[LR338]

The Committee on Health and Human Services and the Committee on Appropriations met at 9:00 a.m. on Friday, November 7, 2008, in Room 1510 of the State Capitol, Lincoln, Nebraska, for the purpose of conducting a public hearing on LR338. Senators present: Tim Gay; Dave Pankonin; Arnie Stuthman; Tony Fulton; and John Harms. Senators absent: None. Also present: Joel Johnson; Danielle Nantkes; and Tom Hansen. []

SENATOR GAY: We have on the phone Dr. Noel Mazade, and he's on a speaker phone here. [LR338]

NOEL MAZADE: Good morning. [LR338]

SENATOR GAY: Good morning, Doctor. We have some senators here and we're going to open a hearing here today, and you're going to testify on a national perspective of what's happening in behavioral health. And we appreciate you doing that. We have an audience here, and I discussed with you about it sounds like they could hear you. [LR338]

NOEL MAZADE: Yeah. [LR338]

SENATOR GAY: If you can't hear in the back, raise your hand and we'll have him speak. But we're interested to hear what you have to say. We have your PowerPoint and... [LR338]

NOEL MAZADE: All right. [LR338]

SENATOR GAY: ...we'll be going along with that. So what I will do is turn it over to you... [LR338]

NOEL MAZADE: Sure. [LR338]

SENATOR GAY: ...and you can go. And then I think what I might do is hold any questions until the end... [LR338]

NOEL MAZADE: All right. [LR338]

SENATOR GAY: ...from the senators on the panel, if that would be okay. [LR338]

NOEL MAZADE: That's great. [LR338]

SENATOR GAY: Okay. Well, I'll turn it over to you. [LR338]

NOEL MAZADE: Is Scot Adams there? [LR338]

SENATOR GAY: Scot is here, yes. [LR338]

NOEL MAZADE: Okay. Well, if there are any remarks I make about Nebraska just based on data that we have way out here in, you know, the Washington, D.C., area, our perspective, Scot, please feel free to interrupt and clarify anything I might say. [LR338]

SENATOR GAY: Yeah. In the end, we'll let him speak as well. [LR338]

NOEL MAZADE: Okay. [LR338]

SENATOR GAY: So if he needs to do that. [LR338]

NOEL MAZADE: (Exhibit 1) All right. Well, it's a privilege to be with you all this morning. I'm fighting some laryngitis here so my voice might occasionally break as though I'm

regressing to adolescence. But hopefully that's not the case. I was asked to provide some national perspective on what's going on in mental health. And the National Association of State Mental Health Program Directors Research Institute is a sister organization to the National Association of State Mental Health Program Directors. We are both separate nonprofit institutes. The NASMHPD as it's called. The other organization membership are Scot Adams and his colleagues across the country, the 55 state and territorial mental health directors, their researches, and of course that organization is concerned about national issues and policy, legislation, etcetera. My organization is a separate organization because our primary and sole function is sole function is to collect data on what's going on nationally without any reference, evaluation or judgment made as to the efficacy, directions, any kinds of evaluative were of a value three, if you will, entity. So (inaudible) I'd be presenting this morning are some observations that we're making here at the NRI, as we call it, that do coincide with certainly with NASMHPD and do coincide with what's going on in other states. So that's what I hope to bring to you this morning. So the next (inaudible). There are a number of issues occurring on a national level. And they certainly include trends in what's happening with state hospitals in terms of patient care, client, consumer, persons receiving mental health services, a critical issue on the integration and interrelationship between physical health and medical status. And a concern about a study that we completed here several years ago around person with severe mental illness having 25 fewer years of life than the general population due to a number is issues. Completely different venue, the issue of returning veterans from the Iraq and Afghanistan wars. Criminal justice and mental health, I know you're involved in that, self-directed care, etcetera. Next are 2007-2009 priorities as we discuss with the state and mental health directors and program directors underneath their offices. Again, integration of health and mental health, and I'll get to that down the road, and the relationship of that to substance abuse co-ocurring disorders and whether or not the system can create a no wrong door to serving persons no matter where they come in to the system no matter how cohesive or decentralized that system might be. Workforce development, a huge issue nationally in terms of the mental health workforce. I'll touch on financing and

funding. Considerations of the role of the state mental health agency itself as a founder, as a manger of contracts, as a promulgator of performance measures, and the kind of management information system statement health agencies need. Whole issues around public safety, that gets into issues of stigma, etcetera. So moving forward in terms of the workforce on the next slide, on a national level realize that the state mental health agencies collectively are spending nearly $30 billion in expenditures each year for a variety of both community-based services and state hospital services. And as in any human service profession, probably 85 percent of those dollars are for the workforce. So the workforce is the mental health system, it is the technology, the tools, the delivery system. So there are many, many issue around a workforce that are concerning the states at this time collectively. The composition of that workforce in terms of the standard professions, it's characteristics. (Inaudible) training do individuals have? The supply size versus the demand side, finding a gap in essence. Training issues. What kinds of training should the workforce receive in terms of current evidence-based practices, promising practices, practices that consumers themselves have found to be efficacious whether or not the professions have embraced those. Many issues around recruitment. Where should the workforce come from? Where is it coming from at this point in the history of public mental health? And certainly issues around retention. The dichotomies between the public and private system. Differences in salary, fringe benefits, etcetera. Certainly an erosion in the number of season clinicians in the mental health system at this point. Persons in their 40s, 50s, 60s who have many years of experience. And obviously those persons in their 60s leaving the profession. Are they being replaced by competent and learned clinicians? Tremendous shortages in certain areas. Child, geriatric, and forensic psychiatry, few and far between, yet these are critical areas for services and certainly psychiatric nurses and shortages there. Lack of expertise in co-occurring disorders. Estimates are that between 60 and 70 percent of all persons in the public mental health system have co-occurring substance abuse and mental health issues occurring. Particular problems in rural areas as I'm sure you're experiencing there. And the whole trend toward the mental health system being looked to as the service system for persons who have been judged to be sexually violent

predators. And that's a major both financial and workforce issue in most states. Cultural competency, diversity. Do we have consumers matched with persons in the mental health system where there's a full understanding of what's going on with someone's life and being able to appreciate that. As I indicated earlier, the graying of the workforce, and leadership succession, and public/private sector competition. We're finding in many states the private sector is certainly attracting, recruiting people from the public system. Over on the next slide, higher education issues. What kinds of training are schools of social work? Departments of psychology, departments of psychiatry, medical schools, and nursing? Are they providing?--in most cases not--in teaching evidence-based practices, both in the classroom and in fieldwork where students are out in agencies? What kind of supervision are they receiving? Are they getting clinically relevant skills? And to what extend is the state mental health agency and to what extent are state hospitals and community-based programs able to influence and interact and interdigitate with in essence the professional corporation venues, schools of social work, etcetera? Is there a link there or are they really in two different worlds where students in mental health professions are really being trained more for psychotherapy with persons who do not have severe mental illness, such as schizophrenia, bipolar disorder, acute depression, etcetera? And finally but certainly...well, the last on the list perhaps ought to be first on this list in terms of funding, recruiting, and training peer specialist, individuals who themselves have been clients and may be current clients in the mental health system whose first person experiences can be just invaluable to others coming in the system. And the extent to which systems of care are recovery-oriented systems of care, which I know is a value there in Nebraska, as opposed to looking at severe mental illness as an exorable, uncurable, and really stigmatizing a condition. So the last several years have been a see change in how mental illness is perceived and the notion of hope and recovery certainly on the forefront. Which leads then to the next issue of consumer empowerment and to what extent do consumers in the mental health system have roles in the design of the system, in the service delivery system itself, and in evaluating both professional performance by the traditional mental health professions as well as pure support services, and what kind of structures are set up in the states.

Probably 30 of the 55 state and territorial mental health agencies now have in the offer of the director of mental health a office and office of consumer affairs which is responsible for being a liaison to the consumer community, to be able to be a third ear, if you will, to understand issues in relationship to the design and clinical delivery of services. The involvement of consumers and advisory boards and governing boards of local agencies and of the state mental health agency are definitely a trend. Performance measures. What kind of performance measures are telling? What kind of performance measure is looked at as a dashboard on your car, if you will? What are the dozen measures that a system is compiling that gives them information about an incredibly complex array of persons, technologies, services underneath those dashboard indicators? And to what extent are consumers involved in developing those indicators and together with management of the system, evaluating and judging where the system is going, where it's been, and where it should go down the road. And finally, the whole notion of personal recovery plans and self-directed care. Is the mental health system set up in such a way and are the information technologies available in the state. For example, the use of electronic medical record, which I know is not prevalent there. To help everyone lay out goals that an individual may have toward their recovery. To fully understand the special role that the mental health service system can play, as well as a persons own support system. So those are just some of the issues that virtually all states are attending to on terms of consumer empowerment or role. And next, we turn to financing issues on a national level. There's no question, just look at the stock market or look at any state agency in terms of the plateauing of both state and federal funds in relationship or juxtaposed with high service demands in the field. And there's almost a cruel kind of gap analysis developing where on one hand public funds are diminishing and certainly the federal government's role in supporting public mental health services is pretty much limited on a grand scale to Medicaid. And as many of you may know, there was an effort, current administration to try to actually decouple and eventually or eliminate or certainly threaten case management, assertive community treatment services at the community level by requiring very strict accounting and not allowing for billing on a team basis on the federal end. And also the state mental health agencies

have been and the Center for Mental Health Services has been really limited to the mental health block grant dollars that it's given to states which are only in the national level 1 to 2 percent of the revenues of state mental health agencies of that $30 billion. So it's a very small slice of the pie. And then of course simultaneously you've got the plateauing of state dollars that are available and all of that juxtaposed with high demand for services. And suffice it to say that just looking at severe illness already is a high demand venue. And then if a state wishes to branch out into health-related issues and welcome more persons into the public mental health system who perhaps have less severe disorders, anxiety, phobias, that type of thing, in a preventive model other dollars to make that happen. And in most states there are not. And that becomes a very cruel irony on one hand to attempt to expand the notion of mental health as a public health issue, as primary prevention, etcetera, and then not have the dollars to do that. So moving forward on financing, whole issues are wanted right (inaudible). What should be the mix of community-based versus state hospital services? What should be the appropriate and effective mix between inpatient and ambulatory services and residential services or between and among assertive community treatment, etcetera? But the notion of trying to arrive at some optimal level of efficient service and effective service is an issue that virtually all states are dealing with. Other state agency analysis. Our focus in the past has been on the state mental health agency, on let's say Scot's agency. And we collect data and information about the state mental health agencies, again, expending these $30 billion on the national basis. Most recently, however, we have moved out in our own analysis to what we call other state agency. And those happen to be agencies other than the state mental health agency, Medicaid, corrections, Social Services, Family and Children Services, juvenile justice, education, housing, about a dozen other state agencies that have something to do with expenditures and serving other individuals, (inaudible) the state mental health agency is serving, and providing and supporting of services out of their own budgets. And our findings have been that broadly speaking, you can in many states take the state mental health agency budget and double or triple it to really understand the full range of state agency, state government expenditures for mental health. And that doesn't count any county, local,

and municipal expenditures. So that $30 billion that I was referencing earlier, when you phone in other state agencies we estimate that most likely nationally expenditures for mental health are probably between $85 and $110 billion a year, a huge, huge industry. And we now have developed protocols and tools to go into an individual state and actually analyze and create and portray a complete profile of what is state government spending on mental health. And I can't emphasize how important that is. In the states in which we've been involved, which have been about a dozen so far, we usually find jaws dropping. We find public administrators in those agencies certainly aware of perhaps their own budgets, but completely unaware of their brother and sister agency budgets. And looking at the total fiscal resources being expended, and then giving very serious discussions about how many of the same person am I serving in my agency that you may be serving also in your agency unbeknownst to each other. And what does that mean for people tin-balling (phonetic), if you will, in between and among different service systems and not getting a therapeutic benefit anywhere. It's because their care has been so subdivided. So that's a critical issue of a national basis. We also see many states moving into trying to analyze, and I get a heady and factual-based way the return on investment for mental health fiscal resources. Also, fidelity to service models. So if you're providing assertive community treatment, to what extent is there fidelity to what that model has been found to be most effective in a particular agency? Do you have ways to go into an agency, and if you will, audit the extend on how they're providing certain services and whether that's fitting a model that shows that this is the way the service ought to be provided? And then again finally, performance measures. Medicaid eligibility and how that juxtaposes with the use of state mental health agency funds, again, a critical issue. To what extent is there coordination between the state Medicaid agency and the mental agency? Moving on, the first map there you'll see just the extent to which how the states are organized, and basically we have three models out here. We've got states like yours that are using a county...around 28 states that use a...well, before I get to that, this particular side is looking at the location of the state mental health agency and state government. And you'll see that you're part of slightly more than half the states that are using a human services agency-type model versus other

states that you see there where the department of mental health as completely independent and as a cabinet-level agency. In a few states you'll see mental health is linked specifically within the health department. So you have a lot of company in terms of the way you have chosen to organize there. The next slide you'll see layers between the state mental health commissioner and the director and the governor. And again, in your particular case you're in the majority there. Over on the next slide you'll see a very telling statistic which has to do with the, again, the extent to which the Department of Mental Health as independent. And you'll see then in 2007 only 13 states that was the case. So it's raising issue about the extent to which the state mental health agency is becoming buried in state government, the extent to which it's visible, the extent to which it wields any kind of political or fiscal power and is able to negotiate directly with its sister agencies. Over on the next slide you'll see the state mental health agency relationship to the Medicaid agency in state government. And you'll see three different models here. In the first, which I think more closely represents you is on the left, Medicaid is located in the same umbrella agency as the state mental health agency, they're collocated. That's in 30 states. In other states, you'll see Medicaid is in a different state agency and that creates its own situations. And in the former, even though the state Medicaid may be collocated, to what extent are they fully integrated in terms of the state mental health agency having access, for example, to Medicaid paid claims data so the state mental health agency can run those data and understand who's being served and paid for by Medicaid? Who are these individuals? What are their diagnosis? What other physical care is being provided, but paid for by Medicaid? And over on the far right there, the red block: To what extent does the state mental health agency have a formal interagency agreement with Medicaid in terms of roles each will assume, access to data, analysis of each others service system, etcetera? Over on the next slide, another issue in terms of the state mental health agency's role, and I guess I'll use the word "power" and influence in setting Medicaid rates for mental health in terms of reimbursement rates at the provider level? And in some states, and you'll see it looks like you fit all three of these to some level, but extent to which the mental health agency is the single agency responsible for setting those rates in mental health versus

negotiating with Medicaid. And even looking at rate setting in agencies that are not funded by the state mental health agency. Moving on, this gives you a broad picture nationally of the state mental health agency's role in three venues: mental health, alcohol and drug abuse, and developmental disabilities services, intellectual disability services. And you know, you're part of a group of only 15 states where the state mental health agency and substance abuse are together. And other probably as you'll see in half the states, mental health has been seen as such a large responsibility that it is...the state agency is responsible only for mental health. In other state, just for one state, you'll see mental health and developmental disabilities. And then in 11 states it has all three. So there's a real mixture, as you can see, across the country of how states have organized in that respect and the meaning that that has. Over on the next slide you'll see how state mental health agencies fund community-based programs. And there are three highly distinct models that appear to be in use. The first, of which you're a part is, the use of counties or regions. I'll throw the behavioral health regions as part of the states in green here. Where dollars are flowing down from the county level, then the county in turn is subcontracting with local provider agencies. In other states, the state mental health agency has chosen not to use a county or regional model, the yellow states, and instead directly funds individual agencies. So in a state like Maine, for example, even though Maine is a small state from a population standpoint, the department of mental health oversights over 200 contracts with local provider agencies. And that creates a direct relationship between then between the state mental health agency and provider agencies. In some states, like Florida for example, used to use a county model, but then decided they wished to have a closer relationship with direct providers. So they have...they did away with those county mental health authorities or regional authorities. So states evolve or change decisions around that. So and then finally a small group of states, those that you see in blue, actually which includes Hawaii, actually run both the state hospital and the community-based programs. So local employees in mental health centers, for example, are fully state employees and they are employees of the state mental health agency. And that obviously has its advantages also. So even though there were counties, there are 4,000 counties in the

counties in the country, but even though in Louisiana and South Carolina, etcetera, there may be counties, those are not relevant to the provision of mental health services. So that kind of gives you an idea of where you're fitting on nationally. Over on the next slide jumping back to Medicaid you'll see also some differences in the use of Medicaid waivers to provide behavioral health services. And you'll see that you're using both the home and community-based waiver and 1915(b) waivers and you're only one of five states that have chose to maximize, if you will, those opportunities. Other states have been more selective for just a whole variety of reasons in terms of their relationship with Medicaid. Also there are differences across the country in the extent to which the Medicaid regional offices will or will not approve certain waivers, etcetera. That's been a national issue where there are then differences in the implementation of Medicaid on a national level due to idiosyncrasies and differences and the Department of Health and Human Services regional offices across the country. So all kinds of dynamics that go on around that. And the extent then to which the mental health system is involved in managed care, and most states are to one extend or another. So those are some kind of data points around what's going on nationally. Turning to the next slide, there's some data here now on state hospitals. And just to give you a sense of this, to contextually it for you, as you'll see in...that slide is detecting 1954 versus 2007. And you'll see a palpable reduction in both the number of state hospitals that are now down to 220 or so going from over a half a million residents at the end of the given year and down to 50,000 roughly now. And where admissions are roughly the same in those two data points and then certainly you'll see in the fifties many deaths in state hospitals for a variety of reasons having to do with safety and inappropriate use of seclusion or restraint and violence on a wards, etcetera. And know that safety issues are prominent in your own priorities there. And over on the next slide you'll see the differences in the number of hospitals that states have. So a state like New York, for example, still has 29 state hospitals, Virginia has 9. And you'll see where you're fitting in there versus other states. And that's a function of a whole variety of issues surrounding on how the state hospital is actually being used. Over on the next slide you'll see the dramatic reduction in the number of hospitals and resident patients at the end of the year. And that shows

you certainly the decline in state hospitals, which then begs to question or segues into the questions of how should the state hospital be used? How is it being used? And in some states, you know, it continues to be used as an acute care facility, and others highly long-term care for people with organic brain syndromes and more difficult to treat issues. Over on the next slide you'll see the dynamic nature of the closing of state hospitals. And in the last couple years, seven hospitals have been closed in four states. Four states report planning to close hospitals in the next two years. But on a national basis out of that $30 billion, just to give you a sense of expenditures, out of the $30 billion, the state mental health agencies are controlling $8 billion of that is devoted to state hospitals. So that gives you kind of a sense of proportion on a national basis and, of course, those hospitals are mostly funded with state mental health agency dollars. But if you go to the next slide you'll see that even though the hospitals continue to exist on a national basis, there's a basically set of decisions that are making more explicit the conscious use of those hospitals. And you'll see running across the bottom of that slide all the various mechanisms that are being used to consider how those hospitals are being operated, their purpose and mission, and how that relates to the community. So the number of states that are reorganizing or consolidating or closing different wards or reducing the size of certain wards depending upon specialized treatment or transferring patients between or among hospitals or replacing a hospital, an older hospital, with a new one. And again, they're closing certain wards. So there is quite a bit going on in terms of looking at the hospitals. Over on the next slide makes the point that said hospitals are not the only beds that have been closing. And you'll see a very dramatic differences in the last five years in terms of the availability of private psychiatric beds, which are declining. And certainly veterans hospitals closing meaning that those individuals who need mental health services may end up in the public section. And certainly what's going on in general hospitals, specialty units in terms of psychiatric beds available, again, declining. In many cases in general hospitals, the psychiatric beds represented really a cash cow, if you will, pardon the term, for the hospitals, and that's not the case any longer. And finally the notion of shortages, on the next couple slides, of psychiatric inpatient capacity. Again, dwindling is the (inaudible) message

there. So we see pressures, if you will, on the state hospital in terms of numbers of admissions, whether or not community-based services are required to be the entity that prescreens an individual before they can be admitted to a state hospital. So there are many states that have several layers of triage before an individual can actually get into the state hospital. Obviously the notion being to try to keep care at the community level. And there are other states that are trying to set up regional acute care, psych beds, again, to make sure that the only persons that are eventually or need to be transferred to a state facility cannot be served anywhere locally for whatever reason. You'll see in the next slide the number of states that report experiencing a shortage of psychiatric beds. And over on the next slide, a number of states that are considering new or replacing psychiatric hospitals. So these obviously are decision around capital construction costs and certificate of need issues in terms of the state certifying beds, etcetera. And of course go back to the workforce issue. What kind of workforce are even available or would be distributed in these different types of facilities? The next slide, shortages of acute psychiatric inpatient capacity. States are now looking to come up with solutions to eliminate some of the concerns around the hospitals and alternative forms of treatment, crisis stabilization programs, assertive community treatment where there are very low patient/staff ratios. So assertive community treatment staff person may be working with only a dozen or so individuals on their case load, but keeping people out of the emergency room, keeping them out of the state hospital, helping them to move forward in their recovery, and have a more intimate relationship. Diversion programs. Mental health courts, and other...alcohol and substance abuse courts for persons primarily who have committed misdemeanors. Diversion from jail or providing mental health services in the jails. Respite residential programs, etcetera. All right. So moving on then to a question of who's being served in the system. And just to give you a sense of that nationally, over 6 millions persons were served by the state mental health agency alone in 2006. That's probably closer 6.5 this year. Ninety-six percent of them served in the community, only 3 percent in state hospitals. You'll see about a quarter of those individuals were employed at the time. Half of them were not in the labor force. Eighty percent living in private residences, 3 percent homeless, and 71

percent or so on a national basis reporting positive outcomes. And again, 62 percent, somewhere between 60 and 65 percent having Medicaid coverage or payment for their services. Again, a critical reason for the Medicaid agency and the state mental health agency to know who is in each other's system here and how individuals being paid because there's obviously an issue of efficiency and covering involved in that. And you'll see fully close to 40 percent had no Medicaid coverage, which means that the state mental health agency or county dollars or other dollars, certainly not private insurance, are picking up those individuals. Insurance of Nebraska itself in relationship to some of these data on a national level, we see when we look at, for example, national data show that if you look at each thousand per thousand population nationally that about 19 out of 1,000 people are receiving mental health services. And in Nebraska, that's pretty close. It's around 18.6, so no differences there. Where you do see differences are in the state hospital utilization per thousand population. In nationally, we've got about .6 persons receiving services, in Nebraska it's about 1.1. But when you look at all the data around length of stay, other positive outcomes, availability of the serve of community treatment, (inaudible) housing, etcetera, on most performance measures, Nebraska is right in line with the country. The only major outlier that we say in some of our data that are not on the slides, I'm just telling you about this now, we look at an indicator of adults with co-occurring mental health and substance abuse disorders. Nationally, that rate is around 24 percent of individuals being served by the state mental health agency system that have co-occurring. In Nebraska, it looks at though it's closer to 80 percent. And the other outlier, nationally about 6 percent of children with co-occurring disorders are being seen. In Nebraska, it appears to be around 28 percent. So that tells you that certainly the state mental health agency is serving a population of individuals who have some serious disorders, if you will, that the state is setting some priorities to serve a population in need, if you will. Moving forward very quickly to some of these other financial data back to the slides. The next slide, trend of state mental health agency spending, you'll see on that slide of a clear trajectory upward from 1981 to our last data available here, 2005. We're currently doing 2006-'07 now. But you'll see that although in real dollars expenditures have gone from $6 billion up to nearly $30. If you consider

inflation and constant dollars, there's not much of an increase. We're basically flat lined in terms of our purchasing power in the public system. And on the next slide you'll see the same phenomena in relationship to per capita expenditures. So you've got around, back in '81, $25 to $20 per capita. Now you're looking at in current dollars nationally around $100 per capita. But again, flat lined and looking at $81. On the next slide, we've tried to take the fiscal data we had here from Nebraska and map that onto current dollars. And you'll see again in line with the country, the red line, Nebraska's current dollars have gone up, inflation adjusted dollars have remained relatively plateaued. And that mirrors the national average. Over on the next slide you'll see again national data looking at the relationship between state hospital inpatient dollars, the red line, juxtaposed with the yellow line for community-based dollar. And you'll see that in roughly around 1994...between '93 and '94 we have this kind of lazy X laying here where there was a crossover, a tipping point, if you will, where state hospital dollars nationally began to decrease at a palpably observable level. And dollars from the state mental health agency devoted to community-based programs dramatically rise. Over on the next slide, we've done that same calculation for Nebraska. And you'll see that inpatient dollars have trajected slightly upward over that multidecade period. Community-based programs have a slight decrease. But I think if we looked at fiscal years 2006, '07 trajected dollars for 2008, now those lines you're beginning to come together. So one might expect that or I guess in this case they may be starting to separate. That is more dollars are going to be devoted to community-based programs than ever before, and that will then reduce the proportion of total dollars for the state hospital. So you'll see some...it looks like movement around those data. Yet on the next slide, again, we simply put the two on the...what I just discussed on the same slide. On the slide following that, the final graph, we're showing that community dollars adjusted for inflation and state hospital dollars. So basically all these data go back to what I was attempting to explain at the beginning this morning that the mental health system as a whole is in a rather acute stage of having now flexible dollars, no new dollars being inputted. And it's difficult if not impossible to say what affect parity will have on this down the road or to what extent the federal government may or may not change, alter,

increase or decrease its investment in mental health. And obviously with the economy in the state it is, to what extent there will be long-term or relatively intermediate-term consequences to having more dollars at the state level available for the department of mental health. Because as we...in most states, mental health is the second or third largest state dollar expenditure. So it's a hugely important component of state government expenditures. If we look at the next slide, we contexturalize...you can contexturalize Nebraska in relationship to where you are on a national level compared to other states. So on this first slide you'll see that you're spending, in terms of your 2005 dollars on a per capita basis, you're lumped in with about 15 other states, kind of there in the middle, you'll find 14 states spending $85 to $130 per capita. And other states, 13 of them spending over $130 for each of its residents. On the next slide you'll see that those same data for community-based expenditures. And there Nebraska is in red, so you're at the lower end compared to the country as a whole. You're one of 11 states you can see there in red, but you'll see a whole number of states that are almost three times the per capita expenditures for community-based programs. As you see, those tend to be clustered up into the northeast, and then some outlier states over on the coast, California, Arizona, Minnesota, etcetera. So there's some difference there. State hospital expenditures on the next slide you'll see that your in the highest category, $35 plus per capita. And it looks at though compared to your neighbors, you and South Dakota are sitting there in green. But, again, if you look over on the East Coast you'll see that there are also a number of states that have high per capita expenditures. And recall those are the very same states that have high community-based per capita expenditures. And there is some research that's showing that states with high per capita state hospital expenditures or presences, if you will, have a higher probability of garnering community-based expenditures. It's as though there's not the direct relationship between the doing away with state hospitals and then expecting more dollars for the community system There's an odd kind of fiscal politics that go on. There's some research suggests in states so that somehow it's important that mental health is represented both by inpatient programs as well as community-based programs. Over on the next slide you'll see a series of bar charts there, vertical

charts...excuse me, bar graphs that show you now Nebraska contexturalized in relationship to the rest of the country. So you'll see that Nebraska is sitting there just in between Nevada and Alabama over on right kind of in about 10 or 11 states. And you'll see also in this chart within any one state, you'll be able to see the proportion of community-based in green versus state hospital in blue. So again we would expect that in Nebraska's case that the state would be moving toward the left as you increase your expenditures for community-based programs, change the proportion, and add more real dollars into the system. But this does give you kind of a visual representation of the highly diverse extent to which the state mental health agency compare with one another. But again here in the next slide you'll see we just contexturalized that down to the great plains states, and Nebraska over there on the far right. What's important about all this also has to do with many times the data can be misleading because even though a state may have low expenditures from the state mental health agency, that does not mean that there are low state government expenditures for mental health. So for example in a state like Delaware, if we looked at the state mental health agency expenditures, well, we might find them very low. But as we dig down into what services are being provided by that agency, we find for example that all children's mental health services are the responsibility of a completely separate state agency. Or we'll find that state mental health agency in another in another state may have an agreement with the corrections department where the correctional system is paying for forensic evaluations and services in the prisons or jails. Whereas in other state, that's part of the state mental health agency budget. So that's why it becomes incredibly important to conduct these other state agency analysis to fully understand the why and wherefores of why the state mental health agency budget appears as it does. And either it's because of formal agreements or that the demand side may be lower or higher due to what else is available surrounding it. So that's the message there. On the next slide, again, you're looking at now the revenue side of things nationally. And you'll see that Medicaid is a palpably important and becoming increasingly important source of revenue for state mental health agencies. All the way from 1990 to 2004, in 14 years, you can see that a dramatic increase in Medicaid on one hand and then the blue line above it, the again

visible decrease in state dollar general funds from the state legislature decreasing. And that can be a real issue because some states...take a state like Vermont, for example, it attempted to maximize all the Medicaid occurrence several years ago. It went after a number of waivers and had individuals become eligible for Medicaid, etcetera. And if there's any slight change in Medicaid regulations in relationship to eligibility, reimbursement levels, etcetera, it obviously can have a deleterious effect on decreasing and disrupting mental health care because the state just becomes so dependent on Medicaid. So that's why there's a delicate balance there for some states to be...although being seduced, if you will, by Medicaid or seeing that mental health services can be reimbursed, to what extent are people becoming...are having the ability to project out and forecast and "futurecast" the meaning of that for financing the public mental health system. So those are critical issues on a national level. Over on the next slide, just looking at the data we have for Nebraska, you'll see some differences from the national data. Where in Nebraska's case, the state under general funds you see some actual increases, and on the Medicaid line well below that on the bottom you'll see some differences in Medicaid revenues in those last several years. Over on the next slide you'll see issues around expenditures for forensic and sexual offender services. And it's obvious to anyone looking at this chart that there's a tremendous increase in the proportion of state hospital dollars going toward these functions and these populations. Forensic that I know in Nebraska, forensic psych services for evaluation, treatment, and restoration become important. And you'll see that that's as true nationally. Moving on, electronic health records. You're doing that in the state hospitals. And again, moving on to the issues of smoking and that's in here because smoking...44 percent of all cigarettes purchased in the country are by persons who have a mental illness. And that obviously has an affect on health status, etcetera. And there are still unlike Nebraska, there are many states that still do not have or that permit smoking in the state hospitals. That's a national issue both for states that continue that practice and for a trend toward trying to eliminate that. Moving on, the next two slides really are trying to make the point that in many states, certainly through the state medical directors and other sources of influence, a greater sensitivity, a conscious sensitivity to not only mental health issues,

but physical health issues, and realizing that a great number of people who come into the public mental health system have concomitant physical issues around body mass index, blood pressure, glucose levels, diabetes, smoking, hypertension, and medical histories that are not very positive. And again, this is leading to this large death rate, if you will, among the population, but also is speaking to the need for mental health care to have available with it both assessment, and that's what this chart is trying to drive home to notion...and this is really coming from the state medical directors. Over the last several months, I've been looking at the notion of what kinds of physical health indicators ought to be part of an assessment when someone walks into a community mental health program or a state hospital? Are people getting these data, blood pressures, glucose levels, etcetera, assessed to determine their physical health status, come up with a treatment plan, and make sure that there's continuity of care on the physical health side, continuity of data to show that peoples overall health is improving because someone's attending to their physical health status either through the use of primary care physicians, psychiatrists who are doctors providing services, nurse practitioners, etcetera. So that's a national trend that's developing in a powerful way. These last slides were speaking to other emphasis that certainly over at NASMHPD at the state mental health directors there's now a new contract from SAMHSA to develop specific suicide prevention toolkits for seniors, for youth, through veterans, individuals in employee assistant programs, etcetera. On the veterans side many states are finding that, as I indicated earlier, people coming back from the wars are coming back with a number of issues I think as we all know. But also that individuals who are active duty military where there may be bases in a number of states are seeking furtively or secretly mental health services from the private and public sector because they do not wish to be identified as consumers in mental health services on their base, that there's a stigmatizing affect or the fear that that will jeopardize their careers, etcetera. So we're finding some states where their active duty military, greater numbers being served in the state system which becomes a real issue again around financing, provisional services, and having a workforce that knows something about PTSD and traumatic brain injury and anxiety disorders and phobias, etcetera. So that's another issue. The rest of the

slides, I'm going to stop here, they deal with mental health courts and other special targeted populations. So let me stop at this point. I've been (inaudible) on here for like an hour or so. I hope this gives you some notion of what's going on nationally, and if you're able to contextualize that there. [LR338]

SENATOR GAY: That's very good information. Thank you. You got time for a few questions. [LR338]

NOEL MAZADE: Um-hum. Oh, sure. [LR338]

SENATOR GAY: We've got some other things this morning to do. [LR338]

SENATOR GAY: Right. [LR338]

NOEL MAZADE: But this was very helpful as far as benchmarking and total view of what's going on. So we appreciate that. I'm going to see if there are any questions from some of the senators. We'll just leave it to the senators now to...Senator Arnie Stuthman has question for you. [LR338]

SENATOR STUTHMAN: Thank you, Senator Gay. In one of the slides, you stated that Nebraska had a very high co-occurring mental health illness. Is there any reason why we have that or is there any study about that? [LR338]

NOEL MAZADE: That would be mental health and substance abuse disorders. Actually, and maybe Scot can respond to that, but just intuitively looking at this nationally, at a national level there has been and continues to be, frankly, almost a destructive dichotomy and a siloing of these two anomalies in mental health where you've got mental health systems that are only looking for and treating and attending to mental illness. And then you have separate substance abuse systems over here that are looking only at substance abuse and not considering other mental illness that might

overlay or coexist with substance abuse. And then you have other programs that may not have diagnosed both of those conditions or on the other end of that continuum, programs that consciously try to assess and develop a treatment plan for both situations. And it could be in Nebraska and I don't know the answer to that. The rate of co-occurring disorders may not be the existence of the rate of co-occurring disorders, may be no different from any other state. But what might be different from other states is that you've attended to that, you focused on that. And therefore when you diagnose or assess somebody coming into the system, you consciously look for both of those conditions, document them. And by doing that, it raises the real number of those co-occurring cases when somebody asks, well, how many individuals in the system have a co-occurring disorder, you're able to more accurately answer that. And because other states don't do that as well, your rate looks higher than other states, but it's because you're doing a good job, if you will just to kind of put that cut on it. In actually finding out if that is the case and having programs that try to respond to it. [LR338]

SENATOR STUTHMAN: Thank you. [LR338]

SENATOR GAY: And we'll have Scot Adams talk on that afterwards. We've got another question for you from Senator Tony Fulton. [LR338]

SENATOR FULTON: Thank you, Doctor. Earlier in your presentation I thought I heard you say that there was a problem nationally with migration of employees from the public to the private sectors. [LR338]

NOEL MAZADE: Yes, yes. What happens is that the private sector in many states is able to offer better salaries, benefits, and basically make a work environment more attractive through that. Or the private sector ends up attracting people right out of schools of social work, departments of psychology, etcetera, thereby making them unavailable to go into the public mental health workforce. But obviously in most cases other than private psychiatric hospitals that might be serving persons with serious

mental illnesses, schizophrenia, bipolar disorder in particular, individuals going into the private sector are working with a less challenging population and are simply not going into public mental health. And we've see very states, frankly, that have probably and robust recruiting efforts to have younger persons go into the public mental health system and make sure they have good supervision and make that a rewording and a socially important career track for them. So, yeah, that definitely is the case. [LR338]

SENATOR GAY: Thank you, Doctor. Doctor, we're going to limit the questions to that because we've got other things to do this morning. I wanted to thank you. That was a great presentation and we will get that...all the members have it and Jeff did a fine job keeping up with you here, so. [LR338]

NOEL MAZADE: Thanks, Jeff. And if there are more data that you would want and of curiosities, that, you know, I was unaware, let me know and we can see what we have available here. [LR338]

SENATOR GAY: okay. Also, could I ask if a question arises later, could we send you an e-mail and... [LR338]

NOEL MAZADE: Oh, absolutely. Oh, yeah, yeah. [LR338]

SENATOR GAY: Okay. We might take you up on that and we want to thank you again for the information. It's very helpful in what we're trying to do here and appreciate it. [LR338]

SENATOR GAY: Okay. [LR338]

NOEL MAZADE: Terrific. [LR338]

SENATOR GAY: Thank you. [LR338]

NOEL MAZADE: Thank you. Have a good day. [LR338]

SENATOR GAY: You bet. Bye-bye. [LR338]

NOEL MAZADE: Bye-bye. [LR338]

SENATOR GAY: Okay. Scot, do you want to follow up on Senator Stuthman's? Did you have anything to say or in general of, you know... [LR338]

SCOT ADAMS: I'd be happy to respond with my opinion with regard to Senator Stuthman's question with regard to the high incidence, apparently, of co-occurring diagnosis in Nebraska and would have a comment or two about other things as well. But I'll be brief. I think that in the Nebraska context, there are I would offer four all other points of view to perhaps explain the discrepancy, which by the way I also see as a very positive kind of things in terms of being able to identify and work with both conditions. First of all, for decades now the Department of Health and Human Services has collocated those functions, if you will, side-by-side. When I got into this business in the mid 1970s, there was the Division on Alcoholism and the Division of Drug Abuse. But they were side-by-side and the same people worked literally in the same cubicle next to one another. And while they had different federal kinds of things, they...it was just a small enough staff that we all worked person-to-person with regard to things. So we have structurally been together and under the same roof for a long time. Secondly, LB1083 of course made us the Division of Behavioral Health. And so we brought that even more closely together and so our mind-set, our rose-colored glasses, if you will, with which we see the world and encourage people to see the world has been very much akin. Third reason is we're a small state, and as we have talked about with regard to some of the workforce issues, when you're the only game in town, you've got to do it all. And so by necessity many people have had to be both mental health practitioner and a substance abuse or addictions resource in the community. And therefore, you

know, you just handle it, you make due and of thing. And fourthly, especially on measures like this I urge a great deal of caution. Measurement error is never to be ruled out on statistics, and especially at the national level where you have a great deal of potential for misunderstanding of even the terms from this state to that state to this state. And so measurement errors is just another way to perhaps explain it. But those would be four different dynamics I think in play. Might I make another comment or two? I think my strongest comment first of all is to say that I find this quite encouraging. If you recall some of the concerns with regard to increasing weights at state hospitals and decreasing beds and shortages and that kind of thing, I think Nebraska is faring fairly well in that regard. On July 1, 2004, we had a 179 patients at the Norfolk Regional Center, we had about 50 people, 50 adults at the Hastings Regional Center, and Lincoln was full as well with the waiting list of about 40 persons to get in on that day. This last week, having closed the adult services at Hastings, having reduced Norfolk to the 30-bed unit, Lincoln still being full, this week we had two persons on the waiting list and we expect to get those folks in this week. That's a pretty good report on that one. My second significant report that I would urge you to consider and keep in mind as you look through this data perhaps at a later point, and one that we will try to ameliorate is this is '05 fiscal data. That means July 1 of '04 through June 30 of '05. The year that behavioral health or LB1083 went into effect is the data that we're using. It's very dated data in terms of the numbers, with regard to that, as Dr. Mazade noted in terms of some of the X crossings of things, we never had that because we had more monies in the community-based services at one point. But we should see the growing movement apart from regional center expenditures to that kind of thing. So I'll leave my comments to those. [LR338]

SENATOR GAY: Okay. And Scot, I'm not going to open this to any questions right now quite honestly because we can get a hold of you and there's just...these are very complex subjects. But we have other things--thank you--we have other things to do. I want to...let's go ahead and we've got a testimony on insurance parity. And it's a quite thing because it's a newer issue. So we won't spend--come on up--so we won't spend a

whole lot of time on that. We'll go to 10:30 because we had about 15 minutes, we'll take a short break, because we do want to hear a lot from the consumers and family members of course who are affected by this, and then we'll round out the morning with that. So go ahead. Martin, you want to go ahead and... [LR338]

MARTIN SWANSON: Thank you, Senator. Good morning. My name is Martin Swanson, spelled M-a-r-t-i-n S-w-a-n-s-o-n. I'm health policy counsel for the Nebraska Department of Insurance and stepping in today on behalf of director Ann Frohman who apologized that she could not be here today. The department has been asked to talk with you about the new federal standards on mental health parity. And these standards require insurers to provide parity between their coverage of physical and mental illnesses. The department has begun to compare these new statutes with two existing Nebraska statutes. I'd like to thank Senator Johnson's office for including us as part of today's agenda. The department stands ready to help you with understanding this new federal law or offer whatever help we can. In discussing the federal law, the new parity provisions were adopted as part of the recent federal legislation addressing the credit markets. The act applies to all plans with the exception of a small group plan, which are 2 to 50 employees. The key is that the mandate only applies if the plan offers medical benefits and mental health substance use disorder benefits. If both are offered, the financial requirements applied to medical and surgical benefits must be similar to the mental health and substance use disorders without separate cost-sharing requirements. Deductibles, copayments, coinsurance, and out of pocket expenses with the exception of aggregate lifetime limit and annual limits, network restrictions must be the same for both mental substance abuse disorders and medical benefits. The act does provide for an exception if there is an increase for the plan year of more than 2 percent in the first plan year or 1 percent in years following the change. If there will be an increase, the requirements do not apply for the plan year. The GAO must analyze the specific rates, patterns, and transient coverage. And finally, the rules and regulations musts be adopted within one year. There is an effect on Nebraska law, specifically on substance abuse. Nebraska's existing mental health parity law and alcoholism treatment laws may

be preempted to the extent that they require less of insurers than federal law. Although the department wants to continue to review this question. Nebraska's alcoholism treatment statutes only apply to alcohol since the statues do not specifically address the treatment of drug addition. In addition, Nebraska law provides a floor for basic coverage or treatment of alcoholism. This floor mean we have to revise to require parity between the treatment in terms and conditions on the medical side of the policy. On the effective mental health for Nebraska, currently under Nebraska revised statute 44-793, Nebraska's mental health coverage mandate, if the coverage is provided for mental health condition, an insurer cannot use a rate, term or condition that places a greater financial burden on an insured for access to treatment for serious mental illness. Nebraska statute limits its mandate to serious mental illness defined as schizophrenia, schizoaffective disorder, delusional disorder, and bipolar affective disorder, major depression, and obsessive-compulsive disorder. A federal statute is not limited by such definition. Nebraska's mental health parity act does not require the same rates, terms or conditions between treatments for serious mental illness and preventative care. Further, the Nebraska mandate restricts the types of care required. The federal act may not allow for this since treatment and limitations applicable to mental health or substance abuse disorder may not be more restrict than the predominate treatment limitations applied to medical and surgical benefit plans. Finally, Nebraska law does not require an insurer to offer coverage for nonemergency services rendered outside of its network of contracted providers. This is clearly prohibited by the federal act if the insurer covers out of network care on the medical side of the ledger. In conclusion, an initial review of the federal act left the department with several questions about the impact on the act on insurers and the insureds. Based upon prior experience, the Department of Insurance believes that some of the questions will be settled through rule making by the federal agencies. Meanwhile, the Nebraska Insurance Code includes laws that may contradict the federal act and will have to be addressed at some point either by amendment or as a result of application of federal preemption. Thank you, and I'll be happy to answer any questions. [LR338]

SENATOR GAY: Thanks, Martin. Any questions by the committee? I don't see any. What would be helpful I think is if we could get a copy of your testimony or if you want to get it back to us is some kind of a brief...I think a copy would be good. [LR338]

MARTIN SWANSON: Absolutely. [LR338]

SENATOR GAY: It's was a lot to digest and it's a complex issue. Senator Pankonin has a question. [LR338]

SENATOR PANKONIN: Martin, just one question. The time frame that you think this will happen on the federal rules and regs and whether we need to make any statute changes and that sort of thing. [LR338]

MARTIN SWANSON: The rules and regs are supposed to be promulgated theoretically within one year. That's what the act says. The act will go into effect in one year, which will be in October because that's when the budget bill was passed and that's the effective date, Senator. [LR338]

SENATOR PANKONIN: So do you think we'll have, like the Banking, Commerce, and Insurance Committee have to look at something this spring yet or... [LR338]

MARTIN SWANSON: Potentially yes, but I think if the federal (inaudible)... [LR338]

SENATOR PANKONIN: Then it's a mute issues, right? [LR338]

MARTIN SWANSON: Right, and like I said, there will be guidance hopefully on time. Yeah. [LR338]

SENATOR PANKONIN: In time. Good. Thank you. [LR338]

SENATOR GAY: Okay. All right. I don't see anybody else with questions. Thank you. [LR338]

MARTIN SWANSON: Thank you. [LR338]

SENATOR GAY: All right. Let's take a break and let's say 20 until we'll come back. [LR338]

BREAK []

SENATOR GAY: All right. Good. Well, we'll get started. We have a panel going to start out, some advocates, and then we want to hear from everyone. I know a lot of you want to speak. And just for courtesy to everybody here, can I see the hands of people that want to speak? So when you look around the room, that's a lot of people and we've got about an hour and 15, hour and 20-something minutes to do it. You know, we want to hear from you, but let's be courtesy to everybody. We're going start out with the panel and they're going to speak, and then give you time to speak as well. If there's any questions, we'll ask you questions. And of course, you know, today we're trying to get a baseline of where we're at and we're identifying a lot of problems. But later throughout the year of course we're going to hear from you as well on solutions. You know how to get a hold of us, so we don't have to do everything today is what I'm saying. We'd love to hear from you ongoing as well throughout the year. So with that, let's get started. Go ahead and... [LR338]

CONSTANCE ZIMMER: (Exhibit 2) Good morning, Senator Gay and members of the Health and Human Services and Appropriations Committee. For the record, my name is Constance Zimmer, C-o-n-s-t-a-n-c-e Z-i-m-m-e-r, and I'm a person with a severe and persistent mental illness as well as the parent of a young adult with severe and persistent mental illness. I'm the vice chair of the Protection Advocacy for Individuals with Mental Illness Advisory Council for Nebraska Advocacy Services. Nebraska

Advocacy Services, inc., the Center for Disability Rights, Law, and advocacy is the designated protection and advocacy system for persons with disabilities in Nebraska. I want to thank the committee for this opportunity to provide a consumer and family perspective about the implementation of behavioral health reform in Nebraska. For Nebraska, to be successful in its behavioral health system transformation and to live up to the commitment of the Behavioral Health Services Acts, LB1083, to make consumer involvement a priority in all aspects of service planning and delivery. It is critical that Nebraska include and incorporate the voices of consumers and family members in the reform of the behavioral health system. The unique lived experience of persons with mental illness, in particular the experience of civil commitment and subsequent involuntary treatment, can provide a critical perspective about how the mental health system should function, what areas need to be improved, and how mental health reform can be most successfully accomplished. Although Nebraska has made some progress in the area of consumer and family member inclusion, we believe that much remains to be done. It is critical that the state stay true to the intent of the Behavioral Health Services Act to achieve a transformation from the current institutionally-based behavioral health system to a community-based system while providing for meaningful involvement of consumers in the transformation effort. Without such a continued focus and adequate funding, Nebraska's behavioral health reform could stall or deteriorate. The Behavioral Health Services Act established an Office of Consumer Affairs and created the Administrator for the Office of Consumer Affairs as a high-level management position within the Division of Behavioral Health. The use of the term "Office of Consumer Affairs" has specific reference to people with mental illness. The intent in doing so was to provide a mechanism and point of accountability for achieving the act's explicit mandate to make consumer involvement a priority in all aspects of service, delivery, and planning. Advocates, especially those of us appearing before you today, pressed Senator Jensen to include language establishing and Office of Consumer Affairs in LB1083. It was our clear intent, at the time, that the administrator of this office be consumer or former consumer of mental health services. It is critical that the Office of Consumer Affairs remain true to the original intent by focusing on the

involvement of persons with severe and persistent mental illness. We believe it's unwise to dilute this effort by including problem gambling and substance abuse responsibilities. A unique lived experience of persons with mental illness is necessary to achieve the transformation of Nebraska's mental health system and any dilution of this focus only distorts the legislative intent of LB1083. It is essential that the Office of Consumer Affairs, as created under LB1083, will remain focused on incorporating the experience of individuals with severe mental illness through involving them in all aspects of mental health service planning and delivery. The term "consumer" is not defined in LB1083. We would suggest that a consumer of mental health services be understood as a person who has a diagnosis of severe mental illness, for instance bipolar disorder, schizophrenia, or severe clinical depression, and preferably one who has received inpatient mental health services in the public mental health system. In order to fulfill the state's declared intent to involve consumers in all aspects of service planning and delivery, the number and proportion of self-identified consumers who serve on boards, and committees, and councils, and advisory groups must be increased significantly. For example, the PAIMI Advisory Council of NAS is required to have 60 percent of its membership be consumers and is mandated to have a consumer as its chair. Without adequate representation and empowerment, it is unlikely that the state will gain significantly the necessary insight and inclusion of persons with mental illness--a clear purpose of the Behavioral Services Act. We also believe that the Behavioral Health Oversight Commission should continue until there is clear and convincing evidence that Nebraska has transformed its mental health services into a recovery-based system which has achieved the full inclusion and involvement of persons with mental illness in all aspects of mental health services planning and delivery. Additionally, it is important to support those consumers and family members who serve on the Oversight Commissioner or any other regional or state committees. Many consumers live with severely limited financial means, and it is often a significant hardship for them to outlay personal funds to travel to meetings and participate without financial support. We would suggest that changes be made to address the financial costs to low-income consumers up front as often consumers find it difficult to wait for their travel and other expenses to

be reimbursed by the state. Of particular note relative to consumer inclusion and listening to the voices of people with mental illness, the Division of Behavioral Health is submitting a proposal, Nebraska Transformation Transfer Initiative Application: Maximizing Consumer and Family Voice at All Levels, to increase peer support services in Nebraska. While this is a laudable effort, the application does not adequately incorporate consumer voices in its design or implementation. The application simply states that the Office of Consumer Affairs will be actively involved in this project from start to finish. However, it appears that neither advocacy groups representing consumers nor any consumers that we are aware of were contacted or consulted regarding this proposal. Furthermore, it is unclear what "actively involved in this project from start to finish" means relative to consumer inclusion. Although the Behavioral Health Reform Act required the establishment of Behavioral Health Advisory Councils for each Regional Behavioral Health Authority to advise their governing boards, which have authority to oversee planning and delivery of services and the overall quality of services provided in the respective regions, such advisory councils must be required to disclose those members who are self-identified consumers. It is important that Nebraska listen and learn from the unique lived experiences of consumers because that is a very powerful way to increase the quality of services and to further develop services that match the needs of individuals who receive services. It is only when the state begins to give consumers a stake and a voice in the development and review of mental health services that things can change for the better. To that extent, it is imperative that Nebraska afford consumers increased opportunities to be educated about different mental health models and services so that a robust knowledge-base can be furthered and progressive changes to services and delivery can be developed by consumers and for consumers. Consumers need to be provided opportunities to attend national conferences and trainings to increase their knowledge and skill-base so that they can achieve meaningful involvement and usher in system changes. The traditional services provided to consumers typically are not recovery-based services. The Division of Behavioral Health needs to thoroughly articulate the necessary competencies that professionals and providers must have in order to offer recovery-based services. It is

essential that Nebraska work to build provider competencies to enable recovery-based services so that Nebraska can achieve a recovery-based system of mental health services. In order to address the concerns we raised, we have offered the following recommendations for the committee's consideration. Specify the duties and responsibilities of the Office of Consumer Affairs and qualifications for the Administrator for Consumer Affairs in statute. We have prepared suggested language based on an analysis of the duties and responsibilities of Offices of Consumer Affairs in other states and from materials developed by the National Technical Assistance Center of the National Association of State Mental Health Program Administrators. Secondly, specify in state statute that the Division of Behavioral Health has the responsibility to develop the knowledge and skills of mental health consumers about how to be involved in all aspects of service, planning, and delivery, and recovery-based alternatives to the traditional ways in which services are provided. Change existing state statutes creating Regional Behavioral Health Advisory Councils to require that at least 50 percent of the members on the council be self-identified consumers or family members. Create a statutory bill of rights for recipients of mental health services. We have provided a model statute that provides an idea as to what we would be seeking. This concludes my testimony and I would be happy to answer any questions the committee may have at the end of the panel. [LR338]

SENATOR GAY: All right. We will hold the questions until the end of this panel, so go ahead. [LR338]

KASEY MOYER: (Exhibit 3) Good morning, my name is Kasey Moyer. I'm here on behalf of Alan Green and the Mental Health Association of Nebraska. Kasey is K-a-s-e-y, Moyer, M-o-y-e-r. First of all, I'd like to thank you for the opportunity to provide comment into the interim study of the progress made in implementing the Behavioral Health Services Act of 2004. As you know, the Act promised the development of a wide array of consumer focused, community-based services that emphasize individual recovery. The cord that ties the act together is the promise that

consumers of behavioral health services will be meaningfully involved in all aspects of service planning and delivery. During the last four years, real progress has been made in establishing services within the least restrictive settings available. However, without the support of the six behavioral health regional administrators, the reform that has been mandated in LB1083 would not be occurring. From the recognition of the reality, value and effectiveness of recovery, to the implementation of the consumer-run services, it has been the regions that have made the commitment to truly transforming the service delivery system. And without their dogged quest for division in behavorial health services accountability, much of the promised community-based funding may never have been released. Within the division, the establishment of the office of consumer affairs and the allocation of funding for the regional consumer specialists has helped to spread the reality of peer support services throughout the state. And initial funding provided to consumer and family advocacy organizations provided the necessary support for organizational development, and later, to allow for the statewide recovery education of consumers. Although we have come a long way, much still needs to be done. We still lack a clear vision of what our transformed system will look like, and all planning and decision making is still being done behind closed doors. Without a clear idea of where we want to go, we will never know how or if we have arrived. What is lacking in a comprehensive vision of what the mental health system will look like, and a true and honest commitment to have consumers and stakeholders actively involved in its development. Collaborative planning was attempted back in 2006, when the division brought together service providers, advocates and consumers to develop a strategic "plan the planning process." The plan was completed, delivered to the division and we have not heard of it since. In 2008, the Mental Health Block Grant Application quoted HHS CEO Christine Peterson as saying, the new division directors are excited about working on the strategic planning process. The division will identify priorities, set goals and establish performance measurements, but there was no mention of any opportunity for public involvement in the process. As mentioned above, consumer inclusion at all levels in the fundamental concept of the Behavioral Health Services Act. However, early on, questions were raised by the division staff as to what exactly inclusion meant, and

how much inclusion was enough. For us the answer is quite simple. Consumers must be actively and meaningfully involved in all facets of the process as long as there are consumers in need of the services that are to be provided. From the division point of view, the creation of the office of consumer affairs, its staff and the creation of regional consumer specialists are examples of the division's commitment to consumer inclusion. In its Nebraska transformation transfer initiative application maximizing consumer and family voice at all levels, division director Scot Adams states that he believes that the LB1083 phase of Nebraska behavioral health reform is now complete. This document was prepared by the division staff and relied solely on state and or regional employees who may have also happen to be consumers to fulfill the requirement of consumer inclusion. We believe the interpretation does not meet the intent of LB1083. Our recommendations: Legislation to amend the Behavioral Health Services Act to define exactly what involvement and inclusion means, and provide the authority to monitor and force compliance. Ensure proper oversight and accountability of a truly transparent system requires public participation in the process. Legislation needs to establish a standing committee that can provide proper oversight into the HHS and division of behavioral health policies and activities. This committee must have the ability to subpoena relevant documents and records. The legislation has a responsibility to monitor compliance to the laws it establishes, and to ensure allocation funding fulfills mandated objectives. Comprehensive statewide planning needs to be done so that there is a clear view of the purpose, direction and desired outcomes of the behavioral health system. This process must include consumers as well as stakeholders as mandated by state law. True transformation of the behavioral health system is possible and will occur. By working together, the division, the regional authorities, service providers, consumers and families, we can develop meaningful solutions to the issues. We are stronger when we stand together, and by sharing and working together efforts will be much more productive. Complete and true reform will benefit and improve the lives of thousands of Nebraskans while showing good stewardship of taxpayer dollars. Thank you. [LR338]

SENATOR GAY: Thank you. [LR338]

LINDA JENSEN: Good morning. I'm Linda Jensen, L-i-n-d-a J-e-n-s-en, and I'm president of the NAMI, which is the National Alliance on Mental Illness, Nebraska. Thank you for this opportunity to speak to you today from the perspective consumers and family members. NAMI Nebraska is the state organization of...actually, it's an international NAMI, the largest mental health advocacy organization in the U.S. We're a grassroots organization that provides education and support services through its statewide affiliates to those whose lives are touched by mental illness. We collaborate with other organizations, government bodies, and advocates to improve services and quality of life for people with mental illness and their families. We have affiliate and support groups in Omaha, Lincoln, Kearney, Grand Island, Hastings, Columbus, Norfolk, Gering, North Platte. And our signature programs include connections and recovery groups. We're trying to grow this into Omaha. We'll have them every night or day of the week, family-to-family education and family support groups. We'll have those across the state. These services are offered to the consumers and family at no cost and are very valuable towards persons working towards recovery and their families. In 2006, NAMI national issued its first grading of the state's report. The nation as a whole received a D, as did Nebraska. Some states even received an F. This report is currently being updated and will be published in spring of 2009. This report will highlight progress made and services needed. Information is gathered from each state organization, the behavioral health administration of each state, and other sources. One of those is a test drive. Imagine that you were moving to Nebraska and you needed mental health services and you knew nothing about the system, so where would you go? What would you use to put into the google? Would you find anything except safe haven? (Laugh) Evidently, people have found that. How consumer-family friendly would these services be? And how long would it take to get services? There may be a list but how long does it take to get services? How long is the waiting list? I applaud Scot Adams and the division for their plans to begin to use a special Web site to help people find services. And I hope they will ask consumers and families to help in the design of it, because we

know the questions to ask. We have asked them ourselves and we're still asking today. Our NAMI Nebraska office gets several phone calls of this type each day and there are no easy answers. Navigation of the behavioral health system in Nebraska is still a challenge. There is really no duplication of services. We still have a severe shortage, and sometimes people must wait months to get appointments just to change their medications. Sometimes they go to the emergency room just because that's the only place they can get served. And then they end up hospitalized and sometimes they wouldn't even have to be hospitalized. I was appointed in 2006 to the Behavioral Health Oversight Commission as we...to improve the inclusion, thanks to the wisdom of Senator Jensen, and we want to thank him so much for all he did to pass LB1083 and to oversee some implementation of it. We appreciated the monitoring that was carried out by UNMC Professor Watanabe and she continued to ask for additional data and tried to put the pieces together to pick up the problems of the system. As we adjourned the commission as we had to, she was beginning to pick up problems that the Medicaid certifications had taken a severe drop. She was also picking up the problem that a lot of people had in the criminal justice system also had mental health problems. I don't know if she's still monitoring that today, is a part of this report. So I hope that she's still monitoring those things today. The new Behavioral Health Oversight is, as some of you know, was appointed by the Governor in July, 2008, rather than the Legislature. And it has 12 members and only 2 are designated as consumer and consumer advocates. So these two appointees are very energetic and tireless in their efforts, but you know, it's really hard when you in a minority and to connect the dots. The main things I want to focus on is development of consumer and families as full partners in the system. I think we've all talked about inclusion, and the development of a consumer focused culture. It's actually a new culture that needs to be developed. It's kind of...you know, we always talk about culture competency. That's the big buzz word. Well, this is a different culture too. I'm a nurse. I'm a nursing instructor, yet when my son was diagnosed with schizophrenia and we became a family of a person with a mental illness, it was an entirely different world, being on the other side of the desk, I guess, you would say, or the other side of the screen. And I've learned so much over the last 17 years from many

people by listening to them. And I'm still learning lots more, so it is just a different perspective that really is so important to help change and to make the services really recovery based. The old saying, nothing without us, you know, about us, without us. And my son actually is now a peer support specialist. I learned so much from even listening to him. I would like to see the division promote the development of peer support services, like we've talked. So far, they've kind of just evolved on their own. And we have added a lot of peer supports in a lot of the regions. I think there's as many as a dozen now in region 3 but there needs to be a training model. Other states do have training models and, but this model does need to be chosen by the people that are already doing it, not necessarily by some other professionals. The division needs to look at changes that need to be made in funding and regulations so that peer support services are funded by Medicaid in some states. Quite a few of the states have gotten, actually certification for that. But we have not wanted to look at that in Nebraska for some reason. Also services such as helping someone with their recovery, under a certified model could really be funded. Not just the old services of so many hours of psychiatry, and psychology, and mental health therapy. All training should have a presentation from consumers and family members. Education needs to also be provided for providers and, maybe, even HHS officials about how to work with peer specialists, and how to really try to understand. It seems like they're always somewhat discounted. They don't really treat the consumers, family members as full partners. Some of the other things we need to develop under quality improvement is a statewide warm line needs to be developed, just a line that people could call and talk if they're feeling really scared or feeling disturbed or distressed. They started to do that with the Spring Center in Omaha and then they were depending on consumers to do it for nothing, find their own way there, etcetera, and of course, it didn't work. But the good thing about it was actually some of the consumers they had trained, actually now have jobs. (Laugh) So they couldn't do it anymore. But, you know, it takes some work and support with those things. There must be a good grievance and complaint system. We must look at a lot of alternatives to the current emergency care system. MHA is trying to develop a Rose House, living room models. The worst place to go when you're really upset is the

emergency room, (laugh) you know, or if you're family member is upset. It's just really the worst place to go. It's just like chaos. So if there would be a place that people could go and understanding staff...now actually some of...I think there is a model that has been developed somewhat too in region 3, in Grand Island, they've developed a crisis center, which has sort of a living room model within it. Self-directed care, I think the gentlemen this morning mentioned self-directed care. That is something that should be looked at. My son did not like day rehab programs. They were too discouraging to him. He was a young man, he'd been in college, he had been in military, he was really discouraged when he went to the day rehab programs, and I know they've got good programs that have helped people. He'd rather go to classes at a college, he'd rather go to the health club, he'd rather go to Borders and sit and read a book, an Italian soda, (laugh) you know, he'd just rather have kind of a "normal life." So allowing for some choice in services could make a big difference too for people. We need models of care for youth transitioning into adulthood. So we would like to partner with the Behavioral Health Division, the RPAs to continue to improve the services. We do have some evidence based models such as Peer to Peer and Provider Education we would like to bring to Nebraska. In closing, I would urge you to leave the management of the system with the regional program administrators. They have been given more freedom to develop new models with LB1083. They've begun to work together. They're trying to work on the hard problems. I want to compliment Beth Baxter from region 3. I think she knows every consumer in that region and she keeps track of how they're doing. Encourage them to open up the system to new providers with innovative ideas, and involve consumers and family members at every level. Managed care before was a disaster and the system lost hospitals and loss of service. Many parts of the system are still in recovery. Capitating the system at full risk may end up actually decapitating the system. We may lose our heads. Thank you. [LR338]

SENATOR GAY: Thank you. Do you want to have that written comments, do you want to give them to us. Did I get them? [LR338]

LINDA JENSEN: Yeah, you've got them. They're in the folder, sorry. [LR338]

SENATOR GAY: Okay. I didn't see...I saw the other two, but, that's my fault. Okay, thank you very much for your input. Is there any questions? Senator Stuthman. [LR338]

SENATOR STUTHMAN: Thank you, Senator Gay. Kasey, in your statement you stated that director Scot Adams feels that the LB1083 phase is now complete. Do you feel that way? [LR338]

KASEY MOYER: You put me on the spot. I'll just take a minute to think about that. I do not feel that it is anywhere near complete. I think we've got a good start. I can see some changes being made and as far as the inclusion, and keep all consumers, family members being actively involved in transformation of this system, still needs to happen. As I stated in the letter, there are a lot of decisions still being made for us and we want to be at the table. There's some neat things going on in other parts of the country. You know, Linda brought up the Rose House, which is a hospital diversion house where people can go for much less dollar amounts than it would cost for someone to go to the hospital. I have just recently implemented in the last year, I supported employment program, thanks to region 5, being able to bring a true supported employment program to Nebraska, and people are going back to work. I just found out that the numbers that I have of folks going back to work is higher than the national average and I'm very happy with that. But I don't know that the state is aware, the division is aware of all these things that are going on that could be brought to Nebraska, and they need us at the table to inform them of that. So I don't think we're anywhere close to complete. [LR338]

SENATOR STUTHMAN: Well, thank you for your comment because I truly believe this is something we can't say, this is complete, put it on the shelf, and just keep working. I think we learn every day how we can improve mental illness and how things work to help those people that do have mental illness, so thank you. [LR338]

KASEY MOYER: Yes, thank you. People with mental illness do recover, we can work, we can live in the community. [LR338]

SENATOR GAY: Thank you. Senator Johnson. [LR338]

SENATOR JOHNSON: Just want to follow up on one thing. One of the complaints that I've heard in the past and I wonder if it's still true, is this, is that if a person starts out from the lower stages of recovery and then gets to a point where they're fully employed, and so on, that then the help disappears particularly for their medications. Is this still a problem and should... [LR338]

SENATOR GAY: All three of you want to answer, but let's pick one. Let's pick one of you. (Laughter) Okay. [LR338]

LINDA JENSEN: Yes, it is if they earn over a certain amount and I couldn't tell you what that amount is right now because it's... [LR338]

KASEY MOYER: It's $960.00. [LR338]

LINDA JENSEN: Okay. Because it's connected to the populous and... [LR338]

SENATOR JOHNSON: Is it an all or nothing thing still? [LR338]

LINDA JENSEN : Yeah, and then they would lose...they could lose their Medicaid. [LR338]

KASEY MOYER: I have an individual who just went back to work, is making $12 an hour. She recently got out of the Regional Center so she does qualify for LB95. But she has in the last year saved $2,000 so we are out there telling her, you need to spend it because if you have more than $2,000 they're going to take her...so, yes, it's still a

problem. People are not allowed to get ahead. [LR338]

SENATOR JOHNSON: Yeah, there's no sliding scale. [LR338]

KASEY MOYER: No. [LR338]

SENATOR JOHNSON: Okay. I would think that would be helpful to you. [LR338]

KASEY MOYER: Very much so. [LR338]

LINDA JENSEN: Well, and medications cost easily $1,000 a month. That's kind of a minimum practically. Well, there's no way they can afford...they're working and don't have Medicaid, there's no way they can afford the medication unless they're making billions. [LR338]

KASEY MOYER: Makes it impossible for them to continue working. [LR338]

LINDA JENSEN: Yeah. So it's caught between... [LR338]

SENATOR JOHNSON: Okay. Thank you. [LR338]

SENATOR GAY: We're going to move on because there's a lot of other people, thank you ladies, very much. And let's just start working our way forward and... [LR338]

KATHY BIGSBY MOORE: (Exhibit 4) Thank you, senators, I am Kathy Bigsby Moore, executive director of Voices for Children in Nebraska, and I will be very brief because I think the voices that you should hear most are the voices that will follow me. Voices for Children has been doing behavioral health advocacy for its full 20 years. Many of you have heard from me previously, but I think the question that Senator Stuthman posed to the previous panel really confirms what we feel, which is that adult behavorial health

reform has begun. We have seen individuals flow from the regional centers into the community and we've seen dollars flow from the regional centers into the community. Unfortunately, the same has not been true for children's behavioral heath. And I think when LB1083 first passed, many had higher hopes for what it would do for children's services. But a couple of years ago through Senator Synowiecki, we realized that was not a reality and he introduced LB542, which really was intended to say, okay, and here's what we're going to do for the children. Unfortunately, even LB542 has not been able to really budge the brick wall, if you will, of the children's behavioral health system. And so the primary focus of children's behavioral health services flows from dollars through Medicaid and child welfare services. So in order to get funding, you have to either be low income or a state ward. You have to have been alleged to have been abused or neglected or have committed a status offense or a criminal offense. And so when we look at the regions, and I think the resounding message is, that we need to regionalize services. That the regional system is the place to really look at shoring up our infrastructures. What we see that is, that about $1.2 million does currently flow into the regions, but only about $5.5 million of those dollars are designated for children's services. So when I look at what's happening today, we see indicators that are painfully clear. I think a couple of testifiers yesterday referenced, certainly, safe haven, the Von Maur incident, the cluster of teen suicides that we've seen publicized in Sarpy County, gun violence in Omaha. The message is clear that there is a need for help. What isn't clear, is where the leadership for change is really going to focus on in the state of Nebraska. And so we force our children and families to struggle to either seek state wardship or constantly do battle for the level of care that they or even professionals think is appropriate. And what we really need to do and, frankly, I was hopeful that the safe haven issue would be addressed simultaneously to the behavioral health issue. The special session will probably prevent that, but we as a state have got to truly address the creation of a pathway of services. Interesting enough, this afternoon there is a meeting at 1:30 of the Behavorial Health Task Force that ultimately was created under Senator Synowiecki's LB542. And so the second handout that I provided you, is just an excerpt from the LB542 report that was released a year ago. And it saddens me,

in a way, to look at the fact that I began meeting with Senator Synowiecki actually two years ago. At this time we had high goals set for moving what at that time we thought was $10 million from the Hastings Regional Center into a fund for children services. A year later a task force was created to look at the creation of a plan. You've got before you the plan and then in bold below each of those items is the response from Health and Human Services. And what you will see is that we have too many reports, too many plans, too many words, not enough action, and not enough strategic action. So I hope you'll take the advice given by people who have been living this every day and that we can all continue to work together through January and February to really figure out what this plan needs to look like. Thank you. [LR338]

EVE BLEYHL: (Exhibit 5) My name is Eve Bleyhl, E-v-e B-l-e-y-h-l. I'm the director of the Nebraska Family Support Network, the family organization for region 6 which serves 40 percent of the state's population. Last year we served 261 families with comprehensive peered peer mentoring support services and we served over 900 individuals, including those families, but also through special activities and special events. I have the flyer, I mean, the folder that's going around. In there I included a copy of family-centered standards as defined by the United States Department of Health and Human Services substance abuse and mental health services administration. I put in what we're calling a reality sheet that summarizes the common family experience in the Nebraska children's behavorial health system. And I have 11 pages of compiled family feedback that was collected, compiled within the past week, based on two questions sent via e-mail. When you've been in crisis with your child, what would have helped had it been available to you? What was the most significant barrier you encountered when trying to get your child the help they need? I also included the Omaha World-Herald recent article on the teen suicides. And we brought families to speak for themselves so I'm going to be really brief. As the executive director of the Nebraska Family Support Network I want to speak to how, although we are an independent 501(c) family organization, we do not have a voice in the children's behavioral health system as the Health and Human Service division of behavioral health does not invite or allow the

executive directors of the family organizations to attend state meetings related to matters relevant to current and future children's mental health issues. Instead, they have insisted that only one person, whom they have appointed, can speak for all the families and family organizations. That person has a very relevant voice, but it's not our voice. Although each region is unique with unique needs and geographical characteristics, Health and Human Services, in general, insists on lumping all family orgs together and denying our independent voices as representation for the families each organization serves. This is so very unfortunate as each organization brings such a wide array of insight and experience that would serve the Nebraska Department of Health and Human Services well in their determination of how to best meet the needs of children, and families in the child welfare and children's behavorial health system. I forgot to say we have two collaborations. We are a child welfare...per our current funding we are a child welfare and children's behavorial health collaboration. And I started to temper this next part. You know, I wrote it last night and then I thought, huh, I don't know. (Laughter) But then I thought if I don't say it, who is going to say it. So I'm just going to read it and think, you know, accept that you're tough enough to hear it. (Laughter) Okay. I would also like to help you get a snapshot into what it's like to be a parent or caretaker of a child with extreme mental or behavioral health issues in this system, particularly in the area of being heard. I have sat in so many meetings with families where they're told not to show emotion or to be angry as they navigate this system of children's behavorial health, too often lived out in the very punitive child welfare system. The professionals get to tell their side of the story, how they see the situation, offer their opinions on how the parents have failed, or what the parents should do, but the parents are stifled when they try to tell it like they see it or have experienced it. Try to picture yourselves as the parents of a very sick child. You've tried everything you know to try, you had to the best of your ability done everything the professional realm has advised you to do. Still your child suffers. Your whole family suffers because mental illness impacts the entire family. You are full of guilt and shame because you cannot meet your child's needs, and the relentless demands placed on you have exhausted your energy, your resources and your confidence. Yet, in the midst of all this

anguish, a part of you knows that your inability to meet your child's needs is not your fault. If your child had cancer and the medical realm denied treatment that might save their lives, the community would be up in arms. Yet mental health carries a stigma that makes the public feel they have a right to blame and shame individuals and families who are afflicted by mental health disorders. As a parent you're terrified that your child might hurt or kill themselves or even others. You are also furious that no one will listen to you. Yet, in court or in family team meetings, where every move you make and every word you speak is being critically observed and documented, you are expected to not show any of your very human feelings and emotions around this issue. And I think it's high time that Nebraska as a state observe a time with respectful silence and we let these families pour out their shame, rage and fear. Let them tell the horrific stories of what they've been through. That we all, for once, just be still and listen without judgment. These families are in crisis. They just want to be heard. They want someone to hear them and help their child. And so frequently, it appears, that nobody cares. And we're asking you to care today. To read the ll pages of parent feedback and to allow the parents at the table, and create a system that really works. Thank you. [LR338]

SENATOR GAY: Thank you. [LR338]

PATRICIA BLAKELY: My name is Patricia Blakely, spelled P-a-t-r-i-c-i-a B-l-a-k-e-l-y. First and foremost I'm the parent of an adult who had multiple, multiple problems in the system, in the mental health system, in detention in the juvenile justice system in Geneva, in multiple hospitals, had dual diagnosis, mental health and substance abuse issues, and was in long-term residential care. So that's from where I come. I am the director of a program called Healthy Families Project, which works with child protective services and also works with families that are in behavorial health. We work with about 200 families a month so we see the problems that families go through. I also work on occasion for the Nebraska Federation of Families as a consultant to the SAMHSA system of care, mental health branch sites in the country. So I really wanted to talk today, because I wanted to talk, having been about 12 years since my daughter was in

the system and working in systems of care for about 9 years, I've seen a lot of things and I've seen a lot attempts at changing services for families. But it seems like really little has changed, even though we work hard to try to do a system of care and family centered practice. I wanted to speak to that a little bit because I wanted to talk about system of care and family centered practices. And some of the things that I personally see that we fail...that we can do better. Family centered practice is, and has some certain principles, you know, it's child centered, family driven, strength based, culturally competent, community-based, and on and on. But I really want to speak to the family driven piece of it because family driven is a big paradigm shift. It's a paradigm shift that is very difficult to make, and it is about working with families where they are and working with them as equal partners. And system of care is a part of the family driven and that's a part that we so often leave out. Because it is the system of care and infrastructure of the system of care that supports family driven and helps support the changes that are to be made. So if we don't have, if we have family driven in our language in what we do without the infrastructure that supports the process to happen, it won't happen. So we wonder why we write, you know, family driven in all of our language, but without that infrastructure that has the partnering family organizations and peers, working together in partnership in the system to make that partnership and that paradigm shift, it doesn't change. It stays the same. The language is there but the services don't change. So that's what I really wanted to talk about. The infrastructure is, you know, the family organizations that work with and the families that work with the families that are in the behavorial health services, or partner with behavorial health services, are a part of the services, they're a part of supervision, they're a part of the care management, they're a part of the directors meetings. There are pieces and pockets of systems of care that we have in our system, but our whole system does not operate as a system. My perspective is, you know, I can speak to that from where I come from which is region 5, and there is...we have the region 5 ICCU which operates under that premise. Families are involved from the top to the bottom of services and partner in everything that goes on. But that's one pocket and that's one piece. That's not the whole service system. So in order to make those services work better for families, that idea has to be incorporated

into the whole structure. And then I want to talk a little bit about another piece of system of care, which is the array of services. In order for a system of care to work for families, there has to be an array of services that meets the needs of all the families that are (inaudible) Now we have services for very high end youth and families that are in the systems that are state wards. And there are relative...I mean, there are services to support them. However, in that array of services, there's many, many services that are missing for families that are on a lower level or looking for services that aren't state wards or aren't in the juvenile justice system. We work with families that are, as I said, in CPS and in the behavorial health system, and we have families call us begging for help. They don't know what to do. They're looking for services for their families but there's very little to offer on a lower level if they aren't state wards. So we have families that are patiently waiting or the kids to get deeper in the juvenile justice system so they can get the services they need. And we have families that go make their children state wards so they can get the services they need. And if they don't do that and they don't have the services available, then oftentimes they wait out long enough and they become a state ward anyway. Because there becomes abuse and neglect and problems in the family that...because they haven't gotten services, they get to that level anyway. I personally think that's horrible. It's something we really have to change. And if our goal is really to address the state ward population in Nebraska, if your goal is really to get off that high list where we're clear at the top of number of state wards (inaudible) then we must do something at a different level, at a lower level, so that the youth and families don't get to that level where they become state wards. If we don't have an array of services that are at a lower level, we're not going to be able to impact the state ward population. There are a number of services that are missing in the service array. First of all, you know, I saw on TV the other night someone running in the community for office speaking that there were plenty of services for people and we didn't need the safe haven. And I thought, wow, that person's never been a family member trying to find services. We're so quick to judge but we don't look at what might be missing and why that's happening. Because what is missing is, we don't have any crisis services. We have the crisis center for adults but what are children and youth supposed to do? There's no crisis center for

them. There's CAPS but it's next to impossible to get into CAPS. So where are they supposed to go? What are they supposed to do? We need some form of mental health crisis situation to help youth. Our youth become the adults. We don't have lower end facilitation. We have, you know, we have wraparound services in the behaviorial, in the regions to help family center, move family center practice and work with families. There are a long, long lists for families waiting to get on them, there's...you know, they have to wait forever. If you need help, you need it immediately. There are, you know, there needs to be help in schools to keep kids in schools. [LR338]

SENATOR GAY: Ma'am, we're going to be discussing that later in the year. [LR338]

PATRICIA BLAKELY: Oh, I'm sorry. Okay. Well, thank you for the opportunity. [LR338]

SENATOR GAY: No, and I don't mean to, but that's a whole separate subject that will be addressed, I know. Not just upcoming but I know in the new session and I just wanted to encourage you to watch out for that because your input would be very good at that point, so. [LR338]

PATRICIA BLAKELY: Okay, well, thank you for your time. I don't get too many opportunities to talk, so. [LR338]

SENATOR GAY: Oh, you know what...I know, there's people very passionate on these issues and I understand and we're still moving through. But I do encourage you really to give some input in on that when we get to it. [LR338]

PATRICIA BLAKELY: Okay. [LR338]

SENATOR GAY: Go ahead. [LR338]

JONAH DEPPE: (Exhibit 6) My name is Jonah Deppe and I'm representing the League

of Women Voters in Nebraska. I am the health director of the League of Women Voters of Nebraska and the social policy director for the city of Omaha. My name is spelled J-o-n-a-h, last name is D-e-p-p-e. The League of Women Voters has always had, since 2004, has had a statement that says that we do support adequately funded mental health care system which provides comprehensive and coordinated services for children and adults with mental disorders. We further support state and local policies and programs which provide opportunities for persons with mental disorders to achieve optimal management of their illness. And while the League really applauds the state for the progress that has been made in implementing the Nebraska Behavioral Health Services Act, and the provision of adult services in the communities where people live, we would like to bring your attention to a population overlooked in the implementation of behavioral health reform act as required in the act. And you've heard somebody talking about that right here. Section 3(11) states...I took this right of the Behavorial Health...public behavioral health system means the statewide array of behavioral health services for children and adults provided by the public sector or private sector and supported in whole or in part with funding received and administered by the Nebraska Health and Human Services System, including behavioral health services provided under the medical assistance program established in Section 68-108. It further goes on in Section 19, item 5, states, encourage and facilitate the statewide development and provision of an appropriate array of community-based behavioral health services and a continuum of care for both children and adults and the integration and coordination of such services with primary health care services. Recently we've heard, and I'm sure you have too, of families abandoning their children in hopes to receive appropriate needed mental health and behavioral health services. And in regards to the requirements in LB1083 regarding services for children, which were ignored in implementing the Behavioral Health Services Act, we'd really like to ask you, who exactly has abandoned the children and youth? Perhaps, we can say the state didn't really abandon these children needing the services, but they ignored the reality that they're there, and that children and youth with mental illnesses exist. And while you ponder the need for additional services and the cost of providing an appropriate array of community-based

services and continuum of care for adults, we request that you consider the children and youth who are not receiving treatment for their mental illness. Yesterday I heard people talking about that youth of 18 years of age cannot receive crisis services in the city of Omaha. Up to age 18, 19 is (inaudible) the adult system. It was also stated that the adult system is crowded and services are difficult to access. But the early intervention, the identification and appropriate treatment for children's mental disease should impact the adult service system by (inaudible) into maturity and become adults. So ignoring the fact that Nebraska has children and youth living with mental illnesses does not make the problem go away. It is time that the requirements of the Behavioral Health Services Act provide services for children be implemented. And so providing an appropriate array should be the next chapter in Nebraska's Behavioral Health reform. And I know you will hear that the state has had an infrastructure (inaudible) who developed an infrastructure (inaudible) and that $3 million has been spent in the state. We don't have an infrastructure identified. (inaudible) have one more year, so hopefully that might happen. Kathy talked to you about what has happened with the children's task force and the recommendation. We really need to see something happening and happening immediately. I think that this has been very apparent in what's happening in children being dropped off at hospitals. And certainly some of those parents have other reasons for dropping them off. There was one family with eight children, but the majority of the children and their families were really looking for services that they were unable to find. Thank you. [LR338]

SENATOR GAY: Thank you. And what I want to do is, I'll take one question for this panel and then I'm going to limit questions, if it's okay. Because how many more people want to talk on this issue? And you can all see that and I know this gentleman has a hand out that he's...you know, so we want to hear from you all, but since we've got four of you. Go ahead, Senator Harms. [LR338]

SENATOR HARMS: Thank you, Senator Gay, I won't take much time. Eve, I'd like to ask you a question. [LR338]

EVE BLEYHL: Sure. [LR338]

SENATOR HARMS: You're description of frustration that parents are going through is right on target. [LR338]

EVE BLEYHL: Thank you. [LR338]

SENATOR HARMS: I've had the opportunity to visit with a number of people and of families that will confirm exactly what you've said. And as I was listening to you talk, it was just like a rerun for me. And if we really want to look at our structure of Health and Human Services, that's the portion that's truly broken. And so, when you look at what's happened at the safe haven, that's the reason they're coming in and giving, placing their child in the safe haven category because that's the only hope they have. It's a family that's in crisis, it's a family that's frustrated. And to confirm this position I will tell you that I caught an interview of the mother who left her child off here from Georgia that was on CNN news. It just literally tore my heart out. I mean, I almost, it tugged at me so badly like it was hard to listen to that. I mean, this is a family that was in crisis and her views were that no one cared. No one would listen to her. She had no other way to go. I mean, the whole things you were saying is exact and correct, and it's most unfortunate that we will not have the opportunity in our special session to address this. Because that's the portion that's really broken, that's the portion that I think we have a responsibility to fix. And I know that Senator Gay will take care of that, and the folks that are in Health and Human Services, but I appreciate you coming forward and just telling the story as it is because you are absolutely on target. And one of the quick questions, and then I know I'll quit here because I know we're in a hurry. You talk about peer to peer. Do you have a train program from peer to peer? How do you handle that? [LR338]

EVE BLEYHL: We do ongoing training all the time. We did lots of training last year because we want our advocates...the characteristics they bring, problem solving,

tenacity, having successful survived the system themselves, that's what makes them so powerful. But we want to help them be prepared to go out. Like just two days ago, they had training on testifying in court because more and more our documentation is being used in the courtrooms to support what the families have achieved. There's...you know, there's a national, they want a national model, a national training. I can e-mail you a copy of the training we provided last year. [LR338]

SENATOR HARMS: Yeah, I would really like to look at that because what I was thinking about is the community colleges would be a perfect place to put that information, because they can do that kind of training in their business or business and industrial training that fits all in the training side. They'd be a great person, a great organization to do that along with the fact they can certify these people, they can give them certificates, they can give them diplomas and you'll know exactly what they've got when they come knocking on the door for that sort of thing. So I would really appreciate that if you get it to me. [LR338]

EVE BLEYHL: I certainly will. [LR338]

SENATOR HARMS.: Thank you very much. [LR338]

EVE BLEYHL: Where will I get your e-mail? Oh, I'll get it off the Web site. (Laughter) [LR338]

SENATOR GAY: All right, thank you ladies. I'm going to go ahead right...this gentleman right here, and I know you've been waiting patiently. I talked to you yesterday and you saw how many people still want to speak. [LR338]

ED CHASE: Right. I'll make this real quick. [LR338]

SENATOR GAY: Summarize, and... [LR338]

ED CHASE: And I know you guys.... [LR338]

SENATOR GAY: Oh, absolutely, but you know, and it's important and...thank you. [LR338]

ED CHASE: (Exhibit 7) My name is Ed Chase, C-h-a-s-e, like the bank, without the money. (Laughter) I came out here from Boston, Massachusetts, where I live. The good news is you saved my son in your mental healthcare system here. The bad news is that once he recovered and was rehabilitated, he was killed in an accident in July. But I don't throw that out to you as anything other than I think I have nothing to gain from here, I'm trying to be as objective as possible. Personally, I spent 25 years in the healthcare system working for Johnson and Johnson running healthcare companies for them in the United States, Europe and Asia. Interesting, in Europe there's no demarcation between physical healthcare and mental healthcare. It's an umbrella called healthcare and you have physical healthcare and behavioral healthcare. And I think with the passage of parity, if it's for real, we're going to get there some day. But I know it's tough and I know at this point mental healthcare is a real, a step-child. And I know to some degree that your hands are tied because you don't have enough funds. But with that, I thought what I could do is, kind of give you some of my observations. And if you turn to the second page you'll see, I really have two objectives here today. The first is to provide you some observations on the mental healthcare system from a family who's been in the trenches for ten years. I'm going to speak to you from ground zero. Second, to present to you some recommendations on how to improve the system. If you will turn to the next page, just to give you a global overview here, dealing with mental healthcare is like wrestling with a jellyfish. It's overly complex, unnecessarily political, and bureaucratic. Having said that, though, there are certain fundamental things that if executed in mental healthcare, it could be highly effective. And if you'll turn to the next page, my first observation is, what you've heard before, mental healthcare is not great in Nebraska and it's not great nationally. I don't want to pick on the people from Nebraska. Despite that, however, you

have a world class program here in Nebraska in the CTP program at Lincoln Regional Center and The Heather. And I'll talk about that more later. Turning to the next page, one of the reasons why mental healthcare doesn't work here, and it doesn't work in the United States, is because it's driven by a false set of assumptions. That is, if you run a business, run an organization and you're going in assumptions that are incorrect, the output is going to be incorrect. And the four fallacies are, first, that serious mental illness is a chronic degenerative disease with little hope of recovery. As you've heard here this morning, as with coma, stroke patients, traumatic brain injury patients, these people can be rehabilitated to live semi-structured independent lives. That can be done in mental healthcare with rehabilitation. Second, patients cannot stabilize in acute hospital settings or outpatient settings. One of the big fallacies is, we take somebody who has had a psychiatric break, we throw them in the hospital for three days, and then we send them out of there, and we think he's going to be all right. And I'll come back to an example of that. People can't get back on their feet and stabilize in outpatient settings. The third fallacy is that efficiency, cost-savings, can be achieved without effectiveness. It's only when somebody has rehabbed that you can start saving money. If the person isn't well, then he keeps recycling back into the system and burns up money after money. So, you know, paradoxically you have to have effectiveness before you can get efficiency. Finally, as a lot of people have said, another fallacy is the communities will never be able to shoulder all the care for mentally ill. In reality, in my opinion, there will always be a need for state facilities. As I said, you can't recover in acute hospital settings as outpatient. There's a limited number of psychiatrists. My son was originally up in the Norfolk area and there was one woman up there for hundreds of people, and I know there are many counties where there are no psychiatrists. There is limited experience, as you have all heard, in the rural areas and there's a lack of local funding. If you turn to the next page, the biggest problem as I see is, when it comes to mental healthcare, the focus is not on treatment and rehab. The focus is on discharge and spending. And when somebody checks into a facility, the first thing they start to do is develop a discharge plan. And as I was telling some medical students the other day, that is so screwed up. When you check into a hospital with a physical health condition,

their focus is on treatment, on recovery. And ironically, the first thing in mental healthcare when you check in, they start, when can we discharge this person. And it's that mentality that pulls us off center from getting somebody better. I'll go on to the next page here and say, and I'm on page 7 now, paradoxically mental healthcare is focused on cost is the key reasons for its inefficiency. That is, the focus on cost makes us inefficient. What do I mean by that? Here is an example what, that happens with a typical patient. They have a psychiatric break, they go to an inpatient facility, they try to get them out of there as fast as possible, and oftentimes they're released with what's called a GAF score. That's a scale a doctor uses to assess the functioning of an individual. And oftentimes, they're released with GAF scores of 30. It goes from 0 to 100. And a person released with a 30 is unable to function in almost all areas. So somebody is released from the hospital now, and you can see in every discharge from every acute patient setting, the doctor has to give a GAF score. And if you go back and look at GAF scores, you'll see patients are released that are zombies. Second, they're then transferred to outpatient settings, sit around there for a while, pushed out of there with GAF scores and prove at say the 50 level, but that level says they still have serious impairment in social or occupational functions and can't hold a job. The end result of all of this, is you have people that never get stabilized, never get rehabilitated enough, and get constantly cycled through the system. So they go in an acute patient, get thrown out of there too quickly, go to outpatient, get thrown out of there too quickly, get thrown out on the street, decompensate, and are back into the acute patient setting. This population is about 15 to 20 percent of the total mentally ill population. My guess is, it sucks up 50 percent or more of your total dollars. And if that person had time to get back on his feet and get rehabilitated, you wouldn't see that. And as I said here, on page 8, the lesson here is that mental healthcare can only be efficient if it is first effective. I'll go to page 9 because I know we're short on time. So what do I recommend in terms of improvement? First, as you've heard here today, I think all of us need parity mental healthcare legislation and I know it's been passed at the national level. You know it's negotiated with the insurance companies so that will give you a perspective of how good it's going to end up being. Second recommendation I would have is, to

structure mental healthcare more on the lines of physical healthcare. So when we think of what we're going to do with somebody that's mentally ill, we should keep as a frame of reference, what would we do for somebody with this condition if they were physically injured. And a lot of that has to do just giving people time to recover and get back on their feet. You know, it's funny, Scot Adams talked about progress the other day, and progress was getting people out of the regional centers into the community. From my perspective, that's not progress at all. That's like shuffling chairs on the deck of the Titanic. Progress is, are these people stable? Are they rehabbed? Can they live independently? And I think what, in all due respect, you people should be asking, okay, Scot, now what is the readmission rate of the people that we're putting out on the street, or rehospitalization rate. What level of functioning do they have? That's ultimately what we've got. Because that's what you do in the physical healthcare area. You know, in the physical healthcare area you break your arm or you have breast cancer or whatever, they're monitoring, tracking your recovery. Here were just pushing people out of one building into another, which to me causes this revolving door and this gross use up of money. Getting near the end here, on page 10, as I started out, you have a highly effective and efficient practice right in your backyard here, at Lincoln Regional Center community transition program. While my son was a sample of one, he'd been all around the country, caught up in the revolving door of mental healthcare, was fortunate enough to get into the CTP program. It gave him time to recover. He was rehabilitated. He went to The Heather. Lived independently in a group home, got a job at Wal-Mart working ten hours a day as a cashier. He had never been able to work before, he was rehabilitated. It is a world-class program and I have attached three exhibits at the end of this that didn't come out very well. But they basically say there's a dramatic reduction in hospitalization at CTP, at The Heather, and what I'm saying is, programs like this should be built on, expanded upon, and would lead to dramatic cost savings. I don't want to take up anymore of your time. I appreciate your input. [LR338]

SENATOR GAY: All right. Thank you very much for that. Does the clerk have any information to get ahold of you then, if somebody wants to e-mail you or something?

[LR338]

ED CHASE: Yes, I'll give her my name and address and all that. [LR338]

SENATOR GAY: All right, thanks. I know you ladies want to start working your way up here in that front row if you can and we'll get to you right after... [LR338]

MARY ANGUS: My name is Mary Angus, M-a-r-y A-n-g-u-s. I'm here on my own behalf and I hope that you will forgive me if I'm a little more emotional than you've seen me, although most of you have seen me pretty emotional. (Laugh) I'm going to be doing some pretty strong disclosure. Senator Johnson has been witness to that and I get pretty passionate. I want to look at where we are right now rather than try to go into where we...how to get to where we want to be. I also would like to thank Medicaid for my existence. Were it not for my ability to access services through these Medicaid, I would not probably be here at all. You just heard the previous speaker talk about the GAF, that's a global functioning score. I have been one of those people that was at 30. I have been one of those...it was many, many, many, many years before I reached 50. I have been accused, perhaps, of having been in too many places, too many committees, talking too many times as if I'm overusing my voice. But I want you to understand that is a function of how desperately serious this has been for me. When I have been doing some of my advocacy, I have been at that 35 and 40 level literally. From the beginning of the behavioral health reform and before that, I have been involved in any number of...it I went into the litany of kinds of committees and things we would be here the rest of the day and so I don't want to go into that. But it is so vital to me that we consumers have a voice and not just a voice, but a full participation in the entire process. Initially, you may have heard, a couple of weeks ago at one of the hearings Kris Peterson talked about the fact that we had had full risk behavioral healthcare, managed care, previously, and had been unsuccessful. There were many reasons for that, one of which was that people were not being given services, they were being denied services. I was told by the CEO of Richard Jung at the time that one of the people that had come in was a

young man who in the assessment center tried to hang himself, and he was denied services under a full risk behavioral health (inaudible) organization. That scares me that we might go into that again. I've been told by my own provider, as well as others, that if we go into additional rates or even under the current system, they may not be able to continue providing services for people with Medicaid. When we talk about...there's been an awful lot of talk about whether we need to be using more of the community services, and I mean like charitable organization. Scot Adams was previously with Catholic charity, there's Lutheran Family Services, Salvation Army, etcetera, they are absolutely strained. We can use those services and I have but they are not going to be able to match what we need to have in this system. I've also been told that we need to keep regional centers open. I am one of the people that would have been in a regional system were it not for the fact that my family was supporting me, both emotionally and financially. I have lived with my parents for 13 years. I'm 55 years old now. I've been in my own apartment for two and one-half years because I was unable to take care of myself in my own home, which by the way I had to sell to pay for my services. Not only am I a person who has been using this system, I'm also the grandparent of a child who has severe, severe problems. He was hospitalized before his 9th birthday. And recently he was put in partial care in the hospital because of the difficulty we've had in trying to help him to deal with the mental illness. We are at a point right now where we are in crisis and we cannot access services. What we have been able to do with the behavioral health reform has been good in a lot of ways but it has not been adequate. I have to thank Senator Stuthman and some other senators who are trying to find ways that we can access services for our children without having to make them state wards. My family has been unwilling to do that in order to get services because of the chance, the high likelihood that they may be having their parental rights terminated, but in any case having much less control over what his care has been. Mental health parity should be able to help that. I mean, I have notes that I've jotted down. I will not try to go into all of them. The problem for me is that for my grandson, there are services he cannot access unless he is on Medicaid. You've heard, I think, that before. He needs more than is available as outpatient or acute setting, and that's not available to him yet. My family

could not possibly have financially supported me to the needs of my medical care. Never, could they have done it. There was one year in which my medical bills, the billable amount was over $180,000 to keep me alive. Without Medicaid I would not be here. If I had to be stabilized and be able to live independently in order to be out of an institution or a group home, then I would probably still be there because I would not be in recovery in those settings. You've heard talk about the workforce development problems in this state and across the nation. And the questions have been sounding like, well, do we have enough community-based services? Do we have enough professionals? Can we trust peers to be able to provide some of those services for us? As if it were the community-based services are the only ones that are having staffing problems. When the head of the labor union for the state employees union who represents both Beatrice State Developmental Center and the regional centers testified about the lack of staffing in Beatrice, he said the same is going on in our regional centers. We have people working overtime many, many hours and are stressed to the limit too. I just...I can't begin to tell you how important it has been to me to be able to have a voice and that that voice not be just my own. I have spoken with and been hospitalized with and met with thousands of other people who experience mental illness, severe, severe mental illnesses. I have been treated in three different states. I have been involved nationally with other advocates. The best practices right now are peers involvement and consumer involvement at all levels. We have yet to achieve that in this behavioral health reform. Rather than get more emotionally involved in this and to continue, I'm going to close right here. I would be happy to type something up. I did not have something prepared until today. [LR338]

SENATOR GAY: Thanks. And thanks for coming, Mary, I know you do a good job advocating. [LR338]

MARY ANGUS: Thank you. [LR338]

SENATOR GAY: Thank you very much. I know...you guys, come on up. We're not going

to rush anyone out of here. I don't want to get that impression. I know I've been probably been pushing you a little more. We do want to hear from you but we're trying to hear from everybody, so go ahead. [LR338]

KIM MACIAS: Well, thank you so much for your time today, senators. I'm actually in town from Phoenix, Arizona, and I knew that I wasn't going to get another day to do this so I really appreciate it. Thank you. I'll be very quick. My name is Kim and I'm here today to represent...I'm honored to be here today to represent my father, Nile, and my family and countless other families who struggle to care for their disabled loved ones every day here in Nebraska. My father is at UNMC right now, and technically he is now homeless. He's lived for five years in assisted living center but last year his kidneys began to fail and the medication that he's taken for decades began to make him toxic. When medicated properly my dad lives a full, he lives a dignified life. He communicates his needs. He plays with this grandchildren. He nurtures his friendships. Since June his doctors have been trying to mix basically a new medicinal cocktail for him that balances his medical disability with what his body can bear. Like this gentleman's story, he's been in five different hospitals for more than two weeks at a time since June, released again, released again, released again. Anyone that's dealt with anyone with a disability, especially people on psychotropic medication knows that it takes many weeks and many adjustments to, you know, get these right. My dad does live on Social Security disability. A Medicaid waiver pays the portion of his rent that his disability does not. If he's out of his home for more than 30 days, even for hospitalization, they take his waiver away. For three months I work to pay the balance that Medicaid covered and finally my savings has run out. My sister and I put his things in the storage last weekend and had to explain to our dad, who is completely unaware of the situation, and just now beginning to regain his mental faculties, that his home is no longer his home, the place he felt safe, the staff that he loved, the friends that he made they're now gone. It broke all of our hearts to tell him this. My sister and I fear right now what this anxiety and the sadness mean for him as he's trying to recuperate. I'm not here today just for me, for my dad, or for my family. I'm here for you and for yours too. As our parents age so does

their mind. Go to any assisted living center, go to any nursing home, go to any long-term care facility and you'll find dozens to hundreds of people with Alzheimers, with dementia, with anxiety, and with depression. I'm here today because almost all of these facilities are unequipped to care for the mental health of our parents, friends, and our loved ones. I'm here to say that I know that we can do better. It's not enough to care for just their bodies. We have to care for their minds. We need a mandate, we need a policy, we need a requirement that all of these facilities staff at least one mental health professional. This individual would ensure the proper measures and activities are tailored to the mental health of those that we love. And let's face it. We're all going to get older and some day this will be us. If there were a mental health professional at my dad's care center, maybe they would have caught his illness worsening. Maybe he wouldn't have been in the hospital for the last five months. Maybe he wouldn't have lost his home. The question now is, where is my dad going to live? The places that accept these Medicaid waivers and other state and federal funds can discriminate against my father, against your grandma with dementia, against the returning Soldiers who are now disabled and have PTSD. Because of their mental disability, and still they accept government money, you can work hard like my dad for many years, you can pay your taxes, you can pay into Social Security, but if you become disabled, these places can discriminate against you, because we as a people let them. We need to change the system. We need to allocate funds to ensure that our older disabled loved ones can receive the care that we generously pay these facilities for. I'm here today to ask for your help. I can't do this by myself. This is an emergency and we know that we're not the only family in crisis. As I look for my dad's new home, I find that places that accept these waivers have waiting lists of 120 people. If my dad were blind, if he were in a wheel chair, if he had another chronic illness, these places would be equipped to care for him. The fact that they refuse to staff accordingly, and still take public funds, is discrimination. It's unfair and it's un-American and it's truly shameful. We find ourselves today discussing the safe haven law and the allocation of a budget meant for social programs. Nebraskans have found in their hearts to take in unwanted and uncared for children from anywhere with no questions asked. I'm here to beg you to allocate some

of these funds today to take care of your own families and your own taxpayers who have answered months and months of questions and are eligible for help that are being discriminated against and desperately need us. I've got several statistics about residents in Nebraska that are being restrained because of inadequate staff to attend to these residents needs and to their safety. I've got statistics on averages in this state, 20 percent of people that enter into these facilities become more depressed and more anxious being there. I've got statistics on people that are 65 and older make up 13 percent of the population. They make up 18 percent of the suicides. These things can be avoided if someone were there and asking them more than, are you depressed, you know. Asking if you are suicidal, saying, how are you doing today. This person doesn't look well. Maybe we need to actually get him to a doctor. Again, I really appreciate your time. I hope that you'll seriously consider moving some funds and actually mandating that there be health professionals, mental health professionals, in all of these facilities for all of these aging people. Thank you very much. [LR338]

SENATOR GAY: Thank you. [LR338]

DANI FITZGERALD-SMITH: Hello, my name is Dani Fitzgerald-Smith, and first of all, I'll be real brief, and I'd like to thank you for listening to our voices. I speak as a family advocate myself. I work for the Nebraska Family Support Network and I've seen and dealt with like many families, and I would say that the majority of all of our families are all dealing with serious mental illnesses. I'm also speaking as a families point of view, my own family. I have three boys and two of my children have mental health issues. My 15-year-old child has been diagnosed dually. He's had several, several problems throughout the last few years. He became a ward of the state so that he could receive services. And being confident that he would get these services, I trusted the doctors and I trusted the people that were caring for him. In turn, he was overmedicated. He was given too much medication and by a doctor that really should not have prescribed these pills. He was prescribed several, overmedicated, let me just put it that way. He was overmedicated for several months and did not receive like tests to show where his blood

levels were, and so forth. Therefore, he did develop liver damage from all this. So I, in turn, I'm going to be real short, I just felt like even though he was given the medical care that he needed, it just wasn't...they failed him day...they just, they didn't do the proper testing, the doctors and the placements that he was given was not right. And all this whole time I tried to speak my voice on this because I knew all along that things weren't right with him, but no one would listen to me. No one would listen to my voice. And so, therefore, it just kind of got shuffled through and to this day my son is suffering other problems now because of that. He's still in placement and I just felt that he was just dealt with wrong. I felt like he, his voice was not heard, and it's become a long process that we don't have the answers to. And basically, that's really all I had to say. [LR338]

SENATOR GAY: Thank you. [LR338]

CONNIE HAMMITT: I'm losing my voice, but I'm going to speak as I've waited 12 years to come before a panel that would listen to what I had to say. I, as a patient, have a child with a mental health and behavioral disorder. I feel as if today is the day to try to the best of my ability to speak before you as truthfully and as honest as possible. If that comes across in a negative way it's because of my experience with the system was negative. Had it been positive, I wouldn't be here today. One of the main issues that I wanted to discuss, and because I am losing my voice, I'm going to make it real short, was that when a parent's voice is not taken, the child is given authority. Time and time again providers would ask my daughter what her mother could do to change things and make it better. Asking a child in front of their parent removes that parent's authority and gives it to a child. In my opinion, that opens a whole new can of worms with children who have mental health issues. We, as parents, need a voice. The damage that's done by not allowing a parent their voice in front of their child, the message that sends is loud and clear to these children. And I say that to say this, up until two years or a year and a half ago I had no voice. My daughter went through the system for 11 years back and forth, in and out of hospitals. We listened to providers tell me I had a problem, that she didn't. And she would take that information and go home and we would have more

problems with her because she would tell me that I needed help, she didn't need help. She listened very loud and clear to these providers over and over. I found the organization NFSN, which I am vice president on our board now. When I found NFSN, I learned then that I had a voice. I learned then that I could speak out. I learned then that, you know, for example, and I'm sorry I have to use this as an example, but I go back to it every time. When we gave up, my husband and I gave up guardianship of our daughter, we did a voluntary state petition. After 12 years we were delighted, in a sad kind of way, to know that she was going to get the help that she needed. And then within a week, I had a caseworker stand in my living room, look me straight in the face and tell me, if I did not do what she said, when she said to do it, I would lose my parental rights. After a ten year battle of trying to get her help, I didn't need to stand there and hear that. I wanted to hear that she was finally going to get help. To make a long story short, we've overcome those obstacles. I've had a voice and ever since then, her treatment has turned around. And now I speak positively to know that if you fight the system, as I say, and you fight it long and hard enough and you continue to stand up for your rights, and you find that one organization that can help you, then as a parent, you can make a difference rather it be in your child's life or somebody else's life. My daughter is going to graduate in six months. I'm here to help that parent behind me. I'm not here to help my daughter anymore. She's getting the help that she needs and I'm happy that she's where she's at. And I, like the gentleman here, I have a son who is 25 years old now. He went through Richard Jung. He was a child, who was labeled at the age of seven, capable of homicide. Back then it was easier to get help and I had a system that worked for me because I was a foster parent who actually worked with children who had mental health disorders, and my voice was heard. Every time I had something to say back then I was listened to. A long story short, he's 25 years old. He has a top secret job, a top secret clearance. He's been in the military for eight years and he just made Staff Sergeant. These children can be rehabilitated if we get the right services put in place. And my voice is gone and I'm sorry, I have to stop talking. [LR338]

SENATOR GAY: Thank you very much. And then, do you want to move that

microphone over for her. And then, if you want to later, give that clerk your name. It's for the record, you don't have to but if you want to. [LR338]

BRENDA LEE: My name is Brenda Lee, and thank you for listening. I come just as a parent today. I have two children with mental health issues that I've struggled over the years to try to access services. I know you've heard over and over today how hard it is to access services. I have two children now in placement, a 16-year-old in Geneva YRTC and the 12-year-old is in Boys Town. One is a state ward and I access...I was told the only way I could get her help was to make her a ward. My other child is now currently placed at Boys Town and she's not a ward. The journeys aren't different. It's still a struggle no matter what and I feel as a community, everybody passed the buck. I think it's so important for people to understand that they focus so much on blaming and not on the help. I'm sure I did make mistakes as a parent, but I don't think that means that my child does not deserve help. There were situations, there were days where safety, my safety, my child's safety was in danger. I called the police like...I called the therapist like directed, the therapist would direct me to the police. I had police tell me that all I needed to do was whup my child and they wouldn't act that way. They'd tell me to grow up, quit being a baby and don't cry. I took my child to the hospital numerous times, directed by all these different people. And there was one day that we were at the hospital, my child grabbed the steering wheel, tried to jump out of the car. I had...she had choked me while I was driving. I had scratch marks. We sat at the hospital for two and a half hours. My child looked at the doctor that was reviewing her with tears in her eyes, swelled up, and said that she wanted to die, that she needed help. Two and a half hours later they came back in and dismissed us and told us that she didn't meet the qualifications. Well, I think, what I'm trying to say to you, the frustration is, that you reach out for help and you reach out for help and you reach out for help, and you just don't even know where to go anymore. And even safety doesn't get you the help that you need. Thank you. [LR338]

SENATOR GAY: Thank you. All right, thank you, ladies. How many more...J.Rock, can

we...I'd like to be brief. [LR338]

J.ROCK JOHNSON: My name is J. Rock Johnson, initial J., Rock, R-o-c-k, Johnson, J-o-h-n-s-o-n. I'm an advocate and a resource, and I deeply appreciate Senator Johnson bringing the study resolution for us as well as the courage that...of Senator Jensen to change things that needed to be changed fundamentally. If you don't mind, Senator Gay, could we hold questions until later and I would be glad to talk with anyone in order to... [LR338]

SENATOR GAY: Yeah. [LR338]

J.ROCK JOHNSON: ...facilitate this process. I want to just speak to some of the things...what I'm focused on is things that you can do. We talk about behavioral health. Behavioral health is a term that was developed by managed care in the early '90s so that it could have the broadest possible scope in coverage of services. You heard about the definition of consumer or peer. It means a person who is using mental health services. The only place in this country that uses it for any other definition or to include substance abuse is the state of Nebraska. It's not a term of art. It has a definition and it was that definition that was intended when LB1083 was passed, and it was understood and there is nothing in the legislative history to counter that. So part of the difficulty in trying to deal with a change that's made like this, which is not adequate, not appropriate, and in fact, the division could bring in people who are adjudicated sex offenders under this consumer label, if it would like, the way it has been using it. Because there don't seem to be any policies or procedures within the division, at least that I have been able to access. I've asked, repeatedly, various people, various committees over time and I have not found that information. There was a request for legislative oversight for the reform, and I think that would be extremely appropriate. We have a situation now where the regional centers are, have come to the end of their useful life to serve people with behavorial health needs apparently. And will continue to function and I will use this term as prisons, we call them treatment facilities. So there are changes being made that

were not contemplated by this legislation. There has been...there's a reference to the Web site that will coming up and I've had an opportunity to really thoroughly explore that. And it's a kind of turn-key operation. You pay money upfront and then you pay a weekly fee forever for that Web site. And a lot of the information is made available by the source and they have other clients. It takes really away from...although local information will be there, but the resources that people might want, might not end up there. There is a talk about a culture change. Absolutely, and the documents that I reference I'll make available either electronically or copies to your office. One is the policy on well-being, a treatment culture shift, which was just adopted by the department in the state of Missouri regarding recovery and resilience. This is not something that we have in the state of Nebraska at this time. We have the use of the words peer specialist, peer support, recovery, but those words are being used by the people who are controlling what they mean, not by the people who actually have the conditions that...there are the people who long to break free from the system that seemingly design to produce mental patients, not people who live in the community who are leaders and who are workers. Senator Nantkes made a suggestion yesterday about the funding and the administration has made very clear there will be no more funding. And I don't know how you transform a system in that fashion, but one of the potential areas might be a pharmaceutical cash fund. The Attorneys General have successfully prosecuted two suits, one with Bristol-Myers Squibb, the other with Lilly, total of about $2.5 million for Medicaid fraud. There's the expectation that there will be more suits of this kind against other pharmaceutical companies, and there's a general problem that's surfacing around ethical issues of people who...psychiatrists who've been researchers who have not disclosed the amounts of money that they have received from pharmaceutical companies for doing research. So that's an area of potential use, just like the tobacco settlement fund, kind of approach. But at least there's already $2.5 million that could be put into a fund and be dedicated for the reform that has been moving along. On NASMHPD, the National Association of State Mental Health Program Directors and that Noel, Dr. Mazade, reported on today was very helpful, I felt. He asked if there were any statistics that we might want and I'd like to see us request the restraint and seclusion

statistics. Ten years ago restraint and seclusion were considered to be treatments. They're still dealt with that way in our service definition for acute hospitalization and subacute hospitalization. These are not treatments. They're treatment failures. So what is their use...what's the use of PRNs, that's when a person is prescribed something that can be used at any time, and other medications for those kind of chemical restraints. So that would be information that NASMHPD would be able to provide us. Fairly recently we started getting substantial amounts, really, of private funds, and that's a very good thing. But the issue also becomes accountability. Some people call it the Mahoney model where the private funds develop the facility but the public maintenance goes on. In the last session of this Legislature, there is a requirement that there be a clause in any contracts with public funding about services, but it was only about services. And that the public council would have authority over that contract, but if there are contracts for other purposes, then the public council, the ombuds office, doesn't appear to have oversight or any structure to oversight. Very concerned about managed care. That was brought up. There are managed care contracts in other states but the...in the MRC report, for example, that's gone to the Medicaid Reform Council, it references three other states. North Carolina is in absolute disaster and meltdown and has been for the last ten years, also Iowa and Pennsylvania. Managed care worked when there was money in the system. We do not have money in our system. That money has gone into the community. So I want to give you a bit of history and I'm doing this in part because it's a more efficient way to do this. In 1994 the Legislature required that the department of public institutions and Medicaid apply for the Medicaid Rehabilitation Option, or MRO. What the state...and that it be budget neutral. The state did apply. [LR338]

SENATOR GAY: J. Rock, can I interrupt you one minute. Do you have that down somewhere that you could send to us? I mean... [LR338]

J.ROCK JOHNSON: Okay, I was wanting to be much quicker to... [LR338]

SENATOR GAY: If you could summarize. The reason I say that is we have a joint

committee right after this and we're digging into time that we could all find solutions in a way. So if we could summarize... [LR338]

J.ROCK JOHNSON: As a core of real persons you probably want to eat in between? [LR338]

SENATOR GAY: Thank you. Well, the other thing is time. We've got other hearings at 1:30. [LR338]

J. ROCK JOHNSON: Yes, the fact of the matter on the Medicaid is a very bad idea. What it's going to do is separate out people with substance abuse and mental health services. It's likely that those...that would be a separate accounting and not be part of the existing Medicaid functioning now in the $60 million IT system that's being built. And in addition, what probably is, maybe, the most important about this, on the 28th of October regulations went into effect, because there's already managed care, is already being done by Magellan. And those new regulations completely eliminated the chapter on quality. They eliminated a requirement that the public council also receive any information about a contract. This is a report card that I was a part of developing, that had to do with managed care. And a bit of how we actually completely got here today, in 1990 the state got a $425,000 contract from the federal government. It was one of 14. It was the only one where the money went directly into the state. It was to hire consumers, develop and implement a curriculum, and to have a very complicated complex mechanism of feedback. It didn't do the last things. The only thing we did was to hire the consumers, they went into the department and were not involved in any kind of outreach activities. They're still employed by the government here today, which is one of the reasons that there was such interest in having a change. The advisory committee, there's...that again, it was changed in 1994. It was changed in 2004. Been part of that, that really needs to be changed again. And the concept of inclusion is after the fact. You know this is a contract that was just sent to this advisory committee and it said that when all the work is done, it sort of, and that's kind of what's been my experience in the

workforce development, is that when we're all through and make all the decisions, then we'll let you become a part of it. [LR338]

SENATOR GAY: Thank you. [LR338]

J. ROCK JOHNSON: So as the woman who was with the Rosa Parks in the negotiations said, we didn't come here for no two seats. Thank you. [LR338]

SENATOR GAY: Thank you. With that, two minutes, I mean, we really need to... [LR338]

JOHN PINKERTON: How about one? [LR338]

SENATOR GAY: One minute would be great. We really need to...because really we do need to go discuss all the things we've heard and how we can proceed forward to come to some kind of solutions and answers on these things. [LR338]

SENATOR JOHNSON: And you know one of the things that we probably ought to do, is the people that talk first, we ought to make them stay the whole time. (Laughter) [LR338]

JOHN PINKERTON: (Exhibit 8) Well, this has been a very informative and humbling time today. I hope everybody appreciates it. I'm sure you all do. One of the things that I'm sure can...oh, I'm John Pinkerton, J-o-h-n P-i-n-k-e-r-t-o-n. I'm a family member, a provider of residential services for 140 behaviorial health consumers. I'm treasurer of NAMI Nebraska and president of NAMI North Platte. If we can eliminate people trying to build empires and servicing the bureaucracy and start caring for people, we could eliminate some of the problems you heard today. Please read my testimony here from me and my wife and please call. Our phone number is on there. Thank you. [LR338]

SENATOR GAY: Thanks, John. With that, though, I am going to close this public hearing. Senator Stuthman has one quick announcement. [LR338]

SENATOR STUTHMAN: I just wanted to make an announcement and it was...has to do with Senator Harms talked about the safe haven part of it. This afternoon at 4:00, Channel 8, Dr. Phil show will have a program on it. I was interviewed for it but they cut me out. They had too many other ones that were, were, (laughter) had points to make, so thank you. [LR338]

SENATOR JOHNSON: Well, and if I...since this was my thing to call this, I just wanted to make it a part of the official record is that I think this has been one of the best hearings that I've been here in my more than six years, and you're all to be complimented who took part. [LR338]

SENATOR GAY: Yeah. Thank you all. [LR338]