State of Rhode Island and Providence Plantations

Public Forums to Identify the Concerns of People with Disabilities and their Families

During the week of the 24th anniversary of the Americans with Disabilities Act (signed on July 26th), the Governor's Commission on Disabilities and many other state and non-profit agencies conduct a weeklong series of open forums to hear the concerns of people with disabilities and their families.

The forums are open for anyone to come in and speak; representatives of the sponsoring agencies will be there to listen. State policy makers and planners want to hear your concerns about current services, unmet needs, and suggestions for improving services and expanding opportunities.

Monday, July 21st, 2014, 1 – 3 PM

Zambarano Unit, Eleanor Slater Hospital, 2090 Wallum Lake Rd, Pascoag

Hosted by Alliance for Better Long Term Care / RI Long Term Care Ombudsman

Monday, July 21st, 2014, 4 – 6 PM

Woonsocket Harris Public Library, 303 Clinton St, Woonsocket

Hosted by Seven Hills Rhode Island

Tuesday, July 22nd, 2014, 2 – 4 PM

Warwick Public Library, 600 Sandy Lane, Warwick

Hosted by the Ocean State Center for Independent Living

Wednesday, July 23rd, 2014, from 5:30 – 7:30 PM

Middletown Public Library, 700 West Main Rd, Middletown

Hosted by Opportunities Unlimited For People With Differing Abilities

Thursday, July 24th, 2014, from 4 – 6 PM

Rogers Free Library, 525 Hope St, Bristol

Hosted by RI Statewide Independent Living Council & National Federation of the Blind of RI

Thursday, July 24th, 2014, from 4 – 6 PM

Charlestown Chambers, 4540 South County Trail, Charlestown

Hosted by Perspectives Corporation & National Multiple Sclerosis Society RI Chapter

Friday, July 25th, 2014, from 1:30 – 3:30 PM

South Providence Library, 441 Prairie Avenue, Providence

Hosted by RI Department of Health

Remarks can be made in person during the forums, faxed to 462-0106, e-mailed to GCD.Disabilities@gcd.ri.gov, or mailed by August 8th to Governor's Commission on Disabilities, John O' Pastore Center - 41 Cherry Dale Court, Cranston, RI 02920. CART Recorders (real-time captioning) and assistive listening devices will be at all sites, courtesy of the Office of Rehabilitation Services / Assistive Technology Access Partnership. The RI Commission on the Deaf and Hard of Hearing will provide sign language interpreters for each forum.

To request information or accommodation, please call 462-0100 or 462-0101(tty) in advance; arrangements will be provided at no cost. Language interpreting is available with the Department of Human Services and requests can be made to 462-2130 in advance.

When making the ADA reservation with RIde to get to and from the public forum, tell the RIde reservationist (1-800-479-6902) that this trip is for the Governor's Commission's Public Forums in order to guarantee your return trip, after normal RIde hours of operation. ADA fare is still applicable. When attending the forum, please use unscented personal care products. Mild fragrances can constitute a toxic exposure for a person with an environmental illness.

Lincoln D. Chafee, Governor

The Public Forums' additional sponsors are: Arthritis Foundation RI Chapter; AccessPoint RI; Gateway Healthcare; In-Sight; Living in Fulfilling Environments, Inc; J. Arthur Trudeau Memorial Center; Neighborhood Health Plan of RI; RI Parent Information Network, Inc.; and RI Disability Law Center.

Monday July 21, 2014 Woonsocket

CHRISTINE GADBOIS: Good afternoon, everybody. What's the official title? Welcome, everybody, to the governor's Commission on Disabilities public forum. There are seven of these I understand happening across the state and the intent is to get input from people with disabilities to some service providers and governmental organizations, et cetera so that services can be improved. So, my name is Chris Gadbois, I work for seven hills Rhode Island and we offer to help the Governor's Commission with hosting the event and moderate. So, welcome and thanks again for coming. I'm going to ask the panel members to please introduce them selves. Could you introduce, please.

DORIAN HAVERS: Dorian Havers.

CATHERINE SANSONETTI: Catherine Sansonetti.

ARTHUR PLITT: Arthur Plitt.

PANEL MEMBER: Rhode Island department of health, office of special health care needs.

CHRISTINE GADBOIS: Can everybody hear? I know the air-conditioner -- we'll try to speak up. But, the point of these sessions is for you all to be able to speak what your concerns are. They will be entered into the formal record and folks at the governor's Commission on Disabilities will be reviewing the input you give in order to work with various providers and government agencies to improve services. So, the intent is not so much for us to speak to you but for you to speak to us. But we'll all try to be mindful of the noise here, try to speak up. So, if folks wanted to speak today, they should sign up in the back of the room, please. And, we do have a couple people that have already signed up to speak, first being Marisel Wells. Would you like to address, please?

MARISEL WELLS: Okay. My name is Marisel. I don't know which way you want to me stand. Let me do this.

FEMALE SPEAKER: You can stay in your seat if you want, whatever is more comfortable for you, just be sure you project.

FEMALE SPEAKER: No problem.

Please spell your first and last name so we can get it.

MARISEL WELLS: Marisel Wells. I am currently a student at stepping up in Providence.

I am in the health care field. I just received my first aid mental health certification. I have worked at an alternative behavioral day school.

I have had two children diagnosed with two different mental health disorders, one is PTSD and the other is ADHD. The PTSD one was very difficult to deal with. Part of my daughter's problem is she has a hard time talking about what happened to her when she was 6 years old, she was assaulted by someone she knew.

And doesn't remember it to this day. It took her a long time to come to terms with it. She has forgiven that person, that person is related. I guess part of the problem she had was, first of diagnosis because it was ADHD first they were getting at. And then -- no, I don't think she has that, she's not hyper, I didn't see any of that.

Then we ended up with another clinician that diagnosed her correctly. When she got diagnosed she ended up a week at Bradley hospital so that was really hard. A lot of out bursts, a lot of head banging. Like crouching and posturing a lot. It's getting easier to talk about the more I talk about it. I use today cry a lot when I talked about it. Because the person that did it to her was her brother, her older brother. He was 16 and she was 6. And as a parent I had to make a really bad choice and I, I don't think it was, a lot of people say it wasn't but I feel it was, I arrested my 16 year-old son.

And that was hard because I had to pick between one child or another. And, I chose my daughter, she was suffering, she had a big welt, her eye was cut, she was all bruised right here and it took three months for that bump to go off her head. It really is hard to really think about that situation and how young she was when it happened. My thing now, towards the forum, more than anything else, when you get diagnosed with PTSD, and you tell people, oh, my daughter has PTSD, first of all, you get, what does it mean? The second one you get is, what happened to her? Then if I say assaulted people automatically think she was sexually assaulted. No, she wasn't, she was physically assaulted. So, you get that kind of stigmatism.

That's why when she was having her problems, sometimes it was best just to not say that she had PTSD. She's just having some problem, some mental health problem. I think it was just easier for me to do it that way, concentrate on her, not have to deal with the outsiders that were passing judgment on her. So, a lot of difficulty in school. I did lose my job because of her. Not because of her, I wouldn't say it that way, because of the situation she was going through. Yeah, another problem that she had is, my daughter didn't like to talk about the situation a lot, so she wanted to stay with one clinician and one clinician only. When the best clinician left and went to another state for another opportunity, that's what really messed her up because that clinician was really, really good.

So she regressed when she was doing really well and then she started up all over again. So that was touch, too. When a child has a mental health condition, they do not want to keep repeating their story to several different people and that's been my problem with both kids because my first one had ADHD. Mom, I don't want to talk to all these different people. I always heard that from him. Okay, well, it's hard to keep one clinician for a long time, for the length of the child's education or however long they need them. So, .

CHRISTINE GADBOIS: Well thank you so much Miss Wells for sharing this. Is there something that you would advise this Commission to consider in terms of helping with that continuity for children with mental health issues?

MARISEL WELLS: Just like, more so, realizing that children have a hard time talking about whatever situation they are in. It's going to take a lot of clinicians for them to go through before they find someone they are really comfortable with and I'm sure the state is looking at it, well, Medicare or health insurance wise, why is this person going to so many different people, they'll probably end up seeing it that way.

CHRISTINE GADBOIS: Thank you so much for offering that perspective, it must be difficult for you to share that. Thank you.

CHRISTINE WELLS: No problem.

CHRISTINE GADBOIS: The next person we have signed up to speak is Brian Newton.

BRIAN NEWTON: Hi, this is my wife Muriel, we are parents of a 43 year-old daughter with down's syndrome, she received services from seven hills Rhode Island. And she's also in a group home. My complaint is the drastic budget cut that is this agency and all of the agencies in Rhode Island have suffered. Yet the state through federal mandate is required to get these folks out into the, into the community now, more so than they ever did in the past.

Provide more vocational training than they ever did in the past. Yet the money doesn't follow.

And, but the layoffs continue. The budget cuts continue. Yet the demands are increasing on this agency. And the staff from top to bottom are just under a tremendous strain to provide these services and it shows, too. It's very difficult for the staff. It shows in the staff, it shows in the clients, and it effects the parents, it effects everyone. Yet the state does not allocate more funding. Year after year after year, they cut. I don't know, what have they cut since 2008, Chris, probably 50 percent of the budget.

CHRISTINE GADBOIS: Maybe not that high but pretty significant.

BRIAN NEWTON: Round it off, 50 percent. That's my complaint.

CHRISTINE GADBOIS: Thank you so much Mr. Newton. Our next speaker is Ellen Kreutler, might have to spell that.

ELLEN KREUTLER: Ellen Kreutler. I'm here representing accessible Rhode Island.

And I just wanted folks to know about the program. Has anyone heard about it before? I know there are a couple people in the room that know about it. It's a resource web site for folks to check on accessibility of a lot of different places around Rhode Island. We do attractions, we do beaches, recreational facilities, dining, places to stay so that people can know in advance that they can be comfortable and get in somewhere. Rhode Island is so old, talk about Bristol and Newport and there are a lot of places it's difficult for people to take advantage. So, we just hit over 900 listings on the web site. The web site is www.access-ri.org. There is some information back here. I just wanted folks to know about it because it's an important resource for people in Rhode Island and people coming from other states. Does anybody have any questions?

FEMALE SPEAKER: As far as accessible, how, these places that you checked out, are they accessible to anybody or accessible to those that can walk?

ELLEN KREUTLER: I'm glad you asked that, we look at wheelchairs, scooters, canes, walkers, that sort of thing. We actually assign letters, P for parking, that there is signage indicated parking. Van parking, that the route of entry is clear with no obstacles and that it's wide enough for folks, that the main entrance is large enough for a large wheelchair and that the bathrooms are accessible. We list the positive features of the facility, we're not the police. We just want to let everybody know, park in the back, that's where the ramp is...any other special features, pools, there is a lift. We have done a elevate hotels recently. We're working with the office of disabilities and health to see how wellness places are represented. We did all of the beaches for this time of year and found all the state beaches have these great beach wheelchairs for folks to use.

FEMALE SPEAKER: Mostly the bathrooms that I have a problem with. We went to go camping at fisherman's last year and I asked them, I said do you have any handicapped accessible bathrooms, she's like yeah right next to where you're camping.

Problem is, it had a step. Handicap accessible once you're in.

ELLEN KREUTLER: We made a comment about that, arc Accessable but you have to navigate (inaudible) something like that. So that's really a great part to the web site. We're starting to work with libraries so we can get the word out. If you don't have.

CHRISTINE GADBOIS: Can I remind people to speak up because of the fan.

ELLEN KREUTLER: Sure. I'm sorry. So, yeah, with the libraries we're making sure it's a resource that the librarians know about because a lot of people don't have a computer to go on. And they can give the call there. Our newest and most exciting thing is that we're doing facilities to (inaudible) so people know the closest best place. So monitoring facilities to make sure folks can get early screening because a lot of people just don't think it's accessible or, we're trying to make places welcoming to everybody. And that's about it.

CHRISTINE GADBOIS: Well, thank you so much.

ELLEN KREUTLER: Public service announcement.

CHRISTINE GADBOIS: Perfect. Our next speaker, just to remind people to please try to speak up because the acoustics in this room are not great and we do have to have our reporter take all of this down. Our next speaker is Jennifer Charbonneau.

JENNIFER CHARBONNEAU: That's me. I feel like coming in here and saying I'm Jennifer -- and I'm -- it's what it feels like. I just have a few thing that is drive me crazy and that's why he shook his head. The handicapped parking for one thing. What can you do about people that park in hand capped parking and do not have a thing in the window? Also, there is a car at Providence place mall that on the second floor, continually parks in the lines. Not hand happened but figures if there are two handicaps there, I can park here. So I can't get out there because I have a ramp in my van.

That and people that stop as an example there is red box up at Cumberland farms heading up into Burrillville and people always park in the handicapped spot. Whether they are anticipate hand capped or not, if they're handicapped that's fine, that's the spot for you but there are people that park there and jump out of their vehicle to look at the movies and I have been so tempted to park behind them and call the cops.

FEMALE SPEAKER: That is a good idea, you should do that.

JENNIFER CHARBONNEAU: I said that to my mom she's like, no, you'll get arrested.

But yeah, if they don't get fined it's not going to do anything. And like at Providence place mall, I got stuck, I had gone to a restaurant and I parked in the normal spot with the lines on the side so I could get out, when I got back, there was a car parked there and they said we can't do anything. What do you mean you can't do anything? Can't you, like, call security, or, but they're like, no, that's not our responsibility. I'm like then what exactly do you do.

PANEL MEMBER: Who said that?

JENNIFER CHARBONNEAU: One of the security guards when they came over. They're like all we can do is get in the van and pull it forward for you. What does that do with this person that's going to keep doing it. And I've been tempted to take pictures of the car and put them online and make them humiliated but I don't know if I can do that either. When it comes to handicapped parking I think it's one of the worst things that handicapped people find, you know, to stop them from being able to go out on their own and do what they want. And, you know, you see a fine of $50 or whatever, people don't care because most likely they're not getting noticed and if they do, 50 bucks no big deal, whatever.

CHRISTINE GADBOIS: Thank you very much, Jennifer. To reiterate, all of the people's comments today are being recorded so that the governor's Commission on Disabilities can review all of these concerns and direct them to the appropriate state organizations, in order to address them. So, they will be heard. And again just to remind for people to speak up, the fan is a little loud. If it gets warm here there is water in the back, on the chair because we didn't have any tables. The next speaker is Manuel Mederios please.

MANUEL MEDERIOS: Right here. Since March I have been a member of -- since March I have been an associate member of the Rhode Island developmental disabilities council.

Prior to that, 30 years I worked for the Massachusetts department of developmental services so I am here really today to hear more from people who have issues so I can get a beg your pardon understanding of what some of the issues are and take that back to the council.

CHRISTINE GADBOIS: Very good.

Well, thank you so much. Our next speaker is Gail Peet.

GAIL PEET: I'm Gail Peet, and I'm here for my daughter Catherine who is disabled and not able to speak for herself. But, she has been in a waiver program, independently living, and just this year, this has been, let's see, since 2000, she was one of the first families in that program, independent living. And what that program does, and people don't know, is, we are able to hire our own staff and we have an agency that is financial, they pay the bills and monitor the pay roll, but we hire the staff and generate the money through our waiver program. Just this year, now what are we, 14 years, we have received a letter in June that said, oh, you have to pay for cost of care. Okay.

I have been on the phone maybe four or five hours trying to find out how this is figured and what is figured into that. And living independently in your own home that is provided by her family, it doesn't cost whatever this amount, $990 a month to live there when you pay taxes of $1200 a quarter. I mean it is totally crazy. And I have made many phone calls. I have been shuttled all around and then I'm back at the social worker, at the department who is trying to help me and I have called long-term care, they said they don't do anything about anything. I mean, there is no answers.

And we do pay for extra medical stuff, but nobody will tell us what it is. And, yes, what is, I think the horrendous thing is the agency that manages our budget for us is now going to be deemed the money we don't pay. Now, is that how other states do it? I just can't believe that they should have to be the collection agency for something that we can't even find out what it is we're supposed to be paying. Everyone says, we don't provide that, medical costs, well, she has to do a lot of vigorous exercise because she's on dilantin (sounds like) -- has to go to the Y and staff to train for the treadmill, oh, I don't know if that would count. Where are the answers? This is crazy so I'm just here to voice.

In 14 years we have not had to go around the barn like this and I still don't have an answer and I don't even know who I'm supposed to talk to.

CARMEN BOUCHER: Can I ask, where are you getting the bill from? Who is the agency billing you.

GAIL PEET: We just switched to Probability. We were with Options down in Barrington for 14 years and we just switched.

CHRISTINE GADBOIS: You've spoken you said with long-term care about how they calculate the cost share? I don't know what you said, you've spoken with long-term care?

GAIL PEET: They say, we don't determine that.

CHRISTINE GADBOIS: Did you speak with someone at the department of human services?

GAIL PEET: I talked to our social worker. And now she is going to try to find out from long-term care who is supposed to be managing my daughter's waiver program but I have talked to the Sherlock Center, I've talked -- I've talked to so many people and gotten no answers.

CHRISTINE GADBOIS: And your daughter's services are through the BHDDH, the DD.

GAIL PEET: Yes, we have our own day program that we run with staff for her. And she has 24 hour care. And that we're not being unhappy with, we get to hire who we want, and decide who manages the house, and for 14 years, all of a sudden comes this bill. Oh, you owe. And what is sad is if your family had provided for you and put you under their social security number, you get more money. We want it, says the state. We want it. Now, that's kind of penalizing families who provide for their loved ones because the state wants to grab it. For what? Come on, show me. The agency provides no services to us except financial management and we pay them a thousand dollars a year for that anyway. I think that this is some idea that someone has decided to put through and I think it is not well thought and we just, we're told, there was no notice. Just a letter that said, okay, you now have to pay this a month and, over a year it's going to be $5,000.

When we can't even make it on what is given by social security. Good thing I work and provide the situation. So, I think that someone told me, and I think this makes good sense. Services, medically necessary have to be done. And the alternative's more costly. What do you want? Back in nursing homes? Back in group homes?

Is that what we're aiming towards? I thought we -- I'm just absolutely amazed at this and the fact that some of the people at some of the people up at the state have been rather threatening. And I think that's ridiculous, because they don't have the answers.

PANEL MEMBER: Can I ask a question? At the Sherlock Center, who did you speak to there?

GAIL PEET: Claire, and she referred me to someone who I talked to her and she went and talked to somebody, and then she called me and said, talk to this person, I did, and they yelled at me and said, well f you don't do what I tell you, you can just do without the services.

Now, there's an answer for you. Plus, I said, what is, oh, no, we can't pay for the Y. I said, why, she has to go, it's medically necessary.

Well, basically, I think what I learned is he didn't know. But, I'm rather persistent and I work professionally. I just, I just think this is so unfair.

And anyone else who might not realize what's going on here might just go, oh well I think we need someone to look into this and see what it is, why, and why are these people all not helpful? Except my social worker is now back on the thing and she's going to find -- but anyway, I'm just telling you, it's very frustrating and I have spent a lot of time getting no somewhere.

CHRISTINE GADBOIS: Thank you very much, Mrs. Peet for sharing this, I know there are a lot of other families getting this news and trying to figure it out. Thank you for bringing it to this Commission so they can address it.

GAIL PEET: It's very sad and it's not the right way to do something.

CHRISTINE GADBOIS: We have no further people that were signed up to speak so at this point we can open the floor to discussion. And I know this lady right here was offering comment.

PANEL MEMBER: I just wanted to ask what your daughter's health insurance is.

GAIL PEET: You have to talk louder.

PANEL MEMBER: What's your daughter's health insurance, Medicaid, Medicare?

GAIL PEET: She has both.

PANEL MEMBER: Does she have a, is she fee-for-service or does she have a plan overseeing her like united health or neighborhood health? Nothing. Just Medicare and Medicaid.

GAIL PEET: Since birth, as far as I -- I mean, you know, since the waiver program.

CHRISTINE GADBOIS: Are there other comments from the audience? Other concerns that people have?

FEMALE SPEAKER: Yeah, has the Obama care thing changed any of the insurance in any way? I know for me it has. They make you step into medications now which I don't think is right. I have asthma, shouldn't I get the correct medication I want, the one I've always been on, now they have me on a different inhaler that's making me sicker instead of better.

You have to try this first before you go onto another one, doctor has to approve it, you need prior authorization. I really don't like the insurance, I really don't. That's half the reason I'm considering going to another state, because of the insurance.

CHRISTINE GADBOIS: Well, thank you, Miss Wells, I think there are, again, the comments you make here are going to go to the appropriate people at the state level so they will hear your concerns, the Governor's Commission will address them perhaps to the insurance commissioner or the appropriate body.

JENNIFER CHARBONNEAU: I'm wondering if, because like what I said about parking the car and calling the police or whatever, what do you do? Do you go and, like the, I live in Burrillville and the Burrillville police station right down the street and so many times, ask what exactly can we do about the handicapped problems around here as far as people parking wherever they want to and parking in the lines. I mean, can I legitimately park behind them and not let them move until they get there?

CHRISTINE GADBOIS: That’s gentleman behind you answering.

RON McMINN: Ron McMinn, Commissioner on the governor's Commission and chair on the accessibility committee. You cannot park behind the vehicle or block them in, in any way. You will get

a ticket. The best thing you've got, if you have a cell phone, take a picture. Make certain that the license plate number and the handicapped sign are shown.

Then you go to the police department and say, look, this is what's happening, I'd like to make a complaint. They'll start looking into it. But for the most part on private property like the mall, stuff like that, they really don't want to get involved. I know I've gone to a manager of a mall and said, look, either you get this problem solved or you're going to have a lot of press outside. It was solved. They don't like bad press. But, if you block someone in, yes, you will get the ticket for obstructing. And the diagonal lines like you say is for your ramp, that's a $75 fine.

JENNIFER CHARBONNEAU: If they park there?

RON McMINN: If they park --

JENNIFER CHARBONNEAU: Take a picture.

RON McMINN: Yeah take a picture of that, also. That's what we recommend. We have been trying for the last several years, I have, since 1995, that there was a program in East Providence that had people volunteer and they were given digital cameras and they went out into, let's say a CVS lot, and every time someone parked illegally, took a nice picture, turned it into the police department and the police department says here is your ticket. So we have been trying to get that program started again. A lot of the police departments are, well, you know...so, it's frustrating. And like you say, the lady who said that had problems with the state, or gentleman, problems with the state, I started at a Commissioner in 1995. We had a staff of 8 and a half people. The half person came in to answer the phones for four hours.

We are now down to a staff of four. The other day, before my committee, to make Allstate buildings, to go, fire access, parking, is 75 million dollars. They gave us 7 million dollars, for five years. So, yeah, it's frustrating for all of us. Even us who volunteer our time. Chris, she'll volunteer, Arthur up there, he's part of the Commission. So, yeah, it's frustrating not only to you but to us. So, best thing, take a picture, bring it to the police department and say, you know, this is what's happening.

MALE SPEAKER: That's good advice. I also think the other end of this, you know who you're dealing with, you don't want to put yourself in a situation with somebody could create a conflict. I think that's great advice.

JENNIFER CHARBONNEAU: Can I ask one last question? What do you do about people who have a temporary handicapped placard but use it months after they're fine. What should you do about that?

CHRISTINE GADBOIS: Again we don't really have the answers here. We are definitely going to register the concerns and have them in the minutes so that folks at the Commission can route the concerns to the appropriate folks and I imagine these types of concerns will go to law enforcement I would imagine.

JENNIFER CHARBONNEAU: Thank you.

MALE SPEAKER: Happens all the time unfortunately.

FEMALE SPEAKER: If it has an expiration date, do the same thing, take a picture, bring it to the police department.

FEMALE SPEAKER: Yeah even the permanent ones do because you have to get it, I think it's every two years, have you to update it like your car, just so that they know that you aren't faking.

MALE SPEAKER: You could call the Burrillville police a few times. I'm sure they might pay more attention when they drive by, see somebody parked illegally.

CHRISTINE GADBOIS: Thank you all for the concerns. The forum goes through until 6:00 so we're all going to stay here and hear concerns until then but people can come and go as they wish.

GAIL PEET: Another comment, if something we suffered about a year and a half or two years ago, we went from the, a service program to a thing called the SIS (sounds like).

Now, we should have given the money to that gentleman instead of spending it on that SIS.

Because my daughter is nonverbal. We sat through a three-hour interview with a person who had been trained -- she asked the most ridiculous questions. My daughter finally got up from where we were sitting and put herself to bed. Okay, can she make a meal? Well if she could, how long would it take her? Now I went to meetings and told them that was asinine, the whole thing, we should have saved our money and just continued in what we were doing but somebody got a grant and hired all these people and it's ridiculous. Give the money to the man that needed it, not hire some more buddies in.

I'm sorry, but that is something someone ought to look at. That is a sham.

CHRISTINE GADBOIS: Thank you very much Mrs. Peet, you bring up a lot of good concerns. Thank you. So again, I know people may want to come and go but the panelists will stay here in case other people come in later. So...

TED CIAVARINI: There is a -- that the state wants us to take our people with developmental disabilities out of our training centers and into the community. The thing with communization for the past 30 years being a very active member of the arc. That's nothing new and I think it's commendable. However, when you consider the persons that you are serviced, individually, there is always a limit. And there is a way, they seem to kind of take everyone and put them in the same box and ship them over into the community for 60 percent of the time of day. My daughter has severely, is severely developmentally disabled.

She is also nonverbal. And places in the community are very difficult for her because they are new to her, at new experience, and without the proper person attending her, it's going to wind up in a tangent (sounds like), you follow? So, I say, how do people up in the state house or in Cranston, far away from the communities that they serviced, come up with these numbers of 60 percent of the time they've got to be in a community setting? It seems that the people who make these decisions are the ones that are furthest away from the problem.

CHRISTINE GADBOIS: Thank you.

FEMALE SPEAKER: I just want to make a comment. I used to work, before when I could walk, and the building was somewhat handicapped accessible, like you could get in the front door but you couldn't get in the one after that because it locked. And you couldn't get to the bathroom. So, one day, my manager, I complained to my supervisor or something and my manager came up to me and said what exactly needs to be handicapped accessible in here and I actually had the guts to say, you need to sit in this chair, ride around the facility and you tell me what needs to be handicapped accessible because until you're in a chair or scooter or, you don't know. Most people have no idea, you see you can get in the front door so it's hand capped accessible. Great, how do I get past that? How do I get into the bathroom?

So, and it actually worked because, then they had the push-button things for the bathroom and the push-button things to get in the door. So, some things did change.

PANEL MEMBER: Did he drive around in your scooter?

FEMALE SPEAKER: My wheelchair at the time.

PANEL MEMBER: Did he?

FEMALE SPEAKER: Yeah. And sometimes that's like what you have to do, is tell someone, until you're sitting in this position, you don't know what needs to be done or what is the problem. Basically. And I think, if anybody ever goes through that and you're in a wheelchair or whatever, tell them, sit here and you tell me what needs to be done. When he did it, he's like, I can't believe what's not handicapped accessible in here. I said, well, you know, that's what you have to do, sit in the chair yourself and go around and find out because, keep knocking on the door please let me in, trying to open the door to the

bathroom without the button. And it's amazing what needs to be handicapped accessible. And just about 90% of the state, but, sometimes you have to do things like that.

And come up and say, well, sit here and you tell me what needs to be done. And it worked.

ARTHUR PLITT: If anyone has any further comments even as you leave, you can always e-mail the Commission or call and leave your comments just in case you forget something, on the way home.

CHRISTINE GADBOIS: Who would they e-mail at the Commission.

PANEL MEMBER: Is it disabilities@ -- the e-mail.

FEMALE SPEAKER: GCD.

MALE SPEAKER: You can go to the web site.

CHRISTINE GADBOIS: So go to the web site for the Governor's council on disabilities and is there a contact us button.

RON McMINN: There will be a list of, like accessibility. It should have a list in there but it will have a main number that you would call. And you can call that or you can send an e-mail to the Governor's Commission on disabilities.

CHRISTINE GADBOIS: Can we tell people the phone number now.

FEMALE SPEAKER: 462-0100. Area code 401.

FEMALE SPEAKER: 401-462-0100.

PANEL MEMBER: E-mail is gcd.disability -- disability@gcd -- gcd.disabilities@gcd.ri.gov. It was simpler.

FEMALE SPEAKER: I have another question, too. I'm currently intern, doing an internship at a nursing home. And my bosses brought this up and I don't understand why this -- I can't fathom it, to make people with dementia do activities at night, what's the purpose? When most of the time they're just tired, once they eat they just want to go to sleep. It is really hard to get anybody with dementia to get any type of activity done.

CHRISTINE GADBOIS: You said that's some sort of a mandate.

FEMALE SPEAKER: Yes it is the state provides that. And I don't think they should. I don't.

PANEL MEMBER: Required to offer it or the person is required to participate.

FEMALE SPEAKER: Not required to participate.

PANEL MEMBER: Required to be brought there.

FEMALE SPEAKER: We have to offer an activity at night. Which, why? Once they eat, they're pretty much tired, who wants to do anything, at that age, why would you want to do anything? We have kept them so active during the day, by the time that dinner comes, they get their medications because most of them have to take medications with food. They're terrorized.

They just want to go to sleep. Just let them rest.

PANEL MEMBER: What kind of an activity?

FEMALE SPEAKER: It has to be motor skill related. It has to be cognitive related.

Anything memory wise. Manual dexterity, anything of that sort. Some of them wake up at 6:00 to take medications and they're sleeping during the day. I just, I don't get why they do that. I really don't.

PANEL MEMBER: My guess is that has a lot to do with the facility's ability to fill -- there is an expectation that the facility is going to offer some type of care or, whether or not it makes sense, it's.

FEMALE SPEAKER: It doesn't though, I mean, I think it's hurting the company more than anything. They have to keep those employees, pay more employees, for what? We're just sitting around pretty much, more than anything.

I'm talking to them more than anything.

PANEL MEMBER: I think that's what the answer is, has to do with billing and they couldn't bill if they couldn't document that they were at least offering it. That drive a lot of what goes on. You can check it out further by talking to somebody there, that's my best -- just the way you're describing it, fits the mold of being able to bill fully for Medicare.

FEMALE SPEAKER: Hard to encourage them to come out when they're in their 70s. I have a 101 year-old lady. What is she going to do? If she's visually impaired or posturing or has hand problems, what can she physically do?

CHRISTINE GADBOIS: Thank you for bringing up those concerns. Again they'll be directed to the appropriate agency that can address them.

FEMALE SPEAKER: Okay.

CHRISTINE GADBOIS: Again, folks are free to come and go. We'll still be here.