



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.

Wednesday July 23, 2014 Middletown

LINDA WARD: We're going to get started. I have such control of this situation. All right. We're going to start. If anybody needs assisted listening devices, they're here. We have the CART reporter and we have interpreters for the deaf and hard of hearing so if anybody needs that, just raise your hand. My name is Linda Ward; I'm a commissioner on the Governor's Commission on Disabilities and chair of the legislature (sounds like) committee, and executive director of opportunities unlimited, working with adults with developmental disabilities. Bathrooms are outside the door. And I'm going to ask the panelists to introduce themselves. And then I'll read the rest of the instructions. We'll start with Jodi.

JODI MERRYMAN: Supervisor at the division of developmental disabilities.

MEREDITH SHEEHAN: Manager of programs and advocacy for the national MS society.

RICK COSTA: Executive board leader statewide independent living council.

KATHY MCCABE: Senior counselor at the office of rehab services.

CHARLES MESSINA: Staff attorney with the Rhode Island disability law center.

LISA ONORATO: With the brain injury association, resource specialist.

LINDA WARD: Again, I want to be sure everybody here signs in, whether you're going to speak or not, it helps identify on the record who is here. I'm going to read this. The purpose of these forums is to identify the concerns of people with disabilities and their families in order to assist the state to develop programs to improve the quality of life of people with disabilities. Also to ensure -- to ensure everyone who wants to speak gets a chance -- that won't be a problem, please keep your comments short and to the point. If you have a critical problem that needs to be addressed, the panel members will be available at the end of the hearing to direct you to the proper agency for help. This isn't the place where they can answer very personal and specific questions.

That would be most appropriately answered after. After the Public Forums are completed in early August, the sponsoring agencies review the testimony, prepare recommendations which will also be posted on the web site by the end of November. The recommendations and transcripts will be printed and sent to state and congressional officials and members of the General Assembly and recommendations will be used to develop policy and legislative initiatives for the next year, or until they are accomplished.

My understanding is the Rhode Island disability law center's panelist will be available to anybody who wants to vote.

CHARLES MESSINA: I will, information is also on the side table.

LINDA WARD: If you need to change address, there is a way -- remind you to sign the attendance sheet. Okay. And, once everyone who has signed up to speak has spoken, we'll go around and ask if anyone else wants to say anything, and then we'll be here until 7:30 no matter how quickly we are done. Just to remind the panelists, your job is to listen, ask questions to clarify, try not to get into a debate with the speaker. And if the speaker is not aware of a service, suggest to speak with them at the end of the testimony. And I am not worried about having time, so, I don't think that's going to be a problem.

FEMALE SPEAKER: It isn't usually.

LINDA WARD: So we have three people who have indicated they want to speak. Cinotti. Feel free.

CLAUDIA CINOTTI: One question I have to ask is, there is an ambulance company, I think universal, the gentleman that owned it died. And that left us in this area and South Kingstown without as many ambulances. And they changed the system on how to handle that.

It's a phone number you call through Medicaid, they handle it. My experience with this was not good at all. Number 1, no one called me to confirm, which, like, how it was set up before, call the ambulance

service for yourself and that company would call you the day before with a recorded confirmation, picking you up at 10:00.

I had big surgeries scheduled for my right hand in January. A week before the surgery, girl from Medicaid called up and supposedly got me a ride there and home because I was going under anesthesia but it was in and out. It was across from Hasbro hospital. So I'm waiting, I didn't get a confirmation call so around 10:30 I said something is not right. So I call up and say, do you know what ambulance service, she says New England. So I called New England directly and the gentleman says I'm sorry but you're not on the list. I said what do you mean? That appointment was made last week. So, in short, they weren't coming to get me so I had to call that woman back from Medicaid. She got a taxi service, I don't know why, from Woonsocket, this woman had to drive all the way to Middletown, I live in a -- for the handicapped, and take me to the hospital. And I said to her, she says, as long as you're through by 5:00, I said, oh yes, definitely. Well, cut the story short, when they called and nobody answered the phone, I was forced to stay overnight in the hospital. Forced. So what did that cost the government and the tax payers? For a night's stay in the hospital. I never got my night time medication so I was up all night, hyper ventilating, and the bone doctor didn't know anything about the type of medicine I take at night so he's giving me 50mg which is like nothing and it made my condition on my disability much worse than what it was. I said I'll take the bus. No, somebody has to come in and sign you out. Unfortunately, I don't have family members, I have one son with traumatic brain injury at the hospital.

LINDA WARD: Have you had more problems with transportation?

CLAUDIA CINOTTI: Two months ago, set up an appointment to see a doctor on the east side for my foot. Two weeks in advance this time. They had the nerve to call me, it was New England again, the day before, and say, you know, we can't take you, do you want to reschedule? I said, not with you. So there is procedures that I'm supposed to be having done and I'm not having them done. And one, actually, my social worker where I go to, she, one, is on the island, so she said that she would take me when I make that appointment and pick me up. But that shouldn't be, this is a service that's offered. Obviously there needs to be another ambulance service to open, we need that in this state, we have people that take dialysis everyday, I'm sure those people are number one on their list to take them from home to their appointment, plus doctor appointments.

So I don't know if anybody else has had any problems with this? Or used this service? But, and no one calls you to confirm.

LINDA WARD: We will definitely take that when we meet as a group because this is not, we've heard it at another forum this week that I was at, same sort of complaint.

CLAUDIA CINOTTI: They made me stay in the hospital, I couldn't believe it. Over hand surgery.

LINDA WARD: It will be in the testimony and we will make sure we figure that out and if anybody from any of the state departments here has any other connection they can do, that would be helpful.

CLAUDIA CINOTTI: Housing. I am trying to get up to the area where my son is at, being on disability, it's difficult to save any money. And I've had two cars that, older cars, this last one I just got in September, and if anybody knows anything about cars, the rear seal went so somebody showed me how to do it to keep it, I have an ex-husband, we're taking his car, which sounds like the transmission is going. We did the bus at the beginning, went from -- to Cranston to Eleanor Slater, we did the bus. But it's an all day affair to Zambarano, hour and a half from Newport, whatever time you get up and when you get to the city, we have to wait an hour and ten minutes for the number 9 bus. They knocked it down to that one bus in the afternoon. The bus used to go to the hospital, they stopped doing that. Then we get on, downtown Pascoag, go on a flex van and get there, ten after 3:00 and it's only an hour and 45 minutes and we have to be back outside to catch that van and I get home at 8:00 at night. So, now I have this issue coming up with my car, and it's like, and I want to get up there, move up there, and they're all

for the elderly and disabled. One place pushed my number back. I said why am I back to 48? Well I told you the elderly come first. I'm not getting anywhere. There is one place I am interested in. Talked to somebody later, and I also heard in the past, correct me if I'm wrong, that if you're on disability, they would move you at least once, my social worker looked into it last year. No. I need to be near my son. He is doing what he's doing because of me. He did nothing at the beginning. Twice for yes, once for no, he was in a vegetative state. That's because of me and his father being there, it's so important.

LINDA WARD: Again we heard from the folks, there was a forum at Zambarano actually on Monday and the folks who live at Zambarano talked very much about transportation as an issue. They also talked about their need to, those who are ready to leave the hospital not being able to get housing. So it's kind of a recurring theme that we're hearing. And we'll, I'm sure, that historically has been on the top of the list.

CLAUDIA CINOTTI: I'm in a handicapped home because I was going to take my son home in 2003, the accident was 2003.

He needs medical care. Sometimes he spikes high fevers like over 105. He needs hospital care, I can't take care of him at home, and everybody, there is nobody left. The family, everybody disappeared. Granted CNA third shift but they can call last minute and say they're not coming and we're older so it's not about me or his father, it's about him. Who is going to take care of him if we pass away. He has to stay where he's at because there is a lot of activities and it's increased his mind being there.

LINDA WARD: Thank you. The next person is Annette -- I'm not going to say it.

ANNETTE BOURBONNIERE: Yeah, the, a different aspect of transportation is what was on my agenda. We have had a problem in Newport with unsafe crosswalks. And we in fact did have a fatality, a gentleman in a wheelchair right across the street from me. This is really unnecessary. The department of transportation has been to Newport, supposedly to address the issues around the main intersection at bell view and memorial. Unfortunately, people with disabilities were sort of cut out of that meeting because we couldn't attend and the sound feed cut off so we were totally cut out of that. So things like audible traffic signals, stopping all traffic to make sure that, because it's an intersection where there are always cars moving. If it's not straightforward, it's turning.

So, there are always, always cars moving so they need to actually stop traffic for pedestrians there. It's really unsafe. So everybody avoids that intersection with the light because of how dangerous it is. Then you go to the next crosswalk down and that unfortunately is where this gentleman was killed. So, we really need audible traffic signals, we need them all over the state. I don't know why we get away without having any audible traffic signals in the state, in Newport county at all. I think there are a few in Providence, but in general, we do not have any at all. We have none to speak of in the state.

Which I think is really dangerous. And we need to really examine our intersections with what is going to be accessible for everybody, not just the person that can make that 20 yard dash.

Because not everybody can. And more and more people cannot. And I think that in general, all people with all disabilities need to be one voice here. So that was my main thing. I would like to add something to the other transportation issue that she had, which is, emergency transportation, car breaks down, you got AAA, no way to get home. I have had to pay \$150 for an ambulance to get home when my car has broken down. And it's not possible any more to even get that. So, we do need some kind of emergency plan. Fortunately I have a new car so I'm not worried immediately. And the third thing is state buildings, why are they not made to be accessible. It's not called DHS any more but whatever it is called, the new one here on valley road. There are no van accessible parking spaces. There is no automatic door openers. It's a state building that serves people with disabilities. Come on. Please. And it's a new building. It's a brand new building.

LINDA WARD: Are you getting this, as well?

ALYSSA GLEASON: I am.

LINDA WARD: She is from the Governor's commission and a staff member, as well. State buildings and accessibility is something the commissioner pay a lot of attention to. We just did, one of the committees just did a review of some of the state buildings and I don't think this is one of the ones pointed out as a problem. Good to know.

ANNETTE BOURBONNIERE: Probably because if it's a new building, it should be built right but it wasn't at all. Getting in there if you're in a wheelchair takes quite an effort to just get in the door.

CLAUDIA CINOTTI: Can I add something to that? Why did they move and there is no bus on that road for people on disability that can't afford a car. And it's a mental health clinic also on that road. And RIPTA was going to put a route on that and they didn't.

LINDA WARD: I can't --

CLAUDIA CINOTTI: That's not accessibility all the way around the clock.

FEMALE SPEAKER: We can get a flex bus now for valley road, I'm not a hundred percent sure but that was supposed to be --

FEMALE SPEAKER: Well I doubt it with the times and everything, there are so many people using the services, like you said more and more people.

LINDA WARD: But I think, again, it becomes, the Commission has the ability to have some input into when they're looking at doing spaces, what is the design and where is the location and again, this is a prime example of one that Alyssa will bring back and obviously the testimony will bring back as a concern.

NIALL TARRELL: I've just been to that building today. When I did get in (inaudible), I am not fully accessible either, too high, there is no easy way to, and there is no privacy whatsoever. So, a failed building, I suppose.

LINDA WARD: Sure sounds like it. I'm going to Niall?

NIALL TARRELL: It's a general question to all of you. I have been living in this country now on and off, six months here, six months in the UK, came back, in the UK. I also strongly believe that people with disabilities -- I believe that people with disabilities should be treated as an asset for the state, encouraged to play a full part in the life of the state. After this, my fourth year, I have seen not much sign of any impetus from the state to actually encourage people with disabilities and people with employ to bring them together. I do feel quite strongly that needs to be more proactive response from the state encouraging businesses, business owners, to achieve full accessibility, best practice accessibility wherever possible and should be encouraged at every level, from the earliest education up to the oldest population.

And every activity that we carry out should consider achieving accessibility wherever possible. And as was said about human services, this is a brand new building, it should be absolutely fundamental when that building was designed and put together, accessibility should be an integral part of its design and the staff should have been trained in how to deliver that accessibility. Everyone was very kind, very helpful, they were having to work their way around at failure to achieve accessibility in the first place so they were having to overcome and not very well the poor accessibility of that building and that is repeated time after time after time. Especially in Newport. Quite a few buildings in the state I have been to, steps to an entrance of a brand new (inaudible) even if it's a single step, sidewalks not wide enough for a portable ramp, these are all basic design principles the state should be having a say. So when the buildings are put together and designs them, the state should be actually enforcing the basics of good design at every level. Most of the buildings built, it's very hard to go in -- to say, oh (inaudible) our budget if we do that, we're bankrupt. Don't give them the excuse any more. Make certain it's done

right in the first place. Then they haven't the excuse of the extra cost. The extra cost if you do it from the ground up is very small, you end up with a much better building. They also need to promote that.

They are just increasing the number of potential clients by at least ten percent. Not just people with disabilities, not just handicapped people but their friends, their relations. Every time you turn away somebody in a wheelchair from a restaurant you probably turnaround three of their friends or relations at the same time so I think the state should be pushing hard to encourage all businesses should people have a disability as a resource, not a burden upon the state.

LINDA WARD: Thank you. Anybody else want to speak that -- well first of all who did not sign in yet? And then, if anybody else would like to speak? Yes, your name?

FEMALE SPEAKER: I'll sign in. I always appreciate the voice that the people looking for wheelchair accessibility bring forward. And I would encourage them, also, to start using terms like wheelchair accessibility, mobility, disability, to give that specific thing because I have found that they have such a strong voice that people seem not to understand that there is another very serious disability and you're seeing the result of the inaccessibility by me losing my voice and it could become a life threatening experience for me. I have asthma, very serious asthma that is triggered by irritants, the medical term is gas, smoke, fumes and vapors with irritant properties. For ten years I have been asking for very, very basic accessibility. When I came into this room, I tried to find a place that was non-fragranced, I couldn't find one in this whole room. So you're experiencing the result of the lack of accessibility for me. It's not a desire to go into a restaurant with a step, it's, I can't even go to a disability forum because I could, well, you're seeing, I'm having airway obstruction, hyper responsiveness right in front of your very ears.

So you're getting to experience what happens to me. So you can imagine the lack of accessibility for me. I can't take a bus. But where this becomes very, very serious is in housing, in the ten years that Linda and, well there is, none of the regular people here, you're all new to my testimony, in ten years, I have asked for accessible housing for breathing disability. This is not new information.

Secondhand smoke, third hand smoke, meaning that which lingers in the walls, and the carpet, they don't go out, I can't live there. Now I have to worry about secondhand marijuana smoke, you know, I mean, I can do everything that I can to make an apartment accessible to me but it goes, it disappears because it's anything in a SSDI range, assisted (sounds like) range, means you're in a multifamily in this state unless you have some connections and there are some people that have managed to get cottages and section 8 home ownership, I haven't had the strength, I haven't had the ability to persist to get those things. I have no assistance. You see what happens to me when I try to have my voice heard. Okay? I can't go to the hospital, I can't take albuterol, avoiding these irritants is the most important thing for me. The apartment complexes in this area are all smoking. Even the tax credited, the section 8 affordable housing choice options are smoking. They have carpets, they have gas stoves. They have gas washers and drier hookups. They have fluorescence lights. They have all kinds of alarms and electronic things that effect people that have, environmental susceptibilities. I have asked for, I call it HOPES, people with asthma that have life threatening health consequences like you're experiencing on me now, or that get headaches from fragrances because even a forum like this is not made accessible for us.

They have done it in other jurisdictions. They've done extreme housing remediation in other, built housing for people that need these types of accommodations. Here, we can't even get a building, a type of a unit that will take a section 8 portable housing choice voucher that at least has a garage separating it from another unit.

CLAUDIA CINOTTI: Say that again because that's where I live.

FEMALE SPEAKER: I know, you said that. So, ten years is a long time to be asking for basic survival needs. I can't go to, the times I have been rendered homeless which has been multiple is unsheltered

homeless. I can't go into a shelter where people are predominantly smokers, it's coming out of their pores, their clothes, I can't be in a place like that, I just can't do it. Now I don't have a back up. I had to sell my van, I had a camper that I used to, when the smoke got too strong from other units, I used to go, I mean that was my first experience with the disability community here is I said it's too cold for me to sleep in my van and HUD is paying and I'm paying for rent in this unit. That was ten years ago. Please, you know, let's bring some intelligence around here. Around this. I mean, American lung association says when you can breathe, that's all that matters.

LINDA WARD: We have the Commission has sponsored, last, I think two or three years, legislation that would require any affordable housing development to have a minimum of one unit that would meet that need.

It's not even gotten a committee hearing. So, as we move forward, if we can, if again, that becomes something out of the forum that we pursue, it will require a lot of work on the part of everybody to have the General Assembly and the state, the extent of the problem, the impact on folks. But it is something, I think it's two or three years we've introduced it. Because your testimony does drive it home.

FEMALE SPEAKER: I'm not certain that a one-unit -- if it's got --

LINDA WARD: Oh no, it was -- taken in mind previous testimony around what it needed to look like.

FEMALE SPEAKER: I guess I bring up the same question I brought up for ten years. I have made myself available. Nobody understands this issue as well as I do because I've met other people. I have sat, back when I was able to get around more, I sat in some of the General Assembly things. And basically was laughed at because the people that they had been listening to is not an asthmatic, she has some kind of something, and she's a smoker.

So, hello, how can you consider this a credible person, a smoker who is saying I need all these environmental controls, talk to an asthmatic, talk to me. This is the first year I didn't bother to put together research because nobody has listened.

Maybe you have, but what good is it? Look at how sick I'm getting and it's getting worse and it's not getting better.

LINDA WARD: Well, we will definitely bring this back. Obviously, in the testimony, but also make sure we bring back to Bob the willingness for you to be more involved in how we go after getting this legislation to move forward.

FEMALE SPEAKER: Nobody has ever contacted me, for ten years.

LINDA WARD: Have you signed in yet?

FEMALE SPEAKER: I will.

LINDA WARD: That will help.

ANNETTE BOURBONNIERE: I don't know if the program still exists but RIPIN was running a program that, they were going to all of the various public housing developments doing studies and looking at ways to make breathing (AB) it was totally for breathing and asthma, and they may have some information on where you can go and find something. Because I know they were doing that a couple years ago.

FEMALE SPEAKER: What's RIPIN.

ANNETTE BOURBONNIERE: Rhode Island parent information network. I know it sounds like it's just for kids but this, they were going into elderly housings.

FEMALE SPEAKER: And so, I do understand that Jim Reid (sounds like), director here worked with the American lung association back in 2005 to bring asthma, you know, whatever, understanding to this area. But guess what, okay, fine, they're not smoking, okay, they have carpets, they have gas stoves, they have, you know, adjacent walls, so, what helps me general -- what helps a child that might grow out

of it is not the same. It would be like saying to you that, but there's only one step there, so deal with it. I've seen you get out of the pool, deal with it. It's not the same. So I pressure comment.

ANNETTE BOURBONNIERE: But they might have more resources for you. I'm just saying that it's worth checking into that, checking into RIPIN to see if they have some other resources. As far as Newport housing authority goes, there is no smoking allowed in any of the buildings at all any more, whatsoever.

And accommodations are often made for people who need special stoves or special other equipment. So, it's worth looking into.

FEMALE SPEAKER: But they don't take the portable section 8 housing choice, that's a project phase (sounds like). The portable section 8 housing choice voucher which someone who needs to be able to move easily.

ANNETTE BOURBONNIERE: I don't know. I'm just throwing these out as, to try to be helpful.

FEMALE SPEAKER: No, I appreciate it. But understand I've beat my head bloody with this matter for years, I've talked with the parent information network, I've talked with all of these organizations. The bottom line is as I said before, the tax credit properties that do take the portable voucher are all smoking. They have no nonsmoking. They have gas stoves.

PANEL MEMBER: So you have a voucher?

FEMALE SPEAKER: The portable.

PANEL MEMBER: When you call the (inaudible), they don't take the voucher?

FEMALE SPEAKER: Been on their wait list for ten years they don't take the voucher, it's a project phase so you get in and it's accessible to you and you need to move, you have to get on another wait list for the project.

Projects are, I need the portability.

PANEL MEMBER: You've been on that list ten years?

FEMALE SPEAKER: It's my only life saver is the portable.

PANEL MEMBER: That would be practical for you then.

FEMALE SPEAKER: I don't know, I looked at it years ago and it seemed like it might.

PANEL MEMBER: Just connected by the garage.

FEMALE SPEAKER: It seemed like it might. That's what the disability -- what's his name -- the other one that works for him, Tim Flynn, he came out to my place in 2004 and that was his only offering to me, but it doesn't work.

You cannot opt into a project.

CLAUDIA CINOTTI: They only have, there's only 15 units and quite a few of the units are group homes.

LINDA WARD: Okay. Well, we will, as always I'm sure this will be on the radar for us to attempt to move forward with.

FEMALE SPEAKER: I, mean the community development organizations, I've been on their wait list, you know.

CLAUDIA CINOTTI: When I move you can have mine, it's a one bedroom. Chain, chains, chains, chains.

FEMALE SPEAKER: They can't enforce not smoking. So it's like I'm sorry, you can enforce it in other states. Why can't -- you can enforce it in the project based section 8s. It's like, work with me.

LINDA WARD: Well we will make this, again, a priority. We have for the last couple of years. Two or three years, so we will work on that again. So, again, did anybody not sign in?

And then if anybody else wants to speak? If you could state your name.

SUSAN NIAZY: I'm Susan Niazi, I've spoken to you, Jodi, I have a cognitively impaired brother, senior citizen, lived in Pennsylvania his entire life and was able to hold a job and earn money that was put into an IRA.

Lost the family home in Pennsylvania so brought him here to live with us in Middletown.

He does not qualify for Medicaid because of the IRA. However he is clearly disabled and my concern is that while he was accepted in the state and qualified for services, which we were very happy to do on a personal day service, because he is not getting, if I'm saying this correctly, matching federal dollars, he was being dropped by the state. Now my concern is twofold, one, will he continue to be able to receive the services he is receiving. What happens when I die, I'm older than he is (inaudible), continuing active. And that I'm not asking for services and I'm not asking for money more than we have right now, it's just that if we should have a change, who will stand up for this man? Who will be there? Jodi you assured me he would continue to be carried by the state but I hope I would get that in writing where now the only thing I have in writing it he has been terminated from eligibility in the state. And that's very concerning to me because at any point that should change. So I would like to know why that decision was made and apparently is continuing without regard to the needs of families with aging siblings or children and then isn't there a way we can keep him in an active (inaudible) if an immediate change occurs, a social worker can step in and be active on his behalf? And the second thing, you really touched home with me when you were talking about the transportation issue because as I go back and forth from valley road dealing with my brother's issues, I have met several people standing outside or walking down valley road to find a bus down at Shaws and I have personally transported people because I was shocked that a bus doesn't take them there so I just wanted to add my voice to that because I've seen the same thing.

LINDA WARD: Maybe when we go to an informal -- you can have a conversation, but I think one of the things we have heard in the past is that good communication is really critical no matter what service system someone is in.

(inaudible) that legislatively, but it's good for the department representatives to hear and be able to bring it back to the department.

SUSAN NIAZI: Thank you.

INTERPRETER: Can everybody please speak up, I'm having a hard time hearing people. Thanks.

LINDA WARD: So, I have Jamie...

JAMIE LEHANE: I'm Jamie Lahane, CEO of Newport county mental health center here in Middletown, serves Newport county, I'm here not speaking as a professional tonight, I'm here speaking as a family member. I have an adult son that had a major psychotic episode his freshman year in college. And I thank God that he, because of good evidence based treatment and support has been symptom free for about, in recovery for about eight years now. I'm also a caretaker for my adult sister who is both blind and has serious behavioral health needs, as well. And what I'm here to talk to people about is the fact that it has not been publicized that in this budget, as you know, funding for state mental health care in Rhode Island has diminished horrifically over the past five years, been reduced by 8 million dollars until this current budget in which in one stroke of the pen this year's budget cut ten million dollars, so that's 18 million dollars, but ten million dollars alone was cut out of community mental health services effective July 1. Who is impacted by that are people like my son and my sister.

Thank God I had evidence based treatment, my son as a freshman in college, and because of family members that knew what they were doing were able to get him the supports, the case management and he graduated on time, didn't miss a beat and if you know anything about the current developmental research on serious mental illness, it's keep those young adults on their horse doing their independent

living, and he is functional disabilities are minimal now because of that. What's just happened is that on the Aquidneck island alone there are 140 people with serious mental illness at my agency alone that require additional case management services that are no longer funded for them.

These are not people with means to pay. These are low income people that just don't qualify for Medicaid so as an individual adult means they make about \$17,000 and they're just getting by.

They no longer have any funding for service.

They are now fortunate that they have health insurance so they have a doctor which is wonderful and we support that. But what people don't know about health care reform is that the kind of comprehensive wrap around services that somebody with a disabling mental illness or substance abuse problem has is not covered by commercial insurance or a large number of folks are on Medicare only and that's my sister.

She is disabled on Medicare, she worked for 25 years of her life. And was very functional until she became ill. She can't get additional case management and other services because Medicare only covers a doctor's appointment, the pill, and a therapy session. Folks with serious mental illness need supported employment to help them get back to work, they need supported housing so they are not homeless, they need medication and case management. We actually deliver medications to folks when they're in a relapse period where they can't take their own medication, keeps them out of hospitals, out of our emergency rooms and more importantly, keeps them well doesn't only impact them, it impacts many families like me and I didn't see one article covering what was a tremendous cut for a whole group of folks with disabilities here in Rhode Island. Largely went unnoticed. Right now, state of Rhode Island pays for no state dollars for mental health care. The only dollars that are paid for mental health care are for community mental health care is through Medicaid and if you don't qualify or get a little bit too much money you're into what's called flex, you have no coverage. We continue to provide services here but our budget isn't able to be sustained the way it is. I'm really not talking about my agency but every mental health center is under duress in Rhode Island and we know there is well over a thousand people in service right now that will not get the level of care they need and there are thousands more as you know that have -- we aren't able to do what a community mental health system was designed to do. I don't want to take up more time; I don't think there's much you can do. There is a family member from a brother of a client at the Kent center in Warwick that if you go on the Kent center.org there is a petition, there is over 500 signatures of family members already, if you don't mind going on that web site, you will see it's clearly marked on the front page for the Kent center to at least add your name and think about it when you come to vote next election.

This was just a real travesty that's gone under the radar. Thank you for listening.

CLAUDIA CINOTTI: I go to your center. And I have been going there quite a few years.

And I got one therapist and she must have stayed with me maybe three months and then she said, well I'm leaving, I have to go somewhere else. And I have a social worker that basically acts like a therapist. But, they're not, two people, you know what I'm saying, when you have a crisis. The way my life is with my, what I have, what I deal with, with my son, not easy. And I haven't gotten back to a life for me. I just had a breakdown like last week and I called and my social worker was out. And so it's too bad for me. I've been to the hospitals, these hospitals too many times; I already know what to do so I stay in my home rather than going through the drama of going to butler.

JAMIE LEHANE: Just having to use a hospital isn't enough. If there is more I can do and we can do, please talk to me after or just call me.

CLAUDIA CINOTTI: All right, thank you.

MEREDITH SHEEHAN: Linda had to step out, anyone that had not indicated they wanted to speak but would now like to? Okay, well why don't we take a few minutes, and maybe let some people connect privately, and then we'll reconvene when Linda is back.

Probably five to ten minutes.