

# Public Forums to Identify the Concerns of People with Disabilities and Their Families Testimony



**July 21<sup>st</sup> - July 25<sup>th</sup> 2014**

Prepared by  
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## Public Notice



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 24<sup>th</sup> anniversary of the Americans with Disabilities Act (signed on July 26<sup>th</sup>), 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 21<sup>st</sup>, 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 21<sup>st</sup>, 2014, 4 - 6 PM**

Woonsocket Harris Public Library, 303 Clinton St, Woonsocket

Hosted by Seven Hills Rhode Island

**Tuesday, July 22<sup>nd</sup>, 2014, 2 - 4 PM**

Warwick Public Library, 600 Sandy Lane, Warwick

Hosted by the Ocean State Center for Independent Living

**Wednesday, July 23<sup>rd</sup>, 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 24<sup>th</sup>, 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 24<sup>th</sup>, 2014, from 4 - 6 PM**

Charlestown Chambers, 4540 South County Trail, Charlestown

Hosted by Perspectives Corporation & National Multiple Sclerosis Society RI Chapter

**Friday, July 25<sup>th</sup>, 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](mailto: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 RIdc to get to and from the public forum, tell the RIdc 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 RIdc 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.

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## Part One: Executive Summary

This year, twenty agencies sponsored a series of public forums across the state of Rhode Island to hear the concerns of people with disabilities and their families. The forums took place from July 21<sup>st</sup> to July 25<sup>th</sup> 2014 in honor of the anniversary of the Americans with Disabilities Act (signed on July 26, 1990).

The public forums serve as a chance for citizens of Rhode Island to voice their personal concerns for themselves and their families. The main concerns found at the 2014 public forums were: healthcare [22 comments]; accessibility and independent living [20 comments each]; transportation [18 comments]; and education/employment [13 comments].

Healthcare was the most often concern raised at the forums. Long term care was the top concern [5], followed by affordability and insurance [4 each], behavioral healthcare funding and case management [2 each]. All the remaining topics were spoken of once: attention deficit hyperactivity disorder; dementia; durable medical equipment; Medicaid; posttraumatic stress disorder; and staff shortages.

Accessibility and independent living were tied for second place. Topics relating to accessibility included: sidewalks [6]; government [5], parking [3 ]; recreation [2]; and business, multiple chemical sensitivity, rest rooms, and voting [1 each].

Independent living topics were transition planning [4]; then affordable housing, developmental disabilities funding, and Supplemental Nutrition Assistance Program [3 each]; followed by adaptive housing [2]; and then co-payments, police & people with autism, recreation, supportive housing and the use of the Supports Intensity Scale [1 each].

The fourth category of concerns was transportation, included; RIPTA bus service [6], LogistiCare/medical transportation, and Ride van service [5 each]; then organ donor designation on non driver IDs, and recreation [1 each].

Education and employment was fifth; job training [3]; and accommodations, college loans, competitive employment, discrimination, IDEA, job coaches, navigating the systems, job opportunities, the Sherlock {Medicaid Buy-In} Plan, and SSI income limit as a barrier to employment.

## Part Two: Community Concerns and Recommendations

The Public Forum sponsors will be meeting in October to review the testimony identify the common concerns and develop recommendations to address each for presentation to the Commission on December 1<sup>st</sup>.

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## Part Three: Testimony

### Monday July 21, 2014 Pascoag

KATHLEEN HEREN: That's our panel, we thank you for being here today. Nobody has listening devices or needs assistance with anything like that somebody told me. The purpose of the forum is to get input from people in the community with disabilities and from that we take it back and try to get resolution to problems people have in the community. If you look at the booklet and turn to the first page you can see the different things that have been accomplished by these forums when they were held. And what we're here today to do is not really to solve any problems. We're here today to have you talk and tell us what your problem is and then the people on the panel will take it back and try to work through those issues for you. There are three people that have signed up to speak and if anybody wants to use the microphone when they're speaking I'll walk up to you. We've limited the time you can speak to ten. I'm looking for my other paper. When you get up to speak, including the panelists, state your name, your organization and your city and town. But if you're one of the people in the audience, when you speak, just state your name and where you're from, what hospital or community. So I want to begin, so we'll have enough time. All right, the first person that signed up to speak is Robin Dolan.

ROBIN DOLAN: Good morning, physical therapist -- Zambarano, and in regards to, my question, my statement is in regards to the patients we service and the clients that need service in the unit. One of my biggest problems is when a low-income client is looking to get Transportation provision of services on the rehab spectrum; the transportation availability is extremely limited. Often not (inaudible) and or hour and a half/two-hour delay. I have one community-based client that leaves her house at 9:30 in the morning to be at a 12:00 class and not picked up until 2:30. The issue for us as rehab providers in this setting and in other settings is also the availability of independent opportunities in the community, whether it's through a TBI center (sounds like) such as (inaudible), trying to get clients into handicapped housing and the length of time a person has to be on the list and how quickly you Housing can start that process, it seems extremely come some. In addition to that, the services are not clearly established for those people who have disabilities as to where to access, in one particular setting, what is available to them when they're independent in the community, or attempting to be independent in the community. Thank you.

KATHLEEN HEREN: Thank you. Would any of the panelists like to ask a question? I have a question, what transportation are you using.

ROBIN DOLAN: The particular client at the aquatics class originally utilizing Ride then LogistiCare (sounds like), that person out of twelve visits attended four because the LogistiCare never showed up or would be extremely late or in actuality, called at the last Transportation minute and canceled. So this person was missing appointments on a regular basis. I actually called and she made a change to another option, whether it's -- it's an ongoing problem.

KATHLEEN HEREN: If you want to call my office on Wednesday morning, I'll help you with the problem, I'm working with the Lieutenant Governor on the issue with the (inaudible). Dennis Arkin (sounds like). I'm sorry, Denise Arkin (sounds like).

DENISE ARKIN: Oh, no, I didn't want to testify.

KATHLEEN HEREN: Ron. Hi Ronald, how are you?



RONALD BRITTAIN: Hi. (inaudible) long I have to be (inaudible), and .

Transition

KATHLEEN HEREN: Is that your question?

RONALD BRITTAIN: And I would like to -- when I have a chance. Okay?

KATHLEEN HEREN: Are you talking about being discharged back into the community, out of the hospital, is that what you mean?

RONALD BRITTAIN: To Florida because I have family.

KATHLEEN HEREN: Well, we have our discharge planners here from, discharge planning for the alliance and a social worker.

JACQUELINE RAMBONE: Hi, I'm Jacqueline Rambone one of the social workers here and Ron we do discharge every three months (sounds like) remediating view and talk about it and I would like to refer you to your social worker to talk to her about the plan. If you do have a discharge plan in place for that, okay?

RONALD BRITTAIN: I really want to leave bad.

JACQUELINE RAMBONE: Right, and we do discharge planning so we can address that with you later, after this is over, okay? Okay?

KATHLEEN HEREN: The next person is, is it Gayle? I can't understand the writing. Gary?

GARY WITMAN: Hi.

KATHLEEN HEREN: Hi Gary.

GARY WITMAN: I'm Gary -- live in Providence Rhode Island and I'm President of Rhode Island Chapter of the United Spinal Association. First of all -- (inaudible), second of all there seems to be a real need for people, handicapped people, don't understand why it is the way it is. Couple comments, first of all one of the things I would like us to do is to see if we can get

Accessibility

our legislators to make all sidewalks handicapped accessible. When I lived in the city of Providence I can't get off my sidewalk and I think it's that way for most people with handicapped disabilities so I would like to -- our legislators to make it mandatory for those sidewalks throughout the state be accessible for those who have a handicapped disability. Generate tens if not hundreds of jobs with tremendous career opportunities. That's the first thing. Second comment is I developed the spinal cord injury in 2010 (inaudible) Narragansett. Ran an emergency department for 17 years, since my injury I have been completely black balled from practicing . No one will hire me with a disability. And I would like to see our legislators to be forced to make it possible for those of us with disabilities to continue with their lively practice. (inaudible)

Employment

KATHLEEN HEREN: What was your specialty?

GARY WITMAN: Medical oncologist internist and emergency room pharmacologist.

KATHLEEN HEREN: Thank you. I think the best thing I could do is tell you that, the information on you and I will go and speak with Dr. Fine (sounds like). Have you talked to him about this issue.

GARY WITMAN: (inaudible)

KATHLEEN HEREN: All right. I will do that. Does anybody else want to -- you have another one for me? Dan Andrew Coury.

DAN ANDREW COURY: I'm not going to -- supposed to talk about but I was just thinking

Housing

about a way to improve for people in wheelchairs, I'm not in this -- I'm not paralyzed, just don't have prosthetic leg on, my -- had leukemia and got paralyzed and the wood shop he used to go to at (inaudible) high school, wheelchair ramp free of charge, credit hours for the high school, they got credit and built a beautiful wheelchair ramp.

And that would be great for people, give kid a chance to participate in helping someone so that they can see what it's like for the disabled people so that when they grow up, they're tomorrow's future, they would be a little more sensitive and helpful to disabled people.

KATHLEEN HEREN: So you would like to see high schools initiated to workshops or the technical schools or something like that?

DAN ANDREW COURY: Projects for a wheelchair ramp or something, elevate to get to a second floor. The wheel chair ramp was at the (inaudible) angle, instead of 35 degrees you have to do 30 degrees, enter up gradually and pull itself up, the wheel chair ramp and then added electric power vehicle on the side with the battery charger, the generator so he was well taken care of when he was living there but he passed on about ten years ago from the leukemia finally took over. But I think that would give high school kid a great chance to help disabled people and would help them understand more. This was a drunk driving accident and it would make them think if they had a chance to see me speak -- him in his wheelchair, the ramp in his yard, it would help them think, sensitivity of other people's feelings and what it's like for them, their decision in life. That's really all I have to say.

KATHLEEN HEREN: I don't have any influence with the School Department, does anybody here? Anybody here think about somebody they could contact.

DAN ANDREW COURY: Barrington is where I'm talking about.

KATHLEEN HEREN: I'd like to give the idea to the School Department, in general.

DAN ANDREW COURY: Yeah, that would be great.

KATHLEEN HEREN: Doesn't have to be just Barrington.

DAN ANDREW COURY: Yes.

KATHLEEN HEREN: All right, thank you. Anybody else?

ROBIN DOLAN: As rehab providers working in this system, one of the things we -- our population is changing in regards to younger age and people such as Dan. We do have barriers is we get them to a certain level within the confines of this facility and they may be looking for community reentry and one of the things some of these individuals may be able to be employed as you so clearly indicated and one of the things is we don't have access to vocational rehab services and a mode to have that available on a transition process for individuals here who may need community reentry.

Employment

KATHLEEN HEREN: Thank you. Anybody else want to ask a question or make a comment?

DAN ANDREW COURY: I have one comment. I was going to go back to CCRI, I can't get up on the city bus because they're so high off the ground with the air shocks so like the short bus RIPTA provided, \$4 each way, it's a little lower, I could probably get in that one but for a regular city bus, it's not accessible for me because I have a fake knee and a fake leg so when I try to like put my good leg -- something like that, I can't get on the bus. I want to (inaudible) state ID about five years ago I had to get a ride there, he's not that safe of a driver so he almost -- (inaudible) on the way. These buses, I don't know, -- down and back up again but I can't get on the bus.

Transportation

KATHLEEN HEREN: Anybody in social services department, would they be able to arrange transportation in any way?

DAN ANDREW COURY: I used to go to Roger Williams College when I had my good leg but the one I have now I need crutches with it. It's not like, it doesn't walk as good as an old fashioned one. It's supposedly state of the art but I have a fake knee with a brace right now so 70 percent of my weight goes on my bad knee and 30 percent goes on my stump, on my prosthetic leg and I wanted to make -- make like (inaudible)

Employment

things like that and I, like Roger Williams College I could do, it's accessible but that's an expensive college and I don't like want to take out that much of a school loan. When they do have services, I already checked on it about ten years ago, they were going to (inaudible) to go to CCRI, more than I needed. So have to carry a lunch to get some food before school and that would have been great. But I just, little bit too smart and mature for junior college, I felt insulted they treated me like a tenth grader (sounds like) so I tried to go back to Roger Williams but I couldn't afford it. If they could get some kind of a certificate program like at Roger Williams College, it costs like \$10,000 for a management certificate.

KATHLEEN HEREN: Social services here so I'm sure they're making notes.

DAN ANDREW COURY: I have no way to get to CCRI except for the short bus. This is a new operation five (sounds like) years ago, 90s, and I'm still paying the school loans from 20 years ago. So I guess junior college is -- financially. But I'm a little bit too smart for it.

KATHLEEN HEREN: Okay.

JACQUELINE RAMBONE: Your social worker, Danielle, that is something you can work with her on and look into going to school if I understand correctly, you would like to do that and transportation would be an issue, there is something through the ORS program offers rehabilitative services that she can help you look into, as well, okay?

DAN ANDREW COURY: Well, would it be -- training or regular school loan?

JACQUELINE RAMBONE: I believe, if you were to go back to the community, then you would be allowed to keep a certain amount of that income, yes.

DAN ANDREW COURY: Okay. Thank you.

KATHLEEN HEREN: There seems to be somebody else coming in. Is that somebody that -- we'll wait a minute.

KATE BOWDEN: Good afternoon, everyone. While we wait for some more people who may testify, I just wanted to let you know that the Rhode Island Disability Law Center have materials about election season, we encourage everyone to get out and make their voices heard through voting this year. I have the materials that, to assist people with voting deadlines and information about voter IDs so help yourself to those, I will make sure there are some at the table and we are also available for trainings, for different organizations, you can contact us through west net (sounds like), so, get out and vote.

FEMALE SPEAKER: Brett would like to speak. This is Brett Roy (sounds like) and he has something he would like to speak about.

BRETT ROY: (inaudible) and I would like to speak about problems we're having on third shift Healthcare with nursing availability. We're getting only one nurse for a whole floor most nights and it's kind of causing a dangerous situation. I just want to put that on record, that's all.

KATHLEEN HEREN: Okay. Talked to the right person here. Is there something you want to say? No? You just came.

MALE SPEAKER: I don't know if this applies to what you are' talking about but I used to go to East Bay Mental Health Center in Barrington and I -- back in (inaudible) ran for Senator (sounds like) or something and he said the budget had to be cut and that is an empty shell [of] what it was from 1985 through the year 2000, I used to go for drug counseling because I was a (inaudible) and the thing they used to do in restaurants where I was from was cocaine and I had a severe addiction and I went through and beat it, now, 15 years straight without even a beer or wine cooler or nothing, I'm just a straight person. But, the budget was cut so badly that all they do is -- he they're not even there for counseling any more. I used to go for like, they

had like a one-on-one buddy system for people that didn't have much interaction with the community years ago, and I would sit and talk to my counselor about the problems with my family life and work and school.

KATHLEEN HEREN: We'll have somebody on the panel look into that for you, okay? Do we have some more people coming in? This is Debbie (inaudible), she would like to say a few things.

FEMALE SPEAKER: I (inaudible) become available and -- out there (inaudible)

KATHLEEN HEREN: So your basic request so to learn a new transportation through Ride program? Okay.

KATHLEEN HEREN: (inaudible) has decided he would like to say something.

FRED DESLAURIERS: Hello my name is Fred (inaudible) I would like to address a problem that we have been having up stairs on 2 (sounds like). Shortage of nurses (sounds like) and I was about to get my -- a buzzer would ring -- and drop the handle on the (inaudible). They are under staffed. The nurses. One nurse on third shift. I think it's --

Healthcare

KATHLEEN HEREN: Is it just eleven to seven?

FRED DESLAURIERS: It's most -- it's happened about three times when I was getting my meds (sounds like) and there was only one nurse on both sides and she had to stop what he was doing with my care. I realized she had to help someone else but it's not good.

KATHLEEN HEREN: All right, I promise you Fred, I'll look into it. This is Chris. Hi Chris, how are you? Would you like to speak?

CHRIS BURR: I had a problem about two weeks ago, there was a helper that refused to do what I say, she (inaudible) because I'm handicapped, she said, you're not handicapped, I have a wheelchair and can't stand up. Anyways, she just (inaudible) halfway. I need help putting the brakes on, it just went on and on and on. I had to go to the bathroom, she wouldn't let me go. I wind up urinating in my bed and she's laughing her head off at me. I want her fired. This just goes on and on. People that actual will I have a handicap. I mean if I didn't have a handicap I wouldn't be here I'd be driving a car or something else, but because I'm paralyzed I can't do what I used to do before. I had a stroke. And it just inn fewer rates me.

KATHLEEN HEREN: Is this a particular shift?

CHRIS BURR: First shift in the morning.

KATHLEEN HEREN: Okay. I'll look into that. I'm the -Ombudsperson- for the state hospital, the staff (inaudible).

CHRIS BURR: Really humiliating.

KATHLEEN HEREN: I promise you, I'll address that. This is Casey, I'm going to bring him a little bit further up so you can see him. Okay, .

CASEY DuBAY: Hi. I just wanted to bring up the, with the, the sidewalks around the building, this building in particular, are like horrible. I'm trying to (inaudible) -- and I have fallen on my face going around the building twice already and personally I'm more concerned about people in like electric chairs because when those fall, they're like bricks, they fall hard and people can get really -- me, I'm just like falling out of my chair. But I'm just really worried about a lot of patients because the sidewalks are absolutely horrible. And I tend to pay attention but you can pay attention and still miss things. Like I said I've already fallen twice.

Accessibility

KATHLEEN HEREN: Where are the sidewalks located they're the worst?

CASEY DuBAY: All around the building.

KATHLEEN HEREN: Just a matter of needing to be repaved?

CASEY DuBAY: Yeah, I think, dug up and redone, the whole thing. If somebody wants me to, I could show them specifically where later on at some point because that's where I'm most concerned about.

KATHLEEN HEREN: We have people in administration here and I think they heard you.

CASEY DuBAY: All right.

GARY WITMAN: (inaudible) about the sidewalks -- this is something where disability community can really make a meaningful improvement (sounds like) in the state. Again, if we can employ -- dozens or hundreds of individuals can re-establish our sidewalks, we can really do something meaningful with the community and we're the smallest state in the country, there is no reason we can't be the first state in the nation to really take some consideration (inaudible). I would like to encourage all of us to write letters to Senator (inaudible), Senator Reed, Senator Whitehouse, Congressman Cicilline, I really encourage them, recognize the need of the disabled and enhance our sidewalks and our curbs throughout the state. Thank you.

KATHLEEN HEREN: Thank you. Anybody else here that is wanting to make comment that hasn't been heard? Anybody?

ROBIN DOLAN: Another statement, I guess. Often at this facility we have the availability for Transportation sports groups for the residents that reside here however there is no availability for them to get out to events in the evening by virtue of transportation issues. Is anyone aware of any other sports group that may be willing to come into the facility in the evenings so they would have access to potentially participate? The other statement would be whether there were other support groups or disability counselors available for some of our residents that could potential will I have the possibility for community reentry and yet we may not have all of the information available. So we have experts here, it would be very helpful for us to assist in having successful reentry program.

LISA KLINE: Sorry, my name is Lisa Kline, occupational therapist here. It would be nice, Transition community reentry is really a very big umbrella. There are so many different facets to that and I think that the residents really do not know what to ask or what to advocate for, for themselves. There may be a program and I don't know if there is, but if there is an opportunity for -- already living in the community with a disability that can be matched up with somebody who is on the (inaudible) for potential discharge, to provide the support, provide the guidance, provide that, to help them navigate once they get out there. So again I don't know if that already exists.

KATHLEEN HEREN: I know it exists with some of the wellness programs and I know they are trying to work that into some of the integrated care programs but I'm not sure, are there people up there that would know most of the answers to this. So, we'll see if we can get you the answer. All right, anybody else that would like to speak? This is Gary, he would like a chance to speak.

GARY CHERUBINO: Hi. My name is Gary Cherubino. I think the state of Rhode Island, I've Accessibility been through other states and seen how better roads are and how the ramps are for the handicapped. And I came here three months ago, three days, excuse me, and I know this building is old, but, I've seen some people have some hard times. So, I know they're working on (inaudible) and -- we have like more access ramps to the building and going out of the building. Not these old wood (sounds like) ramps with nails and, I

see people going off on stretchers (sounds like) and ambulance drivers getting cuts. Chris did, maybe Danny knows what I'm talking about.

MALE SPEAKER: The ramps? That's the angle (sounds like)

MALE SPEAKER: I worked all my life from the blizzard of '78, we all remember that, I have a birth day Saturday, going to be 48 (sounds like), so that's quite some time that things have been going on. But, I think if the State House filled in these potholes in the road and saw the other drivers go through tires or rims or, I've seen cars that got all smashed because of these rims on cars, I used to do mechanics and what it is, you would be driving along and all of a sudden, bang, you pull over, your wife (inaudible) tire, or your spouse, or whatever, and I just want everybody to be safe here. Like (inaudible), she's handicapped, I've seen workers here that are handicapped. So, I think people help each other, it would be a dam good thing. Thank you.

KATHLEEN HEREN: Thank you.

FEMALE SPEAKER: One of the things that would be very helpful is you as the providers Employment within the state, disabled, on a fixed income, Social Security, I think the current limit for them to go and work in the community, they can only make \$700 a month. That rate is like from the 60s and 70s. It really would be very influential if people in power such as yourselves could impact state legislators in regards to looking at where the poverty level is and for someone who may have a, disabled and living on their social security, that income is probably going to be low and they can turn around and allow them to make \$700 a month.

KATHLEEN HEREN: All right, I guess this will wrap this up and I want to thank everybody that came today, our panelists, and I also want to thank people who have spoken, all of the things have been recorded and somebody will get back to you. I will -- yes?

MALE SPEAKER: I'd like to know how I can get (inaudible) I've been here for ten years and Healthcare obviously -- we used to have a treadmill here which was very good because you could get up and walk, they took that away, I would like to see that come back. Figure, if somebody can survive (inaudible) and three weeks later they're walking around, why can't they do that here?

KATHLEEN HEREN: All right. And again, I want to thank everybody who attended today and I'm sure, I know the ones that spoke here will be addressed. Anyone want to say anything before we close? Rory?

PANEL MEMBER: For people working with disabled there are new rules and regulations that Employment allow people who are working to earn more money than the \$700. The Sherlock plan and the (inaudible) allows people to work, the Sherlock plan and the Medicaid buy in, it's an under-utilized program in our Medicaid program but people can earn up to \$35,000 (sounds like) per year and not lose medical benefits, might get a zero check but they have to be enrolled in the program. Wonderful program. But it is a way for people who are disabled to get back to work and earn and keep more of their income. In Rhode Island, people can only have \$2,000 in savings, 4,000 per couple but under the Sherlock it's \$10,000/20,000 for a couple so there is a push to get more people involved in the Sherlock plan which is the Medicaid buy in plan and more people that are working either through ticket to work or the office of rehab services really need to get -- the Sherlock plan and Medicaid buy in. The problem is its under-utilized -- (inaudible) Martin heads up the Medicaid buy in program, it's a wonderful tool for people going back to work so they don't have to lose all of that money they're working so hard to maintain or their Medicaid.

KATHLEEN HEREN: All right. I've been told we can have an intermission and the panel will stay here until 3:00 so if anybody wants to talk to anybody individually, please let me know. Does anybody here want to talk to somebody individually? They'll mingle.

FEMALE SPEAKER: Question for the Office of Rehab Services.

KATHLEEN HEREN: Would you guys like to...(inaudible). All right then I am going to shut the mic off and they will wander around and talk to anybody that wants to talk. Thank you.

(BREAK)

KATHLEEN HEREN: Excuse me, somebody just joined us and wants to speak for a minute. This is Ellen Kreutler from Accessible Rhode Island.

ELLEN KREUTLER: Hi everybody, sorry I was late -- I'm here representing Accessible Rhode Island. Anybody heard of accessible Rhode Island? Yeah? Couple people have. We are -- in the web site telling about all these great national rehab Rhode Island handicap accessibility, we talk about if there's parking, banned parking, it's clear for people in wheelchairs, are the bathrooms accessible and other features that might be in different places around the state. So you know in advance. You get there and everybody can get in. We do dining, restaurants, almost (inaudible) on there now, I think we just surpassed 900. Place to eat, places to stay. A lot of recreational facilities, we just took a look at all of the beaches again and all of the state beaches now have one or two wheelchairs that go on the sand so you can go relax at the beach. What else do we do? Boys and girls clubs, health and wellness places. We're starting to work with libraries in Rhode Island. If you don't have a computer -- online, we have a telephone number, I have some cards here if people are interested. Web site first of all is [www.access-ri.org](http://www.access-ri.org). List of categories and -- we are starting to do the monitoring facilities, as well so you can make a choice of where you would go, accessible for you. There is a phone number. 401-383-8878 or hopefully soon you can call your library and they can be a resource for you, too. Does anybody have any questions right now? Accessible Rhode Island, great resource. I would be happy to give you some of these. If you want to give us a call, we can mail some more out to you. Would anybody else like one? Definitely, good. Anybody else? Great. Working closely with office of disability health, too. All right, that's about all I wanted to say. All right. Thank you. The more people that know about it the better, if you have any ideas for places you want to know, we'll check it out, too. Okay? It's on the web site. Check it out.

KATHLEEN HEREN: All right we're going to be closing down now because the people that have the equipment have to go to another -- I want to thank you again the staff at Zambarano for setting up this room and putting up with me, my first time and the patients for coming down and voicing their concerns. Thank you very much.

(APPLAUSE)

## 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 themselves. 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.

Healthcare
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 I have had two children diagnosed with two different mental health disorders, one is PTSD<sup>1</sup> and the other is ADHD<sup>2</sup>. The PTSDone 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

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<sup>1</sup> Posttraumatic stress disorder

<sup>2</sup> Attention deficit hyperactivity disorder



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 Independent Living 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](http://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.

Accessibility

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

ELLEN KREUTLER: We made a comment about that, arc Accessible 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 --

Accessibility

and I'm -- it's what it feels like. I just have a few things that 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 \$1,200 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.

Healthcare 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<sup>3</sup>, the DD<sup>4</sup>.

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

<sup>3</sup> Department of Behavioral Healthcare, Developmental Disabilities and Hospitals

<sup>4</sup> Developmental Disabilities

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 if 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.

Healthcare

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?

Accessibility

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 all state 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<sup>5</sup> (sounds like).

Healthcare

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

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<sup>5</sup> Supports Intensity Scale

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 Accessibility 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](mailto:gcd.disabilities@gcd.ri.gov). It was simpler.

FEMALE SPEAKER: I have another question, too. I'm currently intern, doing an internship at 

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 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.

## Tuesday July 22, 2014 Warwick

LORNA RICCI: Hello. Can everybody hear me? Do I need to speak a little louder? Is this good? Well, welcome to the Governor's Commission on Disabilities Public Forums. This is one of seven being held around the state.

There is information on the back of the other locations, should you be a little shy today and not wish to say anything, I hope you will, but if you would like to attend one of the other meetings and maybe have a prepared or maybe have your thoughts together, you may want to attend one of the others so be sure to check the Governor's Commission information at the back of the room. Just a few things. Rest rooms are down, go out the door and down to the right and there are phones when you go out to the left if you don't have your cell phone and need to use the lands line. Speaking of folks we do ask you put them to vibrate so when people are testifying that won't be distracting. I need to read something, something important that tells about today's event. Bear with me a minute.

The purpose is to identify the concerns of people with disabilities and their families in order to assist the state and to develop programs that will improve the quality of life of people with disabilities. After this public forum, after all of the Public Forums are completed, probably in early August, the sponsoring agencies will be invited to review the testimony and make -- excuse me -- and make recommendations. All of this information will be available on the Governor's Commission's or Disabilities web site, probably in November.

Transcripts and recommendations will be printed and sent to state and congressional offices. Yes, this information does go higher and gets to the people that need to see the testimony. And it also goes to members of the General Assembly. So, what you're saying today is recorded. It does get printed and it does go onto, hopefully be seen by people who are making a difference in the state. We would like to get started. Just a few things. The panel are here, really to listen and I am going to let them introduce themselves. They are here really to listen to your testimony -- I'm sorry, I'm standing in front of the interpreter, bad, bad.

Just kick. So I'm going to pass it down so they can introduce themselves, they will just say their name and where they are from and then we'll start the testimony, itself. I have the names of those who have signed up. Please, for those who are hear listening, if you hear something that sparks an interest with you, if you really agree, please take a second and come up, have your name, state your name and all you will have to say is I really agree with what was said about a specific topic. This adds a little more strength to the testimony when it's reviewed, that a number of people agreed with that topic that maybe there needs to be something looked at that's important. So I ask you as you listen, if you do feel that way, please, when we have a break, would like to go to the back and sign in, I encourage you to do that. The other thing, we ask that you keep your testimony brief. That you come up and state your name clearly, if you could spell it for our court stenographer, that would be appreciated. And if you could tell us, just the city that you're from, that helps when the congressional group look over, they like to see their constituents and the kinds of concern that is are in their particular community. So I am going to start here, with Sue and introduce the panel and I thank everyone for coming, will be introducing themselves.

SUE ELEOFF: Sue, from OSCIL.

VINCENT DeJESUS: Hello, my name is Vincent DeJesus, here as the Acting Chair for the Statewide Independent Living Council.

PANEL MEMBER: Hi I'm Elaina Goldstein, I'm here from the Legislative Committee on the Governor's Commission on Disabilities.

GAYLE REID: with the Trudeau Center.

COLLEEN POLSELLI: Rhode Island Department of Health, Disability and Health Program.

ELISABETH HUBBARD: from the Rhode Island Disability Law Center.

SHARON THISLEWAITE-MORRA: Sharon Thislewaite-Morra from the Office of Rehab Services.

SUSAN HAYWARD: Susan Hayward, -- Disabilities State Department of Behavioral Health Developmental Disabilities and Hospitals.

LORNA RICCI: Our first testimony will come from Barbara Henry. Barbara. Right hand side. Would you like to state who you are? Okay. That's fine.

BARBARA HENRY: Hello, my name is -- can you hear me? Hello. My name is Barbara Henry. I am blind, and my question, one of my questions is, when you go to get a non-driver's license at the DMV, I attempted to put on it that I wanted to be an organ donor and

Transportation

they only do it for people who drive. And when I asked them why, the worker there could not answer me.

They did not know why. And so, I was just curious if that could be really looked into because it just seems like a double standard to me. Thank you.

LORNA RICCI: How long did you have to wait?

BARBARA HENRY: That really wasn't my concern, it was more that issue.

LORNA RICCI: I went recently and it was a long time. Okay, next is Susan Donovan (sounds like).

SUSAN DONOVAN: Hello, my glasses are in the car so I couldn't see you all from back there. Thank you, Lorna. Many of you may know that I work as one of the program directors of the Rhode Island Parent Information Network in Cranston. We have a call center called

Transition

the resource center and we get over 5,000 calls a year. However, in my personal life which is start to go clash with my professional life, I am parent of a 19 year-old young woman with autism and a couple things that have come up in her transition to adult hood has special meaning now that I am hearing it at home as well as at the office. But I do feel as though we need to provide more support around benefits planning specialists. I think if we want individuals, especially young adults in transition, to be successful in their, with their plans for employment, that we need more folks that are trained and are accessible to speak with these young adults about benefits planning and the effects. And it would be wonderful if we could have folks that would be available to speak to young adults, even before they become qualified for benefits. So that's one thing that I have noticed she is in need of. And secondly would be, you know, and I hate to use this term because I think this term will morph over the next few years but short-term job coaching

Employment

support. For my daughter, in order for her to be successful with her independent plan for employment, she needs a little short-term job coaching. And it gets a little fuzzy as far as who is qualified for that and who will provide it and who will fund that. But as a parent, and yes I was spying on her at Sam's club yesterday afternoon with my trench coat and dark glasses, just keep that in the room, okay? We have so many young adults with disabilities that have such great potential. But they just need a little bit of support. If we as a state could agree that regardless of their level of disability, that we make employment coaching, job coaching, supported employment available for more youth in transition so that they can meet their goals. Thank you.

PANEL MEMBER: Can I ask a question, is she on Medicaid?

SUSAN DONOVAN: Receives SSI and on Medicaid, yes. We were able to find the job coaching, we were creative.

ELAINA GOLDSTEIN: Sherlock?

SUSAN DONOVAN: No, she has Medicaid because eligible for SSI but when we first -- I said, you know, Kel, I think you'll need a little support.

ELAINA GOLDSTEIN: The reason I say this, job coaching is one of the services under Sherlock.

SUSAN DONOVAN: That's great. We don't have that but that's great.

ELAINA GOLDSTEIN: We'll talk.

LORNA RICCI: I'm glad that came up. If there are situations, I know there are wonderful resources here. If you can just say please see me, perhaps at the break or at the end, we have six people signed up -- unless we have a few more come, we may have a short kind of, like an intermission, I guess, where people can talk to folks at the panel, particularly if you're biting at the bit and have an answer for someone who gives testimony. I ask that you just say, I'd like to speak with you later and then you can really have an in depth conversation and I'm sure it will be important. Maryanne Nolin is next.

MARYANNE NOLIN: Hello everyone.

I'm an adult with a disability, probably had it all my life. It's not a visible disability, you might be able to discern a few things. I won't read anything that I wrote but I wrote something that I'll hand in. On April 30th I testified for a bill 7288<sup>6</sup> before our state [House of] Representatives. It would allow people that are on Medicare like myself to have assistance with paying the \$105 that comes out of my \$700 and something check from the government every month. I don't have a clean, clear-cut and dry like I'm eligible for this and that. And, the biggest difficulty I encounter is getting people in the departments and this would be DHS 

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 and ORS and people that are supposed to be fulfilling the Commission's mission statement, to understand that I don't have the capability of organizing my paperwork which is extensive and has been an issue throughout, shall I say, my career of single parenting. And bringing along a child with a disability, who is successfully employed (inaudible) he's got a job, pays taxes, has integrated into his community. I can remember raising him, 15 agencies that I had to be responsible for verifying the same dam exact information for. So backtrack to now. I became disabled in the early 80s and then walked away from it. 12 years I had some employment. It was successful, I was in a job that was kind of way over my head but I loved. Then I stepped down to a position that would have been an aid in that career. And that wasn't successful. Twice we brought in -- this was a different state.

We brought in rehabilitation counselors to my employer to say, I needed accommodations for this. They chose not to do it, they didn't want to. I left that state. I then came at the offer of my family to live with them, my sister had an injury, and then I became homeless in 

Independent Living
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 Rhode Island. I was at crossroads for two weeks, all I could take, I left. Went on my own in the community, drove around one day, this looks nice, room for rent, found that, did that for five months couldn't afford it but managed a way to do it. And I've been before this Commission two years ago, I'm in the exact same place I was two years ago, the difference is I do have a disability law attorney

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<sup>6</sup> 2014 H 6277 An Act Relating to Human Services -- Medical Assistance

that tries to help me with things with ORS. Where I am stuck is, is my worker moved away in November. To another state. I didn't know that, I just e-mailed her one day to find out such and such and he said, hyper link, here is the supervisor, did that, link didn't work so I called again and the supervisor has been my career counselor. The biggest difficulty is that Medicare does not cover case management services. So I can't get that availability. I've gone to Butler, I've talked with them, I've done extensive resource research. The last thing ORS suggested I do is contact the brain injury group in Rhode Island, which I did and they gave me a couple of referrals. And the woman that could do this service for me stated that she cannot afford to accept the voucher. In April, I had my SNAP benefits cut from -- first of all \$200, to \$184 then \$180 like everybody's. I filed an appeal, fair hearing, to say, this is a little extreme. Somebody, I did a direct link (sounds like) to my workers. I heard nothing back. I called the appellate people in the state, hadn't heard -- I said it's been over 60 days going on 90.

I don't know what culpability or whatever they have at this point. Then I called Channel 12 News because nothing was (inaudible).

Channel 12 News advocated on my behalf. And then I called the -- bear with me a minute. The person who schedules hearings again. So we can give you this date, which she did. And she offered another date, I said, no, I'll take the soonest date I can get because being cut from \$180 to \$105 (sounds like) as you can imagine is extreme. Scheduled for April 22nd. I was dog sitting for my sister that week so special trip over to Rhode Island. So I went to Pawtucket office to have my hearing. And the hearing officer and my worker right away said we'll just take care of this. This won't need to go to a fair hearing. I said, great, because I've been trying to do that. So, they did state that they were at fault for not getting back to me and my request sat in a drawer for a few months. And then she said, well, get your paperwork together and within such and such a time, we'll take care of it.

I said I can do this for 2002 (sounds like) another agency this exact paperwork needs to go through. So I waited until I got it all done for housing. And then brought it all in. One day I picked up the phone and she happened to answer it, a miracle, never happens. Scheduled that, went in, showed her all of my paperwork, she told me, by the way the receipts from dollar tree, you can count those, too, you know, that counts towards your medical -- so she indeed verified I had between \$500 and \$600 of medical expenses including Healthcare hospitalizations, co-pays, medicine and all of it. And \$105 a month for this Medicare which is why I went to testify for that bill which got heard and failed. Now if I live in Connecticut all of this would be covered. My \$105, I know that because my mother has been contacted by her health plan offering to pay that for her. I am kind of looking at going out of state because I don't have the same assets. But it's difficult because my family is here. I don't understand why nobody gets this. I have called every agency in that little book older services puts out. For some kind of creative way to help me, at least, I'm not asking for house cleaning in my house, I'm asking for a specific structured way to organize my bills and so forth, to make it work so I don't have to go through this. Taxes, Food Stamps, for housing, for medical. Now there is this qualified Medicare beneficiary program. I found that on my own when looking through Medicare, I sent in the paperwork for that. That mail didn't get to me, what happened with that piece of mail, when I was in the hospital this year it was opened by one of the residents where I live in the high-rise. When I came back, this thing was sitting in my door, wedged in my door, opened, it was from the state Medicare/Medicaid office. The mail had been sitting down on the banister outside my mailboxes. So that everyone can pick up that piece of mail and look at

it and I went into the people where I live and I said this is kind of a problem, not only is that a federal offence for people to look at mail, this shouldn't happen.

So again a piece of mail I was supposed to get last week didn't come to me and I finally called, I didn't go to my residential Post Office this time, I went to customer service of the United States Post Office. Respond within 24 hours. I said this is an ongoing problem, things are getting miss delivered. Don't you think there could be a box we could put it in so the mail could redo it or I asked my housing people, do you think you could put a note where the mailboxes are that it can be put in the rent drop box. Well, you know what happened one time was somebody's AIDS test got opened, that's how that...I feel like after five years in the system like this I shouldn't be here. I feel like having had to do this for the second time I shouldn't have had to do this. I called my rehab worker and they stated they knew -- they would have a new counselor for me to meet which I will be doing at the end of the month. I don't know why I wasn't sent a letter that my counselor was moved. I don't know why I haven't been able to move on in my life. I have tested and tested at a high level for the last evaluation. I used to teach school. My son doesn't know how to cope with me. I'm not his kid. But I am in a lot of distress. I have a lot of anxiety. And it's not easy to come here. I know you people understand this and it wasn't easy to go to the State House. I chose to tell my story and not read it. The toughest thing I deal with by far is the stigma for having the difficulties I do in my life, bar none, it's the stigma that exists, that, you know, when the rescue people pick me up, they say, what are you doing living here? You can dress better and should be out working. Twice that's occurred. I did not need a rescue, I had a health assessment schedule in my home on May the 1st. And this person who was there to just do a health assessment for me, which, I don't know how that occurred in my health plan, said you're not driving yourself to Butler today, I said I have an 11:00 appointment today, she showed up a rescue. I have refused to pay that bill and I have written my appeal with them. I am spending every day of my life arguing for things in my life that just shouldn't be so. I am an intelligent person, I've had several evaluations over the years. I want action and that's really all I want to say today. I don't want to be told you can't work, you're not employable, that is not true. Thank you very much.

LORNA RICCI: Thank you. Norah DiBary (sounds like).

NORAH DiBARI: Can I just talk about anything? I'm here because I want to thank everyone that's helped me at the (inaudible) and I will say I am having difficulties because I have lost my hearing and my eye sight is not, I've had three bouts of cancer and it seems my medical just doesn't help me as far as that's concerned.

And I have talked to the governor, and I have talked to my mayor and they all say, I'm going to help you, I'm going to help you but no one ever gets back to me to help me and I'm not looking for poverty or anything like that but I'd like to have a little help as far as medical is concerned because it seems every time I go to the doctors it's a co-payment, \$40 or \$75 and I cannot really afford it. Right now I'm only on medical -- Medical Assistance -- not Medical Assistance, Social Security, I'm sorry, Social Security, and I would appreciate if I could get some help or something like that but no one seems to want to help you and I live alone and stuff like that. I have taxes to pay and stuff like that so with all that there, seems like every time, Blue Cross, I pay my payments, but it keeps going up and up and they're taking more out of the medical for me than they were putting in. And I would appreciate some help for it. And I appreciate everything you have done for me. Thank you very much. Thanks.

LORNA RICCI: Thank you. Tara Townsend.

TARA TOWNSEND: Hi, good afternoon.

My name is Tara Townsend, Rhode Island Parent Information Network, Warwick resident.  
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Couple of these things are work related. Couple of personal. But, I think RIPIN follows the whole morale guidelines I am going to talk about today. First thing I wanted to mention was transportation in the state. Again. It is much better with LogistiCare (sounds like), they are

Transportation

working with people and we have gotten some phone calls that they're not providing better rides, better suited rides, they still have some learning to do with sending appropriate cars or vans or what not to the appropriate places. And then also making sure that when they are talking with someone that is booking a ride, sometimes people don't remember everything that they need to say and maybe they could, if they have a log that this person has needed to ride alone before, if there is some other issues that they don't feel comfortable being around other people, those things should be noted and brought up when they're booking the ride and then those rides should be appropriately placed with them. So I did want to say that. And the other thing about transportation is I've noticed a lot of consumers don't want to complain to the transportation company because LogistiCare is booking the rides and also logging complains so they're not comfortable with that. I think if there was a way they could do an e-mail complaint form or contact with another agency to do that, I think more people would send in their complaints because I know that some health plans are still logging a lot of them and consumers just won't call LogistiCare. That's all for transportation. Now, this is more in my personal life, we are noticing a lot of work force issues with the health care industry and now that we have,

Healthcare

more people -- coverage and a lot more people seeking doctors and specialists we have noticed in the pediatric world there are not a lot of specialists that are in Rhode Island and of course if you leave Rhode Island your benefits don't always pay for it because it's out of network. So, for example there is no pediatric cardiologist in Rhode Island and I think that we need to work on a way to find, I guess I incentives for more specialists to come into the state and there are not enough DME companies, as well, not enough vendors for medical equipment and supplies, not much of a choice out here the options are you get orders late or not at all or some people don't supply the correct supplies you need or you can't get a certain kind of diaper even though it's been working for five years, they switch and you can't get that same type of supply again, for, I don't know, contract reasons or whatever, but that's not fair to the children, it's not fair to whoever is getting the services or equipment so I think we need to do a better job in finding or contacting with our DME companies, especially for equipment, as well, because even with equipment, some will sell it to you and the next year they don't work with the equipment anymore and you have nobody to go to if the equipment breaks to fix it. That was one other thing I wanted to discuss. Thank you guys for your time.

LORNA RICCI: Marie Bouchard.

MARIE BOUCHARD: I'm not here to testify, just wanted to speak about Accessible Rhode Island.

LORNA RICCI: Is there anyone else signed up? No?

MARIE BOUCHARD: Well that's great then. Thank you. I'm Marie Bouchard, Accessible Rhode Island is an, a resource for the disabled people of Rhode Island and actually for folks coming in from out of state, as well. With the support of the Rhode Island Department of Health, we have launched a brand new web site, the address is [access-ri.org](http://access-ri.org), and on it, there are roughly, just under a thousand listings at this point in categories such as dining



facilities, restaurants, of course, hotels, beaches, walking paths, YMCAs, museums, all of the places, things to do and places to go. And what we have done is surveyed all of these facilities in five different categories. We make comments and, on the parking, van accessible parking. The front entrance, the main entrance, the bathroom, and the route from the parking lot to the facility. So that people, before they go to a facility or want to visit somewhere will be able to have that information. I believe it's the most comprehensive resource available today. And we're moving on, right now, to do assess mammography centers, as well. We're really excited about what a wonderful resource it is for people and there are listings I invite you to visit and if anyone has an interest in being on the site, by all means you can give me a call.

Thanks. If there are any questions, anyone?

FEMALE SPEAKER: Does it include, does it say if it's a pediatric, like a, for children?

MARIE BOUCHARD: It has, the Children's Museum is on there. There are, it doesn't necessarily say, it's just a list of facilities.

There are many categories, though. And transportation is one of them. You talked about transportation. So, it gives you some schedules and the cab companies that have accessibility.

So it's really a great resource. Thank you for your question. Thank you, Lorna.

LORNA RICCI: I encourage everyone to check it out, it's Access-RI. And it's really a wonderful site for our families, as well. Sometimes families are putting together parties or wish to have everyone meet at a certain restaurant, they can go and make sure that restaurant or that facility is accessible to all of the guest that is are coming, including folks maybe in wheelchairs and definitely need to have it accessible for them. Thank you, Marie. Do we have any more testimony? No more signed up.

Would anyone like to speak?

BARBARA HENRY: My name is Barbara Henry. I recently had to go to court for a civil matter in May and when I went to Family Court on Dorrance street and 

Accessibility
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 went to, I guess the counter, or, to get the paperwork and when I asked for assistance in filling out the paperwork, I was told no. I am not eligible. There is no one here to help me. And I just kept questioning, why isn't there someone here to help me? I mean, I had my cane with me, it's very visible.

And then I also thought, what if I was deaf? So, I don't know anyone else's experience regarding court. But, I was really not assisted at all. And this was for a civil matter. So, I just, I'm very curious if there is someone here I can speak with about this. Thank you.

LORNA RICCI: Thank you, Barbara. Anyone else? I guess this would be a good time to have a little break. We will reconvene as soon as we have any other people signed up to testify. We'll just say we're ready to go back. If you would like to speak with our panelists, you heard where they're from and folks that, maybe mentioned something that you think you can help, please, let's talk and see if we can share some resources. And we'll reconvene as soon as we have anyone else signed up to speak.

Thank you.

LORNA RICCI: Excuse me, we have someone who would like to continue the testimony, someone that would like to speak again. There you go, Norah.

NORAH DiBARI: I would like to talk about the bus transportation. I have had a couple of 

Transportation
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 times, in transportation, and I had made the appointment that they would come take me to the doctors and they call me the day before

and said to me the driver would be there at 8:00 but never showed up. I couldn't go to the doctor but I had to pay the co-payment, happened again the same thing but at least this time the girl said I'll try to make it out so you don't have to pay the co-payment and I want to know, why is it that they say, they're wonderful and they'll do everything for you but why did this happen to me and I missed so many doctor appointments because I don't have transportation to get to the doctors and I would like to see if something could be done or if someone could talk about it. I've talked to the mayor about it. Everyone says they'll help but they don't help me. If there's anything you can do for me I'll appreciate anything. Thank you for listening to me.

LORNA RICCI: Thank you very much. Anyone else?

VINNY DeJESUS: Question. Was this a LogistiCare issue? I was just curious, was this a fumble on the part of the Ride program or LogistiCare (sounds like), which handles medical transportation for Ride?

LORNA RICCI: Was it LogistiCare, or was it Ride that you feel was the problem?

NORAH NOLIN: Ride.

VINNY DeJESUS: Okay. I just wanted further clarification.

LORNA RICCI: Thank you, Norah. Anyone else? Hold on. Karen Perrault. Would you like to come up here, Karen?

KAREN PERRAULT: Sure. Hi, my name is Karen Perrault. I wasn't going to come up and I decided to because, I'm all new at this and I went through ORS, and then I got on SSDI.

Employment

And ORS, they got me hooked up with the Goodwill. And, I have a lot of anxieties, and I, I'm kind of like a go getter, if I feel like I can do something, I go get, and sometimes it's not right. But when I was done with ORS, they wrote a, when I was done with Goodwill, I'm sorry, they wrote an assessment on me. On like the first week I did testing and I did, they wrote that, and the second week I think I went out to Burlington Coat Factory and then I worked in their office. In their assessment, I don't even care, I'll make a copy you can read it but it was like, I know how I am and I like saw, I worked for Ride for a long time. I helped people, they loved me, I'm not trying to brag or anything, I'm just saying I always tried to do a good job. And so, I think that I was overly zealous, that's how I would label myself. But when they wrote the report, everything they wrote was negative.

What it did to me, I'm finding it hard to get a job.

I called ORS a couple months ago, I said I need a job and they never returned my call and it just made me more angry. And the things that they wrote, just really made me feel extremely worthless and that I'm not going to find anybody that will want to bear with me and help me. So, anyway, that's basically what I -- I don't know what to do from here. I don't know, you know, how I can get help but I really would love to get a part-time job. I just wish those people saw my heart more than my -- because I was with a lot of handicapped people so I was helping them and I was doing things and getting a lot done.

But the guy viewed it in a way, I didn't listen to instruction, caused chaos and all this stuff. And I want to be open to receive that, if that's the way I was. But a lot of the things that I read in that report was like, wow, they kind of twisted it or something to make me sound like this person that...I don't know. That's all I'm going to say, I guess.

LORNA RICCI: Thank you, Karen. If someone would like to speak to Karen later, maybe.

Anyone else? Anyone else would like to testify? No? Okay. I guess we can continue our networking and we'll stop if someone else comes forward. Thank you.

(BREAK)

LORNA RICCI: Hello. We're done. Thank you for coming. I'll see you at the same place next year, probably. And please have a good afternoon/good evening. Bye now.

### 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 legislation (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

Transportation

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 every day, 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,

Housin

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.

Accessibility

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

Transportation

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

Accessibility

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 Commission 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.

Transportation

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

Employe

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

Accessibility

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

Multiple Chemical Sensitivity

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 backup. 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

Independent Living	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
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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.

Healthcar

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

Healthcare

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 [KentCenter.org](http://KentCenter.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.

## Thursday July 24, 2014 Bristol

RICK COSTA: It's 4:00, let's get started. Welcome to the Governor's Commission on Disabilities Forum. We are proud to say that this forum is being co-sponsored by the Rhode Island Statewide Independent Living Council.

There's a couple of things I have to state before we get started collecting any testimony: I'm told that I have to tell everyone where the restrooms are. I believe if you go out the door to this room and just go right slightly and walk straight, you walk right into the men's and lady's rooms; make sure you enter the appropriate one. And, I'm also told that I'm supposed to tell you where the public phones are, and I don't know if there are any these days, so I have no clue where they are. But, that being said, we if do have anyone who is deaf or hearing impaired, we do have interpreters here and CART services, and we have assistive hearing devices for those who need them. See Alyssa, and she will give you whatever's necessary for you to be able to take part in this forum.

So, why are we here?

Well, we're here so we can identify any concerns that a person or persons with disabilities and their families may have. But, the purpose is to be sure that these concerns are used to form any type of legislation or policies to be able to enhance the lives of persons with disabilities and their families throughout the State of Rhode Island.

So, before we introduce ourselves, I do have to tell you that as a panelist, we're here to hear your concerns, and to ask any questions if we're not clear, so any questions to clarify what your concern is. We're not actually here to get into a full dialogue with everyone.

But, just keep in mind we only have several people, we'll be here for two hours, we only have several people signed up to speak, so, you know, I'm supposed to be able to time everyone.

I don't think that will be necessary. Just keep in mind that there are several others that do want to speak. So, I'll start with the introductions, and we'll move down the panel.

My name is Rick Costa, I'm the executive coordinator for Rhode Island Statewide Independent Living Council.

GRACE PIRES: President of the National and Federation of the Blind of Rhode Island.

DEB GARNEAU: From the Rhode Island Health Department.

JOHN VALENTINE: Rhode Island Department of Human Services.

BRIAN ADAE: I'm a staff attorney with the Rhode Island Disability Law Center, which is part of the national protective and advocacy system for folks with disabilities.

VINCENT DeJESUS: My name is Vincent DeJesus, acting co-chair of the Statewide Independent Living Council. I'm sorry, Acting Chair.

RICK COSTA: What happens with the testimony that we will receive today? The testimony will be collected after all the Public Forums are completed. They will be reviewed, and all the information will be documented and sent to your state legislators, both on the state side and the federal side, and hopefully draw some legislation, again, policy change, to, again, enhance the persons with a disability in your families in this state.

With that being said, I think we can take our first speaker, which is

ALYSSA GLEASON: Barbara Henry.

BARBARA HENRY: My name is Barbara Henry. I have a few concerns.

My first one is with LogistiCare and Veterans. Veterans, right now, can't be dropped off at the VA, and that's a huge issue. And I was asked to bring that up today so that could please be explored.

Transportatio

BRIAN ADAE: May I ask a couple of questions? Am I correct there was another transportation provider prior to Logisticare?

BARBARA HENRY: It was Rlde.

BRIAN ADAE: Is there any particular segment, folks with mobility issues, or across the board?

BARBARA HENRY: It's across the board, but it does impact people, definitely in wheelchairs, so I was asked to bring this up because they're having huge problems getting to the VA.

BRIAN ADAE: Do you have any idea of numbers, or what localities they may be coming from?

BARBARA HENRY: I don't have numbers, but I was told if they have 30 percent service connection, then they're eligible to get the ride to the VA. So, that's where it is conflicting.

Something where the ride doesn't appear, or they're being told, "No, there isn't transportation available," or it's delayed, late.

BRIAN ADAE: What happens? To your knowledge.

BARBARA HENRY: Well, with LogistiCare you have to have 30 percent service connection, and then a lot of the patients, it's just causing a lot of confusion. They're not being told accurate information. So, and if they were part on LogistiCare, I don't know if they still have ADA, Rlde services, but the VA does not provide for every single patient, you know, they'll pick you up, drop you off, VA Services.

GRACE PIRES: These are medical appointments, correct?

BARBARA HENRY: Uh-huh. But you have to have 30 percent service connector.

GRACE PIRES: So how did this change? This is LogistiCare's rule? How did it change? It's a medical appointment. I don't understand why it would have changed.

BARBARA HENRY: I don't have all the details, but I was just told that a lot of people are not getting to the VA.

VINNY DeJESUS: I'm sorry. I was just going to say about the LogistiCare, I was going to add, I do know what she's talking about. One of the many people who stopped using it, even though I use Rlde, it is a mess up, totally. As you see, I'm using my walker now, and for purposes of, like sometimes I don't have control if I can use the walker or if I have to use the wheelchair. For instance, Rlde, I have a wheelchair, and they always have it set up as "wheelchair," and I know LogistiCare will come with a van. I know it's not just me, it's happened with many other people who use wheelchairs and they can't get to their medical appointment which causes a co-pay.

BARBARA HENRY: They'll show up with a taxi, and they need a van.

VINNY DeJESUS. It's not even really a taxi.

BARBARA HENRY: Well, a lot of the patients who use wheelchairs rely on LogistiCare. They'll say, "Technically, we showed up," but they don't have the proper vehicle to transport the patient.

BRIAN ADAE: Brian Adae from the Disability Law Center. We have heard from a number of different sources, as we understood, we don't have a complete picture, but some of the services provided by Rlde are contracted out with the VA at this point in time, or fairly recently were done, and there have been difficulties.

MAJORIE McBRIDE: My husband goes to the VA every day on Rlde. Marjorie McBride. My husband uses the Rlde van every morning and every afternoon to go to the VA Hospital; he doesn't have any problem. He's in a wheelchair, and when the van isn't available, they send a handicap accessible taxi to take him there and bring him home, through Rlde. The VA, itself, does not transport people in wheelchairs, except between the VA Hospital and their eye clinic

and hearing clinic, which is, I can't remember the name of where it is, but they will transport them from the hospital to there. But they can't transport them back and forth.

GRACE PIRES: When he goes to the VA, is he going there for a medical appointment, or is he going there for other reasons?

MAJORIE McBRIDE: For both, and he pays \$4.

GRACE PIRES. He's going under ADA, not medical appointment. I think the people going for medical appointments are having issues.

MALE SPEAKER: That's correct.

GRACE PIRES. He's paying for it. They don't care where you go, as long as you pay your \$4. That's my understanding.

MAJORIE McBRIDE: That's not true. I don't know if they do it anymore, but they asked what his appointment is and when it is. Sometimes.

PAUL DELPAPE: But he, excuse me, if I could interject here. My name is Paul, if his visits are every day, he's paying way too much. He should only be paying \$2 if it's a medical trip. If it's a medical visit, it should be only a \$2 charge.

MAJORIE McBRIDE: Nobody ever told him that.

PAUL DELPAPE: Well, I'm telling you.

RICK COSTA: I think medical was contracted out to LogistiCare. I think RIDE is doing ADA. It's \$4 regardless. Even if it's medical, it's still \$4.

PAUL DELPAPE: Well, the thing of it is, how did LogistiCare get into play here? I talk to Diane Chappel at Ride, they supplemented it out. Since I'm speaking, I might as well tell you a little bit about a mishap I had with them. I made an appointment to see a doctor, and I'm waiting, you know, supposed to be there at quarter of 11 and this and that, I waited the 15 minutes, called: "I called a week ago, you said I was all set, had my ride," this and that. "And when I call you say, I was not on the manifest," and Ride said it wasn't up to us, it was up to them, so everybody's blaming everybody. I said, "You know what?"

Don't worry about it, I'll never use you people again."

The other part of it is, I don't know if you're aware of it or not, if you see doctors today, they take it upon themselves if you don't show, they're charging you regardless whether you're there or not. And I was very, very upset when that happened. So, everybody's blaming everybody, and nothing seems to be getting done about it or taken care of. I'll never use it again. I can't afford to throw money around at a doctor's office if they're not there to pick me up. I'm on a fixed income.

VINNY DeJESUS: One more thing I'd like to input. Recently, I started a part-time job, and I would have to go to aquatic therapy, which is pretty much around the corner, for my arthritis in my shoulders and my balance, and because it's going from work to the doctor appointment, LogistiCare won't pick me up, even though it's not even a mile away from my house, and it's probably like two-tenths of a mile away from where I work.

So LogistiCare pretty much started to save people money to go to doctor's appointments. You won't have to pay the ADA fare. It's not saving you money if you have to pay to go to your doctor appointment. It's a Catch-22.

Say you work until four, you have an appointment at five, you're going to miss it because if you get home at 4:30, LogistiCare will be there.

For instance, I had a doctor appointment at four, and they said they were at my house at two. When I called at three and asked where they were, "Oh, we were at your house at two. " I was



like, "No, you weren't, because I was right at my house. I stayed home just so I wouldn't miss you guys." But I didn't send anything up. I just called RIde and told them how they messed up. I didn't even bother filing a complaint with LogistiCare because it goes nowhere.

They take their own complaints, and then nothing happens about it.

RICK COSTA: Before we go on to someone else, you have another issue?

BARBARA HENRY: Yes. The 2800 block in Pawtucket Avenue in East Providence, it is almost impossible to find a bus stop. I don't, I mean, I don't, it's very, very hard to find, to locate a bus stop to know where the bus is, and I've heard the busses go by. I wave my hand, they don't stop, I have my cane with me, and I really, I mean, this is, this can be taken anywhere in Rhode Island, I'm sure.

There's more bus stops that they're just not, they're not visible, not even visible to some of the drivers, and it's very difficult to find a bus stop. So, if that could please be explored, I'd appreciate it.

RICK COSTA: Thank you. Anyone else speaking?

TODD STEALY: My name is Todd Stealy. I just had a couple of quick things. Seems the common theme is transportation again. I will say this, probably 90 percent of the time RIde is fantastic. Always right there. And if you get an actual RIde employee, they're super, really know how to take care of people. The issue tends to come when they do the contract cab work.

Last week I had to reschedule another appointment again, because the cab was an hour and 45 minutes late. I started calling about 15 after, they said give us 15 more minutes.

And then I call back, give us a half an hour. Now, you're 45 minutes and getting really tight on my appointment.

Then it was like, well, you know, maybe we'll get to you in the next hour. So at that point, I call and cancel the appointment and reschedule, and then low and behold, I'm 45 minutes late and the cabbie shows up and demands I get in the car and go. Check back with your office, we cancelled with ride 30 minutes ago.

In all fairness, it seems to be one cab company more than another.

Checker is really bad. Their drivers tend to be rude. I had one tell me, Checker Cab tell me, the driver said, "I'm in front of your house." I said, "No, you can't be, you must be mistake." "Well, why can't you look out the window and see me?" I said, "Well, I don't need to look out my window because I'm standing in my driveway. And though I'm blind, I'm not deaf, I can hear you." And he was five streets over somewhere else. He got offended because in Warren it's called the "loop rotary." I said, "Sir, when we get to the third loop, you need to hang to the right." He said, "How the hell do you know, you're blind?" I said, after I've picked my face off the side of the window four times, "I used to drive because I wasn't always blind, and I kind of know where I am." So, without bashing a company, some of their drivers can be a little rough, to say the least.

We have a new cab company, I will say this, they go out of their way, they've been using to try to make a good way. Everybody has events and things happen, but for the general rule of thumb, the company out of East Providence just tends to have better customer service.

And the only other thing I'll throw in there about the buses, when the RIde computers went down for three days, and the whole thing, my backup plan was to take the bus. On the way in to Providence, it truly was an accident. I was, I didn't want to get close to the street stay on the sidewalk be safe I thought a good idea would be to hold on to the bus stop sign, which was

really good until the bus pulled in, took the mirror off, hit me in the head, the glass broke all around. I really felt bad for the driver, he was a wreck.

Picked up the mirror, swept up the glass, and off we go to Providence. I was fine.

What I really found to be rather disturbing was the trip home. I had never taken the bus, and when we looked at the schedule, going into Providence wasn't any trouble. Get off at Kennedy Plaza. I noticed on the way in it kept saying "stop requested," so I'm like this isn't -- I've got to come up with some kind of plan here.

So, on the way out, I knew they went 114, found the two little streets, the bridges that go into Warren, I basically knew where I was. I walked up to the driver, the stop at Joyce Street, right in front of the bank, is that a hard stop, or do you have to request it? The driver said, "You have to request them all." I said, "Okay." So I stood there and says that's the one, and I don't actually know, in his defense if I said I was getting off or that's the stop I wanted, but my interpretation was he knew I wanted to get off at that stop, and it seemed like we were rolling a little far. I said, "Are we going to make that stop?" He immediately slammed on the breaks, I picked myself up off the floor, and as I'm doing this he says to me, "You have to request the stop." I explained that's what I thought I did. You either have to push the button or pull the cord.

That's how you ask a stop.

Then I said to the driver, "I get it, but if I look out the window I don't see anything, so how do I know where I am as to requesting the stop?"

He says, "I'm sorry, you're going to have to figure out a better way. This isn't going to work. You people have to realize what you're doing." At that point, the conversation broke down and I got off the bus.

BRIAN ADAE: Sir, was that route 60?

TODD STEALY: Yes, it is. 114 that goes from

MARJORIE J. McBRIDE: He's absolutely right. Marge McBride. The cab company, my husband is scared to death sometimes of the drivers when he gets into the cab because they're a little crazy. They aren't on time, and he usually pleads with RIdE to get a van.

TODD STEALY: The ladies and gentleman at RIdE, the vans, do great work. If anything, I think sometimes they put up with a lot of grief from other RIdE passengers. On one occasion I told a passenger he needed to quit. It was a lady driver and he needed to hush. I didn't want this to turn into a RIDE bashing event. I think they do a phenomenal job.

RICK COSTA: Paul.

PAUL DELPAPE: Thank you for letting me speak. I live in Tiverton, I have for the past 14 years, a native of Pawtucket, Rhode Island.

I don't know how many people are aware of what's going on now, but right now Tiverton has, since I believe either June 22nd or June 23rd, has gotten bus service back again. There are three busses going into to the city, and three coming out. Back to Tiverton.

We had a hearing back in, I believe it was March to explain the theory of it and how the bus was going to run and stuff like that. The bus was going to stop at the Park and Ride, and you had to get to the Park and Ride to grab a bus.

With that said, I spoke to, I believe his name is Mark, that night, and of course I was talking about the RIdE program. Basically, he said to me, that the RIdE program would not be coming to Tiverton. So I said I thought wherever the bus service went the RIdE program went also, and he said, "Well, it's not up to me, it's up to the," I believe the initials are the "FTA," I guess stands for federal transportation association (sic) or whatever.

So he said, "Give me your phone number, and I'll call you and let you know the final verdict." I gave him my phone number, and never received a phone call. Still haven't received a phone call from him to this day.

Which, you know, any respect to him I think is kind of rude. He should have at least returned the phone call. I took the time to give you my information, you could have at least returned the phone call.

Anyway, the other issue I have is this RIde program. I think it's a great program, but years ago, I don't know how many people know this, years ago, it was very independent. What I mean by that is out of Pawtucket you had Cozy. Out of Newport you had Maher (phonetic). I think Providence you had Rhode Island Ambulance, and I don't know what Warwick had, but everybody was independent.

So I don't know what happened, but RIPTA said we're going to take over the RIde program and handle it.

You know what? Since they've taken over, as far as I'm concerned, this program has been going down and down and down, and they just keep cutting routes out, you know, here and there, and wherever they please, and it's making it bad for people that, you know, I'm not saying just for blind people, this program is for everybody now, whatever disability you have, which, you know, is a great thing. And that's my gripe. I think transportation should be available for everybody in the State of Rhode Island. Whether you live in Foster, Newport, anywhere.

You know, and of course the thing is, they always throw in your face, "Well, we don't have the money." I think people are sick and tired of hearing "We don't have the money." Sure, we have family, certain members of the family have to work; therefore, they can't be carting, whether husbands, wives, sisters, brothers, cousins, whatever, we like to be independent as much as we can be, and I think this corridor needs to be expanded a great deal so everybody can be served in the State of Rhode Island.

Now, I don't know what it takes, I know one thing it probably would take, somebody would have to propose a bill and the laws would have to be changed to make this program work.

Yes, it works efficiently for some, but not for all. Thank you.

RICK COSTA: Marjorie McBride.

MAJORIE McBRIDE: My husband is an amputee, 100 percent-Disabled Veteran, and he uses the RIde program every day of the week. We don't have any problem with the program at all. They're very good to him.

We have had a couple of problems, so I'm here to represent the problems that he has had.

For those of you who don't know, he runs an amputee support group at the Veteran's Hospital, and he's been on your TV program talking about what he does there. We went to the East Providence Boys & Girls Club to watch two of our grandchildren swim in a swim meet, it's not handicap accessible.

Accessibilit

So I called the East Providence, the town of East Providence, and they said Well, we just put a brand new addition on, and we didn't make it handicap accessible and we don't have to.

I tried to call your office, but all I got were answering machines, so I left a couple of messages. I didn't get any return calls, but I'm here to tell you, if it's a Boys & Girls Club, boys and girls have handicaps. When you get into the building, the men's restroom is up a flight of stairs, the women's is down a flight of stairs. So you couldn't function if you got in there anyway.

And I don't accept that the Boys & Girls Club, which receives funds from all kinds of people, is not handicap accessible.

What they did offer my husband, there were three firemen there, they said, "We'll be glad to lift you in your wheelchair through the back door so you could sit at the pool and see your grandchildren swim." That's not acceptable.

BRIAN ADAE: When you said you called our office, who did you -

MAJORIE McBRIDE: I called the phone book. He's only been an amputee for four years. We're new to the -- when you have a knee replacement and you get MRSA, you lose your leg. We're new to the whole system. The VA has been very good in hooking him up with different things that are available, but I do know this from being the chairman of the committee that built the schools in Bristol, we had to work very, very hard to make sure that all of our buildings were handicap accessible at the same entrance that students went into who were not handicap. I question why this building is not.

The second thing my husband asked me to tell you is that handicap bathrooms do not service him.

They rely on upper body strength, they don't rely on leverage. Even when he has his artificial leg on, he cannot stand up or maneuverer from his wheelchair into the bathroom. It's an issue at the VA Hospital, everywhere he's been, except for the Coast Guard Academy, which happens to have a beautiful restroom. He asked me to mention that.

The third thing is, if you take a walk down Hope Street here in Bristol, it meets the criteria, but I defy anybody to do it in a wheelchair. He can't get to the bagel shop in the morning where I go to coffee. He can't go to restaurants along Hope Street because he can't get there because the slope is too steep.

So a lot of times, there's a soup kitchen on Hope Street, we'll sit, my friends and I sit out there and help people who are handicap cross and come up because they can't do it.

So, those are some of the issues that we're facing.

We are very lucky with RIdE. We're also very lucky we can afford the \$4 each way every day, and RIdE's very good to my husband, but I'd like to take the people in East Providence and strangle them, because that was probably one of the most embarrassing moments he's ever experienced.

BRIAN ADAE: Would you care to speak to me afterwards, if possible?

MAJORIE McBRIDE: Sure. Thank you.

ELLEN CRELLER: I'm Ellen Creller, I'm with a program called Accessible Rhode Island. We have done a lot of assessments on the Boys & Girls Clubs with handicap accessibility.

Done the Boys & Girls Club, YMCA, a lot of wellness center, attractions around Rhode Island, restaurants, we spend days in Bristol. It's very difficult in the old towns.

I'm going to talk to my colleague Debbie about the East Providence Boys & Girls Club. I didn't do that, personally. Part of our work is to get people to understand.

FEMALE SPEAKER: It's my understanding you can't take federal funds if you're not handicap accessible.

They said they just made improvements. Did a whole new front, and I'm thinking have you ever heard of one of those elevators you put in and it brings you up.

ELLEN CRELLER: I seem to recall something about an elevator, I'm not sure if it was in the process of being fixed or something like that.

FEMALE SPEAKER: I would hope. Thank you.

ELLEN CRELLER: But I want to let everybody know about the program, as well. We try to address transportation issues, as well. We have a page, it's a brand new website. I can leave materials. It's very exciting. We're working with the office of Disabilities and Health, as well.

We have dining restaurants, places to stay, branching out into facilities, as well, so people who know what the facility has in terms of handicap accessibility features, and make their choice from there. There's telephone numbers, addresses.

FEMALE SPEAKER: Thank you, I'd like that.

ELLEN CRELLER: I actually wrote my name and number down for you.

FEMALE SPEAKER: Thank you very much.

ELLEN CRELLER: You're welcome. It's visitors to the state, as well, we're continuing the work and if anybody wants to get in touch with us about anything, please do. Are there any questions?

FEMALE SPEAKER: I have one question. I asked the bagel shop why they weren't handicap accessible. If you have less than 24 seats in an establishment you don't have to be; is that correct? I don't know the answer to that one.

ALYSSA GLEASON: No. No. That's not correct. You can talk with me after, too. I'm from the Commission.

But any place you go in that is a place of public accommodation where the public can go into it even if they say, "This is a private establishment," if the public's welcome there, it needs to be accessible. The only time where someone may be able to say they don't have to be and get away with it is if it's a historical building and they can prove it would ruin the integrity of the building by changing things, but everything else should be accessible.

FEMALE SPEAKER: Even in terms of being built prior to 1990?

ALYSSA GLEASON: If they were built prior to 1990 and have done nothing to the building since then, they have been grandfathered in. If they have done anything to change the building in the last 24 years, which most have, they should have used at least ten percent of their budget to make the building accessible.

FEMALE SPEAKER: That's very interesting. I didn't know that either. All those shops there.

ALYSSA GLEASON: Very few places have not been updated at all in 24 years.

RICK COSTA: Thank you. We have no one else that has signed up to speak, but if anybody who has come in a little late or just wants to make any type of comment can do so now. Otherwise, we'll take a break and if someone comes in...

FEMALE SPEAKER: I'd like to say thank you for taking the time to come to us. It's not easy to go to you all the time, navigating Providence and navigating in the wheelchair, it's not always that easy. I really appreciate you came here.

BRIAN ADAE. May I put in a shameless plug about voting? We register. I have registration to vote. If you have moved recently, we have the necessary documents. Add that small piece in there.

GRACE PIRES: Since we're speaking of voting. Regarding voting, there is accessibility for voting. People who have visual or other disabilities that can't use the normal, the ballots, they can use the Automark machine and every precinct should have an Automark machine.

BRIAN ADAE: I'll ask you about that.

ALYSSA GLEASON: The Commission went around in the spring to every single polling place, I was part of that project, they should all be making changes to be accessible. If you go to vote

Voting

in either September or November and your polling place is not accessible, you're more than welcome to call my office, I'll give you my phone number, and file a complaint, because there's no excuse. We've given grant money, so everybody knows, they all should be accessible.

FEMALE SPEAKER: Does that include big hills?

ALYSSA GLEASON: As much as they possibly can, they should. Whatever's necessary.

RICK COSTA: Okay. So we shall take a break. We're all here until 6:00. If anybody else should come in and wants to speak, we'll be here, but right now, we'll take a break until then.

(BREAK)

RICK COSTA: We're going to turn the floor over to Jim.

JIM CARNEY: I wasn't able to get here earlier because the Ride bus was late.

One of the concerns that I had recently with this whole switching around the bus stops in Providence, right from the beginning, I don't know how many people looked into it, but it was a real eye opener, pardon the pun, for somebody like me that's visually impaired. They told you to go to their website and look to see where the bus stops have been moved to and on their website, they had a map with all the bus stops listed, and which busses went to which stop; however, it was a graphic, so my screen reader wasn't able to read it to me. It was kind of like there was no thought given to that.

Transportatio

I was lucky I had my wife, but the problem with that was that even with the help of my wife, she's not familiar with Downtown Providence, so she was looking, oh yeah, the 55 bus comes here, but then, you know, she wasn't really able to tell me where that was.

So it was really kind of an interesting experience going there the first day.

When I got down there, the signage, there was no tactile signage, there wasn't any braille, and the signs that they had, while they may technically have met the standards in the Americans with Disabilities Act, they really weren't accessible for somebody visually impaired. They're on a white background with a shade of red that really was not enough contrast, and I don't think they were big enough for somebody to see.

I brought this to the attention of the one of the supervisors, and they sent me an e-mail asking me for suggestions, and that was as far as it went, as far as I can see.

It was just, you know, we'll send an e-mail, listen to you, but we're not really going to do anything.

So I think the whole thing was done without any thought to visually impaired people. I don't really think that's unusual for RIPTA. They try to meet the standard, but they don't really think about, well, maybe, is the standard good enough?

I personally don't think it is, and I think they could do some things that are really not going to cost them any more money, or if it does, it's not going to be a heck of a lot.

I'll be interested to know if anybody else shared my experiences.

BARBARA HENRY: This is Barbara Henry. I definitely shared your experience. I was traveling last Thursday to come here with another woman that's blind. We were Downtown, we had a supervisor, Karen from RIPTA, and the bus driver let us off in Warren. So, I walked into a building, and I was on the phone with RIPTA and explaining and saying I don't know where I am. I found out it was Citizens Bank, and all I kept thinking of was I'm happy it was still working hours. What if they closed? I had no way of letting the person know where I was or anything. I did not know where I was, and I saw that supervisor again and told her what happened and she didn't really seem very receptive. Very passive.

FEMALE SPEAKER: That's RIPTA for you.

MALE SPEAKER: Sounds like you got my requested stop that I didn't request before he slammed on the brakes.

My only thought on Jim's thought is before they make the changes, I would assume there's policy discussion, and RIPTA gets a group of their folks together. Is there anybody on the committee or even ad hoc that's disabled at all?

ANGIE STABLE: I'm part of the transportation committee, and we had lengthy discussions on how to make things accessible for all impaired. We'll take it into consideration. Barbara's on that committee with me, so she knows.

It's just, oh, you know, trying to pass us off. It's the same BS, different day. I can quote you their response. I know it like the back of my hand. It's just sickening. They know I feel this way so, I'm not saying anything they don't know.

PAUL DELPAPE: I'd like to make a comment, if I could. Paul. We had this ADA Act, American with Disabilities Act, and talk about all the buildings have to be accessible; it's all part of the ADA.

Should be the same thing in transportation. Should make transportation part of the ADA, and seems to me from all the people I hear talk today they do what they want to do and la-de-da, deal with it.

MAJORIE McBRIDE: In defense of all of those people -- this is Marge McBride -- until four years ago, I never thought of you. I never really thought about what you faced every day. I never really thought about not being able to go places and do things, and then my spouse couldn't do that anymore. I started to think about it. It doesn't make it right; it means we really have to do a good job with educating people who haven't experienced it. I don't think we're doing that. I don't know how to do that, I don't have the answer; I'm just telling you that that's how I look at it.

I see the world very differently now than I did four years ago.

So, while it's extremely frustrating to deal with them, I'm getting it, I'm just not accepting it.

ANGIE STABLE: This is Angie, again. You know, I join every committee, write letters, bring up concerns, and Barbara and Paul, and Grace that's sitting up front there. We educate. It's just they're not getting it, or I don't know, do they want us to make a sign, rent a plane, and fly a banner around? I don't know how more clear we can make things.

FEMALE SPEAKER: You hit them in their pocketbook.

MALE SPEAKER: I have a suggestion. Why don't we approach Scott Avedisian, the Mayor of Warwick.

I doubt anybody here is a voter in Warwick, get somebody who is visually impaired who lives in Warwick voting for Scott, and see them as a constituent and approach him and have him do an exercise, or solicit him to do an exercise with some of these people at RIPTA and take them out for a day, put them so they can't see, give them a cane, and say "Here you go."

FEMALE SPEAKER: That's what I said to the people -

MALE SPEAKER: I think that would be an eye opener, again, pardon the pun, but that would really maybe wake them up a little bit if they actually had to experience what the visually impaired person experiences.

FEMALE SPEAKER: I offered our government here in Bristol, which is a small town, a wheelchair for a day to allow them to do their day's work in a wheelchair, and they refused. So I get it, I just don't know what the answer is, but I get it.

MALE SPEAKER: Jim, I would tell you, they've already proven that it works, just what you just said, put them in and they get a better perspective. I've only been blind for a year, by the way,

so I go along with Miss McBride. I didn't know anybody who was blind until I went blind. For 50 years I went around thinking everything was great until somebody turned the lights out.

I would say this, the Ride van drivers, as part of their training; they've had the ocular training. I only found out because I was talking with one. Part of their customer service and they really understand what it's like.

And how disoriented you could get and all the things we know.

The program's already worked because they've done the pilot, but maybe we need to do it with a few of the administrators, probably solve a lot of problems.

MALE SPEAKER: Needs to be the people in management that are setting the policies.

ANGIE STABLE: I think Mark Therrian needs a good dose.

MALE SPEAKER: Can we spin him four times before we send him loose?

PAUL DELPAPE: I'd like to make a comment. Paul. Mayor Avedesian, he is a nice man, and he is on the board. I don't know how far it would go. He'd tell you to go talk to Mark Therrian first. My interests in Mark are not very high, let me tell you.

We had a hearing in Tiverton, like I said earlier, because Jim, I don't know if you know or not, but now Tiverton has bus service, we have three going in and three coming out of Providence on a daily basis, except, I believe, Saturdays and Sundays, it does not operate.

But, as I said earlier to the people that are here, we have the bus service, but yet we don't have the Ride program, and I was under the impression that where the bus service went the Ride program went and I brought it up to Mark and he said they're not going to allow the RIDE program to come to Tiverton because of the bus routes. I said why not? He said, "That's not up to me, it's up to the FTA."

Transportatio

ANGIE STABLE: Federal Transit Authority.

PAUL DELPAPE: To make it even worse, he says, "Give me your phone number, and I'll call you when I let you know what's going on for sure." I gave him the phone number, never received a call. I don't have too much respect for him.

BRIAN ADAE: Brian Adae from the Disability Law Center. One question I had asked when you were talking about that issue earlier:

When you broached with Mr. Therrian at RIPTA, the Ride service, was it within a certain area of where the bus operated in Tiverton, or was it outside of, I'm not sure of how many blocks?

MALE SPEAKER: A point seven-five mile corridor of the established bus route. I can look up the CFR for you.

BRIAN ADAE: Do you know if it was within the corridor, or was he talking just in general that we're not going to go over the Sakonnet River Bridge, period.

MALE SPEAKER: The second thing you said. What I would be asking for as a starter, if the Ride program would come to the Park and Ride where the busses pick up and he said no.

MALE SPEAKER: They have to do that.

MALE SPEAKER: Then somebody better take it up with him.

MALE SPEAKER: I had some problems with him, and he actually quoted federal regulations, and he said there was case law to back up his position. And when I asked him to cite the federal regulations to give me the citations to the case law, I never heard from him again. So, I consulted the American Civil Liberties Union, and they were very helpful, looked up some things for me, and the case law that he cited and the CFRs that he cited, he was wrong, and when I brought that, after a couple of months with no reply, I contacted him again, and I said, "Okay. Here's the CFR that you're talking about." He got back to me and said, "No, no, no. We



don't function under that CFR." At that point, I complained to the Federal Transportation Authority, and they told me, I mean, my case was not settled in my favor, but they alerted him that this guy's right, that CFR that does apply to you.

FEMALE SPEAKER: It's such a small state. Why can't we take care of each other?

MALE SPEAKER: The other thing I want to talk about or mention, Paul here again. You know, nothing for nothing, but, the baby boomers are starting to kick in, and we're all getting there, and I'll tell you, the best is yet to come, because I think people are going to start screaming and yelling.

Why don't we have transportation?

And I want to say one thing right now, is that I want to thank whoever set this forum up today. I think it's a great idea, and I hope this information that has been talked about today and discussed, I hope somebody really gets to hear our concerns, I really, really do.

Because having these forums, I think, is one way that we can be heard, and I hope somebody gets this info and hears us, I really do.

JIM CARNEY: Jim Carney again. Another issue I have, formerly, on Kennedy Plaza, the Transportatio signage was not great, but at least an attempt. I go to the corner of my street, there's a bus stop right there. And I know where it is. I go someplace else until the city, I have no idea where the bus stops are.

Like Smith Street or Chalkstone Avenue, Academy Avenue. There's no way for me to identify the bus stops unless there's a shelter there.

FEMALE SPEAKER: I said the same thing.

JIM CARNEY: They used to have a bright colored yellow band around the telephone pole where the bus stop is. Now, they have a no parking size sign on the poll.

FEMALE SPEAKER: And you can't wave to the bus, they don't stop.

JIM CARNEY: Even if you're at the stop, sometimes they blow by. I've had that happen.

BARBARA HENRY: This is Barbara Henry. In the wintertime it gets challenging -- going back to people in wheelchairs and using walkers -- they're not shoveling. Even people who can Accessibility walk, it's very challenging to get on the bus with piles and piles of snow, and also just sometimes crossing streets there's not enough lights, possibly audible lights to assist a person crossing the street.

JIM CARNEY: I think there's a lot. And the thing that really, this is Jim Carney again, these are easy fixes. It's not multi-million dollar technology; it's some basic improved signage. Vinyl band or something to put around a telephone pole.

BARBARA HENRY: But they could put a chip in that sign, which beeps on your phone or beeps on whatever you're carrying, it tells you you're within 50 feet of a bus stop, too.

JIM CARNEY: That would be great.

FEMALE SPEAKER: Those are simple things to do if you had an App.

JIM CARNEY: That would be great.

FEMALE SPEAKER: They can have an App to play Crazy George or whatever my grandchildren play, and it costs .99. It can't cost much to put a chip in and for you to buy the App.

JIM CARNEY: And then they'd make money out of it.

FEMALE SPEAKER: Of course they would. With your cane or beep on your wheelchair.

MALE SPEAKER: I think the phone would be a great idea.

FEMALE SPEAKER: Listen, if they can, if you can go on the highway at 70 miles an hour and they can pick up your toll reader, they can put a chip in the sign.

MALE SPEAKER: I agree.

RICK COSTA: Barbara, can I ask you a question? I want to go back a little bit. You were looking for the 60 bus stop, you were looking, and the supervisor showed you where that bus stop was?

BARBARA HENRY: Yes. Last Thursday.

RICK COSTA: Would you be able to find that bus stop without that supervisor today.

BARBARA HENRY: Now, yes, it's across the street from the Post Office. Can I say something else, please?

I'm a mom and my son has Autism, and as many of you know, people with Autism tend to wander. And this, I was not even aware of these meetings until a year ago.

Police &

A few years ago my son wandered, he left our apartment in the middle of the night, I did not know, and the police called, he knew his number, so the police found him and called me.

And when they returned my son, Justin, I was treated very, really, really bad. It was really not a good experience, and when I got my son and we got in our apartment I realized the keys were missing, so I said I think the cops took the keys. And the next night, nine o'clock at night, I'm going to bed with my son, after getting over, you know, and someone knocks on my door; it's a police officer. I never called the police.

And he said to me, I said, "Can I help you? Because I didn't call the police."

He said, "Oh, some woman found your keys." I opened up my door and he knew I lived in an apartment building on the third floor. You had to buzz in.

It wasn't like you just walked in the building. And he got up the stairs, I don't know how, knocked on the right door, and when I opened up my door and I said, "Can I help you?" He said, "Where were you? Where were you?"

Like that, really, really loud looking me up and down and just -- and I was in shock because I was like, "I didn't call the police." He was like, "Where were you?" And I just said, "Can I see the keys?" I took the keys, I shut my door, and then I literally had my back to the door and my heart, at that point, was racing. I felt, I was like, I never called the cops, I don't even know how this could just happen.

BRIAN ADAE: Mrs. Henry, what police department was this?

BARBARA HENRY: East Providence.

BRIAN ADAE: About how long ago did this happen?

BARBARA HENRY: About three years ago. I was walking down the street with my son on Pawtucket Avenue, and a police officer came to me and said, "Oh, is everything okay?"

Like a week later. I'm going to be honest with you, I turned around and told him to go (\*) himself. How do you have a right to come up to me, or even -- I never called the police.

I mean, there was no, I mean, he wandered, he was returned, there was no other involvement with any other agency, but after that experience, I wouldn't call a cop if I was dying.

ANGIE STABLE: This is Angie again. They want to stick it to you. I live in East Providence, I know how they are. The East Providence police are known for being bullies. I'm going to share an experience that happened two summers ago.

There was a neighbor -- thank the Lord he's gone -- that lived in my apartment building, and he was not the cleanest person, didn't take care of his dog, such and such things, and somebody

called the police on him and said my apartment number, so the cops, they have a passkey to our apartments and they have a passkey to the main door, so that's how they get in. He comes, opens my door, this is ten o'clock in the morning on a Saturday. I was indisposed. Didn't expect anything, you know, and this cop comes in my door. I was just like, what the hell. I have a scanner, too, I wasn't paying attention, I had it off, and just hanging out on a Saturday morning in your panamas. And he goes, "Where's the dogs you're choking?"

I'm like, "What?" He barged in my house. Then he took my cat. And, "All right. This is a cat. Where's the dogs?"

"Where's the dogs?" I don't have a dog, and I wouldn't hurt an animal.

The East Providence police are bullies, and you can put it in the record, I don't care.

They're not nice people.

FEMALE SPEAKER: Do you have any recommendations about what we can do, other than coming to these forums, to help make change? You've listened to a lot of people.

BRIAN ADAE: Vote.

FEMALE SPEAKER: I always vote.

BRIAN ADAE: So, I'm sorry, generally speaking, as explained is the Governor's Commission on Disabilities, we, as panel members from various organizations, we work for, we are here to listen, and this gets passed along. The transcript is made of these hearings, and the Governor's Commission for Disabilities circulates that to policymakers. Sometimes the issues are identified out of that to the various agencies and will hopefully assist in addressing them. There were a lot of RIPTA issues in here. I know that sometimes, there used to be a representative from RIPTA that isn't here today. Perhaps, that's something that can be addressed.

We can't really answer questions, specifically.

As far as, generally speaking, I think part of it is to go, as some of you do and have tried with varying levels of success, is go to the agencies directly and complain. Like with RIPTA, you're doing that, not working well. Maybe some of the other places, issues with the police, maybe not internally with the police department, but with the city, East Providence. Three years later down the pike is a little bit late, I know, with those problems, but those are the start.

Developing awareness about the resources that are out there to assist.

I don't know if we have any, there is no centrally located directory of resources, but you can begin to look, for example, for Adults with Developmental Disabilities has a number on their websites, she's aware of that.

They also behavioral health -- am I -- I apologize.

JODI MERRYMAN: I'm Jodi Merryman.

FEMALE SPEAKER: I know this young lady.

BRIAN ADAE: There are a variety of places to go.

FEMALE SPEAKER: Once it's put together, is it a public document. The document you put together is that a public document you circulate to?

BRIAN ADAE: The Governor's Commission, we're not from the Governor's Commission, per se.

FEMALE SPEAKER: The information is a public document?

ALYSSA GLEASON: The transcripts will be on our website probably around November, once we get them back and go through them. The Commission will use it to see which legislation we should support and which ones we should be against.

ANGIE STABILE: I'm on the Legislative Committee. Usually I sit at the table up front, since I got here nice and early, no pun intended, it's a joke.

We read through the transcript from each meeting, each forum, from committees: Transportation, employment, housing, and such things like that, and we put together proposed legislation.

Then, basically, shop for legislators.

What that means is, we look for sponsors of our legislation, and then that gets changed through their legislative council and reworked so we can get it through the process.

FEMALE SPEAKER: You testify?

ANGIE STABILE: Excuse me?

FEMALE SPEAKER: You testify?

ANGIE STABILE: Yes, I do. I'm at the State House all the time.

FEMALE SPEAKER: Thank you.

BRIAN ADAE: There are a variety of sources. The Governor's Commission on Disabilities, their website, and the Veteran's organizations, which you're probably just beginning to learn about, too.

FEMALE SPEAKER: As I said to you in private, I will say it in public, my husband didn't expect to lose his leg, there was nobody for him to talk to about what was going to happen in the hospital at all. One of the reasons he has his support group, which is called Stump Talk, if a Veteran were to lose a limb, at least they could come and talk about it and get to understand what was going on, et cetera, et cetera.

And so, one thing I'd love to see this Commission move out to are those hospitals so there are people available to talk to somebody like my husband while he's, when he's trying to make this decision about what he should do.

There was nobody, there's nobody out there.

Do you understand what I'm saying?

RICK COSTA: Thank you all. Any other speakers? Any other comments to be made?

MALE SPEAKER: Jim.

FEMALE SPEAKER: I have a question; I'm the quiet one here. If there's other people who want to make a difference, send a letter, or e-mail to the Governor's Commission on Disabilities?

ALYSSA GLEASON: I'll give you my information now. My number is, 462-0100. I'm at the office pretty much every day, Monday through Friday, nine to four. If you leave a voicemail, I will get back to you, I promise.

BRIAN ADAE: Does the Commission still, as they formerly had, accept e-mail as well. Would there be an address or e-mail address for that?

ALYSSA GLEASON: Our address is 41 Cherrydale Court in Cranston, and the zip for that is 02920.

FEMALE SPEAKER: What's the e-mail, website, where, if you wanted to give testimony on there?

ALYSSA GLEASON: Our website is [gcd.ri.gov](http://gcd.ri.gov), and that has all of our contact information on there, and the e-mail, I'll give you my e-mail. You can send your testimony to me. It's [alyssa.gleason@gcd.ri.gov](mailto:alyssa.gleason@gcd.ri.gov).

FEMALE SPEAKER: Thank you.

JIM CARNEY: I had a question, this is Jim Carney. You had mentioned that they could look at the transcripts of these meetings, and now, does the Governor's Commission draft legislation on issues, or do they monitor legislation?

ALYSSA GLEASON: Both.

JIM CARNEY: Let's say they draft a piece of legislation, is there any way the Governor's Commission can put it on the website that we can subscribe to?

ALYSSA GLEASON: Our website has a thing called Legislative Letter that goes out every week during the legislative session, and it keeps track of all the legislation we have a particular interest in, gives you a summary, tells you the status, and on our website, it tells you how to sign up, and you get that letter every week.

JIM CARNEY: Okay. Good.

ANGIE STABLE: I used to put them together when I interned there, so it's very detailed. And back in the olden days, we used to have to mail them.

VINNY DeJESUS: I'd like to mention something to the lady in the purple blouse, I'm sorry, I forget your name. I'm going to give you a flier for it. I'm from this Statewide Independent Living Council, (SILC), and our website, there actually is a link just for those, it's basically a survey with multiple questions. Our hope is people with disabilities from around the state would take it and get together, and then we pretty much analyze the survey results and bring up the issues to the proper places. So, anyway, that's risilc.org, and I just was hoping to give you that information. I have, actually, on me, if you want. That's one of the flyers.

FEMALE SPEAKER: Thank you.

VINNY DeJESUS: Thank you.

FEMALE SPEAKER: Oh, and you guys are all on it?

VINNY DeJESUS: A few of us, yes. And if your husband is interested, we're always looking for new membership with new ideas, new brainpower. Any time.

RICK COSTA: Any other comments? 5:35, still have to hangout for 20 minutes. We'll take a break, and everybody can go back to conversing.

(BREAK)

RICK COSTA: May I have your attention, please? May I have your attention, please? We have another person that has arrived and would like to speak.

Antonio Silva, the floor is now yours.

ANTONIO SILVA: I'm from East Providence, Riverside, I went to OSCIL, the organization put a ramp in for me. I have MS, they also helped me put in a shower with no tub, it's really low, and a sliding door with it. And they were very professional, very, I can't say enough adjectives to express how I feel about the work and how they treated us, and so if I could recommend them to anybody, I'm going to. That's it. If you have any questions, I'll get to answer them, also. Thank you.

RICK COSTA: Thank you. Thank you very much.

RICK COSTA: Anybody else?

FEMALE SPEAKER: I actually have something to say. What did you say?

BRIAN ADAE: The Ocean State Center for Independent Living?

MALE SPEAKER: Yes.

FEMALE SPEAKER: I just wanted to say that we, it would have been very hard for us to afford to put in the handicap bathroom, one that has a sink that comes down for him, and all the handles and everything, and he was having a hard time with the tub, and we really couldn't

have afforded to do that ourselves. Maybe eventually we could have, but we really were happy to have that done for us. They're a good agency.

RICK COSTA: Was there a waiting list? When you applied to do that, was there a waiting list?

MALE SPEAKER: I didn't get any indication that there was. They said we needed to do it as soon as possible because from the beginning to signing the papers and approving and all that would take about four months, so about June, it was ready to go so they were right on the ball, as far as the period.

FEMALE SPEAKER: We went through that, we called the MS Society, that's who I started with, and they gave me several agencies, and that was one I called, probably the first one I called, and I said you didn't, the ramp they put in, he's not in a wheelchair yet, we use it sometimes if we go on trips or something, he still has one, he's still walking quite a bit, they said they do have the funds to put it in and went ahead and got it put in and of course will be using it eventually. We appreciated that, too.

RICK COSTA: Thank you. Okay. Anyone else? Okay. Go back to mingling.

It's now 6:00, and the Governor's Commission on Disabilities Public Forum here in Bristol has now come to an end. I want to thank everybody for coming here today.

MALE SPEAKER: I want to thank you for coming here, too.

RICK COSTA: Thank you for coming and taking time out of your busy day and expressing your concerns. Be safe on your way home, and I hope that the Ride works out for everybody that's using it today.

## Friday July 25, 2014 Providence

DEB GARNEAU: Hi everyone, welcome, thank you for coming. So, as you know you are at the Governor's Commission on Disabilities Public Forums and we host these on an annual basis in order to hear from the community, to advise some of the legislative initiatives for the Commission on Disabilities. And so we have a couple of speakers that have signed up, but before we get started, there are rest rooms out that door, take a right and the women's and men's is right there. If you haven't signed up to speak, if you can do so, that would be great.

We do have Spanish interpreters here with us today. So if you would feel more comfortable with having the information translated to Spanish as we go forward, please let anyone know, anyone who is standing in the back or myself know and we will accommodate that.

So, the purpose of the forums is to identify the concerns of people with disabilities and their families in order to assist the state develop programs to improve the quality of life of people with disabilities. So, to ensure that everyone has an opportunity to speak, we only have two people signed up right now but to keep your comments short and, so that we have time to hear from everyone. After the Public Forums are completed in early August, the sponsoring agency will review the testimony and prepare recommendations, which will also be posted on the web site by the end of November. So the recommendations and the transcripts will be printed and sent to state and congressional officials and to members of the General Assembly. The recommendations will be used to develop policy and legislative initiatives for the next year or until they are accomplished. I'd like to have the people on the panel to introduce themselves. As they do, we also want to remind folks that the panelists might ask questions to clarify the topic but are not necessarily here to enter into dialogue and to address specific concerns. So, again, I'm Deb Garneau.

MARK DUMAS: Hi Mark Dumas, Seven Hills Rhode Island.

ANNE MULREADY: Attorney at the Rhode Island Disability Law Center.

CARMEN BOUCHER: Carmen Boucher from the Rhode Island Department of Health.

DIANE SIRAVO-MARCOTTE: Office of Rehab Services.

DEBRA SHARPE: Executive Director of the Brain Injury Association of Rhode Island.

DEB GARNEAU: So we have, we're call our first person. And if you can, when you start your testimony if you could just state your name and maybe we'll ask for some spelling, as well.

So, Lisa.

LISA COUSINEAU: It's too much to discuss according to your, what you were saying, right? It's supposed to be brief and not case specific.

DEB GARNEAU: It's okay, we want to hear from you, thank you for coming. If you could state your last name.

LISA COUSINEAU: Cousineau.

DEB GARNEAU: We want to hear specific concerns, what we might not do is have like the panelist answer you back with like, oh try this, try that, give you phone numbers. We might do it off line but as part of the formal testimony. So we definitely want to hear from people that are here and hear what some of the concerns might be so feel free.

LISA COUSINEAU: All right. I have been raising my grandson since birth. He is on the autism spectrum, he has developmental and cognitive delays. He was involved in early intervention. And then when he aged out of that he was to go to the school system in the town that I live in.

Education

Unfortunately, I had terrible luck with the school system for many years and it started right from that time. Right from the very beginning. They couldn't offer

him adequate arrangement for what he needed. At the time I could afford it and sent him to a very private little place, it was like one adult to every two children. And he did fairly well there. But was still obviously, there was obviously some problems and we weren't sure what they were.

So kindergarten rolled around and I was informed by the principal of the school that I would then be, because they don't have time to do his IEP<sup>7</sup> I would be letting it expire. So from that moment on until now, well, no, not until now, I no longer have an attorney, but from that moment on until I was able to get him out of the school district which was the 7th grade and four hospitalizations later, I had to pay an attorney \$200 an hour to get anything from them.

Anything. And it started right from, like I said, right from the beginning, it's ridiculous. He now attends the Bradley Partnership School where he gets the supports he needs. Unfortunately in 2011 he was hospitalized and he was in the CRAFT<sup>8</sup> (sounds like) unit at Bradley which is a residential program. He was there for eight months. And when he left us to go there, he was receiving HBTS<sup>9</sup>, PASS<sup>10</sup>, all of the services from CEDARRS<sup>11</sup> and also on a Katie Beckett

#### Healthcare

waiver, I don't know what happens when you're hospitalized but once he got home there was nothing and I haven't been able to get him those services back. I am currently working with an agency. They have not, it's been months and there is no PASS worker in site and I was told a couple weeks ago that I should look on Craig's list and hire someone from an agency. Like, that won't be happening in my house, I'm not hiring somebody off of Craig's list. I can't do that. How could I be safe? How can I keep him safe? Anyway, he definitely needs staff. I tried to get him involved in Special Olympics, I met with the person in charge of Special Olympics, every place I turn, it is nothing but red tape, red tape,

#### Recreation

red tape. He can't join Special Olympics I was told because they have, what do they call the sports now, it's like an inclusion -- integrated, yeah, you know what I mean. They have that, they have it in my town but the guy from Special Olympics told me he could not join because he didn't go to school in town. Well that turns out, that's not true because the town funds his education so of course he can go. But I cannot, for some reason, connect with the person in charge. So therefore I have this 15 year-old kid who weighs 200 pounds who is very angry and does nothing except play video games. Which, I have limits on that and I have a contract and all the good stuff and it's all falling to the wayside because I don't dare take anything away because I don't have anything to replace it with and I have no funds left. I have used them all. And right now my husband isn't working, I'm not working, there is no money coming in and I'm dishing out 1200 bucks a month for private insurance, which he is on our insurance and also has Medicaid. Recently in May he had a major meltdown, at midnight he decided to, he wasn't going to live with us anymore because the rules were too tough so he takes off, I live on a highway, he takes off, I'm in my pajamas, outside, running down the highway to collect this child. It was a long struggle before I could get him in then he proceeded to bang, slam, break, you know, it was just uncontrollable. And I took him to Bradley to the access center for an evaluation. I don't know that it was the next day because that was Memorial Day weekend and he agreed to go and I knew they wouldn't admit him because he wasn't in crisis at that moment, but I thought for sure that they would do some sort of a, a good evaluation and give me some good recommendations. They did the evaluation, the

<sup>7</sup> Individualized Education Program

<sup>8</sup> Children's Residential and Family Treatment

<sup>9</sup> Home Based Therapeutic Service

<sup>10</sup> Plan for Achieving Self-Support

<sup>11</sup> Comprehensive Evaluation Diagnosis Assessment Referral and Re-evaluation



recommendations were that I was to call NRI<sup>12</sup> and make an appointment with this gal, I'm not going to give you the names, but, anyway, I did this. And I was told from Bradley that I would be able to get, like, there were five things that they thought they could help me with, in home counseling and help with advocating for the paths (sounds like) worker thing and getting services back, different things. So I called them and it wasn't, that wasn't the right person I was supposed to connect with. So then they told me to call this other person so I called the other person, I made an appointment. And I was told I had to take him out of school that day and take him with me, well, that didn't go over well with him, this is a really angry miserable kid and I can't throw him over my shoulder and take him there. So he agreed to go, I told him, don't worry we won't be there long, we have an appointment. We get there, there is no appointment, it's first come first serve. We were then shuttled off to a waiting area where we sat for a couple hours with some screaming toddlers that he has no tolerance for then we see this social worker for two more hours who after I give him every bit of personal information that I really don't care to share with somebody that isn't going to be able to help me, he looked at me and said, we can't do anything. We can't help you at all because he is on your insurance.

I said I don't understand that. He gets care all the time, he's been on my insurance since he was born and it's out of state, it's not Rhode Island Blue Cross. But the deal with that is the Healthcare reciprocating state you live in picks it up and Medicaid picks up the rest. Well this guy insisted that was not happening and I could not get those services and I asked him, well, is there anything you can tell me about any kind of community supports, this kid has to have some peers his own age. No. No, I don't know anything he said. He said if you want you can sign him up for an art program through River's Edge in Woonsocket, then he told me it's a year's waiting list and have I to tell you my son is colorblind, he's not interested in art and if that's all they could do, really, a year's waiting list, we were just in a crisis and I'm telling you there will be another one down the pike and it won't be long. He keeps asking me, when are we going to have a pass worker, I don't know, Aiden, I try and I make phone calls every day.

To make a long story short, well not that short, but he, I was told to contact the gal at Bradley that did the eval, if that didn't work out. So the person at NRI did tell me, he was going to see if he could get somebody from FCCP<sup>13</sup> to, you know, give me a hand. They're the ones by the way that told me to hire somebody off of Craig's list. So I called the gal back at Bradley and I got, I was told she was busy, blah, blah, blah, she'd call me back so a day went by, didn't hear anything, I called back. Didn't call me back.

Somebody else called me back and I was told, and I swear to God, I was told that there's nothing we can do. This is the way it is. Next time he is in crisis, you call 911, they will take him to Woonsocket Hospital, which does not have an adolescent or child psyche unit, I've been there before, they look at you and tell you there's nothing wrong with him because by the time all is said and done the crisis has passed.

And they're not equipped to handle that so I was told call 911 they'll transfer him there, as soon as you get there you can argue with the doctors and advocate for them to transfer him to Rhode Island Hospital where he can then sit and wait until a bed is available and get transferred once again to Bradley. It just seems like a ridiculous amount of money Medicaid is dishing out for him to take a ride and no service. I just feel like I'm dealing with yet again the School Department where everybody is in a reactive mode and nobody wants to do a thing

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<sup>12</sup> NRI Community Services

<sup>13</sup> Family Care Community Partnership

before the crisis. She said well if you don't like that, that's what she said to me, if you don't like then you can take him in your own car and drive him here. I said do you realize you're asking me to get a 200 pound angry frustrated in the middle of a meltdown, into my car and drive down a highway and put not only us but everybody else in danger? I can't do that. She said, well, nothing I can do. So, here we are, about to be the people on the front page of your newspaper, I feel, saying, you know, gee, why didn't these people ask for help. That's what it seems like we do in our society, it's all after. I'm tired of fighting this fight. He's angry, he has every right to be angry. There is nothing, I can't get nothing for this kid.

DEB GARNEAU: Couple clarifying questions but I didn't know if the panelists do as well. Are you involved with the CEDARR program?

LISA COUSINEAU: I'm supposed to be.

DEB GARNEAU: That's where the PASS comes through?

LISA COUSINEAU: They can't find anybody.

DEB GARNEAU: But the CEDARR provides care coordination, supposed to.

LISA COUSINEAU: Supposed to, they come by and update a plan that's not in place.

DEB GARNEAU: HBTS program.

LISA COUSINEAU: Ended in 2001 because, I used to get services through Seven Hills for years. And when he was hospitalized in 2011, when he came home I couldn't get anything back.

DEB GARNEAU: So the HBTS program is supposed to be time limited however it can re-spark whenever there is, you know, increasing need. The pass programs are usually for people who are, know somebody who can, you know, .

LISA COUSINEAU: I'm his grandmother. I live on a highway. My neighbor to the left is disabled and the one to the right has a special needs child. Really who am I supposed to ask, I have no family.

DEB GARNEAU: That's usually what the PASS program is reserved for so there is an opportunity to reignite with the HBTS program. Any --

CARMEN BOUCHER: just for the purpose of trying to document where the concerns are coming from, what school district will you be referring to?

LISA COUSINEAU: I don't think I should do that, they're in so much trouble now.

CARMEN BOUCHER: we're just trying to help and to help, we appreciate you coming here.

LISA COUSINEAU: I live in a really small town and I have to live there, I don't have an option to leave. No.

CARMEN BOUCHER: that's fine. Thank you.

LISA COUSINEAU: I'm sorry.

MARK DUMAS: I have a question for you, are you on a waiting list for either HBTS or PASS.

LISA COUSINEAU: On a waiting list for PASS, on one for respite care for years and said take me off, find someone that can find someone to.

MARK DUMAS: Currently on a waiting list for PASS.

DEB GARNEAU: Because they can't find a worker.

MARK DUMAS: Also sounds like from what you described that needs of your grandson might exceed that at this point in time which would be HBTS.

LISA COUSINEAU: The thing is if he had those services in place I don't feel like he would be as -- he's stuck, he's stuck in the house. There's no sports for him, there's nothing. I can't

even sign him up at the Y, I can't afford it, I've spent every penny I have. I can't do it. I don't know what to do for this kid.

MARK DUMAS: The unfortunate part of that is, there is an endlessly long waiting list for HBTS services across the state. Unfortunately you're not the only one, which is really unfortunate.

LISA COUSINEAU: But he does have private insurance and the information I get from them is just another big thing. I talked to somebody from my Blue Cross two days ago and I was given a list of three or four names to contact for in home services because I do have that on my insurance that I can have behavioral therapy in home for somebody on the spectrum.

And the people that I called, no. One of them had nothing to do with anybody on the spectrum; it was somebody dysmorphic program.

DEB GARNEAU: So, if, unless there are other comments from the panelists.

LISA COUSINEAU: It's just, given information, you're online all day, on the phone all day and you feel like you've done nothing.

Nothing except talking and talking and talking.

DEB GARNEAU: I think we would like, a few of us would like to connect with you individually but we do have others that we want to hear testimony from and I'm sure we'll have a break so we'll be able to do that. Ellen.

ELLEN KREUTLER: Hi everybody, I'm with Accessible Rhode Island, and I don't have a specific problem, I am here to hopefully offer a solution for people using wheelchairs and that sort of thing. It's a web site resource called accessible Rhode Island. And we've gone around the entire state to assess facilities as to handicapped accessibility. The parking, whether the van can park there, and people can easily get out using wheelchairs/scooters.

Whether the main entrance is clear, the route and whether the bathrooms are handicapped accessible, we have a rating system. We've done boys and girls clubs, some other categories, a bunch of health and wellness, YMCAs, a bunch of restaurants, libraries, right now we surpassed 950 places across the state, every town. And we are trying to just get the word out for folks so they know this is available.

I have cards it's [www.access-ri.org](http://www.access-ri.org). And we include accessible places but also places that aren't accessible so families know in advance before they get there. If you don't have online access you can give us a call, the libraries are going to start working with us, soon you can call libraries, hopefully. Are there any questions?

No? All right, I just want to let everybody know.

After that whole story, it's just like...a whole different. Apples and oranges.

LISA COUSINEAU: Sorry.

ELLEN KREUTLER: Oh, please, I was happy to hear about that issue.

DEB GARNEAU: If you could.

CARMEN CALES: Carmen Cales, I'm a parent of a child with a disability, she's not a child any more, sorry, she's 30. So this organization, is it like a resource, if I want to go somewhere I could find out if it's accessible.

ELLEN KREUTLER: Resource online.

It's searchable, it has all different categories, dining, places to stay, things to do, we just updated all of the state beaches. They have beach wheelchairs there now. And a lot of other places. Working with the office of disabilities so everybody can have fun, the whole family can go. And know that it's okay to get in there. We have a little comment section, too. Maybe not

++totally accessible but -- I have cards I'll pass around for everybody. And we also have a brief description on this form, as well. Thank you.

DEB GARNEAU: At this time I don't have anyone else who wishes to speak -- are there others?

CARMEN CALES: I just didn't know what the platform was. My name is Carmen, I am a Woonsocket resident, I have a daughter with -- cerebral palsy, during the years she was in the school system I was very fortunate, she got all of the services she needed and beyond.

Once she finished school, the transition, that was another piece that was a little bumpy. I just Transition couldn't find services that would accommodate her needs because even though she is in a wheelchair and physically she can't do much for herself, mentally she is a very bright young lady and they would always try to put her in groups where the kids her age were very, very mentally challenged. And she didn't fit in that group.

Then the other group, they were physically able bodies so she didn't fit in that group either. So ultimately, she's not home. Several, I would say like three years ago, she decided she wanted to move out. That it was time for her to move out.

Housing She wanted to venture on her own. So I started finding out what was available. And there were some apartments available for people like her.

And, but what I didn't know, when you apply for these apartments you're supposed to apply for services, as well, which, I did not know that and I spoke with United Cerebral Palsy, they were the one that is told me about this place on Phoenix Avenue in Cranston, I applied, 3 years on the waiting list, they called her, she gets her apartment, we spent a ton ever money furnishing it, and once we moved her in, I was just ignorance of myself, my husband and I assumed that she was going to have her services. And that's when the gentleman at United Cerebral Palsy said, no, you had to apply for that but nobody had told me this so three months go by, we tried through BHDDH, her social caseworker. He said no sorry if you didn't apply for it, the state shuns on that because it's like you did it intentionally thinking we were going to give you services, that was not the case.

Low and behold after three months we had to give up the apartment because she wasn't going to be safe there on her home so she's back home. Since then she's been extremely depressed, she's on medication. She is now losing her hair. And all this is due to that. And so, I'm, I've been trying to work with her caseworker. She told me that the only way they would even think of giving her 24/7 services is if my husband and I die, if we abandon her or if we abuse her, if she is unsafe, that's the only way she would get these services. So I guess my complaint is, what is out there for these people like my daughter that mentally, they want so much but because, you know, they're, physically, she's in a wheelchair she can't do anything so for her to really be out there like she calls independent when she really n my eyes she will never be independent but in her eyes just leaving home and having her own place, that's independence for her. So, I just don't understand the system. Right now's', I'm lucky enough that she does have, through the options program, through BHDDH, she does have assistance, I get 84 hours a week for me to hire my own personnel. And so she does have sort of like a social life, they take her out, she does things she wants to do, but still she's at home.

So, like I said, extremely depressed, losing her hair. So she's going through this transition and I'm trying to find out how can I help her get her own place and move forward so that's where we're at.

ANNE MULREADY: Can I just ask you, you said you had, she had gone to live I think in a place UCP served but did you ask other providers if they had any ability to serve her before you chose options? Did you look, were there other providers.

CARMEN CALES: Because I already had in the state these 84 hours they were giving me and maybe it was bad on my part, just assuming the services came with the facility, that I never asked. I assumed the services came with the facilities and once we got her in there that's when I said, okay how does this work, who is going to take care of her. That's when the news came, no, you had to apply for that a long time ago.

DEB GARNEAU: So it was the 84 hours that she still would have received them.

CARMEN CALES: She does have them still.

DEB GARNEAU: She would have received them in her own apartments as well.

CARMEN CALES: She needed 24/7 and the only way the state would take that on is if she shared the apartment with somebody else, if they were shared hours but there was no apartment available for her to share with somebody else.

DEB GARNEAU: So clearly there is a range of services for adult developmental disabilities that, we've heard that quite often, that Rhode Island doesn't offer this range of breadth of services.

CARMEN CALES: And my question is, I mean, is that so that because an adult lives with her parents, unwilling the parents either are physically incapable of taking care of her or like they told me unless we die or abandon or abuse her, there is no way of her moving forward with services beyond what she has.

DEB GARNEAU: Does anyone want to respond to that?

ANNE MULREADY: I don't know if somebody was attempting to say unless there is an emergency we don't have anything for you currently, I don't know if that's what was meant, those seem to be emergency circumstances that you just identified but I don't know that they should be a reason for you not to be able to access services otherwise.

DEB GARNEAU: There is a movement currently around setting up more community based options for care, residential care. Where in the past there was group homes and other types of facilities that were more readily available. I think there is a movement towards having adults be part of the community and not be put into (inaudible) care or not have that as one of the main options. Did you want to --

SUSAN HEYWARD: I happen to work at DD so I just wanted to say I would be happy to speak with you during the break. (inaudible) Susan Hayward, . Sorry. Thank you.

DEB GARNEAU: Okay, is there anyone else who would want to have an opportunity speak? If not, we can break and we certainly will be here but we would like to, I think, have some individual conversations, as well.

## Written and Emailed Testimony

### Pearle Lake Testimony (pearlelake1@sbcglobal.net)

To the Office of the Governor,

Hello, I will not be able to attend the public forums about concerns of the citizens with disabilities and their families. However I'd like to express my thoughts.

My sister is a resident of Rhode Island, and the Perspectives Corporation does a wonderful job in providing the care and services she needs.

My concern is the same as others whose loved ones require assistance and care; that the funds for these services are not reduced. Thank God we are living in times when people with disabilities receive the respect and dignity they so deserve.

Independent Living

I am thankful for Perspectives Corporation, and other like-minded service providers. Please continue to allocate and increase funding for these providers.

My sister is happier because of the caregivers. I know for a fact there are folks who call themselves caregivers, and then there are those who are the real deal. Perspectives is the real deal.

Sincerely,

Pearle Lake

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Via Phone: Testimony of Ronald Gizzarelli

Notes taken by Lauren Colwell on 7-18-2014

-I will submit this through mail, but I don't have enough time to go to the forums.

-I want to plant the seeds, but I am too old to plant the seeds. I have a lot of ideas and I don't like seeing people left behind.

- I believe there are not enough things off-line. People who cannot access the computer are limited. The organizations' websites are not accessible to people who are blind or have no hands and who do not have enough funds to have accommodations.

Healthcare

-I would like to see all the commission names on advertisements and notices

-I believe nursing care needs to be more affordable for people who have low income

-When I call companies, the automated voice system is hard to use. It is hard to reach the right person when pressing specific numbers.

-

Testimony of Paul Delfino in regards of Jennifer Delfino - 7/24/2014

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good afternoon:

my name is paul delfino:

this is regards to my wife Jennifer delfino:

I have a couple of questions:

over about maybe 6 months my wife was told she needed a power of attorney for health care the place where she was staying .so there was one in place over the past weeks she has explained to me that she does not want it anymore she has

Healthcare

requested on many occasions to have it destroyed they have refused her request

this is a choice she is making to do on her own they have told her the following :

- 1.people might think you are crazy if you rip it up
- 2.this is not your choice it is your husbands
- 3.people will not love you if you rip it up

I have talked to the state social worker she has they say they are violating her right she want it ripped up they are refusing ..

paul delfino

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East Providence, Rhode Island 02914

This letter is to document my continued concerns regarding the quality of care I have received and not been able to receive since my odyssey began as an adult with a disability in this state. I have spoken before at this venue two years ago. My testimony was considered and I was able to talk to people after this event. Unfortunately, more of the same has continued in my situation and in many instances things have deteriorated in both the service realm and in the lack of accountability by agencies whose job it is to fulfill the mission of your commission.

My experiences are too numerous and complicated to explain however I will list compelling concerns that I

SNAP

have gone to great lengths to address. I have advocated and argued on behalf of my difficulties before the Appellate Fair Hearings unit with the SNAP office in Pawtucket, I have a letter and an appeal before Blue Cross and Blue Shield on account of some very dubious medical interventions provided by a nurse with the independent contract agency who is expected to provide : "wellness assessments in the home". I have called Channel 12 call for Action News to assist with issues

Healthcare

with SNAP in March and April of this year. Indeed, I have attended what I was told would be a Fair Hearing concerning the 95% reduction in SNAP Benefits that I have relied on.

Only to be told that we would be able to settle this here, that the department was at fault (and what what was this Channel 12 Call for Action about?) And I then received a letter for the Appeals council that I had given up my rights for a fair hearing and appeal and that the issues before them were void and moot, I have worked with the George Wiley Center and met with Mr. Christensen at DHS. All on my own. That is just the tip of the ice berg.

Last summer I became the victim of Medicare Fraud when I was sent home with a highlighted cheat sheet of drug plan providers from a local SHIP counselor. I was phished over the phone and told later by the Office of Elder Affairs that the counselors are not supposed to send us home to do our own homework with that kind of a cheat sheet. Now my Medicare plan is on a seven year

I still have unresolved issues before the Office of Rehabilitation Services about my Employment Plan and lack of services and follow thru. Believe you me, I have tried to call, email, advocate, involve and answer

Employment

numerous questions before this agency. Most distressing is that fact that in November I lost my long term counselor because he moved away and I was never notified to that effect. I emailed him and he told me to email his supervisor which I did. With meetings

together so far I have acquired a set of eyeglasses so that I can read appropriately and had a few meetings with the Federal Hill agency about job related interventions. All of that dropped off the end of the earth. This year and this year alone I have only accomplished the receipt of eyeglasses which took over six months to receive since the eye exam ..

I have told ORS that I would like to work in some capacity to be a recovery coach and peer adviser something that the doctors at Butler has suggested I would be very good at. I am hoping to be reimbursed for this 375 dollar amount as I spent it out of my own money. I am working as a volunteer with two agencies

related to recovery but my bills for my personal care remain high and I know there a sometimes long waiting lists for most things.

Another hospitalization has occurred to me this year, as a result of all the stress stated above. I have also testified before the RI House, Capital TV on bill 7288 which would have allowed some of the medical offsets to be in play for additional medical assistance. All to not avail.

Most distressing are the denials for services that were agreed upon by my attorney, myself and my counselor last summer, These were actually eventually denied and removed because they felt that I was requesting cleaning services in my home. Not at all the request.! I find it unbelievable that I am in the same place I was two years ago before your commission. It's feels as if it is my job to do all of their jobs. The way paper work has sat in files and phone calls not get returned and the months on end that go forward with nothing but this kind of advocacy work that I am forced to do all the time. I feel exhausted all of the time and like it is time that I just quit or disappear.

I am more than disappointed because I and we have been here before, thinking this will help this time.

To resolve the problem, I would appreciate your active and unrelenting advocacy to see that I am met with the respect and dignity I deserve for half of the effort I have put in to assisting myself with these unmet needs. This ineffectual "work" is a drain on all of us.

The question I want to ask ORS is do you not believe that I am teachable, trainable or employable? How many more years do I have to have a work plan that sits in a drawer, or be surveyed for whether or not I am work ready

Sincerely,  
**Maryanne Nolin**  
Enclosure( s)

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Hi,  
My name is Laurie Johnson. I live in Warwick, RI. I tried to get to two different forums, but it didn't work out.  
1) I would like TWO ramps at places like the Kent County YMCA where there is such a large clientele that I often have to wait for someone else with 

Accessibility
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 mobility needs or for someone with a stroller.

2) I would like the SNAP program to take into account when someone has a medically-necessary diet. (Gluten-free food costs much more than "regular food").

3) I would like it if service vehicles and police would get a stiffer fine than others for parking in handicapped spots. Too often I have been unable to park because a construction or electrical or some other repair vehicle is there. Once I tried to get the police to move their vehicle but the one I stopped said his partner, who was almost in the building, had the keys and they were only going to be a minute anyway. (No they wouldn't move.) Is there some way you could let people know that if they take a picture of someone that's parked in a handicap accessible spot and send it in to a police station they will take care of it?

4) I would like Insurance Companies to go under some kind of "audit". They need to make sure that each of their departments know what the other one is doing. When I was in College I took a course showing how to do this, I believe it was called "Business Analysis". Right now, the insurance company I had LAST year has one



department trying to answer my Grievance/Appeal while another department is "egging on" a collection agency. In January, that insurance company sent me a HIPAA Notice that said my insurance ended 1/21/2014 instead of the 1/01/2014 that it should have said... leading me to think I had paid for something I hadn't, now... everything's a mess and I want to remind everyone that on average every American will spend 4% of their life disabled.

4) I would like HIPAA to be "re-visited" or "re-vamped". If the ACA really does what it is supposed to, then someone needs to change the pre-existing/portability exclusion, etc. I just spent time reading it, and it is ALL to protect and benefit the insurance companies. I gather there was a time when those companies worried that if a person discovered they had some serious illness that person would hurry to get a good insurance plan to help with expenses... THAT makes sense. Insurance companies want to protect themselves, okay... but isn't the WHOLE point behind insurance to share the expenses? I suppose part of it is to keep some people employed too, but doesn't the client count? Are those companies in existence ONLY to make a profit?

5) I would like someone to look at Medicare Part D. I just got FORCED to get it, 

Healthcare
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 because I and my husband went off his insurance for the ACA. After looking at a comparison, I chose one and it changed my part A & B, too. I thought Part D was something separate. I am no longer going to the Doctors because a lot of them are no longer in my network. Something I didn't have to worry about until I chose a Part D!

Thank you for your time. I hope I didn't ramble or vent too much. Please do what you can, and thank you for helping with the scents that people used to use EVERYWHERE!

Sincerely, Laurie May Johnson

PS I am the President of a group of people that has MS and those that love us. I would like someone to come to the Key Club in March 2014 to explain our rights. We meet on the first Thursday of the month at Greenwood Community Church on 113 in Warwick. If you can tell me someone is coming, I will make sure there is PLENTY of advertising about it so that many people will have the opportunity to come and learn.