[LR283]

The Developmental Disabilities Special Investigative Committee met at 9:00 a.m. on Monday, June 23, 2008, in Room 1507 of the State Capitol, Lincoln, Nebraska. Senators present: Steve Lathrop, Chairperson; John Harms, Vice Chairperson; Greg Adams; Abbie Cornett; Tim Gay; Arnie Stuthman, and Norm Wallman. Senators absent: None. [LR283]

SENATOR LATHROP: My name is Steve Lathrop. I'm the Chairman of the commission that was established by the Legislature to evaluate developmental disability and the care provided to the developmentally disabled by the state of Nebraska. Today is our first hearing. And I'd like to start, if I may, by giving you a little background. Maybe I should introduce the other members of the commission, and then I want to visit with you a little bit about the structure of our hearings today and tomorrow, as well as the structure of how we're going to proceed with this inquiry over the coming months. I'm joined today by other members of the commission which include Senator Norm Wallman, who is seated to my left, Senator Adams from York, Senator Gay from Papillion, Beth Otto who is our clerk, Sean Schmeits who is my legislative assistant, and also John Harms from Scottsbluff, Senator Abbie Cornett from Bellevue, and Senator Arnie Stuthman from Columbus. We are the commission that has been appointed pursuant to LR283, which brings us here today. We have in our effort to develop some structure to how we're going to make this inquiry concluded that the best approach for us as a commission is to hold two days of hearings each month between now and the time our report is due on or before December 15. In June, today, we are going to take up what I would generally regard as background issues. We have invited speakers to discuss those matters. I am familiar with the fact that, and I have received, as we all have, an awful lot of e-mails and inquiries from people who have an interest in this matter. We're glad you're here and in attendance. We have heard from a number of family members who have people that are family members that are either at Beatrice or receiving community-based care. We will make time for testimony from those people, from those family members, and from those guardians, but it probably won't be until August. Our August hearings will include an opportunity for people to tell us what their family's experience has been with Beatrice, also to have employees at Beatrice or otherwise in the system to testify concerning Beatrice and the care that's provided there, and perhaps the staffing issues that are prevalent. Today what we will take up is, and this is to give you a little bit of an outline of what we will do and how we'll proceed today and tomorrow. We are going to initially take up background just to educate the members of the commission on the background of people with developmental disabilities, the spectrum of their disabilities, as well as their needs. And Dr. Bruce Buehler is here to testify about that. He was formerly the director of Munroe-Meyer Institute in Omaha. We will also take up and listen to testimony from invited speakers on the subject of the legal requirements the state has to families and folks with developmental disabilities. And we will have and hear from Bruce Mason, with NAS, and also from Ms. Fenner, and I think she's with Health and Human Services. She's a...after we hear or take testimony regarding the legal requirements, we will also then take testimony regarding resources. And we will hear from John Wyvill, who will give us an overview of Health and Human Services and the way Health and Human Services provides resources to families with a loved one that has developmental disabilities. John will also provide us with other testifiers who will take more specifically, including Ron Stegemann, from Beatrice Development Center, to talk about what services are provided at Beatrice, what services are provided in the community. And then last...the last thing we'll take up today will be the number of people receiving services so that we get an idea of the census or the population of people receiving services from the state for developmental disabilities. And that discussion will also include an overview of the waiting list--what it takes to get on the list, what does the list look like, how many people are waiting, and what kind of services are they waiting for. So that's an overview of what we're doing. You can see, with the people invited to testify today that we probably won't have time to take testimony today from the public, although we remain very interested in what you have to say, and you're welcome to talk to any of us. We will afford folks an opportunity to testify in one of the upcoming hearings. A couple of housekeeping things. If you testify, we need to have you fill out a sheet that will provide us with your background. Those sheets are up here, Beth? [LR283]

BETH OTTO: Yes. [LR283]

SENATOR LATHROP: Okay. If you have any handouts, you can provide them to us and we'll pass them out. Hopefully, you've brought seven copies if you do have handouts. And otherwise, I guess, we'll just get started. And with that, we'll ask Dr. Buehler to testify. [LR283]

DR. BRUCE BUEHLER: First, I'll try a kind of broad base and talk about developmental disabilities and all. But, I think, the easiest way to do this is please interrupt me at any time, makes it easier. [LR283]

SENATOR LATHROP: And I'll do that first by asking you to tell us your name and tell us your business address and spell your last name for us, if you can. [LR283]

DR. BRUCE BUEHLER: I'm Bruce A. Buehler, B-u-e-h-l-e-r, M.D. And right now I'm at the University of Nebraska Medical Center. And I'm executive director of the Center for Human Genetics at the university. Maybe it would be helpful to tell you a little bit of background then? [LR283]

SENATOR LATHROP: I think that would be a good place to start. [LR283]

DR. BRUCE BUEHLER: I started out in 1974 as the director of the Sunland Training School, which is the regional center, comparable to Beatrice, in the state of Florida. I was the medical director there for a period of time, and then I moved to medical director of Utah State Training School at American Fork, which also is the regional center for the entire state of Utah. And from there I came to Nebraska, in 1981. And since then I've essentially worked in the community with individuals with special needs, developmental disabilities, developmental delays. And I do clinics throughout the state. I spend time on the road about two months a year in Scottsbluff, North Platte, Kearney, Grand Island, Hastings, and we also have some clinics in both Winnebago and Omaha. So we have been very involved in dealing with children and adults with special needs, which is probably the broadest term. So how would you like me to proceed, sir? [LR283]

SENATOR LATHROP: Well, I appreciate the background and that's very helpful. And now maybe you could share with us and educate us, if you could, with respect to the spectrum of people with developmental disabilities and what their needs are, sir. [LR283]

DR. BRUCE BUEHLER: Unfortunately, the term developmental disabilities is a federal term. It's a term that is mandated. And you all know the law, and you know what it says. But in reality it's any child with special needs. And that's probably a term that's grown over the years because many of the individuals may have only an orthopedic issue and be developmentally close or often even okay. The biggest change that's happened over the years is, when I started in the seventies, we essentially tended to go toward institutionalization for children under a certain level of function. Today because of the community movement, because of other issues, we have moved a large number of those children back in or kept them in the community from the beginning. And probably the overriding view today in developmental disabilities is as much as possible inclusion. And inclusion being that you can actually stay in your community, and if possible in your home, but if not possible within some type of setting. But you also will have the chance to interact with your peers, work with individuals of your same chronologic age, and learn the social skills, which is as important as the intellectual skills. Where we have come into problem, and it's a problem that we see, I think, in may areas, but in developmental disabilities, because it's such a broad base, behavioral issues fall into that category. And we have to remember that when we say somebody has a developmental disability and is able to function in the community that's excellent, and that's where they should be. But if you have a child or an adult who has a developmental disability but is unable to control themselves, is unable not to injure themselves, it not able to not injure others, then we have very few options because the community is not set up at this time to take care of severe behavioral developmental disabilities. And what are we talking about? Well, the original group that we saw in this category would be people that were untreated for certain metabolic diseases, which thank goodness we now have a state metabolic screening program, newborn screening which has weeded out a lot of these children early and allowed them to have a normal life span by diet and intervention. But many of those individuals weren't picked up in the sixties and had to go to institutions. They have self-abusive behavior, they will actually injure themselves severely, they will injure others, and it's not that we can easily behaviorally manage those issues. And for the community it's a very difficult task because these individuals are often aging, they're getting older, they're bigger, and for physical reasons they need one-on-one, two-on-one, three-on-one types of care. So right now in the state what we look at is trying to start with a newborn or an infant that I see in a clinic. And the first thing I'm going to do is look to see if I can find a diagnosis. And why are we diagnosing them? Because we can get school systems started immediately if we have a diagnosis. And this is either called other health impaired, or falls under the mental retardation dogma, which is essentially an IQ of 70, which you can't test in a newborn, obviously. So what we do is we get them into the systems early. This has made a major difference in the demographics. We've been able to keep many children in the community because of early diagnosis and because of early intervention. The problem is we've also stressed the system because we have diagnosed these children three, to four, or five years younger than they would have been in the past. About four or five, this child would have showed up in my office showing delays. Today I'm diagnosing them at birth. That's four or five more years that the education system has to respond. And so it has put a fairly significant burden on the community. Because we have newborn screening, one of the big advantages has been children with PKU, who were a significant number of children in institutional settings. Children with other metabolic diseases we're now screening for that. And about 95 percent of those children are not only treatable, but actually do not require special ed services later in life. So screening has become a major change in the demographics in order to try and catch the children early and prevent the disease. We've also been able to work with families where there is a history of problems, and we've been able to work with them early and get those children started earlier because of the genetic history and/or the background. So the demographics have changed because the children can be picked up earlier, therefore in community services. But what we have found is that getting children into an early program is not only important from the intervention standpoint, but what we've found is that most children who are functional can be independent, can do their dressing, do those other types of things, require one big issue, and that's socialization. So one of the areas that we are working on but still have a great need for is the schools are required for both cognitive and all the things that they do to educate, but socialization is becoming one of the major issues that we'll be facing for those individuals who stay in the community. A child with autism needs cognitive training, but a child with autism needs to understand how to walk in a room and say hello, and welcome you and know that there's something they should do. As one young person with autism told me, I have to Google what I'm thinking, because I don't know what to do, but I can bring it up on a card and I know what to do that way. So our schools have moved not only into cognitive, but heavily more into socialization. As you would guess, institutionalization is not an easy socialization issue. It's not easy to set up a socialization program of your peers and drive that. And so we are very cautious today in putting individuals into an institutional setting when they have potential to socialize and to develop certain skills. Then why would we be looking at any issue of individuals having to be in more of a restricted environment? Today I would say the majority of issues are not as much physical as behavioral. Once you deal with individuals who have special needs sometimes the behaviors become beyond any system we can work. And the most common behavior is self-abuse and other forms of abuse. And this is not within the purview of most communities to essentially give those services. And so if you start looking at the populations that are developing in centers, whether they be large or smaller, they often have dual diagnosis--they have a disability, and they have a developmental behavioral problem that creates significant need for staffing. And so I would see the dichotomy that occurs today in society is all children start, if possible, in the community setting. That's our intent. That's how they get to me, that's how they get to the schools, that's what caseworkers do and so on. But over time those children who separate out and are severe behavioral, along with physical disabilities, there has to be an alternative. I assume the committee will decide what that alternative is and what the best alternative is, but there probably today is not services for those individuals. Now an individual with developmental disabilities actually can be diagnosed up to the age of 22. So developmental disabilities encompasses a very large group. And if you take the national demographics, roughly 15 percent of the population falls in the developmental disability range. But that would include autism, that would include learning disabilities, that would include attention deficit hyperactivity disorder. It's broad, but it is a significant proportion of individuals. In general, majority of developmental disabilities that we deal with are lifelong. These are not things we're going to tomorrow are going to go away and we will have cured them. What we will have done is integrate them into the best possible. And I believe you'll hear throughout your testimonies and all of the discussions you'll have that the driving principle for children with special needs and disabilities is quality of life. We're shooting for quality of life. We're not looking to see that every child has to be the same or fit into a mold, but they have to have the ability to maximize their quality of life. And if that's best done in one setting or another setting, that requires the input. And I will say that probably developmental disabilities more than any other area of medicine and/or education requires a team. It's not something you can do as an individual. I, as a physician, cannot walk in and say, this is the best place for this young man or young woman. What I can say is this young person needs these services. And what are the agencies that we can deal with? Well, we have HHS, of course, and Medicaid system. We have insurance companies and they will pay for some of the interventions that we...are necessary. We have the schools, which are mandated, start at zero. We're one of the outstanding states, by the way, in serving young people who have disabilities of any kind. And we, in general, try to find most advantageous setting for them. One of the things that we have found is also we need to develop parent training. And so a lot of the work that we do also is to help the parents understand the issues they're dealing with. It's very easy to say I'm going to keep my child in the community and I'm going to have that child served in the community. But you have to remember that at the best they're going to get 8 hours of service in school, and there's 16 more hours of essentially 24-hour care. And parents have a huge amount of caring. So if we're going to maintain major community programs, we have to also maintain support for parents, because parents, like all of us, burn out. That shouldn't be an option that we can't deal with that, but it's something that you need to be aware of. And it's an expense that on the books doesn't look realistic initially, but you realize that if the parent decides to take care of their child at home, that child gets to be 110 pounds, because they grow up, how do you get them out of a bathtub? Now it's simple things that we don't think about, but it's how we do it. If that child is 250 pounds, is not cooperative, is not...then you may have to go to some type of institutional, or residential, or regional center because you can't physically and/or developmentally deal with that. Is here still quality of life? Of course, we still can maintain within any setting a quality which says the person or the client, whatever term you want to use, gets the best care. The educational responsibility right now in this state is essentially to take the individuals we identify, and they can be identified in multiple ways, I would say the majority, about 90 percent of kids, get into the system through physicians because the parents come and say, he's not walking, he's not talking, he's not speaking, she's not making milestones, you know. And then the schools become involved. And so early intervention is probably at this point one of the most usual methods into the system that we have today. The second step is then to develop a school program and to work within it. But for many of our individuals that we deal with that we diagnose early, we also have to take into account some are on respirators. They actually got to school on a bus with a tank of oxygen and a breathing machine in order to get their services. Now that is a maximum amount of effort, and it may be the best effort, but it's one that has to be done if we're going to serve them in the community. And in some cases it may be beyond what we are able to do. We have...many of our children have fairly significant seizures, and those need to be treated, if in the community, with medication given in the schools. There needs to be medical personnel in the schools because these children are actually medically fragile. And so what would have in the past, maybe 40 years ago, immediately gone to a larger institutional setting, may be in the community but requiring multiple resources. We also have a category that most people don't think of in developmental delays, which is other health impaired. These would be young people who have...a child I just diagnosed recently who has both of his arms missing, born that way. Developmentally he appears to be on scale. Looks like he can do a lot of the development, but he certainly can't function in a classroom in the same way another child does. So in that case we have to make adaptations, so the school has to offer PT, and occupational therapy, physical therapy, other forms of support in order to make that child able to be educated. And the rule of the schools essentially is to deal with anything that impairs the ability to be educated. So that means they're going to deal with orthopedic problems, they're going to deal with other problems. For potential today in dealing with the population, and by the way doing multiple state clinics I'm all over the state seeing individuals. There comes a certain point where none of the community services will be sufficient. Child is...when an adult or a child is becoming an adult the child has too many issues, the behavioral issues are beyond control, and so whatever decisions the committee has to make, there probably has to be an alternative to adjust the community, because the community may not be able, in this day and age and in this site to serve that individual in an adequate way. We don't want a young person nor an adult harming themselves because they can't get the support they need. And I mentioned socialization and I'll go back to it. We worked very hard on cognitive, we worked very hard for young people to learn, to reach their max, and I think it's...as long as the dictum that we're all working under is quality of life, then that's an individual issue for every person with special needs. You are going to hear the work developmental disabilities, that's a legal term. And it essentially means a disability that occurred within the first 22 years of life, the majority being around birth or soon after. You're going to hear about developmental delays. That's a whole nother term. That's a term where someone has capability, but will reach it at different points. They will learn throughout a lifetime, but they'll continue to need input. And right now that's the second step in this pattern is many of our individuals reach 21 and systems stop. There's no easy placement in the community for adults. There's no agency, essentially, other than vocational rehab, who is essentially mandated to try to help these young people now become adults and transition. So we're talking about group homes. We're talking about support systems, support systems for the family. So we need to be very sure as we think about this that we don't think of this child as 0 to 21, and then everything ends because it's not going to happen. That child is going to go on and live 60, 70, 75 years. So in thinking about finances and costs, etcetera, we can't just assume that at the end of 21 we've ended our support. And that has major fiscal implications which are far beyond me. The last point, I think, is that the number of children and adults who will continue to come into the system is going to grow, it's not going to get smaller. And the reason it's going to grow is that we can diagnose more things than we ever could. Today I could take a blood sample from you and I can do 2,500 of your genes. I can know a lot about you in a single blood sample. Or I can take a newborn who's not fitting the pattern and diagnose that child at birth that I wouldn't have even considered diagnosing until the teenage years. So the impact is that the numbers won't go down. And the question is, where is the best service, since the numbers will actually go up. And as we maintain children, especially premature infants, infants of printing, infants that have been exposed to alcohol, exposed to other agents, we are going to see an increasing population that we have to deal with. Senator, I hope that's a start. [LR283]

SENATOR LATHROP: That was very helpful. I do have...maybe invite you to talk about a couple of things while we have you here. And that is you've given us sort of a definition, you've given us the definition of developmental disabilities. Can you share with us the spectrum? We have some people with physical, as you say, orthopedic problems, we have people that are cognitively impaired, and we have some behavioral issues. And those are perhaps three of the defining characteristics of people with developmental disabilities. But in terms of the population that we provide services to are they...they come to us, some with physical, and some with cognitive. Can you maybe address the population,... [LR283]

DR. BRUCE BUEHLER: Sure. [LR283]

SENATOR LATHROP: ...and give us an overview of that, if you would? [LR283]

DR. BRUCE BUEHLER: I'll use my clinics as kind of a way to think about how the division occurs. We see individuals who have had massive brain damage in utero, or have had an injury, not as common as we thought, but at birth, or has had a bleed from prematurity or something else. The brain is clearly damaged--hydrocephalus, water on the brain, other types of problems. These children are very clearly going to fall on that spectrum. And many of them will fall in what we call the severe, profound range. And just for your understanding, the schools use a very simple and straightforward rule, and that is IQ 70 or less is served no matter what else disabilities there are, now whether they're physical disabilities or whatever. And those are the children where we know from the beginning, as we tell the parents, they've had a static brain injury. And we're not going to fix that. What we are going to try to do is maximize the ability around that. And I use the analogy with my families that essentially, no matter what we do, let's set the bar the highest we can and see if the child can make it, but also understand we may not get there and then we have to be realistic. So we have that group of individuals who are going to be severe and profoundly retarded, and the word retarded, unfortunately, still remains in our vocabulary, and they are not going to be able to do life skills, function on their own, get up and get dressed, get their food and do those types of things. And therefore they will need care. Where that's best done usually a very personal with the family, with a team trying to decide. But do they learn? And I think the biggest issue we've all had to learn is they continue, as children and as adults, to gain some skills. But they're not going to gain enough skills for independent living, not going to happen. Then we have a population in the moderate range of developmental disabilities. And that's probably your majority. And as an example, and again only an example, I will use Downs Syndrome because we have been lucky and smart enough to put these individuals in the community and allow them a lifestyle. And they are functional. Many individuals with Downs Syndrome have an IQ well below 70, some at 70, but many have social IQs above 120. They can walk in a room, talk with you, do a job, have a quality of life, and even in some instances a marriage, whether or not they have a family. So that group is a whole different relationship. And those are the children who generally stay in the school system for the 21 years. And then we try to transition them into a setting outside. The law now is federally, I believe, it's 14. We are using 16 as essentially the milestone. At 16 we expect the children to have a transition plan. Are they going to vocational school? Are they going to go out and have a job? Are they going to learn a job while they're also learning cognitive things? And that's really important that we have that transition because otherwise then they would be dependent, and there's no need for that. We had individuals on the mild spectrum, and that's a group that's growing the largest. We've had a 400 percent increase in the number of children with autism in the state of Nebraska in the last three years. Now you can say, is this an absolute epidemic? Well, when you do data from other countries that have not had mercury in their vaccines, who have not had changes in their definitions and all, the absolute number of increase national or worldwide seems to be at 16 percent. But we are seeing a 400 percent increase, and that means we are diagnosing it and had missed it, or we're opening our criteria. So the second level or the third level is those individuals who, with education, with socialization, should be very functional. And that is the mild range. And that's the area where we've had the greatest success, and that's where the community does best is taking those children (inaudible). Now what about the orthopedically handicapped? Well, we get a lot of children who have cerebral palsy. And it's a very broad useless term in many ways. But many of them are physically involved enough to be wheelchair bound, to need intervention, to need care in the schools and all that. And they require a huge amount of resources to get them in and out of a bus, to get them to the school, to essentially get them where they can interface with their peers. And that is a group that we call orthopedically handicapped. Many of them have an IQ near the norm, but they have no speech, or they have no communication and they have to use machines or some other way. And so that's the area where orthopedically handicapped has also increased. We have children who need what you would not consider in your mind educational, but their physical needs, to be able to educate the child. And so it's a combination of both. And this is an area where the schools and HHS and education department have worked closely to try and determine what's medical and what's educational. It's a very hard line to try and draw. But these are the kids that because of their orthopedic handicaps cannot get out or do the things they need to do to get an education. And that group in the past would probably have been in a regional center, 40 years ago. Today they're in the community, so it requires many more resources. [LR283]

SENATOR LATHROP: Those folks with the orthopedic injuries or orthopedic conditions can also have the severe and profound problems, moderate problems, and mild problems cognitively? [LR283]

DR. BRUCE BUEHLER: Correct, and that's why, unfortunately, you're going to find as you go through developmental disabilities is like a big pot (laugh), it doesn't have a nice easy definition, other than the federal. But, yes, many of our children who are cerebral palsy to an extent can also have brain damage that is quite severe, and therefore require those services that are above and beyond. Where you get into institutional issues or issues of care is if a person cannot in any way support their own care--button a shirt, pull a shirt over, get out of bed. You're reaching a point where is that educational, or is that medical? And that's when you have to look at regional centers, because this is a...or nursing homes or whatever options your looking at, because it's so labor intensive to get each child taken care of. I'll give you an example. We have children we take care of that become so tight that you cannot clean then in an adequate way. And we actually have to do surgeries to release those so we can just clean the individual, keep them healthy, and well. That is not easily done in a community setting in many places. So there will always be that population who are more in the severe physical or severe physical and developmental range who will require specialized care.

And you reach a point where specialized care, you need an infrastructure, and the infrastructure has to be large enough to support that group. If you do it on a one on one, it's very, very difficult. [LR283]

SENATOR LATHROP: One last question I have and then we'll ask you to address this for me. And that is can you give us an overview of how long those, if you can generalize for me, how long people with developmental disabilities typically stay in the family home or in the family setting? Do we run into them at some typical age? [LR283]

DR. BRUCE BUEHLER: I think that's a truly changing demographic. When I started in the seventies, I would say 10 to 20 percent of the children I saw at that time would eventually wind up in an institutional setting. Today I'd say that percentage is down significantly and probably not only less than 5 percent and so on. But in that group we're talking about very, very significant involved individuals who have both behaviors and physical. So the severity of the individuals who are not staying in the home is far greater than it was 40 years ago. And there really aren't a lot of options for the system, nor for the family. What we are seeing is a majority of individuals today with developmental disabilities are showing up within the 22 months or in the first 24 months of life. At about two years we are generally able to pick up. The Academy of Pediatrics now requires that every pediatrician screen children for developmental disabilities twice in their first two years, and they screen for autism twice in the first two years, and therefore we're finding these children that we may well have let go in the past. So it's a younger population. And those are almost always started in the community because you don't know their potential, you can't test a 2-year-old to really see where they're going to be when they're 15. And so they start there. When the system reaches a point where they no longer can care for them, it's usually in the early to middle teens when that individual is having such significant behavioral problems that schools have a very difficult time. And clearly when they reach adulthood and they become at a point where they not only can't function, but they can be dangerous to themselves or others, then you have very few options at that point. And so I would say that the general time is late teens and adulthood. [LR283]

SENATOR LATHROP: Very good. Thank you, I appreciate that. Does anybody have any questions? Senator Stuthman. [LR283]

SENATOR STUTHMAN: Thank you, Senator Lathrop. Dr. Buehler, you had stated behavior is a major issue. Does this behavior come from...you know, is it inherited or is it induced because of drugs and stuff like this? [LR283]

DR. BRUCE BUEHLER: Well, that's an excellent question. We'll take, for example, the most common behavior problem we used to address in institutional settings, was untreated phenylketonuria, PKU, which we screen for in newborns. Those individuals because of the buildup of this toxic chemical in their blood will begin to become so aggressive and so self-injurious, and their behaviors are almost impossible, they will actually tear their own skin, they will bite and so on, and that's clearly genetic, that one is clear. There is a group which has emerged, unfortunately, which is fetal alcohol syndrome, some cocaine and methamphetamine, although the community has done an excellent job in trying to incorporate where the behavior is damage. And no matter what we do the child is going to continue to have certain problems with priorities, with understanding consequences, not understanding what is required of them to fit in society, and that is brain damage. So there are both sides of that. And then in the genetic realm individuals may have a syndrome, but in general, and I'm sure others will testify far better than I, behavior management in most of those cases can reduce the behaviors quite significantly. But whether you can do it in a community setting, whether you have to do it in a regional setting is a really big issue, because sometimes it requires a huge amount. I have a young man we're taking care of right now through our center whose number one priority is to put his head through a window. He will run across a room, if he can find a window, and stick his head through it. Now that's self-injurious, obviously dangerous, and his behavior is at this point something we're trying to control. Very, very difficult individual. So many of your patients in regional centers have those kinds of behaviors that require two and three attendants just to keep them from injuring themselves. So I think your question is correct. Genetic...you have a...the one thing that always comes up, is it parenting? We spend a lot of time with parents and we work with them. And I would say in general, this is a generalization, most parents are not only committed, but they will do anything you ask them to do to try to help their child reach their max. But there's a certain point at which some of the behaviors can't be extinguished. [LR283]

SENATOR STUTHMAN: Thank you. [LR283]

SENATOR LATHROP: Senator Harms. [LR283]

SENATOR HARMS: Thank you very much for coming. I appreciate your expertise in this field. I have a couple of questions I'd like to ask you. Let's start with assessment. [LR283]

DR. BRUCE BUEHLER: Yeah. [LR283]

SENATOR HARMS: How do you actually determine what kind of assessment you're going to use? Do you just...you talk about drawing blood and from that you can get about 4,500 different approaches to, I guess, issues. What do you actually use for the assessment to start with this child? Do you actually draw the blood? Is that where you start? And then let's go...answer that one, and go a step further. [LR283]

DR. BRUCE BUEHLER: No, actually it's truly observation. [LR283]

SENATOR HARMS: Okay. [LR283]

DR. BRUCE BUEHLER: We will come in the room, I always bring a psychologist, usually a behaviorally trained psychologist, and we observe the child. We'll actually ignore the child for about 15, 20 minutes to see what they do. Then we'll go and look at both parents' histories, just to see if there is a history of developmental problems in the family. Then I'll do an actual physical exam. And I would say less than 10 percent of those I assess will I do blood on, because clearly they are delayed, but they had an injury at birth. I might do an MRI to look at their brain and see what was injured or I may, in some instances, just on the family pedigree, know that I'm dealing with a familial type of delay that's going to be part of the family. What I do next is send them into the school system. Put them into the school system through the early intervention program and I see them back in six months. And now I have objective reports from special educators, occupational therapists, physical therapists, speech therapists. And I have a better picture. And in general that winds up with us doing about 10 percent to 20 percent of the children that we see on some type of genetic testing. But 80 percent it's pretty clear that this child is delayed, needs services, and qualifies under the educational rules. I'm a doctor. I can send them to the school under other health impaired. But the school still has to certify them under their own rules, which is correct. So they will get a second eval., which is quite a bit more extensive than mine, to try and decide if they truly fit into the educational system. [LR283]

SENATOR HARMS: Now once that child has been placed in like, for example, into the school, then is it the school's then responsibility completely to take over the care of that child? Or are you still in that monitoring process, even though six months out...are you still involved, or what happens? [LR283]

DR. BRUCE BUEHLER: We stay involved and the reason is that most schools feel that the medical input is critical to them. If a child is losing skills or regressing, this is a great concern for schools obviously, they're going to send them back. So I see a lot of these children multiple times. Actually, I've now, in the last year, been to 22 graduations of kids I diagnosed at birth. And so you follow them in a long-term. Why a medical model? Well, the medical model, along with the psychological model, which is part of this, is a screening tool. It helps the schools to get started. Any parent who has concerns about their child can contact the school directly and the school will come out and evaluate them. [LR283]

SENATOR HARMS: Now let's say that the child, from your evaluation that the child needs to be placed in the Beatrice center, that they need special needs that our schools cannot provide, that a community-based program cannot provide. And a child is placed in to the center. Who's responsibility is it once that child goes in the center? Do you still stay in contact with the center? And the second part of it is, well, just answer that first. [LR283]

DR. BRUCE BUEHLER: At this time, no. There are physicians in the center who become the primary care physicians. They will utilize me as a consultant on occasion to look at possible reasons that certain things are happening. But, no, it becomes essentially internal medical care with the people that are at the center. I will tell you today, in general, very few of the children we see are automatically set up to go to Beatrice. They're set up to go into the schools, and then we look at the record. And probably that's why we're talking teenagers and adults more commonly. [LR283]

SENATOR HARMS: If...what I'm really trying to get to then, once they're in the center itself another physician takes over. [LR283]

DR. BRUCE BUEHLER: Yes. [LR283]

SENATOR HARMS: Are you familiar how that works within the center? Because my concern really centers around follow-up and constant rediagnosis and that whole issue that's going. Because when you read the federal report here it's very clear that we've been unable to do that. It's very clear that we've not followed up in assessment. It's very clear that there are major issues here. And what I'm trying to get to, and that's what this committee is about is to center into that issue to determine what we have to find...what we have to do to resolve those issues. What do you see as an expert in your field as you view into that center in regard to that issue? [LR283]

DR. BRUCE BUEHLER: Having been a medical director at two training schools, I think it is a major issue for every training school to reassess. I mean it's very hard. It's easy to say, okay, we don't have the staff, we don't have the resources. But I believe today if we were looking for the ideal there should be consultation, there should be clinics at Beatrice with specialists to reassess individuals. And I set that up in Utah, and I set that up in Florida, and I believe it can be done here as a way of bringing in expertise. But no doctor has, none of us have all the expertise. But I think that a medical team approach, which includes behavioral, etcetera, is always helpful for the people who are doing the care and the treatment. [LR283]

SENATOR HARMS: Now the center is independent or integrated into the system? [LR283]

DR. BRUCE BUEHLER: At the present time, the way I understand it, and I do not know Beatrice well and I will defer to my colleague, it is not, as I understand it, a medical facility which is an open door, bring in medical and other expertise. They have their own system and their own individuals. And I don't work through that. I work through medically handicapped children's programs, through HHS, and that's how we do our clinics. [LR283]

SENATOR HARMS: Let me go back to the community-based program for a moment. I know that one of the goals is for Beatrice to bring down the number of people that are in their control and place them into community-based programs. What do you know about Nebraska community-based programs? And are we really prepared to address those issues appropriately? And then are they staffed appropriately as your expertise views that? [LR283]

DR. BRUCE BUEHLER: Well, I will say at the present time, and again because of my own experience with families and patients, we are doing a superb job for up to 21. There is no question that the services are there. The schools will go overboard to help that individual. But then there is a cliff. And the drop-off is massive. If the individual does not have potential to transition into a more routine environment, we are far underserved with group homes, we need more. And one of the things I tell my parents when I diagnose their children at birth is, start thinking about what will happen when they're 21, because children want to leave home and there's a point at which children should leave home. And that system, no, is not adequate at this point. It's mostly private sector. It is not set up to adapt. There are many excellent programs out there, but they're probably well overloaded. [LR283]

SENATOR HARMS: Thank you very much. [LR283]

DR. BRUCE BUEHLER: You bet. [LR283]

SENATOR LATHROP: Senator Cornett. [LR283]

SENATOR CORNETT: Actually, I have a number of questions,... [LR283]

DR. BRUCE BUEHLER: Go ahead. [LR283]

SENATOR CORNETT: ...but they have a wide range here. In the beginning you said that early diagnosis of metabolic disorders, like PKU, has actually stressed the system more because of the early diagnosis and the children moving into the system earlier. Am I correct? [LR283]

DR. BRUCE BUEHLER: No, I may have misstated. [LR283]

SENATOR CORNETT: Because I...(inaudible)... [LR283]

DR. BRUCE BUEHLER: Yeah, that wrong balance, yeah. What I meant to say was earlier diagnosis of nontreatable conditions. [LR283]

SENATOR CORNETT: Okay, that was my... [LR283]

DR. BRUCE BUEHLER: Yeah, has stressed the system. [LR283]

SENATOR CORNETT: Because if they're treatable then they actually don't move into the system, am I correct? [LR283]

DR. BRUCE BUEHLER: Exactly. [LR283]

SENATOR CORNETT: Okay. [LR283]

DR. BRUCE BUEHLER: And they were a significant PKU and untreated metabolic disease was a significant population that arrived in regional centers. [LR283]

SENATOR CORNETT: Okay. The next question has to do with autism. When you said that there was a 400 percent increase in diagnosis in the state of Nebraska, do you feel that is...is it the majority of better diagnosis techniques, or do you actually see...are we actually seeing a rise in autism itself? [LR283]

DR. BRUCE BUEHLER: In most difficult studies that we can come up with the CDC, and I've worked with them, feels that 150 children born today will have autism. And that figure seems to be fairly static right now. But that group went undiagnosed for probably ten years. So the 400 percent is better diagnosis. The actual increase is probably about 16 percent in actual numbers of children born today with autism that would have... [LR283]

SENATOR CORNETT: And you said worldwide that increase was approximately 14 percent? [LR283]

DR. BRUCE BUEHLER: Sixteen. [LR283]

SENATOR CORNETT: Okay, no, 16 percent worldwide. [LR283]

DR. BRUCE BUEHLER: Yeah, worldwide. [LR283]

SENATOR CORNETT: Got it. Okay. [LR283]

DR. BRUCE BUEHLER: And California, it was an 800 percent increase. [LR283]

SENATOR CORNETT: Because of diagnosis. [LR283]

DR. BRUCE BUEHLER: Because they opened up their diagnosis and the numbers just soared. [LR283]

SENATOR CORNETT: Under that question, has nothing to do with committee itself, but other bills we've had, you mentioned mercury. Because we've heard...we hear conflicting testimony continually on whether mercury-based vaccines are actually causing an increase in autism or if it's other environmental factors, or just simply early...different diagnoses. [LR283]

DR. BRUCE BUEHLER: It's a very difficult issue to answer. The vaccine issue may be easier only because we have data from Denmark, where they didn't have thimerosal in the vaccines. [LR283]

SENATOR CORNETT: But don't you only use thimerosal now currently in combination vaccines, like the flu vaccine, and regular children's vaccines don't have thimerosal don't have thimerosal in them? [LR283]

DR. BRUCE BUEHLER: Correct. [LR283]

SENATOR CORNETT: Okay. [LR283]

DR. BRUCE BUEHLER: And you can elect to get a nonthimerosal flu, actually. But what we found is we can't say, okay, mercury didn't cause it because mercury in fish have gone up, mercury in tuna have gone up. We don't know. We know today, in a recent study done, that we were part of the cooperative. There are chromosomal abnormalities which appear to account for some autism. But that person can have that chromosome abnormality, not show autism, and something in the environment kicks it in. Could be anything. And that's where all the work is going now is how can we look at the environment which may be...and the environment may well be in the womb. And so we've going to have to start even preconceptionally if we're going to make a difference. [LR283]

SENATOR CORNETT: Okay. And again that had nothing to do with this? [LR283]

DR. BRUCE BUEHLER: No, that's... [LR283]

SENATOR CORNETT: Back to Senator Harms's question when we were talking about whether we have the community-based services. When you're talking about someone that has a very self-destructive or violent behavior towards others, but right at the cutoff for what's considered a normal IQ or not, those people are very difficult to deal with. Having spoke to a number of people over the past few weeks, some of the people that are severely physically handicapped would be much easier to place in say, for instance, nursing homes or nursing care facilities, particularly as they age. When you mention we don't have the group homes available, is a group home even an appropriate setting for people that need two on one or three or one care? [LR283]

DR. BRUCE BUEHLER: Probably not. There you reach an infrastructure issue. You've got 24/7, you need people who are trained in children who are abusive to themselves or others. That takes a great deal of expertise. So I don't know that a group home is going to solve that issue. What we are trying to do, and I think all of us are all in the same boat trying to pick out those that we may be able to modify behaviors to where they can live in the community. But there's a certain point at which you may not be able to. And when we talk about self-abusive, we're not talking about just hitting your head. [LR283]

SENATOR CORNETT: No, I know. [LR283]

DR. BRUCE BUEHLER: We're talking about severe self-abuse. [LR283]

SENATOR CORNETT: Well, that brings me to one other question. And it has...because I deal with a constituent who I've been working with now for four years. She has an adopted daughter with special needs that was born of a severely drug addicted mother. She has above average IQ, a significantly above average IQ, but she's unable to differentiate between reality and fantasy. So the school, for instance, has pulled her off the ledge because she thinks she can fly. There...she sees a cartoon, she believes that that is reality. They have no idea what to do with this child as she's moving into her teenage years, because she's very large girl. Because they're diagnosed as psychiatric issues, but normal IQ, what happens to those people that truly have these disabilities? Because we all know that we are not equipped to deal with mental illness at this level in the state. I mean we don't have the facilities. [LR283]

DR. BRUCE BUEHLER: One of the important things in this case would be probably the word mental illness doesn't apply as much as brain damaged. [LR283]

SENATOR CORNETT: Brain damaged, exactly. [LR283]

DR. BRUCE BUEHLER: That's right. And so... [LR283]

SENATOR CORNETT: And that's where we're running into a problem. [LR283]

DR. BRUCE BUEHLER: And there you're talking about, okay, I can teach this child to act good in a certain setting. Okay, if it's the same setting every day, if the plates don't change color, if you get up exactly the right time, you go to school at exactly the right time, I can do okay. But as soon as you change my routine I don't know what to do. [LR283]

SENATOR CORNETT: That's very bad for this girl, yeah. [LR283]

DR. BRUCE BUEHLER: Yeah. And so those are the population that will need other services that we have no idea today how to provide because their impulsivity, their lack of consequences, their inability to judge what's right or wrong easily, not their bad, they just don't understand somebody says go steal that car, or take that car and drive it over and we'll all run off. You want to please your friends and you don't have the concept of what you've just done. These are going to be our most difficult individuals because of the comment that you made, and that is they are generally intellectually intact. [LR283]

SENATOR CORNETT: But that's...and that's where we're running into the problem is the school is saying this girl needs to be placed in an institutional... [LR283]

DR. BRUCE BUEHLER: Right. [LR283]

SENATOR CORNETT: ...of some sort. But none of...there is no place really that we've been able to find for her, working four years now, because she is IQ-wise fairly normal. But she is still brain damaged. [LR283]

DR. BRUCE BUEHLER: Unfortunately, she's wise enough to also talk her way out of many things and have an excuse for every reason that she did things. This is a population we are facing that is very difficult. This is the fetal alcohol, fetal drug effects. [LR283]

SENATOR CORNETT: I was going to say we see that increasing because of the drug abuse and the alcohol. [LR283]

DR. BRUCE BUEHLER: Yes, and I really think not this committee, but we need to continue to look at ways preconceptually to try to decrease the expose rate. Because it's not something we ever fix. [LR283]

SENATOR CORNETT: No, it's not, but... [LR283]

DR. BRUCE BUEHLER: It's not going to go away. [LR283]

SENATOR CORNETT: But that's a separate issue, trying to prevent it. What...do we need more programs for people like this? Do you see this in a community-base, or are we going to end up having to do something like a state facility for these children? [LR283]

DR. BRUCE BUEHLER: I think it can be community-based and it will take a situation in which it's a regimented day. It's not cognitive, it's not trying to teach them reading and writing, it's doing a task that's important, that they've contributed. But that the limits are set continuously. So these are more behavioral units as opposed to institutions. And that behavior has to be maintained at home, or a group home, wherever it is, and there has to be consistent...in general, children who are damaged by drugs and alcohol do best when everything is consistent, they have a routine. That's what we need to set up. And that at the present time isn't a major issue with our group...our work systems.

[LR283]

SENATOR CORNETT: So as you see us progressing forward as a society, we probably need to look at evolving our system from where we were in the past with metabolic disorders to brain damage from drugs and alcohol and (inaudible) different systems. And we're not equipped to deal with that yet. [LR283]

DR. BRUCE BUEHLER: Correct. I think we have the intent to deal with it, but there is no agency, no group tasked to do that, it ends at school. [LR283]

SENATOR CORNETT: Thank you. [LR283]

SENATOR LATHROP: Very good. Senator Adams. [LR283]

SENATOR ADAMS: At one point during your testimony you said that you've run clinics throughout the state. [LR283]

DR. BRUCE BUEHLER: Yes, sir. [LR283]

SENATOR ADAMS: The problems are everywhere. What about the services? Do we see great...do you see disparities in services provided from one end of the state to the other? [LR283]

DR. BRUCE BUEHLER: Excellent question. I would say that our state is probably up in the top five in the country in getting services to people, especially in rural areas which are very difficult. But we run into the same issue that you'll be dealing with, with regional centers--staffing. And so although the systems are good and the people in the systems are excellent, the number of needed professionals is still shy essentially west of Lincoln. We start to run into one speech pathologist trying to cover 250 miles, and ten speech pathologists sitting in the city. And that's where we run into difficulty. Is the quality good? Whatever they can deliver it's superb. The children get excellent services. But I have a young lady I've worked with now for 25 years who is an OT. And her average driving a year, just to see her patients is 55,000. She has a trunk, thank goodness they make a big Buick, she puts all the stuff in it, and she heads out to the road. She's out on the farm, she's out in the rural areas. She can only go so long. So I think there we have a major issue. And I'm sure the ESUs would comment on this and the school systems. As much as they can give their professionals, they will give top flight service. But it's staffing, which is going to be an issue in any of these. [LR283]

SENATOR ADAMS: Thank you. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: To follow up with Senator Adams' question then, you had said several times the schools are doing a great job in this area. But would that go so...are schools are differently providing services, or metropolitan areas doing a, I would say a better job, but how do we address that? Are they teaming up and how do they provide all these services that you say they're doing such a good job with? [LR283]

DR. BRUCE BUEHLER: Well, I will say two things. The metropolitan area is a different system because you have school districts who essentially create their own programs and have the personnel necessary, in most cases, to deliver. That's one system and that works well in Lincoln and it works well in Omaha. When you get west of Lincoln, now you're looking a the ESUs and the local school districts. And I am always surprised and amazed at the amount of resources that these counties put into their schools to develop equivalent programs. But they use the ESU because the ESU can give them an OT or a PT, if they couldn't hire themselves, on a full-time basis. And so I think the western part of the state had adapted immensely well to the large spaces to cover. The metropolitan schools have one major issue and that's transportation. Even though we're in a single unit, getting kids to the school is touch. Whereas on the western side, an awful lot of the families they just know they're going to have to bring the child in, or the school has already figured out a system. So I would say if you were to try to do a comparison across the state, you would find very little difference other than the number of professionals available. I think that's where we run into problems. When I go out to Imperial, or Ogallala, and I'm working in those areas, one of the things I always ask is, if I recommend five days a week of speech, could anybody do that? They've got one (laugh) speech pathologist, she's going to do five days a week with that child and nobody else. So you have to be realistic. On the other hand, we know from our own data that the number one caregiver in the school setting is the parent. So you train them, and they learn how to do what you could do with their child, and they give the care. And that I find exceptional in this state. Families take on the responsibility, they do the physical therapy, they do the occupational therapy, they work with them. [LR283]

SENATOR GAY: Okay. [LR283]

SENATOR LATHROP: Any other questions? I do want to follow-up on those, because I'm listening to you say that in Nebraska we do very well right up to age 21, and then there's a cliff. You've also...so let me talk just about the school age kids, if I can or those that are...that get services because the schools have a duty to provide that service. [LR283]

DR. BRUCE BUEHLER: Sure. [LR283]

SENATOR LATHROP: You said that we are...that we don't have as many speech pathologists, for example, out in greater Nebraska as we do in Omaha. Notwithstanding that, are we still doing a good job for those school age kids? Is that the point you were making? [LR283]

DR. BRUCE BUEHLER: Yeah. I think the fairness here is that the philosophy as you go farther into greater Nebraska is the parent is an active caregiver. And so a speech pathologist may come up only once a month, but they're going to go over that child with you, show you how to do it, if by chance we can have both family members there...many of my therapists will go at night or on weekends. And what they do is make the family, the caregiver, with the right knowledge. So it's a practical way to approach it. We did a study several years ago looking at how much physical therapy a child needs. And once a day, once a week, once a month, the outcome was essentially how much the parents did. [LR283]

SENATOR LATHROP: So if they have to go through range of motion, you can teach a parent to do a range of motion where that... [LR283]

DR. BRUCE BUEHLER: Exactly, and the parent will actively do it. And they've got 16, 18, 24 hours to do it. I have them do it while the child is bathing, or when the child is relaxed, or just before they go to bed. I can't get a therapist, obviously, to come and do that. So a lot of it is giving you the services, but also expecting and I think getting parental involvement, which is critical. [LR283]

SENATOR LATHROP: If we take that period of time after the cliff, child gets to 21 years, is your opinion still the same that out in west of Lincoln that the services are still adequate to meet the needs of that community, that developmental disability community? [LR283]

DR. BRUCE BUEHLER: It gets much more sparse for reasons of settings. You know, you've got to have a job, a vocational program, you've got to have a community support, you've got to have probably a group home nearby, or someway, or the families have to be able to transport or get transport. There isn't as dictated a treatment plan as there are through the schools. It's very set, we know what it is. So I would say organizationally maybe the biggest issue, but on the other hand, there are many superb group homes, superb activities for individuals. And I don't mean activities, I mean jobs, reasonable and relevant jobs. But it's probably not sufficient for the population that's aging. I think doctors have done a good job in longevity, but that will include our population. And we have to be ready for that. [LR283]

SENATOR LATHROP: Okay. So let me go back to my question, if I can. And that is, do we see a difference then in the resources that are available to a 30-year-old man with special needs that's in Omaha versus the same person or a contemporary in Scottsbluff, or Imperial, or Ogallala? [LR283]

DR. BRUCE BUEHLER: I would say in general we find the same lack of sufficient services in both settings. They're not there, not intentionally, it's just very difficult to provide in those settings. [LR283]

SENATOR LATHROP: All right, thank you. Any other questions? Seeing none, thank you very much for coming down today. It's very helpful. [LR283]

DR. BRUCE BUEHLER: My pleasure. [LR283]

SENATOR LATHROP: Our next witness is going to be Bruce Mason. And that will take us really to the second piece or the second item on our agenda, which is the legal requirements the state has with respect to care for the developmentally disabled. You've filled out a sheet? [LR283]

BRUCE MASON: Yes, I have, Mr. Chairman. [LR283]

SENATOR LATHROP: All right. You can set it in the box there, that would be great. And if you could start with your name, spell your last name for us, and give us your address, we'll have you share some information with us. [LR283]

BRUCE MASON: It's Bruce Mason, M-a-s-o-n. I am the litigation director for Nebraska Advocacy Services, located in Lincoln, Nebraska, on 13th and N Street. I have been a practicing attorney specializing in representing individuals with disabilities and their families for longer than I would like to announce publicly, some 35 years or so. And I would...want to thank the Chairman and members of this committee for this opportunity to discuss matters that I consider of extreme importance for our citizens who are developmentally disabled and their family members. And with a significant amount of humility, I hope I can aid you in this significant endeavor. Let me start off by giving a brief story. Over three decades ago, in 1972, a much younger lawyer with a lot more hair, just two years out of law school met with parents who...and family members who had family members at the Beatrice state home, back in 1972, and who pleaded with him to help them with the conditions at the home. Their stories of staff shortages, neglect, lack of meaningful treatment programs, unexplained injuries suffered by their sons and daughters gave him little chance to refuse their pleas. They had at that time lost hope and felt abandoned by state officials, back in 1972, who were responsible for the care of their sons and daughters. That young lawyer, on September 28, 1972, some dates you never forget, filed a class action premised upon the legal argument that the due process clause the Fourteenth Amendment protected those at Beatrice from physical and psychological harm. And that if they were going to be confined there in the custody of the state and deprived of their liberty, they must receive treatment. In 1972, at the time that that class action for residents at the Beatrice state home was filed, that was literally an argument of first impression in this country. It had been accepted only by one other federal judge, and that was what they call a mountain Republic judge in the northern district of Alabama, Frank Johnson, who would later head up the FBI, who had ruled in a case, Wyatt v. Stickney, that persons confined in a mental institution with mental retardation had a constitutional right to treatment. And he was in the process of formulating the extent and the parameters of that treatment. Well, this young lawyer, back in 1972, with the assistance of the newly formed section of the Office of Special Litigation within the Civil Rights Division of the Department of Justice, they reached an agreement, in Horacek v. Exon, with Nebraska's Attorney General, then Paul Douglas, and Governor James Exon's private attorney, Norman Krivosha, who would later become the Chief Justice of the Nebraska Supreme Court. And this settlement agreement was approved on October 31, 1975, by United States District Court Judge Albert Shatz, in consent decree. That consent decree recognized the constitutional rights of the citizens at Beatrice to be protected from physical harm and psychological harm, and to have a right to treatment or the term of art is habilitation with individuals with developmental disabilities. More than, you know, three decades later, that same lawyer, now older, thinner on top, and thicker in the middle, appears before this committee that has an opportunity to finally fulfill completely that promise that was made by state officials in 1975. So as that the citizens at the Beatrice State Developmental Center will have their full constitutional rights protected. What was a novel and innovative proposition in 1972 and 1975 is now, in 2008, settled constitutional law, not subject to question. And those mandates of that constitutional law are unequivocal and inescapable for the state of Nebraska. The state is clearly obligated, constitutionally obligated to protect its citizens at Beatrice under the clear mandates of the Fourteenth Amendment, to protect them from physical harm, psychological harm, unnecessary restraint, and that restraint means both physical restraint, and chemical restraint, or the use of psychotropic drugs, and neglect, and to provide them with treatment or habilitation consonant with their individual needs. There is no exception to this clarion call of these constitutional mandates for the state of Nebraska which resonates from the pronouncements of recent United States Supreme Court decisions, as early as 1982. Hopefully that I and esteemed counsel, Ms. Jodi Fenner for Health and Human Services, will not bore this committee with the nuances and subtleties of constitutional law, but we'll attempt to give a general framework or outline so that you can understand the three primary duties that impact on the individuals that reside at the Beatrice state home and the duties that Nebraska assumes when a person with a developmental disability enters the gates at the Beatrice State Developmental Center to live. The first and primary most important duty, and it's not really...requires rocket science, is the duty of protection. That's the easiest way to say it. I mean if you consider one of the seminal amendments of this government, which is the Fourteenth Amendment, enacted as a result of the Civil War, it's the duty of protection, equal protection. The United States Supreme Court, in 1982, in Youngberg v. Romeo, placed its constitutional imprimatur, its approval on that argument that was raised in Nebraska in 1972. The persons...and they held that persons with a developmental disability who reside in state facilities, such as Beatrice State Developmental Center, have a constitutionally protected liberty interest in safety. The court further held that the state has an unquestioned duty to provide reasonable safety for all of the residents within the institution. Included within the meaning of that duty of protection of reasonable safety, the residents must be protected from unreasonable restraints, as I said before. And that includes chemical and mechanical. And also within this umbrella of this duty to provide reasonable safety, the state must provide medical care, appropriate, adequate medical care, food, shelter. And furthermore within this duty to protect they...the state of Nebraska and its officials must provide reasonable safety so that the person that lives there is not verbally assaulted, physically assaulted, abused, humiliated, or his medical and psychological needs ignored. Our own state statute, 83-1202(8), echoes that primary responsibility of protection. And the clear intent of this body is unequivocal in that. And I quote from that section, the first priority of the state in responding to the needs of persons with developmental disabilities should be to ensure that all such persons have sufficient food, housing, clothing, medical care, protection for abuse or neglect, and protection from harm. This is an affirmative duty. And this affirmative duty, I submit to this committee, is very significant. It's an affirmative duty and an entitlement that individuals with developmental disabilities that reside at the Beatrice State Developmental Center have. And it's enforced by a federal court because of that special relationship that the courts have recognized between the state and a vulnerable person with developmental disabilities. We must remember, generally, federal courts have held that the constitution is a negative charter. It only requires the states to refrain from acting. This, on the other hand, is at the other spectrum and says, there is now an affirmative duty to protect. And this affirmative duty arises under the constitution and that special relationship that is created when the state assumes total custody and control of an individual that is vulnerable and has a developmental disability. This affirmative duty received its, once again, judicial blessing from former Chief Justice Rehnquist in DeShaney v. Winnebago County Department of Social Services that explained that affirmative duty arising. It's very simple that when an individual's liberty is restrained, or his or her freedom of action is restricted, that restriction of an individual's freedom of action, which occurs in an institutional setting such as placement at Beatrice, that triggers the liberty clause of the due process. So, therefore, the second prong of that special relationship or that duty to protect arises from a very fundamental concept in the law that when the state, by its officials, place a vulnerable person, such as at Beatrice State Developmental Center, in danger of physical or psychological harm because of inadequate staffing, inadequate training, or inadequate supervision, that that duty to protect is breached. So it's the inadequacies or the neglect that in fact places the vulnerable person in a more vulnerable position that creates the duty, the second constitutional leg or constitutional right. And by the way, I should add also that the restatement of torts, Sections 3-14, 3-19, also, which is well established, also well recognizes the special relationship that when you take custody of a person, that you therefore create a duty to care appropriately. And that if you fail that duty, either by omission or commission, that in fact you're responsible for the consequences. So the special relationship really encompasses and sort of adds depth to the constitutional duty of protection. The second primary duty that the state assumes for those individuals that reside at the Beatrice State Developmental Center is that those individuals must receive training or habilitation or treatment. The United States Supreme Court, in the Youngberg case, addressed that in 1982 and agreed when they said, persons with developmental disabilities have a constitutional right to minimally adequate training. Specifically the minimally adequate training, the court acknowledged, required by the constitution is such training as may be reasonable in the light of the institutionalized person's liberty interest and safety and freedom from unreasonable restraints. That's a mouthful. Essentially what it means is that the essential component of habilitation really, or treatment, for a person with developmental disabilities is a regular systematic provision of activities, programs designed to help them to develop new skills, and maintain skills that they've already learned. That may go from the gamut of self-help skills that we would...we have all seen. And for those of us that have had children and raised them, from learning how to dress, toilet, teeth brushing, feeding, all the way up to more refined skills. But it's the gamut, because every individual at Beatrice Developmental Center has the ability to have some level of skills. Therein lies what the treatment must focus on that individual ability to develop those skills to the best possible extent. And the test, and this is not an impossible task that the courts place on the facility or state officials, such as at BSDC, but the test is whether or not those officials, those individuals at BSDC have provided adequate minimal levels of constitutionally required care depends on if, and this is the crucial element and this is really important, on if that facility's practices substantially depart from generally accepted professional judgment. If the facility's practices substantially depart from generally accepted professional judgment. That's the Youngberg court speaking. How do we achieve evidence that those practices either comport with or depart from, you know, professional...a substantial departure from accepted professional standards? We find that neither the opinion of other qualified experts, or violations of national regulatory standards or guidelines. So either similarly situated experts say, in my opinion this is improper and this is a substantial departure, or guidelines. Regulatory standards in fact set out the professionally accepted standard or care. And I'm sure that every member on this committee has had at least a passing knowledge of the Centers for Medicare and Medicaid Services volumes of reports that have in fact come in and surveyed the facility at Beatrice. Those are the national standards that determine professionally accepted standards of care. All right? Because it's an ICF/MR, which simply means an Immediate Care Facility for individuals with Mental Retardation. So therefore what are those standards? That...those standards give us the road map, they give us the blue print to say, are you meeting the standard of either protecting the residents from harm, or are you meeting the blueprint for treating them and habilitating them? Okay, they set up standards to provide adequate staffing levels, and to ensure the provision of active treatment. It's very important because those standards require active treatment to reduce dependence upon drugs and physical restraints. As Dr. Buehler commented on earlier that behavior management is a crucial component in order to shape behavior that's appropriate and desirable. And those behavior management programs are an essential element of that. In particular the CMS standards found, for those that have an interest in the arcane, 42 C.F.R. 483.420(a)(5), and only the federal regulation can go on and on, requires that the facility ensure that clients are not subjected to physical, verbal, sexual, psychological abuse. They also require the facilities to provide sufficient direct care staff to manage and supervise the residents to ensure that the clients are provided active treatment to reduce dependency on drugs and treatment. Adequate staffing becomes crucial. Now the third and most recent duty of the tripartite duty that the state of Nebraska assumes when an individual goes into the facility is the duty of integration, inclusion, or it's referred to often as the integration mandate. And that arises not from the constitution as much as from the federal Americans With Disabilities Act of 1990, the ADA. State simply, Justice Ginsburg, of the United States Supreme Court, in 1999 in Olmstead v. L.C., held that undue institutionalization of confinement of persons with mental disabilities, as Dr. Buehler said mental disabilities is a legal term, qualifies as prohibited discrimination by reason of a disability under the public service portion, or Title II of the ADA. What does all that mean? Justice Ginsburg noted the extensive history of isolation and continued segregation of persons with disabilities and recognized that unjustified institutionalization is a form of isolation that is a prohibited discrimination for the reasons as follows, first,... [LR283]

(EQUIPMENT MALFUNCTION -- SOME RECORDING MAY HAVE BEEN LOST) [LR283]

SENATOR LATHROP: We have the audio part all worked out, so we're ready to continue with the testimony of Mr. Mason. [LR283]

BRUCE MASON: Thank you, Mr. Chairman, members of the committee. I was discussing what Justice Ginsburg had written in the Olmstead decision, that unjustified institutionalization and isolation is a form of discrimination. And she really based that conclusion in violation of the ADA upon two primary reasons, and that's first that continued institutional placement of persons who can handle...and the operative words are "who can handle and benefit" from community settings perpetuates unwarranted and stigmatizing assumptions that the person so isolated are incapable or unworthy or...of participating in a community life. This is clearly analogous to discrimination based upon racial or sexual stereotypes that's prohibited by law. Secondly, her other reason was that confinement in an institution, a total institution such as Beatrice State Developmental Center, severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment. What all this means, the bottom line for the state of Nebraska, is that the state with its professionals must conduct reasonable assessments in determining whether a person at Beatrice is either, one, able to handle or, two, can benefit from community settings. If, based upon that assessment and that answer to either one or two is yes, that resident is a qualified individual within the meaning of the ADA, and the duty to integrate him or her in the community arises. Now this duty to integrate...yes. [LR283]

SENATOR LATHROP: Can I interrupt you just a second? Pull that mike a little bit closer and then I'll ask you to speak up just a little bit more so everyone can hear. Not everybody can. [LR283]

BRUCE MASON: Okay. [LR283]

SENATOR LATHROP: All right? Thanks. [LR283]

BRUCE MASON: So this duty to integrate has an additional qualification under the federal regulations and this becomes important because this clouds that clear mandate somewhat, and it also puts state officials in somewhat of a conundrum, and let's talk about that briefly. And that federal regulation found at 28 C.F.R. 35.130(9)(e)(1) 1998 reads: Nothing in this part shall be construed to require an individual with a disability to accept an accommodation which such individual chooses not to accept. The regulations further read that persons with disabilities must be provided with the option of declining to accept the particular accommodation, and what those regulations mean by "accommodation" is placement in the community setting. So that...those regulations impact somewhat on the duty to integrate in that they have an option of declining. So here's the problem the state faces as they attempt to implement this duty to integrate. Most of the residents at the Beatrice State Developmental Center have guardians that have been appointed by the respective county courts throughout the state of Nebraska. Many of those residents are unable to articulate/express their desire to live in a community. Many have been there for decades, 20, 30, 40 years. So what happens when a guardian objects to the placement of an individual that the state officials and professionals have assessed as either can benefit from or can handle community setting? So the simple question is then posed: May the opposition by a guardian to community placement of a resident who, in the assessment of the state's professionals, can handle or benefit by placement in the community circumvent or thwart the integration mandate of the ADA? That's the crucial question and the answer is a qualified "no." And I suggest, respectfully suggest, that it's a qualified "no" because a guardian's desire or wish is a significant and important factor, but it is not the sole controlling factor that would determine the ultimate placement of that individual to fulfill the integration mandate of the ADA. Ironically, we, in the lawyers that drafted the consent decree back in 1975, in Horacek v. Exon, anticipated this very problem. And Sections 21 and 22 in the Horacek settlement agreement consent decree really provide, like Ariadne's thread, a way out of this labyrinth for you, being Phaestus, to mix my mythology here. Because those sections of the agreement establish procedures and a hearing process which met the constitutional due process requirements for community placements of an individual qualified, and whose guardian or family member objected. These sections of that agreement entered into with the state...by the state in 1975 no longer...it has lapsed, but they become relevant and germane to the current problem that state officials face as they attempt to place people that are qualified into the community and meet the integration mandate. Let me read that Section 22 because I think it's highly pertinent to the discussion at hand: Objections by parents or legal guardians shall not be used to preclude placement of any member of the class in any program or facility which is indicated by proper evaluations to be in the therapeutic interests of such member of the class. A hearing which meets the basic standards of due process, as defined herein, shall be held to ensure that such objecting views of parents and guardians are heard and that the placement to be made is in the best interests of the members of the class, commensurate with his or her needs and his constitutional rights to receive adequate care and habilitation in the setting least restrictive of his personal liberty. Section 21 defines the basic standards of due process as: a due process hearing shall include a clear and concise, understandable notice to the person with the developmental disability and his parents or legal guardian of the hearing, and at least...at least two weeks prior to the hearing to determine placement out of the facility; (b) Appointment of competent counsel to represent the person with the developmental disability; (c) the presence of the person with the developmental disability and the guardian or parent at the hearing; the presentation of clinical evidence in either support of the decision to place out or to retain in; (e) the opportunity to cross-examine all witnesses and present evidence; (f) findings in writing on the basis of clear and convincing evidence; and (g) the right to judicial review of that decision. Therein lies the ability to finally resolve this issue of that the guardian, in and of themselves or herself or himself, should not be able to obstruct/impede the constitutional mandate of the Americans with Disabilities Act for that individual that's a qualified...qualified meaning can benefit from or can handle community placement. So in conclusion, those individuals or persons that are citizens who live at the Beatrice State Developmental Center have a judicially enforceable right or entitlement from the state of Nebraska. This entitlement is to be protected from physical/psychological harm; to be free from unnecessary restraints, either chemic or physical; to be protected from abuse, physic or verbal; and to be provided with appropriate medical care and not neglected. Second: to receive active treatment or habilitation based on their individual needs with the appropriate and accurate assessment of their needs, the development of programs by professionals and staff, which are implemented by adequate numbers of appropriately trained and supervised staff members. And finally third: to be integrated in community settings if either, after assessment, they are deemed either able to handle or to benefit from those community programs, and due process hearings have been held if in fact guardians object to the recommendations for community placement. Finally, I would like to thank the Chair and the committee for this opportunity to discuss. I truly apologize if I've stayed too long on a matter which has occupied over, you know, 35 years of my professional life as a civil rights lawyer in the state of Nebraska. And if there's any questions, I'm more than willing to attempt to try to answer them. [LR283]

SENATOR LATHROP: Very good. Senator Harms. [LR283]

SENATOR HARMS: Thank you very much for coming. I appreciate you bringing your expertise to us. Since 1972 to now, I'm sure you probably have read the different reports that we've had and the issues we've had at Beatrice. [LR283]

BRUCE MASON: Yes, sir. [LR283]

SENATOR HARMS: It's pretty clear to me that we have been...and I'm no attorney, but just reading this last report it's pretty clear to me that we're in violation of an awful lot of things that you've just brought up, and there's an awful lot of liability laying out there in regard to this center and what's occurred. Because if the report is accurate, it's very clear to me that that's a major issue that we ought to be concerned about here. [LR283]

BRUCE MASON: I would agree. I also was one of the primary authors of our report which preceded the report by the Department of Justice, in December of '07 we issued that report, and there is no question about it. And, to be honest with you, Senator, and I'm going to steal a line from a singer that I have followed throughout the years, that you...Bob Dylan, you don't need to be a weatherman to know which way the wind's blowing, and that's absolutely right. There's no question about that. And it is not that there is malevolent individuals there but the problems that have existed have existed over a period of time and we've engaged in a dance. CMS comes in, they evaluate and they find fault, they find inadequacies; a plan is developed, they go away. And they come back and say, you promised to do it, you promised to do it, but it wasn't done and now you're in violation. This has gone on. I mean the issues that I dealt with in 1972 have resurfaced like the Phoenix from the ashes of that consent decree in 2007-2008. [LR283]

SENATOR HARMS: Well, thank you very much. That was my observations and, you know, quite honestly, as I look at it, it's truly an embarrassment and I think it's time to fix this thing. Thank you. [LR283]

SENATOR LATHROP: Senator Adams. [LR283]

SENATOR ADAMS: The criterion that you were talking about earlier that applied to Beatrice, we heard in earlier testimony, as I'm sure you did, too, that from 0 to 21 the schools are dealing with a lot of this. Do these same kind of legal requirements and responsibilities fall on the school that fall on state institutions such as Beatrice? [LR283]

BRUCE MASON: With the passage of the Education of all the Handicapped Children, later to be turned into the Individual (sic) with Disability (sic) Education Act, which is the mandate of special education, there are obligations that fall within the state or within the school districts. An example: a school district is obligated to provide a free and appropriate education to an individual with a disability under IDEA, I-D-E-A--it's now been changed but for the purposes of this discussion. That's up through the age that Dr. Buehler testified to earlier. And if they can't provide that in the school setting then they must provide it in an alternative setting, and the state of Nebraska funds that federal mandate also and assists the school district. So at one time there were individuals that were of school age at the Beatrice State Developmental Center. Instead of their going into the Beatrice school system, which would be where BSDC is located, they would be educated in a segregated setting on the grounds of a school even though they should have been educated the Beatrice School District, paid for by the Millard School District if they felt they couldn't handle it. Now I don't know if I've answered your question. I'll go back to it and try it again if I haven't fully answered it. [LR283]

SENATOR ADAMS: No, I think you have, but I guess I was wondering, too, more specifically, you talked about the protection, the safety, those kinds of things. I'm assuming that the schools are held to some equivalent standard. [LR283]

BRUCE MASON: Somewhat equivalent. The reason that there is a distinguishing characteristic in the case law that's developed is that they, the courts, have in fact said that you don't have full total custody of the person. It's that custodial confinement that triggers the special relationship and also triggers some of the constitutional obligations under the Fourteenth Amendment liberty clause. So schools don't have total confinement of the individual. Now ordinary negligence standards--you should have known, you didn't act when you, you know, you should have acted--that commission/omission would apply, but not constitutional standards. However, those programs in the community that provide residential 24-hour service, in fact, those constitutional requirements would attach to those individuals that are in those programs. [LR283]

SENATOR ADAMS: Thank you. [LR283]

SENATOR LATHROP: Senator Wallman. [LR283]

SENATOR WALLMAN: Thank you, Chairman. Yes, Bruce, are we under the same obligation? Say we place a client or resident in community-based and the community-based is not doing the job, and that person gets abused or hurt. Are we at risk there too? [LR283]

BRUCE MASON: It would be my position, and I think the law would support that, yes, if, in fact, you place that person in a residential setting within the community, because that, you know, you cannot contract away your responsibility. And one of the...you know, the Achilles' heel of all of this and that you folks in this committee are somehow, in your Solomonlike wisdom, are going to have to deal with, and I don't know, is the fact that we have developed a dual system of care instead of a unitary system of care. So we have Beatrice component here and then we have the community programs, like they're separate universes. What should be simply developed is a unitary system from cradle to grave based and each according to his or her needs, and where there's a spectrum, where each one has a role and a part based upon the evaluation needs assessment of that individual as they progress through their lifetime. And I know this is a major concern for parents that take, you know, their responsibility to raise their son and daughter with a disability in their home and to keep them there. As they start to age, as the inevitability of that process goes on, what am I going to do to Billy, to Susie when I'm gone; what's going to happen; where is that? And because of the hodgepodge mosaic that we've woven, instead of the unitary system, that we can't answer that effectively and that creates uncertainty and we fail to meet our obligation as government, which is the primary obligation, as you well know, to protect those that can least protect themselves. [LR283]

SENATOR WALLMAN: And on this assessment issue, who is all involved in that? Just state officials? The doctors? The local regional centers? How do we say it's misdiagnosed or something? You know, somebody has to come back and we have a waiting list to get in there. Who assesses all of those? [LR283]

BRUCE MASON: You know, that's a great question and we back in '72 attempted to address that by having individuals representing the community services, representing the state, and parents, and professionals from the university that would be considered not involved in the process, those, that was the assessment component so that there would be an objective standard developed so that nobody could say, you know, just the state's officials are doing an inadequate job or the community people are doing it in such a way because they don't want to take...they only want to take the high draft choices, the blue chipper, so to speak, you know, the five-star recruits; you know, they don't want to take the walk-on that causes problems, to use that football analogy. So that's really crucial. That assessment process can be done and is really the heart and soul, the foundation of the overall development of this unitary system. [LR283]

SENATOR WALLMAN: Thank you. [LR283]

SENATOR LATHROP: Senator Cornett. [LR283]

SENATOR CORNETT: The trend currently is to move to community-based, basically, and that's what we've been hearing, that a lot of these people need to be moved to community-based residential care. When you talk about one system, are you talking about a state managed system from birth to grave, basically? Or are you talking about combining services with the private sector, as we currently are? When you talk about one system, how would you achieve that? [LR283]

BRUCE MASON: What I'm talking about...and that's an excellent question, Senator, because it sounds a little bit socialistic and it wasn't meant to be socialistic at all because I'm quite the opposite part of that spectrum. But what I meant was that was a coordination, the belief, the paradigm that it would a unitary system based upon the individual's needs and abilities, as those needs and abilities change, involving private, for-profit, not-for-profit, state contracting, but where the rights would flow with the individual, the services would flow with the individual there. It would be... [LR283]

SENATOR CORNETT: Okay. (Inaudible) [LR283]

BRUCE MASON: It would be coordinated. There would be a plan. [LR283]

SENATOR CORNETT: That's not the way it sounded originally. (Laugh) [LR283]

BRUCE MASON: And I apologize. I did not articulate it very well and I didn't want to mislead the committee. But it is...and I use that term "unitary" because Beatrice has a component part. Even the regional centers, the Lincoln Regional Center, they all have a component part. We now heard Dr. Buehler and I think you asked the question, rightly so, what about this individual that has this mental illness that developmental disability services say, well, no, this is a mental illness, this is this, and they get shuffled back and forth? You know, it's like the "SODDI" defense--some other dude did it. You know, that's what we're trying to avoid, that, so that it's not the label that's important, it's the assessment. [LR283]

SENATOR CORNETT: The assessment. [LR283]

BRUCE MASON: And then we can plug in the services along the road. [LR283]

SENATOR CORNETT: When you talked about that even if we are moving to community-based services, that doesn't...the contractual agreement does not remove the liability of the state. Correct? [LR283]

BRUCE MASON: If, in fact, the state exercises some degree of supervision and requires certain standards to be met, yes. And I can say that because as...in my past, one, I was general counsel for one of the community programs, ENCOR, which is up in Region VI and encompasses the Dodge, Washington, Sarpy, Cass, Douglas area, and in fact there was still a state obligation. It's just not a question of handing over bucks and saying... [LR283]

SENATOR CORNETT: Okay. [LR283]

BRUCE MASON: ...do something. [LR283]

SENATOR CORNETT: So just to clarify, that if the state contracts with the private provider, that certain standards must be met under that contractual obligation, otherwise the state is...can be liable. [LR283]

BRUCE MASON: Right. If they fail... [LR283]

SENATOR CORNETT: Okay, that's... [LR283]

BRUCE MASON: ...to supervise that the contract is being implemented appropriate, which means protecting the individuals that are the third-party beneficiaries,... [LR283]

SENATOR CORNETT: Uh-huh. [LR283]

BRUCE MASON: ...to wit, the individuals with the developmental disabilities. [LR283]

SENATOR CORNETT: One of the things that we have...I don't know about the rest of the committee, but have heard from a number of parents are that this brings back the issue of the parents' objections are not necessarily taken into account if the child needs to be moved or the adult needs to be moved to different services: We don't want our child moved; we like them where they're at. And I've heard it from both sides, from people at Beatrice and from Health and Human Services, that they don't feel that they can move people or...because of...or they're going to go ahead and move them even with the objections of the parents. Where does the individual come into play and their wishes? There was one group of people that I met while we were at Beatrice that had been in the same room together, three of them, for a number of years and the parents have requested that if they are outsourced that they are moved together. At what...who is taking into account, besides the parents and what the state wants, what the individual wants? These people have been together for the majority of their lives. Separating them would be very traumatic at this point. [LR283]

BRUCE MASON: Right. Right now, with all due respect, no one is taking that into account. Under the suggestions that I outlined that we initiated back in '72, a person would be appointed to represent that sole person, just like in juvenile court, just like in divorce cases. [LR283]

SENATOR CORNETT: A guardian ad litem? [LR283]

BRUCE MASON: And very much a guardian ad litem that the whole purpose, the whole focus of that representation is what's in this person's best interest. [LR283]

SENATOR CORNETT: Because some of these people are at a higher functioning IQ, whether they have behavioral disorders or not, they know what they want and that may not be what the state wants, that may not be what the community-based program wants, and it may not be what the parent wants. But there seems to be a component missing. [LR283]

BRUCE MASON: And that's why the procedure that I recommended that we did was successful. As individuals were placed into the community out of BSDC back in the seventies, under the provisions of the consent decree, there was a mechanism where guardians and parents could object, their wishes could be heard, and yet the interest of the individual could also be represented solely and that there was an opportunity to have a hearing on this. And it doesn't have to be a full-blown trial. [LR283]

SENATOR CORNETT: What happened to that? [LR283]

BRUCE MASON: Well,... [LR283]

SENATOR CORNETT: When did that go away? [LR283]

BRUCE MASON: The consent decree... [LR283]

SENATOR CORNETT: Expired? [LR283]

BRUCE MASON: ...only has a limited life. [LR283]

SENATOR CORNETT: Right, it expired. [LR283]

BRUCE MASON: It had about ten years, ten-year life, and it expired. [LR283]

SENATOR CORNETT: And the consent decree was not renewed and nothing... [LR283]

BRUCE MASON: Yeah, that's right. [LR283]

SENATOR CORNETT: And that process was let to lapse. [LR283]

BRUCE MASON: Yes. And in perhaps looking back, as historians are often...have the benefit of looking back, maybe there should have been efforts to continue that. Because apparently the same problems that existed that precipitated the filings exist in 2006 and '07 and '08 that suggest... [LR283]

SENATOR CORNETT: When did the decree lapse? [LR283]

BRUCE MASON: Oh, don't ask me hard questions, okay? I think it was '85, I want to say, about '85, 1985. [LR283]

SENATOR CORNETT: And it took approximately ten years to revert back to where we were in total, to where it's brought attention to itself. [LR283]

BRUCE MASON: Yeah. I don't think it...I think it probably reverted back more quickly but, you know, therein lies one of the problems of a facility, that sunshine oftentimes takes a longer time to get in because there's less access of individuals and people in that. And there were some CMS reports in the nineties that suggest that there were problems but not to the full extent that we have now documented in 2005, '06 and '07. [LR283]

SENATOR CORNETT: Thank you. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: Thank you. This is just a follow-up to Senator Cornett's questions. So we had a mechanism to look out for the patient here, but are other states? Do they have some kind of mechanism like this? Because the guardians are, you know, if they...what you said, they can't make that decision, it's not their right to make a decision, are other states have a hearing process like this or are we unique? Are we the only state that's dealing with this? I can't imagine we are. [LR283]

BRUCE MASON: No, we're...Senator... [LR283]

SENATOR GAY: So what are the other states doing then? [LR283]

BRUCE MASON: In answer to your question, I think what's important to understand is that the guardian has a significant...their wishes should be very significant. They're responsible under the law. The law recognizes the guardian can choose certain medical treatments and certain courses of action to help or hinder the person; however, they should not be the sole factor. That's what I'm suggesting. They should be one factor in a myriad of other factors that are considered, all focused and try to narrow in on what's the needs for this individual here. And so that aspect, I wanted to clarify that; that I'm not saying they should be disregarded. I think that the law would say otherwise. Other states have done that and other states have implemented a similar-type hearing process. During the great bulk of the deinstitutionalization process in this country, which would have been in the mid-seventies to the early eighties, there were a significant number of hearings. Now facilities have generally, in recent time, attrited out, if you want to use a word like that, in the sense that the focus is not because there is not a placement in; populations are aging and facilities are in fact shutting their doors because of the simple fact that, you know, there isn't an increase in population. It's becoming cost-ineffective to have a massive facility unless you're going to use it for some other reason. So other states have utilized these hearings and these hearings work. They're just basic due process, you know, that comports with it. Health and Human Services has their own procedure, a similar due process hearing for someone that's denied services, that they contend they should either have more services or some services, that are on the waiting list, and these are administrative hearings. We're not...I am not a very bright individual. I can't...I steal ideas like, you know, I'm an engineer. I take this idea from this state and that. I don't have the ability to create innovation like that, but I do have the ability to go to other states and see what other states are doing, and that has been successful. [LR283]

SENATOR LATHROP: I do have some things I'd like to clarify with you, if I can. You told us that in 1972 you represented folks that lived at Beatrice... [LR283]

BRUCE MASON: Right. [LR283]

SENATOR LATHROP: ...in a class action against the state of Nebraska and that was in a lawsuit filed, wherein Jim Exon was the defendant. [LR283]

BRUCE MASON: One of the defendants, yes. [LR283]

SENATOR LATHROP: That resulted in a consent decree in 1975,... [LR283]

BRUCE MASON: Right. [LR283]

SENATOR LATHROP: ...which remained in force for at least ten years. [LR283]

BRUCE MASON: I believe, and don't hold my feet to the fire on ten years. It was about ten years, I believe. [LR283]

SENATOR LATHROP: At that point in time, the consent decree is dismissed and the terms of that were no longer controlling. [LR283]

BRUCE MASON: That's correct. [LR283]

SENATOR LATHROP: Your hearing process, the due process out of paragraph 22 that you described from the consent decree, is not the law in Nebraska, but that is your suggestion for a way out of what you described as a conundrum. [LR283]

BRUCE MASON: Yes, that is, Mr. Chairman. [LR283]

SENATOR LATHROP: Which is the competing interests between having integration, on the one hand, which is required by the ADA, and the wants of the patient or the resident, rather, and the...or the guardian of that resident. [LR283]

BRUCE MASON: That is correct. [LR283]

SENATOR LATHROP: Do you have a judgment, a legal judgment, not just an opinion but a legal judgment as to what weight the state must give the judgment or the opinion of a guardian or a parent or the patient or resident for that matter? Is there a weight where we say that's 90 percent of the consideration or it's 60 percent? Do reported cases give us the weight to provide or to apply to the judgment of the guardian? [LR283]

BRUCE MASON: The standard that would be utilized in a county court proceeding as to that the action of the guardian was antithetical to the interests of the ward, and those are legal terms, would be an abuse of discretion; that it would be not based upon the best interests of the ward. That's the same standard, best interests of the ward, that juvenile court uses--the best interests of the juvenile. That is a flexible, case-specific, factual-specific standard. So I would say that clearly the law would require the actors, the state actors, to give deference to the guardian's wishes unless the guardian, in face of the professional's opinion, unequivocally said this person can benefit/thrive in a community setting and needs to be placed out. At that time, then in fact the guardian is no longer acting in the best interests of that individual and, therefore, placement into a community setting would be appropriate. [LR283]

SENATOR LATHROP: And I suspect this is going to be an important consideration as we move through this process so I want to ask a follow-up question, or make sure I understand it, and that would be we would, in the first instance, give deference to the judgment of the guardian unless we could establish by clear and convincing evidence that the guardian is abusing their discretion or judgment and not observing the best interests of the ward or the protected person. [LR283]

BRUCE MASON: Yes, except I would go into the intermediate step. How would we determine that that is an abuse of discretion would be that the professionals, both in the community and in the state facility, have assessed the individual and that the individual's wishes, if those wishes are able to be communicated, and he or she has represented that it's the considered judgment of the professionals that placement in this facility--Beatrice--is no longer appropriate for that individual and is not in his best interests. So it's a collective decision. [LR283]

SENATOR LATHROP: But as a lawyer, you recognize, you use the term abuse of discretion, also a legal phrase. Not...there's volumes of case law that are on what abuse of discretion means. That's a very difficult standard to overcome, would you agree? [LR283]

BRUCE MASON: I would agree and I think that's why it's imperative that the state give at least a certain deference to it, but not to surrender their obligation. Because ultimately, it's the state of Nebraska's obligation to make that decision, what's in the best interest, and legally, politically, morally, ethically, the wishes of a family member are important but they cannot be determinative only of the ultimate placement of that individual. Why? Because that individual's family member and that individual, they may be at odds with each other, and it's the state's duty, not to the family member but to that individual, and that ultimately is where that duty resides and reposits. [LR283]

SENATOR LATHROP: But as we look at the process, the first thing we do is defer to them. If we don't like that, we'd have to have a hearing. At a hearing, we'd have to establish...someone wishing to move that resident to a community center would have to establish that the guardian is abusing their discretion, which is a pretty high legal standard, in order to prevail in making a move from a Beatrice-type facility to a community-type facility. [LR283]

BRUCE MASON: They're abusing that discretion if the evidence, by clear and convincing, shows that therapeutically it's in the best interest of the ward or the individual, the resident, to be placed in the community. Therein lies the abuse of discretion. If in the light of clear therapeutic evidence that in fact it's in Bill's best interest to be placed in the community, then that goes...that becomes a res ipsa loquitur that that's an abuse of discretion, because it's not...the guardian is no longer acting in the best interests of the ward. The best interests of the ward, with all the available scientific evidence, all the available professional evidence says this person can benefit there. [LR283]

SENATOR LATHROP: And you and I can imagine what that hearing would look like. It would be in front of an administrative law judge or some such person. But at that kind of a hearing, the state would present evidence that says this is why we think it would be therapeutically beneficial for this particular individual to go to the community, and the family is going to come in with somebody else that's going to say the guardian has a pretty good point here; this is a good place, there's reasons why we think it's a good place. And then a judge would have to decide whether or not, in the face of competing evidence, whether it's an abuse of discretion to...by the guardian to insist that the person remain at Beatrice. [LR283]

BRUCE MASON: Because it's not in the best interests of the individual. But we do that in all kinds of procedures so... [LR283]

SENATOR LATHROP: We do. [LR283]

BRUCE MASON: ...and we did it there. That's right. [LR283]

SENATOR LATHROP: I just wanted to clarify your testimony so that I understood it, because I suspect, looking down the road, that this is going to be a central issue. [LR283]

BRUCE MASON: There's no question in my mind, from 30 years of experience, plus years, that this is going to be...this is going to be the line in the sand. [LR283]

SENATOR LATHROP: I wanted to clarify a couple of other things. You used the phrase "our report," and "our" refers to the NAS? [LR283]

BRUCE MASON: Yes, the...which... [LR283]

SENATOR LATHROP: And I'm not sure you made it clear your association with NAS and what NAS is, so maybe you could take a minute to do that. [LR283]

BRUCE MASON: Okay. First of all, I'm the litigation director. My job is to oversee the litigation. I've been doing that for a good number of years. And the Nebraska Advocacy Services is the Center for Disability Rights Law and Advocacy in Nebraska. What NAS is, is that there are a comparable entity in each of the 50 states. We're funded by the federal government to protect the rights of individuals with disabilities. I sit on the national legal committee for all of the P&As, protection and advocacy. We take a look at what's going on nationally; we decide to enter, as amicus curiae, friends of the court, in cases before the Supreme Court, Courts of Appeals, help other sister/brother PNAs throughout the states. There's one of us, there's an NAS, in every state and territory. [LR283]

SENATOR LATHROP: And that's by virtue of the federal government. [LR283]

BRUCE MASON: By virtue of the federal government. [LR283]

SENATOR LATHROP: And their responsibility is to make sure that those with developmental disabilities are properly cared for. [LR283]

BRUCE MASON: And those that have a mental illness. That's why we're actively...and I've litigated the conditions at the Lincoln Regional Center, the Hastings Regional Center where women were sexually abused while in the custody of the state of Nebraska and receive...and had it entered into a consent decree with...called the Caroline C. case and just recently settled those damage claims that you all had to approve for those women that were assaulted and sexually harassed while they were residents there. So we deal with that. We also deal with individuals in the community. I filed a wrongful death case against Beatrice that was settled. I filed a wrongful death case against a community program, for the death of an individual with a developmental disability, because of their negligence. So that's what we do. We attempt to seek full inclusion of individuals and to protect their civil rights and, at the same time, to ensure that their constitutional rights are being protected in whatever form we find those individuals to be, in whatever setting. [LR283]

SENATOR LATHROP: And just as an aside, the NAS does a lot of that by advocating, as opposed to just bringing lawsuits? [LR283]

BRUCE MASON: Yes, absolutely right. [LR283]

SENATOR LATHROP: Okay. That whole bringing lawsuits makes people nervous sometimes. [LR283]

BRUCE MASON: Absolutely right. And, you know, we have a variety of other things that we do that are, as having practiced law for a long time, I'd say are much more important than litigation. You know, the courtroom is not always the best form in which to either reach resolution of the issues, and that's why this due process hearing becomes important. Because what happens is, is that having represented parents and guardians, when they make a...for 30-some years, when they make that difficult decision, years ago, to place a person in the situation such as BSDC, that's a decision made with great anguish and they...it's so difficult to express the feelings that they go through and then to hear that, well, we want to move him. I mean it just brings up all these emotions. That's why this due process hearing brings the parties together and there's a sense that somebody is finally listening. And we may not agree but let's try it. Let's work it out. Let's work this out a little bit and see what happens and we'll make sure that nothing is going to happen to your son or daughter, as best we humanly can. We can't guarantee everything. I mean, there's only two guarantees in life and that's death and taxes, so... [LR283]

SENATOR LATHROP: I have one other point. I do, I really appreciate you coming down here. It's been very helpful. You have given us the constitutional requirements the state has towards people who are under our care and whose liberty has been compromised with a placement in a facility. You've also expressed the importance of developing an integrated system and that testimony regarding an integrated system, the state would benefit from having somebody who evaluates the person and then we'd go pick the services we need. That's your opinion about what we could do better and how we could function better, as opposed to a legal requirement. [LR283]

BRUCE MASON: Absolutely right. [LR283]

SENATOR LATHROP: Okay. And that comes as...it's your judgment, after 35 years of being in this area. [LR283]

BRUCE MASON: Of seeing that it just doesn't work. [LR283]

SENATOR LATHROP: Okay. I just want to make sure we didn't... [LR283]

BRUCE MASON: And, as Senator Harms suggested, it's broken; it needs to be fixed. [LR283]

SENATOR LATHROP: Right. I think that's all I had, if anybody else has other questions. In seeing none, again, thank you for coming down, Bruce. I appreciate it. [LR283]

BRUCE MASON: Okay. Thank you. [LR283]

SENATOR LATHROP: And I think we'll next hear from Jodi Fennel? Is it Fennel or Fenner? [LR283]

JODI FENNER: Fenner. [LR283]

SENATOR LATHROP: Fenner. All right. Like Mike? [LR283]

JODI FENNER: Yes. [LR283]

SENATOR LATHROP: Family? [LR283]

JODI FENNER: No. [LR283]

SENATOR LATHROP: Okay. I had him for constitution a law up at Creighton, so...all right. [LR283]

JODI FENNER: (Exhibit) Well, good morning. Can you hear me? Good morning, Senator Lathrop and members of the committee. My name is Jodi Fenner, that's F-e-n-n-e-r. I'm the legal services administrator for Health and Human Services. I'm here today to provide additional overview of the laws pertaining to the state's obligations to serve individuals with developmental disabilities and to identify the source of our legal duties. I appreciate the opportunity to present this information to the committee, and I will try to be brief in areas that Mr. Mason has already covered. To begin with, the obligation of government to care for individuals in society who, for various reasons, are unable to care for themselves derives originally from our common law. This has been recognized as early as the King's Court in fifteenth century England. This obligation, referred to as <u>parens patriae</u>, as first articulated to cover individuals with mental retardation and other developmental disabilities in 1963 with the passage of the Maternal and Child Health and Mental Retardation Planning Amendments. These amendments provided grants to states for planning and comprehensive action to address this sensitive population. Later, in 1979, the United States Supreme Court, in <u>Addington v. Texas</u>, recognized that the state, in performing their voluntarily assumed mission of serving those with mental and developmental disabilities, should not impose unnecessary procedural obstacles for individuals needing those services. Then in 1993 the Supreme Court further recognized that, under the states' police powers, the state has, and I quote, a legitimate interest in providing care to its citizens who are unable to care for themselves, as well as authority under its police powers to protect the community from any dangerous individuals. And that was <u>Heller v. Doe</u> in 1993. Then again in 1999, the U.S. Supreme Court, in <u>Olmstead</u>, recognized that individuals with disabilities are inherently entitled to respect, dignity, self-determination, personal responsibility, the ability to pursue meaningful careers, privacy, and inclusion, integration, and full participation with society. Many have argued that Olmstead doesn't apply to this population of the developmentally disabled; however, the federal government has interpreted Olmstead to apply to all individuals with disabilities, including those with developmental disabilities. Olmstead requires the state, when it is providing care to individuals with developmental disabilities, to ensure that such care is provided in the least restrictive setting available, taking into account the resources available to the state, which also entails balancing those needs with others with disabilities, and the desires of the individuals being served. Olmstead does not take away an individual's right to choice, nor does it mandate the state provide an entitlement program to individuals with disabilities. It has been interpreted by the United States Department of Justice to require states to assess individuals to determine whether the lesser restrictive placements options are available and to provide informed alternatives to these individuals served. Olmstead is, in essence, a safeguard to ensure that states do not impede an individual's inherent civil rights. The Department of Justice's tool to enforce the Olmstead requirements is CRIPA, the Civil Rights of Institutionalized Persons Act. That's found at 42 U.S.C. 1997. Under CRIPA, the Department of Justice can impose civil and/or criminal penalties. The federal government imposes other obligations and restrictions on the states by attaching substantive requirements to their purse strings. Examples of these, and just a few examples, are Section 1905 of the Social Security Act that authorizes the Medicaid waiver funding program through joint federal and state developmental disabilities programs; and another one is 42 C.F.R. Sections 440 and 441, which cover home and community-based services. Generally, these funds and accompanying regulations are funneled through the CMS, the Center for Medicare and Medicaid Services. CMS has broad authority to interpret and apply their requirements on states. Their regulations generally relate to the standard of care and the requirements related to the mandatory active treatment and habilitative programs for individuals. Unlike the Department of Justice, who has prosecutorial enforcement powers, CMS essentially takes away your money. And finally, in 1971, in not necessarily date order, but the Developmental Disability Assistance and Bill of Rights Act created the DD Planning Council. This is a federally funded program that's administered by the department's Public Health Division and its Community Health and Planning Protection Unit, but it operates independent of the department. Just a couple of the things that it does: The Governor has 23 members that are appointed for three-year terms; essentially, the purpose historically is to reverse the bias against people with disabilities by focusing on these things--independence, productivity, integration, inclusion, and self-determination. The council has grant powers and other things, but it's important that it does operate completely independent of the departments. Those are...in general, that's the federal overview, and then moving on to the state overview, state law relating to individuals with developmental disabilities is derived from the Developmental Disability Service Act, and that's found in Nebraska statutes 83-1201 through 83-1227, and a copy of that is provided in the packets that we're providing to you today. And we also refer to this as the DDSA. This act defines a developmental disability as mental retardation or a severe, chronic disability other than mental retardation or mental illness which: (a) is attributable to a mental or physical impairment other than a mental or physical impairment caused solely by mental illness, because those people are treated through the behavioral health statutes; (b) is manifested before the age of 22 years; (c) is likely to continue indefinitely; and (d) results in various things--the case of a person under 3 years of age, at least one developmental delay; in the case of persons 3 years or older, substantial limitations on the following areas of major life activity, and there we have self-care, receptive and expressive language development and use, learning, mobility, self-direction, capacity for independent living, and economic sufficiency. The act, which was initially adopted in 1991, actually several years before the Olmstead decision, sets forth the Legislature's intent with regard to DD services, and I do want to walk through those because one of the things the act does, and we'll talk about this in a moment, is authorize and actually mandate Health and Human Services to adopt regulations. The Legislature's intent actually guides all of those regulations and it explains where departments...where we're coming from. Number one, all persons with developmental disabilities shall receive services and assistance which present opportunities to increase their independence, productivity and integration into the community; two, all persons with developmental disabilities shall have access to a full array of services appropriate for them as individuals; third, they shall have the right, to the maximum extent possible, to live, work and recreate with people who are not disabled; fourth, they shall, to the extent possible, be served in their communities and should only be served by specialized programs when their needs cannot be met through general services available to all persons, including those without disabilities; five, they shall have the right to receive age-appropriate services, consistent with their individual needs, potential and abilities; and six, they shall be afforded the same rights, dignity and respect as members of society who are not disabled; seven, they shall be assured a uniform system of compensation and training, and a full range of work site enhancements which attract and retain qualified employees. And eight and nine are priority systems: eight, the first priority of the state in responding to the needs of persons with developmental disabilities should be to ensure that all such persons have sufficient food, housing, clothing, medical care, protection from abuse or neglect, and protection from harm; and then nine, the second priority of the state in responding to the needs of persons with developmental disabilities should be to ensure that all such persons receive appropriate assessment of their needs, planning to meet their needs, information about services available to meet their needs, referral to services matched to their needs, coordination of services delivered, support sufficient to allow them to live with their natural families or independently, transportation to facilitate access to services, meaningful habilitation, education, training, employment, and recreation designed to enhance their skills, increase their independence, and improve their quality of life. In essence, the Legislature has set forth what we as an agency are to focus on, and has established a priority system for us to allocate the resources that you provide us. And that is exactly what we do through the regulatory process. In 1994 the Legislature recognized, in Section 83-1202.01, that there were not sufficient appropriations to fund developmental disability services for all those that were eligible. Thus, the Legislature amended the act to commit to pursuing full funding of community-based developmental disability programs in a reasonable time frame. As the eligible population has grown, this time frame has changed over time. We started with a goal of 1996, that was later amended to the year 2000, and now the statutory goal is 2010. Other significant impacts of the DDSA are, and all of these are in your packet: they create the position of the Developmental Disabilities Service Act director, that's 83-1209 and it sets forth the duties that the director is to undertake; the act creates local field offices throughout the state to assist with developmental disability needs; third, it assigns the responsibility for costs of services to individuals receiving services; fourth, it creates the Advisory Committee on Developmental Disabilities, which I'll talk about in a moment; it establishes requirements for the DD regions, such as the quality review team; sets forth requirements regarding contracts for special services, employment background check; and creates an administrative process to address complaints with regard to the department's implementation of the act. The DD Advisory Committee that I just referenced, that was created and it's comprised of a representative of a statewide advocacy organization for persons with DD, consumers, family members, and elected officials and interested citizens. Again, this is a committee appointed by the Governor, 16 members for three-year terms. Unlike the planning council, this is actually something internal to DHHS. Their membership and a summary of their ongoing activities can be found on the Department of Health and Human Services' Web site. The link is indicated in your...the packet that we're providing you. For the public, it's quite easy to go to. You just go to community-based services and you can follow the links and get there. Finally, in addition to the requirements set forth in the act, the DDSA, the Legislature directed the department to adopt rules and regulations to implement the act, and we have done so. These regulations have been promulgated in Titles 203 and 205 of the Nebraska Administrative Code. Those can be found on our Web site as well. They have also been included in your notebooks today. In addition to the DDSA, there are a handful of separate statutes that were adopted as early as 1885 to create the Beatrice State Development Center, define its purpose, and address collection of costs for BSDC services. Those statutes begin at 83-217, and you're also being provided with a copy of those today. In summary, what these statutes direct us to, and I'm quoting, the BSDC is to provide residential care and humane treatment for those persons with mental retardation who require residential care, shall study to improve their conditions, shall classify them, and shall furnish such training in industrial, mechanical, agricultural, and academic subjects as they may be capable of learning. Whenever the Department of Health and Human Services determines that continued residence in the Beatrice State Developmental Center is no longer necessary for the welfare, care, treatment, or training of such person, it shall have the authority to discharge or transfer such persons, as provided in 83-387, and 83-387, we've talked about the hearing process that was in the prior settlement agreement and it, in essence, it is in statute. Discharge pursuant to 83-387 requires reasonable notice and any individual being discharged from a facility has the right to appeal their discharge. The only difference in the, as I understand, the terms of the settlement agreement and the statute is under the statute we don't provide attorneys for individuals who have appeals. They either represent theirselves or their guardians hire a counsel for them. To date, we're not aware that there's ever been an involuntary discharge from BSDC, so this statute hasn't necessarily been utilized. We haven't had any appeals filed under this statute for discharge. In general, that's a summary of the state and federal laws that we apply at the Department of Health and Human Services, and I'm happy to answer any questions you have. [LR283]

SENATOR LATHROP: Very good. Thank you. Senator Cornett. [LR283]

SENATOR CORNETT: With the findings from the federal government, do you feel that...obviously, we haven't met our own standards or the federal government's standards currently with the current findings. Do you think that...well, trying to ask without being (laugh)... [LR283]

JODI FENNER: That's okay. [LR283]

SENATOR CORNETT: Do you think that BSDC is moving, or has over the past couple years...because I've been in the Legislature longer than a couple of the members of the committee but less time than Arnie. In the four years I've been here, we have heard over and over again BSDC is getting better, it is getting better, it is getting better, and then we find out last year that it's not getting better, it's getting worse. Do you feel that corrective...that the steps that had been being taken over the past few years were in the appropriate direction? And obviously this committee wouldn't be here if we didn't feel that changes need to be...needed to be made. Do you feel that corrective steps had been attempted, and was there any improvement made since the beginning? Because the reports that we have, if you look back over time, it actually looks like we've regressed since we started, rather than progressed. [LR283]

JODI FENNER: I think that depends on when you say when is the beginning. Is the beginning in the 1970s? Is it in '85, when the prior settlement lapsed? What we currently have, the three current reports--CMS, DOJ, and CMS...and Nebraska Advocacy, I'm sorry, I misspoke--those reports detail activities in 2006 and 2007. And if you look at CMS's first report, and not first actual report but their 2006 report, they indicated substantial improvement had been made and that's why they continued funding, so they gave the facility a second chance. And the reality is that even with all the resources that were thrown at the issues to be addressed, we didn't make the changes in the time manner in which they wanted them to be made. And I don't know that that would have been possible. Are we moving in the right direction? I can tell you we've talked at great length routinely with the Department of Justice. They do think that we're moving in the right direction. They seem to believe it's going to take longer than I think everybody...obviously, if this is a problem we could have solved a year ago then we should have done so. But in my discussions with the Department of Justice, I think we agree that we have to do the right thing and if that means moving a little slower than necessary than that's what we have to do. [LR283]

SENATOR CORNETT: What concerns me is losing the funding. [LR283]

JODI FENNER: Uh-huh. [LR283]

SENATOR CORNETT: How can we move forward if we don't have the funding? If the Department of Justice thinks we're moving forward and we're progressing towards achieving their goals, why are we facing losing our funding if they feel we are...have been improving? [LR283]

JODI FENNER: The Department of Justice doesn't deal with the funding issue. They deal with the civil and criminal penalties. [LR283]

SENATOR CORNETT: Correct. [LR283]

JODI FENNER: CMS deals with the funding issue. [LR283]

SENATOR CORNETT: How does CMS feel we're doing? [LR283]

JODI FENNER: Well, they just...the way CMS responds when you ask them, and I can say this because we did and when they came and did their outgoing report to the public, several members of the public asked, well, what do you think we need to do, and their response is, it's not our job to tell you what we think you need to do; here are the conditions of participation; we're telling you, you don't meet them. They really aren't receptive to open...haven't been receptive to open communication and giving specific suggestions. Department of Justice has been much more helpful in that manner. I don't know if that's the standard CMS practice. My understanding is they've been asked to come speak to you. We would really enjoy knowing specifically what they think we should address first. We are asking to have settlement negotiations with them, as we have done with the Department of Justice. We're hoping that those will be fruitful. I don't think it's in anybody's best interest that we lose funding, because the people who are harmed are the people who are entrusted to our care. And I firmly believe that CMS cares for those people as much as we do. It's a matter of we have to get through the technicalities and legalities of the process. Maintaining the funding is a priority for us, ranking right at the top, but we have to multitask and deal with all of the issues at once. [LR283]

SENATOR CORNETT: But we don't...do we currently have a plan in place on how to meet those steps for CMS if CMS won't communicate to us what their priorities are? [LR283]

JODI FENNER: Well, we actually have an opportunity to. Well, they'll be in court. We've actually filed our initial documentation to the arbitrator. [LR283]

SENATOR CORNETT: Correct. (Inaudible) [LR283]

JODI FENNER: Now they have to come back and respond to that. They have indicated that they're willing to open up discussions now that we're in litigation. And from their perspective, maybe they didn't want to have those discussions earlier because they knew that we would be in litigation. I have no way of reading their mind. But it's our hope that we will do that. We do have a plan of correction that we developed and that we're implementing. That is what we shared with DOJ, and DOJ thinks that we're on the right track. Are there things that we could do better? Yes, and they've suggested a few things and we've implemented those into our plan. You know, it's our hope that we'll be able to CMS and the funding issue will be resolved, and we need to work through the next few years to get the facility to where it needs to be, not to get the facility to where it was in 2006, because I don't think anybody reading those prior reports can say that that's even where the facility should have been. We need to disregard what's happened in the past and look to the future and see what are these individuals entitled to. These are individuals who are entitled to dignity and respect and inherent constitutional and civil rights. This Legislature recognized that in the early nineties and I think that you're affirming that by doing what you're doing now. [LR283]

SENATOR CORNETT: One last question, and this has to do with something that you said at the very end of your discussion, that the guardians have the right of appeal... [LR283]

JODI FENNER: Yes. [LR283]

SENATOR CORNETT: ...if the state wishes to move them to a community-based... [LR283]

JODI FENNER: Uh-huh. [LR283]

SENATOR CORNETT: ...but that the patient does not, as an individual. I mean they...if, say for instance, you have someone in there that their parents have died. They don't have the resources to hire an attorney for themselves for the appeal process. [LR283]

JODI FENNER: They have the... [LR283]

SENATOR CORNETT: Who is their representative? [LR283]

JODI FENNER: Well, the federal government funds Nebraska Advocacy, who can act as their representative. [LR283]

SENATOR CORNETT: But who...I mean a lot of these people wouldn't be able to contact Nebraska Advocacy themselves. [LR283]

JODI FENNER: Nebraska Advocacy is there... [LR283]

SENATOR CORNETT: Are they there? [LR283]

JODI FENNER: ...almost on a daily, weekly basis. [LR283]

SENATOR CORNETT: Okay. [LR283]

JODI FENNER: They have access to...I mean, if somebody was being discharged and complained, they have a representative who is there routinely that they could complain to. [LR283]

SENATOR CORNETT: A lot of the people that we saw wouldn't necessarily be able to complain. [LR283]

JODI FENNER: That's correct. [LR283]

SENATOR CORNETT: Do...and this goes back to the gentleman, I believe it was Mr. Mason, that was speaking earlier, do you feel that the patients need something equivalent to a guardian ad litem for themselves, to represent their interests? If their guardian is not alive or is not showing interest in them, who is going to represent the person? [LR283]

JODI FENNER: That is a very difficult question because, as you indicated, Senator Lathrop, a court appoints guardians. [LR283]

SENATOR CORNETT: Correct. [LR283]

JODI FENNER: It's not as if a family member just decides to be a guardian. They have to go to a judge and convince the guardian that they are going to act in the best interest of their loved one or in the interest of whoever it is who's been entrusted to their care, may not necessarily be a family member. If we were to believe that a guardian was not behaving appropriately, we absolutely would go to a court and ask that the court readdress that guardianship. So do we need a separate guardian ad litem in that process? Goodness, that's certainly a policy decision. It's something you could do but... [LR283]

SENATOR CORNETT: It's something that we did under the consent decree in the seventies, maybe not a guardian ad litem but somebody to represent? Is that what Mr.

Mason said? [LR283]

JODI FENNER: And I don't know that detail. I, from my perspective, we have Nebraska Advocacy, who is federally funded...or federal mandated, state funded, so that they can represent the interests of individuals in these institutions. But also, again, when you say somebody who's nonverbal, if we have somebody in our care who isn't capable of making medical decisions themselves, we would ask the court to appoint a guardian for them, to find a guardian for them, and we do that routinely, not just in this program but in APS and in other issues. So I would hope we would never have someone who couldn't vocalize their objections, either themselves or through their guardian. [LR283]

SENATOR LATHROP: Senator Stuthman. [LR283]

SENATOR STUTHMAN: Thank you, Senator Lathrop. Jodi, when you speak about an institutional setting and a community-based setting... [LR283]

JODI FENNER: Yes. [LR283]

SENATOR STUTHMAN: ...for the patient, does the funding follow the patient? Is there different funding mechanisms in the different settings? [LR283]

JODI FENNER: Yes, there are different funding mechanisms through the different settings. We have community-based funding. We have funding for BSDC. In the last legislative session you did pass a bill that allowed us to...the funding from individuals with BSDC who we are moving into the community, for those people the funding follows the person. [LR283]

SENATOR STUTHMAN: Okay. Thank you. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: Yeah, thanks. Jodi, I've heard, well, when Bruce Mason was speaking to us, he used the term "best possible extent," "generally accepted development." You used one in your slide,... [LR283]

JODI FENNER: We like those terms. [LR283]

SENATOR GAY: ..."maximum extent possible." I mean, to me, these are big, broad, vague terms. And I guess who do we look to when we're trying to narrow it down? And, I mean, that could be anybody in this room's opinion of what "maximum possible extent" is. But is CMS...where do we go find CMS regs or whatever it is to decide where these things are? Even if we had a hearing with an advocate and a guardian and all this stuff, what rules are we playing by to decide whether they're receiving the best care, the maximum possible extent, or how do we decide these things? Are they in a reg, federal regulations or...? [LR283]

JODI FENNER: No, the "maximum extent possible," that was language that the Legislature adopted and probably because it is hard to determine, as a Legislature, as you're probably seeing, struggling with this issue, how would you pass legislation that said you must do this in this case? You would have...whereas in your packet, your DD statutes are pretty thin. They would be like the Tax Code if you tried to articulate every requirement. You could do that, but I think that's why in 1991, when the act was passed, they used that understandably vague language. As courts have interpreted language like that, we are required to use reasonable judgment in interpreting that. And again, the word "reasonable," attorneys love that language and apparently senators do, too, because it's all throughout the statutes. That's a really tough one. [LR283]

SENATOR GAY: Well, how about this one: CMS doesn't use "reasonable." It's like you're going to do this, this, this and this, to me, from what I've seen. I've only been here a couple years, but it's very specific of what they'll pay for, what you got to follow, what you're going to do. So is that anywhere that I can go and have someone look it up for me and say, these are the 120 things we must follow? Or maybe it's 20, maybe it's 80, I don't know. Is that anywhere in the statute? [LR283]

JODI FENNER: Even then, what CMS does have is it has conditions of participation. And I'm sorry, Director Wyvill has more of that CMS outline that he'll be visiting with you this afternoon about, but it's not as open and shut as you mention either. It is in statute and they do have regulations that interpret their statutes and they can be found on the CMS Web site. But even with CMS, you know, one of the, for example, one of their guidelines will be to provide adequate protection and safety measures. We've asked them, what do you want us to do differently? Because as I understand it, and I've only been with the agency since November, we weren't doing things that much differently in 2006 than we were in 2005, 2004, 2000, 1995. I think as Bruce Mason indicated, we probably should have been doing things a lot better for a very long time. So I don't know. Does that mean that the surveyors are just being more sensitive? I don't know. But the conditions for participation are on the CMS Web site. They're not always as clear-cut as we would like them to be. I think a lot of it is common sense, are we providing care and safety and protecting the rights of individuals who are entrusted to our care, and clearly that's something we can do a better job at and it's something that we're working towards. [LR283]

SENATOR GAY: Thank you. [LR283]

SENATOR LATHROP: I do have some questions, and maybe some things that I'd like to clarify. You were here when Mr. Mason testified? [LR283]

JODI FENNER: Yes. [LR283]

SENATOR LATHROP: Yes? [LR283]

JODI FENNER: Yes. [LR283]

SENATOR LATHROP: Okay. And the substance of his testimony was this; that the Constitution, the United States Constitution, and in particular the Fourteenth Amendment, provides certain protections to people who are in custodial care. And would you agree with Mr. Mason that's the case? [LR283]

JODI FENNER: For individuals in custodial care, yes. [LR283]

SENATOR LATHROP: Right. And he suggested that the constitutional implications mandate that we...that the state has three different duties: first is to protect the safety; second is to provide habilitation; and then the third is to integrate as much as possible. Would you agree with his testimony that the constitutional requirements for someone in state custodial care give rise to those three duties? [LR283]

JODI FENNER: I think that's a combination of the Americans with Disabilities Act and the Constitution, yes. [LR283]

SENATOR LATHROP: The first two come from the Constitution and the third one, the integration, comes from the ADA. [LR283]

JODI FENNER: Yes, that's correct. [LR283]

SENATOR LATHROP: Okay. Now just as a matter of lawyer to lawyer, when we talk about federal law and, in particular, when we talk about a constitutional requirement, we can't legislate our way around that. [LR283]

JODI FENNER: Absolutely not. [LR283]

SENATOR LATHROP: True? So to the extent we see a second priority for the state of Nebraska is habilitation and that is a constitutional requirement, our statute doesn't control that situation; it is a constitutional requirement and we have a constitutional duty to habilitate people who are in our care. [LR283]

JODI FENNER: That's correct. [LR283]

SENATOR LATHROP: Would you agree with that? [LR283]

JODI FENNER: Yes. [LR283]

SENATOR LATHROP: Okay. You talked a little bit about corrective steps leading to improvement. I did read the NAS report, or most of it, last night and it chronicles, sort of, our relationship with CMS since 2001. And you've seen that report, have you not? [LR283]

JODI FENNER: Yes. [LR283]

SENATOR LATHROP: And as I read that report, it looks like CMS has come into the state of Nebraska and they've said these are the problems, and they have...we have these constitutional requirements and we...if they are, if I can use the term, they're the skeleton and the flesh comes to us through the CMS rules and regulations. Am I right? [LR283]

JODI FENNER: Yes. [LR283]

SENATOR LATHROP: So what we have to do, what our standard of care is isn't exactly unknown or isn't exactly a mystery. It's actually found in the CMS code, true? [LR283]

JODI FENNER: Much of it is, yes. [LR283]

SENATOR LATHROP: Okay. So we know what we're supposed to do and they come in and they do evaluations. And as I read the history of our CMS evaluations and the state's response, it looks something like this. CMS comes in and says these are the problems. The state has responded by saying, we'll do this to fix it. CMS has come in and said, okay, what did you do? And we've said, well, we didn't even get everything done we said we'd do. And they say, you know, you're out of compliance. And then we say, well, we'll do this to get into compliance. And that's been the history since 2001--a series of evaluations, promises by the state followed by more evaluations where we admittedly haven't done what we promised we'd do and we remain out of compliance. [LR283]

JODI FENNER: That is correct. [LR283]

SENATOR LATHROP: And essentially what's happened to us, to us being the state of Nebraska, is that finally CMS said enough is enough. And we had in...I think it was December, we made our last promise and they came in since December and said, we're decertifying you because you've given us promises and you're not fixing the problem. Would that be a fair summary of our relationship with CMS since 2001? [LR283]

JODI FENNER: I think that's correct. [LR283]

SENATOR LATHROP: Okay. Mr. Mason also testified regarding...and I suggested, in questioning him, that it was going to become one of our central issues, and that is this idea of or the concept of to what extent does a guardian have control over whether someone remains at Beatrice versus goes into the community because that's what state personnel and doctors and so forth think ought to happen. And if I understood Mr. Mason, he suggested that there is...and he called it a conundrum, which is the tension between providing full integration and respecting the opinions and wants and the expressions from family and guardians. And you...that really is one of the conundrums in providing care and addressing placement for people with developmental disabilities. Would you agree with that? [LR283]

JODI FENNER: It can be. [LR283]

SENATOR LATHROP: And he has suggested that...and I want...I'm trying to get your opinion because... [LR283]

JODI FENNER: Okay. [LR283]

SENATOR LATHROP: ...I do, I think this is going to be central to much of what we do at Beatrice, and that is to get to the bottom of to what extent does a guardian have a say in the matter. And he has suggested that the ADA will provide deference to the guardian but that the guardian, while their opinion is entitled to substantial weight, it isn't control. Would you agree with that much or can I take you in little bits through that opinion? [LR283]

JODI FENNER: I would say it's not the sole controlling factor. [LR283]

SENATOR LATHROP: But it's entitled to substantial weight, or do you not agree with that? [LR283]

JODI FENNER: I do agree with that. [LR283]

SENATOR LATHROP: Okay. So, so far, the way we would sort that out is at one of these 387 hearings, an involuntary discharge hearing. What we would do is if a parent or a guardian objected, then we would have a hearing, and at that hearing the question would be whether the objection of the guardian to the involuntary discharge from Beatrice is an abuse of discretion. Do you think that that's how we would sort out, as lawyers, how we would sort out what weight we give the guardian's opinion? [LR283]

JODI FENNER: Yes. [LR283]

SENATOR LATHROP: Okay. So you are in agreement with Mr. Mason in that respect. [LR283]

JODI FENNER: Yes, I am. [LR283]

SENATOR LATHROP: And the last thing maybe, to follow up on a question Senator Cornett had, there is...Mr. Mason, in the consent decree, had provision in paragraphs 21 and 22 for the appointment of counsel for people at these administrative hearings. [LR283]

JODI FENNER: Uh-huh. [LR283]

SENATOR LATHROP: Our statute does not. Is that the case? [LR283]

JODI FENNER: That's correct. [LR283]

SENATOR LATHROP: And when Senator Cornett was talking to you about guardian ad litems, guardian ad litems are different than having a lawyer. [LR283]

JODI FENNER: Absolutely. [LR283]

SENATOR LATHROP: Anybody can serve as a guardian ad litem as long as they are suited, educated, and have the interests of the ward as their primary consideration. [LR283]

JODI FENNER: That's correct. I think there's actually some court training that goes into that process as well, but in essence that's correct. [LR283]

SENATOR LATHROP: But it doesn't make them qualified to serve as counsel. [LR283]

JODI FENNER: Absolutely not. [LR283]

SENATOR LATHROP: Okay. So how we sort that out is the person that's the guardian speaks for the ward, and if that person is...appears to be losing interest or appears to be not providing for the best interests of the person for whom they've been appointed then we can go back to the county court in whatever county that appointed them and have them remove. [LR283]

JODI FENNER: We can ask a judge to look at that. [LR283]

SENATOR LATHROP: And that's our remedy in that instance. [LR283]

JODI FENNER: It is. [LR283]

SENATOR LATHROP: Okay. I think that's all I have, unless that's provoked any other questions. Doesn't look like it. Thank you very much for your testimony. [LR283]

JODI FENNER: Thank you. [LR283]

SENATOR LATHROP: And seeing that we're at 5 after 12:00, I think that will give us a good opportunity to take a break. [LR283]

SENATOR GAY: How are you going to do next few people coming up? Is there an order? [LR283]

SENATOR LATHROP: Yes. What we will do after we get back from lunch, just to kind of give you a preview, I think we'll start out with John Wyvill, who will give us kind of an overview of Health and Human Services, and then we will hear from Ron Stegemann, and we will hear from somebody with respect to community-based care. Am I right? [LR283]

JOHN WYVILL: And Lee, Lee Zlomke, Dr. Zlomke. [LR283]

SENATOR LATHROP: Okay. And by the end of the day we will also take up the population or the census of people who are receiving services from the state and those that are on the waiting list. Okay, why don't we get back together at 1:30. Thank you. [LR283]

RECESS []

SENATOR LATHROP: ...the second half of our presentation, that's going to bring us to John Wyvill. Welcome. [LR283]

JOHN WYVILL: Thank you, Senator. Good afternoon, Senator Lathrop, and members of the Developmental Disabilities Special Investigative Committee. My name is John Wyvill, W-y-v-i-l-l, the director of Developmental Disability of the Division of the Nebraska Department of Health and Human Services. Most especially, I appreciate the Legislature taking on this issue. We all have the same goal of ensuring the best care possible for clients at BSDC as well as others with developmental disability. We are open to giving you any information that you need on this issue. On May 20 of this year, all of you toured the Beatrice State Developmental Center. We enjoyed having you at BSDC and hope you learned much from your visit. I would like to thank this committee for allowing us to present more information in the area of developmental disabilities. I will begin my testimony by providing you with an overview of Developmental Disability Services through a PowerPoint presentation which will be the 25,000-foot view, so to speak, which includes information on intermediate care facilities for persons with mental retardation and community-based services. More details on this overview relating to fiscal issues will be provided tomorrow morning. After this PowerPoint presentation, please, you can ask any questions you may have. After my presentation, Dr. Lee

Zlomke, the acting director of psychology at BSDC, will provide information on the spectrum of individuals with DD, as well as their needs. Lee will then answer any questions you may have. After Lee testifies, Ron Stegemann, the chief executive officer of BSDC, will provide information on DD services available throughout the state, and Karen Kavanaugh, the administrator of DD community-based services, will then provide information on DD services available through community-based providers, a review of the numbers of persons receiving DD benefits through the state and/or community-based providers and the waiting list for persons awaiting services from the state for DD. Also for the benefit of all of you, we have compiled a booklet for our testimony today that's in here and also if you look at a tab on PowerPoint, you have our respective PowerPoint presentation as well as the supporting documentation. If you will wait a minute before I get started, so you can look and find that within that. There will be a couple of slides that I'll be going through very quickly because they've been covered by previous speakers and don't want to waste your time to get into the heart of the matter. First of all, for our mission statement for Developmental Disabilities: Through quality enhancement, support effective services that build on a person's strength and maximize independence. That is the mission statement for us. The next slide that will come up is the organizational chart of Developmental Disabilities which will be effective July 1. As you notice, we have recently announced the reorganization of Developmental Disabilities in which under one umbrella, under myself, the director, we have community-based services, Beatrice State Development services, and also planning and programming in the development section with Karen Kavanaugh as acting director for both. Previously, service coordination is currently right now under Children and Family Services. With the move of over 200 employees over on July 1, DD service coordination will be under the umbrella and you will see that the continuum of services will be under, for program and personnel, will be under one administrative umbrella. Who receives services from DD will be persons with mental retardation and/or developmental disabilities receive services. Eligibility is defined in Section 83-1205 of the Developmental Disability Services Act. Just as a point of clarification, this is an eligibility program; this is not an entitlement program. Services are provided by 33 public and private community-based providers at 70 certified programs at the Beatrice State Developmental Center and at the Bridges Program. The next three slides that I have discuss the Developmental Disabilities definitions that we have touched on with previous speakers so we will just go right through those. And based on the estimated number of people with developmental disabilities in the state of Nebraska, there are approximately 27,940 people have a developmental disability and that number is estimated based on a 2000 study showing a 1.5 percent (inaudible) percentage prevalence of developmental disability in the general population and a 2006 census estimate of over 1.7 million people in Nebraska. The number of people that we serve through DHHS is 4,512 in community-based services as of September 2007, and as of June 30, 2008, we have 276 people at BSDC. The question about how many people we serve also depends on, if you look at a chart, and at least with my eyes it may be a little too small for me to read here but up on the chart here, several clients that you will find during the testimony may receive different kinds of services. So if we look for the years of 2004, 2005, 2006 and 2007, you will see the breakdown of what kind of services a client or the family may need, which is day services, residential services, respite services or services at BSDC. We have other individuals that will be testifying later today that will be going into more detail to give you an idea. The next shot that we have is, Senator Lathrop had asked for the whole universe of DD funding, so to speak, in the state of Nebraska. And if you look at it in round numbers, we're looking at over $273 million that we're talking about broken down by federal money, general revenue money, and cash money. And in the next slide we have, and this information will be...Sandy, from Legislative Fiscal Office, will be working with a much more detailed report tomorrow. But how we are funded, if you look at the pie chart, we have community-based DD waivers that take up 52 percent. We have medical services for DD clients, community-based services which is state funded only. We have BSDC, and then you have private ICF/MRs representing 7 percent. Then you have DD service coordination which is $10 million and then you have DD administration and then that should give you an idea to get your hands around the number of dollars and the breakdown of funding. We receive federal funds through a variety of different ways, first of all, through the ICF/MRs. And then we have five waiver programs that will be discussed later. That will just give you an idea of the various waivers and the uses of them, for example. We have the comprehensive adult waiver program that is approved for 2,630, and as of the end of May we are using 2,369 of them. And you can see the breakdown of the other waiver program and then the administrative fund. Then we go to the heart of the questions that were brought up earlier about what is an ICF/MR. An intermediate care facility for people with mental retardation is primarily for the diagnosis, treatment or rehabilitation of the person with mental retardation or related condition. An ICF/MR provides, in a protected residential setting, ongoing evaluation, planning, 24-hour supervision and integration of health or rehabilitative services to help individuals function at his or her greatest ability. They also provide health or rehabilitative services for individuals with mental retardation and they are surveyed by the Center for Medicaid and Medicaid Services. ICF/MRs provide active treatment or training on goals and objective to promote engagement of the individual doing daily activities. ICF/MRs promote independence and return persons to their home community. ICF/MRs provide residential care and day services environment and ICF/MRs provide a full range of services, including medical services and therapy. Center for Medicaid and...Medicare and Medicaid Services, Title XIX regulations of Medicaid, have the regulations governing the intermediate care facility for the mental retarded as part of the federal Social Security Act. So when you were hearing about the testimony earlier, you have the federal Constitution, then you have Congress that enacts laws, and then you have the regulations on a federal level that are promulgated pursuant to that grant of authority. All facilities that an ICF/MR must meet and include eight conditions of participation and 56 standards. Those eight conditions of participation are up on the PowerPoint presentation just for illustrative purposes of the areas that we must meet which is client protection, facility staffing, active treatment services, client behavior and facility practice, healthcare services, physical environment, dietetic services, and the governing body. The governing body consists of the director of Developmental Disabilities, the chief clinical officer, BSDC's CEO and medical director. And in closing, the last slide just gives you an idea of the number of ICF/MRs in the state of Nebraska. There are three others, three others, and Mosaic has one at Axtell, Beatrice, and the tri-city region, which is Grand Island, and those numbers there of 108 individuals, 127 individuals and 9 individuals give you an idea of the private ICF/MRs. Members of the committee, this concludes my general 25,000-foot view or overview of Developmental Disabilities that will hopefully help you in the weeks and months ahead. [LR283]

SENATOR LATHROP: Are there any questions for Mr. Wyvill? I do, if I can, John. If you don't mind, can you just give us, when we talk about...since we have toured Beatrice, I think we have an idea of what Beatrice is but when we talk about a community-based program, and I know you have somebody coming up to talk about them specifically but as long as we're on the big picture overview, tell me in a big picture way, first, what we do in the community-based programs and then, if I have a son or daughter that lives in my home and I want them to continue to live in my home, what are the array of services that are provided to day services? [LR283]

JOHN WYVILL: (Exhibit 1) Okay. Well, first of all, for community-based services, those services can be delivered in a variety of settings. They could be in a home, they could be in a group home, they could be that one of the providers may have a day program in which a client will be transported to a facility, like for example, DSN. Disability Services Network may have a vocational center where the client goes or what you've heard in the past, maybe called a sheltered workshop, where they'll go and they'll do work there. If you are a parent of an individual that's currently at home, what happens, you will be in contact with a person in service coordination, which is we have service coordinators throughout the state that will be working with the family and the guardian or the parent and see what services that they want. It could very simply be working with vocational rehabilitation, which is in the Department of Education, to see if there is any employment opportunities. It could be as simple as just coordinating respite care or other services to make sure that the family get relief. It just depends on the nature of the disability and nature of the services that they need. It just depends, Senator. [LR283]

SENATOR LATHROP: Okay. So we can, in terms of community-based care, it can range from going to a community-based provider and I'll use ENCOR as an example, staying in a group home which might be a residence in a neighborhood with four or five residents, developmentally disabled residents and they have staff from ENCOR and they kind of live in that environment and go to work during the day. [LR283]

JOHN WYVILL: Um-hum. [LR283]

SENATOR LATHROP: That's an example of a community-based program. Is that a typical community-based program? [LR283]

JOHN WYVILL: From my experiences, yes. [LR283]

SENATOR LATHROP: Okay. [LR283]

JOHN WYVILL: The thing that we can do the best way that I think of for looking at it is, if you think about BSDC and you've heard others talk about an institution or facility, everything is provided there. So to use, from Arkansas, use the analogy of Hillary Clinton that use the book It Takes a Village to raise a child, everything is provided at the ICF/MR. The "village" is the ICF/MR. In a community-based there are several different things you have to go and it depends on where the residence is and what services they're trying to access. They have to go to the doctor. They have to go to get day services or they have to coordinate with somebody. At an ICF/MR they have to coordinate there. And that's one of the discussions that Mr. Mason was talking about. There you're taking...the advocates feel you're taking away choice because everything is provided to them there. [LR283]

SENATOR LATHROP: Okay. And you mentioned in the last slide ICF/MRs. I was thinking that it was only Beatrice and you mentioned Mosaic. [LR283]

JOHN WYVILL: There's three private ones. [LR283]

SENATOR LATHROP: The three private ones. Can you describe those? Are they homes or is that...these numbers look like they're institutions. [LR283]

JOHN WYVILL: To be perfectly honest, Senator, I have not been to visit those facilities so I could not tell you. [LR283]

SENATOR LATHROP: Okay. We'll save that question for somebody that follows. [LR283]

JOHN WYVILL: Okay. [LR283]

SENATOR LATHROP: Any other questions? Senator Wallman. [LR283]

SENATOR WALLMAN: Thank you, Senator Lathrop. Yeah, John, thanks for being here. How many day-care centers do we have in Nebraska, private, besides...does the state have some, day care, you know strictly day-care centers for...like, I know Madonna has one in Lincoln here. [LR283]

JOHN WYVILL: We don't have any day care at BSDC. I think a long time ago we did for our employees to use that for services. [LR283]

SENATOR WALLMAN: I also mean for clients, you know, that need watching during the day. Madonna has some, if you had a stroke or something, you know, they have...you can drop off your loved one there and have day-care services. Now do we pay for that as a state, you know? [LR283]

JOHN WYVILL: It depends on what services...it depends on whether they're respite services or day services that they have. It just depends on what the providers do. Miss Kavanaugh, who will be following up on me, can give you a more illustrative response to your question, Senator. [LR283]

SENATOR WALLMAN: Thank you, John. [LR283]

JOHN WYVILL: Okay. [LR283]

SENATOR LATHROP: Anyone else? Okay. Thanks, John. [LR283]

JOHN WYVILL: Thank you. [LR283]

DR. LEE ZLOMKE: Good afternoon, senators. My name is Dr. Lee Zlomke, Z-l-o-m-k-e, and I'm acting clinical director of psychological services at the Beatrice State Developmental Center, and that's a position I held from 1987 to 1997, so I'm back on a contract basis at this point. The address of that is in Beatrice, Nebraska, at 3000 Lincoln Boulevard. I have had 30 years of experience in providing services to persons with developmental disabilities both in residential facilities as well as community-based facilities and through private practice, both in Lincoln, as well...kind of an urban area for Nebraska and as well as outstate as far out as Ogallala and have seen some autistic individuals out there. So currently I am a clinical supervision consultant at Nebraska Mental Health Centers. I am CEO and kind of a jack-of-all clinical trades for Pediatric Psychology Associates, which is a private practice psychological services firm dealing with persons with developmental disabilities and mental health problems as well as children and families, and then also working under contract as the acting director at BSDC. I have a doctorate in psychology from University of Nebraska at Lincoln. I've been a certified and licensed psychologist for 20-some years and I'm a (inaudible) child forensic psychology as well. So I'm here to provide you with some information relative to the spectrum of individuals with developmental disabilities as well as providing some information about their needs that reach a medical necessity level of care and through community-based services and at the Beatrice Developmental Center. So to break those out, this is information that's been put together around April 3 so some things are slightly different with changes in needs and populations but we should be pretty close on these numbers. Some of the numbers are not exactly comparable between the community-based programs and BSDC, that some of those numbers are not collected in exactly the same way but I'll try to go through that and kind of show you where the major differences are. I'll try to talk to you about where the substantial differences are and how those might impact some of our treatment decisions. So the first slide we're talking about, the average age of persons in community-based services is 35.2 years, and at BSDC the average is 49 years, so obviously, quite a difference in that population characteristic, and you can see in later slides the BSDC numbers as well. As far as the level of mental retardation or developmental disability, cognitive disability that are seen, some, a few, in the community have no developmental disability or mental retardation. That's been deferred. There probably are problems there but it's difficult to determine exactly the level, is usually the case on those. Persons with mild deficits: 49.4 percent in the community, while at BSDC only 16 percent have mild disabilities. Moderate disabilities: 29 percent; at BSDC, 11 percent. Severe disabilities: 10.6 percent; and at BSDC, 12 percent. And profound disability: 6.4 percent, while at BSDC 59 percent of the population has profound developmental disability. And then unspecified: another 1.4 percent. Additional mobility and other support concerns are also as follows and this is coming from Centers for Medicare and Medicaid summary statistics. Autism: 261 individuals in the community or 6.5 percent; and BSDC has a similar number, fairly close. Cerebral palsy: 14 percent; BSDC's numbers again close. Epilepsy controlled: 14 percent; BSDC's number is close to that. Uncontrolled or difficult to control seizure disorders: 12 percent in the community; 39 percent at BSDC, a significantly different population there. Ability to walk: in the community is 91.5 percent and this is one of those areas where the numbers are difficult to compare so we'll talk about that a little bit when we get over to the BSDC side. As you can see, the vast majority of persons in the community are ambulatory and can walk, whereas at Beatrice, probably around 50 percent, so quite a bit of difference there. Limited to bed most of the day: only 6.6 percent of population in the communities; the population at BSDC would be significantly higher and we can talk about that a little bit later. Or ambulating with an assistive device: 17 percent in the community; 52 percent at BSDC, so quite a difference in the amount of orthopedic supports that are required. Hearing impairments, hard of hearing: 4.8 percent in the community; 26 percent at BSDC. Or completely deaf and hearing impaired: 1.9 percent; and similar number at BSDC. Visual impairments, some level of impairments: in the community at 8.7 percent, that would be noncorrected or unable to be successfully corrected, whereas 47 percent at BSDC, quite a difference. And then completely blind would be 4.3 percent in the community and a similar number at BSDC. And another statistic that is not in your file but we needed to talk about would be those persons with severe and persistent mental illness in addition to their developmental disabilities and that is 46.3 percent in community-based programs and 66 percent at BSDC, again, quite a significant and apparent difference there. And speech and language numbers are not collected in the community to a great extent nor is tube feeding or persons who require tube feeding accounted for in community-based programs. So just on a couple of those numbers that were a little bit difficult to understand, at BSDC 52 percent of the individuals have wheelchair, need a wheelchair for mobility, as opposed to ambulatory, 96 or 90-some percent in the community could ambulate. So there's quite a difference in the amount of ambulation support that's required. And speech and language: at BSDC 96.6 percent of the individuals there have identified communication skill deficits and that might be, they have good articulation, they can say the words or they have significant...they have ability to communicate simply but have difficulty in social language or complex language to meet their needs; 96.6 percent have speech and language needs that have been identified. Feeding tubes we talked a little bit about. In the community those are not tracked, but for BSDC, 19.6 percent of our individuals are fed through a gastric tube and take nothing by mouth, which requires quite a bit of medical intervention and specialized training of staff. So when we're considering this previously discussed demographics, we must be able to keep in mind that the acuity or severity of the resources that are required is also something to be careful with; that even if the numbers are equal, there may be quite a difference in how severe those problems are being presented or how much attention or clinical expertise is required to meet those needs and we want to be careful in making those comparisons to look at the severity of the problems. You have people who may, for example, may self-injure by mouthing on their hand, just sucking on their hand which can lead to skin breakdown and can lead to callouses and that can cause some medical problems, as opposed to people who are actually gouging at their eyes. It might be different in how you have to treat that but they would all be in the same category of self-injury so we want to be careful about that. So at that point, that's my prepared testimony at this time. I thank you for this opportunity. I'd be happy to answer questions, particularly if you have any about treatment needs of individuals that have dual diagnosis for mental health and development disabilities problems as that's kind of where I spend most of my time. [LR283]

SENATOR LATHROP: Very good. Thank you for your remarks. Are there any questions? Well, I do have a few that I'd like to visit with you about. You said that from '87 to '97 you were actually employed at Beatrice in the role of director of psych services? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: Is that right? And today you serve in an acting capacity on a contract? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: Can you tell us what you do now or what you used to do when you did this full-time? I appreciate your overview and the statistics that you've given me. Now I'd like to talk to you about your role as a psychologist at Beatrice. What do you do there? [LR283]

DR. LEE ZLOMKE: Well, previously I was director of clinical psychology and we had a department of 13 psychologists, all of whom started...many of whom started at the same time I did. We came in as a response to the Department of Justice settlement that had been testified to earlier. We came in to help upgrade the services in response to that and several of us have stayed for a long period of time after that. So I was that and then I also, later, towards the end of that, I was clinical director of all clinical services that were nonmedical. So I had a big role to play, I think, in all the active treatment services and therapies that went on that were not directed by the physicians. Now, I'm there about 16 hours a week, soon to be 8 hours a week, so obviously I have a much smaller footprint on how things can be organized and the clinical services that can be developed. I'm really now trying to focus more clearly on just plans, strategic plans and implementation and training of on-site staff to continue to make the improvements that are necessary to have minimally adequate behavioral health services there on campus. [LR283]

SENATOR LATHROP: "Minimally adequate" is the measure? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: Let me...we heard this morning that residents at Beatrice State Development Center have a constitutional right to habilitation. Are the psychological services that are provided under your direction part of that habilitation? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: So as...for people who are confined as folks are at Beatrice, they have a right, a constitutional right, to receive services that allow them to improve or to advance, given their limitations. Is that right? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: And your role in that process is to treat the psych or the psychiatric or the psychological, rather, part of that process. Is that right? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: And when you came in 1987, you said that was in response to the consent decree we heard discussed this morning. Is that right? [LR283]

DR. LEE ZLOMKE: I started in '78 and became director in '87,... [LR283]

SENATOR LATHROP: Okay. [LR283]

DR. LEE ZLOMKE: ...but in '78, that's when we came on. [LR283]

SENATOR LATHROP: But it was in response to the fact that the habilitation wasn't happening. The consent decree is entered and now we're going to undertake to upgrade the services at Beatrice and they brought you on board for that purpose. [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: At that time in '78, what was the population at Beatrice in round numbers? I won't hold you to it. [LR283]

DR. LEE ZLOMKE: Maybe a 1,000. [LR283]

SENATOR LATHROP: Okay. Awful lot of people. [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: You became the director a few years after you arrived. How many psychologists did we have on staff at Beatrice when these efforts at habilitation to include psychological services was being done? [LR283]

DR. LEE ZLOMKE: Well, when I felt we were at our very best, when other facilities across the country came here to see how we did active treatment and psychological services, was in the early to and mid-nineties, in fact, and then at that point we had 13 psychologists on staff with...all of whom had around eight years or more of experience in behavioral health treatment with persons with developmental disabilities and we supervised approximately 60 subdoctoral people that helped in those areas. [LR283]

SENATOR LATHROP: You have mentioned something that I've heard said before and that is, at one point, and you said the early to mid-nineties, we were the gold standard in how to do this correctly. [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: And that was at a time when you were the director of the nonmedical services? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: You just told us how many people worked and provided psych services at the psychologist level and at the level of trained staff. How many, when you came on board as an acting director, how many psychologists did we have working for us at Beatrice? [LR283]

DR. LEE ZLOMKE: I'm not really sure at that time. I think it was probably about nine and now we're at seven and a half. [LR283]

SENATOR LATHROP: What do we need...what's the population there right now? [LR283]

DR. LEE ZLOMKE: Two hundred and eighty-ish. [LR283]

SENATOR LATHROP: Two hundred and eighty-ish. How many do we...is there a standard for how many we should have, given the patient population? [LR283]

DR. LEE ZLOMKE: The Department of Justice, I think, talks about in some of their letters, it's not really a standard, but they talk about a 25-to-1 ratio. And it's not real clear if they mean those are persons with direct psych needs or if that's your total population, some of whom may not need direct psychological intervention. [LR283]

SENATOR LATHROP: So how close, when you came on board as acting psych director, were we to the goal? [LR283]

DR. LEE ZLOMKE: Well, to be minimum, we were probably 30 percent short. [LR283]

SENATOR LATHROP: You know, you and I had a conversation the morning of the tour. Am I...I'm remembering that right? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: You and I talked before we started the tour. I thought you told me we didn't have any psychologists there? Am I thinking of a different discipline? [LR283]

DR. LEE ZLOMKE: We didn't have...we don't have a full-time psychiatrist. [LR283]

SENATOR LATHROP: Maybe that's it. You said something...I mean, if we look at the understaffed piece of Beatrice, how many full-time psychiatrists should we have? [LR283]

DR. LEE ZLOMKE: It's hard to say but we certainly...I think in the past we've had a little over half-time and did pretty well with him at that level, and we have fewer individuals now so I would think at the bare minimum it would be half-time, and I think the standards have been interpreted even more strictly lately so it may need to be a little bit more than that. [LR283]

SENATOR LATHROP: All right. Are there professional disciplines that we should have at Beatrice that we don't have? And I know you and I had a conversation about some and maybe it was speech therapy, I'm not sure. Do you recall the conversation? [LR283]

DR. LEE ZLOMKE: Sure. Speech therapy, we're very short and I think we've had two resignations since then. [LR283]

SENATOR LATHROP: What's very short? [LR283]

DR. LEE ZLOMKE: I think they were less than half-staffed when they had the two. I think they have...it may be that we have none now or very shortly. [LR283]

SENATOR LATHROP: How many should we have? If we have none now, how many should we have at Beatrice? [LR283]

DR. LEE ZLOMKE: I don't have that. I don't have that number. [LR283]

SENATOR LATHROP: Is it two or ten or can you... [LR283]

DR. LEE ZLOMKE: Well, I think they've...I think... [LR283]

SENATOR LATHROP: I'm not asking you for the exact number, but I'm trying to get a sense of the staffing issues in the professions as we look at staffing issues at Beatrice. [LR283]

DR. LEE ZLOMKE: I think they've thrown around numbers like four to six, around in there somewhere. [LR283]

SENATOR LATHROP: Okay. So instead of four to six speech therapists, we have none. [LR283]

DR. LEE ZLOMKE: I think we're looking for some contract people. [LR283]

SENATOR LATHROP: That's been ongoing. I mean, we were there May 20, a month ago, and that was the situation and we haven't found any. [LR283]

DR. LEE ZLOMKE: Um-hum. I'm not up on that. [LR283]

SENATOR LATHROP: Are there any other professions, healthcare professional fields, for which we have similar understaffing? [LR283]

DR. LEE ZLOMKE: I think at the present time, for neurology, we have a part-time consultant. That is stretched very thin. I know our medical staff are very concerned about that, to get more neurology help, and that will be very difficult to find in the state. [] [LR283]

SENATOR LATHROP: And by that, you mean a neurologist? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: A medical doctor with a speciality in neurology? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: How many do we need in an institution that has people with these profound levels of disability? [LR283]

DR. LEE ZLOMKE: It's hard to say. I would think, when we were talking with the medical staff, I believe they were talking a third or to as much as a half-time consultant. [LR283]

SENATOR LATHROP: So half the time of one... [LR283]

DR. LEE ZLOMKE: Um-hum. Yes. [LR283]

SENATOR LATHROP: And how many...and do we have anybody doing that right now? [LR283]

DR. LEE ZLOMKE: He's on contract. I don't know how often he's down. [LR283]

SENATOR LATHROP: Are there any other medical specialties or care providers that were...I know we have and we can talk about the techs and the people that are the hands-on folks but how about the other specialists? [LR283]

DR. LEE ZLOMKE: It's a strong standard of care. It's not written anywhere but it's highly suspicious if you don't have certified behavior analysts on staff. They're master's degree, some can be a bachelor's degree, but it's specialized training for behavior analytic interventions and they're...they have to pass a nationally certified test and be trained under supervision. And I think there's only one in the whole state of Nebraska and we don't have him. But it's...DOJ will be very concerned if we don't find a few of those somewhere. [LR283]

SENATOR LATHROP: And they've expressed that. [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: How many does DOJ think we should have? [LR283]

DR. LEE ZLOMKE: I don't think they...I don't think they've put a number on that but a significant...so those would be part of our psychological staff if we were fully staffed and we'd say we'd need ten, you'd hope to have four or so of those would be behavior analysts. [LR283]

SENATOR LATHROP: Are there any other specialists or care providers that we should have and don't? [LR283]

DR. LEE ZLOMKE: I think those are the major ones I can think of. [LR283]

SENATOR LATHROP: I think that's all I have. Senator Adams. [LR283]

SENATOR ADAMS: While we're on numbers, I need to get something straight. Did I hear you say that when we reached the gold standard we had a census of about 1,000 clients? [LR283]

DR. LEE ZLOMKE: No, that's where we started. [LR283]

SENATOR ADAMS: That's where we started. And at that time we had 13 psychologists? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR ADAMS: And now were at about 280 with how many psychologists? [LR283]

DR. LEE ZLOMKE: Seven and a half. [LR283]

SENATOR ADAMS: And we're not at the gold standard. [LR283]

DR. LEE ZLOMKE: Well, when we were at the gold standard we probably had about 460 with the 10...with the 13 psychologists, so we downsized at lot during those early years. [LR283]

SENATOR ADAMS: All right. Let me ask you, if I may ask one other question about speech pathologist. Do you have an opinion as to why we cannot attract speech pathologists to fill these obvious positions? [LR283]

DR. LEE ZLOMKE: It's a very popular job to be trained in right now. School districts are recruiting them all over the state at a fairly high level of pay, so it's a combination of money and the job type as well. So schools, I think both of the people that we have leaving are going into schools so it's nine months. You know, you get some summertime off. And most folks are not trained coming out in the population like ours and so that's...it's stretching them a little bit and sometimes they're not really interested in doing that as your first job. So I think there's a combination of salary and the type, what the job really entails. [LR283]

SENATOR ADAMS: I don't mean to be discrediting what you're saying, but a year ago at this time we sat in a task force on special education and we were being told what a shortage we had in speech pathology because your world and the hospital world are robbing them all from education. [LR283]

DR. LEE ZLOMKE: Well, we'd like to rob a few more. (Laugh) [LR283]

SENATOR ADAMS: Thank you. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: You discussed the shortages in these professions and that's going on really statewide in all the medical field. Yours is very specific. It sounds like what your looking...can you go out around the country and recruit, I mean, like any other person would, to say, we need these a little worse than you, we'll pay up a little more? Or is it such a narrow field that we just can't find anybody? And why are we not...I guess what are the steps, if you can answer this, what are the steps we're taking to recruit? Because it's been now ongoing a year. We know our problem, we can't recruit them. Senator Adams just talked about the speech pathologists, that's a more growing field, I guess, but are there just so few we can't get them or? This always bothers me because I hear this when we're talking anywhere in the medical field--we just can't get these people. Why can we not get them here, in your view? And I know that's a big broad question, but in your view, why can we not fill these positions? [LR283]

DR. LEE ZLOMKE: Well, it has been difficult forever. It always has been. The way we got fully staffed a couple decades ago was we grew our own. The CEO at that time, together with the state government, let them have an education initiative where tuition was paid for, they got some released work time, we did a lot of support to help and we took a lot of people who were master's degree folks and turned and got them to go back and finish their doctorate and kept most of those people for ten or more years at the time. And that's how we got...that's the only way we got fully staffed even then. We started an internship program and were successful in keeping somewhere between a third and half of those individuals for the first 10 or 15 years. We just finished two new...we just finished two interns being trained at BSDC this month and the end of next month. Both are going back, making 70 percent more than we're able to offer here. And they are just not interested in staying, I think, even if we could get even with the money. They just want to be from where they came from, so we just weren't able to keep them. But that's why we try with that internship program to grow some people and get them interested in staying and we're hoping to be more successful with that. But we do advertise, we talk to other universities that turn out a quality of individuals that we would like to have. I work with...I supervise eight interns at one facility and two at BSDC and we talk with them about all the interns that they know and we've made contacts with them trying to say, we've got jobs here and you could come, and no, nobody even applied. So it's not like we're turning anybody down. [LR283]

SENATOR GAY: So a little follow-up then. [LR283]

SENATOR LATHROP: Sure. [LR283]

SENATOR GAY: So, I mean, that doesn't sound like a program that gets done overnight. That's a long-range planning issue. [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR GAY: How long of range, I mean, to start something? [LR283]

DR. LEE ZLOMKE: It took us from '78 to '80 till about 1985 before we got to where we thought, in the consent decree, we were doing good care. So it's a seven, seven-year project under really good circumstances that I considered at that time. [LR283]

SENATOR GAY: Thank you. [LR283]

SENATOR LATHROP: Senator Cornett. [LR283]

SENATOR CORNETT: Just a quick question, and I may have heard you wrong. Did you say your hours were being reduced? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR CORNETT: Has the population decreased enough where...why are your hours being reduced? [LR283]

DR. LEE ZLOMKE: I just don't...I don't have that much time to give to it anymore. [LR283]

SENATOR CORNETT: Okay. It's your decision. [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR CORNETT: Got it. All right. [LR283]

SENATOR LATHROP: Maybe the obvious question is, we must have needed a director and the best we could do is get an acting director to come in and work 16 hours a week, now soon to be 8 hours a week. Have we replaced you? [LR283]

DR. LEE ZLOMKE: Not that I know of. [LR283]

SENATOR LATHROP: Is that process under way? Are we advertising for that position and...? [LR283]

DR. LEE ZLOMKE: I'm sure that they're in talks with...because I think it will probably need to come through an agency of some kind, I would imagine. [LR283]

SENATOR LATHROP: A headhunting agency? [LR283]

DR. LEE ZLOMKE: Yes. I would think they're doing that. We've been talking about those things for quite a while. [LR283]

SENATOR LATHROP: All right. Senator Cornett. [LR283]

SENATOR CORNETT: You have a private practice now currently, correct? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR CORNETT: What are the considerations that you have decided that it's...I'm looking at, it is a financial issue, a time issue? What would be our obstacles at hiring someone for the position that you're currently holding? [LR283]

DR. LEE ZLOMKE: Well, for me, just that I've been there, done that, you know, I'm not...so and it is very...it's going to be high stress, it's going to lots of hours, it's going to be just plain a lot of work and a lot of change, a lot of turmoil, a lot of staff being pretty upset. I mean, it is a high stress time to make this many changes. And there's always the uncertainty of where is this going to go, where is it going to wind up? Are we going to be able to pass? So then you start to say, well, I've got a lot of practice going, do I give that all up and I get into this? If this doesn't work out, it's not so easy to get that all back. And I've kind of been into, for me personally, I've been into just doing a lot of different things, not one thing. So for me that's kind of where I would be looking at. I think, you know, to find someone that wants to be a director, if you've already been a director, to come here to do this under these kinds of conditions is a very difficult decision to make and if you haven't been, you're sort of unproven and you never know what you're really going to get when you do that. [LR283]

SENATOR CORNETT: And at 16 hours a week that you have been working up until now, would you consider that an adequate number of hours or should the state be looking for a full-time person for your position? [LR283]

DR. LEE ZLOMKE: Oh, it definitely needs to be full-time. [LR283]

SENATOR CORNETT: Do you know if that's what they are doing? [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR CORNETT: Okay. [LR283]

SENATOR LATHROP: Any other questions? Senator Adams. [LR283]

SENATOR ADAMS: I was just curious a moment ago when you said, why would someone want to come under these conditions? What are these conditions? [LR283]

DR. LEE ZLOMKE: The pressure from CMS and DOJ and, you know, the press of, oh, it's not a good facility, bad things are happening there, why can't people do better work, how could you be in charge of that and then look what it's doing. And so there's just a lot of pressure from people that there's a hundred things that need to be done. You need to continue to do really good care and get a lot better and justify what you did before and there's just many, many priorities, all of which are number one. [LR283]

SENATOR ADAMS: Thank you. [LR283]

SENATOR LATHROP: We didn't talk about this but this just occurred to me and that is the fact that we have psychological services. A lot of the people that are at Beatrice, perhaps by virtue of the very nature of the disability, it's not just low cognitive folks but there are people that have psych issues and you're working on behaviors and things like that and that's what your role is. [LR283]

DR. LEE ZLOMKE: Yes. [LR283]

SENATOR LATHROP: Okay. Thank you. I think that's it. I appreciate your testimony today. [LR283]

DR. LEE ZLOMKE: Thank you. [LR283]

SENATOR LATHROP: Ron, did you fill out one of these sheets? [LR283]

RON STEGEMANN: I did and I happen to have it right here. [LR283]

SENATOR LATHROP: Great. You can just drop it in the box and we'll start with your name, and spell your last name for us, too, if you would. [LR283]

RON STEGEMANN: I will. Good afternoon, I'm Ron Stegemann, S-t-e-g-e-m-a-n-n, chief executive officer of the Beatrice State Developmental Center, which I will refer to as BSDC throughout the rest of my time, that is located in Beatrice at 3000 Lincoln Boulevard. Prior to my appointment in December of 2007 as the CEO at BSDC, I was an employee for 18 years in various positions of increasing responsibility engaged mostly in the provision and monitoring of formal habilitation services. I've had the unique experience of working, at some point in time, with every home at BSDC and have experienced working with a wide range of intellectual and developmental disabilities and challenging behaviors. My purpose in being here today is to provide an overview of services provided by BSDC, the outreach and intensive treatment services, or OTS program, at BSDC and the Bridges Program located at the Hastings Regional Center, and to respond to any questions you might have to the best of my ability about those services or about the spectrum of services provided at BSDC. I would like to thank you also for visiting BSDC and seeing our facility firsthand. The Beatrice State Developmental Center was established in 1887. BSDC is a 24-hour intermediate care facility for persons with mental retardation, ICF/MR and related conditions. As such, BSDC, with approximately 750 employees, currently provide services 24 hours a day, seven days a week, to approximately 275 individuals who present needs throughout the entire spectrum of intellectual and developmental disabilities, including those with challenging behaviors. Along with providing residential services, BSDC provides medical and nursing, psychiatric, psychology, social work, dietetics, habilitation, dental, pharmacy, cosmetology, recreation, vocational, and religious services. Therapies available include occupational and physical therapy, recreation therapy, speech language therapy, behavioral therapy, and an audiologist. BSDC currently has 23 homes on campus and offers a full-sized gymnasium, zero-entry swimming pool, chapel of all faiths, senior center, social center, exercise room, and a cafe and snack shop for resident use. BSDC is the only ICF/MR that is administered and funded by the state of Nebraska. There are also three private ICF/MRs in Nebraska that serve approximately 244 people. The outreach treatment services program, or OTS program: The purpose of the outreach treatment program is to go into the community to help individuals and the community treatment team reduce problematic behaviors and improve quality of life. An OTS consultation involves a team from BSDC, such as a psychologist, human services treatment specialist, psychology intern, from the Beatrice State Developmental Center observing the individual in residential, vocational, community and/or educational settings. The OTS team also reviews the individual's file, examines behavioral data and interviews the individual and his or her family, front-line staff, teachers and other treatment team members. OTS consultations occur over a three-day period. During the first day, an initial meeting is conducted with the individual's community treatment team in order to update referral information and develop common goals for the OTS consultation. After the initial meeting, the OTS team begins observing the individual and interviewing members of the community treatment team. The OTS team typically observes the individual until he or she retires to bed or throughout the night if behavioral issues include the nighttime. On the second day, the OTS team begins observing the individual when he or she awakens for the day. The OTS team continues to observe the individual and interview the community treatment team until midday, when the OTS team begins developing the recommendation package that will be presented at an exit meeting on the third day. The purpose of the OTS recommendation package is to assist the individual and the treatment team in reducing problematic behaviors and improving quality of life. As noted, the recommendation package is shared with the entire treatment team at an exit meeting on the third day of the consultation. A treatment team may or may not agree with the OTS recommendations. The treatment team will decide which, if any, of the OTS recommendations will be adopted. After the three-day OTS consultation, the OTS team will continue to consult with the individual's treatment team for at least 90 days in order to monitor progress and answer questions regarding recommendations. A follow-up trip can be requested and would include part of the OTS team returning to observe, collect information and provide a refinement of recommendations. The intensive treatment services program, or ITS: I will now share with you an overview of the intensive treatment services program. The ITS program is for individuals whose behavioral challenges require attention in a more secure environment. For this, BSDC offers a short-term, 90- to 120-day admission to ITS. The overall goal for an individual who enters this program is to return to their home community. It is a eight-bed, coed living environment on the BSDC grounds, and is licensed as an ICF/MR unit. Designed to meet the needs of those who have developmental disability and who also may be affected by mental illness, the ITS program utilizes a biopsychosocial approach to assessment, diagnosis, and behavior stabilization. Treatment encompasses a wide variety of modalities including behavior management, individual counseling, psychoeducational groups, recreational therapy, vocational therapy, and opportunities for individualized experiential learning. Recommendations for future supports are offered. Community staff training needs and environmental considerations are addressed and discharge plans are formulated in cooperation with service providers and/or family members. Follow-up services are available to facilitate successful transition from the treatment setting back to the community home and to provide continued support as recommendations are implemented following discharge. And lastly then, I will give you information on the Bridges Program. The guiding vision for the Bridges Program is that the provision of specialized supports will enable individuals with developmental disabilities, otherwise removed from society or restricted in some way, to have and experience opportunities for choice, empowerment, community involvement and to gain the skills necessary to live as responsibly and independently as possible. This program is a specialized developmental disabilities residential service designed to provide a structured therapeutic environment for persons with challenging behaviors that pose a significant risk to members of the community. These specialized services include treatment of the challenging behaviors, mental healthcare, habilitation services and the supports necessary for each person to realize their personal goals related to treatment and habilitation. The program is located on the grounds of the Hastings Regional Center where it has the capacity to serve up to 14 adult males. It is licensed as a Center for the

Developmentally Disabled, or CDD. And habilitative services are provided throughout each person's waking day, seven days a week, as well as providing overnight awake supervision. A program of the Division of Developmental Disabilities administered by the Beatrice State Developmental Center, BSDC chief executive officer has primary authority over and responsibility for the overall operation of the program. The Bridges Program manager has authority and responsibility of the overall on-site administration and management of the program. BSDC psychology services administrator provides the oversight and direction of the clinical treatment program. To be admitted to the Bridges Program, the person must have been diagnosed with mental retardation or a related condition and, as such, is eligible for services from the Department of Health and Human Services Developmental Disabilities System. These adults may need minimal to moderate support with activities of daily living but their behavior poses a moderate to severe and/or persistent threat to others. Intensive specialized treatment and a secure level of supervision are provided to prevent serious injury through aggressive acts or sexual behavior. The Bridges Program will be utilized when all other treatment options and less restrictive environments have failed or are unable to meet the identified needs of the individual. The goal of the Bridges Program is a reflection of its philosophy. That is, to help people gain the skills necessary to live as independently as possible through the provision of intensive, therapeutic treatment in a structured setting. To meet this goal, an array of service options is available and will be customized to each person's unique strengths and needs. Thank you. I'll be happy to take any questions you may have. [LR283]

SENATOR LATHROP: Senator Harms. [LR283]

SENATOR HARMS: Thank you. Thank you very much for coming. You know, I've listened carefully since we've come back from lunch about what you've all said. I guess what really bothers me is that what you're saying is really good but doesn't seem like it's working. When I go into the report, go into the findings, none of this stuff matches up. I mean your philosophy is good, but doesn't seem to be carried through, doesn't seem to be working, or we wouldn't be here having these discussions on these issues that were talking about now. So if that's true, whether the observation is correct or not, if you got all the power in the world, how would you fix this? [LR283]

RON STEGEMANN: If I had all the power in the world? [LR283]

SENATOR HARMS: Absolutely, and didn't have to answer to anybody, how would you fix this? [LR283]

RON STEGEMANN: Staffing, and that's not specifically the direct care staff. While that's been a large focus, I think Dr. Zlomke spoke about other staffing deficiencies that we have and he talked about in the area of psychology, it also exists in occupational therapy, physical therapy. We need a specialized group that contains speech language therapy, OT, occupational therapy, a nurse and others to be involved in dysphagia that work specifically on swallowing disorders. So it's a combination, it's a staffing issue but it's not one specific area where we're short of staff. It's not just psychology or just speech therapy. It is across the board. [LR283]

SENATOR HARMS: Okay. I'd like to go a step further then in regard to the staffing side of it. As I look at this, just reviewing it and after the tour that we had in Beatrice, it also looks like we had some really serious management issues so are you including staffing in that as part of the problem or just a shortage of staff? Because quite frankly, when I look at the issues you have in management, the simple fact is you have no communication, well, I shouldn't say...very little communication, it's not consistent. You don't have a computer system that functions appropriately, you don't have follow-up with staff in regard to medication and the issues and your reports are faulty. All those things add up to me, tells me that we have problems just in the management alone of this operation. Is that a correct observation? [LR283]

RON STEGEMANN: There have been issues associated with the management as well and those are issues that we are addressing currently. [LR283]

SENATOR HARMS: And so what are you doing with those issues? [LR283]

RON STEGEMANN: For the issues that you talked about with, for our computer system, Avatar has been brought in to BSDC but is hasn't been fully implemented, so we need... [LR283]

SENATOR HARMS: Just fixing...excuse me, sir. Just fixing the computer does not make it a manageable system. I mean, if the document is correct, which we looked at and read, which I took some time to read, you have a communication issue just within the organization. The left hand doesn't know what the right hand is doing. How are you going to bring it all together to make this functioning so that the people that we've placed in your trust is being appropriate. I said to the attorney that was here earlier that I think there's some real issues here of liability, I think there's some real issues here of accountability, and how are you going to resolve that? Because it all fits back to management. No matter what you do with your staffing, no matter what we do with the computer technology, it boils down to can we manage this system. And what are you going to do to fix that aspect because the rest of it will start to fall in place when you have strong management with the right background, the right degrees and the right educational services. [LR283]

RON STEGEMANN: First of all, for my clarification, which document are you referring to? [LR283]

SENATOR HARMS: Pardon me? [LR283]

RON STEGEMANN: Which of the documents are you referring to? [LR283]

SENATOR HARMS: The report that we had when the feds were here. [LR283]

RON STEGEMANN: The CMS, the Department of Justice? [LR283]

SENATOR HARMS: The last one that you had. You know, you've got more than just one. It's the last one we had, the last when the feds were here that deals with Beatrice Development Center. It shows us the plan of all the issues that you've had, and the problems that you have; going to lose, what, $28 million... [LR283]

RON STEGEMANN: Oh, so that would be the CMS report, okay. [LR283]

SENATOR HARMS: The whole thing is what I'm really driving at. That's the last one that I've looked at. It's the last one. That's what brought all of this. That's why we're all here at the table today, is that issue. And that's pretty clear and pretty distinct to me and they spell out pretty clearly what the management issues are here and so that's what I'm really driving at is, I mean, you can fix all these things but if you don't change the culture of the organization and I've been in plenty of operations where the culture had to be changed, not easy. And if you can't change that culture, you're not going to be successful here. [LR283]

RON STEGEMANN: Right. And there's no doubt that culture does need to change. One of the things we've been trying to do and Mr. Wyvill has been very helpful for me in my role is to make the facility more of a transparent organization so that it's not a small group of people in a room making decisions about what's going to happen at BSDC, so that we get out and we get information from the folks that live out there, the folks that work out there, and we make those decisions as open to everyone who wants to be involved as possible. We now have a leadership team that's representative of the entire campus. We've invited staff into those meetings, we've invited individuals into those meetings, so it's not so much a closed-door system as it had been for probably about the previous ten years from that. And we do have a lot of work that we need to do with the management issues. There's no doubt about that as well. However, as someone shared with me once, it takes about a hundred miles out in the middle of the ocean to stop a fully loaded tanker. When CMS hit BSDC in 2006, with all the issues that they brought forward in their first 431-page report, we were a tanker in the ocean and we were fully loaded, so it will take us time. And as Dr. Zlomke said just a little bit ago, it took them about seven years under ideal conditions to build a fully functional system. [LR283]

SENATOR HARMS: But, you know, we've had this issue since 1972. Then we fixed it for a short period of time and brought it back where we are, and maybe then worse than it was in '72. You've got the same issues. So my question really is, how much longer can we wait? And I'll leave it there, Mr. Chairman. [LR283]

SENATOR LATHROP: Questions? Additional questions? Senator Stuthman. [LR283]

SENATOR STUTHMAN: Thank you, Senator Lathrop. Ron, you talked about, you know, the staffing part of it. Do you feel that if there was more money allocated, increased wages would attract a lot more people for staffing? [LR283]

RON STEGEMANN: I can't really say whether or not that would bring more people into BSDC. That's one of the things that's been thrown around in the media. The staff at BSDC have indicated that they feel like they're not being compensated at a rate that's high enough where...and that very well may be true. But if you look at the level of pay that human services...employees in the human services field receive statewide, we've looked at Beatrice, we've looked at nonrelated positions within our area and it seems that the compensation is at a relatively high or higher-than level than all those rates of compensation. A big concern that I have was from the gentleman who sat in this chair before me, was that I...along with his having been there and done that, so to speak, and he was kind enough to come back to BSDC and really try to help us through that, is our ability to attract and keep qualified experienced professional staff in order to provide the services we need to provide. I'm not sure that were at an appropriate level for those folks, based on our having to bring some, for instance, pharmacy staff in and at at-will positions because their pay grade wasn't high enough to do it otherwise so. [LR283]

SENATOR STUTHMAN: Thank you for that. I have one other question. I don't know if I heard you right. How many employees do you have there? [LR283]

RON STEGEMANN: There's approximately 750 at the present time, I believe, and that's total. [LR283]

SENATOR STUTHMAN: 750 employees and 280 patients? [LR283]

RON STEGEMANN: I think, as of this morning, we're down to 272 and we do also, with that 750 employees, that's full-time employees, we have currently about 100 on-call staff who work directly with individuals also and that's not even a part-time level, it's an on-call type position so. [LR283]

SENATOR STUTHMAN: Okay. Thank you. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: Thanks. Ron, we toured Beatrice but in Beatrice there's that Mosaic. What's the difference between what you're doing and what they're doing? [LR283]

RON STEGEMANN: There isn't any other than the fact that they're smaller. [LR283]

SENATOR GAY: They're smaller. No difference whatsoever. Did they take the same level, do they provide the same level of care? [LR283]

RON STEGEMANN: Typically, and I'm more familiar with the Mosaic program in Beatrice certainly than in the other two locations but they don't. Because they're a private provider, they have the ability to pick and choose to a certain degree who they have in their program. So they don't have the severe behavioral challenges that we have at BSDC, and they wouldn't necessarily have the severe medical conditions that we see at BSDC. So they kind of fall in the middle somewhere, so to speak, in terms of developmental disabilities and ranges and some of those challenges that exist, and as a state organization we serve whoever comes, so. [LR283]

SENATOR GAY: So there's a big difference then between that, and then in Axtell is there another facility? [LR283]

RON STEGEMANN: There's one in Axtell and I believe there's a small one in Omaha, I believe. [LR283]

SENATOR GAY: So the same situation goes there, what you're telling us, they're picking a little easier clientele? [LR283]

RON STEGEMANN: I'm not going to say that but they do have the ability to kind of pick and choose who they're going to provide services for. [LR283]

SENATOR GAY: Okay. Well, I guess, what I was asking you though, what is the difference? And you're telling me the difference is the patients. You've got a lot more intensive care than they have, is what your saying. [LR283]

RON STEGEMANN: Right. They can terminate services; we don't. [LR283]

SENATOR GAY: And you don't have that ability whatsoever? [LR283]

RON STEGEMANN: Right. [LR283]

SENATOR GAY: Okay. Thanks. [LR283]

SENATOR LATHROP: Senator Adams. [LR283]

SENATOR ADAMS: If I might, I'd like to go back on the line of questioning that Senator Harms had started--the culture. You're there, you've been there, so in your opinion, describe for me that culture that needs to change. [LR283]

RON STEGEMANN: One of the big pieces of the culture that needs to change, unfortunately, arose out of what Dr. Zlomke alluded to earlier, was that at one time the BSDC was the gold standard in terms of providing services certainly in the Midwest and probably nationally, and that was about the time I came on board as well, in 1989. Because we were considered to be one of the best programs in the nation, we became very protective of that image and so we quit going, once we had grown our folks to a certain degree, we quit going outside for new and innovative ideas and information. So we became a little bit...we excluded ourselves to a certain degree. Secluded ourselves from the rest of the DD world, so to speak, and said, well, we can do this on our own, we've done it before. And we have to change that. We need to get up to speed with the rest of developmental disabilities across the United States, and so that's part of what has to change. We have to get out of the idea that we know what we're doing, and that we don't need any assistance, because it's obvious that we do need to get new and innovative ideas and we need to upgrade our thinking with how we're going to be providing services. [LR283]

SENATOR ADAMS: Anything else? [LR283]

RON STEGEMANN: Another big piece of that that's different, of course, than when Dr. Zlomke was talking about periods of time ago, we do have a core group of wonderful and committed veteran direct care staff, as well as professional staff throughout the organization. Part of what's a little bit different now is some of the younger employees that we're getting on board. I remember attending a Sharing Our Best conference that we had at BSDC probably not more than five or six years ago or possibly a little later, and they told us, you will be getting employees in here that will not stay longer than a year or two and it isn't because they're bad people, it isn't because they're, you know, they shouldn't be in this field. It's just that that generation won't stick around very long. And so somehow we have to find a way to get people new into the organization to commit to the organization, to stay for long enough so that we can meet what's in the standards, which says that you need to have knowledgeable, trained staff that are providing services for the individual. If they're not staying longer than a year or so, it's very difficult to say that these are indeed knowledgeable and trained staff. So that's a big piece, I think, needs to change as well. And then, to kind of add to that, I would go back to what Mr. Mason said this morning in making BSDC. He talked about a one-system sort of issue. BSDC and the developmental disability system in Nebraska do need to come to a much better relationship in terms of statewide--how are we going to go about the business of providing services to people with developmental disabilities? And that's something, I think, that can be very exciting and that I'm looking forward to BSDC being a part of this, how do we bring all this together and really come up with an effective service delivery system that includes BSDC, that includes the private providers, mental health services, all of those issues, so. [LR283]

SENATOR ADAMS: May I ask one more? [LR283]

SENATOR LATHROP: Certainly. [LR283]

SENATOR ADAMS: What do you think, in your opinion, has caused the riff, I use that word, that presently exists that needs to be unified or bridged? [LR283]

RON STEGEMANN: Between...in the system? [LR283]

SENATOR ADAMS: Exactly, the various... [LR283]

RON STEGEMANN: I don't know that there's necessarily...hasn't been a riff that's been created. It's kind of, within my experience and having been there about 20 years, it's always been kind of BSDC was down in Beatrice and doing their thing and the rest of the system kind of was out there doing its thing. So I think it's important now and I think the opportunity exists and I know Mr. Wyvill supports that becoming more of a one system where the right hand knows what the left hand is doing and there's much less confusion within that. And I see the future of BSDC as being...I talked about our intensive services unit, a short-term program where folks can come in who may need some stabilization, who may be struggling a little bit, and teams that we can send out for our OTS program to go out into the community and provide some expertise and assistance and stabilize in that environment. I see that program as possibly expanding at BSDC and becoming a resource statewide when people get into situations where they need additional support, and also a choice for families, for individuals in Nebraska, for those who have developmental disabilities, a choice of living, learning environments, if that's the one they're willing to make. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: To follow up on Senator Adams' question, that was where I'm going too. It just doesn't seem like anyone is working together. You have, you know, you guys doing your thing, then you've got community-based people doing their thing, and you know, it just seems like there's no correlation between the two. And I know with reorganization, that's what I've been looking for and I'm sure everyone here is. That's why we reorganized HHS and that takes effect July 1, so I don't have a big heartache with that but that's exactly what needs to be done, not just in this but in all your departments. And I know you play one portion of that and that's what the main focus is today. But hopefully, as we do a...Health and Human Services is doing a interim study on one-, five- and ten-year goals that we want prioritized, and Senator Stuthman will be working on that this summer and all of us will, but this is a perfect example of why we're trying to do that. I mean, you've got to work together. If we have a program, an internship program, that was the best and we let it pretty much disappear, then that's not going to happen overnight but we all need to be working together to get employees, do all these things we want fixed. And I know it's going to be tough and you can't...it's more of a statement, I guess, than a question, but it is frustrating when you don't see people working together, creating their own little island so. [LR283]

RON STEGEMANN: Well, just as a kind of a comment towards that, I think the reduction in census at BSDC and the number of folks that have gone into the community-based developmental disabilities provider system, as well as other services outside of BSDC, is evidence of a start that that is changing so...there's no way that we could have reduced our census and there's no way we can meet our goal without there being services out in the community and us working together and with service coordination in order to make that happen. So I think we have a start for that. [LR283]

SENATOR LATHROP: Any other questions? Oh, Senator Harms, sure. [LR283]

SENATOR HARMS: Have you given any thought to, you know, in the areas that you're really short, where you really need the help of working on an arrangement with the state and colleges to be able to give students, who are in that field that you're short, tuition waivers, free tuition, maybe their books and their fees, if they would come back and have to work at Beatrice for maybe five years, ten years, getting the brightest kids you have, students you have, and also in that whole process, having an internship where they'd come back and spend, you know, six months with you in some type of an internship to start to help us, you know, ease that stress and pressure? I know that they're young and inexperienced but at least they're going to be educated and they're wanting to learn and give that, because some...I know we've done that in rural America with the family physicians where they go to Chadron State College and some of these others and they complete their degree and they come back, have to spend so many years in that portion of rural America to pay it back or they have to pay it back in cash. Have you given that any thought to give us some help and some relief that might get these younger students, younger people turned on and into Beatrice? [LR283]

RON STEGEMANN: Actually, I reviewed the information specifically that you're talking about within the last couple weeks where it had the rural initiative. Now whether or not we could get something like that going at BSDC, based on my review, I didn't see that we would necessarily qualify for that. [LR283]

SENATOR HARMS: Well, we're going to change the law. [LR283]

RON STEGEMANN: Okay. [LR283]

SENATOR LATHROP: It's our prerogative. (Laughter) [LR283]

SENATOR HARMS: There's no problem, we've go so many people in here. (Laughter)

[LR283]

RON STEGEMANN: Okay. [LR283]

SENATOR HARMS: I guess what I was just asking if you'd have any interest. If we have to massage that around to where you qualify, would you be interested? [LR283]

RON STEGEMANN: Absolutely. Absolutely. [LR283]

SENATOR HARMS: Thank you. [LR283]

SENATOR LATHROP: Senator Cornett. [LR283]

SENATOR CORNETT: I haven't read the contract that you have with your employees and I know that different state employees have different contracts and some have tuition reimbursement. Do you have anything like tuition reimbursement for any positions now in your contract? [LR283]

RON STEGEMANN: Yes, we do. And I don't know specifically who that would affect and that's all done through our human resources department. But we do have tuition reimbursement. [LR283]

SENATOR CORNETT: Do you know to what extent you already have that? Is it 50 percent? [LR283]

RON STEGEMANN: I believe it's 50 percent for educational needs, general needs, and up to 75 percent if it's specific to your job and your position to improve. [LR283]

SENATOR CORNETT: And is there a payback period like there is, I know, for legislative staff, that they have to work so many years after receiving that tuition reimbursement or pay back a percentage, depending on the number of years they work after? [LR283]

RON STEGEMANN: Yes, there is, but I can't tell you specifically what that agreement is. [LR283]

SENATOR CORNETT: Do you know if any number of employees are utilizing that currently? [LR283]

RON STEGEMANN: I can't tell you. I know that within the last year, they always send out information that money is available and then they tell us when it's gone, so I'm assuming folks are using it so. [LR283]

SENATOR CORNETT: Interesting question: Are you...how much are you budgeted for?

Is there a cutoff point where then you don't authorize people even if you need... [LR283]

RON STEGEMANN: That I'm not sure about. We have to...we'd have to check with folks in our human resources who manage that piece of it for us. [LR283]

SENATOR CORNETT: Thank you. [LR283]

RON STEGEMANN: Kind as Dr. Zlomke alluded to earlier, they...there was a huge initiative at the time when he was at the master's level and went through and got his psychology degree and there were several of his colleagues that went through and did that. We basically paid for them to get doctorates. [LR283]

SENATOR CORNETT: And then they were required to work for so many years to return that? [LR283]

RON STEGEMANN: Right. [LR283]

SENATOR CORNETT: Do you know if people are being denied tuition reimbursement currently? [LR283]

RON STEGEMANN: I can't tell you that. [LR283]

SENATOR LATHROP: Okay, I do have a few questions if everybody else is done. [LR283]

RON STEGEMANN: Yes, sir. [LR283]

SENATOR LATHROP: You talked about, going back to the staffing issue, there are...and we're going to have a day probably in August where we'll talk about staffing in more detail but I do want to ask you this and it's kind of a staffing/money question. And that is, you talked about there is a chronic shortage of direct care staff, which would be sort of the tech level people that are involved in the face-to-face care of the residents, but also that you had shortages in occupational therapy, physical therapy, speech therapy and nurses who can work with swallowing disorders, among other things. [LR283]

RON STEGEMANN: Right. [LR283]

SENATOR LATHROP: Apparently you have a problem with finding a director for psychological services and a neurologist to provide staffing at Beatrice. Are there other areas or does that cover it? [LR283]

RON STEGEMANN: There are other areas. I'm currently in the process of working on getting four administrative level staff in, in the areas of active treatment, residential services, quality improvement, and then someone to run our investigations. [LR283]

SENATOR LATHROP: Okay. [LR283]

RON STEGEMANN: And we're in negotiations for a contract to get that completed. [LR283]

SENATOR LATHROP: These staffing shortages have been the subject of CMS reports and they are not new to you, is that true? [LR283]

RON STEGEMANN: Yes. [LR283]

SENATOR LATHROP: And the fact that you have staffing shortages, is it because we, as a state, have not allocated the money for you to hire these positions or you just haven't been able to fill them? [LR283]

RON STEGEMANN: I'm not sure which it is or if it's a combination of the two. [LR283]

SENATOR LATHROP: A little bit ago there was...and I think this was in response to some questions about the difference between the Beatrice and a Mosaic, for example, and the point you made was is that Mosaic or some of these community-based providers who want to develop their populations in their programs can essentially come to Beatrice and read through people's files, do an evaluation and an assessment, and then decide if they want the person or a particular person at Beatrice or not. [LR283]

RON STEGEMANN: No, we wouldn't let them come and do that. [LR283]

SENATOR LATHROP: Isn't there an evaluation process if you propose to have somebody move from Beatrice to a community-based program, that community-based program can do an assessment to see if they're willing to take that person? [LR283]

RON STEGEMANN: If it was on the person's initiative and/or their guardian, then we would allow them to look through that information, yes. [LR283]

SENATOR LATHROP: I'm not suggesting there's anything wrong with that but the net result is that you end up with the population with the most needs. Would that be a fair way to put it? [LR283]

RON STEGEMANN: Yes. [LR283]

SENATOR LATHROP: Because when somebody comes, they may say, well, I can't take somebody that has cognitive difficulties and cerebral palsy and behavioral difficulties, I can't take those people into my program, and so that person remains at Beatrice. [LR283]

RON STEGEMANN: Yes. [LR283]

SENATOR LATHROP: And what has happened by virtue of that process happening over and over and over is that the Beatrice Development Center has, generally speaking, the higher needs population than do community-based programs. [LR283]

RON STEGEMANN: Generally speaking, yes. [LR283]

SENATOR LATHROP: We can agree that that's generally true. [LR283]

RON STEGEMANN: Yes. [LR283]

SENATOR LATHROP: I want to ask you about the criteria and I don't know if the criteria for people to remain at Beatrice is a function of that process, which is to say nobody in the community has picked them up, or if they are there because of particular needs that they have. I want to give you...remind you that when you and I did a tour there were...we were going through one of the houses or one of the buildings and you suggested that some of these people have behaviors that can be misunderstood out in public. [LR283]

RON STEGEMANN: Right. [LR283]

SENATOR LATHROP: All right. They might approach somebody and somebody in public might misunderstand the nature of their attempt to approach them, just as an example. [LR283]

RON STEGEMANN: Right. [LR283]

SENATOR LATHROP: So what's the criteria for retaining people at Beatrice? Is it because we can't get them into a community? Or do we have a criteria for retaining them because of their behaviors, because of their needs? [LR283]

RON STEGEMANN: I don't believe there's a criteria for staying at BSDC, if there is a provider out there who can meet an individual's needs that can serve them in the community. So there's no criteria then to stay. [LR283]

SENATOR LATHROP: No one could argue with that statement. The question is, in reality, are there people that can...providers that can meet those needs or does the fact that we have this population at Beatrice with significant needs suggest that Beatrice is the only place where those needs are being met in the continuum of care providers?

[LR283]

RON STEGEMANN: Presently, yes. Yes. [LR283]

SENATOR LATHROP: Now, that being true, can we talk just for a second about what that means. Are these folks who are at risk to harm themselves or somebody else? Is that part of the Beatrice population? [LR283]

RON STEGEMANN: Yes. [LR283]

SENATOR LATHROP: And they are the folks that, for whatever reason, don't seem to be placed in the community. [LR283]

RON STEGEMANN: Right. [LR283]

SENATOR LATHROP: And there are people who have behaviors that can be misunderstood and, as a consequence, they could be at risk or someone in the community could be at risk if they were in a community-based setting. [LR283]

RON STEGEMANN: Yes. [LR283]

SENATOR LATHROP: So do I understand then that at some level we need a Beatrice for these folks who are safety risks in the community? [LR283]

RON STEGEMANN: Yes. [LR283]

SENATOR LATHROP: Defining what the criteria is or what that population should be may be for another day, but at least we can agree that we need Beatrice for ITS, we need it for some of the other services, and we need it for those people who are at risk, whose safety is at risk if they're in the community. [LR283]

RON STEGEMANN: Yes. [LR283]

SENATOR LATHROP: All right. That, I think, is all I had and I don't know if that's prompted any other questions. Senator Wallman. [LR283]

SENATOR WALLMAN: Thank you, Senator Lathrop. Yes, hi, Ron. [LR283]

RON STEGEMANN: How you doing? [LR283]

SENATOR WALLMAN: Is there a waiting list of clientele that wants to be admitted to BSDC as of right now? [LR283]

RON STEGEMANN: It is my understanding, there is no waiting list for BSDC... [LR283]

SENATOR WALLMAN: No waiting list. [LR283]

RON STEGEMANN: ...with the exception of, they do maintain a list of individuals for our ITS program so that they can be prioritized in the event that they would need those services. [LR283]

SENATOR WALLMAN: Okay. Thank you. [LR283]

SENATOR LATHROP: I think that's all we need. [LR283]

RON STEGEMANN: Thank you. [LR283]

SENATOR LATHROP: Thank you very much for your testimony. I think Miss Kavanaugh is up next. Good afternoon. [LR283]

KAREN KAVANAUGH: Good afternoon, Senator Lathrop and members of the committee. My name is Karen Kavanaugh, K-a-v-a-n-a-u-g-h... [LR283]

SENATOR LATHROP: Miss Kavanaugh, I'm going to...just before we even start, let's have you move that mike a little bit closer and speak up just a little bit louder so everybody in the back can hear you. You have a soft voice and we want to make sure we get a good record and that everybody has a chance to hear what you have to say. [LR283]

KAREN KAVANAUGH: Okay. I am acting administrator of the community-based services and planning section of the Division of Developmental Disabilities. My purpose in being here today is to provide additional information about the developmental disabilities services available through community-based providers and the numbers of persons currently receiving those services. On the community-based side, the division provides services for 4,116 persons as of June 6, 2008. These services include day or vocational services, residential and respite services. Within the Division of Children and Family Services, DD service coordination provides services to just over 4,500 persons, which would include the 4,116 persons served by the Division of Developmental Disabilities. The service coordinators will move from Children and Family Services to the Division of Developmental Disabilities on July 1, 2008. A fundamental premise of DD service provision is that we do not attempt to recreate services that are available to every citizen of a community. Instead, we support people to fully integrate into their community and access community resources. What the Division of DD does do is to support development of specialized services. This means that funding comes through the Developmental Disabilities Division and goes mainly to specialized community-based service providers with whom we contract to provide services specially designed to meet the needs of persons with developmental disabilities. Habilitation is the difference between providing care and specialized service delivery. Day and residential services are expected to include habilitation training and supports designed by the person's team to help the individual become as independent as possible. Specialized respite is not intended to be habilitative, because it is generally short-term relief for the usual unpaid caregiver, who is generally a family member. However, staff who provide the service must have an awareness of the person's strengths and needs in order to meet their needs. Community supports waiver services are services which are not provided by specialized providers, but it is more than simply care, as you will hear later. Community supports waiver services are designed to give the person and family a choice that includes no requirement of habilitation and allows more flexibility to meet the needs of the person. There are currently approximately 3,500 people receiving day or vocational services. These services are delivered during weekdays, during the time that people generally work or are in school. For the rest of the day and weekend, residential services are available. There are currently just over 3,000 persons receiving these services. Day and residential services are further designated as either assisted or supported services. More often than not, assisted services are provided in group settings where staff are providing service to more than one individual on an ongoing basis throughout the time they are in the service, while supported services are generally provided on a face-to-face basis for brief, discrete periods of time. Assisted residential services are delivered to individuals who require the ongoing presence of provider staff to meet their residential needs. Assisted residential services may take place in a group home setting or an apartment where two or three individuals live with staff present whenever any of them are at home, or in an extended family home where an individual lives with a family who is paid by the specialized community-based provider to provide habilitative services. In assisted residential services, one can expect staff to be present overnight and during any daytime hours when individuals are at home. Supported residential services, on the other hand, are delivered to individuals who require the presence of staff only intermittently to meet their residential needs. This may be because the individual is more independent and can live in an apartment or house without supervision most of the time or because there are natural supports in place, so that 24-hour provider supervision is not needed, such as when an individual lives in the family home and provider staff are needed only a few hours a day or week; i.e., in-home supports. In either type of residential service, the community-based provider is expected to provide habilitative training and supports designed to meet individuals' needs. Typical training programs would teach skills such as hygiene, socialization, communication, and independent living skills such as budgeting and shopping, cooking, housekeeping, and laundry. Behavior management programs may be a part of an individual's residential services. Provider staff may also need to support individuals in either setting, with transportation and duties such as writing checks, handling mail, medication administration, and going to the doctor. The decision as to which type of residential service the person usually gets comes down to the person's need for supervision and supports, as well as personal choice. Similarly, assisted day services are for individuals who require the ongoing presence of provider staff to meet their needs during normal work hours. Assisted day services may take place in a shelter workshop, volunteering at community settings, or during work crew activities such as working on a mowing crew or a janitorial crew in local businesses. Also included are work stations in industry, where provider staff may operate a work crew in a factory setting. In assisted day settings, one can expect staff to be present during any hours when individuals are getting day services, generally weekdays. However, this service can be adjusted for work crews that work evenings or weekends. Supported day services are for individuals who require the presence of staff only intermittently to meet their needs during work hours. Supported day services are generally provided face to face and may involve job coaching or individualized support to apply for jobs, work as a volunteer, or work on specific work-related skills. Again, in either type of day service, the community-based provider is expected to provide habilitative training and supports designed to meet individual needs. Specialized respite services are also available. These are services where families can receive trained staffing support to give them a short break from caring for their own child. There are currently 480 families receiving this service. Respite services include supervision and activities organized to meet the physical or psychological needs of the individual, which may include intervening with inappropriate behaviors. The community supports program is the most recent addition to the Division of DD-funded services, having been approved as a Medicaid waiver in August of 2006. The community supports program is a program where persons, with the aid of family and friends, hire and fire their own personal provider to meet their needs. This program allows persons to self-direct their services, thus increasing their control and the accountability of their provider in meeting their needs. People accessing this service assign or agree to allow DHHS staff to contract with independent, nonspecialized providers, authorize services, and pay providers for the services provided. Currently, there are approximately 60 persons in the community supports program. In some respects the community supports program shares some similarities with supported services. There is an exception that the individual will not generally need ongoing supervision from a provider but will get face-to-face services to assist with activities of his or her choice. Typically this funding pays for assistance with personal hygiene and grooming, housekeeping, accessing community resources, activities and events, obtaining and maintaining employment, developing self-determination and self-advocacy skills, or maintaining a personal and social network of persons who can provide supports. Unlike other services, the community supports program can pay for personal emergency response systems, assistive technology and supports, home modifications, and vehicle modifications. Currently, funding is limited to the eligible person's authorized amount, or $20,000 per year, whichever is less. In this final part of my testimony, I will discuss the number of persons who have requested services but are not receiving them. There are many ways of discussing waiting lists, and I will try to provide sufficient explanation, to avoid confusion about the numbers. When asked about a waiting list, we can provide either the total number of persons who are waiting for services, including those who are past their date of needs, and those who are requesting services in the future. This can provide a relatively inaccurate picture of the number of persons who want services now and in the future, as the request for services extends 20 years into the future, and there may be additional requests after today that will be for services before the year 2028. Therefore, the figures shown here will be for persons who are truly waiting for services; that is, those who, had funding been available, stated that they wanted to begin services prior to June 1 of this year. There are a total of 1,772 persons who fit into this category. Of that number of persons, 738 are currently receiving some services and are requesting additional services. The remaining 1,034 persons are not currently receiving any hard services from the division, though they may be receiving service coordination. The breakdown of services requested is as follows. Note that the numbers will add up to over 1,772, as some persons are waiting for more than one service. There are 422 requests for day services, 1,559 requests for residential services, and 316 requests for respite. There is an obvious disparity in the number of requests for residential services, especially relative to the number of requests for day services. This occurs, as the Legislature has funded day services for graduates from Nebraska high schools for the past 15 years. Thus, most persons have been able to have funding to meet their day service requests, which has significantly reduced the number of persons waiting for day services. This is further illustrated when we look at the waiting list requests for persons who currently are in services. Of those 738 persons, there are only 46 requests for day services, 57 requests for respite services, but 691 requests for residential services. Thank you. I would be happy to answer any questions that you may have. [LR283]

SENATOR LATHROP: Senator Stuthman. [LR283]

SENATOR STUTHMAN: Thank you, Senator Lathrop. Karen, just on your last comments, as far as the group of people that are not getting any service,... [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR STUTHMAN: ...what are they doing? Are they just staying at home? Are they just not...don't have the, you know, the ability or they are not receiving service? And most of them are day service, where someone needs to just be there for the day, or something for them to do. What are they doing? [LR283]

KAREN KAVANAUGH: It depends on the person and the family. Some of those children may be very young children who are still just living in the family home, but their families have thought ahead and are requesting services far into the future. And then there are another group of individuals who would be living their lives in their communities, with natural supports. [LR283]

SENATOR STUTHMAN: One other question that I have, Karen, is do...the people that are receiving community services, do they come from communities or do they come from an institution? Do you see many come from an institution to the community service? [LR283]

KAREN KAVANAUGH: I think the data would reflect that there has not been a great number of people coming from the institution in recent years; however, of course, this year there's been a significant impetus to have people move from the institution into the community. Many of those early placements were going to nursing facilities in communities, but we are also seeing people that are coming out into community-based services that are authorized for specialized community-based services. [LR283]

SENATOR STUTHMAN: Thank you, Karen. [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR LATHROP: Senator Cornett. [LR283]

SENATOR CORNETT: Is there a waiting list for 24-hour care? People that...like parents that know they're no longer able to care for their children, that would not be eligible to live on their own? [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR CORNETT: So we have a waiting list currently for people that need 24-hour care. [LR283]

KAREN KAVANAUGH: If you look at 24-hour care, I guess I'd look at it from the perspective of, that means that they're looking for day services and residential services. [LR283]

SENATOR CORNETT: Yes, not something...do we have anybody waiting--and I know this was asked earlier,... [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR CORNETT: ...for a place like Beatrice, where they need 24-hour care in the same facility? [LR283]

KAREN KAVANAUGH: In an institutional facility? [LR283]

SENATOR CORNETT: Yes. [LR283]

KAREN KAVANAUGH: The only waiting list is again, as Ron had stated, the people who are waiting for the ITS services, because technically, ITS is an admission to BSDC.

In order to receive that service, though, it's considered a short-term service. [LR283]

SENATOR CORNETT: Then when...if there's a waiting list for those people, when they move out of that program, are we talking about putting them into 24-hour care facilities in the community? Or...I mean, if they need that now,... [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR CORNETT: ...aren't they going to need that in the future? [LR283]

KAREN KAVANAUGH: It depends. Again, of that set of people that are waiting for ITS services, typically it means that there is something going on in their life that's maybe a crisis, and they're natural supports are struggling. So they may come in, get intensive services. They come out with their...they will have stabilized some of their behaviors, and there's a plan to support the person. After that, it continues to be their choice as to what type of service it is that they may request after that. [LR283]

SENATOR CORNETT: I'll give you an example, and I haven't looked into it, but I've gotten a letter from someone that lives in my district that is elderly. They've had their child living with them with support services coming into the house and helping them. [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR CORNETT: That person is significantly disabled. They...the parents feel that they need to move into some type of 24-hour care--a nursing home, a...some type of community-based program--something. And they said that they've been on a waiting list for a significant amount of time for that. [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR CORNETT: What is the standard or average waiting time for someone that needs to be placed? [LR283]

KAREN KAVANAUGH: That I could not tell you. I don't have that information. I do have a staff person that's here in the audience who may be able to answer that question. [LR283]

SENATOR CORNETT: Okay, thank you. [LR283]

SENATOR LATHROP: Any other questions? Yes, Senator Wallman. [LR283]

SENATOR WALLMAN: Thank you, Senator Lathrop. Hi, Karen. In regards to oversight of your caregivers, do you do that with the department? How do you do that in your different departments; you know, the degree of care they need, the caregiving, you know, how they are, as far as abusive? How do you deal with that issue? [LR283]

KAREN KAVANAUGH: The oversight? There's a few layers of oversight. First of all, the community-based provider is expected to monitor their services delivery themselves. So every one of the providers is required by regulation to have monitoring systems in place. We also have service coordinators that are located across the state in communities. They also go in and provide monitoring of service delivery on a regular basis. They have routing, set times that they are required to do monitoring, but they also can go in at any time, and often do, just to stop in. And at that time they can also complete monitoring. There is a feedback loop to the provider, so that they know what they saw and can respond to any concerns that were found. And then the state also does certification activities of all of our providers. Those certification activities are completed by staff in my office, as well as staff through DHHS public health licensure. [LR283]

SENATOR WALLMAN: So you set up contract agreement with HHS, right? How do you... [LR283]

KAREN KAVANAUGH: The providers have contractual agreements, yes, with DHHS. [LR283]

SENATOR WALLMAN: Thank you. [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR LATHROP: Senator Adams. [LR283]

SENATOR ADAMS: Do the private providers have the same kind of staffing issues that we heard about this afternoon? [LR283]

KAREN KAVANAUGH: Most of the private providers don't have the staffing issues, as far as the professional staff as was indicated at BSDC, because typically they're going to get their services, their ancillary services like speech pathology, OT, psychological supports, those are going to come through the community. So if they...I guess it depends. When I think about it, it depends on the perspective of the provider and where they're located in the state, if they're having more difficulty than not in accessing those services. [LR283]

SENATOR ADAMS: Then as a follow up to that, do we find in rural Nebraska more staffing issues than eastern Nebraska, I mean, finding those... [LR283]

KAREN KAVANAUGH: As far as professional staff? [LR283]

SENATOR ADAMS: Yes, yeah. [LR283]

KAREN KAVANAUGH: I think that...someone had said earlier that it seems that west of about--in my opinion--west of about Grand Island or so, you start to have a less immediate access to professionals in the state. However, I know that a lot of folks travel to the larger communities in the state to get services and supports for people, as well as they'll use telehealth, if that's available. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: I've got a question on transportation, getting clients to...let's say you have a vocational opportunity, the transportation needed to get people around. Is that the state's responsibility, or the region? Or how is that all taken care of, if you're moving people constantly to services? Is that a state responsibility, or is that up to the local counties and regions? [LR283]

KAREN KAVANAUGH: To get them where? I'm sorry. [LR283]

SENATOR GAY: Well, let's say you're (inaudible) transportation issue to get to, let's say there's a work site. We have a vocational opportunity. Is it the state is paying for that or the counties? [LR283]

KAREN KAVANAUGH: We have built into our rates reimbursement for our providers. Transportation costs are figured into that. [LR283]

SENATOR GAY: Coming out of the budget of the budget we looked at prior. [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR GAY: And then on some of these vocational services, or the...I think it would fall under the day and residential maybe, where jobs are set up for people,... [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR GAY: Is that...how are we doing on that as a state? Not enough jobs? Or is it...how is that coming along? I know, you know, there are certain things that are set up, employers are providing jobs. But how are we doing on that as a state? And then also, is there any tax advantage to those employers to do that? [LR283]

KAREN KAVANAUGH: The first part of your question, it depends on the provider. We have some providers who specialize in vocational services, where that is their focus primarily, is to develop job opportunities for people in the community. So that service is available specifically. We have what is called a supported employment rate that we also pay our providers, which is sort of an incentive for finding real jobs for folks, that are at minimum wage and that are up to 40 hours a week. So that has helped to improve the job opportunities for people in the state. And some folks it just depends. I think that people are always looking to develop new opportunities. Some people are entrepreneurs on their own, and that can be encouraged, as well as working through a provider helping them to find a job. As far as if there's any tax incentive, I don't know. [LR283]

SENATOR GAY: Is there a certain portion...are all portions of the state working on that? I know... [LR283]

KAREN KAVANAUGH: On finding jobs for people? [LR283]

SENATOR GAY: Yeah. I'm familiar with eastern Nebraska, but would you say it's comparatively going well everywhere, or better in certain parts, or... [LR283]

KAREN KAVANAUGH: I think everybody finds job opportunities for people that are looking for them. Sometimes those jobs are paid; sometimes they're not paid. [LR283]

SENATOR GAY: Thanks. [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR LATHROP: I do have a few questions myself. I was trying to follow you on the statistics, and the only chart that I had was this one, and you were saying numbers and I couldn't find them on your chart. So I'm going to take a minute, if I can, to ask you a few questions that will help clarify something for me. I understand that there are two groups of people when we talk about a waiting list. There are those that have asked for services, some of which may be for services in the future, and then there are those who are past their need date--am I using the right--past their date of need. When you told us that there the waiting list had 1,772 people, those are folks who are past their date of need, is that right, and do not include the population of people who may have asked for a service in the future. Did I understand that correctly? [LR283]

KAREN KAVANAUGH: There are a total of 1,772 people who are waiting for services, yes. [LR283]

SENATOR LATHROP: That's past their date of need. That 1,772 people doesn't include the folks who have said, my Billy is 12, and I would like him in a residential setting when he reaches 21. Am I right? [LR283]

KAREN KAVANAUGH: Yes. (Laugh) [LR283]

SENATOR LATHROP: Okay. Do you know what that...and maybe that list of people who were asking for something they don't even want yet but will want in the future, maybe that's not as important to us, other than to tell us what it's going to look like in the future. But we do know there's 1,772 folks who have said, I need something and I needed it yesterday. [LR283]

KAREN KAVANAUGH: Right. [LR283]

SENATOR LATHROP: Okay. Of that 1,772, how many want a residential setting for somebody in their family? [LR283]

KAREN KAVANAUGH: One thousand five-hundred and fifty-nine are waiting for residential services. [LR283]

SENATOR LATHROP: One thousand five-hundred and fifty-nine. So out of our list of 1,772, 1,559 of them want a family member or a loved one or someone for whom they are guardian, they want them placed somewhere where they can be...have a new home. [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR LATHROP: And I suppose that waiting list suggests to us that the capacity of our system, both in community-based care and Beatrice, isn't big enough to meet the needs of everybody who wants residential services. That seems obvious. Would you agree with that? [LR283]

KAREN KAVANAUGH: The capacity? [LR283]

SENATOR LATHROP: Yes. In other words, we wouldn't have a waiting list with 1,559 people on it if we had the capacity to take them all in. [LR283]

KAREN KAVANAUGH: True. [LR283]

SENATOR LATHROP: Okay. We asked you...or you were asked about how long...what's the average time people wait on a list, and you said there might be somebody here today that could tell us. If I have somebody, I made a request, and I've been waiting for X number of months, you can find that out for us? I'd be interested in that, the waiting list. [LR283]

KAREN KAVANAUGH: Don Severance is here from our office. [LR283]

SENATOR LATHROP: Maybe we'll have Don come up, after you're done, just briefly to answer the waiting list question. [LR283]

KAREN KAVANAUGH: Okay. [LR283]

SENATOR LATHROP: Community-based care can take on many different forms. It can be a residential setting, where they might be in a group home and be provided a job, help finding a job, and different services they may need. [LR283]

KAREN KAVANAUGH: Residential services are separate from day services. Day services are the kinds of services where a person would typically be supported in finding a job. Residential services are typically for providing supports to the individual through the hours after they would be either home from school or home from a job, so the evening hours and the weekend hours. [LR283]

SENATOR LATHROP: I want to make sure I'm not mixing these up, or maybe you're giving me a better understanding. The 1,559 people, are they looking for a place to live, or are they looking for help...some of them looking for a place to live and some of them are looking for something else? Does that make sense? [LR283]

KAREN KAVANAUGH: Um-hum. Of the 1,559, they are waiting for a place to live,... [LR283]

SENATOR LATHROP: Okay. [LR283]

KAREN KAVANAUGH: ...outside of their family home. [LR283]

SENATOR LATHROP: Outside of...yeah. They're probably young adults or middle-aged adults, perhaps, and the family has said it's time for us to place my son in a residential facility, and now they're waiting. [LR283]

KAREN KAVANAUGH: Um-hum. Yes. [LR283]

SENATOR LATHROP: Do we...I'm thinking that list can be shorter--and this is a question--but I'm wondering, is there a way to make the list shorter by doing a better job of providing day services? Are we at our capacity there? And another way to ask the same question may be this: Do we have people that get on the residential waiting list because they are not getting support for day services and they finally say, they're not coming here to help me during the day; I might as well get on the residential list? [LR283]

KAREN KAVANAUGH: I don't believe that's the case. As Jodi Fenner had testified, we serve people through a priority for funding in this state. So that's typically why people are waiting, is that they have not yet been found to be a priority for our services.

[LR283]

SENATOR LATHROP: Okay. The process of getting on the waiting list, that involves some request, and then are they evaluated by someone with Health and Human Services? [LR283]

KAREN KAVANAUGH: Yes. They make a request. That request can come from the family. It might come from the school. They might be directed by a physician. But the fact is they're directed to service coordinators who then will determine if the person is first, eligible for our services according to the definition of a developmental disability. So once they're found to be eligible, then their name would be placed on the waiting list for what type of services that they're requesting. [LR283]

SENATOR LATHROP: Do we have a waiting list to be evaluated by a care coordinator? Or if I have a request or a need and I want to be evaluated, does that happen automatically and right away? [LR283]

KAREN KAVANAUGH: You can be evaluated for eligibility right away. [LR283]

SENATOR LATHROP: So there is no waiting list for evaluation for eligibility? [LR283]

KAREN KAVANAUGH: No. [LR283]

SENATOR LATHROP: Is a person who wants services from the state of Nebraska required to hire their own coordinator to evaluate their needs? [LR283]

KAREN KAVANAUGH: They don't hire them. [LR283]

SENATOR LATHROP: Are they required to pay for that evaluation? [LR283]

KAREN KAVANAUGH: No. [LR283]

SENATOR LATHROP: Is there any requirement that a person or a family who has a need...are they required to pay any fees or expenses or retain any kind of a consultant or person in the private sector to assist them in this process? [LR283]

KAREN KAVANAUGH: No, they're not. I guess I should state, if the person would...well, you're asking for eligibility. I believe the answer is no. [LR283]

SENATOR LATHROP: Maybe the question is more general than that, and you're...the record won't reflect this, but you appear a little hesitant as you're providing my answers, so I want to stay with the question a little bit longer. If I want services for my son or daughter and I come to Health and Human Services and I say, you know, I need to be evaluated or my daughter does, to see what kind of benefit she might qualify for, are there any financial hurdles I have to clear in order to get those benefits or that evaluation? [LR283]

KAREN KAVANAUGH: No. [LR283]

SENATOR LATHROP: Go ahead. [LR283]

KAREN KAVANAUGH: If you are assigned a service coordinator, you may be...they have to determine if you have an ability to pay or have a share of cost. [LR283]

SENATOR LATHROP: I don't have to pay to find that out. [LR283]

KAREN KAVANAUGH: To my knowledge, no. [LR283]

SENATOR LATHROP: Okay. So if I...the process would go something like this: I have a need, I contact HHS. They say, you'll have to speak to a service coordinator, and then there's an evaluation process, part of which is to determine whether or not I have the money to take care of this myself. [LR283]

KAREN KAVANAUGH: To get into services? [LR283]

SENATOR LATHROP: No. [LR283]

KAREN KAVANAUGH: No. No, that is not my understanding. [LR283]

SENATOR LATHROP: So all we do is look at need of the patient? or the... [LR283]

KAREN KAVANAUGH: When we're determining eligibility, we look at it according to the definition under the law. [LR283]

SENATOR LATHROP: Part of this is financial, isn't it? I mean, if I have a lot of resources and my son or daughter is 16 years old, will you say to me, you can pay privately; you don't qualify? Here's a list of people that you can talk to. [LR283]

KAREN KAVANAUGH: Oh. If you...anybody can private pay. Yes, I'm sorry. I did not understand that. Anybody can choose to private pay. [LR283]

SENATOR LATHROP: Do I have to no longer have an ability to private pay to get the services from Health and Human Services? [LR283]

KAREN KAVANAUGH: No. [LR283]

SENATOR LATHROP: So whether you're Warren Buffett or somebody who's unemployed, these services are available to both populations,... [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR LATHROP: ...the rich and the poor. [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR LATHROP: Okay. And there's no fees or charges we have to pay for the evaluation. [LR283]

KAREN KAVANAUGH: It is my understanding, no. [LR283]

SENATOR LATHROP: And just so that I'm clear on this, we have a population at Beatrice that's 273 now? Does that sound right? [LR283]

KAREN KAVANAUGH: That's approximate; 272. [LR283]

SENATOR LATHROP: Two seventy-two? And you told us generally where we're at in the...who's receiving services, and that would be page 44 of your... [LR283]

KAREN KAVANAUGH: Who's receiving services, okay. [LR283]

SENATOR LATHROP: Yeah. We have assisted residential and supported residential, and that's about 3,000. [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR LATHROP: Thirty-five in assisted and supported day services? [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR LATHROP: Four hundred and eighty in respite and sixty in community support. [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR LATHROP: And that's the entire population or all the people that the state of Nebraska currently serves with developmental disabilities? [LR283]

KAREN KAVANAUGH: Yes, through community-based services, through community-based services. Oh, and then you said BSDC, but that doesn't include...well, that the state of Nebraska serves, yes. [LR283]

SENATOR LATHROP: So we're on the same... [LR283]

KAREN KAVANAUGH: Yes. Community-based services and BSDC, yes. [LR283]

SENATOR LATHROP: Okay, okay. I just wanted to make sure I understood the statistics and the numbers, and that's all I have. Senator Cornett. [LR283]

SENATOR CORNETT: When you said there are 1,500 people on the list, and you said that a lot of them were there because they hadn't been approved yet, their eligibility hadn't been approved, correct, for 24-hour care? [LR283]

KAREN KAVANAUGH: No. They have been determined to be eligible if they're on the waiting list. [LR283]

SENATOR CORNETT: If they're on the waiting list. Okay, so we have 1,500 people waiting currently. We have 272 people in Beatrice, and in January we had how many--300? [LR283]

SENATOR LATHROP: Three zero eight. [LR283]

SENATOR CORNETT: Are we bumping people on the list to place people that are currently at Beatrice, in the community? [LR283]

KAREN KAVANAUGH: No. People... [LR283]

SENATOR CORNETT: How are we getting those people placed while we still have a list going for people that need 24-hour care also? How are they being integrated into that list? [LR283]

KAREN KAVANAUGH: The budgets are separate. [LR283]

SENATOR CORNETT: They are separate,... [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR CORNETT: ...but the beds are the same, aren't they? The number of beds available... [LR283]

KAREN KAVANAUGH: In the community? [LR283]

SENATOR CORNETT: ...for community-based are the same, whether they're coming from BSDC or from your waiting list. [LR283]

KAREN KAVANAUGH: There's not a stagnant number of beds that are available in the community. Providers can develop and open new settings as folks are needing their services. [LR283]

SENATOR CORNETT: Are they developing new beds; if we have 1,500 people, plus people at BSDC that they're trying to place? [LR283]

KAREN KAVANAUGH: If the funding is available, yes. [LR283]

SENATOR CORNETT: Is the funding...all right. The goal is generally to keep people in community or move people to community-based services, correct? [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR CORNETT: Do we currently have enough beds, enough community-based services, to achieve that goal? And if not, what funding do we need to do that? [LR283]

KAREN KAVANAUGH: It is my understanding that as we have been placing people from BSDC into the community, that service coordination has not been finding that they have not been able to find providers that have homes available for people to move into. [LR283]

SENATOR CORNETT: Then why do we have a waiting list? [LR283]

KAREN KAVANAUGH: Because we haven't appropriated a certain amount of money that we can spend for our services in community based. We do disburse that money out to the people who are currently being served. We can only bring people into services as we have people who drop out of community-based services. [LR283]

SENATOR CORNETT: BSDC, though, has separate funding, correct? Those people...is that what you said? [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR CORNETT: So you have funding for the people that are on the waiting list; you have funding there for people that are currently placed. The number of beds is approximately the same. I know more beds are not being created. Do we have enough beds for those people? Are we bumping people that have been waiting on a list out of a placement in a 24-hour care facility, to place and reduce the numbers at BSDC? [LR283]

KAREN KAVANAUGH: No, I do not believe that we are. [LR283]

SENATOR LATHROP: Senator Stuthman. [LR283]

SENATOR STUTHMAN: Thank you, Senator Lathrop. Karen, when we're talking about people on the waiting list,... [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR STUTHMAN: ...that funding source, and then we've got the funding source for the people that are at Beatrice, now when the individual moves from the institution to the community-based, does the funding for that individual come from the other one, that it follows the patient, as we had stated earlier today? But does it come from a different pot? [LR283]

KAREN KAVANAUGH: Eventually that money will come from BSDC. It will be transferred into the community. [LR283]

SENATOR STUTHMAN: It will be transferred into the community-based setting funding portion of it,... [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR STUTHMAN: ...that it will follow that individual. [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR STUTHMAN: So that individual, you know, that funding stream follows that person from the institution to the community-based, and...but does it take a bed away from a person that's on the waiting list for a community-based service? [LR283]

KAREN KAVANAUGH: I do not believe that it does, again, because providers can open settings. [LR283]

SENATOR STUTHMAN: If they have funding. [LR283]

KAREN KAVANAUGH: If the person comes and has money with them to purchase services, you can have...that person, then, is able to. Often they come...it might be a couple of people that need to come together, but the provider...I have not been informed of providers not being able to serve people because they did not have homes available for those people. [LR283]

SENATOR STUTHMAN: Thank you. [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR CORNETT: The people that are on the waiting list, they've been approved and are eligible, correct? [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR CORNETT: Does that mean they already have funding available for them? [LR283]

KAREN KAVANAUGH: No. [LR283]

SENATOR CORNETT: So they are approved and eligible, but they don't have funding, and it's actually the funding that you're waiting for to find them beds. [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR LATHROP: Senator Wallman. [LR283]

SENATOR WALLMAN: Thank you, Senator Lathrop. Yes, Karen. This money, so-called, like Senator Stuthman...following up on Senator Stuthman's question. Is that for a year, or is that forever, or how does that work for the funding that follows the patient,... [LR283]

KAREN KAVANAUGH: It will be... [LR283]

SENATOR WALLMAN: ...or the resident? [LR283]

KAREN KAVANAUGH: Right. BSDC's...the budget at BSDC will be reduced to support the services for the individual who has moved out. That would not be a forever-and-ever kind of thing, because when the person comes out into the community, then they will be funded through the community-based side of things. So it's a one-time kind of thing. [LR283]

SENATOR WALLMAN: Thank you. [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR LATHROP: Senator Gay. [LR283]

SENATOR GAY: Karen, of the 1,772 on this list, 1,559, you said to Senator Lathrop, needed...were waiting for residential services, maybe a group home, maybe, you know, whatever. So 1,559 could be in a group home. Some can be in group home, some have to be in--I don't know what the term would be--but more intense situation. [LR283]

KAREN KAVANAUGH: It might be that they're living in their family home with supports. It might be that they're in an apartment or a group home. [LR283]

SENATOR GAY: But they want to get into a residential setting, like a group home. Is that what you're saying? [LR283]

KAREN KAVANAUGH: But residential services include they could be served in their family home. [LR283]

SENATOR GAY: Okay it does include. They could be in their family home. [LR283]

KAREN KAVANAUGH: So it's a wide variety of settings. [LR283]

SENATOR GAY: They just want the services. Okay, so of that 1,559, then, how many want to go to a group home, like...that are saying, hey, you know, parents are getting older. I need to go take care of... [LR283]

KAREN KAVANAUGH: I don't believe that we keep the data that way. [LR283]

SENATOR GAY: You don't keep track of that? [LR283]

KAREN KAVANAUGH: Uh-uh, not specifically what kind of service they're asking for. [LR283]

SENATOR GAY: So we've never done a recent study saying, oh, by the way, I need 150 new group homes around the state, and it's going to cost $28 million? We don't have any study like that? Probably cost more than that. But labor issues--we can't...getting labor to go into group homes now is hard to get. So we haven't taken into account any big study to say what we really need in the future? [LR283]

KAREN KAVANAUGH: Not that I'm aware of, no. [LR283]

SENATOR GAY: There's no...okay. That's what I wanted. Thanks. [LR283]

SENATOR LATHROP: You have, with that last bit of testimony...maybe I misunderstood you. When you said they had 1,559 people on a waiting list, I thought that was to go into a home. [LR283]

KAREN KAVANAUGH: It's for residential services, and residential services are assisted or supported, so if they want assisted services, typically that's where they need more support. But we don't keep the numbers so that we know who's asking for assisted compared to supported. We just know that they're asking for residential. [LR283]

SENATOR LATHROP: Tell me what...define the difference or explain the difference. Which one is where you literally want to go live someplace in a home in the community,... [LR283]

KAREN KAVANAUGH: With staff there all the time, for example? [LR283]

SENATOR LATHROP: Yeah. [LR283]

KAREN KAVANAUGH: That would be assisted services. [LR283]

SENATOR LATHROP: All right. So that's where you go to live someplace else, and the supportive services is where they might come into my house in the morning and help a young person or a disabled person get...brush their teeth, get on the bus, and off to work. [LR283]

KAREN KAVANAUGH: Um-hum, yep. [LR283]

SENATOR LATHROP: And as you sit here today, you don't know, out of 1,559, you can't tell us what percent is waiting for one or the other? [LR283]

KAREN KAVANAUGH: No, I can't. [LR283]

SENATOR LATHROP: No idea. [LR283]

KAREN KAVANAUGH: No, I'm sorry, I can't. [LR283]

SENATOR LATHROP: Your job is to be the coordinator of community-based care? [LR283]

KAREN KAVANAUGH: I'm acting, yes. [LR283]

SENATOR LATHROP: Acting? [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR LATHROP: And you can't tell us, out of 1,559, what percent is waiting to go into...or looking for assisted residential placement? [LR283]

KAREN KAVANAUGH: I can't. I don't know if Don can or not. [LR283]

SENATOR LATHROP: Well, he doesn't...he's shaking his head no. With 1,772 people on the list, what's the priority? How do you establish a priority among the people waiting on the list? Is it first in time, or is it based upon need? [LR283]

KAREN KAVANAUGH: It's...a person can...let's see. Let me think about this. A person has to be a priority, to be considered to be a priority. [LR283]

SENATOR LATHROP: There has to be a criteria beyond just asking to be a priority, or everybody would do it. [LR283]

KAREN KAVANAUGH: It's date of need, unless we get special appropriations. Sometimes we get...the Legislature will authorize certain...a portion of money to go to serve a specific population. For example, we recently...in recent years we had a pot of money that was going to individuals whose caregivers were elderly, so then we approached those people who were waiting for services to ask them if they wanted services. [LR283]

SENATOR LATHROP: We have no such pots at this time, though, do we? [LR283]

KAREN KAVANAUGH: No, just the day services. [LR283]

SENATOR LATHROP: So all we have now is "first in time, first in line." [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR LATHROP: So if we have a person with developmental disabilities, and I'll use an example that was given to us this morning by Dr. Buehler, which is a person who is going to run across the room and try to stick their head through a window. That person, if they just got on the list two months ago, they have to wait for 1,500 or 1,700 people to get their services before that family is going to get residential assisted services. [LR283]

KAREN KAVANAUGH: They can request to be considered as a priority, and that's a process that they can go through. [LR283]

SENATOR LATHROP: All right. It sounds like, unless we substantially increase funding, that the only way the line is going to move people through it is through attrition. And can you tell me what the statistics are with respect to attrition for people in Nebraska who are receiving benefits for developmental disabilities? [LR283]

KAREN KAVANAUGH: No, I can't. [LR283]

SENATOR LATHROP: Is there anybody that came here today that could tell us how many people actually go off the rolls of receiving benefits or services for developmental disabilities? [LR283]

KAREN KAVANAUGH: If anybody is here today that could, it would be Don Severance. [LR283]

SENATOR LATHROP: Okay. Senator Cornett. [LR283]

SENATOR CORNETT: Back to the list. You have...say, for instance, you have someone in Beatrice that they're trying to find placement for in a community-based setting. You have someone that is approved, that is on the list for funding. Who is going to get that bed? Who determines that? The bed that is available, because if there is not the funding and they're not currently...the bed is available...even private sector resources are limited. They can't just open up a bed tomorrow. They have to have staff to do that; they have to have the support. Are we trying to outsource to community-based services for...and while we have a facility open where people do have care currently--given, we need to improve that--at the jeopardy of people that are trying to find community-based services, like a 24-hour bed? [LR283]

KAREN KAVANAUGH: Right. I would say no. [LR283]

SENATOR CORNETT: When Senator Lathrop talked about the priority, when they can request a priority, how is that determined, if a person has someone that obviously needs to be placed, like the gentleman--or not obviously that particular person, but someone that truly has a need, maybe more than another person and they request a priority, how is that priority determined? [LR283]

KAREN KAVANAUGH: There is a... [LR283]

SENATOR CORNETT: And who makes that determination? [LR283]

KAREN KAVANAUGH: It is looked at locally. Each service area has a service coordination committee that takes a look at priorities in their area, and they, of course, determine if they believe that person to be a priority for funding or not. If they do not believe that that person is a priority, then that person is informed of that decision. If...and that's according to the definition under the law, as far as needing services, okay? [LR283]

SENATOR CORNETT: But everyone on the list, it's already been determined that they need services. [LR283]

KAREN KAVANAUGH: That they're eligible for services. [LR283]

SENATOR CORNETT: That they're eligible for services. [LR283]

KAREN KAVANAUGH: Um-hum. And so a local committee will look to determine if that person is a priority one according to the law. If they believe that that person is a priority,... [LR283]

(UNKNOWN): (Inaudible.)

KAREN KAVANAUGH: Okay, thank you. I'll remind you again: The first priority of the state in responding to the needs of persons with DD should be to ensure that all such persons have sufficient food, housing, clothing, medical care, protection from abuse or neglect, and protection from harm. So the local committee will look at information that has been present to them, to make that determination. They may believe that that person has sufficient supports, even though it's difficult for the family, that they believe that person has sufficient supports. And they'll notify the family. If they believe that the person may be a priority, they would make that recommendation to Lincoln. In Lincoln we would review it again, and again look at the case, the information that's provided, and make a determination if we support that it is...the person is a priority for funding or not. There's a number of different factors that are considered in making those decisions, and it may be that we will make recommendations back to the local office, if we find the person not to be a priority, for other sorts of services that might be available to the person in their community to support them in their current situation. [LR283]

SENATOR CORNETT: Is funding specific to the individual? Say, for instance, you have one person that has higher needs than another one. [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR CORNETT: Is funding based on individual needs? [LR283]

KAREN KAVANAUGH: Yes. [LR283]

SENATOR CORNETT: So if you have a person that needs three-on-one staffing, they will have funding for three-on-one staffing, if they move into community-based services? [LR283]

KAREN KAVANAUGH: When they come into community-based services, we do an assessment. It's called the ICAP, and I believe that we're going to have testimony on that tomorrow, where we talk about the funding. But yes, we go through what is called the objective assessment process, which determines how much funding is available to each person for them to purchase their services. And then they make choices about how they spend that money, if they want residential or... [LR283]

SENATOR CORNETT: Who is "they"? [LR283]

KAREN KAVANAUGH: The individual and their support system will decide what services they want. If they want, for example, residential services, they can decide if they want assisted services, where they get much more...the 24-hour type of support, or if they want just supported, where it's just less. [LR283]

SENATOR CORNETT: Again, back to people that require two- or three-on-one, 24-hour staffing, the people that will either harm themselves or harm someone else. If they move into community-based services--because I've heard a number of times when we were on the tour that that was the ultimate goal,... [LR283]

KAREN KAVANAUGH: Um-hum. [LR283]

SENATOR CORNETT: ...is the funding there for community services to be available for that population, because it's not a choice at that point necessarily, whether they have two- or three-on-one staffing that's a requirement. They may want to choose. One gentleman we talked to said that, you know, he wants to go get a job, he wants to do this, he wants to do that. His choice and his guardian's choice might be for him to do that, but it's not in his or the community's best interest. [LR283]

KAREN KAVANAUGH: If the person chooses to come...that they want services in the community, we would go through the objective assessment process to determine how much money is available for that person to receive supports in the community. That happens for every person who receives community-based services. [LR283]

SENATOR CORNETT: Okay, thank you. [LR283]

KAREN KAVANAUGH: That is what the determination is. [LR283]

SENATOR CORNETT: Okay, yeah. [LR283]

SENATOR LATHROP: Anything else? I don't see any. Thank you for your testimony and your appearance here today. I think we're probably going to...I think the last person is going to be Mr. Severance. Is that right? That's right? Okay...who is going to clear everything up for us. (Laughter) Why don't you start out with your name. Spell your last name for us, and then give us a little background on where you fit in at Health and Human Services. [LR283]

DON SEVERANCE: Okay. My name is Don Severance, and it's S-e-v-e-r-a-n-c-e. I'm a disabilities services coordinator with developmental disability system, so I've been with the system for about 30 years, but the first 25 was down at BSDC, and the last five years have been in Lincoln with the developmental disability system, so. [LR283]

SENATOR LATHROP: Okay. What does your job involve? [LR283]

DON SEVERANCE: I oversee the quality improvement and the funding methodology for the system. [LR283]

SENATOR LATHROP: Okay. So you're going...are you coming back tomorrow? [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR LATHROP: We have you set to come back and talk about the formula and tell us about how much money will follow someone, depending on their needs, and how we go through the formula. [LR283]

DON SEVERANCE: Yeah. [LR283]

SENATOR LATHROP: We won't have you do that again tonight. We'll wait until tomorrow. But we did have, it looked like, three issues that people turned to you. And one of them was the time folks spend on a list. We have 1,559 people, apparently, past their date of need or a list for residential services, and it sounded like the last...Ms. Kavanaugh thought you had the answer to how long do people wait on the list. [LR283]

DON SEVERANCE: Currently, there are people with requests back to January of 2003. So currently, there's people that have been waiting for close to 5.5 years. [LR283]

SENATOR LATHROP: And these are people who are past their date of need by 5.5 years. Do you have...is that typical of people who request residential services, 5.5 years? [LR283]

DON SEVERANCE: It varies based on, again, when there's been funding available to be able to address the waiting list. I mean, it gets shorter, and then it gets longer, you know, based... [LR283]

SENATOR LATHROP: Okay. If we currently have people that have been there 5.5 years, what's the average, sir? [LR283]

DON SEVERANCE: Probably about three, is what I'd guess. [LR283]

SENATOR LATHROP: And that's for residential services... [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR LATHROP: ...past the date of need? [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR LATHROP: Why are we almost two times the average right now? [LR283]

DON SEVERANCE: Because there hasn't been any funds specifically appropriated to address the waiting list since the Tobacco Settlement money. There was $5 million back in 2001-2002, and as that money was used, but since it's long-term services, it continued to be used by the same people. And so we aren't able to bring other people off the waiting list. [LR283]

SENATOR LATHROP: So the only way someone can begin to receive...be taken off of the waiting list and start to receive services, because we're not increasing funding or haven't, is for someone to leave the system? [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR LATHROP: Now the other question we had for you was the attrition rate. I was trying to do some math. It looks like we have about 7,000 people receiving services through the community-based programs, and we have 272 people at Beatrice. Is that our population of people receiving... [LR283]

DON SEVERANCE: There's about 4,500 in the community, when...you're adding up the day and residential. Some of those people are receiving both day and residential, so there would be duplication. [LR283]

SENATOR LATHROP: Oh, okay. So 4,500 in community-based programs, and 272 at Beatrice. Is that our entire population, or am I missing somebody? [LR283]

DON SEVERANCE: Yeah, I believe that's the state funded. [LR283]

SENATOR LATHROP: So if we have about 4,700, 4,800 people, how many people leave and make room for someone to come off the list in a year's time? [LR283]

DON SEVERANCE: Okay. Lately, it's been about 200 people, slightly over 200 that have been leaving services, a year. [LR283]

SENATOR LATHROP: And is that because they leave the state or they die, or what accounts... [LR283]

DON SEVERANCE: There's a variety of reasons. Yeah, some do leave the state. Yes, there is some attrition by death. There are some people that basically gain enough skills to where they don't want our services anymore, or they choose some other type of service. [LR283]

SENATOR LATHROP: Okay. So if we have 200 people leaving, they are making room for 200 people to come off of the 1,772-person list; is that right? [LR283]

DON SEVERANCE: Some of those people are graduates that left, and so the way we've been funding graduates in recent years, it has been based on a kind of attrition model, of what the net increase in graduates is. So we have like 200-and-some graduates, or close to 200 graduates that start services each year that are funded by the Legislature. But some of that 200 attrition is actually graduates that have left services over time, so. [LR283]

SENATOR LATHROP: And you use the term "graduates" for the first time that anybody has used that today, so maybe you can share with us what that means. [LR283]

DON SEVERANCE: Okay. Since...I believe it was in 1996 that the Legislature said that anybody that graduated from Nebraska high school, turned 21 and graduated from a Nebraska high school, would receive services. So they've received day services since that time. So that's the past 15 years. So anybody who is eligible for our services, turns 21, from a Nebraska high school, is able to receive day services. [LR283]

SENATOR LATHROP: I know that explanation had something to do with attrition, but I'm not sure what. (Laughter) I mean, we had...I'm not...and believe me, I appreciate your effort to explain this to me. What I understood is 200 people are leaving, and that makes room for 200 people off the list. Is it more complicated than that? [LR283]

DON SEVERANCE: Well, yeah. I think it is. [LR283]

SENATOR LATHROP: Okay, then explain it to me, if you can. [LR283]

DON SEVERANCE: Yeah, some of the people are off the list, because some of the people on the list usually are people who want day services out in the future, because they're going to be graduates. So some of those positions that...the attrition is graduates that came in, and it's filled by graduates, I guess is what I'm saying. It's not all coming off the waiting list necessarily, because they are entitled, by the way the law is written, to be able to receive services. [LR283]

SENATOR LATHROP: So we have 200 people leave for whatever reason. Do we first allocate their empty spots to people that have graduated from a Nebraska high school? [LR283]

DON SEVERANCE: Yes. [LR283]

SENATOR LATHROP: How many of those folks do we have every year? [LR283]

DON SEVERANCE: There's about 170 to 200; it varies by year. [LR283]

SENATOR LATHROP: So that leaves room for 30 to 0 people to come off of the waiting list and actually get services. [LR283]

DON SEVERANCE: That's correct. [LR283]

SENATOR LATHROP: So that list, while it's 5.5 years old right now, is going to do nothing but get older and older and older before anybody on that list is going to get residential services. [LR283]

DON SEVERANCE: That's correct, unless there's other funding. [LR283]

SENATOR LATHROP: I think I understand it now. The split of the...I'm going to ask you this. Ms. Kavanaugh didn't know, and I'm going to ask you if you have an idea. We heard there's 1,559 on a waiting list for residential services. Do you know how many of those are actually looking for placement in what she described as assisted residential versus supported residential? [LR283]

DON SEVERANCE: I don't have those numbers with me. I could get them for you. [LR283]

SENATOR LATHROP: Do you have an estimate, though, as a percent? [LR283]

SENATOR LATHROP: Maybe you could bring that with you tomorrow and answer that question for me, if you don't mind. [LR283]

DON SEVERANCE: Yeah. [LR283]

SENATOR LATHROP: Are there other questions for Mr. Severance? Senator Cornett. [LR283]

SENATOR CORNETT: Mr. Severance, again it goes back to a constituent. We had someone that graduated from a Nebraska high school. They left the state; when they came back, they were not eligible any longer, for 24-hour services. We had to do an appeal to your department, or to the services for that person. But I just want to be clear. Because we offer day services for people that graduate, we don't have funding left over for anyone else, basically? [LR283]

DON SEVERANCE: Yeah, most of our budget has been a continuation budget, so it's pretty well covering just the people that are in services, because it's long-term care, really. [LR283]

SENATOR CORNETT: And that doesn't cover necessarily 24-hour care, then? [LR283]

DON SEVERANCE: For some people it is, because they receive both day and residential, so that would cover 24 hours? [LR283]

SENATOR CORNETT: Okay. [LR283]

SENATOR LATHROP: Any other questions? I have none. I think that will do it. We'll look forward to seeing you tomorrow. And I think that concludes our hearing for today. We'll start again here tomorrow at 9:00 o'clock. [LR283]

Chairperson

Committee Clerk