out bachelor's, master's level people, and Ph.D.s. A lot of the Ph.D. folks, they don't want to do this. They'd do, rather, marriage and family therapy. They don't want to deal with seriously mentally ill people that could possibly shoot somebody. I mean that's not for the timid or the weak to work with this bunch, right? [LR300]

SENATOR LATHROP: So what education? If...I'm having trouble understanding your testimony. [LR300]

BILL REAY: Yeah. [LR300]

SENATOR LATHROP: Do you think we need to train the people who are the front-line workers... [LR300]

BILL REAY: Yes. [LR300]

SENATOR LATHROP: ...better, or we need more master's... [LR300]

BILL REAY: Yes. [LR300]

SENATOR LATHROP: ...or more Ph.D.s? [LR300]

BILL REAY: Yes. [LR300]

SENATOR LATHROP: All of the above? [LR300]

BILL REAY: Yes. Yeah. [LR300]

SENATOR LATHROP: Okay. [LR300]

SENATOR KRIST: Senator Harms, follow up? [LR300]

SENATOR HARMS: Yes, just one other thing, Dr. Reay. In our final report, in our recommendations that we made with just Beatrice, the issue that Senator Lathrop led to go out and investigate that particular area, we talked about having them sit down, someone sit down with the university and higher education and see if we couldn't begin to develop apprenticeships and internships where you're supervised by the university or the community colleges, or whatever level it happened to be that you're in, to give these young people the experience on-line to determine what it's like to be in that kind of environment and that kind of setting. [LR300]

BILL REAY: Absolutely. [LR300]

SENATOR HARMS: And I don't think they did that. And if they have, they haven't been very successful with it because we're still failing... [LR300]

BILL REAY: Yes. [LR300]

SENATOR HARMS: ...in that particular area, so. [LR300]

BILL REAY: There's a lot of pushback from the universities to get out into the community. They don't like to do that. It's hard work. [LR300]

SENATOR HARMS: But I think that it should be a part of their curriculum... [LR300]

BILL REAY: Yes. [LR300]

SENATOR HARMS: ...and it should be a requirement to participate in this. [LR300]

BILL REAY: I agree. [LR300]

SENATOR HARMS: Because if you can get a master's degree and doctor's degree, which I have done, and unless you're in the field and have the experiences, it doesn't mean anything. [LR300]

BILL REAY: That's right. [LR300]

SENATOR HARMS: I mean you don't know how to actually get involved and how to deal with someone who's mentally ill or who has physical problems. It's hard to make that adjustment. And you can go all the way through that program and all of a sudden realize, I don't belong here. [LR300]

BILL REAY: Right. [LR300]

SENATOR HARMS: This is the wrong degree for me to be in because I don't know how to do that. [LR300]

BILL REAY: Correct. [LR300]

SENATOR HARMS: I think we do a disserve to the students also. [LR300]

BILL REAY: I do too. [LR300]

SENATOR HARMS: Thank you. [LR300]

SENATOR KRIST: Senator Gloor and Senator Bolz both had a question. But just on that, a very quick question for the senators, a piece of legislation we passed last year, LB361, has now required a new evaluation, a new education, a new training program for our probation officers. They're becoming hybrids. They're becoming folks who are both in social work and probation. So the...conceptually what you're talking about is not far-fetched from what this body has done in the past. [LR300]

BILL REAY: Great. [LR300]

SENATOR KRIST: Thank you. Senator Gloor. [LR300]

SENATOR GLOOR: Thank you, Senator Krist. Dr. Reay, I guess I would say, in the interest of recognizing that the staffing issue is still a problem but trying to compare it to acute care is, in fact, not correct. And in fact, in acute care I would say it's reversed. The sickest patients usually are the ones for which we pay the most. [LR300]

BILL REAY: Uh-huh. [LR300]

SENATOR GLOOR: And few people would argue that cardiologists and neurosurgeons and orthopedic surgeons don't do well... [LR300]

BILL REAY: Yes. Right. [LR300]

SENATOR GLOOR: ...or that there isn't in many cases such a rush to get those individuals trained, that now we in fact suffer from the opposite, which is it's hard to find the primary care physicians and the internists to provide for more routine care. So more routine care or primary care kind of goes for want because there's been such a focus on the high end and the sickest patients. And the difference there I think is a reimbursement issue, that I think when you deal with behavioral health what you're dealing with are complexities that make it difficult for insurers to feel comfortable reimbursing. And so part of what we have to look at here is, how do we pay for some of these services for our most desperately behavioral illnesses? I think that's got to be part of the overall formula. [LR300]

SENATOR KRIST: Thank you, Senator Gloor. Senator Bolz. [LR300]

SENATOR BOLZ: Hi. [LR300]

BILL REAY: Hi. [LR300]

SENATOR BOLZ: I'm curious to get your opinion. I've looked at this issue a little bit, and as far as I can tell there are several models out there but two that I'm familiar with are better leveraging Medicaid dollars to do training and staff development within our current pool of folks, and then another approach is partnering with maybe the College of Direct Support or some of the other national organizations that have a curriculum out there and seeing how that can be implemented at the community college level. Do you have any insight into whether or not one is preferable over the other, or if we need both, and? [LR300]

BILL REAY: My advice would be both. [LR300]

SENATOR BOLZ: Uh-huh. [LR300]

BILL REAY: One is a work force development issue and the other one is a reimbursement issue. And they're both values, clearly,... [LR300]

SENATOR BOLZ: Uh-huh. [LR300]

BILL REAY: ...how you're going to value what you're doing. But I think there's room for both and both are necessary,... [LR300]

SENATOR BOLZ: Uh-huh. [LR300]

BILL REAY: ...especially in a state like this. [LR300]

SENATOR BOLZ: And one other question, if I may. I'm sort of familiar with your organization... [LR300]

BILL REAY: Sure. [LR300]

SENATOR BOLZ: ...and I think that you serve some clients who are accessing your services and are engaged in the foster care system. Is that right? [LR300]

BILL REAY: That's correct. [LR300]

SENATOR BOLZ: Can you shine any light on the...your experiences with the way in which foster kids are assessed when they come to you? Do you feel that the child welfare system is doing a good job of assessing their diagnoses and their needs before they come to you, or do you feel like that's an ongoing challenge? [LR300]

BILL REAY: That's a great question. The problem, and I don't want to belabor this too much and take up too much more time, but, quite frankly, there is not one single child welfare system anymore. You've got half of it in Omaha privatized. The problems with that system are horrendous. You get other places in Lincoln where the state has taken it back over. You will get more consistent reports. The turnover at that organization is so bad that you can have four or five workers within a two-month period that don't have records. And so you are literally having extremely difficult folks that they don't even know who they are. And so to even get to the point of whether or not they're evaluated properly is like four steps down the road. And so to answer your question, it depends. It depends on who is making the referral. It depends on who the unit supervisor is. And in many respects, because of the way things are right now, there's no stability. And you have tribes. I refer to them as little tribes. And so if you're lucky to get a referral from a good tribe, then you will have complete information. If you get it from a bad tribe, you will not get complete information. [LR300]

SENATOR BOLZ: That's helpful. It sounds like work force issues are pretty central. [LR300]

BILL REAY: Again. [LR300]

SENATOR BOLZ: Thank you. [LR300]

BILL REAY: Again, yeah. [LR300]

SENATOR KRIST: Thank you, Doctor. [LR300]

BILL REAY: Thanks. [LR300]

SENATOR KRIST: Any other questions? Thank you very much. Thanks for coming. [LR300]

BILL REAY: Okay. [LR300]

SENATOR KRIST: Next on the list is Will Spaulding. [LR300]

WILL SPAULDING: Good afternoon. [LR300]

SENATOR KRIST: Good afternoon. Please state your name and spell it for the record. [LR300]

WILL SPAULDING: (Exhibit 5) Dr. Will Spaulding, S-p-a-u-l-d-i-n-g. I'm here representing the Nebraska Psychological Association. I'm a professor of psychology at UNL. I train graduate students to work in this area. I really had not prepared to speak specifically to the training issues, but I would be happy to do so if you want to continue the topic that you started with Dr. Reay with regard to where psychologists wind up in the system and why we don't have enough of them. What I do want to tell you about is the Nebraska Psychological Association started analyzing these issues when we first heard about LR300. We produced an analysis that is summarized in a letter that we sent to Senator Lathrop last month. I've made copies for you that you have in your hands now. That letter is also a cover of a stack of other studies and historical information and related stuff, which in the interest of saving trees I didn't make copies of. But I have arranged to send it to your staffs electronically so that you can access the information that the summary letter refers to. So what I'll do is tell you the major points of the conclusions of our analysis. First, our bottom line recommendation to the committee is follow the money. Follow the money liberated from the regional centers by LB1083 in 2004; track the consequences of closing programs; determine who is responsible for what outcomes; look at the regional mental health plans implemented after LB1083 became law and up to the present, and at the hemorrhage of resources away from the historical institution population that those plans reflect. Look at what has happened in the regional centers. Look at the living conditions in the so-called assisted-living facilities and the day programs that now amount to adult baby-sitting. All of these serve the previously institutional population. The results all fit together into a big picture of state-level policy and administrative failures that have been accumulating for almost ten years now. Leading up to that bottom line are the following points about the system. First, the bureaucratic organization that divides developmental disability and behavioral health into two silo-like divisions is fundamentally an anachronism. The fundamental structure of the behavioral health organization at the state level needs reform. Next, the crack between the DD and the BH systems into which some have historically fallen has become a chasm. We need to reevaluate the state's role in providing a safety net for those whose needs will not be met by privatized healthcare. Next, the state service system and regulatory structure remains overly dependent on hospital-based, so-called medical mental health services, and that has created large gaps in the service continuum. We need leadership that understands modern psychiatric treatment. Next, the private sector is not stepping up to develop community-based alternatives. There are four interrelated reasons why community-based private sector alternative services are not developing. Those are: number one, a failure in fiscal accountability at the state level, allowing resources for the institutional population to go to other purposes and other providers; second, a lack of planning that reflects no understanding of the institutional population's needs; third, risk issues that the private sector cannot efficiently manage characterize the population that we're talking about; and finally, market forces deincentivize serving the institutional population. There are compelling reasons why private providers are not doing this and that's not going to be corrected by privatization. We feel that the overall solution is a mandate for technical competence at the state level and an affirmation of the need for a safety net for the most vulnerable individuals still at risk for institutionalization. The solution must also include systematically changing the bureaucratic culture that has prevailed for many decades and several Governors, and the lack of accountability in the relationships between HHS, regional-level administrators, and private sector providers. NPA looks forward to working with all of you further in figuring this stuff out. We are confident that given enough time and effort we will find ways to make lasting changes for the better in the mental health system. Thanks. [LR300]

SENATOR KRIST: Thank you, Dr. Spaulding. Any questions for the doctor? Senator Harms. [LR300]

SENATOR HARMS: Thank you very much for coming. I noticed in your letter that you sent to Senator Lathrop or the letter that went to Senator Lathrop, under the private sector, the fact that they're not doing what they should do. Could you help me better understand about the planning process and what your thoughts are in regard to that? How would you go about actually putting this thing together and getting it to the planning process with the private sector or the public sector? [LR300]

WILL SPAULDING: What the planning process has to do and which it's failed to do is anticipate and allow for the fiscal incentives against serving the population that we're talking about. Historically, this is a population that's been served in the public sector. Even if the funds are available, the private sector doesn't have the history or the track record and many of the work force issues that Dr. Reay is talking about, sufficient to serve this population. In order to deal with that reality, there has to be some high-level planning and some regulatory change to make sure that the funds that we intend for the population actually wind up in the services for that population. [LR300]

SENATOR HARMS: In order to bring this together, who should have the responsibility to start this process, the planning process, bringing people together, sitting down at the table and getting after this particular issue? [LR300]

WILL SPAULDING: Well, let me answer it this way. When the behavioral health reform happened in 1998 that created what we now call HHS, the state agency responsible for this population was the Department of Public Institutions, another anachronistic name. With that reform, the DPI was simply eliminated. It disappeared. It went away. In the lead-up to LB1083, one of the major issues for further reform was the realization that we have to have a state cabinet-level agency that actually has explicit responsibility for this population. We didn't have that then and, thanks to LB1083, we got a division in HHS that has nominal responsibility for that. The problem has been that there has been no action on that responsibility. [LR300]

SENATOR HARMS: Do you think that bringing in someone from outside of the circle and maybe attach that person to our own Health and Human Services Committee that could do the planning to start this process? Because when you get into this sort of thing, the politics are going to be very heavy. You're going to get into somebody's pocket and somebody else's pocket, and they're not going to like this whole thing. And so to keep a neutral environment where you're not influenced by the external politics, do you think it would be wise to bring someone in that could work with either the Health and Human Services or somewhere else to begin to address that issue? [LR300]

WILL SPAULDING: Well, that's a good question. I don't think it has a straightforward answer. I think that the more voices that are brought together is always for the better. One might ask if, you know, if that hasn't been the case in the past, why hasn't it been the case? I don't see any lack of inclusion in the discussion. I think the problem is a lack of responsibility and accountability. It's not like we don't know how to do this stuff. I certainly agree that there are difficult political decisions to be made. I think the key is not to figure out technical complexities. The key is a political consensus that the state has a responsibility to provide a safety net. And by "safety net," I'm not talking about the insurance underwriting state safety net of insurance funding for people that can't afford it. I'm talking about services that cannot be obtained any other way. There's a population of people that the marketplace will not reach, that privatization will not reach, that Obamacare and insurance parity will not reach. It never has. That is the population for whom the only safety net is going to come from state resources. And in order for that to work, there has to be a political consensus that the state is going to provide that safety net. We don't have that consensus now and there is no safety net. [LR300]

SENATOR HARMS: One other question? [LR300]

SENATOR KRIST: Sure. [LR300]

SENATOR HARMS: Okay. Thank you, Mr. Chairman. Could you talk a little bit more about the...in this letter you talked about the risk issues. Could you do that one more time for me about you were talking about the risk issues of the private side that had concerns. Could you explain that maybe just a little more to me, please? [LR300]

WILL SPAULDING: Sure. Deinstitutionalization, as I'm sure most people know, happened in the 1970s. Since that time, the people that were in the institutions were there because they were mentally ill and dangerousness. It was a risk factor that defines that population. In fact, in a very general sense, it's the risk factors that are defining the population that we're talking about much better than any other thing, like IQ or severity of symptoms. We're...when the system evolved since deinstitutionalization, what did not evolve was a component of the mental health system to take over the risk management role that had formerly been within the institutions. You take that same population out of the institution and into the community, the population doesn't change, the risk factors don't change. What changes is they're now in a care environment where the mechanisms for managing those risks simply have not come about, and that's a major disincentive for that part of the provider community to provide those services. As Dr. Reay was saying, these people that we're talking about are at risk. They're at risk for themselves and they're at risk to the public as well. And in order to have them living in the community, we have to put new mechanisms in place to manage those risks, and that has simply not been done. And that's why the provider, the private provider community is--one of the many reasons--not stepping up to take over services for that population. [LR300]

SENATOR HARMS: Looking at the environment that we find ourselves in, through all your explanations in regard to where we are today, do you absolutely feel that we can actually manage this risk... [LR300]

WILL SPAULDING: Yes. [LR300]

SENATOR HARMS: ...by taking control of it? And do you think we could bring people to the table and get rid of all the politics and say what's best for our clients is the following, and then put their shoulder to the wheel to make this happen? Do you really believe we can do that? [LR300]

WILL SPAULDING: Well, we certainly have the scientific and technological means by which to do it. What we lack is the political will to actually provide this safety net that's not going to be provided any other way. [LR300]

SENATOR HARMS: Thank you. Thank you, Senator Krist. [LR300]

SENATOR KRIST: Thank you, Doctor. Any other questions? [LR300]

SENATOR LATHROP: Can I make just a quick point? [LR300]

SENATOR KRIST: Yeah, Senator Lathrop. [LR300]

SENATOR LATHROP: As I read the letter, pardon me, as I read the letter, this is kind of my understanding, but your point is we let these people out of the regional centers when we deinstitutionalized. Then they're out in the regions trying to get care or needing care and bringing risk to the community. And the providers that are in the community are more interested in representing the people who don't...aren't as difficult to care for. [LR300]

WILL SPAULDING: Absolutely. [LR300]

SENATOR LATHROP: And so as we've left it to the free market of the regions, the providers are saying, I really don't want those people that used to be in the institutions. And so now no one is caring for them. [LR300]

WILL SPAULDING: That's right. [LR300]

SENATOR LATHROP: And now the risk is sitting there. And what you're suggesting today is, if we're going to deal with those people and not bring them back to the institutions, then we need to have providers in place. We need to bring the services here and then we need to pay for them so that they can care for that population. [LR300]

WILL SPAULDING: And my argument, further, is the money. It's not like we need new money. The money is there. We need a regulatory infrastructure that requires that if you're going to get that money you have to provide appropriate services to that population. And that's not what's happening now. [LR300]

SENATOR LATHROP: And what...are you suggesting then that the regions need to get the money with some mandate to provide services to that population? [LR300]

WILL SPAULDING: Mandate, regulation, requirement, whatever you might call it. And the presumption of your question is that the regions are capable of that anyway, and I don't think that's a certainty either. As has been discussed, you've got an accountability system where regional administrators report to county commissioners. And I think that, you know, for a populace democracy, that sounds pretty good. But I think it's asking a lot of a county commissioner, who's got things like bridges and road safety in mind, to make these very complicated decisions and perform oversight of the mental health system. [LR300]

SENATOR LATHROP: Do you think that those services or those providers are present right now? Is it...is it...have we got... [LR300]

WILL SPAULDING: Right here, you mean? [LR300]

SENATOR LATHROP: No, no, I don't mean in the room, but I mean have we gotten to a place now where everybody has elected to take care of the person who's going to be the easiest to take care of for the money they're getting, and now this population that used to be institutionalized is not getting care? Have the providers, the good care for them gone, or are they around and people are there to provide the care; no one's making them? [LR300]

WILL SPAULDING: Well, it's both. And I know you've heard that answer before, but it's both of those problems. The provider community, as it is today, would not be able to provide sufficient services to the entire population if their lives depended upon it. If, however, there was an appropriate infrastructure over time, there would be the same kinds of fiscal incentives to develop those capabilities and it would happen. But I mean, you know, to use my own students as an example, you get a doctorate, you're highly trained to assess these very complicated problems and direct treatment, and then you realize there's no...you can't make a living doing that, at least in Nebraska, so you go somewhere else where you're appreciated. And that's a snapshot of the problem right there. [LR300]

SENATOR LATHROP: That's all I have. Thank you. [LR300]

SENATOR KRIST: Senator Crawford. [LR300]

SENATOR CRAWFORD: Thank you, Senator Krist. And thank you for your testimony and this letter. I haven't had a chance to read it in depth yet, but I get a sense from it that it talks a bit about autism, which is why I wanted to come back to the question I asked earlier to get your perspective on the piece of this that is causing a problem because of how we treat habilitative care, what we call medically necessary care. So you've mentioned the chasm between DD and Behavioral Health, but is the way that we treat mental health care in Medicaid also a piece of this puzzle that's causing people to fall through the cracks? [LR300]

WILL SPAULDING: It's a piece of the puzzle, but it's not the piece where the solution... [LR300]

SENATOR CRAWFORD: Okay. [LR300]

WILL SPAULDING: ...is to be found. You know, the way Medicaid is going, it's going to increasingly look like the rest of the private insurance industry, and it's going to be most effective at taking care of the people that the private insurance industry has historically taken care of. [LR300]

SENATOR CRAWFORD: Okay. [LR300]

WILL SPAULDING: And that does not include people with developmental disabilities or this between-the-cracks population. And I would want to emphasize as part of my answer that we draw a lot of arbitrary distinctions between subgroups in this area. You mention autism. That's a good example. As you may know that the diagnosis of autism as well as mental retardation has dramatically changed with the new edition of the canonical diagnostic manual. Mental retardation, what we used to call that, what we used to call Asperger's syndrome and autism and several other disorders now fall in a single category of neurodevelopmental disorders, all interrelated. There are no real fine lines between subcategories of that population. And this whole silo business, the significance of that is that we have very well-defined bureaucratic structures trying to deal with a very ill-defined patient population. And that's exactly why the cracks appear. [LR300]

SENATOR CRAWFORD: Excellent. Thank you. Thank you. [LR300]

SENATOR KRIST: In other models, we've seen the individual and a case plan written for the individual, as opposed to categories of treatment and how they are funded. Do you see logic in going towards a case plan for an individual in terms of a funding mechanism? [LR300]

WILL SPAULDING: Yes. One could even argue that the strongest trend in modern psychiatry is toward that type of approach, often discussed in terms of functionalism. One of the moving ideas behind the new diagnostic system is that we need to move away from these arbitrary categories and pay more attention to the functional needs of individual people. [LR300]

SENATOR KRIST: That would inherently mean that the money that's given at any level would have to be withheld and that the patient would need to be treated before a provider would be cared for. Is that logical? [LR300]

WILL SPAULDING: Well, I think that, sure, that's certainly logical. It applies generally to healthcare. Again, I would say that the really critical factor in this is a political consensus that we are going to take care of this population, because that's what we don't have now. [LR300]

SENATOR KRIST: Thank you, Doctor. Seeing no other questions, thank you very much. Thanks for coming. Has Ms. Lempke arrived? She was... [LR300]

MARLA FISCHER-LEMPKE: I'm here. [LR300]

SENATOR LATHROP: She's still, yeah. [LR300]

SENATOR KRIST: Okay. We skipped over you so... [LR300]

MARLA FISCHER-LEMPKE: That's okay. [LR300]

SENATOR KRIST: All right. Hi. [LR300]

MARLA FISCHER-LEMPKE: (Exhibit 6) Good afternoon. My name is Marla Fischer-Lempke, M-a-r-l-a F-i-s-c-h-e-r hyphen L-e-m-p-k-e, and I'm here today to represent the Ombudsman's Office. We're authorized by statute to take complaints against agencies of state government. The primary concern that...I feel like I'm going to be repeating information, but the primary concern that we hear in this area is the gap in services. We've had at least five cases this year presenting concerns in this area. Three of those were opened in the first part of the year and continue with no resolution, and actually you've heard from two of those families today. The primary difficulty seems to arise from the fact that it's up to individuals and families to find out exactly what each system has to offer them. Then it's up to them to figure out how they're going to fit within that system, the documentation that they need, etcetera. Most families start with the DD system. They follow the referral process, get documents that are according to the checklist, to the best of their ability. But if they can't find those documents, that becomes a problem for them. If they're initially determined ineligible, they have to gather additional documentation for an informal dispute resolution process or an appeal. They might have to hire an attorney. They often call our office, but in the meantime, they receive no services. In a recent case we handled, and this was not my case, but a man with DD couldn't provide school records to show he had a developmental disability, because those records were destroyed in a flood at the school district's office. He also had a mental illness, so proving his developmental disability was next to impossible. He also didn't have any people in his life to help him advocate. He had a sister; she had her own issues. He contacted us. But in the process, he left the state. He wasn't supported. He never got the services he needed. Hopefully he's...I mean he's now homeless, I'm told, involved in the drug trade, and hopefully he can stay out of the prison system. If a person has a mental health diagnosis, they're often referred to the behavioral health system or a Medicaid block grant, but often, you know, people are told there as well those services are not for them. We've heard about the funding mechanism in place. Often the duration and scope of those services are not appropriate for people with DD. So basically, people are kind of at the breaking point. Their families are exhausted. They don't have anyone to help them and they still have no services. People access our office, they access advocacy groups, and here we all are. (Laugh) And basically, there's really no data to know how many people are going unsupported, and I think that's another critical piece that's missing. So that's about all I have that's a little bit different. [LR300]

SENATOR KRIST: Thank you. [LR300]

MARLA FISCHER-LEMPKE: I'll take any questions, if you have any. [LR300]

SENATOR KRIST: Sure. Thanks for coming. Any questions for Ms. Lempke? Thanks for all you do in the Ombudsman's Office. Your office has been invaluable in the time that I've been here, so we appreciate all of your efforts. [LR300]

MARLA FISCHER-LEMPKE: Well, thank you very much. [LR300]

SENATOR KRIST: Thank you. Beth Reynolds-Lewis? No? Okay, going, going once, going twice. Any other testimony for LR300? You raised your hand. Okay, please come forward. Hi. [LR300]

JUDY DOMINA: Good afternoon. My name is Judy Domina, J-u-d-y D-o-m-i-n-a, and I am here as a parent of a child with a dual diagnosis. And the reason I decided that I needed to testify this afternoon is because my child is 14 years old and I just wanted to give you a look at the last...a look into our life since July 31, because I think it's important that you see what our life has been like for the last 132 days. My son returned home from a placement out of state. He was placed out of state. Two years ago right now we were looking for a placement for this child because there wasn't any place in Nebraska that would accept him. His IQ is 62. He was 12 years old at that time, over 200 pounds, and as tall as I am. And when he became agitated at Boys Town Residential Treatment Center, it would take six men to restrain him. So he had an anger management control problem, plus lower functioning, and there wasn't a place to put him in the state. Fortunately, NFC was case management, because I did have to make him a state ward. I had adopted him five years prior, but I had to make him a state ward because Magellan denied services for him because he was not responding to mental health treatment due to his DD problems. He has been denied DD because of his mental health problems. So I had to make him a state ward. NFC did find a placement in Montana, AWARE, which specializes with children with DD and mental health issues. He was there for 18 months, had successfully transitioned into school, public school, was playing on the football team, was mainstreaming in some of the classes at school, was actually selected in the drama class to give a presentation to the Missoula School Board for miming, because they found out when they put the makeup on him and he could perform. He couldn't otherwise. And was actually featured in a news article...a news station broadcast in Missoula, so he thought he was a star. But as you know, we want to bring all of these children back to Nebraska so July 31, Zachary (phonetic) was brought back to my home with wraparound services in place. By August 27, he was back in the hospital at Immanuel. He attempted to run into a very busy street, Pacific, next to Boys Town, while we were there for a psych med evaluation, and wanted the cars to hit him. He was...remained at the hospital until December (sic) 6 and then was placed at Boys Town for evaluation. On October 17, he had to be readmitted to the hospital again because he was banging his head against the wall, trying to commit suicide. As of today, this is Zachary's (phonetic) 54th day in the hospital on his second stay. He's been home for 132 days and hospitalized in a psychiatric unit for 64. In this time he's been denied for DD services; Magellan has denied mental health services. We are appealing the DD services. There are no placements in Nebraska for him at this point, no facility will accept his placement, and it's been determined that it's not safe for him or for myself to bring him home. We do have two placement options, that's AWARE, where he was at before in Montana with a bed available December 16, and there's a placement in Illinois. The guardian ad litem does not want him placed in Montana because it's too inconvenient for him to visit him there, even though he's been successful for the last...was successful for 18 months. I just wanted to give you a bird's-eye view of what it's like living in a situation like this, and also to reiterate that I don't know that you can legislate this problem away. I don't know that you can throw money at this problem, because a huge issue is, as Dr. Reay said, the culture, the staffing, and the training. Thank you. [LR300]

SENATOR KRIST: Thank you, Judy. You've been before the Health and Human Services Committee before and I thank you for coming back again, sharing a story that must be a bit painful. And I don't do this very often, but what I will guarantee is that through the Ombudsman's Office we will find out about why the guardian ad litem has so much input and why he's being denied services in the state of Nebraska at this point. And I see Marla is making copious notes. [LR300]

JUDY DOMINA: They're already involved, yes. [LR300]

SENATOR KRIST: Yeah, well, I want to be involved with that response, because that's, to me, almost another unacceptable situation. Any other questions? [LR300]

SENATOR LATHROP: Can I ask just a quick question? [LR300]

SENATOR KRIST: Senator Lathrop. [LR300]

SENATOR LATHROP: Judy, is there a provider in the state of Nebraska that could take care of your son? [LR300]

JUDY DOMINA: No. [LR300]

SENATOR LATHROP: Okay. So when we...it isn't a funding issue but it's a... [LR300]

JUDY DOMINA: It's not a funding issue. [LR300]

SENATOR LATHROP: ...the fact of the matter is he has such high needs that there's only a few places in the country. [LR300]

JUDY DOMINA: Yes. [LR300]

SENATOR LATHROP: Okay. Thank you. [LR300]

JUDY DOMINA: Yes. [LR300]

SENATOR KRIST: Any other questions? Thank you so much for coming again. [LR300]

JUDY DOMINA: Uh-huh. [LR300]

SENATOR KRIST: Any other testimony? Yes, sir. [LR300]

DAVID PAN: Hi. [LR300]

SENATOR KRIST: Hi. [LR300]

DAVID PAN: Afternoon, Senators. My name is David Pan, it's D-a-v-i-d P-a-n, and I'm a regional director with Telecare Corporation, and we're one of those private providers that Dr. Spaulding talked about. We...I've been...I've been a social worker. I'm a social worker by training, education. I've done it for almost 42 years. I've worked in Iowa, Wisconsin, Texas, California. Telecare Corporation is...currently we contract with Region 6, with Region 6, Region 4, Region V. We operate two facilities in Omaha and Bellevue. They're primarily secure psychiatric facilities, long-term psychiatric facilities. About four or five years ago we began discussions with Patti Jurjevich about this very issue. And this is not unique to this area. This is...I've seen this in every state I've ever worked in. In California, the agencies responsible at the state level are called regional centers, ironically, that handle intellectual disabilities. They had this very same problem and so they worked with the counties in California and asked, were there any providers who could provide this specialized care. The counties came to us because we contract with a number, almost all of the counties in California for a variety of services. We operate everything from acute psychiatric hospitals to community-based crisis walk-in centers, mobile crisis teams, community ACT teams. In California what they asked us to do was to put together a program that could work with people with mental illness and intellectual disabilities who...people who are experiencing bipolar disorder, who are having hallucinations. And so the first one we did was in Redwood. It's called Redwood Place. It's in the bay area. And we worked with the regional center, we worked with the counties. And what it is, is a resource center for community-based programs or for the regional centers who have difficult people. We specialize in the most difficult and challenging behaviors imaginable. We have forensics ACT teams. If you're familiar what's happening in California, they're depopulating a lot of the prisons and people are coming back from the counties. We're working with those individuals, those individuals who have mental illness or intellectual disabilities who need...who are coming back into the community from prisons. What Redwood Place...and then we have a second facility in Fresno called Sanger Place, specializes in people that are not being successful in the community. What they do is they come into our facility, which is a residential program with the specialists. We work with them for anywhere from a month to two months, develop a plan, bring in whoever the community-based provider is going to be, train those individuals in what we found, work with them, and then have the person go back into the community. I wanted to bring this to your attention because, as I said, we had had discussions in the past with Patti Jurjevich at Region 6 about doing this. And at the time, things weren't working out. So I wanted to let you know that this is available. If you have any desire and need to look at our facilities in California, we could arrange that for you and you could make some decisions after that. [LR300]

SENATOR KRIST: And I was going to ask a few of the other testifiers if somebody is doing it better in other states or some other models are out there, and this is one of those and I appreciate you coming forward and saying. [LR300]

DAVID PAN: You're welcome. [LR300]

SENATOR KRIST: Any other questions? Thank you. [LR300]

DAVID PAN: Thank you. [LR300]

SENATOR KRIST: Thanks for coming forward. Any other testifiers for LR300? Yes, ma'am. Anyone else? Well, you are the last one. [LR300]

JENNIE THOMPSON: My name is Jennie Thompson, J-e-n-n-i-e, Thompson is T-h-o-m-p-s-o-n. I am here today on behalf of my son, Devin, who is ten. And I just wanted to stick this picture up to make sure everybody knows who my son is and this is why I'm here, because so many people look at Devin on a piece of paper and they have no idea who Devin really is and what his services really are. My husband and I adopted Devin when he was two years old. He came to us at 11 months in foster care. After we adopted him, four months later he had a life-threatening seizure and was robbed of his ability to talk, walk, communicate, do anything independently. Due to the fact that his adoption was already final, we could not utilize any services from Health and Human

Services. His adoption subsidy was already complete. When we did apply for help from the Aged and Disabled Waiver, we were told that Devin has $150 in his respite subsidy that we should be using to meet those needs. It was not meeting his needs. Once I appealed that decision, we did lose because they said that $150 is there for him to...basically to meet his needs. So for the next three years after that appeal, I tried finding services for Devin in any way that I could to help keep him in the home. By early 2010, my husband and I were in over our head and we couldn't take care of him. We were struggling as our family was growing. And we then turned to Right Turn, which was an agency to help out with some of those parents who have adopted. Our mentor at the time felt that it was probably worth our time to apply for the Aged and Disabled Waiver one more time. I did get a call later that same week, after she had talked to somebody, and they said regulations had changed, he would be covered. He was then covered for 30 days before I got a letter in the mail saying Devin is going to be taken off of the waiver as his needs are being met by the $150 adoption subsidy. I appealed again in September of 2010, and which it did come back in Devin's favor. The Department of Health and Human Services was unable to explain how that $150 a month designated was sufficient to meet Devin's needs. At the time, Right Turn also helped in getting some extra services for us to take care of Devin, which was chore services at the time. In May of 2013, I again was contacted by Health and Human Services saying that the Aged and Disabled Waiver was once again being taken away as Devin's subsidy was meeting his needs. We were also informed that his PASS time, which he was getting 15 hours a week, would be decreased to 5 hours a week. I felt like they weren't understanding the fact that Devin's subsidy was created before he had the seizure, before he lost his abilities, so that money was not covering what we needed. The chore services were decreased from 15 hours a week to 5 hours a week because they said they were no longer going to pay us to do our parental duties; we should be asking our families, relatives, and neighbors to be doing that. There was a needs assessment completed--my husband and I didn't know that--which was only going to qualify Devin now for assistance with lifting 20 times a week for five minutes each. Which means I was responsible for finding somebody to help me lift my son in and out of bed for five minutes a day, once in the morning and once in the evening. Health and Human Services could not tell me how I was supposed to do that. Without these services, we were afraid we were going to lose our son and our home, so we did hire an attorney. My husband and I have spent $8,000; all...both appeals came back in our favor. We were told we were going to get the 15 hours a week in chore services and that his Aged and Disabled Waiver was to stay in place. Devin is on the DD list, got on the list end of 2010. Tuesday, Devin's Aged and Disabled worker came out to our house and said we had to redo our needs assessment, which I was confused because we were told we were good until next May, and she told me again her supervisor from Health and Human Services directed us to only tasks that required two people, which obviously our money that we spent for that attorney and that hearing meant nothing apparently to Health and Human Services, because they're still claiming there's a regulation, which they still cannot show us what that was. They couldn't show our attorney that either. I feel like our life has been put under a microscope. My job has been affected. My husband's career has been affected. He has to stay home now with our son to help take care of some of that as our family has grown. I felt like the people who are making these decisions for Devin, they couldn't tell us how many times a day his diaper was changed, how many times he was fed, how many times a day he was suctioned. They knew nothing although they were willing to take this time away from him. I am upset to hear about some people who get this waiver who, you know, have never had to appeal, but here we are, almost on our fourth appeal, you know, and I really just dream of a day where I can interact with my son like I do with my other kids and not just have to care for him. And we will do whatever it takes to keep him in our home, but at this point if...you know, it's a battle. It is a constant battle, so. And this is kind of just another example so you know what a family goes through on a daily basis trying to struggle for services. My time is up. [LR300]

SENATOR KRIST: Thank you so much... [LR300]

JENNIE THOMPSON: Yes. [LR300]

SENATOR KRIST: ...for coming forward and telling your story. And he's...that's a good-looking kid. [LR300]

JENNIE THOMPSON: He is, very. (Laugh) [LR300]

SENATOR KRIST: (See also Exhibits 15, 16, and 17.) Any questions? Thanks again for coming and sharing. I know it's not easy to do that. With that, we are going to close the hearing on LR300, and start right in to LR143. So if you don't want to stay for LR143, please leave quietly. And I know there's some folks who are waiting to come in for LR143. [LR300]

EASE

SENATOR KRIST: Okay, I'd like to jump into it right away. The day is becoming long in the tooth, as they say. And there's one testifier that I'll ask to come forward first, and then I'll open it up for testimony. This is my resolution. It's LR143. I'll ask my colleagues to look down particularly at (3) on page 1 of LR143 emphasizing the value of allowing parents to have careers while we help care for their children; (4) how children's day health services are reimbursed and advantages and disadvantages of combining the current piecemeal method, which we have referred to many times today as silos, reimbursing child's healthcare services; and (5) how children's day health services are reimbursed in other states where the same or similar services are offered. And if someone is doing something better that we can emulate or change the way we're doing things and we've talked about that a couple times as well. This is all because you have a green copy of what is LB8 that was presented last year and is still in committee. LB8, if you'll turn to page 2 of the LB you'll see that in definition, as we all know, if it's not underlined, it already exists in statute. When it's underlined, we're creating when we want to create a change. On page 2, (2) the department may already "(a) enter into contracts and interagency agreements, (b) adopt and promulgate rules and regulations,

(c) adopt fee schedules, (d) apply for and implement waivers and managed care..." This is all the things we have talked about all morning and most of the afternoon that we are asking the departments to do to try solve these problems and reach into silos and create funding streams that take care of, in my estimation, individuals, the individual patient. And then if you'll look at page 3, the underlined "(5) Prior to January 1, 2014, the department shall adopt and promulgate rules and regulations providing for payment." Probably line 23 is the reason that this bill cannot come out in its present form because everyone knows that saying "necessary and reasonable costs" is a lawyer's dream. So that needs to change. There's no doubt about it, but we can find a way to make that work. With that, I hope that you see the relevance in terms of linking these two LRs together and talking about the things we are talking about. And I would ask Natasha Page to come forward, please, first. And I asked Natasha here because I think when you start tying things together and you look at the face of the child, there are definite reasons why we want people to continue to have their careers and be in place and do their things and help them with the issues that they have. You've got the whole family almost. [LR143]

NATASHA LUDWIG-PAGE: Close. [LR143]

SENATOR KRIST: Close. Thank you. [LR143]

NATASHA LUDWIG-PAGE: Hi there. I'm Natasha Ludwig-Page, N-a-t-a-s-h-a, last name, L-u-d-w-i-g-P-a-g-e. This is my husband David, D-a-v-i-d, Page, and our daughter Marin (phonetic). Our son Jameson (phonetic) is currently at school. We are here on behalf of our children, Jameson and Marin, to ask for more consistency, transparency, and understanding when it comes to caring for both of our children, both of whom have special needs. A quick background for you, Jameson was born at 36 weeks. At about four months old he was not meeting all of his milestones, so we took him to the doctor. Six years and countless tests later, we have learned that our amazing boy is legally blind, has epilepsy, he cannot talk, has difficulty walking, cannot feed himself, and isn't potty-trained. Marin--this one back here--was born at 24 weeks. If it can happen to a preemie, she did it; bowel perforation, brain bleed, eye and heart issues, etcetera. And as you can see, she is dependent on a tracheostomy to breathe but also a G-button for food and regular monitoring of her shunt for her brain bleed and her oxygen saturations. When we are not available, she has to have professional nursing care as we cannot just take her to a neighbor as has been suggested to us. And that's our nurse back there. As parents, we want not only to provide what's best for our family, but also to be productive members of society. However, all too often recently it seems more so a choice has to be made; one or the other, both not being logistically possible. I'm a teacher and my husband is a sheriff's deputy, so you can imagine our schedules. Neither of us works a typical eight to five, Monday through Friday. David often has to work late, work unexpected accidents, fill out reports, answer emergency calls. Not only do I teach teenagers, but I'm also evaluated on my professional development and involvement in schools. This often means taking a course to learn new technology--SMART Boards are the latest one--working a track meet or sponsoring a cocurricular club. These, not to mention our personal businesses, all of which we do to try and make ends meet and provide for our children. Yet we often meet resistance when trying to fulfill these professional duties. For example, just before Thanksgiving I was asked about working wrestling meets and basketball games, but I could not. The managed care company that we're currently working with for Marin says they would not approve any additional hours since we were in the middle of a certification period. So not only is this costing us money that we could put towards the betterment of our children, but it's also potentially hurting my job evaluations. And we're left wondering if instances like these could end up costing us our jobs down the road. We know these services are not cheap, but we are here to put a face to the need, to show that my children are worthy human beings, not just dollar signs. At the same time, it's not only cheaper to have our children at home versus being placed in an institution, it's also better for the children, the parents the family, and the community at large. By having my children at home, we are able to constantly and consistently work on skills: Jamie's (phonetic) feeding, Marin's mobility. Elsewhere, work on these skills might be 30 minutes twice a month. They also receive the love and attention of their family, something every single child deserves. Our community also gets the exposure to differences because as we know we aren't cookie cutters. Everybody is different, and we all have to be exposed to that in order to learn and grow and respect those differences as well. However, we're constantly coming into issues with managed care, being told that, okay, this is...we have respite hours, work hours, sleep hours. And all of that has to be submitted 60 days ahead of time. And there's no leeway in there which is in essence impossible. But that's really all I have if you have questions. [LR143]

SENATOR KRIST: Any questions? Thanks for coming. We really appreciate it. The one issue that I would ask you before I let you go, you were told with very, very, very short notice that your fee schedule was going to change and that... [LR143]

NATASHA LUDWIG-PAGE: Absolutely. [LR143]

SENATOR KRIST: Okay, and that also your nurse could not accompany Marin to doctor's appointments even though there was no one that could actually service the trach if need be. [LR143]

NATASHA LUDWIG-PAGE: Correct. [LR143]

SENATOR KRIST: Has that been resolved or are you still fighting that with your providers? [LR143]

NATASHA LUDWIG-PAGE: It's still somewhat up in the air. We did...just to give the rest of you a little bit of background, Marin goes to physical therapy about once a week for an hour because she's not mobile, and our nurse accompanies her. And we were told that those would have to be considered respite hours which from our understanding, respite hours are supposed to be for parents to get a break because it's a little bit stressful. At first we were like, you've got to be kidding. Then we did end up pushing the appeals, pushing documentation from both the school physical therapist and the physical therapist that we work with privately. We did end up getting those hours back, although we have not officially seen anything. But that is due strictly to the fact that they are providing different services. In regards to the doctor's appointments--again physical therapy, just using that as an example--if Marin's trach comes out, you have about 30 seconds until she starts to suffocate. Physical therapists aren't trained for that. And it's actually come out during physical therapy sessions before. And the physical therapist, Jennifer (phonetic), has kind of freaked out, as would most of us if we hadn't been trained. And David and I went through six weeks of training in the NICU before we were allowed to take her home. [LR143]

SENATOR KRIST: So if you, the parents, if you and David weren't the ones that were transporting, if it was your father or someone else, traditionally it's been the nurse that's been there, that's been assigned to you to be able to take care of it. [LR143]

NATASHA LUDWIG-PAGE: Absolutely. [LR143]

SENATOR KRIST: But what we were saying at some point, we, the state, were saying at some point is that service is no longer provided to you because... [LR143]

NATASHA LUDWIG-PAGE: Correct. Since...the impression that I got was, since my father was driving Marin and the nurse to the appointment, that, okay, he could also put the trach back in. And he does not have that training. [LR143]

SENATOR KRIST: But the rules and regulations say that the nurse cannot provide transportation to the child to OT/PT, is that correct? [LR143]

NATASHA LUDWIG-PAGE: She cannot provide transportation, no. [LR143]

SENATOR KRIST: Okay, so chicken or the egg, which one...yeah, exactly. And these are things that I think we've heard from other families. But we really thank you for coming. [LR143]

NATASHA LUDWIG-PAGE: You are welcome. [LR143]

SENATOR KRIST: Yep. And Marin has been a treat for a couple hours. I wanted to make sure that you got in and out. [LR143]

NATASHA LUDWIG-PAGE: Thank you. [LR143]

SENATOR KRIST: Thank you so much. Any other testimony on LR143? Welcome. [LR143]

MIKE LEBENS: Thank you. [LR143]

SENATOR KRIST: If you'll state your name and spell it for the record, please. [LR143]

MIKE LEBENS: (Exhibit 7) Okay. Mike Lebens, M-i-k-e L-e-b-e-n-s. I'm testifying in support of LB8. Good afternoon, Senators. My wife and I have been involved with Children's Respite Care Center, CRCC, for over a decade in various board capacities. CRCC is a state of Nebraska children's day health service. For the past few years, I have held the position of board chairman. Through my involvement, I have developed a deeper understanding of the breadth and complexity and comprehensiveness of the services CRCC provides to the Omaha community and the financial challenges they have faced historically and especially over the last several years. As chairman of the board, I have a fiduciary responsibility to help ensure the long-term sustainability of this organization. It became clear there was a glaring disconnect between the state regulations requiring services and the reimbursement for those services. In subsequent testimony today, you will be provided details about the tortious complexity of the current reimbursement for certain services and specifics on other services required by regulation for which there is no compensation. My task today is help you understand the nature and extent of a children's day health service in Nebraska, CDHS, and how CRCC is impacted as a CDHS. A children's day health service as defined in Nebraska statute "means a person or any legal entity which provides specialized care and treatment, including an array of social, medical, rehabilitation, or other support services for a period of less than twenty-four consecutive hours in a community-based group program to twenty or more persons under twenty-one years of age who require such services due to medical dependence, birth trauma, congenital anomalies, developmental disorders, or functional impairment." CRCC as a CDHS serves children with complex medical health, developmental, and mental health issues, many with overlapping diagnoses. CRCC fills this role as a community-based, least restrictive, and developmentally appropriate environment. The sheet of diagnoses in your packet provide an accurate overview of the mulifaceted needs of the children attending CRCC. CRCC is now the only children's day health service in the state of Nebraska. As such, the regulations require agency to provide many services to our kids, the cost for which is presently not reimbursed. And for to service for which CRCC currently receives reimbursement, the compensation does not come close to covering the cost of the services. In 2007, a cost-benefit analysis of CRCC's services to Medicaid clients was conducted to determine the economic impact to the state if CRCC ceased to exist. The net savings for manualized alternative care cost and social cost federally and for the state of Nebraska was $3,425,000. I have included the executive summary of that study in your packet. A review of the 212 clients enrolled in CRCC in November 2013, current clients, showed alternative care option demographics had not changed since the 2007 study. These underfunded services continue to provide an annual net savings to the state of Nebraska and the federal government and would continue to provide significant net savings if CRCC was fully compensated for the cost of providing the services. An organization cannot be expected to operate without fair and reasonable rates. LB8 in no way is intended to establish a special reimbursement methodology for children's day health service but rather provides the rates established for such services bear a direct relationship to the cost of providing them. Since it appears to us that Medicaid's program payment for various services has no relationship to the cost of providing the services, we would like to know how rates are currently determined and to modify rates to cover the cost. The Center for Medicaid Services Regulations require that state payment rates be sufficient to assure an adequate supply of services by providers. Paying for services at significantly less than their cost violates the regulation, and it cannot be expected to assure an adequate supply of services will be provided. In paying for services, it is important that the costs are covered and at the same time assure taxpayers' dollars are not expended to pay providers any more than the actual cost. As Senator Krist mentioned, the supporters of LB8 are not wed to the "necessary and reasonable" language, which was an issue when LB8 was considered in the last session. And we would be happy to consider alternative language that describes the manner in which the payment amounts for services are devised. We realize the committees are tasked with a challenging issue. In your careful consideration, I think you will conclude that CDHS is an economical community-based alternative and worthy of forwarding out of committee with your support on the floor. Thanks for this opportunity. I'd be glad to answer questions. [LR143]

SENATOR KRIST: Any questions? You...Senator Gloor. [LR143]

SENATOR GLOOR: Thank you, Senator Krist. Thank you, Mr. Lebens. Can I...this is just a quick question, but quite frequently when the testimony involves dollars and cents, people talk about costs when they're talking about charges, and they about charges when they're talking about costs. Could you tell me if when we're saying costs here whether we're referring to the actual cost of service or the... [LR143]

MIKE LEBENS: Yeah, that's the objective is to make sure that the cost of providing the...the actual cost of providing the service is paid for and basically no more or no less. [LR143]

SENATOR GLOOR: Okay. Thank you. [LR143]

SENATOR KRIST: Senator Crawford. [LR143]

SENATOR CRAWFORD: Thank you, Senator Krist. Could you explain why in the cost page it says "Excludes therapy costs"? [LR143]

MIKE LEBENS: Probably the reason for that...I think there was some exception made to how therapy is compensated for. So in an effort to make a fair comparison, the idea was just to exclude that and deal with other costs since therapy... [LR143]

SENATOR CRAWFORD: So do the children receive therapy at your facility? [LR143]

MIKE LEBENS: There is therapy provided. [LR143]

SENATOR CRAWFORD: Okay. So that's part of what happens there... [LR143]

MIKE LEBENS: That's part of what happens at CRCC. [LR143]

SENATOR CRAWFORD: ...but not part of this cost analysis. [LR143]

MIKE LEBENS: But it's not part of this discussion. [LR143]

SENATOR CRAWFORD: All right. And is that therapy reimbursed by Medicaid as well, likely, sometimes? [LR143]

MIKE LEBENS: Actually, I'm not sure. I know there's...it's partially funded through just...directly funded when applicable. Also, there's insurance. And I'm not sure if Medicaid is involved to be honest with you. [LR143]

SENATOR CRAWFORD: Okay. All right. Thank you. [LR143]

SENATOR KRIST: I'm seeing some head nods, Senator Crawford. So you'll probably hear that if somebody else is going to come up and... [LR143]

MIKE LEBENS: Yeah, there are going to be some additional...there's going to be some additional testimony. They may be able to answer that question. [LR143]

SENATOR CRAWFORD: Thank you. [LR143]

SENATOR KRIST: Any other questions? Thank you so much. And thanks for coming down. [LR143]

MIKE LEBENS: Thank you. [LR143]

SENATOR KRIST: Any additional testifiers? Welcome. [LR143]

DANIELLE OHLMAN: Thank you. [LR143]

SENATOR KRIST: And if you'll just state and spell your name for the record. [LR143]

DANIELLE OHLMAN: (Exhibit 8) My name is Danielle Ohlman, D-a-n-i-e-l-l-e O-h-l-m-a-n. Good afternoon. My name is Danielle Ohlman. I am the mother of Logan Epp. Logan is 12 years old and 1 of my 4 children. At two weeks old, Logan was diagnosed with enteroviral meningitis, a septic infection that caused multiple organ failure, severe neurological damage, and a lifetime of disability. When Logan was six weeks old, the doctors told me that he would not survive. If Logan did survive, he would be blind; he would be deaf; he would need a tracheostomy to breathe; he would never walk; he would never talk; and he would never, no matter how much time I spent with him, be able to recognize me as his mom. Logan is now 12 years old. He can see me; he can hear me; he breathes on his own; he walks; he runs; and most importantly for me, every time he looks at me, he calls me Mom. While I have cherished every day that Logan has been with me, we have not been without our challenges. Logan clearly cannot care for himself. He needs help with all activities of daily living including bathing, toileting, dressing, and feeding. He has behavior issues that require constant and consistent supervision for his safety and for the safety of others. Developmentally, he is a toddler. And my three-year-old daughter is currently passing him in developmental milestones. In 2012, we almost lost Logan to fulminant liver failure. Logan received a new liver in March of 2012 and has been doing well ever since. But consequently, Logan's needs are extremely complex and require a very high level of care. I've been asked to speak to you today regarding the importance of the children's day health service from the perspective of a parent of a child with severe disabilities. I am here to tell you that the children's day heath service serves a very necessary, very important purpose. Logan and I have been affiliated with CRCC, Nebraska's only children's day health service, since 2001 when Logan was 4 months old. I, like most parents in my situation, was in no way prepared to care for or to raise a child with such significant needs. But then the first year of Logan's life, my husband walked away from our family. I was left in a house I couldn't afford, a job that couldn't support my family, and a child that required constant supervision and care. That was 11 years ago. I am now remarried. I am now a college graduate. I have an amazing job at a local nonprofit. I am my son's main caregiver and his most powerful advocate. And I am a voice for families whose voices remain unheard. I can tell you with the utmost certainly that I would not be any of these things had it not been for Children's Respite Care Center. They were the first people who told me that my life did not have to end just because I had a child with special needs. While I was at work, the staff worked tirelessly helping Logan learn and progress. They helped me excel in a career that by all accounts I would have never had without them. They have helped my son become a part of his community and a part of a very special, very meaningful social group of his peers. They have brought the community into their spaces and have increased understanding, tolerance, and acceptance of my son and others like him. There is not one good reason that children's day health services should not exist. In my opinion, there should be more. There should be at least one in every state. It's hard to think that in my lifetime families were forced to place their children with disabilities in institutions or to keep them in their houses because there were no services or social acceptance of their children in the community. For years, families fought and legislators worked at state and federal levels to bring individuals with disabilities into the community. And with the help of the home- and community-based waivers, the services these children and adults needed to help them live within their community were finally provided to them. Had there not been a push from parents just like me to fight for inclusion for our children, we wouldn't have had any need for the ADA or IDEA, laws that exist to plan for and protect those Americans with disabilities within their communities, young and old. The children's day health service is a natural extension of this movement and a shining example of the progress of the movement within the state. The purpose they serve is invaluable. Children's day health services allow children with disabilities to thrive in their communities among typical children as well as their peers with disabilities. These facilities not only care for children, but they employ some of the most knowledgeable and up-and-coming teachers, therapists, nurses, and administrators that are on the forefront of special education, therapy, nursing, and healthcare. They provide hands-on training for students from numerous fields working towards professions in healthcare and in the field of disability. What would I do or what would I have done if CRCC didn't exist in Logan's lifetime? I can honestly tell you I have never really thought about it. I am so thankful that I had the choice to send Logan to CRCC. If I would have had to rely on one individual to handle Logan's care, what would I have done if that person would have called in sick? I most likely would have had to miss work. If someone calls in sick at CRCC, I will still make it to work and that is a fact. And my ability to have consistent attendance in my employment has allowed me to progress in my career. Logan would never have developed the social skills he's gained, made the advancements he has made, have the friends that he has, or touch the lives that he's touched if he had not attended CRCC. I can't bear the thought of Logan having to spend almost every hour of every day stuck in his home with no friends and no social interaction. Taking away such an important facility would only be a shameful step back to the days when these children didn't see the outside of their own homes but for doctor visits and for trips to the store. The value that CDHS's have in the community can only be expressed by those who live, work, play, teach, and train there. They are an indispensible part of my family's life. Facilities like CRCC should be supported by DHHS and by the state of Nebraska. The families that use them should be protected from the constant targeting by DHHS to cut the funding that allows us to send our children there. I know that many times your decisions come down to money, funding, financial sustainability. But sometimes the right decision is just that and nothing more, the right decision. Children's day health services keep families together. They help keep parents employed. They help us excel in our careers. They help us to be better parents and caregivers. They help us to keep our children at home where they belong. Children's day health services empower parents to not let go of every single dream they had before their lives were derailed. There is no amount of money that can outweigh the benefits of what CDHS's provide. I don't want my child to spend all of his days locked in his house with a private-duty nurse. I want him to be a part of his community. My hope is that you will embrace the concept of the children's day health service and do anything you can to protect it. It literally saved my life. It saved and enhanced Logan's life immensely and empowered me to be here to sit in front of you today. Thank you. And sorry. [LR143]

SENATOR KRIST: Just warning everybody else, I never cut a mother off. But I'll cut the rest of you off. (Laughter) That's okay. Thank you. [LR143]

DANIELLE OHLMAN: I kind of assumed that. [LR143]

SENATOR KRIST: I know. Thank you. Thank you so much for coming and giving us your testimony. [LR143]

DANIELLE OHLMAN: Sure. [LR143]

SENATOR KRIST: We really appreciate it. Any questions? Thanks. [LR143]

DANIELLE OHLMAN: Thank you. [LR143]

SENATOR KRIST: Next testifier. Welcome. Please state your name and spell it for the record. [LR143]

TERRY KRUSE: My name is Terry Kruse, T-e-r-r-y K-r-u-s-e. I'm Brady Kruse's dad. I'm sure all of you know by now that. I was at a parents meeting a few weeks ago. And I had the head of the parents meeting ask me, just exactly what do you do, Terry, which made me think a lot before I came on Saturday to be here today. So we'll see what I do. I've listened and watched you guys and you ladies today. I've seen a lot of really positive things. I've heard a lot of good questions. I've heard a lot of good testimony. I'm encouraged, I really am. I've been to a lot of these since 2009. And there's a lot going on here. I was encouraged in March. And in March, I walked out of here and there was a woman out in the hallway that I was introduced to. And I talked to you--all of you I think, most of you here--about helping her. And she was from Omaha and her son's name was Paul (phonetic) and her name was Randi (phonetic). I met Randi Saturday. I drove to Omaha and spent a few hours...I met Paul. I spent a few hours with Paul and his mom Randi. And I wish you could have seen what I saw. We did get some help. She got some help, and her son went from uncontrolled angers of fit to disgruntled disagreements is the way mom puts it. He is a joy to watch now. He has multiple movements that he uses to entertain himself and to communicate with. And a majority of those were destructive just a few months ago. And through the help that you gave to them by putting pressure in the right places, they got help. And this little guy is a joy to watch now. And I actually got a wave when I left just from that short interaction with him. So you see, we can get these things done. We've heard that today. The technology is there. It's the politics, and it's the money. We've looked at this thing since 2009--I have. Most of you have been here since that time. Most of you have looked at it with me at the same time. I said to you in March that the political atmosphere is starting to change. Now is the time to get started and really get something done. We need to address this even more so now and move to get things done. The questions that were asked today: Where do we start? Where do we start? How do we educate to get these things done? I have some concerns that have bothered me. I've been up here several times--last year, this year--about fundings that were cut. We had fundings cut for day care. We had a group of a couple hundred last year with...because they were Falls City, Sioux City people, where fundings were cut. I met a dad today. You heard from him, Dave; 40 percent cut. Why is that happening? Why does that continue to happen? There are continuous funding cuts being done with these people. Why does that happen? Where does that come from? I don't understand. Why would there be any cuts at all? Where is that coming from? I'm getting the light already. So the money has to be there. We have to find a way to address that. And I don't understand why all the cuts. And another thing, I want to tell you about my daughter. She's a substitute teacher in four small communities around North Platte. Now think about this. She asked me just a couple of weeks ago...she said, Dad, something has to be done. All four of the small schools I teach in have individuals that are DD individuals, you know. And she said, all we're doing is baby-sitting. They're not getting any instructions. They're not getting help. So we have individuals like that in the schools. We have individuals like that in the hospitals. We have individuals like that in the penal systems in the smaller communities. Why? Because we shut down BSDC and pulled people out of there, went to residential. That's the way the whole nation has gone, but we have to find a way to take care of the people in the residential. And that's what you've been hearing about today. So I would ask you as being a parent of one of the 47 that were moved out of BSDC, I looked at that. Those people that we lost then, they're...that started this. That made us look at what's going on. So I ask you, for the sake of the ones that we lost, let's get something done. And let's take care of these people, and let's get it started now. [LR143]

SENATOR KRIST: Thank you so much for coming. I really appreciate your testimony. Any questions? Thank you very, very much. [LR143]

TERRY KRUSE: Thank you. [LR143]

SENATOR KRIST: Thanks, Terry. Next testifier. Please state your name and spell it for the record, please. [LR143]

JUSTIN KRIST: (Exhibit 9) My name is Justin Krist, J-u-s-t-i-n K-r-i-s-t. I'd like to express my sincerest gratitude for your time and attention today. My connection with the Children's Respite Care Center as a board member is a result of the experiences I've had as a brother of a special-needs sister. I have firsthand knowledge of both the difficulties families face while caring for those with special needs and the strength they derive from these experiences. My purpose today is to speak with you about how other states are building out programs intended to optimize the care and cost for special-needs children. There are an estimated 10.2 million children with special healthcare needs in the United States. That is one in five households. This means one in five households in our community are caring for a child who has or is at increased risk for chronic physical, developmental, behavioral, or emotional conditions and also require health and related services of a type or amount beyond that required by children generally. The healthcare costs for these children are significant as we've heard today. The average medical cost per year for a child with special healthcare needs is three times more when compared to children without special needs. So how are other states rising to this challenge? We have provided a very simple summary grid of 13 states with programs which happen to be similar to CDHS in how they are reimbursed. We believe these programs provide us with a good guide for how models are working to meet the needs of children. We can make the research available that went into the full set of understanding what these states are doing and how they're doing it. We also had the legislation behind them, all hundreds of pages are available just within a phone call. Let me walk you through the grid. The "Reimburse" column is nothing that is of big surprise. It simply places Medicaid right there at the forefront. The "Called" column is the name. Notice several states have children's day health services or like services. They go by many names. And we've heard about the need today; Prescribed Pediatric Extended Care Center, Medical day services for children, and Medical Day Care. The "Other

Distinctions" column is something that I'd like to point out. The variations of a children's day health services program is the fundamental thing that you'll see as a like item across this category. States that appear to be doing this well have one thing in common. They are focused on bringing together regulations, rules, and definitions to govern how the nursing, therapy, mental health, and other support services should be provided in a facility-based setting during day hours, not 24/7. They all are reimbursed by Medicaid. Also, there are multiple studies and examples that we have of this approach being financially efficient and effective for the care in terms of how it is qualified, the patient's experience, the child's experience, and the family's experience. States do vary in the execution of this model: how services are authorized; acuity scales; case managers' assessments; how the services are reimbursed, bundled, per diem, hourly, fee for service; and what the age span is for these services also varies. Florida and Pennsylvania have regulations and qualifications that appear to be most similar to Nebraska's. While the rate methodology varies widely as to how it is calculated, it is important to note that it is in line with the resources required to provide the care and services as it is consistently applied, meaning the cost and the reimbursement make sense. Unified service care rates can be a more efficient rate methodology and can be associated with the care type. For example, short, long term, or intermittent medical due to medically complex conditions are all areas. And an example would be Florida. It is important to note that there is no regulatory prohibition on such payments, and indeed the Nebraska Medicaid program presently reimburses certain services on a per diem unified rate. Twenty-four years ago when CRCC opened, it was an innovative care model. There are still few organizations like CRCC nationwide. However, the numbers of organizations like CRCC are growing in cities where the population base is large and children have these needs. We believe we are seeing this trend due to the cost-effective nature of this model and its ability to provide holistic care and treatment. All of us as citizens of Nebraska should support and encourage agencies providing cost-effective, community-based services to families. That's all I've got for you. Let me know if you have any questions. Again, we have significant research available that talk about the legislation and the programs available to children in these states. We would love for you to have them to make an educated decision about opportunities and options around these programs. [LR143]

SENATOR KRIST: Thank you. I think I know where to get a hold of you. (Laughter) Any questions for Justin? Thank you so much for coming. Any other testifiers? And I misread a note. I think someone is here to represent Vivianne...Director Chaumont. Can I ask you just to go last. Is that okay? [LR143]

RUTH VINEYARD: Sure. [LR143]

SENATOR KRIST: Is there anybody else that needs to testify? You may have already...be there. [LR143]

JENNIFER HAMANN: We have two right over here. [LR143]

SENATOR KRIST: Two, okay. Only two more. Thank you. [LR143]

SENATOR LATHROP: No, there's three. [LR143]

SENATOR CRAWFORD: Three. [LR143]

SENATOR KRIST: Three? Sorry, three. [LR143]

SHARI WELLS: (Exhibits 10, 11, and 12) Good afternoon. My name is Shari Wells, S-h-a-r-i W-e-l-l-s, and I'm the director of nursing at Children's Respite Care Center in Omaha, Nebraska. I've been a nurse at CRCC for nearly 16 years, and I've cared for an adopted son with special needs for 23 years. My goal is to describe what care a children's day health services agency provides. I will also highlight how the current funding mechanisms do not cover all the services that the CDHS regulations mandate. If you would, please refer to the left column of your diagram labeled "Funding and

Services Matrix." The statute defines CDHS as "including an array of social, medical, rehabilitation, or other support services." The licensing regulations spell out how we are to staff and carry out all the services listed in the left column. I believe these areas are important to help children with complex care needs. These regulations have given us a great framework for more coordinated care. Despite the value that our children are receiving in quality of care, if you'll refer to the funding matrix again I will describe what providing these services has cost our organization and where the regulations do not provide adequate reimbursement. Please note the blank spaces. They represent services regulated but not reimbursed. Also note the piecemeal nature of the funding sources. Each source has its unique process and each inadequate to meet the level of care provided. Point in fact, when the only other CDHS in the state closed October 1, we coordinated to take in many of their children into our care. However, we receive roughly half the reimbursement rate from Medicaid for the same service and the same length of time. Likewise, the mental health day services that are now regulated by CDHS are not reimbursed by Medicaid or Magellan. As important, many of the funding sources listed here are increasingly denying clients access and authorization. The mandate for cuts in Medicaid has led to across-the-board denials for eligible children who have been approved in the past but are now denied without substantial changes in their health or abilities. Not only does adequate and unified reimbursement for CDHS need to be the goal but also a process for fair and unified assessment of need so eligible clients will not be denied access to cost-effective, family-supportive CDHS services. If you would direct your attention to the chart entitled "CRCC Census." We analyze current client acuities and categorize them. This analysis found, as you can see in the green table on the right, that 40 percent of our clients are under the age of 5. These children are too young to enter the school system full time. And 26 percent of our families have one parent. If CRCC were not able to provide for the complex needs of their children, over 50 families would potentially have to quit their jobs to care for their child. The other 74 percent would surely face difficult economic decisions in deciding how to provide care for their families. I see and hear from these families daily and know that CRCC contributes to their economic stability. Medicaid does reimburse for some nursing services, but doesn't begin to cover the man-hours needed to fulfill these regulations. On page 2 of the funding matrix, note that the cost of meeting these regulations increased our operating expenses, especially in the area of personnel, by almost $200,000 annually. Quite simply, to provide quality care you need an adequate number of highly trained staff to care for this population. The pay grade that we are now able to give our valued employees does little to keep them at CRCC. Losing an employee to a substantially higher wage for similar work continues to be a challenge. For example, I recently hired two qualified, experienced RNs who took a $10 and an $8 an hour pay cut just to come work for us. I thank God for them, but sadly we lose many more good staff because they cannot afford to live off the wage that we can provide at this level of reimbursement. The people who leave love CRCC. They just can't afford to stay there. Senators, I urge you to push for a unified rate that will more accurately reflect these needed services. Thank you. [LR143]

SENATOR KRIST: Thank you so much for coming. Any questions? Senator Gloor. [LR143]

SENATOR GLOOR: Thank you, Senator Krist. And thanks for your testimony. The census chart, is this a set balance that you try and keep of... [LR143]

SHARI WELLS: This is... [LR143]

SENATOR GLOOR: ...or are you just...is this a snapshot yesterday or over a year? [LR143]

SHARI WELLS: This was November, 2013. [LR143]

SENATOR GLOOR: Okay. [LR143]

SHARI WELLS: We went through our census and categorized them based on their diagnosis and their nursing care needs. [LR143]

SENATOR GLOOR: But does it also represent a fair balance of the mix of patients that you can...clients that you can take? In other words, if moderate care needs due to functional impairments ended up being only 10 percent, is that all right? [LR143]

SHARI WELLS: We would have to hire more. [LR143]

SENATOR GLOOR: You'd need to hire more for the other categories. And so I go back to my question. That is, is hiring highly dependent... [LR143]

SHARI WELLS: Yes. [LR143]

SENATOR GLOOR: ...or do you try and control clients that you accept to manage it? [LR143]

SHARI WELLS: No. We accept who comes to our doors. We adjust our staff to our needs. You know, I've hired more nurses in the past two years just because we've needed. There's...the CDHS is awesome. I love it personally because it helped us to implement some things that we've wanted to do but didn't have the framework. But at the same time, it costs so much more time. You know, just getting the mandated plan of care, those are usually four pages long that the nurses have to write. It's a long...it's a big process. [LR143]

SENATOR GLOOR: Sure. Thank you. [LR143]

SENATOR KRIST: Senator Harms. [LR143]

SENATOR HARMS: Thank you, Senator Krist. Thank you for testifying. On your one chart that you have, it's on funding and service matrix. On the backside of this you have total of $160,000 to $190,000. That's a big jump. That's about a $30,000 difference. Does that include all these other additional expenses, or is that above and beyond what you listed here that says, additional expenses incurred due to? [LR143]

SHARI WELLS: I believe that it includes that. I could get you more information about how exactly it includes it but... [LR143]

SENATOR HARMS: Okay, the other I would be interested in knowing on this chart...the blank spaces that you have on the front page, is there any way that you might be able to fill that in and give us some idea of what those costs are for each of those categories? [LR143]

SHARI WELLS: That, again, we would have to study and get you some specific numbers. [LR143]

SENATOR HARMS: That's what I would like to have you do. [LR143]

SHARI WELLS: Yes. [LR143]

SENATOR HARMS: Even if you indicate that's an estimate, I can understand that. But it would be...it's just easier for those of use who go to the bottom line, like on the Appropriations Committee. It's easier for us to understand just exactly where those dollars are and what those costs are. [LR143]

SHARI WELLS: Certainly. [LR143]

SENATOR HARMS: I would appreciate that. Thank you. [LR143]

SHARI WELLS: Certainly. [LR143]

SENATOR HARMS: Thank you, Senator. [LR143]

SENATOR KRIST: Thank you. Does your practices of hiring, was it driven a little bit by the closing of Children's Hospital in terms of care with the number of clients that you took on or patients you took in? [LR143]

SHARI WELLS: A little bit but not much. I mean, that was not a huge number. We expected it to be larger. [LR143]

SENATOR KRIST: Okay. [LR143]

SHARI WELLS: But it did drive somewhat, yes. We did have to hire staff for that number. [LR143]

SENATOR KRIST: Senator Crawford. [LR143]

SENATOR CRAWFORD: Thank you, Senator Krist. I just wanted to clarify from Senator Harms's question, the spots where it's missing, is that missing information or these are services that aren't covered? [LR143]

SHARI WELLS: Those are services that are not covered. [LR143]

SENATOR CRAWFORD: Okay. Thank you. [LR143]

SENATOR KRIST: Any other questions? Thanks again. Thanks for coming. [LR143]

SHARI WELLS: Thank you. [LR143]

SENATOR KRIST: Next testifier. Please just state your name and spell it for the record, please. [LR143]

JOYCE DAVIS: (Exhibit 13) My name is Joyce Davis, J-o-y-c-e D-a-v-i-s, and I'd like to say hello to Senator Crawford who works with me at Creighton University. I'm assistant dean for the School of Nursing. However, today I am here as a private citizen. And also, Senator Watermeier, you and I are both graduates of Syracuse High School, about 15 years apart. (Laughter) [LR143]

SENATOR WATERMEIER: You still look a lot younger than I do. [LR143]

JOYCE DAVIS: You say that to all the girls. I first learned about Children's Respite Care about 22 years ago. I managed a philanthropic foundation. And the directors came to First Data and asked if we would give a grant to Children's Respite Care. As part of the due diligence, I went out and visited. At the time, I had two children in day care so I knew how...a challenge it is to find day care that's convenient and you could afford and has good people running it. Well, I went out to this center, and it was located in the Millard Public Schools. And as I walked in I thought, this is just like Brooke (phonetic) and Scott's (phonetic) day care. You could hear the commotion. You could hear the laughter. You could just hear the...you see the engaged teachers. You know, you could just feel the activity. But the big difference was is these little children were in wheelchairs. And many of them had tubes running all over their little bodies. And it was suddenly very different than my children's day care. And I thought how fortunate it was that there were working moms like myself that had a day care that was a typical day care for their very atypical little children. Later on, I stayed in touch with Children's Respite Care and Terri (phonetic) said, we really would like to find a location in the Omaha Public Schools. At that time we had just finished putting a big CE wing on my church. So through some conversations, Children's Respite Care operated out of the Presbyterian Church of the Master for many years. It was a mission for the church, and it worked. It fulfilled a need so that the children could get access into public transportation with the Omaha Public Schools. Today, I'm a board member. So I've stayed with Children's Respite Care for many years. And our board meetings are filled with hearing the frustrations of the staff trying to meet the fiscal responsibility and also hearing from the parents about how challenging it is to keep their children in day care and always have this fluctuation going on and what's going to be reimbursed and what's not. I was with Michelle (phonetic) last week at the Nebraska Child Health Advocacy Summit. And we heard loud and clear, early intervention is the greatest indicator of positive income. And while there's much research that I could go into, I'm not going to at this point but to say that to watch those children to have interaction with other little children their age I think is invaluable. Their therapists come to them so they're there. So it's a very normal activity. Mom can bring them...mom or dad can drop them off. They can stay there. They can play. They can make friends. They learn their ABCs. They do things typical children do. And then mom picks them up at night. And I'll be the first to tell you that I was a much better mother because I wasn't with my child eight hours a day, and if they were here they'd say the same thing. Care coordination and support for at-risk pediatric patients reduced the number of unplanned hospitalizations and reduced the overall cost of medical care. And there are research that I'm sure has been given to you today to support that. Parents of special needs have higher divorce rates, increased parental stress, lower labor force participation. I have a grandchild that is special needs. He had a tummy button until he was five years old. His mom, his dad, his grandmas, and his grandpas all knew how to work that button. And we shuttled that little guy to and fro. The parents both worked, and if it wasn't for all the grandmas and grandpas getting him to the speech therapist and all those places, they could not have done it. And we were the only ones that knew how to get him to the emergency room when that button comes out which is really scary. I thought about little Marin when I heard that testimony. The most specific findings, that children served in these areas have the highest quality of life. They get the physical care. They get the sociopsycho functioning. And they get to be like typical little children. And when they're in an institution or they're at home, it's not typical. They don't have interaction with other little children. Children's day health serve as a combined best practices for children with special needs. It gives them the care. It gives them the integration. It gives them the social, the emotional, and the educational support that they so desperately need. The value is measured by the decrease in medical spending in short and the long run. I think I have a chart that was sent out to you. To me, it's a no-brainer. Ten hours of care at CRCC versus a private-duty nurse. It costs so much more to have a private-duty nurse. And then you don't have all the other benefits that come with it. I urge you to do the research. And I guess what I would leave with you today is when you do the research, if you need more information call me. Come to me. We're here to provide whatever information we can to help you make a good decision. Thank you. [LR143]

SENATOR KRIST: Thank you so much, Joyce. Any questions? Senator Bolz. [LR143]

SENATOR BOLZ: Hi, Joyce. I just want to make sure that I'm understanding the information that you're sharing with us correctly. Am I to understand this chart to say that it's possible that we're providing services to kids in these higher-cost settings like an ICF/MR, that given more opportunities could be moved to a lower-cost service? Or is it that each of these serves a different level of medical need? [LR143]

JOYCE DAVIS: Okay, I'm going to take a stab at this. You heard from Marin's family. Now they have the private-duty nurse. And that's what they're paying for ten hours for that private-duty nurse. I don't know Marin's situation. It could be different, but let's just talk about her. If Marin was at CDC, that same ten hours would cost that amount of money. But while Marin is there, she'd have the physical therapist. She'd have the occupational therapist. She would have a nurse that were there that if that trach came out, there would be somebody wonderful like Shari right there getting that little...getting her to the hospital. I don't know if she would put it back in. I don't know. And I always have to tell people, even though I'm assistant dean for the School of Nursing, I'm not a nurse. (Laughter) I just want people to know that because they'd say, what do they teach them at Creighton? So that's what we're trying to illustrate in this model right there. You know, the intermittent nurse that can come in part of the time, continuous, and then the private-duty nurse. And that's what the...an apples to apples for ten hours of care would be. [LR143]

SENATOR BOLZ: So what I'm hearing you say is that a family with a child who has needs like Marin's would likely be using multiple types of services. [LR143]

JOYCE DAVIS: Yes. [LR143]

SENATOR BOLZ: But if we can get more utilization of the CDHS services, that is higher quality and likely to be more cost effective. [LR143]

JOYCE DAVIS: It would be more cost effective, yes. And it also would be much...I mean, I listened to that, the mother's schedule. And I listened to the father's schedule. They need to go to work and concentrate on their work so they can be a better parent when they come home. When they're at...when these little kids need all this therapy, they're not shuttled to and fro. It's all right there. And if you would visit Children's Respite Care, you would see that it's a very interactive agency but yet the therapists are often just come into the room. And it's not in an office somewhere. [LR143]

SENATOR BOLZ: That's helpful. Thank you. [LR143]

JOYCE DAVIS: Yes. [LR143]

SENATOR KRIST: And before you leave because I want to talk about this point, this morning we heard that you can't have those services at Children's Hospital because you can't take that child and pay for him out of this pot of money if you send him there. What we're saying is in this model, this is what it would cost versus just the private-duty nurse here. And in this model, there are other services available at the institution which right now we're being told they're not capable of paying for in the DD or in other services. So that's political will. That's what we're hearing, is the difference between looking at a model and saying, you can't do that, or looking at a model and saying, why can't I do that because it makes more sense doing it that way. I don't mean to testify on your behalf. [LR143]

JOYCE DAVIS: No. [LR143]

SENATOR KRIST: But I think it's important that we understand. It's a great question. And if you understand the money questions are coming from right here. These are our Appropriations members as well. So thank you so much for your testimony. Any other testimony? Hi. [LR143]

JENNIFER HAMANN: (Exhibit 14) Hi there. I'm Jennifer Hamann. My name is spelled J-e-n-n-i-f-e-r H-a-m-a-n-n. I'm the former board chairman of Uta Halee Girls Village the year we closed. I currently serve on the board for Children's Respite Care Center here in...in Omaha, not here in Lincoln. I'm here to testify in front of you because I'm experiencing deja vu with the families trying to get the services for Uta Halee back in that day, watching the families at CRCC trying to get their kids the care at Children's Respite Care Center. Here's why it's my little nightmare I'm living. First of all, there's new requirements that are imposed on these agencies. At the time I was at Uta Halee, we had new requirements. They are costly. They cause a burden to these agencies. It's more expensive. One example at Children's Respite Care Center is that they require a psychologist for children's day health services. At Uta Halee, we were a new PRTF, psychiatric residential treatment facility. We had to have a plethora of medical and behavioral health specialists to satisfy the requirements. And you've heard a lot about requirements so I'm going to move on. I'm not here to tell you that the requirements are bad or that they're not needed. But if you make the requirements, you have to help pay for them because these agencies can't survive without them. Like Uta Halee, CRCC serves these kids that have special medical complexities. We've all seen it today. I've learned that the staff at CRCC is so amazing and so dedicated to...you know, us as community members in Nebraska by adopting...they've adopted six of their foster care kids in that program. So you've got people in the trenches who are looking out for all of us with these children and trying to make a difference. And we know the cost effective of when they adopt the children and how that helps get these kids out of the state system. You have, in the documents that I sent around, a memo to the Governor and to you from Kerry Winterer. It's dated from September 13, 2013. In that it states he "is committed to continuing the collaborative relationship with these providers...toward the common goal of serving youth and families 'with the right service, in the right amount, at the right time.'" Yet if you look in that same report, 96 (sic--93) agencies have closed. Uta Halee closed before then. This report found that these losses were not in the formal treatment services but to less intensive community-based service providers like Uta Halee, like CRCC. And by cutting the aid to those community-based services, to these providers these people have to take them to...in the Uta Halee situation, those kids were shipped out of state. Let's talk about dollars and cents. That's a lot more expensive. For CRCC kids, if we have to close those kids have to go to an Ambassador program, you know, like a nursing care facility. So it's important to understand the dollars and cents of these community-based services. And I know you're familiar with them. That's what we're trying to do at CRCC, the right service for the right amount at the right time in a less intensive community-based service. During the last five months when I was the board chairman at Uta Halee and we were hemorrhaging, we were hemorrhaging. We met the new PRTF requirements July 1. We had the requirements. You guys worked hard to make sure that the payments for those were to be adequate. But you know what? It was crickets chirping. Nobody could get in the doors. All the providers who went to PRTF could not get the kids. Where'd the kids go? Poof, they're gone. And that's what the same experiences that we're seeing here at CRCC. If you meet the requirements, you agree to pay for it, get those kids in the door because what's going to happen is going to be just like Uta Halee. They have to close. You can't keep bleeding profusely when you have a staff member who's like a professional, a psychologist or psychiatrist, whatever the situation is for the requirements. You can't have them sitting in your staff and not have the kids in the door and not having the funding come in. And when we had to close those doors--I'm not kidding you--days after, I had so many phone calls. Mary Fraser Meints had so many phone calls from so many senators. And you guys worked with us at that time trying to get through to Kerry Winterer and say, hey, what's going on? Why can't you get those kids in the door? You did work for us. You did. I mean, short of taking our clothes off and lighting our hair on fire, we worked hard to get through. But still, there were no changes made. They would not make the changes and so we had to close. And then after it's closed, you're calling. What can we do? We want to save you. Can't we bring you back? I'm like, for five months we've been hemorrhaging. Where...you know, nobody is listening. You tried for us, but nobody really listening. Don't let this happen again. Do not make it late like that. Don't make the same mistake. CRCC, as we have said, is the only game in town for these kids. Do it for these children. They need this care, and they need your help. Thank you. Any questions? [LR143]

SENATOR KRIST: Any questions? [LR143]

JENNIFER HAMANN: Yes. [LR143]

SENATOR CRAWFORD: Thank you so much. [LR143]

SENATOR KRIST: Senator Crawford. [LR143]

SENATOR CRAWFORD: Thank you, Senator Krist, and thank you so much. Since I wasn't here at that time, can you just clarify what you see as the main reason the kids weren't getting in the door. [LR143]

JENNIFER HAMANN: Can I be honest? [LR143]

SENATOR CRAWFORD: Sure. (Laugh) [LR143]

JENNIFER HAMANN: I feel like it was a game played with DHHS. So if they agree to...they set these regulations. Okay, we agree to pay for it. We're not going to get those kids care. It's going to cost too much money. I mean, those kids ended up in the detention center in Kearney. We are like, where are the kids? Some went to Kansas. Some went...you know, they did not want to...they would just deny them the care. I don't know why. I mean, is there just some evil monster that's not going to let them in because they look at the numbers? I'm not sure, but it was just maddening when we were all set and situated with the right regulations and the right requirements and all...a lot of providers had the same problem. You can't just sit there and pay that staff member when they...and you know those kids are there. And we know these kids are here, and we know these kids are needing the help. For example, for CRCC we had a kid that was denied--a three-year-old, he was a toddler--denied having care at CRCC and he had an ostomy bag. So I'm not a nurse either. But yeah, we had another kid who was approved. He had a breathing treatment. I mean, it's just like a Russian Roulette. You get in; you don't get in. I mean, it's a game playing up there. And it's just ridiculous. We can't have this game playing anymore for these agencies. These are people who are doing our work as citizens. They are taking care of our children. We can't kick them any more when they're down. We just can't. And you guys know that. [LR143]

SENATOR KRIST: Any other questions? Thank you so much for coming. [LR143]

JENNIFER HAMANN: Thanks. [LR143]

SENATOR KRIST: Next testifier. Anybody else that needs, wants to testify? Okay. Welcome. [LR143]

PATRICIA COTTINGHAM: Thank you. [LR143]

SENATOR KRIST: Please state your name and spell it for the record. [LR143]

PATRICIA COTTINGHAM: I am Patricia Cottingham, P-a-t-r-i-c-i-a C-o-t-t-i-n-g-h-a-m, interim director of the Arc of Nebraska. The Arc is an organization that provides advocacy and support to people with developmental disabilities and their families. I would like to thank you all for allowing me to testify today. I'm going to try and make it really short. We've heard a lot of testimony today. And for the most part, I just kind of wanted to sum up a little bit of what I've heard as well as what I've heard across the state. In his novel Anna Karenina, Leo Tolstoy begins with the observation that all happy families resemble one another, and each unhappy family is unhappy in its own way. Public policy ought to acknowledge that one size fits all does not answer the questions that have been raised today. The Arc of Nebraska recently in a collaboration with Munroe-Meyer Institute and the DD Planning Council asked families to share their experiences and desires with of supports offered by the state of Nebraska. We had approximately 362 families who completed a rather lengthy survey that we sent out. And what we found was that Nebraska has many programs to assist families in meeting their needs. However, the families identified gaps and difficulties with accessing those programs. As expected, all families did not express the same needs. All families expressed a desire to simply have the support required to maintain the integrity of their families; nothing more, nothing less. For example, many families who had children experiencing autism spectrum disorders expressed frustration with their inability to obtain behavioral supports that were promised by the autism waiver, another unfunded program. Many families identified respite and child care services that they would like to access. And Nebraska has many programs that provide this support. However, the requirements built into the programs often makes them inaccessible. In conversations with people who are tasked at administering respite programs, they expressed frustration with the confusing array of challenges associated with accessing those supports. Many families reported that income guidelines are so narrow that they do not qualify for assistance, but they do not make enough money to pay for the supports that they need. In a 2011 report developed by the National Women's Law Center, they found that Nebraska ranked last among states in income limits for the child subsidy program. Nebraska reported an income at 120 percent of federal poverty level for families that had not previously been receiving TANF funds which was the least amount of all the states. We are all very aware that early and intense support to families of children who are at risk either through poverty or disability or both can be cost effective by fostering better developmental outcomes. And we do see reliance on prison and institutional care in later life. Nebraska has many good programs to support families, and a great deal of information has been shared today about those programs that we do offer. There's a danger, however, that we will respond with another new program that will further complicate this landscape. Without addressing the underlying structures that support these programs, we will be back at this same place in another few years. We need to address methods we use to help families navigate this maze of support so that they can identify the most effective ways to meet their unique needs. The buzzword in supports, be it social or medical, is person centered. For supports to children living in their family homes, we focus our attention on family-centered supports. Systems must work together to provide the type of support. Person- and family-centered supports cannot be realized when families are told that this is what we have to offer and we will try to fit it to your needs. Only when families are told that...or when families are told that some services they need are offered through another division and you can't access both at the same time. If we are indeed interested in wrapping supports around families, we need to surround them with the right array of services and find ways to fund them across the silos that we've been looking at today. [LR143]

SENATOR KRIST: Thank you. Any questions? [LR143]

PATRICIA COTTINGHAM: Thank you. I'll just add that the report that we are developing as a result of the survey will be done at the end of this month. And so you'll have a copy of what families told us. [LR143]

SENATOR KRIST: Looking forward to it. Thank you very much. Thanks for coming. [LR143]

PATRICIA COTTINGHAM: You're welcome. [LR143]

SENATOR KRIST: Ruth. Thank you for your patience. [LR143]

RUTH VINEYARD: Good afternoon, Senator Krist and members of the committee and Senator Lathrop and members of the Developmental Disabilities Special Investigative Committee. My name is Ruth Vineyard, R-u-t-h V-i-n-e-y-a-r-d. I am a deputy director with the Division of Medicaid and Long-Term Care at the Department of Health and Human Services. And I first want to extend the director's apologies. She really wanted to be here with you today and was unable to attend. In addition, Courtney Miller, my colleague, the deputy director over the waiver program, was unavailable today. So the director asked me to stand in and provide testimony regarding LR143, specifically the recent changes to the payment rate structure for childcare for children with disabilities through the waiver program. I'm going to give you a little history. In 2008, the Division of Medicaid and Long-Term Care received clarification from the Centers for Medicaid and Medicare Services, CMS. The childcare services paid through the Medicaid Aged and Disabled waiver program needed to be medically necessary and above traditional childcare supervision. At the time, Medicaid was paying the full cost of care including basic supervision. In July of 2009, the proposed changes to correct the situation went to public hearing. The department reviewed public comment and additional clarification with CMS and the Aged and Disabled waiver was submitted for renewal with the necessary changes included. This was approved by CMS and was effective in August of 2011. Subsequent to this approval, the department began to review and rewrite the entirety of the Aged and Disabled waiver regulations. In July of this year, the director asked that the childcare section be extracted from that process and expedited because Medicaid was out of compliance with the approved waiver as it related to childcare. In August of 2013, a provider bulletin was released and letters were mailed to the impacted families advising them of the change. The change was effective October 2013, and I'll give you the very basics of that change. The parent is now responsible...parent or caretaker is now responsible for the cost of childcare supervision. This rate is the rate for childcare set by the department, Children and Family Services. The Medicaid waiver then pays anything above and beyond that rate for medically necessary care. So an example might be a provider is approved at a rate of $10 an hour. The childcare rate that's established may be $2 an hour. The parent would pay the $2 an hour. The Medicaid waiver would then pay the additional $8 per hour. Or if that rate was $12 an hour, the family would still pay the childcare rate of $2 an hour, and the department would pay the additional $10 per hour. And that rate is established based on the needs of the child. This only applies to children under the age of 13. And I think one thing I wanted to clarify is low-income families may apply for the childcare subsidy to help support their portion of the obligation. So if their rate is $2 an hour and a low-income family qualifies for childcare subsidy, that portion may be covered by the childcare subsidy program. And that rate $2 to $2.25 an hour depending on location. There was subsequently a public hearing held on November 7. From comments received, the department changed the process by which families' obligations were determined for in-home care. So an individual in-home care provider is typically paid minimum wage at $7.25 an hour, which would have required the family to pay $7.25 an hour for in-home childcare. We were able to modify that and allow for the parents' share to be at the licensed exempt provider rate which is the $2 to $2.25 per hour. I realize that's very basic information. I'm happy to answer any questions that I can. Probably more likely, I'll take those questions back for the director or my colleague to answer for you. I also have Pattie Flury who is the unit manager for the Waiver Program with me today. [LR143]

SENATOR KRIST: The question I'm about to ask is a loaded question, and I really don't expect you to have the actual answer because I think it requires a little bit of preparation and potentially referral to the legal department before you answer it. But when you change something that's in statute and there are rules and regulations, you're required by statute to have a hearing prior to the change. And then you're required to have, in our absence, the Governor sign the change before it's put into force. Now, the chronology that you described to me and the chronology that's been described by many of the folks who are receiving childcare subsidies care violated the statute, violated the principles involved that we live by in the state, which is before you change policy or procedures, you need to promulgate them and the Governor should have signed them into force. So although I understand the chronology for the purpose of this hearing, I think that it's pretty apparent that when you extracted that portion and you decided to reduce costs, it wasn't in the best interest of those people that were being served. So again, I don't...I mean, we've had this discussion. They've had this discussion privately. The CEO Kerry Winterer has been involved with it. Director Chaumont has been involved with it. You immediately withdrew that from your Web site, that it was even there. I just think that that's indicative of the lack of trust that some of my constituents have come forward with in terms of how it was handled. [LR143]

RUTH VINEYARD: If I may, I actually... [LR143]

SENATOR KRIST: Sure. [LR143]

RUTH VINEYARD: ...believe I can answer that from a comment that the director put into a letter that she responded to, if you don't mind. [LR143]

SENATOR KRIST: That would be Senator Mello's letter? [LR143]

RUTH VINEYARD: It would have been to Senator Adams. If I may. As to the timing of the regulations--and this is from Director Chaumont--I take the concerns that you have expressed in your letter very seriously and agree that complying with the state statute is important. The medical assistance program sets forth stringent requirements about how to administer the program. The Nebraska Revised Statute Section 68-905, the statute provides that as a matter of public policy, the medical assistance program must be administered in a way that qualifies for federal matching funds under federal law. At Nebraska Revised Statute 68-906, the statute provides that for, purposes of paying medical assistance, the state accepts and assents to applicable provisions of federal law. In Nebraska Revised Statute 68-907, the terms Medicaid, state plan, and waiver are defined to clearly require the department to administer the program in compliance with federal requirements. In sum, state statute requires the department to administer the medical assistance program in compliance with federal requirements, and the program needed to make changes to the way it administered the childcare waiver services in order to be in compliance with the provisions of the home and community-based services waiver for the aged and disabled. Lack of compliance with federal requirements put the program at risk for loss of federal funds. The program chose to be in compliance with federal requirements and state statutes and the Medical Assistance Act requiring such compliance as soon as practicable. In this instance, we believe the requirements of the Medical Assistance Act took precedent over rule-making requirements. [LR143]

SENATOR KRIST: So the implication or the reference to being out of compliance with CMS is the reason to violate state statute and to work in an expeditious manner to not even get the signature of the Governor to move forward? [LR143]

RUTH VINEYARD: I believe what she is saying is that we were following state statute by taking the action that we did. [LR143]

SENATOR KRIST: Well, we will have to agree to disagree on that one. [LR143]

RUTH VINEYARD: Okay. Thank you, sir. [LR143]

SENATOR KRIST: Thank you. Any other questions? Senator Bolz. [LR143]

SENATOR BOLZ: I've briefly reviewed this change. And one concern I had and maybe you've addressed it already, but I'd like to hear your response to the question which is, I'm concerned that because the children that we are talking about, their medical and behavioral needs can change quickly and they can change dramatically. Is there a process in place for an expedient change in the reimbursement rates? Is there an appeal process put in place related to this change? [LR143]

RUTH VINEYARD: So are you talking, Senator, about the rates for the provider, the specific provider? [LR143]

SENATOR BOLZ: Um-hum. [LR143]

RUTH VINEYARD: I'm sorry. I don't know the answer to that but will follow up. [LR143]

SENATOR BOLZ: Appreciate it. [LR143]

RUTH VINEYARD: Okay. Thank you. [LR143]

SENATOR KRIST: Thank you for your patience. [LR143]

SENATOR LATHROP: I do have a question. [LR143]

SENATOR KRIST: Senator Lathrop. [LR143]

SENATOR LATHROP: How long were we breaking the federal law before this became an emergency? [LR143]

RUTH VINEYARD: We were aware...let's see...the... [LR143]

SENATOR LATHROP: No, we were doing it wrong which is the reason we changed it in the manner that Senator Krist just talked about. How long were we doing it that way before it got changed? [LR143]

RUTH VINEYARD: I'm sorry. I don't know the answer to that, Senator. [LR143]

SENATOR LATHROP: Was it that way for years? [LR143]

RUTH VINEYARD: Yes. [LR143]

SENATOR LATHROP: Okay. So we did it wrong, and we were breaking federal law by paying too much for years and years. And then it became an emergency and we changed the rule, gave these people about two weeks' notice and then didn't have the Governor sign it. And you did it all while we were out of session. That about it? [LR143]

RUTH VINEYARD: The time line I laid out is the time line that events took place. [LR143]

SENATOR LATHROP: Okay. Thank you. [LR143]

SENATOR KRIST: Any other questions? Thank you for your patience and sitting around until the end. [LR143]

RUTH VINEYARD: Thank you. [LR143]

SENATOR KRIST: This will conclude the testimony today for both of the LRs, and I thank you for your patience and for taking time to come talk to us. [LR143]