



State of Rhode Island and Providence Plantations

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

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

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

Monday, July 21st, 2014, 1 – 3 PM

Zambarano Unit, Eleanor Slater Hospital, 2090 Wallum Lake Rd, Pascoag
Hosted by Alliance for Better Long Term Care / RI Long Term Care Ombudsman

Monday, July 21st, 2014, 4 – 6 PM

Woonsocket Harris Public Library, 303 Clinton St, Woonsocket
Hosted by Seven Hills Rhode Island

Tuesday, July 22nd, 2014, 2 – 4 PM

Warwick Public Library, 600 Sandy Lane, Warwick
Hosted by the Ocean State Center for Independent Living

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

Middletown Public Library, 700 West Main Rd, Middletown
Hosted by Opportunities Unlimited For People With Differing Abilities

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

Rogers Free Library, 525 Hope St, Bristol
Hosted by RI Statewide Independent Living Council & National Federation of the Blind of RI

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

Charlestown Chambers, 4540 South County Trail, Charlestown
Hosted by Perspectives Corporation & National Multiple Sclerosis Society RI Chapter

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

South Providence Library, 441 Prairie Avenue, Providence
Hosted by RI Department of Health

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

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

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

Lincoln D. Chafee, Governor

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

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 them selves. 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. 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 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 (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, PASS, all of the services from cedars and also on a Katy Beckett 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, 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 mid night he decided to, he wasn't going to live with us any more 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 recommendations were that I was to call NRI 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 is 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 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 everyday.

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 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 equipt 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 likes 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 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 respark 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 grand mother. 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 some body 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. 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 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.

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 in 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, unwillingly 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.