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Developmental Disabilities Special Investigative Committee
August 21, 2008

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The Developmental Disabilities Special Investigative Committee met at 9:00 a.m. on Thursday, August 21, 2008, in Room 1524 of the State Capitol, Lincoln, Nebraska, for the purposes of conducting a public hearing the Beatrice State Developmental Center. Senators present: Steve Lathrop, Chairperson; John Harms, Vice Chairperson; Greg Adams; Arnie Stuthman; Norm Wallman. Senators absent: Abbie Cornett, Tim Gay. []

SENATOR LATHROP: (Recorder malfunction) Steve Lathrop. I'm the Chair of the commission established by the Legislature by resolution LR283. Our purpose is to investigate the services provided by the state to families and to folks with developmental disabilities. We had hearings in June and we're today having hearings, the purpose of which is to hear from families and those who have an interest in the subject matter, what their perspective is on how the state is providing care and services to people with developmental disabilities in the state of Nebraska. That includes the Beatrice Development Center, of course, but it also includes, and you should feel free to comment, on the care and the services provided with community-based providers. This commission that I'll introduce in just a moment comes from a different...a variety of backgrounds. I happen to be an attorney in Omaha. We have folks that are retired teachers, former school board members, farmers, and bankers. So what we're doing is educating members of the Legislature through this process on developmental disabilities and the services provided by the state, and any shortcomings we may have in the provision of those services and problem areas. So we look forward to your testimony today. I'll start maybe by introducing the folks that are on the commission and that are here today. I have, to my left and your right, Norm Wallman who's from the district that includes the Beatrice Development Center, and he's serving on the commission. Also Greg Adams, who's from York. I'm from the 12th District or in the Omaha area. And then we have Senator Stuthman who's here today from Platte Center, which is basically Columbus, for those of you who might not know where Platte Center is. Also on the commission are Senator Cornett, who has a conflict today; Tim Gay,

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who's from Papillion, also has a conflict; and Senator John Harms from Scottsbluff had a conflict this morning and I think he'll be here this afternoon and tomorrow. We are assisted: our staff today is Beth Otto, who's our clerk; and Doug Koebernick, who's my legislative assistance; and Matt Boever, who is our staff, and that's the guy in the dark suit over there and is working with us today. We have...I really didn't know what kind of a response we'd get today, so I didn't know if we would simply open the mike up, let people sit down and talk as long as they wanted to. But, as you can see, we have an awful lot of people here, which is terrific, and we want to hear what people have to say. Can you, by show of hands, tell me how many of you wish to testify today? Okay. That's good. We're glad you're here and we're interested. Just a couple of thoughts, if I can. I'm going to repeat some of the things that we say in Judiciary Committee, where we have a lot of hearings and a lot of bills that we deal with, and that is you are welcome to submit your testimony, if you like, in writing, if you are bashful about public speaking. That information will be copied and passed around to the committee. When you speak or before you speak you have to fill out a form so that our committee clerk can keep track of who's spoken, you know, get the name right for the record. So we have forms that need to be completed before you testify. You'll put them in the box here and then we can keep track of who's testified and we get your name right in the record. We will ask you, if you can, to listen to what everybody else has to say ahead of you and then if you can avoid repeating the same things so that what we are getting is new information each time somebody testifies. And to...I don't want to, at least initially, to limit people, too, and we don't have the light system today. But if we start going too long, I'll just ask you to kind of try to keep it in the ten-minute range if you would. If we get much past that, I may interrupt you and ask you to wrap it up. The reason we do that is not because we're not interested in what you have to say, but because we won't leave here till 8:00 tonight if we listen to everybody say everything they absolutely want to say. But we do want to give everybody a fair opportunity to speak, and the people behind you that same opportunity. So I think...oh, this is being recorded. You have to speak into the mike. And we also ask that everyone here turn their cell phones off, all right? Cell phones, pagers, what ever that's going to make noise and interrupt the hearing, we'll

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ask you to turn that off, if you wouldn't mind. And then we have no order. I have no slate of speakers. So what we'll do is just say that if you want to speak maybe you come up to the front row and just sort of sit in a chair there and position yourself by completing a form and then we'll just call on the next speaker after we've heard. Today the folks that we hope to hear from are people, families who have loved ones that are getting services for a developmentally disabled member or ward, people who have an interest in it, interest groups, those who have been around the provision of developmental disabilities services long enough to have an idea of how we're doing, what we're doing, what our shortcomings are, and what we're doing that seems to be working. So with that, I think...sign-in sheets, printed materials...if you have printed materials that you want to hand out, you can hand them to our page over here. This young man will pass them out. You don't have to hand them out or leave them on the table. And with that, I think we'll start. Okay, thank you. So our first speaker. []

JOAN O'MEARA: Good morning, senators. []

SENATOR LATHROP: Good morning. []

JOAN O'MEARA: My kids evidently knew that you were going to say this, because they made me put it on cards. They said, don't get long-winded, Mom. []

SENATOR LATHROP: Okay. And what I should say, because I don't know you any more than somebody's mom right now, we'll have you start with give us your name... []

JOAN O'MEARA: I will. []

SENATOR LATHROP: ...and spell your last name for us, and then we'll go from there. []

JOAN O'MEARA: (Exhibit 1) My name is Joan O'Meara, O-'-M-e-a-r-a. I am the mother and guardian of Cindy O'Meara and I'm president of the Family and Friends Association

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of BSDC. I have worked in the field of mental retardation for 54 years, both personally and as a teacher of special education. I am no stranger to the levels and needs of those with MR. Cindy is severely/profoundly retarded. She had open heart surgery, club foot surgery done before she came into the institution. She is blind in one eye, deaf in one ear, and is diabetic and is wheelchair confined. My daughter has been at BSDC for 44 years--a place she calls home. She is happy, safe, and well cared for by dedicated and well-trained staff. There is a doctor, dentist, nurses, dietician, psychiatrist, psychologist, a physical therapist, all on staff. She and I have the right of choice to live at BSDC. The Olmstead decision gives us that right. We are moving people out to reach a number, quote, which is frightening to me. To me, it is like dumping. Many have gone to nursing homes because they are old and not learning. There was a study made a few years back that those put in nursing homes out of familiar environment lasted for only two or three years. Is this what we are doing--pronouncing the death sentence for them? Wouldn't it be humane to let them live their final years in familiar surroundings--their home? We parents have been told that BSDC is a learning institution. I haven't found anything in the papers establishing BSDC that mentions that. Those who favor community programs say that we are isolated. Not true. Cindy has a better social life than I do. She goes to Omaha and the Lincoln zoos, Brownville, football games, car races, movies, out to eat, shopping in Lincoln and Beatrice, parties, barbecues, just to name a few, plus her family visits her often. Some can live in community homes but only if those community homes meet the needs of that individual. Community programs are facing problems just like we are--not enough staff, not enough qualified staff, not enough homes. You need to find your own doctor, dentist, psychologist, etcetera, and that's not an easy task. Most doctors will not take retarded people. Rules and regs are not the same across the state and no one to look over their shoulder. If this were to happen, there would be quite a few homes that would be closed. I spoke to CMS and asked them why they don't visit community homes. Their answer: They are too spread out; it's not realistic for us to do it. So if we transfer a person, we want to make sure that that person is going to a home that is equal to the environment that they have now. But if these environments are not regulated then we have problems. There's a long waiting

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list for community programs and I have a paper here. The numbers are terrible. They need to be also serviced. This, as a list, will grow continuously year after year. Especially when those who are attending high school graduate, they need a place to go. They don't have one. And how would you feel when an opening happens but you are passed over because BSDC has priority needs to reach a number? Some of these parents are up in years and have been on the list for many years, 5 to 14 years. We're robbing Peter to pay Paul in doing this. Some parents have tried community placement and found it fearful and unsafe for their child. They turned to BSDC and found a haven. The whole DD program needs to be revamped from the top on down. Rules and regulations across the state, community, and BSDC must have the same rules, an unbiased overseer is needed to look to see that these rules are followed. And when a change is made, whether it's from BSDC to a community home, that person goes to see that that community home is going to meet the needs. Or even if from one community home to another community home, that, too, has to be supervised so that these people's needs are served. Changes need to start with those at the top. We need qualified, experienced people. Start with listening to the staff. They know what's needed. The direct-care people are not stupid. They've been in the field for many, many years and know what is happening. We need to bring BSDC back to the status of Cadillac among centers, as it was in the 1990s. How can you find out how it was? Ask an old worker who has been there for 30 years. They know what was going on then and what made us good. Why weren't they included in the changes that were made? They weren't. And we spent oodles of money on bringing people in and not to any avail. This committee is the first one to listen to we parents. We have fought for over 15 years, going from the top to the bottom. You finally have heard our voices and you're giving us hope. The right to choice is essential. Thank you for listening. []

SENATOR LATHROP: Thank you. Are there any questions? Senator Adams. []

SENATOR ADAMS: I heard... []

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SENATOR LATHROP: Miss O'Meara. []

JOAN O'MEARA: Excuse me? []

SENATOR ADAMS: Would you be willing to answer? []

JOAN O'MEARA: Oh, I'm sorry. []

SENATOR LATHROP: He wants to ask you a question, if you don't mind. []

JOAN O'MEARA: Oh, sure. Go ahead. I thought I was through. (Laughter) []

SENATOR ADAMS: Well, not with this group. []

JOAN O'MEARA: Oh. Okay. []

SENATOR ADAMS: I have heard it said more than once, and you said it just a moment ago, that in the 1990s we had a Cadillac program and we don't now. Now I've heard what others have said has happened. In your opinion, what's the difference today compared to the 1990s? []

JOAN O'MEARA: We had a very qualified person in charge at BSDC with great experience and really listened to the workers, making themselves visible and asking questions and listening to them was very important. We had people from all over the world coming to our program that we put on in April, I think it was, and they were just amazed. But since then, we have continuously slipped. Our one who was in charge at that time passed away. []

SENATOR ADAMS: Okay. Is there anything else? []

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JOAN O'MEARA: No. []

SENATOR ADAMS: Okay. Thank you. []

JOAN O'MEARA: Any more questions? []

SENATOR LATHROP: Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. []

JOAN O'MEARA: Yes. []

SENATOR STUTHMAN: Joan, do you feel that an individual that has a disability is a lot harder to accept more than a normal person? []

JOAN O'MEARA: Oh, oh, yes. Yes. You are disturbing their whole environment, the people that they are around, their fellow peers, and the workers that are there to help them. Yes, I think that they are, especially those who are severely/profounded retarded, and then behavior problems begin to act out, behavior that you have at one time had them contain those behaviors, and now you're switching them again. That upsets them. Look at it this way. When my mother was living with me, she was 91 years old and she had the beginnings of Alzheimer's. If her day was disturbed, like if she didn't have coffee at the right time or she didn't have something that she was supposed to do at the right time, she became very upset, very much so like the people that we're talking about. Now there are some individuals who are mildly retarded, no, that wouldn't. []

SENATOR STUTHMAN: Okay. Thank you very much. []

JOAN O'MEARA: Uh-huh. []

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SENATOR LATHROP: Good insight. Thank you. Our next presenter. []

KATHY HOELL: Senator Lathrop, I'm just going to thank you for letting us have this opportunity. My name is Kathy Hoell, H-o-e-l-l, and many of you do already know me. However, today I am here testifying as an individual, an individual that resided in an institution for two years. Those two years felt like ten years to me. My life back then was extremely depressing. I had no power to decide things for myself. I got the roommate they selected for me. I had to eat when they said I had to eat. I had to eat what they said I had to eat. I couldn't go to the bathroom when I wanted to. I couldn't go to bed when I wanted to. But, however, the one thing that I did learn very well, and it's a word that gets tossed around a lot, is behaviors. I had a roommate who screamed every time she didn't get what she wanted. She screamed loudly. And if she didn't...if that didn't work, she stole things. I learned this behavior. People in institutions learn behaviors from other individuals in the institution. I got to a point where I called my grandparents one night and started screaming at them. These people never did anything to warrant that type of abuse from me. However, my institution was a nursing home. The fact is an institution is an institution is an institution. They've transferred enough number of people out of Beatrice and put them in nursing, so they've just changed the institution. I really do appreciate the enormity of the task you've taken on. However, the disabilities service system in Nebraska is very fragmented. We need to have a unified system and, as Joan was saying before, we need to start at the top and go down. Ideally, what we would have is a division of disability service so all disability services are in one location; there is no wrong door. People are going to get the services they need. We have another problem in Nebraska and that's the DD waiting list, and we have an unofficial behavioral health waiting list and, in my opinion, the only way these are truly going to be dealt with is to make disability services in this state an entitlement where, if you're declared disabled, you get services. Because my fear is this Legislature will throw money at the DD waiting list, because they've had so many years of broken promises, and they're going to make that behavioral health waiting list an official waiting list. And I don't want to see anybody having to wait to get services. In the community, I have a right to go see

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the doctor to choose. I have a right to do what I want to do, go to movies, and everybody deserves that same right. In regards to what Senator Stuthman asked earlier, I've known a lot of people who have come out of institutions over the years, yet they might a little...been a little tentative to be in with, but it's the best thing they ever did. And a lot of them will tell you, they'll go back kicking and screaming; they are not going to go back voluntarily. Because their lives are so much better and so enriched by the people that they meet every single day of their lives. Thank you. And if you have any questions... []

SENATOR LATHROP: All right. Thank you, Kathy. Anyone have questions for Kathy? Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Kathy, thank you for coming and giving us your testimony this morning. Do you feel that if everyone that is...has a disability...you stated that they should all receive services. []

KATHY HOELL: That's right. []

SENATOR STUTHMAN: How are we going to be able to fund all of that, or how is there going to be enough people to provide these services throughout the state of Nebraska and all over? []

KATHY HOELL: The state of Nebraska has neglected the disabilities system for many, many years and we're seeing it now, with the cuts in Medicaid and everything and the problems that are flourishing at BSDC. Nebraska's home- and community-based service system in the DD was the gold standard back in the sixties and seventies, but that's because the state of Nebraska was funding it appropriately. But if the state of Nebraska would rebalance its budget, by rebalancing it I mean take the money that you're throwing at these antiquated institutions, trying to keep them running, and put that money into home and community-based services, we'd have money to adequately pay

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people. And, people, right now you can make more at McDonald's than you can as working at a home care provider. So we've got to figure out a way to rebalance that money, and it can be done. Other states are doing it. Forty-seven states have recently closed their institutions for developmental disabilities. []

SENATOR STUTHMAN: Another question, Kathy, is, you know, we have a waiting list. Do other states have a longer waiting list or are you aware of that? []

KATHY HOELL: Some do. Some do and some don't. The ones that don't are not...they're at the same point that we are. They think by cutting back on the home- and community-based services, which is essentially what we're doing in this state, they are cutting back what people receive. When they don't receive the new supports, they end up going into institutions. We're paying more money to the institutions. []

SENATOR STUTHMAN: Okay. Thank you, Kathy. []

SENATOR LATHROP: Any other questions? I did want to ask you, you said you testified as an individual. Are you here representing any particular group? []

KATHY HOELL: No, I'm not. []

SENATOR LATHROP: Just your own perspective. []

KATHY HOELL: My own personal opinion on all of this. []

SENATOR LATHROP: Very good. []

KATHY HOELL: And I've got an opinion. Just ask anybody that knows me. []

SENATOR LATHROP: Well, we appreciate it and it's good to hear from you. Thank you

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for coming down today. []

MARGARET HUSS: Do I put this in here? []

SENATOR LATHROP: Is that a handout or a...? []

MARGARET HUSS: It is. I only have a couple of them but it's for you guys. I could give it to... []

SENATOR LATHROP: Okay. The best thing to do is put it in the box. Okay. []

BETH OTTO: That would be fine, or he could make copies, too, of some of it. []

MARGARET HUSS: I have a couple extra copies, but I don't think I have enough for everyone. []

BETH OTTO: Yeah, he can make some copies. []

MARGARET HUSS: Good morning. []

SENATOR LATHROP: Good morning. []

MARGARET HUSS: (Exhibit 2) My name is Margaret Huss and I live in Omaha. My last name is H-u-s-s. I grew up in the Florence area with nine siblings, including my brother Clete, who has been a resident at BSDC for over 25 years. Clete has profound, lifelong disabilities. He has a seizure disorder. He's nonverbal. He's considered profoundly retarded. He's been described as functioning at a preschool level. Yet, he is also six feet tall and he's a physically robust man. He needs assistance with each and every activity of daily living. He has received wonderful assistance with basic human needs and much more at Beatrice. My parents chose BSDC for Clete, when he became a young adult, as

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the best of all available options. I know with a certainty borne of experience that this continues to be the case. Cletus receives compassionate care at Beatrice in a homelike environment. He's cared for by people who have known him for years. And he also has many enrichment opportunities at BSDC, more than I think he would ever have in a community-based setting. I'm here on behalf of Cletus and others like him who cannot speak for themselves. My goal is to address some of the commonly held misconceptions in this very complex, emotionally charged area. Because of its complexity, I've also supplemented by brief statements with some authoritative material, which I urge each of you to read at your leisure. I want to thank each of you for the opportunity to speak today. One main misconception is that community placement is always the best option. The reality is that for some high-needs individuals places like BSDC offer the least restrictive environment. A person with mild disabilities who can take a bus to a job at Hy-Vee or Wendy's can have a happy life in a group home setting, but my brother will never be like that. I am happy for those who do thrive in the community, but I know it's not for everyone. At BSDC, however, Cletus does have wonderful opportunities besides just living in a residential cottage. He goes swimming every week at a pool that's there on campus he gets to walk to that's maybe two blocks away across an open field. He loves to be outdoors and at Beatrice there are adult-sized recreation equipment, basically playground equipment. He gets to have access to that on a daily basis. He goes to Mass every Sunday because a priest at...from Beatrice comes out and there's a nice chapel there, and so he gets to participate in that. He's in a walking club on campus. They have three-wheel bicycles there, again built for adults, and that's one of his...you know, he's very happy to be able to do that. Those are just a few of the things that he does, not once a year but every single week, and I think any one of these activities in the community would present a logistical challenge. He'd be in a group home in Omaha. He wouldn't be riding a bicycle on the street. Each one of those activities that he participates in because of the campus setting he would need transportation for, and with each of these things he does need constant assistance from someone. He's not doing this on his own. For those reasons and many more, I think that BSDC is the right place for him. I know that facilities are not

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in vogue. I've never really understood, however, the advocates of the one-size-fits-all approach who sometimes seem uncomfortably delighted with bad news about BSDC making the headlines. And, by the way, one reason there is so much bad news is because facilities like BSDC get lots more scrutiny than do their group home counterparts. This is both a benefit and a burden. As an example, the Department of Justice was able to investigate BSDC pursuant to a federal law called the Civil Rights of Institutionalized Persons Act. This act only applies to persons residing in places like BSDC or nursing homes or prisons. I asked the DOJ attorney who drafted the settlement agreement--his name is Rich Farano--whether there was a statutory scheme that protects the civil rights of those in community settings. He told me he knew of no such laws. Thus, as it stands now, those in prisons have more protections than disabled persons who live in community settings. Does this seem right? When we push high-needs folks out into the community, I'm not sure that no news is good news. Who will advocate for them? Another misconception is that community placement is mandated by the federal government. The reality is that nothing in the Americans with Disabilities Act or the Supreme Court's decision in Olmstead or any other statutory scheme requires community placement. In fact, just the opposite is true and to support this I've provided a letter in the materials I've given to you from the director of Government Relations and Advocacy of the VOR, which is a national advocacy organization. This person is an attorney and the letter was addressed to Nebraska state officials last month and it details the actual state of the law. I urge you to read this if you have not already had an opportunity to do so. The final misconception I wanted to address is that facilities like BSDC are more costly to operate than their community-based counterparts. Again, the reality is far different. The bottom line is that, when all factors are taken into account, savings do not occur when states close institutions and shipped residents to group homes. If the state of Nebraska closed BSDC, taxpayers would not save money. To support this, I've attached a 2003 authoritative article in a peer review journal which looks at cost comparisons and historical research over a 25-year period. The article is 20 pages long, but as policymakers I urge you to read it. It will help you understand the complexities involved

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and may also help avoid making decisions based on fault assumptions that ultimately could result in lower quality of care for our most vulnerable citizens. I would like to ask add that a number of other states have passed or are considering laws that would prevent the closure of state facilities like BSDC except as approved by the state legislature. Such a law in Nebraska would provide increased protections for our most vulnerable citizens because it would empower citizens, via their elected representatives, to have a voice. Such decisions could not then be implemented solely by the executive branch or by appointed administrators. I urge you to consider introducing similar legislation in the Unicameral. There are, as I said, a number of states who have already done this: Ohio, South Carolina, Washington, Oklahoma and others. In closing, I would like to thank you again for your willingness to take on this challenging task. I urge you to do what you can to ensure the ongoing viability of BSDC. It's a good and needed facility. Where there are problems, let's fix them. The community is not for everyone. It comes with long waiting lists, compromised care, and limited safeguards. I believe Nebraskans are sensible people. We know a range of options are necessary and, with your help, we can decide for ourselves what is best for Nebraska. Thank you. []

SENATOR LATHROP: Thank you very much for your testimony. Senator Adams has a question for you. []

SENATOR ADAMS: Thank you, Senator Lathrop. Obviously, from your testimony, you're satisfied with the care at Beatrice, but let me follow up with another question that I had asked an earlier testifier. Have you seen a difference in the quality of care from the nineties to now, and, if so, what might that difference be? []

MARGARET HUSS: I was a young adult when Clete first went there and so my perspective is a little bit narrower than some of the people who have been around much longer. But I think that there have been struggles at BSDC. Places could always be better and I think there have been struggles with staffing, getting...this is very difficult work. As the previous...as Kathy pointed out, some people can make more money at

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Wal-Mart in Beatrice than they can taking care of basic human needs for severely disabled people. So I think that staffing has been an ongoing problem, especially in recent years, of finding and keeping quality staff. And I think that there are very many compassionate people there, but it is very difficult work and that's one thing that I think is a constant grind. And I do agree that there was a wonderful administrator out there who lived on the campus and that helped immensely. Although we call it a facility for the people who live there and their families, BSDC seems like a community, so sometimes I think we're arguing about semantics more than anything. And the community-based programs, of course, also have severe problems with staffing shortages and lack of funding for services. []

SENATOR ADAMS: Thank you. []

SENATOR LATHROP: Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Margaret, do you have any information or do you have any knowledge of a community-based service that could provide something close to what your brother is receiving? I know you said, you know, they could go swimming, he could do a lot of activities and stuff like that. Is there anything in the state that could provide something close to that? []

MARGARET HUSS: Well, I, as I said, of the options currently available, I still feel that BSDC offers the most rich and best environment for my brother. I do attend, because I try to be as informed as possible--because I'm his guardian and I, like most of us, take that seriously--I go to fairs and I'm fairly familiar with what's going on in the community. If Cletus was to be placed in the community, it would be in Omaha because that's where his home base is. Every year, as part of his annual evaluation, the Eastern Nebraska Office is contacted about his needs and every year we get a letter back saying there's nothing in Omaha that would meet his needs at that time. And when you work with someone who's disabled, you know in your heart that the things he needs and the

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places he would have to go to get them, he'd spend more time in a minivan than he would participating in even one or two of these. And it's while he's doing that, where are the other guys who live with him who also need one-on-one? It just becomes very difficult logistically, and if you thought about it you'd, you know, you can see that that's the case. So right now, no, there's nothing that would provide him as rich a life as he has there. []

SENATOR STUTHMAN: Okay. Thank you. I do want to make two points, if I can. You've provided us with a handout and mentioned that the state would not save money by moving people to community-based care, and you have an article that's in the handout. But if I understand the substance of the article, that is, at Beatrice people receive a variety of services that we'd have to contract for once they move. And so if we're looking at the costs--we have a place for them to stay and all the services at Beatrice and we can take them to a community-based program but then we have to find a doctor and transport them to a doctor and to each one of these services and contract--and you're saying the costs to do that, to bring in all those people, to participate in the same things that they're getting at Beatrice, costs more than just having all those services right there. Is that the... []

MARGARET HUSS: That's right. That's right. And...right. And the people who now live at BSDC are high-needs people and they are probably more expensive to care for than a mildly retarded person who can navigate in the community on their own. []

SENATOR LATHROP: Okay. []

MARGARET HUSS: That's part of it. But I will add that this article, as this article points out, when there are savings, and again this article is a review of 25 years of other articles, looking to see if things that they found could be generalized. When savings do occur in the community, this article concludes that they only occur when services are cut and quality of care suffers. So there are ways to save money, but it's at the cost of

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compromising care. []

SENATOR LATHROP: Okay. The reason I bring that up and that I wanted to summarize the point of the article is that if anybody wants to address that point that you're making with the article and that you made with your testimony, they should feel free to. Because I think that is a...I don't want to call it fact but it's something that people talk about when they say there's Beatrice, we could save a lot of money if we move these people to a community and use that providing more services. []

MARGARET HUSS: Exactly. I know that that is a commonly held belief, both here and many other places. That's why I thought it was important to bring this article forward because this is a, you know, it looks at all sorts of stuff and comes to some general conclusions that might be useful in policymaking. I do have other copies of that article if there are people in the audience who...I don't have enough for everyone, but I have a few in my things I'd be glad to share. []

SENATOR LATHROP: Okay. And one other point and that is you are the second person already this morning to talk about the appropriateness of Beatrice for the profoundly disabled and referred to those with mild disabilities as able to navigate in the community setting. Your judgment, if you can--you sound like you've studied this topic, not just serving as a guardian for your brother but you've studied the topic so I'll ask you--where's the line at which a person in your judgment is...reaches a level of profound disability or profoundness in their disability where you think that Beatrice is the appropriate setting, versus someone who's more mild and might do better in a community? []

MARGARET HUSS: I don't know. I think some of that is driven...will be driven by the person and their needs. What, you know, what the law says and what is that there are usually three things you look at and it's...community placement is appropriate where the person can benefit from it, where there are resources available, and where the person

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chooses it, or their guardian. And sometimes it's the professionals who say, this person could really benefit from what's going on over here, and that's how you find out about whether it might be appropriate. Most of the people, I believe, at the State Developmental Center have been adjudicated mentally incapacitated so they have guardians so they're not capable of, what I guess it would be, making an informed consent decision. Every time my brother needs some healthcare, he's, you know, we may try to explain something to him but he's not capable of deciding if he's going to have this procedure or that. That's my decision. And I think that that's what makes it difficult. I think if a person has a guardian, then it's a person who needs help making those sorts of decisions and looks to professionals and to their guardians for that. []

SENATOR LATHROP: So you regard it not as a level of profoundness in a continuum or a spectrum, but a decision of the guardian. []

MARGARET HUSS: Well, the guardian is acting on behalf of that person and in their best interest. If the person is able to...I think we've seen...I've seen people who once lived at the State Developmental Center because of a historical anomaly that that was the case back in the day. I guess there used to be 3,000 people there and many of them didn't belong there. That was true across the country. When I see those people, I am amazed and I think it's wonderful that they never belonged there, obviously. And I don't think that the institution is for everyone and I don't think that the community is for everyone, and I don't know where you draw the line because I'm not a professional. []

SENATOR LATHROP: Okay. []

MARGARET HUSS: But I do think that it's best for people with profound disabilities, yeah. []

SENATOR LATHROP: Okay. Thank you. Senator Wallman. []

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SENATOR WALLMAN: Thank you. Thank you, Senator Lathrop. Yes, ma'am, how did you...were you the guardian that placed your brother there, or your parents did that? []

MARGARET HUSS: My parents were still alive and they...it was, of course, as anybody would tell you here who's a parent, is a very difficult decision. And he lived at home until he was really physically a man. He was, I think, 17, and I'm ten years older than him so I was around and I became a guardian with my parents, who are both now dead. But it was their choice and it was...they looked very carefully at what would be the best place for him. []

SENATOR WALLMAN: So they found out through various agencies about Beatrice, huh? []

MARGARET HUSS: Right. They first went through public schools in Omaha and through the ENCOR program, the Eastern Nebraska Office of Retardation, I believe, and he had services for a time in Omaha and, for him, they were minimal and not appropriate. And Beatrice turned out to be the best of all options. []

SENATOR WALLMAN: Okay. Thank you. []

SENATOR LATHROP: Very good. Thank you for coming down today. []

MARGARET HUSS: Thank you. []

NANCY WEBB: (Exhibit 3) Hi. My name is Nancy Webb. I was in Beatrice for...I went to Beatrice when I was 5 years old and got out when I was 27 years old. I didn't really like Beatrice, but I have to...let me tell you what it was like to live in Beatrice. I did not like living there. Even when you didn't do anything, they still put you over the tub, bathtub, and spanked you. We couldn't go anywhere outside without a staff. The food couldn't go anywhere outside...oh, was not good. We got three meals a day, nothing more. I went to

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school in Beatrice. I worked with the babies. We were not paid for any work. My bed was in the dormitory with about 20 other women. One day we had Dave...Beatrice told me I was getting out of Beatrice. I didn't think this was a good idea. I was...this was my home. There was...there I grow up and this was all that I knew. I was afraid. I did not want to leave. Kathy Kosse and Nancy, another Nancy, two nice women from ENCOR, came to pick me up and take me to my new apartment in Omaha. It took awhile for me to feel comfortable there. Often I will..I felt at home. Omaha has been my home ever since. Life was opened up for me. I have my own friends. Part a friend after working for 33 years where I was paid. I volunteer at a doggy day care, Noah's Bark. I go to Tulley's Kennels with...where I help the puppies to socialize with people. I love animals and they love me. I live with a extended family. I love where I live. I have my own room, my own things, my own...my things and my kitty cat. I don't want to ever to go back to Beatrice again. I want to see the people there get out into the community. Beatrice is not a good place for anyone. My mom always said, let my people go. []

SENATOR LATHROP: Thank you. []

NANCY WEBB: You're welcome. []

SENATOR LATHROP: Any questions? Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Nancy, you were placed there when you were five years old? []

NANCY WEBB: Yeah, and I got out when I was 27. []

SENATOR STUTHMAN: And...27. Do you think with the services that we have now in the communities, would a five-year-old ever be put into Beatrice now? []

NANCY WEBB: No. []

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SENATOR STUTHMAN: You don't think they would because of, you know, the technology we have, the people that work with the individuals in the schools and stuff like that. So it's, you know, I feel kind of bad. To me, it's unfortunate that you had to be there at such a young age. []

NANCY WEBB: Yeah. []

SENATOR STUTHMAN: You know, a five-year-old... []

NANCY WEBB: Yes. []

SENATOR STUTHMAN: ...is really young yet, so... []

NANCY WEBB: Yeah, I went there when I was 5 years old and I got out when I was 27. []

SENATOR STUTHMAN: Twenty-seven, so...and you're very content where you're at right now. []

NANCY WEBB: Yes. []

SENATOR STUTHMAN: Okay. Thank you. []

NANCY WEBB: You're welcome. []

SENATOR LATHROP: Very good. Thanks for coming down. []

JOE VALENTI: Is it okay if I pull another chair around? []

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SENATOR LATHROP: Sure. []

JOE VALENTI: Otherwise, she's going to correct me from the back row here, so I just...
(Laughter) []

DEE VALENTI: Cute. Real cute. I'm not done with you yet. (Laugh) []

JOE VALENTI: We need Steve's services. Our name is Dee and Joe Valenti from Omaha, Nebraska. Last name is spelled V-a-l-e-n-t-i. I think I've sent all of you a couple summaries of your previous hearings. I'd like to, before I get into a little bit of testimony, Senator Lathrop, you had a question about assessment and how do you make a decision between, you know, be at Beatrice or a community-based and developmental disabilities. I think Dr. Buehler testified in one of your first meetings in June and I thought he did a great job of doing a little bit of an analysis that needs to be done, and also, as you might recall when HHS testified, there is a program called ICAP which does an analysis also that my wife Dee could talk to a lot better than I could. But again, I think those programs are available to do an analysis on whether or not be it the institutional setting of Beatrice, which really is a misnomer and I agree with the people that have testified before us that it's really a community. It's not an...I wouldn't call it an institution at all. I would also point to you, we'll probably come from a little bit different angle. Our son Donny is 20 years old. Is at Beatrice today. He was first there in 1999. We adopted Donny when he was three and he was originally...and he was born in 19... []

DEE VALENTI: Eighty-eight. []

JOE VALENTI: ...98...'88, '88. So...and we adopted when he was three in 1991. He was first placed in Beatrice in 1999 in the ITS program. I would encourage you, as well as I would encourage HHS, to look at the ITS program as far as the subject we're going to talk about, which is our son is oppositional defiant behavior. If you read the articles which I think have been really well written on the Robbie Hawkins story in Omaha,

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Nebraska, which was very, very unfortunate, the system failed Robbie. The difference between Robbie Hawkins and our son Donny would be that I don't believe Robbie was classified as MR. I think he probably had some intellectual level, which was probably be it the good or the bad news, unfortunately, but his diagnosis, the process that Robbie went through over all of those years since he was four is very similar to our son Donny--in and out of different institutions in Omaha, be it Immanuel Hospital, be it St. Joe Hospital, whatever the case might have been in Omaha at the time. The system is really broken. I can't even imagine the task that you have before you. I'm sure when Senator, Speaker of the House Senator Flood appointed this committee, I'm not sure any of you probably had any comprehension of the depth of the issues that are facing the state of Nebraska. And back to funding, I'm not sure where the monies come from, but all I know is the attorneys always have a saying when we deal with them in my business as you either pay now or pay later. And I think we're going to have to pay now or we're going to pay later. I think the cost of prisons are much higher than the cost of being at Beatrice on an individual basis, and I think you've got other testimony to that effect. So again, we are very supportive of Beatrice. We are very fortunate that our son Donny could be there. He's in a group home type of setting today. The community-based programs I think ultimately really could handle Donny, but as was testified earlier, and I won't be too redundant, the...it's really sad that the oversight, the development of community-based programs in the state of Nebraska have not been truly explored. I think again, I think for some of the folks that have testified, I agree from what they've said and I understand community-based programs would not be appropriate probably for them. But for our son Donny, who is probably, with the oppositional defiant behavior and also an MR classification, he's been terminated from three group homes since 1999 and that's why he's back at Beatrice again. But the reason Beatrice works for him, and I would say, quite frankly, the ITS program really worked for Donny, is because of the level of oversight, the level of training that's available in those kinds of programs. What happens when they go into a group home environment--and I also think I wrote you about this and I also wrote Sean about this, is that...is they do...HHS is required, and appropriately so, to do an analysis under the

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ICAP program, which then funds ours for the placement into the community-based programs. And what happens is there's a disconnect, or whatever the case may be, between the funding and then the group home provider because of how they interpret funding for those hours. And then that gets very, very complicated and one which you probably won't want to get into today because I couldn't explain it if I tried. But the bottom line is they do not...they're not able to staff it to a level which, you know, is appropriate for that need and, i.e., in this case would be one-on-one care. They interpret one-on-one care to be different than what we would interpret one-on-one care and what Beatrice basically is able to provide on a one-on-one basis, and that's really the breakdown occurs, in our mind, with a lot of, I think, consumers who could be placed in community-based programs, is how it's funded and how it's administered. But the training is a huge, huge issue with community-based programs, the training and oversight and management of those programs, be it from HHS who tries but they maybe...I don't know if they're understaffed or overstaffed. Again, I think that's a bigger issue than I could address today. I would also say in Donny's case we had a very unfortunate happening before he ever got to Beatrice, is that to get him the services that he required we had to make him a ward of the state. Again, that's a much more complicated topic than you'd want to get into today, but again I think there's a lot of...like I say, there's a lot of dysfunction in the system. And we were paying...and I would go to Senator Stuthman's question. As much as I hate to say this, some of us are able to pay some funding for our children or our relatives or whatever the case may be. We were paying upwards of \$3,000 to \$4,000 for Donny's care. That ended when we had to make him a ward of the state just to get him the services that were necessary. So that is not a good situation. I mean, if you've got someone paying \$3,000 to \$4,000 a month and then you force them into a situation where they don't pay it any longer because you make them a ward of the state to get the services that he needs, I'd say something is wrong with the system. But again, we are very pleased with Beatrice. I know there's a lot of...and Dee is starting to read the 40 pages or so of the DOJ report. But again, I don't...and I think your question about what happened in the nineties would be my question, too, what changed between nineties and 2008. And also, I would also say to

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you that the public school system, which was also brought up in the previous meetings, the hearings, they do a heck of a job and I would say the Lincoln Public School system did a heck of a job with Donny and did a lot better job than the community-based programs did. And there's a reason for that. They get funded by the counties, as I understand it, and they really have better oversight. And then also I would say that we're very pleased with Beatrice, like I was saying earlier, but the ITS program is there. It's working, at least in my mind. It always worked for Donny for these types of issues. So I think you've got a format, an outline, a summary of how to do it. It's just how you extend it into the community, you know, community-based programs for those types of individuals. And I'll let Dee add what she needs to add. []

SENATOR LATHROP: Can we...let me visit with you, if we can. []

JOE VALENTI: Okay. Okay. []

SENATOR LATHROP: Just...it keeps the record more straight if we talk one at a time,... []

JOE VALENTI: Okay, that's good. []

SENATOR LATHROP: ...and so I'm going to take an opportunity just to clarify something. You talked about the ITS program being helpful and useful and beneficial for your son Donny. Tell us what the ITS program is so that we have that. []

JOE VALENTI: I'll let Dee probably address it, if you don't mind, but it's an Intensive Treatment Program that Beatrice has. It's housed in a separate facility, I think it's, what, 202? Well, it's probably not important. But anyway, but the staffing, quite frankly, is different. It's a much higher level of staffing, at least we feel it is, even though I think he's being cared for appropriately today. And then the follow-up, the continued meetings that you have every 30 days with that staff and the administrator of that program is just

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very intense and they bring a nurse, the physical therapist in, they bring the administrator in, they bring the activities director in. Everybody comes together. The teacher comes in on a every 30-day basis so you're constantly monitoring, you know, monitoring what's happening. []

SENATOR LATHROP: And I asked a question before about where, in my own mind, looking for where Beatrice is a compelling placement and where the community is a compelling placement. Is your son...one of the criteria that we heard in June, when we held our hearings, was safety. Is he a safety risk if he's out in the community... []

DEE VALENTI: Yes. []

JOE VALENTI: Yes. []

SENATOR LATHROP: ...to himself or to other people? []

DEE VALENTI: Yes. []

JOE VALENTI: Yeah, he's been cited a couple times for be it inappropriate sexual behavior, as well as he would run, he would... []

DEE VALENTI: Elope. []

JOE VALENTI: ...flight, elope. []

SENATOR LATHROP: Okay. []

DEE VALENTI: And property destruction. []

SENATOR LATHROP: Okay. Before we have Dee testify,... []

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JOE VALENTI: Okay. []

SENATOR LATHROP: ...let's see if anybody has any questions for you, Joe. []

JOE VALENTI: Okay. []

SENATOR LATHROP: Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Joe, first of all, I appreciate the fact that you brought to the surface, the fact that you are...you've been paying. You know, you had been paying for services for your son, \$3,000 a month or so like that. But in order to receive a service from the state you had to make him a ward of the state. You had to cut the tie between the family and then you were not responsible anymore for those \$3,000. I have always said that, you know, I would hope that, you know, that a family could continue to help support that. But the fact of breaking that tie from, you know, part of your family to the ward of the state is something that I don't like to see happen. But that's the way it is right now. And I would wish that, you know, somewhere down the line that we could change something like that where, you know, you've got the financial resources to help supplement that and receive those services. I think it could be a win-win situation. But the fact, you know, what...how do you feel about making your son being a ward of the state? []

DEE VALENTI: Do you want me to go ahead? []

JOE VALENTI: Yeah, you can go ahead. []

DEE VALENTI: You know, that was not our choice. We did not want to make him a ward of the state. First off, we didn't even want to place him out of our home. But based on professional opinion and his safety and ours and his growth potential, we needed to

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learn to love him from a distance. So we opted to. He started out in the ITS program, as Joe said. From there he was recommended into community-based services, which he, you know, he was terminated from three of them. I don't know what the magic number is, how many you terminate them from before you try to find another option, but three was enough. You know, making him a ward of the state was the most unbelievable thing I could imagine having to had to do. I mean, we had to do that just so he could get what he needed to be a viable human in society. We had to make him a ward of the state. Where does that make sense? []

SENATOR STUTHMAN: That is one of my concerns too. You are looking for a place for him and willing to pay some. []

DEE VALENTI: Well, absolutely, and we, I mean, we were willing to do whatever it took to make him a viable contributor to society. []

SENATOR STUTHMAN: And you were financially able to... []

DEE VALENTI: Correct. []

SENATOR STUTHMAN: ...contribute. []

DEE VALENTI: Correct. []

SENATOR STUTHMAN: But in order for this...to find that place you had to make him a ward of the state and then they took care of the bill. []

DEE VALENTI: Yes, Senator, that is correct. []

JOE VALENTI: I know HHS is here. Hopefully they're not recording our names and our financial ability or whatever. (Laughter) No. []

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SENATOR LATHROP: They're here. (Laughter) []

JOE VALENTI: They're here. []

SENATOR STUTHMAN: But, no, you know, and I'm sure there's other situations that would be in the same situation that you are, that could financially help if they find the right place for the individual. []

JOE VALENTI: I think as someone testified earlier, Senator, I think that there's just...there's just not this...and maybe there's no way to have a door that you go through and then kind of then move to the other possibilities. You know, you go through so many different doors in there as you're trying to do, and I know it's...you're not going to get it done in just these hearings. It's trying to find a more congruent system, I guess I would say, and it's not congruent today. []

SENATOR STUTHMAN: Thank you. Thank you. []

SENATOR LATHROP: Do you have anything else to offer, Dee? []

DEE VALENTI: No. Honestly, I mean again, I think Joe has said it and I'll just echo what others have said before me and that is, you know, again, obviously, through the, you know, the report that was done on Beatrice, there are some things that can be done better. But you know, I truly do believe it's a systematic problem and it's a lot bigger than Beatrice and it's a lot bigger than our son. And, you know, it's really scary what's going to continue happening and what do we do for these individuals who didn't sign up to live this life? []

SENATOR LATHROP: Right. Thank you. Any other questions? Seeing none, thank you, folks, for coming down. []

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JOE VALENTI: Thank you. []

CONSTANCE ZIMMER: (Exhibit 4) Good morning, senators. My name is Constance Zimmer, Z-i-m-m-e-r. I'm the chair of the Nebraska Statewide Independent Living Council. Nebraska SILC is an organization that exists because of a mandate under the Rehabilitation Act as amended in 1992 to advocate for independent living for people with disabilities. Nebraska Statewide Independent Living Council wants all people with disabilities in the most inclusive environment possible. Over the last few years, we have watched Beatrice State Developmental Center fail Centers for Medicaid and Medicare surveys repeatedly, and then fail a Department of Justice inspection while a report was released by Nebraska Advocacy Services outlining the abuse and neglect people with disabilities suffered. Our brothers and sisters in disability deserve better than this. If a person in society performed the kind of abuse and neglect that occurs at Beatrice, they would be punished by the law. But apparently the state of Nebraska allows it to take place in one of its institutions and it's allowed. When we look at all the different parts of the disability system, we see that it is broken badly. Several speakers before me this morning have said that very clearly. The set of parents just before me made that very clear that the system is not congruent at all. There is abuse and neglect at Beatrice, multiple allegations of rape at the regional centers, the official waiting list for developmental disability services, the unofficial waiting list for services in behavioral health, the Thomas Fitzgerald Veterans' Home in Omaha failed its inspection by the Department of Veterans Affairs, and the cuts to Medicaid services that limit supports and services that people need, people with disabilities need to live in the community. It's an extremely monumental problem. It's very complex. It's obvious that it cannot be fixed piece by piece by piece, but the state has to repair the entire disability system holistically, not just the system that serves people with developmental disabilities, although they have a very significant need for that. We need to make disability services in Nebraska an entitlement. This means that if a person is declared disabled they receive the needed supports and services right away. Another suggestion is to create a

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separate division of aged and disability services. This would keep the system open to all. When things are behind closed doors, we don't find out right away what's going on and especially what's going wrong. Nebraska Statewide Independent Living Council knows this committee was charged with only looking at Beatrice State Developmental Center, but we believe if you do not look at the whole system holistically more problems will develop. []

SENATOR LATHROP: Very good. Thank you. Are there questions? Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Constance, you dwelled on abuse and neglect at the Beatrice State Home. Several times you brought that up. Do you feel that there is any abuse and neglect in a community-based setting? []

CONSTANCE ZIMMER: I'm sure there is. []

SENATOR STUTHMAN: So it would probably be similar to that then too. []

CONSTANCE ZIMMER: And we would need...any community setting programs that are set up and utilized, I think we would have to scrutinize them as closely as Beatrice State Developmental Center and the regional centers are scrutinized. []

SENATOR STUTHMAN: Okay. Thank you. []

SENATOR LATHROP: I do have a question, and maybe I'll ask your opinion because you're maybe the third person already this morning that brought up a notion that Bruce Mason shared with us when he testified in June, and that is the idea of having a holistic approach or if someone needs care they can come into the system and get what they need and right now it's fragmented. And can you tell us what that would look like or what you think we need to do that we're not doing in terms of providing care in an easier way

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for folks that have developmental disabilities. []

CONSTANCE ZIMMER: I think if we had a department of disabilities services, and within that department were the psychiatric services and developmental services and services for the aged, you would have fewer instances of families needing to surrender custody of a beloved son in order for that son to get essential services, because it wouldn't be so piecemeal and you're folding together... []

SENATOR LATHROP: How is it piecemeal now? If I...and just take a hypothetical person in need. They're now through the high school. They've graduated so they're done. The school system is done providing them care or services and now they're 30 years old and they need help. You want to take him into the state's system to get him care, him or her care. What needs to...what's happening now versus what you envision would happen where we have a more streamlined or holistic approach? []

CONSTANCE ZIMMER: Well, if I was queen of the world,... []

SENATOR LATHROP: Let's go with that. []

CONSTANCE ZIMMER: ...when a child aged out of the school system and they can be served under the IDEA until they're 21, that several years before they reach that age or they had to transfer out, the school system, which does unilaterally an excellent job of serving these children and serving them in the community, according to their distinctive needs, they would be transitioned out of that school setting into a community setting and there wouldn't be the gap between the excellent services in the school system and excellent services in the community of their choice. []

SENATOR LATHROP: But you talked about it being fragmented. And I understand that the schools...and that is the one thing that we've heard that's been very encouraging is everybody seems to be complimentary of the way these services are provided through

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the school systems. But where is the fragmentation going on right now? If I want to have...if my son or daughter needs to see a speech therapist, is this...where is the lack of... []

CONSTANCE ZIMMER: When they're no longer in school, you're on your...if your child is with you, you're on your own to try to find somebody who will serve your child. Many caregivers, providers, professionals will not serve a child with disabilities. I have a son with severe...multiple and severe disabilities. He only, in his lifetime, have spent one month in an institution. He has lived with us all the rest of that time. He's 24 now and is living independently in the community, but that took...was virtually full-time work by two parents to make that possible. []

SENATOR LATHROP: Let me back up. If you want to get speech services, if you want to then get physical therapy, occupational therapy, and to have a psychiatrist involved in his program or treatment, do you have to go to a different department in state government to make all that happen, or is there one contact? Maybe that's what you're saying--there ought to be one contact and these things just happen. []

CONSTANCE ZIMMER: One department of disability services that would be able to point you towards the resources and help you coordinate them. Now you have to go and find each and every one of them. It's very hard to convince one, the dentist, to talk to the speech therapist, or the occupational therapist to talk to the primary physician. But if there was a coordinated system it would work much better and their quality of life would improve. []

SENATOR LATHROP: And how has that happened? If you take your son to dentist A and to speech therapist B, what's not happening today that you think is going to happen under a different system? I'm just trying to learn. I'm not... []

CONSTANCE ZIMMER: That system would also be providing case managers and

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resource developers, people who would be developing the resources that would serve people, case managers who would be able to interact with the professionals and lead them to collaborate with parents and so the child can live a life in the community. That's very hard to do personally. []

SENATOR LATHROP: Are we missing...okay, are we missing then the case coordinator? []

CONSTANCE ZIMMER: Case coordinators, we are. And another thing we're missing that would be very important is resource developers, people who develop the resources, find them, make them available. And we also are developing a set of peer reviewers who can make frequent visits to community sources of service to make sure that their quality is what it should be. []

SENATOR LATHROP: So your vision, when you talk about having it less fragmented, your vision would be that there would be a coordinator, somebody out there developing providers so that you don't have to call 42 dentists to find someone that will treat someone disabilities,... []

CONSTANCE ZIMMER: Uh-huh. []

SENATOR LATHROP: ...and then someone who's also going to oversee or make sure these are good folks. []

CONSTANCE ZIMMER: Peer reviewers who are making frequent and often...and come often visits. []

SENATOR LATHROP: Okay. You've answered my question. I appreciate that. Are there any others? []

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CONSTANCE ZIMMER: Thank you. And I can't iterate enough how the school systems have figured out how to do this and perhaps we need to consult with some of the experts in the school system to find out how to do it without dropping stitches. []

SENATOR LATHROP: Okay. Senator Wallman. []

SENATOR WALLMAN: Thank you, Senator Lathrop. I guess, ma'am, in regard to the school systems, I appreciate what you brought up. I used to be on the school board. Do you think that the school systems, the community-based, you know, care people should get in contact with the school system and that would be a resource for them? And also what if nobody takes a child in community care? Then what would you do? You know, I appreciate you take care of your son or daughter by yourself and I know that that's a job. And so what would be your options then, you know? What do you feel? The state has to have a... []

CONSTANCE ZIMMER: To have there be significant interaction between that child's IDEA team and wherever they are going. They're going to...that child is going to live somewhere--they're either going to live with their parents; they're going to live, Beatrice; they're going to live in a group home--but to have a lot of interaction before that cutoff date. Because the schools have figured out a program that works very, very well for that child and it's very distinctively individual, you can be sure of it. And I think the school system has a lot to teach us and the other disability systems about how to be inclusive and serve people in a community, because that's where they serve them, in inclusive school communities. []

SENATOR WALLMAN: Thank you. []

SENATOR LATHROP: Very good. []

CONSTANCE ZIMMER: Thank you. []

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SENATOR LATHROP: Thanks for your testimony. []

SANDRA HAM: I do have handouts. Good morning. []

SENATOR LATHROP: Good morning. []

SANDRA HAM: (Exhibit 5) My name is Sandra Ham, H-a-m, and I live here in Lincoln. And I will warn you I do have a written text here but I probably will end up going off, just based on some of the conversation we've had this morning. I want to thank you for the opportunity to speak to you today. I'm here, of course, to talk about BSDC, but I'm also here mainly to talk about community placement options for BSDC residents. My son has lived at BSDC for the past six years. Ian is currently 23 years old and he was diagnosed with autism as a toddler. He also developed insulin-dependent diabetes at age seven. Diabetes is a difficult diagnosis to deal with, but especially so for someone who has a developmental disability. Prior to BSDC, Ian lived in a group home setting. He received services from two different providers over a period of a little over three years. In the group home there were many issues. I can't even begin to go into all of them. There was a constant staff turnover; inadequately trained staff in diabetic care; very little, if any, medical and nutritional supervision. The staff operated pretty much on their own, particularly with the first provider we had. The overriding concern for both providers was profit. Ian was at risk because of the diabetes and development of behaviors of elopement--running away. There were escalating numbers of police calls to aid in the search for him, or calls because of citizen encounters with him as these behaviors developed. These calls also often included paramedics to assist with the medical needs when he was finally found. I will briefly describe only three incidents to convey the seriousness of the risks he incurred. One incident that occurred required a police officer to be called to a convenience store at midnight. The police officer saw a nonverbal teen and thought my 16-year-old, disabled son was high on drugs. They handcuffed him, in the process stepping all over his bare feet. When they saw the MedicAlert bracelet, they

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proceeded to the nearby group home. The knocking on the door woke up the sleeping staff person. He was unaware Ian had even left the house. Another situation involved a group home staff person stopped for DUI. My son was a passenger in the car at that time. This same person had been responsible for blood testing, insulin dosage, injections, and meal preparations for Ian, in addition to being responsible for other daily needs typical of a developmentally disabled child. The third and worse example was when Ian ran away from the group home at 8:30 in the evening with no coat on a bitter, bitter cold, winter night. The police, group home staff, and I searched for him. The local TV station made a plea to the public to watch for him. And finally, two and a half hours later, he was found miles from the home. We are thankful that he survived. And, senators, as we drove and drove, seeing the two police cars that had been part of that search drive past me, the thought that went through my mind was they found my son's body, not my son alive. It was a most horrendous night. After months of trying with other events that I haven't even listed, I finally got the news that Ian could move to BSDC. My son has finally gotten what group homes could not or would not provide. There is always staff to monitor Ian 24/7. There is always a nurse on call 24 hours a day. Most importantly, there is oversight constantly. While I agree improvements are needed, BSDC is a superior provider to any of those in the community-based setting. BSDC is the safest place for my son and others with high medical and/or at-risk behaviors. And I would like to touch on a comment made earlier, a question about abuse in community homes. Oh, most certainly there is, because I personally made reports and I know my son's doctors made reports, and I know a teacher that reported abuse allegations, and the only investigation was done a week after he left that first provider and, by that time, he wasn't there and all of the original staff that these allegations concerned had left, either on their own accord or after being dismissed. So please, please don't think that a group home is this wonderful environment of caring people, not to say that there aren't some, but in many instances there was one person to care for five boys. My son was given high hours, high needs, high dollar hours. He also lived with two other boys in a similar situation. They all collectively probably should have gotten close to one-on-one staffing, and in the mornings there was one person to care for those five children. The

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group home situation, in my opinion, for a high-needs person, is not and will not be the answer. They are not willing to spend the money necessary. Even if they are funded, they will not spend the money necessary. The bottom line is and will always be profit. Thank you. []

SENATOR LATHROP: Thank you. I do have a question for you. You've brought up, maybe for the first time that I've noticed this morning, the idea that someone with high needs can go into a community-based program. They go through an evaluation process that decides how much money is going... []

SANDRA HAM: Uh-huh. []

SENATOR LATHROP: ...to paid for that person. And are you suggesting today with your testimony that the person may be evaluated, the evaluation may show that they need to have one-on-one care, but when they get to the group home they don't necessarily get the care that the evaluation... []

SANDRA HAM: Yes, absolutely that is the case. Absolutely. []

SENATOR LATHROP: That would be your experience. []

SANDRA HAM: Without a doubt, with my son and, like I say, with other children that were in specifically the first group home provider. They had a situation where legally they should have only been allowed to have four boys, but there's some glitch that allows for emergency placement. That emergency placement was a long-term situation that only ended when I and two other parents pulled our children from that home because of all that was going on in the way of abuse and neglect. []

SENATOR LATHROP: I'm sure that there are, you know, there's very good community-based providers and there's some... []

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SANDRA HAM: Certainly. []

SENATOR LATHROP: ...that are trying to do it by the seat of their pants and make money. []

SANDRA HAM: Yes. Absolutely. []

SENATOR LATHROP: And so I don't know about how a generalization like that carries over to all providers, but you've brought the subject up and it's something that we can watch for. []

SANDRA HAM: Definitely. And I do...please, please allow me to say I have come across amazing people that worked with my son in the group home. One in particular loved my son dearly and cried when he had to go to Beatrice, but she understood why that was necessary. With every behavior, with every elopement he was coming closer and closer to injury or death for himself. And I also want to point out that police and firemen were called, other individuals helped in these situations. There were times he was in public places, he went into private homes. At any time he could have, inadvertently, hurt someone just by trying to run, pushing them. Someone could have interpreted him as an intruder, as the policeman did, perhaps on drugs and chosen to defend themselves. It was a constant, constant concern prior to getting him placed that a situation like that would occur, or him running. He would go miles from where he lived, running down 84th Street, running down O Street, the chance that he could dart in front of a car and someone would crash into another vehicle to avoid hitting him. I mean, there was just so much going on. And even the best of those in the group home and the most committed just didn't have the ability to protect him. You know, it really does come down to, even with the best of group homes, they just aren't set up for someone with these at-risk behaviors and this high medical needs. []

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

SENATOR ADAMS: Did your son get services from the public schools? []

SANDRA HAM: Oh certainly, excellent services. []

SENATOR ADAMS: Okay, you've already answered part of the question. So you thought those services were good. []

SANDRA HAM: Absolutely. []

SENATOR ADAMS: Where would you say there was a break point between the good service that the school was providing and maybe a limbo that you were put in as to what to do next, and what...it's been brought up before, what could we learn from that? []

SANDRA HAM: I really was uninformed as to what options were out there. Ian lived in my home. I'm a single parent and I was his only caregiver, pretty much unaware that there was even support out there. I had a health crisis and that's what prompted me to place him in the group home. Prior to that time, I did it all myself. The disconnect really is communicating to parents options and, as you've heard from other people, the availability of these options, because sometimes we're talking waiting lists. In my situation, I didn't have to declare him a ward of the state. My situation allowed him to be placed at the top of the list and get services. But I'm a rare person. You know, there's many that are still waiting for that support that would like to keep their child in their home but they need that help. It is a very difficult situation to do with a married couple, yet alone a single person. And while the school tried very hard, they can't necessarily bridge that community involvement, those other things that aren't necessarily explained to them. It was a long process of calling people and getting bits of information and someone else might lead me to somewhere else, but I had to do it on my own. No one shared that. []

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SENATOR ADAMS: So as long as...excuse me. As long as the school was involved, you knew where to go to get...to ask questions. []

SANDRA HAM: As it related to school, I did. []

SENATOR ADAMS: Right. []

SANDRA HAM: I cannot say...there was some information shared, but I wouldn't say there was a packet handed to me with here are some great resources for you and your son, here are agencies and programs that you might be interested. That did not happen. That developed on my own investigating and calling. []

SENATOR ADAMS: Okay. Thank you. []

SANDRA HAM: Anything else? []

SENATOR LATHROP: I don't think so. []

SANDRA HAM: Thank you. []

SENATOR LATHROP: Thank you for your testimony. []

SANDRA HAM: Uh-huh. []

SENATOR LATHROP: I think before we take the next person, we'll take ten minutes just to give the committee members a chance to get up, move around, stretch your legs. Thank you. []

BREAK []

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SENATOR LATHROP: (Recorder malfunction) There were an awful lot of people that raised their hands and I appreciate your limiting your testimony to ten minutes or so, and we're doing well but let's start with the next speaker. Good morning. []

LAURA LIVELY: Morning. My name is Laura Lively. I'm from Omaha. Our daughter is at Beatrice. She's 57 years old and has been there for 40 years. We're very satisfied with her treatment. She was a very premature baby and blinded by too much oxygen in her incubator, and also profoundly retarded because of an immature nervous system. She functions about like a two- or three-year-old, which many of our adult children there do, and has to be supervised and treated like a toddler. It's a perfect place for this kind of child because there's no other facility for that, and it's very frightening to think we might lose it. There have been so many agencies involved in criticizing Beatrice the last several years that we've lost sight of the good things about it, and there really are many good things. The staff that directly cares for the residents are, for the most part, on a par with saints, as far as I'm concerned. The problem now is many of them are retiring because they've been there a long time and we're getting new people, and younger people don't always want to do this kind of work so we have to have some incentive for them, and I know that you understand that. It just seems like so many agencies have become involved that we've lost common sense in thinking about these really low functioning people. It's wonderful when they, you know, can go into the community but this type of child can never handle that. So that's what I have to say. []

SENATOR LATHROP: Okay. Thank you very much. []

LAURA LIVELY: You're welcome. []

SENATOR LATHROP: Let me make sure there are no questions before we excuse you. Senator Stuthman. []

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SENATOR STUTHMAN: Thank you, Senator Lathrop. Ma'am, your daughter receives those services at Beatrice. Are there a number of people that are in that same environment that receive the services? []

LAURA LIVELY: Yes. Yes. Uh-huh. []

SENATOR STUTHMAN: Okay. If your daughter went to a community-based service, do you think there would be that group of people there? Would she be just the only one receiving the service? And do you think there is...or are there services to be provided? []

LAURA LIVELY: For years they've tried to establish that kind of a facility and it hasn't been done. Years ago Dr. Menlosino (phonetic) tried to do it, a unit that he started within county hospital, but it never really got off the ground. And the safety of this kind of resident at Beatrice is imperative. They just...they have no judgment and no ability to, you know, make decisions. It's really sad. []

SENATOR STUTHMAN: So there would be real...it would be a difficult situation if your daughter had to be sent to a community-based service... []

LAURA LIVELY: Very. []

SENATOR STUTHMAN: ...if there was some provided, and there may only be one or two individuals. []

LAURA LIVELY: Yes. I would feel that she was not safe there. []

SENATOR STUTHMAN: Okay. Thank you. []

SENATOR LATHROP: Thank you. Any other questions? Thank you, Ms. Lively. []

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PATRICIA CRAWFORD: Hi. I'm Patricia Kelly Crawford. I live in Omaha. Our son Matt is a resident at BSDC and BSDC is a wonderful home and an essential facility tailored to fit the needs of residents who have severe and profound mental retardation and multiple handicaps. A significant asset is the documentation of incidents which triggered this investigation. The identified incidents are painful for all concerned, but it's impossible to improve any program if there's no record or admission of events which need to be eliminated or modified. The Centers for Medicaid and Medicare, which makes the...has a huge book of rules--it's about this big I think--for ICF/MR. BSDC is an ICF/MR, an intermediate care facility for mental retardation, is enormous and a real protection for people with intense needs. Our family with other families has great respect and appreciation for the dedicated and caring staff of persons who perform very difficult jobs. Matt has been at BSDC since age 14 and is now 47 years old. The middle of five children, he lived at home with his two sisters and two brothers, his dad and me, and attended a day program from the time he was about three years old. His care was always difficult for all of us, but mostly for me. From about age ten or so it became obvious to our family that we were not able to meet his many needs, as his behavior became very difficult to manage. He has no speech, has profound mental retardation and needs a great deal of support in his life. And I'll never forget when we...the first time we ever visited him after he went to Beatrice. As we were preparing to leave, he sat in a chair as far from the door as he could get and I called him and said, Matt, come here, give us a kiss good-bye, and he wouldn't move. And so, you know, he has no speech at all, so I interpreted that as to say that he...this is my home now, leave me here. The two ladies who received him when he entered BSDC still care for him today--now that's got to be kind of a record--along with other dedicated staff members on three shifts. He thrives on the structured schedule which is a source of security and contentment for someone who has no speech and very limited receptive language. His needs dictate three shifts of staff daily for his safety. He benefits from protection from ordinary hazards such as traffic, and he swims every Saturday in a pool with no deep end. He's joyous when his dad and I visit, and is similarly happy to see us leave. For Matt, it's his least restrictive environment. And I thank you for taking on this important investigation--I

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knew when you took it on that you didn't know what you were getting into workwise (laugh)--using your free time to improve BSDC and it's very much appreciated by all of the parents and relatives, and we do hope you'll finish the job for people with mental retardation by investigating community services as well. And we certainly strongly recommend a substantial raise in pay for direct-care staff, which will attract young workers and augment the staff now and in the future, and contiguous states pay workers in ICF/MR considerably more than Nebraska. I'm going to answer some of the questions that were asked earlier. I've been taking notes. The thing about OAITs, that the Valentis mentioned, it means outreach and intensive services system, and they set it up at Beatrice State Developmental Center with the idea that people from Lincoln or wherever could bring their difficult clients and retrain them, and then those people rendering the OAITs service would train the teachers, the parents, the group home people how to deal with a person with difficult behaviors. But so often what happens is they take them off all the drugs and they get them squared away and to behave better and are more happy, but then the community programs don't want them back and so then, you know, they end up staying at BSDC. And I'd like to say this in regard to costs and so forth. At BSDC, this is what people would need in community-based programs, and it's probably an incomplete list: a psychologist, M.D., nurses, including...I don't know what I wrote there, dentist, recreation, transportation, dietician, speech therapist, occupational therapy, social workers, P.E. instructor, and work opportunities. And in that regard, Matt, he is paid for his work. He wears high-end sandals and he owns a couple of pieces of furniture which he's bought with his wages. And I'd also like to make you understand that every month several hundred dollars from his dad's Social Security goes to Matt's support there, and before he was...he went there at 14 and when he became 19, I guess for those five years, we paid big bucks for his treatment. And another thing that's interesting. We've got two dental schools and two medical schools and we've got plenty of nursing schools in this state. I've always thought that their students should be rotating through Beatrice State Developmental Center, which eventually they'd end up in community-based...in communities practicing medicine or whatever, and then they'd have some experience. They will have seen profoundly

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retarded people or severely retarded people before and might accept them more easily into their practice. And then I think this...regarding the Olmstead decree, recognized an ongoing role for publicly and privately operating institutions, and I quote: We emphasize that nothing in the ADA--that would be the Americans with Disabilities Act--or its implementing regulation condones termination of institutional settings for people unable to handle or benefit from community settings, nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it. So I thank you very much. []

SENATOR LATHROP: Thanks, Pat. Appreciate your testimony. []

PATRICIA CRAWFORD: Do I just put this here? (Exhibit 6) []

SENATOR LATHROP: Yes, that's perfect. And you filled out a sheet and put it in there as well? []

PATRICIA CRAWFORD: I did do that. []

SENATOR LATHROP: All right. Let's see if anybody has any questions for you before you get away. []

PATRICIA CRAWFORD: Oh, sure. []

SENATOR LATHROP: Senator Adams. []

SENATOR ADAMS: I'll ask you. Have you seen a decline in care in the last...since the 1990s? []

PATRICIA CRAWFORD: At BSDC? You know, I really haven't in my son's living unit, his cottage, but I'll tell you we had one...we had a couple of really good CEOs of BSDC

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probably in the nineties. We had Hugh Sage, who was excellent, and then we had Ken Peterson after Hugh Sage left, and Ken Peterson, God rest his soul, he died at age 50, but that guy, he would...he said, I run a 24-hour facility, he said, so he would visit the various residences during the night, you know, at 2:30 in the morning or something like that and pat the people on the back and thank them for their service, and he'd see the second shift another time. But I'll tell you, the parents really appreciated that loving care he gave, so that would be the downside, is that I think in recent times we've had, oh, since about the mid-nineties, we have had not very effective CEOs. Now I'm not saying about Ron Stegemann, because he's only been there for a very short time, but we had one CEO who was fired and then we had kind of a triumvirate, or something like that, for awhile and that didn't work out very well at all. And now we have the new CEO so we are very hopeful that he'll do a really good job. Okay? []

SENATOR LATHROP: Okay. That's it. []

PATRICIA CRAWFORD: Thanks a lot. []

SENATOR LATHROP: Thanks for coming down, Pat. []

PATTY BRUMM: (Exhibit 7) Hello. My name is Patty Brumm, B-r-u-m-m, and I guess he's giving you a copy of what I'm going to testify. And I want to thank you, the committee, for allowing me to speak today. My sister Jeanne resides at the Beatrice State Developmental Center and has been there for 20 years. She has moderate mental retardation, as well as profound emotional problems. After thoughtful consideration, it is our family's opinion here needs can most suitably be addressed at BSDC. We believe community placement would be detrimental to her welfare. Jeanne's immediate family includes her father Steve, who is here today; her sister Mary, also present, who is a retired teacher; her brother Bob, a practicing M.D.; and myself with a background as a pharmacist. Jeanne is currently 52 years of age. She has recurring, severe emotional problems. Despite being on medication, she continues to have a high

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risk for violence, both self-directed and directed towards others. As a youth, Jeanne was shuffled from school to school, program to program. She was expelled from all of them. These include LARC School and General Arnold School in Lincoln, both public special education programs. She was expelled from private facilities, such as Villa Marie in Waverly and Harry S. Truman Neurological Center in Kansas City. All explanations for the expulsions cited her extreme aggression toward herself and others. Eventually, when all attempts at placement failed, Jeanne was placed in the Nebraska Health and Human Services system at the age of 15. She began her residence at BSDC in 1988. At BSDC, Jeanne's multidisciplinary team of caregivers can be assembled quickly to troubleshoot her problems in crisis situations, such as an escalation in Jeanne's extreme emotional and physical outbursts of self-injurious behavior and aggression. Her team includes specialists in the areas of psychiatry, psychology, social work, physical therapy, nursing, pharmacy, direct-care staff, case managers, and others. Their efforts have been valuable. Most of Jeanne's team are employed on site and are within walking distance of each other. They frequently work with Jeanne and can observe here in her own environment, enabling them to expedite a proper plan of action. An example of the team working effectively is a situation where Jeanne was unable to see her new psychiatrist in the on-campus clinic, so the BSDC pharmacist escorted him to her living unit where he could meet Jeanne and evaluate her. This would not happen if she were in community-based housing. With all due respect to community-based services, in our opinion, this rapid response could not be possible in the community where care is decentralized. We know how difficult it is to get health professionals in the same room, particularly on short notice, because the logistics are too cumbersome. In our view, it is impossible for a team of professionals who likely are dispersed throughout the city to assemble with little notice to address emergency type behaviors of one of our clients like Jeanne. These emergency situations are not emergencies in the sense of a cardiac arrest but, rather, where a patient is in extreme mental distress and would harm herself and others. Jeanne's current ability to see her physician, dentists, physical therapists, pharmacists, and many others within walking distance of her living unit cannot be matched in community-based housing. In the community, a visit to a physician would

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involve getting Jeanne into a car, driving an agitated client, and waiting in a waiting room. Each step of this process has a high potential for failure due to Jeanne's tendencies toward disruptive behavior, which is obviously not compatible with a roomful of waiting patients. Consequently, the doctor's visit would often be postponed. Considering Jeanne's behaviors, we anticipate most of her appointments would be delayed to the detriment of her mental and physical health. Our loved one Jeanne benefits significantly from the controlled environment at BSDC where she has a multidisciplinary team who know her. She needs direct and easy access to all these professionals who communicate directly with each other. We fear the necessary coordination of care and treatment for Jeanne cannot be accomplished by a group of community-based and geographically diverse caregivers who primarily communicate with written notes and reports. We urge the Nebraska Legislature to provide adequate support and ensure proper funding for BSDC and its important mission of meeting the needs of its disabled residents. We believe such a setting must continue for all individuals who will fail in community-based situations. Thank you. []

SENATOR LATHROP: Thank you, Patty. Are there any questions? Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Thank you for your testimony, Patty. []

PATTY BRUMM: You're welcome. []

SENATOR STUTHMAN: The success of your sister you feel is mainly because of the team of workers at BSDC that has... []

PATTY BRUMM: Yes, that contributes largely to it, uh-huh. []

SENATOR STUTHMAN: ...has made the difference, as compared to the

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community-based setting where there probably isn't that team there to work with? []

PATTY BRUMM: Yes. And I know in the community-based setting you wouldn't have a physician right on campus where you can actually walk to the clinic. There's neurology clinics, ENT clinics, ortho clinics, you know, all these different clinics, they're readily available. And Jeanne, with her behaviors, be very hard to get her into a doctor's office if you could find a doctor who would see her, as I'm hearing maybe that's not even possible out in the community. []

SENATOR STUTHMAN: So you're very content with the fact that that group of people, she's able to visit with them, address the situation, and that's been the success at BSDC. []

PATTY BRUMM: Yes. And they include us in on phone conferences while they're meeting if we cannot attend. They have special meetings with her because she has these emergency-type situations, and we've been on phone conferences so we can be included as a family. Of course, we're welcome to come out and be present, but I'm from Omaha and can't make it short notice and her dad is from Lincoln. And so often we are included and I just feel that I like the multidisciplinary approach which I just don't see happening if she's not at a place like Beatrice. []

SENATOR STUTHMAN: Thank you. []

PATTY BRUMM: You're welcome. []

SENATOR LATHROP: I do have a couple questions for you. Your sister Jeanne, is she a safety risk if she's out in the community? []

PATTY BRUMM: Yes, she is. She's a risk to herself, because she has self-injurious behavior, and she probably would exhibit some of those behaviors of trying to run away.

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She can injure others as well. So I think she would be a risk. []

SENATOR LATHROP: Did she ever have a go-through any community programs, or did she go right to Beatrice? []

PATTY BRUMM: No. []

SENATOR LATHROP: You talked about some of the things that she did before she was 15, but... []

PATTY BRUMM: No, she...at the age of 15 she entered the regional care system and she was not a ward of the state. My mom and dad were her guardians and they did pay for that until she was of an adult age. []

SENATOR LATHROP: All right. []

PATTY BRUMM: No, there weren't any community programs that would have taken her at that time. []

SENATOR LATHROP: Okay. Very good. Thank you. []

PATTY BRUMM: Okay. Thank you. []

MARY ANGUS: (Exhibit 8) Senator Lathrop, members of the committee, my name is Mary Angus, M-a-r-y A-n-g-u-s. I am the registered lobbyist for the Arc of Nebraska. As I sat here, I've got a prepared presentation, but I wanted to let you know that I would like to answer some of the statements that were made. Some of that will be in my testimony. The Arc of Nebraska is a support and advocacy organization with and for people with developmental disabilities. We are an affiliated state agency of the Arc of the United States and have 17 local chapters and approximately 2,500 members across Nebraska.

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We live by the core values of mission and principles, leadership, community participation, diversity, integrity, and excellence. We advocate for the rights and full participation of both children and adults with intellectual and developmental disabilities. We recognize the importance of this committee and, as others have said, you've got your work cut out for you and really admire you for your willingness to work on that. You've asked us to assess the Beatrice State Developmental Center. I'm not going to go into everything that you've already seen in terms of the evidence that has been presented to you through the CMS, or Centers for Medicare and Medicaid Services, reports; Nebraska Advocacy Services; and the Department of Justice. You have all seen those reports. What I'm going to do is kind of focus on fleshing out a few things. Obviously, they've already established that they have failed to be in compliance and have been seen as in violation of the Civil Rights for Institutionalized Persons. They have a longstanding, longstanding problem with staffing. In addition to understaffing, which has been shown in all the reports as being over the years, they have many staff who float from one unit to another. These staff often have no knowledge about the unit, nor do they have knowledge about the people who are on that unit. Many have no basic care training. They are assigned to people who may have G-tubes, feeding tubes, or J-tubes, which is especially a problem because if they do not know how to manage the pumps, when to change the feeding bag or when to...how to position someone who is using a tube, we can have many problems such as increases in the risk of pneumonia, complications with medical devices, and delays in getting medical treatment. The communication is a problem. There may be not enough communication between managers and direct-care staff. People who work there have expressed greater levels of stress and fears of suspension. They don't have any understanding as to what that might mean, how they might be suspended and when that might happen. You might want to ask employees tomorrow about what's called the "West Texas vacation." That is something that they use as a reference to being on suspension and there's kind of like a...it's a trophy kind of thing if you manage to make it through and survive a suspension. We've heard about families that have been apparently very, very fortunate in their care at Beatrice. As we heard in testimony on the 23rd, Beatrice has too few professional

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staff. In the June hearings, we were told there are 30 percent of the level of people needed for the numbers there of psychologists. There was at that time, and I don't know if this has changed, no full-time psychiatrist. They should have four to six speech therapists. At that time they had none. They're underserved for neurology and behavior analysis. They have failed to meet goal A-2 of the three-year state plan developed in June of 2007. Two of the objectives which they have failed to meet were an increase in quality assurance at Beatrice and maintain federal certification. I fail to see how they can maintain it when they have not accomplished it. The other thing is to ensure a well-trained cadre of staff at all levels. The reports detail information about staff not having the ability to treat or to work with people with various medical needs, in particular. Beatrice eats up 18 percent of the funding allocated for the developmental disabilities services, but only 4 percent of the people in the state who are using or are waiting for services are in Beatrice. Almost 80 percent of the people with intellectual disabilities who have uncontrolled seizures live in Beatrice...I mean, live in the community. Over 90 percent of those who also are blind live in the community. The percentages that were given in the June hearings were misleading and I believe they presented a picture of Beatrice that would lead you to believe that the population at BSDC has greater levels of disability than those living in the community. In your testimony there is a charge just of the one level, and that would be a level of intellectual disability, showing the percentage of the total population who are living in Beatrice and the total population who are living in the community, along with the numbers that that means. Beatrice is an outmoded, outdated institution which is contraindicated by all of the research and violates the rights of people with disabilities. People with challenging behaviors consistently improve or at least remain the same after moving into the communities. People with complex medical needs sometimes need specialized medical care and services, often are treated, in using creative methods of dealing with those, are treated in the community. The Council on Quality and Leadership reports that we don't trade off on health and wellness or safety when we move people into the community and allow for a greater level of self-determination and choice. People who have grown old in institutions have also been found to be able to move out of the only

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home they've ever known and be happy with that move. Fears that people with intellectual disabilities will be worse off, unsafe, or lonely should not be used as reasons to keep the institution open. Rather than using these scare tactics as excuses, we should identify the circumstances that in the community increase the risk and manage those using such means as personal relationships, social networks, increased self-determination, and increased control. We must develop a holistic and unified service system and supports in the community for people with intellectual disabilities which provide for adequate needs for the ones that have been found to be...found in the assessments. Finally, we have a concern about tomorrow's hearing being at BSDC. The location is very convenient for current employees, but it's problematic for self and other advocates. Transportation is virtually nonexistent, and for people who have either lived there or previously worked there, it can actually be traumatic to return to the grounds. We have provided testimony in your packets from a woman who so fears that she will have retaliation or will be sent back to Beatrice that she wishes to remain anonymous. She was almost afraid to put in any testimony. I have used only her words. The location also reduces the opportunity and the likelihood that the public, in particular people with developmental and intellectual disabilities, will be able to observe the hearing, and the location predisposes testimony that will be favorable to the institution and could serve as a deterrent to individuals wishing to testify about conditions that have been adverse. We believe that it has been...remained open for political reasons--it is best for the town, it is best for the employment situation--but not because it is best for the people who live there. We hope that your charge will be taken without the predetermination that you would keep Beatrice open. In terms of some of the other information that you've been presented, I have on my right here the staffing requirements under the regulations for centers for developmental disabilities is one in eight, one staff to eight persons. In the evenings or off times it is one to ten persons. I can show you the regulations on that if you'd like to see them. The problem with many of the staff there is that they're not trained and that they're overwhelmed by the amount of work that is there. In Department of Justice reports, as well as reports that I've gotten from employees, there is oftentimes a group of people who are not doing any of the work. They are socializing. The

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Department of Justice says that while they were there they were playing cards. That leaves the people who are willing and committed to doing that work to have to frantically get around to get it done. When we have staff that are unable and untrained, unable to be able to recognize a medical emergency when they see it, we have delays in services. In fact, there are times when someone who is using a feeding tube may be aspirating, could be...could be actually turning blue, and they have to call a nurse who may not be very close by. The nighttime, there may be only one manager for the entire campus. The supervision is lacking. There have been times where a nurse has been called, and had she not been called at that point there would have been more serious repercussions. The incident that was reported in the newspaper and to which you've got...you finally were able to get information actually was a case in which the person called for help but didn't realize it was an emergency. And when that person said, we've got a person here who is unresponsive, the operator thought they meant that they were nonverbal or they were not coming when they were called; did not recognize that it was an emergency. So that delayed the system's response even further. I am also presenting you with some testimony from three other individuals who asked me to present it, one of whom is the woman I spoke of earlier who wishes to remain anonymous, another is a parent of a person with Down's Syndrome, and the third is another person who has been in Beatrice...or, no, her mother was in Beatrice and she writes, I would not be here if my mother remained there. She also writes that my mother did not know how to parent me; I was fortunate that my father was able to do that. Because at Beatrice she was not taught how to be a parent. I'll leave these for you, Senator. That's what I have. I think that...oh, I know, there was one other thing that I wanted to say, and that is the folks that have been testifying before me are absolutely correct. We need to have better supervision or better oversight on community providers. One of the problems is that the regulations are different. One of the things that we're going to find, I think, in the LR156 discussions about the wait list is that, you know, we will be looking at that. Another question I heard earlier is other states, do they have wait lists. I have a PowerPoint that was provided in January of this year to the officials in Florida, by officials in Florida. They report that there is a waiting list of approximately

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15,000 people, however, 10,000 of those are children. That leaves approximately 5,000 on their waiting list. I don't know the exact population of Florida, but I would venture to guess that it is the ratio of people...the population to the number of people that are on a waiting list is probably pretty equivalent or we may have actually a higher ratio. I'm not sure about that. I'd be glad to answer any questions that anyone might have. []

SENATOR LATHROP: Yes, Senator Wallman. []

SENATOR WALLMAN: Yeah, thank you, Senator Lathrop. Yes, Mary, I see you're a lobbyist for Arc, which is fine. []

MARY ANGUS: Uh-huh. Thank you. (Laugh) []

SENATOR WALLMAN: But do you have a guideline where you actually train people to be caregivers for profoundly disabled people, nonverbal? []

MARY ANGUS: The Arc of Nebraska does not, but what we have looked at is the figures that were given us in June to show that about 60 percent of the people with profound intellectual disabilities are living in the community. The Arc of Nebraska does not provide any of that kind of training. Thanks for your question, though. []

SENATOR WALLMAN: Thank you. []

SENATOR LATHROP: Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Mary, in some of the testimony that you have given us, you stated in there that Beatrice eats up 18 percent of the funding, but houses only 4 percent of the people receiving or waiting for services. []

MARY ANGUS: Yes, sir. []

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SENATOR STUTHMAN: What...explain that waiting for services. How do you fund people that are waiting for services? []

MARY ANGUS: Well, no, I was...what I'm talking about there is that when you add the number of people who live in Beatrice, the number of people who are in community-based services and receiving services, and that 1,772 people that we heard about are on the waiting list, those are the people who need services or are getting services. If you divide the number of people who live in Beatrice by the number of people who are receiving or waiting for services, you get the figure of 4 percent. If you do not include the people who are on the waiting list, so you reduce that amount to the somewhat over 4,000 people who are receiving services in the community plus the 276 who are in the institution, then you get a figure of 6 percent of the people in the state who are getting services through the department live in Beatrice. So 18 percent of the funding goes to Beatrice, but only 4 to 6 percent of the people are served there, depending on whether you add the waiting list in. []

SENATOR STUTHMAN: Well, I don't know why you would add the waiting list into it because they're not receiving services or anything, are they? []

MARY ANGUS: No, and that's part of the problem. They have been found eligible but are not receiving services. But I'd be glad to leave it at the 6 percent... []

SENATOR STUTHMAN: Yeah. []

MARY ANGUS: ...and say that 18 percent of the funding goes to Beatrice but only 6 percent of the population of people receiving services live there. []

SENATOR STUTHMAN: Services. []

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SENATOR STUTHMAN: But those are the ones that are needing the highest level of care, right, so...? []

MARY ANGUS: I would disagree with that. We have 60 percent of the people with profound intellectual disabilities who are living in the community. We have almost 80 percent of the people who have uncontrolled seizures living in the community. We have almost 90 percent or over 90 percent of the people who are also blind living in the communities. A case in point is a dear friend of mine who...Tim Kolb, who is ventilator-dependent, quadraplegic, has basically only the use of his facial muscles. He uses a puff and sip tube to control his wheelchair. He lives in his own home with his wife using a care attendant. []

SENATOR STUTHMAN: Okay. The other question that I have is we've heard testimony this morning from individuals that are just very satisfied, you know, with the services that they are receiving there and now you're saying that the reason it has remained open is because it's best for the community but not best for the residents, so...now we've heard of people that are,... []

MARY ANGUS: Uh-huh. []

SENATOR STUTHMAN: ...you know, happy with the services that they are receiving there. They've been through group homes, they've been through things, and now they have finally found a place where the family is content, they're content, and they want to stay there. And in your statement it says, you know, that it's not best for the residents. So explain that a little bit to me. []

MARY ANGUS: Well, respectfully, Senator, I would say that what we have heard from is families and guardians who say they're happy and content with the services. The other thing that I have heard over and over and over again is that there are not adequate services in the community. People have actually, you heard before, had to place their

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child as a ward of state in order to get services. That's not the only area in which you can only get services if you're a ward of the state. That's actually true also in some of the behavioral health services. We have not heard from people currently living there about that. We have heard from a woman who spent 22 years living there who is very, very happy being out. I really couldn't say to you how many people who are actually living there might be able to testify about their contentedness or not. I would just respectfully remind you that they're guardians rather than people who live there. []

SENATOR STUTHMAN: Okay. Thank you. []

MARY ANGUS: Thank you very much. []

SENATOR LATHROP: I do have. In some respects, I'm a little troubled by your testimony and in this...in this respect, I guess, because when this commission was established and the problems at Beatrice became evident and people started to approach me, different groups, folks from your organization and from the Friends and Family of the Beatrice Development Center, it became evident to me that there are two camps and they're philosophical camps. And we have a camp of people that is typified by the folks from the Family and Friends of Beatrice. []

MARY ANGUS: Uh-huh. []

SENATOR LATHROP: They come, as they have today, and testify that things are great and they're very happy and they know that their son or daughter or their ward is safe and secure and getting services. Then we have folks from... []

MARY ANGUS: You can call it my camp. (Laugh) []

SENATOR LATHROP: ...the Arc. Yeah. Well, I'll call it your camp... []

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MARY ANGUS: Okay. That's fine. []

SENATOR LATHROP: ...or the camp that you've just...and I listened to you today and you're...we're very familiar with the criticisms of Beatrice. Believe me, we know that there are shortcomings at Beatrice. But we're hearing people say that's...you know, for somebody who's profoundly developmentally disabled, it's a good spot for them. They're safe. They have behaviors that are...that will get them in trouble in the community, that will make them misunderstood in the community. We need that. And you come in today and you give us the list of the problems at Beatrice and I'm wondering, the philosophy of the Arc is close Beatrice and spend the money on community-based care. []

MARY ANGUS: Yes, sir, systematic closure, yes. []

SENATOR LATHROP: That's, in a nutshell, you have no use for Beatrice or an institution setting and it's your philosophy that everybody ought to be cared for in the community. []

MARY ANGUS: Yes, sir. We've also testified at previous hearings, as a matter of fact when they were discussing setting up this committee, and we have been in communication with families who were unwilling to testify on their own, saying that they were unhappy with the conditions there because they were afraid. []

SENATOR LATHROP: Believe me, there have to be families, certainly people whose son or daughter has sat with broken extremities for four days before somebody figured it out,... []

MARY ANGUS: Uh-huh. []

SENATOR LATHROP: ...or who died because they didn't get CPR in a timely manner. Those things are going on. I appreciate that. But I don't understand why you don't have

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any place for an institution when we have heard this testimony in June:... []

MARY ANGUS: Uh-huh. Yes. []

SENATOR LATHROP: ...There are some people who are at such a safety risk that we can't find a spot in the community for them. []

MARY ANGUS: Yes, I understand that. Yeah. []

SENATOR LATHROP: They can be people who are so profoundly retarded, people whose behaviors make them a safety risk either to themselves or to the folks that they might encounter in the community, and it seems to me that we...that it's not black and white, that there might be, as we try to find what the continuum of care ought to be for people who have developmental disabilities, that there's room for both. []

MARY ANGUS: I understand that. []

SENATOR LATHROP: And I wonder if you'd still be critical of Beatrice if it were well-run and we didn't have these problems today? []

MARY ANGUS: Actually, so much of the research is showing that people benefit by leaving institutions or living in the community. I believe that the diversity of our people in the community can only be enhanced by being experiencing people with developmental disabilities going to our movies, going to the grocery store, living in our streets, living in our block. I will say that there are problems with behaviors. One of the things that we have found is that they either don't deteriorate but more likely are improving. One of the things that we have found is that people who are unable to communicate in the typical sense, I believe it's...well, I'm not positive but I know it's over 40 percent of the people in Beatrice at nonverbal. When you are nonverbal, it's very difficult to get somebody's attention or to be understood in the way that you want to be understood. All of us have

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experienced the frustration of somebody not knowing what we were talking about, not being able to understand, or not wanting to do what we wanted to have happen. As that happens, naturally--and I'm a psychologist by training, a master's level, not doctorate--what we find it that the frustration increases. One of the components of frustration is anger and we become angry and are more likely to act out. As you heard from Ms. Hoell, her own behaviors--and I'll tell you there are people that wish she weren't behaving the way she is now--however, her own behaviors deteriorated when she was in that nursing home. Her own behaviors improved when she left that institution. So I just think that we have to look at...outside of the box. There are things that need to be done in order to increase and improve the quality of services in the community and the wide variety of services that can make a difference. []

SENATOR LATHROP: Okay. []

MARY ANGUS: (Laugh) I apprec... []

SENATOR LATHROP: Well, I just...it seems to me... []

MARY ANGUS: No, I really do appreciate... []

SENATOR LATHROP: ...we're trying...we're here trying to find a solution or at least get our hands around the problem, and... []

MARY ANGUS: We seem unyielding. []

SENATOR LATHROP: Yeah, a little. []

MARY ANGUS: Okay. []

SENATOR LATHROP: I mean not...I don't mean that to be critical, but you obviously

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have a philosophical position... []

MARY ANGUS: Correct. []

SENATOR LATHROP: ...and I guess I don't know that we're impressed that there's no place for Beatrice and the services that it can provide to the people who can't... []

MARY ANGUS: Understand that. []

SENATOR LATHROP: ...safely be in the community. []

MARY ANGUS: I guess one of the things... []

SENATOR LATHROP: That just seems to me to be as black and white as your philosophy. []

MARY ANGUS: One of the things I'm asking is that this committee not have a predetermined notion that it can't be closed. I doubt very much that you would take me very seriously if I said it should be closed today. I would like a systematic closure. I heard earlier that people on my side of the fence, if you will--I'd rather not think of myself as on one side of the fence versus another because I'm here on behalf of people with developmental disabilities with whom we have worked and spoken--there was a comment that people are excited when they hear about the bad things at Beatrice and I will tell you that I, for one, get very excited, but it is not in glee to see that there's more evidence that we should close it. It is in a desperate feeling--how can these things go on? How can we treat people in ways that allow excessive falls, increase risks of pneumonia, etcetera? How can we do that? So my excitement is not in glee. []

SENATOR LATHROP: Right. I believe you. I believe you and I don't want you to think that I look...I take a dim view of your philosophy. I recognize it but, at the same time,

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when we toured Beatrice and some of the testimony we heard in June was... []

MARY ANGUS: Uh-huh. []

SENATOR LATHROP: ...I think they were referred to as blue chippers, you know, the community-based programs. They might come to Beatrice and say, well, here's a person that would be relatively easy to care for, we'll take him into our program. But here's a guy, who maybe he's a runner, maybe he acts out, maybe he will be misunderstood when he approaches... []

MARY ANGUS: Uh-huh. []

SENATOR LATHROP: ...people on the street, and they say, no, we don't have a place for him. And so I don't know. I think... []

MARY ANGUS: What has happened... []

SENATOR LATHROP: ...you make it black and white and I guess I'm not persuaded, at least... []

MARY ANGUS: Oh, I understand that, sir. []

SENATOR LATHROP: ...two months into it, that that's that black and white. []

MARY ANGUS: I also...there have been programs, for instance the crisis intervention team training for law enforcement, that helps them to understand and deal more effectively with people who are in crisis with mental health issues. I think there are a variety of ways that are a little outside the box that we could look at and I guess I'm not going to apologize for having a black and white view. []

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SENATOR LATHROP: You shouldn't, and I'm not... []

MARY ANGUS: No, I understand that you don't. Yes. []

SENATOR LATHROP: ...believe me, I'm not being critical, maybe making an observation. []

MARY ANGUS: No, Senator, you're not being critical. Thank you. []

SENATOR LATHROP: Okay. Senator Wallman. []

SENATOR WALLMAN: Thank you. Yes, Mary, I find it ironic we have a waiting list and why do we have a waiting list? Do we not have enough direct-care providers, you know, at home-based care? []

MARY ANGUS: That's not really the case. What we have is a waiting list because people who have been seen as eligible for services are not getting them because the state has not got that as a priority. Right now, as you heard from Mr. Wyvill, the state does not see community-based services as an entitlement. He actually challenged you to see if you wanted to get a legal opinion about whether that should be the case. The fact of the matter is when someone is deemed eligible or found to be eligible--I guess "deemed" isn't quite the right word--if the service provision by the state is not adequate or they haven't got the money then you don't get the services. That's it. There are also factors that are happening right now that will make it more difficult and more likely that we would need to have a decision that community-based services are actually an entitlement. Because, as you're seeing with the Medicaid reform, one of the things that we've heard today is they're getting speech therapy or they're getting some kind of physical therapy. We just had a cap placed on those treatments in the community. So what we need is to have both the entitlement language and the oversight of community services. There are lots of things that could be done to improve that situation. []

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SENATOR WALLMAN: Thanks. []

SENATOR LATHROP: Sure, go ahead, Senator Adams. []

SENATOR ADAMS: I don't mean to belabor Senator Lathrop's point,... []

MARY ANGUS: Uh-huh. []

SENATOR ADAMS: ...but it keeps coming back to me. So if there are inadequacies at Beatrice and there are inadequacies in funding and, therefore, in services even in community-based programs, why wouldn't we want to direct our attention at providing the quality and, at the same time, why wouldn't Arc favor choices and Beatrice potentially being one of those choices? []

MARY ANGUS: You know, I'm not sure how I would respond to that. I mean... []

SENATOR ADAMS: Okay. []

MARY ANGUS: ...I understand the concept of having that choice of an institutional setting. You know, at the risk of being...seeming more extremist, the situation at Beatrice has been bad for a long time. It was incredibly bad in the sixties and there was actually a lawsuit against the state in order to improve that. The Legislature at that time passed a record number of legislative bills to address community-based services and we were honestly the international model for the provision of community-based services. We can do that in this state. What happened after that is was that services declined in Beatrice again. We found that in the nineties we were starting to have...as you've heard, it seemed to be less quality after the nineties, again, and I don't have enough information to be able to say that, although I do some folks that could probably talk to you about that. []

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SENATOR ADAMS: Thank you. []

MARY ANGUS: Thank you. []

SENATOR LATHROP: Guess that's it. Thank you for your testimony. []

MARY ANGUS: And thank you for your openness with me. Thank you. []

PATRICIA MCGILL SMITH: (Exhibit 9) I didn't know when I would be compelled to come to the fore, but I was just compelled. My name is Patricia McGill Smith, that's M-c-G-i-l-l, no hyphen, S-m-i-t-h. I am a parent and a grand parent of two people with developmental disabilities. My daughter is 38 years old with autism; my grandson is 19 and has Down's Syndrome. And for 34 years I have worked in the field as a professional, working on behalf of parents and families in Nebraska and nationally. I worked 17 years in Washington, D.C., and served in two presidential administrations, administrating special education and rehabilitative services. I only tell you that because my amount of information that I carry is considerably more than the average because of the experiences I have had. I directed the programs, many of which we're talking about right now today. You asked us to assess BSDC and I'm going to skip that because we already have done that. You're aware. You've had all of the reports and the reports are not good. But I sit here today...and I have made so many notes I don't know where to start with my notes, but I know where I'm going to start. I'm going to start with my daughter Jane. My daughter Jane is now 38 years old, but she was diagnosed at age 14 months, and I will tell you the difficulty that I was having and my family was having at that time. If a really fine Catholic priest and a really good physician told me that she should have been institutionalized at that time, I would have jumped at the choice, and they could have made a compelling argument. I have six other children and it is very difficult to raise seven children with a child with special needs, a husband who is having extraordinary difficulties and, I mean, we were just in trouble all over the place. I did not

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make that choice, but I have enormous empathy for the people you have listened to and you will continue to listen to today because of a choice they made that now is causing them so much stress and so much trouble. And I have worked with parents all over the country and, indeed, in many places in the world that have faced some of these same choices. The parents that spoke about the...giving their child up as a ward of the state, when we lived in Virginia, Jane was having these enormous problems and we had legal problems and we had law problems, and I was a single parent, and the state of Virginia offered to have her be a ward of the state. And I said, well, what does that...what would that mean? Well, then we make all the decisions for her. I said, that will be over my dead body. No. But then a very good friend of mine said, but, Patty, what are you going to do if you can't get the help you need? Fortunately, people came to my aid and fortunately we worked through some of those problems, but it is not easy so don't get the impression that it's easy if a parent has a kid in the community. Jane is now 38 years old. I could not believe, if you'd meet her today, the woman that you would know if you knew that baby. I just can't tell you what the community supports that have been around here all these years to help her to develop to her fullest potential have been just extraordinary. Some of the people in this room are some of the extraordinary people who have helped me and my daughter and now my grandson. And I tell you this because some of the information that's being shared would lead you to believe something maybe differently. It isn't that it wasn't easy. When we came back from D.C., we moved back in 2000, we thought we could get community services right away. And there had been a big mix-up on the money, that HHS misplaced a bunch of money, and so there was no admissions. So for a year we had no services. Can you imagine an autistic woman with compulsive...extraordinary compulsive problems with no services? And I think Bob Brinker is in the room and it's because of him that she had gotten some services when we didn't expect it. I mean, have you ever heard of anybody getting services that they didn't have the hours for? My daughter did because somebody had the compassion to understand that that was needed. And why do I talk about Jane? Because I want you to know that the parents who made decisions to institutionalize their children did it for whatever emotional, social, whatever reason if they couldn't take care

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of their person, and so many times I couldn't take care of Jane. And when they placed them they were not wrong. There is a...this two camp thing, Steve. There is a misperception that if you put a person in an institution that you were wrong and we're right, and that is not correct. People make decisions based on their lives and what is happening to them. I am just grateful I didn't make that decision because then what happens is if they...if the institution closed in the next couple years or whenever, what happens, then that decision has to be overturned and that decision is very, very difficult because it was made with so much emotion. You cannot tell me that these people did not have huge emotional stress over making that decision. And so then, when somebody comes along, some young whippersnapper that says, you know, like we're going to fix things up, well, no, it's not such a big fix-up. And I want this committee to understand what the emotions that the parents are telling you today, that these are real and the defense that they have Beatrice is because they found...it was like an island. It was like a place of hope for them. And even when...in the face of reports that say things are not going well down there, the parents do not see it that way. And I don't know if their person is having trouble or not. I can't tell. The reports are pretty dim. You must say they're pretty dim. They're bad. I wouldn't want my child living someplace with reports like that. So it's a real push-pull thing. I mean, it's a tremendously push-pull thing. And I want the parents to understand that when they made a decision they were not wrong, and that's an enormous thing to keep in mind. Because people, like I've said before, they think it's wrong. And I want to talk about the Arc of Nebraska and the Arc of the United States. They moved to the living with the core values of what Mary Angus just spoke, and it took them years to get to those core values. And the reason is, it's actually like why we're sitting in this room today, and they finally determined that they could no longer hedge it, they could no longer say, uh, it's over here, (inaudible). No. They had to declare we will stand by our core values and the core values speak of living in the community. But I wish that your committee could go to some of the places in the country and visit. Go to Minnesota. They haven't had any state institutions for I don't know how many years, maybe ten. How have they done that? You need to ask the questions. There's a wonderful man named Conroy in Pennsylvania that has done the

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research. He has followed like when the institutions closed in Kansas. That's the one I'm most familiar with. They did a follow-up of all the parents and people for like two years, find out are the people happy, are they satisfied, did it go well. I've told you about "No-No Nanette," Nanette Whitesell (phonetic) from Indiana. She is a parent that opposed having her daughter in the community and then, when the switch came, she's going around the country trying to tell people...and I've asked John Wyvill if we could please bring her to Nebraska so she could explain to the parents what she went through and how that all happened for her. I want to answer just a couple other questions that just went by, besides the business of the core values of the Arc, which are enormously important. I'm speaking today, incidentally, as a parent. I didn't...I'm not speaking as the past-president of the Arc. I wanted Mary to do that and she did a fine job. And I wanted for me to be able to just talk to you about the things that I felt were so important. ICAP was mentioned a little while ago. You want to know what some of the problems in this state are? They have underfunded the community-based programs. Why do you think that a service provider would say we can't take that person? We called it cherry-picking in the old days, you know, but they take people that are...don't laugh...they take people who are less disabled because they're easier to serve, quote, unquote. There was a day, and you've got Bob Brinker in this room, and ENCOR has not turned down anybody for like...they're probably at 38 years right now because 1968 was out of the darkness, 1970 began ENCOR, and they have never turned down anybody. They have a medical unit. They have always had a medical unit for children. They have a medical unit that is for adults. I asked Bob at the break. Currently, there are six people living there. They have to live in a medical unit where there's nurses available, where there are people who could work with the G-tubes and whatever kind of tubes or whatever kind of feeding. It is a misperception to not understand that the services that have been talked about. And I, even on one of my pieces of paper, because I was getting so frustrated sitting there, I just made a quick note. Jane has a fabulous psychiatrist or counselor, a service coordinator, the best dentist and doctor in all of Omaha. She has in-home supports; work supports, though not enough hours--I've sued...tried to sue the state twice over it; participates in Curves; works at a program called Ultimate Live, run

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by the Omaha Arc. Respite, lifetime respite care comes every month. I can have like \$125 to help with that. We have...she is in continuing education program to improve reading. She's in a social club, People First. She goes to Sacred Heart Church. She has been an extraordinary minister of the Eucharist only for people at home, you know, at home sick. And she works at the church office and she also works at the Heart Ministry Center. And this young woman, who could not do anything but roll around and not do anything when she was a baby, rides the bus to work on her own. Now how did this happen? And she would be level...in the level, in the beginning, of, let's see, in the beginning she was severely disabled, then she became moderately disabled, and now they think she might be mild except her behaviors with...her behaviors of working with the obsessive compulsive behaviors. She's probably severe and, as an adult, that's a very severe problem. You need to know that the telephones for my house are over there in that bag because I cannot allow there to be telephones in the house with her under supervision. And the good news is, is that with all the difficult behaviors, the police called in, the courts called in and all the things that we've happened, too, because Jane is supported in the community, we have been able to learn how to deal with those behaviors. And there are people in this room that are acutely aware of her obsessive behaviors. Because she can get lost, she can get running...she doesn't get lost but she can go out in the neighborhood and cause trouble. There's a lot of things. She lives, incidentally, in the lower level of my house. She has her own apartment. That is her desire. Let's see. The President, President Reagan...or, Reagan, oh boy, am I behind on times, Bush, the guy that's there now, seven or eight years ago he started the President's Freedom Initiative which was to address the Olmstead opportunity for our country to have more people get out of nursing homes and out of institutions. It is noted that the state of Nebraska has never had an Olmstead committee. They say they address Olmstead with everything they do, but every other state that I know has Olmstead committees that have worked on this intensively. Okay, there's one answer that you didn't have. Let me just think of a couple more. I have no many notes, I can't believe it. There's a tremendous disconnect...the one lady that spoke who was the single parent, it is just horrific that someone like that does not have more help that they

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need and they have to make choices that they did. I mean there's respite care. There's all kinds of care and yet, because of inadequacies of service structures to tell people what's going on, it doesn't happen. Oh, I know, schools: You need to know that the schools are mandated. This is the big difference. Community-based services are not mandated. They could be. All that's mandated is you have a service coordinator, and what's the other thing you can have, you guys? You get to have two things. []

MARY ANGUS: Graduates (inaudible). []

PATRICIA MCGILL SMITH: Uh? []

MARY ANGUS: Graduates have an entitlement. []

PATRICIA MCGILL SMITH: They get what? []

MARY ANGUS: Graduates have an entitlement. []

PATRICIA MCGILL SMITH: Yeah. Oh. Oh, oh, yeah, graduates have an entitlement for a certain period of time after they graduate. They can get help to get into services. Those are the only two entitlements that the state of Nebraska. So is it any wonder, if there is no entitlement to services? And I'm going to just say it the way I see it. The state of Nebraska, and this isn't just this administration, it's a bunch of them, they have just squeezed and squeezed and squeezed the service structures in the community. They have not squeezed and squeezed Beatrice. Beatrice's money has gone up while ours has gone down per capita. And that has caused a tremendous problem. I couldn't believe that I figured out that I got more services for Jane in Virginia, which was, I thought, the worst place that ever had services in the community (laugh), and I've had to fight for almost everything that Jane has, and fight I do and I'll continue. But I need to tell you that...oh, my last thing. We have gone to the state and we have proposed that there would be some kind of working together of the parents and people in Arc to work

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and to try and help the parents and the people coming out of the institution. I did this years ago. I trained older parents and pilot parents to be willing and ready to be able to work with people in the...to move from Beatrice into the community, and it worked. It worked. I can tell you the two ladies, they were fabulous. They did a great job. I learned last week that they want to have this kind of help to the people that are going to be transitioning out of Beatrice, but they're going to have the service coordinators do it and if there will be some volunteers to help. Well, that sounds like a great plan but I must say if there is not some kind of training for the people who are trying to do this helping, that's a bad...that's a bad recipe. And so I would just urge that we take a look at trying to urge the state to pay particular attention. Because you cannot have people trying to help the folks, as you've heard them today so passionately speak about their needs for their children, and have people from the community, if they are not trained. Because the worst thing you would ever do is be judgmental of these parents or if you didn't understand where they're coming from. And so I just add that because that's something that the Arc would want to do but we will not put our people in a position where they are not trained and really ready to be able to help in the manner that possibly they could. And so on that note, oh, on ITS, ITS and the...that's a support for the community as well as Beatrice, and when the lady said that sometimes the people just move over and stay and that the communities don't want them back, that is a very hard indictment of the community services, because they don't think there is enough money to serve the people. The ICAP is limiting. CAP means cap, cap, cap, that's the way I interpret it. And so if the money is limited and you don't have enough money to give 24/7 or you don't have enough money to do a one-on-one--when we had that bad incident here in Lincoln it was supposed to be one-on-one services--that is part of the problem. And so I wrote the word down here, Solomon, and so you all are going to have to have the wisdom of Solomon to try and figure this out, but there are pathways that have been done in numerous states: Massachusetts, New Hampshire, California, Michigan, Minnesota. I can tell you, I've given you, Steve, all the documents the other day of exactly how states have gone about this, and it has not been horrible. It has been good. It has been good. But the state of Nebraska has to step up to the plate and the legislators are going to

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have to step up to the plate with the financial support in order to get this to happen. And my last note, one more thing, you asked the question, is there enough money in the system? I am appalled that we're keeping Hastings open with, what, 14 people out there and 43 people? A whole institution for less than 60 people? You've got to be kidding me. I mean, you are the stewards of money. You are the stewards of our taxes. I know it's political. I don't care. I, frankly, don't care. Norfolk, they're going to keep Norfolk open because they're going to make it into something else. Do you not understand that you're spending way too much money to serve too few people? So you close the darn institutions, and the same thing with Beatrice. Beatrice's budget last year was \$52-something million. I think it's slated for \$47 million or \$48 million this year. I think Mr. Wyvill, the...if you did the division it would be \$190,000 per person at Beatrice. You've got to be kidding. We're going to continue this? And I'm not trying to give the people sitting behind me a bad time. I just want people...I've never argued on money in my whole life. I argue on philosophy and rights and civil rights of people. I'll argue on money today because you are the stewards of our taxes. And I don't know how you can continue to keep something going that is at that ungodly amounts of money and think that that's okay. My daughter's services, incidentally, probably in-home/work support, I think she gets about \$28,000 or \$29,000 a year and it's because I provide quite a bit of support for her. She lives downstairs at my house. Any questions? And am I passionate, Steve? Yes. []

SENATOR LATHROP: Yes, you are, and it's good to have you here because, you know, you give us a perspective that's important to this process and I greatly appreciate it, as I do the information that you gave me and the time that you and I have spent talking about these issues outside of this forum. We'll see if anybody has any questions. Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Patty, you are really excited about the community-based services I gather, we gather that. []

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PATRICIA MCGILL SMITH: You darn betcha. []

SENATOR STUTHMAN: The problem that I have, you know, with Nebraska, we've got all of our population, Omaha and Lincoln area. And out west, Columbus, you know, further west than Columbus, you know, you get up to O'Neill, Valentine, up that direction, how can we provide a community-based service in those remote rural areas? []

PATRICIA MCGILL SMITH: Oh, I think you can. You're already doing it. You have the regional programs all over the state. Columbus has them. O'Neill has them. Valentine has them. Grand Island has a large amount of services. Kearney has a large amount of services. I can't give you the numbers. There's probably people in the room that could give you the numbers, but there are literally hundreds of people being served. Now there is one problem and this is something that has to be worked on. The people who have higher medical need, let's say, you know, that possibly they need more medical service, they might not be able to go back to Scottsbluff or Ainsworth if they can't get the help that they need. They may have to live in an area that, you know, psychiatry, psychology...I mean, I gave you the list for Jane. And incidentally, I have found that some of these doctors and the people that serve my daughter are absolutely the top in their field. It's hard to find them. You have to work hard to get them but, by cracky, they are not not wanting to serve her. They're fabulous. So, I mean, this idea that we can't find people to work, it took me some doing to do it, and I would help anybody. Oh, that's one thing I didn't say in my testimony. I will help the state get to be where they need to be. I will help any parent. I've helped hundreds of parents. I will help them to figure out how they can get their services and I will teach them. You asked whether the Arc teaches. We teach about advocacy. We will teach parents how to advocate in the community, how they will try to work to get the state to understand we need more money in community services, because we need to strengthen the community services. This has been one of the...it's been a "ch-ch-ch dun-da-dun." And the state, I'm sorry, I've done a lot on whether the service...I mean, Jane gets 27 hours a month work

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support. That is not enough, you know, and we need to get people to understand this. I mean, it's really hard to sit with a bunch of people sitting behind me that their people are being served at these huge amounts of money and my kid can't get ten more hours to help her go to her job every day. I mean, there's an imbalance here and we need to solve it, and you all have the best chance that we have ever had because it's like a crisis beyond any crisis we've ever had because they're pulling money away from Nebraska. DOJ is, you know, looking down your shoulders and over your heads. The community services are stressing. I mean there's just...it's like a...it's like a conundrum, but it can be solved and there are states, I am telling you, there are places that have gotten through this. They've written papers about it. They've told you how to do it. They've researched it. They've...I mean, let me give you one quick story, and I talked to this father. His name is John Clark (phonetic) and he told me I can talk about him. John Clark had a daughter names Gina (phonetic). Gina is one of the first children that ever came back from Beatrice. She was put in Beatrice when she was probably months old. She came out when she was about, I think, three or four years old. She went to the Maximation Unit for children. Gina laid flat on the floor. Gina did not walk, talk, feed herself, toilet herself or anything in the whole wide world. And John Clark, if he could have come today, said he would testify that absolutely the best decision that was ever made was to bring Gina back to the community because they could go see her every day of the week and twice on Sunday if they wanted to. It got to the place where Gina recognized them when they came in. Many, many people got to know Gina and Gina became a part of a community, even though she was extremely...she's the most disabled person I ever knew. And John told me I could talk about it before this committee. I didn't write it, but he said I could talk about it, because Gina is a person who was severe/profound, profound, profoundly disabled and was served. And I asked Bob Brinker. Yes, they still have the medical units. Yes, they have units that support people. People don't know this. Bob Brinker talked to that day about it, and a lot of the other service units. Now you asked the question about across the state. It is harder. It is harder out in the state if you have very, very complex needs. And I subscribe to the idea that either someone at Munroe-Meyer, they go across the state and they have

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(inaudible) that they help people. I subscribe to what has happened in Beatrice when they had people that worked out in the community, because getting help for behaviors is one of the toughest ones. And the lady and the man talked about every 30 days they would check to make sure that the gains that they had made with behaviors, if we had not had people to help my Jane with her behaviors she might be in jail or she might be dead. I don't know. I'd be dead trying to take care of her because Jane's behaviors have really been tough, if you know autism and you know compulsive behaviors. And I am telling you, she lives a wonderful life because she is supported. []

SENATOR STUTHMAN: Patty, and the reason I ask these questions as far as the community-based services, and I'm very supportive of community-based services,... []

PATRICIA MCGILL SMITH: I know you are. I know you are. []

SENATOR STUTHMAN: ...but as an individual that was a part of the mental health, the regions and... []

PATRICIA MCGILL SMITH: Uh-huh. Oh, the mental health reform? Yeah. Yeah. []

SENATOR STUTHMAN: ...and on that reform there and seeing what had happened when they released some of them and where they ended up, and I'm very cautious as... []

PATRICIA MCGILL SMITH: Oh, and well you should be. []

SENATOR STUTHMAN: ...as to, you know, not just closing the door and... []

PATRICIA MCGILL SMITH: No. No. []

SENATOR STUTHMAN: ...sending them out with a bag full of medications and find your

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own service. []

PATRICIA MCGILL SMITH: Right. And the Arc has never suggested that. The Arc has always said, and people leave out the one word, systematic, systematic deinstitutionalization. We...when we called for that two years ago publicly, we asked for it because of the first report that came from CMS. We asked for systematic deinstitutionalization. It's in my notes. Had you done that then you would be out of a world of hurt that you're having right now because you would have moved in that direction. And not having moved in that direction, now we've got all this stuff going on and it's not easy. It is not easy. And you're right. If you dump people in the community, it's the worst thing you could do. []

SENATOR STUTHMAN: And they end up in a prison if they have... []

PATRICIA MCGILL SMITH: They end up somewhere, not the place you want them to. []

SENATOR STUTHMAN: And that's what I want to be very cautious of... []

PATRICIA MCGILL SMITH: Yeah. No. No. []

SENATOR STUTHMAN: ...mainly because I have seen what had happened with that situation. I am one that, you know, I think that we need to move these people out, if possible, but not move any more in, you know,... []

PATRICIA MCGILL SMITH: Oh. []

SENATOR STUTHMAN: ...just like with the mental ones, you know. Keep them in the community to start with. []

PATRICIA MCGILL SMITH: Right. []

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SENATOR STUTHMAN: Never let them get to that institution. []

PATRICIA MCGILL SMITH: Well, and one of the things that's very frustrating for the Arc, I've tried to get many of the young parents to get interested in this issue. They just go like, my kid is never going to go there. We're...they just act like it's not there. But when they get a kid 18 or 21, they're going to find out like, oh, I think I should have been working on that, you know? []

SENATOR STUTHMAN: Yeah. Thank you. []

PATRICIA MCGILL SMITH: You're welcome. []

SENATOR STUTHMAN: Thank you. []

PATRICIA MCGILL SMITH: Anybody else? []

SENATOR LATHROP: I think that's it. []

PATRICIA MCGILL SMITH: Thank you, Steve. []

SENATOR LATHROP: Thank you. You'll be the last witness for the morning. Just so that we have an idea of what our afternoon looks like and how much time we might be looking at to hear from everyone else, can I see a show of hands of folks who intend to testify but have not yet testified? So five, five or six? Okay. Very good. Thank you. We'll see you back here at 1:30. []

RECESS []

SENATOR LATHROP: (Recorder malfunction)...start with our next witness. []

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LYNDA SWANSON: Okay. I'm Lynda Swanson. I'm from the Norfolk area. My son has been in Beatrice for about two years. I started out...I'm basically going to kind of give you a summary of where we...from the beginning. When he was three, he was diagnosed with being mild to moderately retarded. It took me making doctors angry in Norfolk to get him to Omaha to be tested to find that out. When I got back into Norfolk with him, they did get him right away he started at Head Start in Norfolk right away. He was in Head Start until he got to kindergarten. And the only school in Norfolk that was actually suited for his best interest was Bel Air in Norfolk. The teacher up there worked wonders with him up until he was of age, before he went into sixth grade. And then he went into the middle school system. Things at that point started changing a little bit, behaviors started showing up more. He was considered speech impaired, too, where he wasn't able to talk real well or communicate real well. They...and the behaviors just kept getting worse because I think it had a lot to do with probably because he wasn't able to communicate and express himself when things weren't right. After he got through his middle school years, he went into the junior high and then it really got bad because the resource teachers treated him like he was a two-year-old. They'd take things up to him and say, well, hey. When he was having problems, they'd take teddy bears up to him and say, you want to play with the teddy bear, little things like that and it just really set him off. He just...I mean, he tore the resource room apart. I was up there probably three to four times a week because they were having problems with him. It finally got to the point there where they had to...the principal there said, well, we can't deal with him anymore, we can't have him here because, you know, because of his behaviors. When he turned 13, he was placed at Envisions in Norfolk and I had to actually go into the court and turn him over to the state in order for that to happen because I didn't have the funding to pay for what he needed. And the Envisions at that point it just started, they hadn't been really in place that long. It worked out really well for a few years until he got a little older. The school system, I was still struggling with them, and finally it took...I had the school board in Norfolk with Envisions and sat down with the staff of Envisions and actually started a school in Envisions for the handicapped, for kids that couldn't function

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in the public school system. He was in that program until he graduated. Well, no, he was actually he was still...he was in there until he turned 19, and handicapped kids usually stay in the public school system until they're 21. When he turned 19, I had to go back into court and basically take custody because once he's 19, the state's no longer in the picture. Well, they're still in the picture, but just a guardianship of him at that point. And throughout that process there was instances in the settings out in the community where staff...you ask them questions, the part that really frustrates me in the community settings sometimes is you ask staff questions and they look at you like, well, I don't know. It's like, why don't you know? You're working with my son, you should know when I ask you a question. There was two instances where there were sexual abuse involved in that situation. The same child, the first time they removed the two, they separated them, put the other one in another home. And then within a month or so, they had them back in the same house again, and then it happens again. It's like, I went in and actually...I mean, the staff that were involved were fired on the spot. I made sure of that. They had tried to...I mean, they're sitting watching TV and not paying attention to what they're supposed to be doing. These kids are in these homes because they need to be in these homes, and this staffer is supposed to be doing their jobs. I had staff that were very familiar because I spent...I sat on the Envision's board when he was there. I went to the home quite frequently just to check on things, just popping in out of nowhere sometimes just to see what was going on. I had staff that would actually come up to me sometimes and tell me things that were going on that I wasn't aware of. I thought, well, I'm on the board, I should know what's going on. Well, there was things they weren't telling me. Once he turned 19 and I took over the guardianship and his financial part of it, Envisions didn't want anything to do with us anymore. I think...I don't know if it was because I had more power now because I was in that position or what. But they said, well, we can't serve him anymore, so you need to find another placement for him. We looked all over the Norfolk area in the area where I was at and there was nothing for him, nobody would give him a chance because of his behaviors and things. And they had his medication, he'd been in and out of the psych ward up there like probably once a week for a while there, and they had his medications so messed up that he was a

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mess. Nobody could work with him to help him because he was self-abusive and he'd hurt others. And there was a staff member that was in Envisions that was really, really close to him that she tried to stop him from going outside and he beat her to a pulp. She looked like she'd been in a domestic fight. And that's one thing with my son that you can't...when he's angry, you can't step in front of him because he just...it's like he blacks out when he gets that mad. He isn't aware that he's hurting somebody. Well, once they decided that they weren't going to help him anymore, we started looking and there was no...all the places...there's places in Norfolk, but none of them would help. Finally, there was a place in Lincoln that said they would help and we got him there and he got settled in and everything as fine for a while. And the medications and stuff were so messed up that they couldn't help him. And we'd been looking at Beatrice for a long time, but we were just having problems getting him in...getting him the help he needs. And finally it took, I mean, it took me and other team members and stuff and social workers and stuff, and finally we got him in the door. It was a blessing for me to get him into Beatrice because the staff were there and the doctors and the nurses and the people that could monitor his medications and maybe get him straightened out, you know, where he can function a little bit. His favorite things are movies and DVDs, DVDs and Christian Music. He's a Christian music crazy person. He just...that's all he talks about, wanting to go see the bands. Or if there's certain movies he likes, he can sit down and tell you about pretty much what the movie's all about, and by the time he gets done, you wouldn't be able to...you wouldn't want to buy it because you'd already know all about it. He can do that. It's just...and it's tough. I had to...having to give up my rights when he was 13. I knew as a parent if I wouldn't have, he wouldn't be where he's at today because there was a lot of things as a parent you want to hold back from your child, you want to protect them, you don't want anything to happen to them. And that's probably what it would have done. I'd have smothered him, you know. Today he's able to, I mean, he can communicate with you. It's tough for him sometimes to get out what he's trying to say, but he can talk to you now and he couldn't do that before. He can go out into the public sometimes and just be able to do things that he couldn't do before. Before, he could go out in a store or something, if he got near videos and movies and

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stuff, he had a behavior because he wanted those things. He wanted...he obsessed over things that people wouldn't think was a big deal. There was instance of cops. There was...in a video store or whatever. He wanted a certain thing and they couldn't have it and the staff were trying to redirect him and try to help him. And the person in the store automatically calls the cops. They told him he's okay, we can deal with this. But they automatically call the cops. The cops come in, basically don't even ask any questions, just roll him, cuff him, and pull his arms up behind his...up like this and take him to the cop car, don't even, you know, don't even ask questions. Well, is this person handicapped or something like that, didn't even say anything to him. And it scares him. Cops today still sometimes make him very nervous. He doesn't like being around them because of that. I know being at Beatrice has made me more relaxed. I know when things are happening, they call me. After an incident, if there's got to be a meeting, then I'm immediately called. If there's a medication change, I'm immediately called. They keep me informed about what's happening with him. Every day that I talk to him, he calls me everyday and he always asks me when I'm coming home. I wish I could have kept him home when he was a child. Financially, I couldn't. I would have dearly loved to have the avenues to do that. Still today it would be good, but the way this society is financially I'm not made of money and I can't, you know...and he needs around-the-clock supervision. He's a runner. He gets...I mean, he loves to go and talk to people. He'll just walk up to somebody and say, hello, my name is so-and-so. I mean, and he's a very happy person when things are going right. And if it wouldn't have been for Beatrice being there when I needed them, I don't know where he'd be. []

SENATOR LATHROP: You're satisfied with the care he gets there? []

LYNDA SWANSON: Yes. Yes, I am. []

SENATOR LATHROP: Very good. Well, thank you for your testimony. We'll see if there's any questions. I don't think so. Thanks for coming down. []

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LYNDA SWANSON: Um-hum. Okay. []

SENATOR LATHROP: We appreciate it and you're experience too. []

LYNDA SWANSON: Yeah. Thank you. []

JACK NICHOLS: (Exhibit 10) Good afternoon. Thank you for holding these hearings and I'll do what I can here. I got a couple of things I'd like to say. It don't make sense, but it will. []

SENATOR LATHROP: Maybe we'll have you start with your name. []

JACK NICHOLS: My name is Jack Nichols. []

SENATOR LATHROP: Okay. []

JACK NICHOLS: I live in Omaha. My wife and I have a son at BSDC. Please let me say two things and I'll tie them in connection to today's hearing. Many of us have heard conversations about pain of childbirth. You have to experience to really know, such as what we're doing here. Another one that's off the wall, on a dark night, a man walking through a cemetery fall into an open grave. After trying to crawl out, he gave up. He laid down in the corner and fell asleep. Soon after that, another man fell in the same hole. He struggled to crawl out. Making enough noise, he woke up the first man which in turn stood up and tapped the second man on the shoulder and said, they will come for us in the morning. The second man made it out very quickly. Thus, here we are being tapped on the shoulder and it's time to make it work. Like the witness in the pain delivery, it's hard for me to tell you what a parent goes through with their special needs child. I can tell you of our travels, fear, hope, disappointments. In Omaha, we have experienced St. Joseph's Mental Center, which is closed now, Richard Young's, which is closed now and I believe it's reopened now for a temporary fix instead of taking them to the

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emergency room. Immanuel Hospital has a unit there, and it's five days and you're out. Douglas County Health Center, he was a resident there for three years, but determined not compatible with our needs and the mental ward kept him for five days and out. We've experienced a group home in Kearney. Wow! What a shame our mental health in Nebraska. That was the closest to Omaha that would even try our needs. But when things got bad there, they had just called the police to help them because they used, for the night staff, would be students and they would talk about their dates. And this all disturbed me and needed a listen to. Then when money gets tight, send them to Richard Young in Kearney, then to Norfolk. We've experienced Norfolk Regional Center a few times, three or four, I don't remember exactly. It was a warehouse for the needy with few group sessions, maybe a walk-around campus. It may be closed by now. We've experienced Lincoln Regional Center because Norfolk Regional could not handle the challenge. Yes, forensic building where they bring the killers for testing. Wow. What peers. Lincoln Regional has a wonderful staff, including the late Dr. Martin and social working Stan on the fifth ward who with the communications as social services Mike Cool got us here where we are now. Beatrice State Developmental Center has it all. They have the staff that have the love for their job. Who else would do this for the money they get? We have seen great structure which keeps the residents active, such as movies, bowling, exercise every morning, jobs on campus, outings, classes for self-worth and proper behavior, meetings with the staff members to cover all aspects of the developmental, physical, and mental needs. Always, including we as guardians which I am so disappointed that the years of our worry can be overruled because of someone that don't know the person needs space. Thank you for taking the challenge of trying to understand the workings of this special, special needs person. Like the analogy of childbirth, it is very hard to paint the travels other people have gone through. And now the worry of the unfairness of folks that are being moved to community-based homes that may or may not fit their needs. No way the quality given at BSDC and of course the fear that places can terminate at will, especially when the one-year guarantees funding runs out. Thank you. []

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SENATOR LATHROP: Thanks, Jack. Anybody have any questions? Senator Stuthman.
[]

SENATOR STUTHMAN: Thank you, Senator Lathrop. Jack, you had experience, you know, this situation where you...was this your son? []

JACK NICHOLS: Yes. []

SENATOR STUTHMAN: Was at the Norfolk Regional Center? []

JACK NICHOLS: Three or four times. []

SENATOR STUTHMAN: Three or four times, and they could not help him there or what was the problem? []

JACK NICHOLS: They actually kicked him out, transferred him to Lincoln Regional for the forensics...just what's wrong with this guy, you know, because of his anger. He was born fine and at three years...about three and a half years old he developed a hand-foot-mouth disease with a real high 105 degree temperature. Shortly after that, he started seizures before he went to school. But we got him into school and the seizures increased no matter what the doctors did. And then of course with the peer pressure of stay away from me, you know, I don't want to get what you've got, anger come in and it got to the point that they put him into special ed and real good clear through high school. I mean, it was tough. But as soon as he graduated from high school, we're done, find your own way. So we ended up calling the police and they took him to St. Joes Mental, and they said, hey, he's 19, he can walk. So we had to get an emergency guardianship and it just...they sent him to Norfolk again. It's just been a roller coaster and John has gone two years now. This is how long it took us to get to Beatrice. And about a year into it, they had ten months of anger-free, they have found the magic. But now they're taking kids off of his unit which makes him feel uncomfortable. And they've

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been talking to him about moving, of course, and he really likes it where he's at. And another thing, Mary mentioned something about there's nobody here from Beatrice. Maybe if the employees get done early enough, you can pull some of the people in to testify or maybe go around and talk to them. The residents, as I think you're going to find, most of them are happy there. Of course with anger management, that varies from day to day. []

SENATOR STUTHMAN: Um-hum. Well, the concern that I had and the reason that I asked you a question, Jack, is because, you know, the mental part was the Norfolk institution is where it's at. []

JACK NICHOLS: Right. []

SENATOR STUTHMAN: But you are so much more satisfied at Beatrice then with that type of a situation. []

JACK NICHOLS: That is...don't even describe how thankful we are. And I call it a campus. I notice everybody's throwing around an institution. It's a campus. It's huge, everything is there. []

SENATOR STUTHMAN: Um-hum. []

JACK NICHOLS: It's not an institution. Norfolk is an institution. []

SENATOR STUTHMAN: So by having him there, you're satisfied and it is accomplishing his need also. []

JACK NICHOLS: Absolutely. []

SENATOR STUTHMAN: Okay. []

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JACK NICHOLS: He's told us over the phone, thank you for sending me here. And he's...everything's there. They take him to Lincoln to the football games. I mean, he's got to come up with the money to pay his own way. They take him to Lincoln sometimes for supper. They take him to movies Tuesday nights off campus. He has three jobs he does. And it may be meaningless to some people, but they started a new program there and he has expressed that he wanted to be a mechanic. So they started a brand new program, never happened before, that he goes out in the morning and checks a vehicle over. He has a check sheet. Check the headlights, taillights, turn lights. You know, he don't drive it because he can't drive, but tire pressure, tire depth, and he loves it. When he's done with that, he goes in the...they have a deal for lawn mowers, a contract with some lawn mower company where they package up so many washers, so many bolts and nuts. I don't know what all, but he does that. And then in the afternoon, he delivers the paper. Now of course it takes two staff members to go with him because he's on risk alert. But I don't think you're going to find that at a community-based service. I know in a community-based, if you didn't notice it here today, I won't say a whole thing other than if my son would say he needed to go to the rest room, somebody would go with him and wait until he's done and come back. I've seen it happen and I worry about one person saying they've got the phones here. Is that child left alone? Beatrice won't let my son be alone. At night, he's in a double room with somebody else. But still, they go in every 15 minutes or so and check on him. []

SENATOR STUTHMAN: Okay. Thank you very much. []

JACK NICHOLS: Sorry about that. []

SENATOR LATHROP: Any other questions? Doesn't look like it (inaudible). Thanks, Jack, appreciate you coming down today too. []

JACK NICHOLS: Appreciate you having us. []

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BRAD MEURRENS: (Exhibit 11) Good afternoon, Senator Lathrop, committee members. For the record, my name is Brad Meurrens, B-r-a-d M-e-u-r-r-e-n-s, and I am the public policy specialist for Nebraska Advocacy Services, the protection and advocacy system for Nebraskans with disabilities. I am pleased to speak before you today and wholly support this committee's intent to fulfill the state's moral and legal obligation to protect the human and civil rights of vulnerable persons who are in its care and custody. The evidence is clear that Nebraska failed and continues to fail to provide for the safety, appropriate habilitation, and placement in the most integrated setting. We remain hopeful that the result of the committee's work will achieve such an outcome. As we have recommended in our report, An Indictment of Indifference, state officials should conduct independent comprehensive evaluations and objective assessments of all individuals at BSDC and prepare a plan with time lines to significantly reduce, by placement into appropriate community settings, the current population to a level consistent to meet the habilitation needs of the people living at the facility. Pursuant to an access agreement with the Nebraska Department of Health and Human Services, NAS staff is present at BSDC twice a month to directly observe the treatment of residents. Based on our observations and review of documented BSDC internal investigations, several continuing problem areas must be brought to this committee's attention. First, although the total number of reported abuse and neglect incidents has decreased somewhat, the severity of abuse and neglect incidents remains significant. Second, BSDC staff often do not receive adequate training and often are not aware of proper agency protocols. Third, accountability at BSDC is problematic. The investigations suggest an unwillingness on behalf of some administrative officers to act on, and staff to corroborate, reports of abuse and neglect. Fourth, devaluation of BSDC residents is common and reinforced through the abusive and offensive language some staff use when instructing or interacting with residents. Documented in the internal BSDC investigations are instances where clients are called filthy names. See incident 3 and 7 in the written testimony that I've handed to you. These instances and many others throughout BSDC investigations further document the need for a significant change in

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the organizational culture at BSDC that is based on respect for and valuation of people with developmental disabilities. Abuse and Neglect: As figure one demonstrates, BSDC residents are still subject to substantial incidences of abuse and neglect. According to the internal BSDC investigations and our analysis, there were 57 cases of founded abuse or neglect from September 2007 through July 2008. Now, we do not contend that every staff member at BSDC is abusive to residents. However, the number and types of abuse and neglect instance, whether founded or unfounded, remains alarming. Examples of recent instances include: physical and verbal assaults on residents by staff; staff not intervening when witnessing staff-on-resident assaults; delayed reporting of injuries to residents; staff attempting to cover up or deny incidents took place; staff attempting to coerce silence on part of abused or neglected residents; and neglectful supervision of residents. And these claims are all documented in the written testimony that I've handed to you in more detail. Staff training: Based on our observations and the investigations, some staff are inadequately trained to work with residents at BSDC and others are unaware of or ignore the proper procedures and protocols established by the BSDC administration. Examples of instances of inadequate training include: improper care of residents; staff not current with CPR certification or performing CPR when necessary; and staff performing techniques for residents unauthorized by the BSDC human rights committee. Staff training is critical to changing the organizational culture at BSDC. To that end, we strongly recommend that social role of valorization become a mandatory part of the preservice training requirement of all staff working at BSDC. Accountability: In order to provide the best quality care for residents in the 24-hour care and custody of BSDC, it is imperative that the BSDC administration take appropriate action to prevent and rectify incidents of abuse and neglect. Based on data from our observations at BSDC and the results of BSDC's own internal investigations, it is clear that the BSDC administration often fails to take appropriate actions necessary to maintain high quality staff or fail to remove staff found to be abusive toward residents. The investigations clearly show that some BSDC staff have continued to engage in abusive and neglectful behavior despite being reprimanded previously about treating residents with dignity and respect. For example in one incident, an individual who has

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had two confirmed allegations of neglecting residents. And in another incident a supervisor overlooked inappropriate behavior by other staff. Furthermore, our investigation or the investigations and our analysis has found instances where employees have chosen to quit working at BSDC because they feel the administration does not address the problem when transgressions occur. Based on our observations, investigations, and the CMS and DOJ reports, it is clear that it is time for state officials to act decisively to ensure that residents at BSDC are safe, receive appropriate habilitation, and are placed in the most integrated setting. I'd be happy to answer any questions the committee may have. []

SENATOR LATHROP: Senator Harms. By the way, I should have introduced Senator Harms who was... []

SENATOR HARMS: Late. []

SENATOR LATHROP: ...had a conflict this morning, but has joined us this afternoon. Glad to have you. []

SENATOR HARMS: Thank you, Senator Lathrop. Bradley, I'd like to ask you a number of questions. First of all, let's start with your statement that you talk about comprehensive evaluation in assessment by moving clients into a community setting. Do you honestly believe that we have a community-based program (inaudible) to address adequately these clients? []

BRAD MEURRENS: Some of them, yes. []

SENATOR HARMS: So some of them, yes. Give me an example. []

BRAD MEURRENS: Well, I would say there are community programs in place that could handle or that could take in residents that may not have a certain disabilities.

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They may not have overly profound disabilities. There are certain, you know, community agencies that can handle different levels of disability. So I think, you know, it...there are those community placements where persons that are BSDC could be placed with relative ease. []

SENATOR HARMS: That's part of my concern is that evaluation and appropriate assessment in placing someone in an environment without really knowing for sure whether that program is probably adequate and having the support services to be able to help that individual. I fear that we'll put them in a more difficult environment. So that's why I'm concerned about what you comments on that aspect of it. I want to talk a little bit about changing the culture. Let's talk a little bit about how do you see changing the culture of that environment? Because I agree with you. I just want to know what your views are in regard to that aspect. []

BRAD MEURRENS: Well, I think, you know, one of the easy...and easy way to start getting at the root of the problem is like what we've called for in our reports, Indictment of Indifference, is infusing social role valorization programs. An idea that people with disabilities have valued social roles and have value as a person. Infusing that theory and that curriculum into the preservice and sensitivity training that BSDC staff go through. Also I think that there needs to be quick and decisive action taken by administration when incidences of devaluation, either through language or through actions of staff, there needs to be decisive action taken, you know, for those individuals to stop doing that behavior or something to that effect. It's going to have to come from the top down. But I think that we need to start looking at the culture of the organization, and in looking at places where that culture can be changed. []

SENATOR HARMS: Yeah. So in viewing your comments, we really haven't addressed the other issue and that's management. I mean, when I look at all of this and I've read as much as I can humanly, possibly read until that I've been given, it boils down to the fact we have absolutely no management or the management is truly lacking there. Is

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that your observation? []

BRAD MEURRENS: Well, I think that's when we talk about accountability and the, you know, management looking the other way when instances happen, and documented instances of administration looking the other way and that can't happen. I mean, we agree. The management is a critical piece. []

SENATOR HARMS: Because without strong management, all the things we're talking about now will in fact not happen. []

BRAD MEURRENS: We would agree. []

SENATOR HARMS: Yeah, just will not happen I can tell you. I've been down this road before in another environment and I can tell you that unless you straighten that part of it up, we can do all the things in the world here but it's not going to occur. []

BRAD MEURRENS: We would agree. []

SENATOR HARMS: Okay. Thank you. Thank you, Mr. Chairman. []

SENATOR LATHROP: Senator Stuthman. []

SENATOR STUTHMAN: Thank you, Senator Lathrop. Brad, in your testimony here, and I'm going to dwell on a couple of issues here. On the staff training, and you state here where based on our observations. Give me a little bit of an example of your observations. Were you personally there? Was your group personally down there? Where did you get the information from? []

BRAD MEURRENS: I myself was not personally down there. But as we said earlier, we have an agreement with BSDC that we have staff that's down there doing those

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observations twice a month. []

SENATOR STUTHMAN: Twice a month? []

BRAD MEURRENS: Yes. []

SENATOR STUTHMAN: Okay. And you state there's been inadequately trained, you know...staff that has not been trained to work with the residents and are unaware or ignore the proper procedures and protocols. Explain that to me as far as what you think is inadequately trained. []

BRAD MEURRENS: Well, I think one example is the recent story about the individual that was having a heart attack, and the staff...there were three staff members who just kind of stood around and didn't perform CPR and didn't really know what the proper procedures were, called the, you know, emergency medical technicians. And we found that in the investigation as it says in the written testimony in more detail, there were like 99 staff that was overdue for CPR training and that's like the direct care staff. There were several other, you know, on call staff and other staff that were overdue for CPR training. There was an individual who authorized in a person's care plan and unauthorized technique which has to be authorized by the human rights committee that they never approved this, but yet it was...you know, this technique was in the person's care plan. So then again I think the incidents of staff being verbally and physically abusive to residents is another glowing example of inadequate training. []

SENATOR STUTHMAN: When you made the statement that they were overdue on their CPR training or update or recertification, these people had been, you know, have had CPR training, in other words, right? []

BRAD MEURRENS: I don't know. I didn't do the investigation. But that could be an assumption, yeah. []

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SENATOR STUTHMAN: I mean to me, you know, making the statement, you know, that they were overdue on it. Yes, they were overdue on it as far as paperwork is concerned, but if the individual had CPR training, he's still got CPR training. Whether he could do CPR tomorrow because his training was...his certification was over. []

BRAD MEURRENS: Sure. []

SENATOR STUTHMAN: I mean that's the situation that I'm a little bit concerned about. So but I, you know, I put a lot of trust and faith in individuals that come here, parents or guardians, and make statements of what's happening there. And I'm just a little bit concerned about, you know, you bringing these allegations here, and to me it's secondhand is what it is. []

BRAD MEURRENS: Right, but the allegations that I'm bringing to you are documented founded by BSDC internal investigations to be founded incidents of abuse and neglect. It's not just my word or something that I'm making up. These are actual documented founded incidents of abuse and neglect. Now like I said, I'm not going to claim that all staff are bad or treat residents poorly. I don't think that's true. There are certainly some and I think the 12 pages of the written testimony that I handed in, I think would speak loudly to that. I can't speak for the experience of all family members and all residents of the institution or facility. But I think that the numbers of incidents that are occurring that are documented and have been founded should give us some significant pause to reexamine these issues that I bring before you today. []

SENATOR STUTHMAN: Okay. Thank you. []

SENATOR LATHROP: Senator Adams. []

SENATOR ADAMS: Brad, you represent Nebraska Advocacy. So my assumption is

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you're going to advocate for anyone with special needs. Would that be correct? []

BRAD MEURRENS: We advocate for persons with disabilities, yeah, whether that be a physical disability, developmental disability, psychological disability, yes. []

SENATOR ADAMS: Okay. Good. The incidences that you bring forward I don't question whether they occurred or not. I guess what I'm wondering, and I realize that the charge of this group has been primarily to look at Beatrice, but we can't help but look beyond that. Are there incidences where your organization is called upon by parents and guardians of people who are in community-based programs needing your advocacy services? []

BRAD MEURRENS: I was speaking to our legal staff and our executive director, and they had indicated that we have had incidences where that has occurred and we have gone in and taken action against and advocated for persons who are being abused within the community settings, yes. []

SENATOR ADAMS: Okay. Thank you. []

SENATOR LATHROP: Senator Harms. []

SENATOR HARMS: Thank you, Mr. Chairman. Bradley, the information that you've documented here, if I recall, a lot of this is really supported by the federal review. You know, a lot of the things you've brought out are things that we have that were identified in the report that we've recently been given in regard to what the federal government...the feds have found. Is that correct? []

BRAD MEURRENS: Well, I think they're consistent with the reports and the findings of the feds. []

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SENATOR HARMS: That's the point I'm after. []

BRAD MEURRENS: But I think if I'm not mistaken the federal...the DOJ report, for example, came out I think in March, and these are up until July of 2008, several months after. []

SENATOR HARMS: The point I'm after, there's a theme that goes through this and it's consistent. []

BRAD MEURRENS: Yes, it is consistent. []

SENATOR HARMS: Okay. Thank you. []

SENATOR LATHROP: I do have a question for you. Senator Adams was asking you if you've advocated for folks in community-based care. You've seen similar problems in some of the community-based programs, am I right? []

BRAD MEURRENS: You know, I'd have to defer that to the legal staff. []

SENATOR LATHROP: Okay. []

BRAD MEURRENS: But... []

SENATOR LATHROP: Let me ask you this then. []

BRAD MEURRENS: Okay. []

SENATOR LATHROP: Do the community-based programs have the same level of scrutiny as Beatrice? []

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BRAD MEURRENS: To the best of my knowledge, no. But again, I would defer to the legal staff to really get that accurate answer. You know, we would be happy to engage in a conversation about increasing our role of to oversee or be that sort of watch dog group for more community-based residences. []

SENATOR LATHROP: I appreciate that and I think that would make people in this room more comfortable. Part of the problem is is that we seem to compare apples to oranges because over at Beatrice we have the Department of Justice, we have CMS, we have state regulators who are in there doing surveys and looking for violations. And we don't have reports of similar surveys that have been done in the community-based programs. So almost because there's a void when it comes to how are they doing? Is there abuse and neglect in the community programs? We're kind of start out by assuming that the troubles in Beatrice and everything's okay in the community programs. We don't know that to be true. []

BRAD MEURRENS: You're right. And we would be happy to engage in conversation about increasing our funding, state funds for to do some of that activity. We'd be happy to talk about that. Yes. []

SENATOR LATHROP: Okay. Thank you. Any other questions? Doesn't look like it. Thanks for coming down. []

BRAD MEURRENS: You're welcome. Thank you. []

SENATOR LATHROP: How are we doing for witnesses? Looks like we have...Joe, you wanted to take... []

JOE VALENTI: Could I respeak to speak to incident 003. I know you were questioning.
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SENATOR LATHROP: That's...yeah. Let's have you sit back down and tell us your name again. []

JOE VALENTI: Joe Valenti again, V-a-l-e-n-t-i. You have incidence 003, which involves our son unnamed. And that incident did occur, and the only way we would have known about that incident and thank God for the Beatrice residence teenagers reported that incident at the YWCA. And I called that family and thanked them because I got it off the police report. So just to verify, Senator Stuthman, any of your questioning, not in a bad way. Whether or not this incidence occurred, I can verify with you that that incident did occur. And those employees were dismissed. I would like to address Senator Harms's question about management. You're right. You're not going to change the culture without changing management or at least adjusting management and management's philosophy. But with management as you know, let's just call it for the sake of discussion that you have first level management, you've got second level management in Beatrice, and then you've got maybe third level at HHS and/or fourth or fifth or whatever the case may be. And then you've the Governor. So I mean, again, it's a systematic problem as I stated before. And I'm sorry, I know you were tied up this morning, but you just can't start with Beatrice. You've got to start up here and work its way down because that's the only way culture is going to change in my opinion. []

SENATOR HARMS: Right. I don't disagree with that at all. []

JOE VALENTI: Okay. []

SENATOR HARMS: Thank you. []

JOE VALENTI: Thanks. []

SENATOR LATHROP: Thanks, Joe. []

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JOE VALENTI: Thank you. []

JUNE CLAPPER: I'm June Clapper. []

SENATOR LATHROP: We'll let you sit down and you can get near that microphone so we can all hear you, and then we'll have you tell us your name. Okay? []

JUNE CLAPPER: (Exhibit 12) Hello. My name is June Clapper. I have lived in the Lincoln Regional Center and went to the state home. I've stayed in Lincoln Regional Center for about four months. Then I went to Beatrice in 1964. I live in Omaha now. I'm...do stuff with the Ollie Webb Center too. So I worked at Methodist Hospital in Omaha for six years. And then I did all kinds of stuff. []

SENATOR LATHROP: Yeah. Go ahead and tell us what you... []

JUNE CLAPPER: I've known some people that live in Beatrice. []

SENATOR LATHROP: Okay. []

JUNE CLAPPER: And I lived there for six years. Then I moved to Omaha on a job...what do you call it...job placement, and then I got fired from there. So I've been doing other stuff. I've been to conventions out here at Kearney, Nebraska. I always went to the Crossroads to do my shopping for clothes. Then I went out there to Bag 'N Save to get my groceries. And then I've also been on the quality review team. That wasn't put in here. I have to...been to some of them homes where people stayed. There's a lady by the name of Cathy McGuire (phonetic) asked me if I'd join a review team. Well, I've been to some of them homes where residents lived. I've been through Omaha, Bellevue, Papillion. To me, I'd never go back to Beatrice. No way in hell! Because I've got relatives that live down there and there was relatives that worked at the state home. And I would ever go back there. But I know some people that lived in another home that

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was in Beatrice. It's called the other institution that they have down there. I've been around as long as you know when. I was born in 1943. My father had a heart attack in '61 and that's when I had to quit school. So I went through to sophomore year. When my father had a heart attack, I got taken out of school. []

SENATOR LATHROP: All right. We'll make sure no one has any questions. Doesn't look like it. Thanks for coming down. We appreciate it, Ms. Clapper. []

JUNE CLAPPER: Sure. []

SALVADOR GONZALEZ: Good afternoon. My name is Salvador Gonzalez. I'm from Omaha. I have a 48-year-old Downs syndrome daughter. Just to give you a little background, Sandra's (phonetic) mom and I was divorced back in 1972 and she took Sandra (phonetic) to Beatrice and left her there without my knowledge. And so I went to court, got the custody taken away from her. Sandra (phonetic) was the first one to come back, one of the first ones to come back out of Beatrice, you know, back in the last '70s because of the court order. The main reason why I'm here was because Sandra's (phonetic) hours that she's getting. The hours that she's getting was back...set her back in the late 1970's. She's got 25-hour day service hours and 124 hours residential hours. It's really difficult to get her into a decent placement because of the hours. When the providers looked at (inaudible) and they say, you know, how many hours she's got? Well, the first thing they say, well, we can't provide services because of this...because the hours she's got is not...you know, just can't do it with that. So back in April of '06, we took and put her in the ITS...I think it was the ITS program, they called it, Beatrice. Is that it? Did I say that right? And she was there for three months, and I was very pleased. I was very pleased with that program. Sandra (phonetic) done very, very good except that I wanted her home because Sandra (phonetic) and I had been very, very close. She spends every other weekend, holidays, just as much as she can, you know, I bring her home with me. So I want her to be home. But what is happened is is that she's had to get into services with roommates that are very, very abusive because of the

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hours. And that's the whole thing is it's all about the hours. She just can't go any place else, you know. So I've had her out of two different places I have had to take her out of. I'm in the process of taking out of another one now because of the abuse that goes on there. I didn't come down here to talk about that. But in listening to things that were said by some of the other people ahead of me, you can't just take people out of Beatrice and place them in home-based programs and then forget about them because that's what's happening in some of...there are some good programs. There are some good providers I would say. But like I said, Sandra (phonetic) has had to go with places where there's a lot of abuse. I've got pictures here that would contradict what this fellow here was saying about abuse that goes on in the residential settings. I didn't want to bring that up, but in listening to things, you know, there's the good, the bad, and the ugly. And I just wanted to have a placement for Sandra (phonetic) because Sandra's (phonetic)...I'm the only one Sandra (phonetic) has. She has no one else that's going to look after her. So I wanted her in a good place where she would...that I could be happy that she's going to be if something happens to me. I'm up in my middle 70s. And so, you know, I got to have some...want to be comfortable with some place. But with the hours she's getting, that can't happen. And like I said though is that I've always said when I started reading about the committee that was investigating Beatrice, I've always said that same committee has got to come and start investigating some of the home-based programs also because you can't just take them and walk away from them and think that everything is going good. You know, it's not, it's not. Believe me, it's not. I don't know. But the reason I came down here for was because I want to know is when are we going...when are you going to look at these people that have been out of Beatrice for all these years. And yet their hours have not changed. I mean 25 hours for a day service? Come on. You know, you can't...nobody wants to take them for that. So you know, that's my big question is when are you going to do something about that? That's all I have to say. []

SENATOR LATHROP: All right. We probably have some questions for you, and I know that you're explanation of your experience...first of all, your daughter, was she at

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Beatrice for a time? []

SALVADOR GONZALEZ: Back in the '70s... []

SENATOR LATHROP: When your ex-wife put her there? []

SALVADOR GONZALEZ: Yeah, she was there for two years. Um-hum. []

SENATOR LATHROP: And how old was she when she came out of Beatrice? []

SALVADOR GONZALEZ: Well, she was probably about 18, 19, something like that. []

SENATOR LATHROP: Okay. And since then, she's...you're involvement with the state in the provision of services for your daughter has been on a community-based program basis. []

SALVADOR GONZALEZ: Um-hum. Um-hum. []

SENATOR LATHROP: And when you talk about the hours, because I think Ms. Patty Smith talked about that as well, and that is you have so many hours. Does that go through the ICAP formula and then somebody says you get this many hours to work with and you can go get this much care for that? []

SALVADOR GONZALEZ: Yeah. Yeah, back at the first part of this year, believe filed a--I don't know what they call it--a grievance or something. So we come down to Lincoln and testified to try to get them more hours, but we were rejected. I think it was... []

SENATOR LATHROP: So the hours is sort of the credit you have to work with to go out and get services within the community. []

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SALVADOR GONZALEZ: Services for her, correct. []

SENATOR LATHROP: And your concern today that you've expressed to us is however they evaluated my daughter, they understated the hours she needs for services. []

SALVADOR GONZALEZ: But this goes clear back when she come out of Beatrice clear back in the '70s. I mean, come on. I mean, the Legislature has gotten wage increases in your wages, I mean, from over 30 years, over 30 years. You know. Cost of living has gone up and everything. I mean... []

SENATOR LATHROP: So what you're concern has to do with the number hours... []

SALVADOR GONZALEZ: Yeah. []

SENATOR LATHROP: ...they give you to work with to get the care. []

SALVADOR GONZALEZ: And you know I put the blame on the system because I'm saying is, okay, if she had more hours, then she could go to places that she could get better care instead of having to go someplace where there's abusive. When she has to go someplace where people have more hours, when you have people with more hours, then there's more problems. That's why they've got the more hours. You know. []

SENATOR LATHROP: And if she doesn't have enough hours, why does she have to go to places where people have a lot of hours? []

SALVADOR GONZALEZ: Because they won't... []

SENATOR LATHROP: I don't understand that. []

SALVADOR GONZALEZ: Because they won't accept her because they don't have

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enough...there's not enough...I can't explain it as good as probably the social worker did. []

SENATOR LATHROP: You're doing fine, you're doing fine. []

SALVADOR GONZALEZ: But the way I understand it is that they have to have enough hours in order to pay for the help and everything that they have. And so they have to have so many hours in that one unit, place. And she usually goes someplace where there's two other ladies, like there's three people. You know. []

SENATOR LATHROP: So whether you're a recipient of these benefits or a provider, hours become a commodity. []

SALVADOR GONZALEZ: Oh, yes. []

SENATOR LATHROP: And a provider has to have so many hours going on in a day of services in order to make ends meet. []

SALVADOR GONZALEZ: In order to make ends meet. []

SENATOR LATHROP: And so they have high-end people, and your daughter ends up because she's a low hours person... []

SALVADOR GONZALEZ: Because she's low, yeah. []

SENATOR LATHROP: I get it. []

SALVADOR GONZALEZ: I mean, that's where she's at today, you know. []

SENATOR LATHROP: Okay. []

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SALVADOR GONZALEZ: And it's just a matter of time because I can't keep her where she's at because of the abuses. I fielded stuff that's going on there. []

SENATOR LATHROP: And she's literally being physically assaulted by other residents. []

SALVADOR GONZALEZ: Um-hum, um-hum. []

SENATOR LATHROP: I got you. []

SALVADOR GONZALEZ: And when I talked to this gentleman here, I was talking stuff, like that, I did call his office and I did talk to them and they were supposed to get back to me. And I did explain what was going on and everything, and I never did get a phone call back. But I did explain to them about the abuse that I thought was going on. And I never got a phone call back from them, so. []

SENATOR LATHROP: You talked to other people who are users of the community-based programs? []

SALVADOR GONZALEZ: Have I talked to... []

SENATOR LATHROP: Yeah, other families. []

SALVADOR GONZALEZ: Oh, sure, sure. []

SENATOR LATHROP: So you are...you are the first one that's come in today with an experience about someone being abused in a community-based program, so I'm curious. Do you know of others with similar experiences or is yours an isolated one? []

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SALVADOR GONZALEZ: Well, offhand I can't really answer that question. You know, but I have proof to backup what I'm talking about. []

SENATOR LATHROP: Oh, I'm not suggesting that you don't or that I don't believe you unless you have six more families that agree with you. I'm just wondering if you had heard of other instances. []

SALVADOR GONZALEZ: Well, yes because I've known of people that have withdrawn people out of services because they were dissatisfied of what or how things were going on there. []

SENATOR LATHROP: Okay. []

SALVADOR GONZALEZ: So you know, where they have taken them back home or they've taken them and tried to get them into another provider, you know. []

SENATOR LATHROP: Okay. []

SALVADOR GONZALEZ: But just like I said is that I've taken Sandra (phonetic) and we've put her in the ITS program hoping that by the time she got out of...when she come through that, hoping that she was going to get more hours that would make her more attractive to a provider. Well, she did for six months, but then her hours went all the way back down to the original 124 and 25. []

SENATOR LATHROP: Got you, got you. []

SALVADOR GONZALEZ: You know, and that just... []

SENATOR LATHROP: We have some other questions. Senator Harms. []

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SENATOR HARMS: Thank you, Senator Lathrop. You talk about abuse and I'm assuming your daughter was abused. Is that correct? []

SALVADOR GONZALEZ: I'm sorry? []

SENATOR HARMS: Well, you were talking about abuse and I'm assuming that your daughter was abused. []

SALVADOR GONZALEZ: Yes. []

SENATOR HARMS: Okay. Did you file any kind of a complaints... []

SALVADOR GONZALEZ: No, no I haven't. []

SENATOR HARMS: ...about that or did you follow that up and ask for this to be stopped? []

SALVADOR GONZALEZ: You mean did talk to... []

SENATOR HARMS: Yes, did you file it with the... []

SALVADOR GONZALEZ: With the PS? []

SENATOR HARMS: Yeah. []

SALVADOR GONZALEZ: APS. You don't know how many times I have picked up that phone and dialed the number and didn't go through with it because I'm the kind of person who don't like to get people in trouble, and I was afraid of getting...I was hoping that for some way, some how I was just hoping...because I need someplace for my daughter to be. []

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SENATOR HARMS: So you were more concerned...you were afraid that they would probably mistreat your daughter? []

SALVADOR GONZALEZ: Yeah. I was the repercussion. I was afraid of that, sure. []

SENATOR HARMS: Or they might just move you out so you're on your own. []

SALVADOR GONZALEZ: Well, no not so much that. Some repercussion things may be going on that I'm not there that I don't see or hear about, you know. I mean some of the things that I do here or sometimes staff will say things to me about different things that happen, you know, where a staff might say, well, this other staff person...basically the abuse is not from staff people. It's basically from roommates, other people, and that's what I'm saying is that with the hours, she has to go to a place with other roommates that are higher hours, but they also have higher needs. And I've incidents where the staff would say, well, so-and-so was beating up on Sandra (phonetic) and I had to go in between them and intervene. You know, stuff like that, you know. And then when I bring this up to the management, well, then it always seems like it doesn't happen, it didn't happen. And then before I know it, that staff person is gone, you know. []

SENATOR HARMS: So you did really make a complaint or you did bring it to... []

SALVADOR GONZALEZ: To management? []

SENATOR HARMS: To management's attention. []

SALVADOR GONZALEZ: Yes, yes, yes. []

SENATOR HARMS: That's what I was really looking for. []

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SALVADOR GONZALEZ: But as far as APS goes, Adult Protection, no, I haven't. But like I said is that I wake up steadily at night and I think about and I wake up the next morning and say, I got to do this today, I got to do this today. And I've picked up the phone and dialed the number and I hung up because I just, you know, I just don't want...I did call the advocacy. I did all them. That's...you know, and they did, the lady that I talked to did instruct APS to report it. And like I said, if I hadn't done it, you know...
[]

SENATOR HARMS: Well, you shouldn't have to have that kind of fear. []

SALVADOR GONZALEZ: I'm sorry? []

SENATOR HARMS: You should not have to have that kind of fear because if something takes place, we ought to react in the appropriate manner, and your daughter and you should not be at risk. []

SALVADOR GONZALEZ: And but sometimes you feel like they're all alone, you know. []

SENATOR HARMS: I understand that. []

SALVADOR GONZALEZ: Just like the first lady that came in. I could relate to some of the things that she was saying, you know, because you're all alone. You don't get no help. []

SENATOR HARMS: That's what I'm saying. []

SALVADOR GONZALEZ: You know, where do you go? []

SENATOR HARMS: Yeah, that's why I'm saying you shouldn't have to worry about that. You should have the environment where you can actually have the freedom and the

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opportunity to make the complaint and it would be reviewed and investigated and dealt with. []

SALVADOR GONZALEZ: But who do you complain to, you know? Because you can say something, complain on something, and then management will come up with a different story because they can put down anything they want in the books and it's my word against their word. And then when I get to the service coordinator, then she'll say, well, they said this or they said that. Please, that's not the way it happened. You know, but you know, it's my word and it seems like the service coordinators always take the side of the managers. That's the way it always seems. And so then basically then you're all alone. You know, but I think that the hours, I think that that basically, you know, when I sit there and I think about the whole thing boils down to that and I blame the Legislature because they are not funding the money for Sandra (phonetic) to get decent care that she is entitled to. I feel she's as human as just anybody else and she's entitled to it. You know. []

SENATOR HARMS: Thank you very much. []

SALVADOR GONZALEZ: Thank you. []

SENATOR LATHROP: Thank you. Senator Wallman has a question for you. []

SENATOR WALLMAN: Yeah. Thank you for coming down. So you feel that the home-based care is not watched over close enough, you know, like the BSDC were pretty much watched over by, you know, by the Department of Justice. []

SALVADOR GONZALEZ: Correct, right, right. I think they should be watched over better. Yeah. []

SENATOR WALLMAN: Okay. []

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SALVADOR GONZALEZ: I mean, don't get me wrong. You know, I mean I know there's some good ones out there. You know, and I've been there when it was really good. But Then I've seen it with staff changes and getting rid of...it seems like sometimes they get rid of the best staff, you know, and then it just goes down hill. It needs to be monitored. It needs to be monitored. Like I said, as I sat there reading...I read all the reports about Beatrice and I say, you know, they need to do the same thing with some of the home-based programs. []

SENATOR WALLMAN: Thank you. []

SALVADOR GONZALEZ: Thank you. []

SENATOR LATHROP: Thanks, Mr. Gonzalez. Okay. []

ANNIE ADAMSON ANDERSON: Hello, Senator Lathrop, members of the committee. My name is Annie Anderson, A-d...I'm sorry. I'm doing my maiden name. Adamson Anderson, A-n-d-e-r-s-o-n. I am the parent of a 21-year-old son named George (phonetic) who has a developmental disability. I am from Omaha, Nebraska, and in Omaha is where we have raised my son. I also have two other siblings. And today I just wanted to give you an example of some of the many community services that were out there from my son and still continue to be out there for him. I feel as a young man that we have gotten to a huge milestone in his life at age 21. Two months ago, he was able to move into an apartment on his own, which is something that we as a family have dreamed about and he as a young man has dreamed about as well. I would like to say that I don't think that that would have been a possibility considering the severity of his disabilities and what he was born with if we had not had all of the community services, the array of services that Omaha provide with us, to us. It was not always easy to find the services and that is something that we also need to work on. And when I was first presented after my son's birth with a place to make that phone call to, oh, you have a

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child born with a variety of different disabilities, here's a phone number that you may want to call. It was very difficult for me as a parent to make that initial phone call. I didn't want to be judged, you know, by these people. I wondered would they judge me for the decisions that I have made? Would they judge me for what has happened to my son and the kind of disabilities that he has. It was very difficult to make that initial phone call. But I believe that when I sat down and made that phone call, that a whole chain of events happened that has been very important in my life, as well in the life of my child. What I did was I opened a door and it was very scary to let all these strangers come into my life and my son's life. But I opened a door and I let these folks come in because the bottom line for me was that they had trained many more years and had much more knowledge than I myself had had. When I got pregnant and had my son, I had no idea that he would be born with so many different types of disabilities. No one in my family had ever encountered this before. When I was in college, I did take some classes and things about people with developmental disabilities, but again I said I just never imagined that it could happen to me. And so opening that door and letting these individuals come into my life was difficult for me. It was exceedingly difficult for my husband. He had always been born and raised thinking that we as a family can do this together, you know, we're going to be able to do this. We don't need to go out there and ask for help. And so it was a lot more difficult for him. But when we opened the door, we were pleasantly surprised to find that not only were there an array of services for my son George (phonetic), but also those people that were connected to those community services, they really are the people that have given us the information that we have needed. And I noticed that today during testimony you were hearing things about school districts. And I would have to say that the early intervention programs in a variety of different school districts in the state of Nebraska are absolutely excellent. As you move your way through more services as my child has become older, sometimes you do lose some of that excellence and you do see a slip in quality. And I attribute that often to the fact that people will buy into the philosophy that my son is a valuable human being. But when it comes to giving their dollars to support that for a lot of the community programs, sometimes they will say, yes, this needs to be done. But when they actually come to

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following up with the dollars, it does not always happen. But we are very happy with the services that we have received through the community. And I just wanted to end by telling you what some of those services are so you at least understand that there are many services out there. Obviously my son was born and spent 124 days in a hospital, so a lot of our services that we received were through some of the hospitals. And in the Midwest here, we are very fortunate to have some of the quality. If my son had been born anywhere else, the doctors had told me that there was a chance that he would not even be alive today. So we used services through the hospital. We used services through the NICU, which is a neonatal intensive care unit. And through that NICU we were introduced to a support group, and through that support group is when we began to meet other parents who then would network with other professionals. And we began to find out what kind of community services were out there for our family. So we went through the NICU support group and went onto another program called a parent-to-parent program. Right now I think there are 700 parent-to-parent to programs across the United States. In the state of Nebraska, we were fortunate enough to be one of the very first parent-to-parent programs. We've since won many awards for establishing these types of programs in the state of Nebraska. We have a lot of national attention over that type of thing. And in this program is where I began to learn more and more about what community resources were out there through the different people in the program, through the different type of service that it provided us. We used respite services when my son was growing up. We used psychological services as he was growing up. And keep in mind that as we were educating ourselves as parents and as we were trying to make sure that we were enhancing our problem solving skills in case they were ever needed, my son was also using occupational therapy in the community. He was using speech therapy in the community, physical therapy in the community. He also used eyeglass services. And at times it was very difficult for us financially. When my son came out of the hospital, he was close to being a million dollar baby. And my husband and I always thought that with my husband's good job that the insurance would cover all types of services and things that we needed. And unfortunately we found out that wasn't true. There was a cap on my husband's insurance policy, and my son went

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over the cap the first four months of his life. And so not to say that it was an easy go it. It was very, very difficult. And as a human being I think I learned the majority of my problem solving skills and how to make good decisions based on the fact that I had a child born with a disability. He went to the Omaha Public Schools. He received van services through the schools. My husband and I went to Health and Human Services several times to seek out financial assistance to help us in areas when we could not pay. We did our best as a family and as taxpayers of the state of Nebraska to pay everything that we possibly could to make sure that George (phonetic) got the kinds of services that he might need. We used the services at Munroe-Meyer where he went and had some testing done. We used the services at the parent training institute. It's called PTI Nebraska now. Each state in the United States has a parent training center where families can go and get information about educational services or those types of services as well. We were one of the families that learned about that and took advantage of all that type of information which greatly helped us as we went through our educational process. We also were involved in a program called the PRISM program, parent resource information and support meetings through the Ollie Webb center. And that's where we became more knowledgeable as parents about what services and things were out there. When we went to PRISM, which was offered every month, they would have guest speakers come in and talk to us parents on topics that were of interest to us: guardianship, financial assistance, where to go next for help, problem solving, social skills, those types of things, how do you talk to doctors appropriately, how to use the right language when you need to get a service and go in and speak the language that they would understand. We learned all of those things through the PRISM program. My son also was affiliated with the Ollie Webb Center. It used to be called Go Ark at one time. Through the Ollie Webb Center, we as parents were able to get support, and he was also able to go through a variety of mentoring programs called the just friends program. He went through best buddies, which is actually a national program. It's a Kennedy Shriver funded program. He was able to go through best buddies and make friendships. All along the way while we are getting this assistance and he is getting this assistance, we were asking my son, what did he want to do? What

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were his dreams? What did he want to seek out? We were able to listen to what my son said and definitely make some of our choices based on that. George (phonetic) will be getting involved in the ultimate life program, which is an adult program that will pair him up with a buddy to go do the things that as I age I'm not able to do with him. My son has a lot of value to me, and the society that I live in has a lot of value to me as well. I don't think I could imagine myself being here today talking in front of you if it wasn't because of all the other parents and all the other professional that took a chance on my family and my son. So I just wanted to give you a just a peek into when it works well in the community, it means that my son will probably be a very successful individual. I know that we have things ahead of us. I know that there's things out there that we have not personally experienced yet or encountered yet. But I also know that I have a personal board of directors that I carry around in my mind, and I built these board of directors based on meeting people such as Patty Smith, based on meeting people such as June Clapper who has a disability, based on meeting Ollie Webb who had a disability. I have gotten this personal board of directors in my mind so that whenever we need to solve problems or we need to look for services. But whenever there's not a service out there or whenever there's a service that needs to be changed or needs to be looked into that I have the freedom as a family to go in front of those folks and talk about what we need, and to maybe give you a little bit of information that you might need in your decision making. And so I think that we show an example where we have used an incredible amount of services in the state of Nebraska. Do we need to change how we deliver services? Absolutely, absolutely. I echo a lot of what was said today about needing some more oversight. And I think what it boils down to to me in a lot of cases unfortunately is the funding. We could do so much more in the community where individuals feel more comfortable. We could do more of those things in the community if there was more funding funneled in those directions, and I truly believe that. So when I look at Beatrice and I look at the situation, I can't help but look at how much it's costing for one individual as compared to what I have personally experienced by using services in the community. I also look often into what other states have done. And that would be my suggestion is that we look at what other states have done because certainly other

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states have deinstitutionalized their states and still been able to provide services in the community that were more than adequate. []

SENATOR LATHROP: Very good. Thank you. []

ANNIE ADAMSON ANDERSON: Thank you very much. []

SENATOR LATHROP: Senator Harms. []

SENATOR HARMS: I'm sorry. Thank you, Mr. Chairman. Annie, in regard to the services you have, are those services...how are they funded, do you know? There are probably a variety of ways. []

ANNIE ADAMSON ANDERSON: Oh, certainly. []

SENATOR HARMS: Okay. Do you know... []

ANNIE ADAMSON ANDERSON: Some of the services that we get are funded through the United Way. Some of the services that we get would be funded through the state. I know PTI Nebraska is federally funded. []

SENATOR HARMS: Okay. So I really impressed with the services, and thank you for sharing that because I did not have the background to understand that this many services were available. Now when you look at urban America and you're fortunate that you're in Omaha... []

ANNIE ADAMSON ANDERSON: Absolutely. []

SENATOR HARMS: ...because you have this services. This probably an unfair question and if you don't know it, it's okay. As you move out of the Omaha and the urban areas

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and you get into rural America, do you see these same services being available or all of sudden does it just narrow down and you don't have much left? What are your observations? []

ANNIE ADAMSON ANDERSON: My observation and my experience is that in some of the more rural areas, obviously you're going to have to travel further. I mean, I think that's just a daily part of their lives is that in order to get some of these types of services, they're going to have to travel. And I can't really speak to some of the exact services that I receive in Omaha, but I can speak to the parent-to-parent program and the parent-to-parent support that we had. That was really our initial point of entry into finding out all about the disability world and realizing we need to make a connection. I can tell you that there are many parent-to-parent programs across this state of Nebraska. And so that really was our initial point. And I anticipate by hearing some of the families today that perhaps they didn't have that entry into the disability world, whereas we did. But I do know in the state of Nebraska, there are parent-to-parent programs scattered all throughout the state. []

SENATOR HARMS: Thank you. []

SENATOR ADAMS: Any other questions? []

ANNIE ADAMSON ANDERSON: Thank you. []

SENATOR ADAMS: Thank you for your testimony. Is there someone else who would like to testify? []

JOAN OMEARA: I would like to say a few things before we close. []

SENATOR ADAMS: Please come back up and again restate your name for the record.
[]

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JOAN OMEARA: Sure. My name is Joan O'Meara, and I'm president of the BSDC Family and Friends Association. And we were not here, the BSDC people, to defame any community program. I'm on the Governor's committee, advisory committee, for DD. I'm the only one from Beatrice. The rest are all from community programs spread across the United...through Nebraska. We all agree that something must be done with the DD program. There has to be changes. One shoe does not fit all. I don't care...community programs are necessary, in-home care is necessary, and so is BSDC necessary. The mentality of the retardation is so long and so vast and so changed you can't say that someone at this end will fit into the shoe at this end nor can I say that this end is the only way that this should be here. I agree. There are some that need to live in community homes and wish to live in community homes. There are others who can't. They can't speak even. And we have to make as parents choices. And one of the choices should be the fact that there is this large spread of availability for DD people, and that we could be picking out where our child is best suited. Right now, my child is best suited at BSDC. She's been there for 44 years. To change her would be detrimental. She calls that place home. I take her out every week to go to eat. We eat in the car because Cindy (phonetic) is in a wheelchair and I can't handle picking her in and out. And she loves McDonalds. So we go to McDonalds. The minute she is finished eating, she said, I go home. And that was the only word she can say, and momma or Pat (phonetic), her brother or Cat (phonetic), her sister Cathy (phonetic). Otherwise Cindy (phonetic) does not speak. She speaks with her hands, like her mother, so that we are able to understand her. But what I want you to all get out of this is not that we have two camps here. We don't. We have one united camp. We need to work for developmental disabilities that Nebraska is the best in the nation, and our hope is in you. You finally have heard our voice. You have no idea how we have cried about the injustices that were going on. And I didn't want you to feel that we're tearing down one program for another. We're just citing where it fits one, it's not fitting the other. So I thank you for you time, and I call you the "magnificent seven". I don't know of anybody that would walk in through a wall of fire and that's about it. Thanks so much. []

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SENATOR LATHROP: Thank you. []

PATTY SMITH: Could I just add one more thing that might help? []

SENATOR LATHROP: Sure. []

PATTY SMITH: The gentleman that spoke--my name is Patty Smith--the gentleman that spoke about the hours and the ICAP and that, I could give you a little bit more clarification on it. There is this ICAP process that they do not implement. Jane (phonetic) is right now in her third ICAP and the last two haven't been implemented yet. So now we'll have three ICAPs that are not implement, and it's because the state has not been able to move. It's all tied up in the Bill M. case and tied up in committees. But it's been tied up for I think it's almost ten years, about nine years of tied up. And as a result of that, and maybe I'm not explaining it properly because I don't know all the state stuff. I just know what it did to us. By making the hours so few, especially when the gentleman told you about the day hours and then the night hours, what that sets up is a very difficult situation because if you only get 27, like that man said I think 26 or 7, Jane (phonetic) has like 27 or 8, you then have only got enough hours to go to a workshop or to an enclave, which means a kind of a mini workshop place where it's better than a workshop, but it's an enclave in a business let's say or maybe the dishwashing at Creighton University at their dinner there you know. And so those are the only two things you can do. And at that, one parent called me the other day and not the...his name is Joshua (phonetic), they will not accept his 29 hours because he's too difficult to serve at a workshop. So they're just stuck. They can't get him into a workshop. And the state will not...and they appealed it and lost. And so by not implementing this ICAP, and you gentlemen are going to have to figure out what this all is because if you don't, you've got one more stumbling block in trying to solve some of this. Because if they don't implement those ICAPs, like for instance, Jane's (phonetic) ICAPs clearly state that she needs more hours. I mean, it's all documented. But they won't implement them

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because they're waiting because of these problems of the...they say it's the up-and-down hours. They're trying to get people to go down in hours so they can go up on hours. I mean, I'm telling you guys if it took you nine years to figure this out, I mean, this is a long time to figure something out. And now we have...I'm on three more committees this fall that are trying to solve some of these problems. Well, it's a lot of bureaucracy. But what it does to the people and what that man said to you, you know, when he said that she had smaller amount of hours and then she's put into a place with people with more hours. What that means is that these people with the more hours have somebody who has more difficult behaviors. So you put his daughter in with the, you know...and then she is getting into a situation she doesn't need to be with. And he is not the only parent. I can tell you of parent after parent who has come to me and said, how can we get the hours balanced out better? I am very fortunate because (a) I'm still living, and that Jane (phonetic) has the apartment in my downstairs because she doesn't need...she has 62 night hours. So if she was going into an apartment, she'd be in the same problem that this gentleman was because she'd be real short on hours. And so it would be really good for you to spend a little bit of time...Mr. Severance was here in June, if you recall, talking to you about how they do these ICAPs. And I got to tell you something, I like Don Severance, I like all of these people. But if you cannot figure out how to solve a problem in eight or nine years, the state's got a problem, and it's causing people trouble, and it's causing trouble for the providers. And so I just want you to assure that because he explained it quite well. But I know the part about how the state has...because we went through these appeals as much as we have, and we have not won any appeals. I spend more money than you'd ever want to hear appealing and got nowhere. And so it causes a lot of trouble with her trying to work because they said at the beginning they said she couldn't work, like for ten hours a week they had her...that's another whole story, they had her at SSI all messed up. So you just need to know that the state has got to start implementation of ICAP, and they need to get...actually what the people are fighting over is that it isn't a good system. And I told you that the other day, Steve. It does not measure the right things. And so they need to find a way to have a proper measurement of their assessment of people. Then assess the hours and fund

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them. And this also, if you stop and think about it, has grave consequences for the providers. So I just wanted to mention that to you because the gentleman did a good job at beginning of it that I wanted to put more on the end of it because the ICAP process is not being used. It's just talked about. []

SENATOR LATHROP: Before you leave, let me just make sure I understand the ICAP process... []

PATTY SMITH: Okay. []

SENATOR LATHROP: ...and remember how it was explained. But they go through an assessment process. []

PATTY SMITH: Yes. []

SENATOR LATHROP: And that's supposed to be... []

PATTY SMITH: A paper... []

SENATOR LATHROP: ...an objective process to determine... []

PATTY SMITH: Yeah. []

SENATOR LATHROP: ...what each individual who is looking to the state for services... []

PATTY SMITH: Right. []

SENATOR LATHROP: ...what their needs are. And then they go through the ICAP process to weigh how much services a person with... []

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PATTY SMITH: Will get. []

SENATOR LATHROP: ...that level of need requires. And then they get so many hours of credit... []

PATTY SMITH: Right. []

SENATOR LATHROP: ...that you basically can spend... []

PATTY SMITH: They're units. []

SENATOR LATHROP: Units? []

PATTY SMITH: Units of service, yeah. []

SENATOR LATHROP: Units of service that you can spend in the community. []

PATTY SMITH: Right. []

SENATOR LATHROP: And what you're saying is if they go through the ICAP process...first of all, you don't think that's a perfect process and that it's flawed. []

PATTY SMITH: Right. []

SENATOR LATHROP: But even when it comes up with a certain number of hours, they're still rationing those units. []

PATTY SMITH: Yes. And because of this...this fight started before I ever came back in the year 2000. It was already roaring then. The advocates and the people in different

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positions that have been on all these committees--I wasn't on them--have told me that all of the committee said they should do it this way, and the state says they should do it this way. And that battle still goes on, and in another month they're going to have a gentleman from Minnesota come down, Charlie Lakin (phonetic), and he will be the specialist that will come in and try to help people to understand what it is they can do, could do, would do. But I think that it's important for you to know that like that gentleman is saying that he's like banging his head trying to get what his daughter needs. He appealed it, they won't change, it's insufficient, and it causes his daughter problems because she's getting into the wrong...you know, she's got the wrong...and this is probably common, this thing of getting to the right roommates and the right people. If you get the right one, it's great. For my daughter, my daughter does not want to live with anybody. She has autism. She does not want to share her living area with anybody. And to the best of our ability, we'll let her be like that. When I die, she gets my house and somebody can come live where I live. That's the kind of a service where you have a host family. I'm her host. And I want her to live in that kind of a situation because she does not want roommates. And so that's one way...there's ways you can get around some of these things. But you gentlemen need to know since you've got so many things to figure out, like what it takes...and my last thing, the state now is saying that they will adequately really try to figure out what people leaving Beatrice are going to get for hours. And I don't know what process they're going to be used. I haven't been told. But I've heard the community providers have said that within 6, or is it 12 months, they're going to cut it back to the ICAP. That is a terrible plan. I mean, if it takes this many dollars to serve them for 6 or 12 months, why would you think that this is somebody that really needs a lot of...(end of recording) []