

## 2015 Public Forums on the Concerns of People with Disabilities and their Families

Governor's Commission on Disabilities, John O. Pastore Center, 41 Cherry Dale Court, Cranston, RI 02920  
[Gcd.disabilities@gcd.ri.gov](mailto:Gcd.disabilities@gcd.ri.gov) 401-462-0100 (voice) via 711 (tty) 462-0106 (fax)

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### July 30, 2015 Zambarano/Eleanor Slater Hospital

FEMALE SPEAKER: I'll bring the microphone over to you, you'll be able to ask that question to the person on the panel or to me. Let me introduce to you our panel. (Inaudible).

THE SPEAKERS: We can't hear you.

FEMALE SPEAKER: (Inaudible).

FEMALE SPEAKER: Everybody hear her?

FEMALE SPEAKER: Oh, come on. (Inaudible) access point Rhode Island, I provide support for folks with disabilities (Inaudible).

FEMALE SPEAKER: (Inaudible).

FEMALE SPEAKER: I'm Jennifer McCarthy, I work here at the facility overseeing rehab services, physical therapy, occupational therapy, speech therapy, psychology, social work, and therapy recognition and also our community (Inaudible) that are affiliated with Zambarano.

FEMALE SPEAKER: I'm Meredith, I'm the community programs manager for Rhode Island for the national multiple sclerosis society. I work with our clients who have MS who live in Rhode Island, providing patient education programs as well as service to all of our health care professionals in the state who treat people with MS.

FEMALE SPEAKER: Hi, my name is Kate Sherlock, I'm from the Rhode Island Disability Law Center. We are Rhode Island's designated protection and advocacy system, and provide free legal advocacy on disability related issues for folks with disabilities. We come to the public hearings to hear from you about issues that are affecting you so that we can be informed as we set our priorities for things that we will work on in the coming year, so we appreciate you coming here today.

FEMALE SPEAKER: Hi, I'm Colleen, from the Rhode Island Department of Health, office of special needs and disabilities.

FEMALE SPEAKER: I'm Karen, I'm from the division of developmental disabilities.

FEMALE SPEAKER: I'm from (Inaudible).

FEMALE SPEAKER: Maureen is our interpreter today, so I want you to be able to, for anybody who is not able to hear, Maureen is here to give you the interpretation. Let me say that last year we were very successful with this particular forum, in being able to help somebody be discharged back to the community. So, if you have a question, or if you have a problem, let us know what that is today, and I'll come down to you with the microphone and then I will come back and I'll give you the microphone to the person that wants to answer it. Raise your hand whoever has a question and would like to speak about it. Your name.

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FEMALE SPEAKER: (Inaudible) in her late s, and she has psychiatric issues, she's also very functioning. She's about to fail out of (Inaudible). I am wondering, is there anything in the state that is between Eleanor Slater and the freedom of a regular group home for someone? She has (Inaudible), OCD. The alphabet soup. She's been in state care since she's been about. Can you tell me, what options or housing are there out there? They are recommended a locked facility (Inaudible).

FEMALE SPEAKER: Does anybody want to tackle that question?

FEMALE SPEAKER: Does your daughter have services through a community mental health agency yet?

FEMALE SPEAKER: Yes, she does, she's had them for quite a while through the Providence center.

FEMALE SPEAKER: I know that the Providence center does have different levels of community living for security purposes. My recommendation is to work through them because we've discharged from our psychiatric side to the community often through the Providence center utilizing those services. They will have a better knowledge of what they can offer or what the community has to offer for your daughter.

FEMALE SPEAKER: I'm just warning you all, I am going to trip before it's all said and done.

FEMALE SPEAKER: My other question, on the flip side of what you do, how do you voice the criteria to get into Eleanor Slater for Psychiatric or mental health issues?

FEMALE SPEAKER: So what would have to happen is the agency that your daughter is serviced through, they would fill out an application online to Eleanor Slater Hospital. A doctor has to complete the application, and list what her diagnoses are. And what would happen is that application gets submitted and reviewed by our medical protector. And then it's given to our social services department where they go up to do a site visit and determine level of eligible at that time. They would have to do an interview, get records. You have to go through that process to determine the eligibility. That's how it's done. But there is an application online for Eleanor Slater Hospital, and for community social worker, I'm assuming she has one with the Providence center, would be responsible for filling that out and submitting that and getting the necessary paperwork. Okay?

FEMALE SPEAKER: Hi, if your daughter wanted to get in touch with us, I can't promise that I will have representation, but I will at least provide a little counseling. We are from the Rhode Island Disability Law Center. If you got the packet, our phone number is on there. It is - - .

FEMALE SPEAKER: Does that answer all your questions?

FEMALE SPEAKER: Yes.

FEMALE SPEAKER: (Inaudible) mental health advocates office to see what they're doing, not only for each person, but global. (Inaudible).

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FEMALE SPEAKER: Anything else that you'd like to ask? You're all set. Who else now would like to pose a question?

FEMALE SPEAKER: (Inaudible) I just wanted to speak about (Inaudible). I just wanted to speak and say thank you to Zambarano, it was quite a journey for us for getting her here. I have to say the level of care, comfort, kindness, has been unparalleled, and at her quarterly meeting, they have addressed all of her issues that Jen was talking about, like speech, physical therapy, and all the different therapies that my sister has been able to receive. It has made her quality of life much better than what it was before she came here. One summer I just had to put a bag in my car because she was kicked out of her ten-year home. And it was very, very difficult. And we didn't understand about (Inaudible). And she has received beautiful care here. At the quarterly meeting, this is the only way I can thank them publicly and let them know that the level of services is unparalleled. My mother also died from this disease and my grandmother. The only thing I would like to request is the level of care here, the quality that deal with here on a daily basis are so wonderful that I pointed to, this is like a beautiful painting in a not so beautiful frame. And it's a little concerning (Inaudible). For any way for those that are here always, maybe they don't really have the opportunity to be discharged. It's their home, and if I could get them into (Inaudible) (Laughter) I will do that. My grandmother was at the IMH in Cranston, and this is back in the late's. It was a very scary place. I was a child, and we would take her out at home for Sunday dinner, and going here, or bringing her back home, was almost traumatic. And this is no way near that. But it's a beautiful location. I would like some things to be done that would benefit not only the people that are here, obviously, but the people who work here to come into a place that's as beautiful and welcoming as they are. That is my one wish. And they also take people out. Sometimes there's a waiting list. They can't always go out when they want to because of transportation. So if the transportation buses without either be augmented, getting the additional ones so more people could have an opportunity to go out. It's nice to get away for a while and have that little reset, art, baseball, whatever it is, allowed to take them to a beach. They have my thanks. Thank you.

FEMALE SPEAKER: I just want to add to that, when it became apparent when you and I were talking on the phone, I'm Kathy that you talk to all the time that her sister was not going to survive if she remained in the home she was. And it's not that the home was dirty or it was horrible, but the home wasn't here. And they were not sensitive to her needs. And loading up people with psych topic medications, so I begged them on my hands and knees to take this patient, because I knew if she didn't get here she wasn't going to survive. That's how bad it was. And to see her here today and put a name to the face, that makes me very happy. Her sister is a wonderful advocate, too. She was a little nervous when I mentioned Zambarano to her, but once she was here I didn't hear, so I assumed everything was fine. This is the most wonderful place in the world. If you follow what the new director is saying, she does want to make aesthetic changes to both hospitals. Don't ever judge a book by its cover. Some people think they walk into some of these facilities and they see all these lovely curtains, I look at the care. You can walk into this hospital any time, and the patients are always clean. I put people in here that were absolutely at the bottom of the level of the care they could be at and come back six months later and could barely recognize them. I'm a very big fan of Zambarano. Who else

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now would like to pose a question? Nobody has a question. You would like to? Wait a minute, Kate, I think this question is for you. She hasn't gotten any ID cards.

FEMALE SPEAKER: So, I won't get into generally what your ID situation is, but if my answer doesn't help you, we can meet with you individually. The state gives out free ID cards for people. If you have the information you need to get one of those, one of the places that they give them away is at the rally for recovery in September that is health around Roger Williams Park in Providence. Not the park with the zoo, but the one down the hill from the State House. But if you contact the Secretary of State's office, they can tell you other ways to get that. If that is not sufficient, please call us up and we can talk about that.

FEMALE SPEAKER: Okay? All right. You're welcome. I saw a lady back here that wanted to ask a question.

FEMALE SPEAKER: It's more that I wanted to tell a story.

FEMALE SPEAKER: Oh, all right. She's going to tell a story.

FEMALE SPEAKER: I have a friend who's, years old. And four years ago he fell and broke his femur, and he has an intellectual developmental disability. Kate, do you remember this story? Anyway, he has a guardian. For four years until now he remains in that nursing home, more because the guardian finds it convenient to keep him there. I want to know if there's any recourse for his friends to be able to say, hey, you know, maybe you could try, whatever?

FEMALE SPEAKER: Let me ask you something, what would you like to do? You'd like to have (Inaudible) where would you like him to go?

FEMALE SPEAKER: (Inaudible) group home. He still isn't walking. I guess while he is in the nursing home he was recovering from the break and slipped and broke his leg again.

FEMALE SPEAKER: Take the Mike.

FEMALE SPEAKER: Sorry.

FEMALE SPEAKER: So he fell and broke his leg again. And that was probably four years ago. So he just remains there. But friends of his have been there and visited and said, you know, is this really where you want to be? And he always says no. But the guardian says that that's where he's going to be.

FEMALE SPEAKER: Well, in my guardianship, the board has a right to participate in his care. So, I mean, guardianship is not the ultimate dictation. We're having this problem with a lot of guardians.

FEMALE SPEAKER: So, an individual can challenge a guardianship in a number of ways. They can challenge a guardianship with clinical evidence that they can make their own decisions. They can challenge a guardianship with evidence that they can utilize alternatives to guardianship. And they could challenge it with a combination of those things. Even if the individual remains under guardianship, we take the position that it's the guardian's job to effectuate the individual's wishes if

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possible. But the individual, themselves, has to be willing to want to make that challenge. So, for us to be of help. Other people might be able to figure out another way to do it, but we take direction from the client. And, you know, family/guardianship challenges, sometimes there are other people who want to make them more than the individual does just to keep the peace in the family, so.

FEMALE SPEAKER: Would this person be willing to call the Disability Law Center?

FEMALE SPEAKER: He's (Inaudible) by the guardian. So if I connect with that individual, and there are, he has a good number of friends who all kind of support him, and will be there to support him. He's all excited. But then he talks to his guardian about it, and one of us will get a call from the guardian basically saying, shut down.

FEMALE SPEAKER: You know something, what you can do is call my office. Write this number down.

FEMALE SPEAKER: I have your number. Advocates in action.

FEMALE SPEAKER: I thought I knew you. Okay. Call my office and ask for myself or Donna. I can start a lot of trouble, can't I, Kate.

FEMALE SPEAKER: Sometimes for me.

FEMALE SPEAKER: Well, I mean, everything is not perfect. Who's the next one who wants to ask a question? There has to be something else. Come on, don't be shy. This is especially set up for you.

FEMALE SPEAKER: Hi, good afternoon, my name is Cindy, (Inaudible) registered nurse and have pretty much been representing state employed nurses for about that long, as well. I have just a thought about (Inaudible). Just a couple of nurses that I represent (Inaudible) they work for nursing homes and hospital patients looking for (Inaudible) I'm not exactly sure how people get sort of brought to the forefront, if it's through the agency, itself, or if it has to be a family, or if the client (Inaudible).

FEMALE SPEAKER: Now, are you referring to somebody who is a patient here, or a patient at a nursing home?

FEMALE SPEAKER: No, I was referring to this lady's.

FEMALE SPEAKER: She knows enough to call my office. Usually it comes into my office if it's a long-term care facility, or it's Eleanor Slater and it's in this hospital and you don't feel that the people are listening and the person wants to be discharged. Then I'll come up, review the chart, sit down with the families.

FEMALE SPEAKER: (Inaudible).

FEMALE SPEAKER: Okay.

FEMALE SPEAKER: (Inaudible).

FEMALE SPEAKER: Oh, okay.

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FEMALE SPEAKER: I thank you all for coming. I appreciate the opportunity to ask this question, too. Some years ago we had to make a decision for my mom to be placed in a long-term care facility, of course we chose here. And for obvious reasons. I can tell you that even for somebody who worked here (Inaudible) it is an incredibly cumbersome system, this long-term care system of ours. There's not one place where some people can really get an answer. There's not one place where there's a point where you can enter into it. In fact, several times I got wrong information about the application process to this hospital from our own, at that time, which was MHRH. So I'm wondering, it seems like there's multiple avenues, still. And for someone who is trying to access the system, I think usually it's when they're at their most stressed out time. It's a very difficult time. Oftentimes we're not thinking clearly. What we need is, I think, a route that is easy to navigate, that the steps are clear to follow. And even now I, well, not that I don't think that's the case, I know it's not the case because (Inaudible). So I would just, you don't need to respond. I just offer that as a suggestion.

FEMALE SPEAKER: Last night I took one of those monkey surveys. I can never get over that word. And it was supplied by health care (Inaudible), that's actually an agency for the State of Rhode Island. It's always looking to improve. The main thing they were asking is to set up a (Inaudible). One of the things, when I answered all the questions, I felt that you need a person to talk to. That's the first thing. You can have all these, you know, I have to laugh when they talk about patients, you know, using the internet and families. Do you know how many people that are in their is and is that know how to use a computer? Not that many. You need to be able to talk to somebody on a to basis. They are working on that one right door. So, that is in the works. They were supposed to be working on it before. I don't know what happened to it. But I do definitely believe a lot of times things could be a lot better if you had a person to talk to, instead of going on a website, which most people can't understand. To my knowledge, you can't ask the website a question, so. Anybody else? Come on. Everybody is just happy, nobody has any questions.

FEMALE SPEAKER: There's no air-conditioning in here.

FEMALE SPEAKER: We need air-conditioning in here.

FEMALE SPEAKER: Not just here, I'm guessing the whole place.

FEMALE SPEAKER: Kate wants air-conditioning for the whole place. We'll make that a direct request to the director.

FEMALE SPEAKER: The basement is on the second face of air-conditioning, but the actual air-conditioning on all the rooms above this, every room has its own air-conditioning. Not a wall unit (Applause).

FEMALE SPEAKER: I'm hot.

FEMALE SPEAKER: Excuse us, Lady Jane, she's hot. I always tell this to my husband, everybody's cool but you. Would any of the panel like to get up and do any discussion? It's a little hard to be the MC here with no questions. Does anybody want to dance? (Laughter) hold on.

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FEMALE SPEAKER: If you don't have questions, does anybody have any issues that are of concern to them that they would like the Governor's Commission, or any of the other panelists, to be focusing on?

FEMALE SPEAKER: Come on. Don't be shy.

FEMALE SPEAKER: I showed up really late because I was trying to get out of work to get here. I don't know what's been covered so far. I'm a half hour late. I live in this town. I work in Providence. And I just know that transportation is a real issue in this area. So I don't know if people discussed that.

FEMALE SPEAKER: Nope.

FEMALE SPEAKER: Because I can't imagine, I work with people looking to get jobs, and I can't imagine trying to do that in this town. Because there's way, if you don't have a car, you can't get around. I'm just wondering if anybody has spoken to that.

FEMALE SPEAKER: I can tell you in the last year and a half the State of Rhode Island has went through some major changes with transportation. They now have an outside vendor that's doing a lot of the transportation. The people that would handle this transportation would be RIPTA. Now, I don't know if anybody here is writing that dough down and would like to attack RIPTA.

FEMALE SPEAKER: (Inaudible) it is limited. And usually for somebody with a disability you can arrange for a RIDE bus to actually pick them up and take them. Zambarano is a stop town for the RIPTA service. There's a spot near the IGA that is a stop. And Harrisville, Mapleville, there is a route all the way around. Then they have the flex bus that runs between. So, I don't know if that helps at all. But our social workers here do coordinate with RIPTA and the RIDE program to get our patients, you know, rides into the community that they may need, and about the state. I don't know if that's something you can look into.

FEMALE SPEAKER: Does that help you?

FEMALE SPEAKER: Yes and no. The people I work with have certain physical disabilities, so they don't need RIDE.

FEMALE SPEAKER: All right. Anybody else?

FEMALE SPEAKER: My name is Karen Tamodio, and I'm from the Glocester. I also work in long-term care. I came today because I have a brother, he's. And he lives in a home. And -- I don't want to get emotional here. I work full time at a nursing home, and I am having problems now for quite some time, he goes to seven hills, is finding someone to help care for him at the house when I go to work in the morning. And I tried all kinds of agencies, seven hills, tried to get somebody from the community to be able to be a caretaker so I can go to work in the morning, and I still have not been able to get that help. And as he's aging, his dementia is causing an issue. I was wondering if there was another avenue I can go to for some kind of help. I was paying finally out of my pocket. It's kind of draining me financially. I was wondering if there was some other agency available.

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FEMALE SPEAKER: Who wants to take that?

FEMALE SPEAKER: Hi, does your brother have, your brother should have, in addition to day support hours, he should have community support hours?

FEMALE SPEAKER: We haven't been able to find anybody in this rural area.

FEMALE SPEAKER: So it's finding a person to fill that. Okay. You can look into it and see what you can do to help, but, you know, there are a lot of vendors who are having some staffing shortages. So, hopefully, that will be corrected soon. We are working on that. And hopefully there will be more people available for the hours.

FEMALE SPEAKER: Have you heard of the person choice program?

FEMALE SPEAKER: No.

FEMALE SPEAKER: Who would like to explain that? I'm no expert on this.

FEMALE SPEAKER: (Inaudible).

FEMALE SPEAKER: That's when you can hire somebody.

FEMALE SPEAKER: She can.

FEMALE SPEAKER: You can. Great.

FEMALE SPEAKER: So, (Inaudible).

FEMALE SPEAKER: They do send me statements about what they're spending on him, but I don't know that, they told me that I would have ten hours, but I don't have any help. I've been waiting a couple of years. And he has Down syndrome. I don't have any family to help me with that.

FEMALE SPEAKER: (Inaudible).

FEMALE SPEAKER: I'll give you my card before I leave today, and you e-mail me. You use e-mail, right? And I'll send you a list of people that can help you out, especially at DHS with a personal choice worker. Unless anybody can do something else here. What?

FEMALE SPEAKER: Yeah, there's an option through division of developmental disabilities. You have a choice of working through an agency, which is seven hills, which you're doing. Or you can do personal choice, which means you can choose to develop your own program and your own -- and hire your own staff.

FEMALE SPEAKER: You have options, right? Mix it up with person choice, which is different.

FEMALE SPEAKER: (Inaudible). I'm not the disability expert.

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FEMALE SPEAKER: Right. So you could speak with your brother's social worker and ask about what your options would be about maybe doing a day program, and then taking the community support hours and seeing if you can do something with that.

FEMALE SPEAKER: Yeah, it's just finding people.

FEMALE SPEAKER: Yeah, finding people, there's a big problem.

FEMALE SPEAKER: I mean, it takes a long time. It's been years.

FEMALE SPEAKER: (Inaudible).

FEMALE SPEAKER: I got a card.

FEMALE SPEAKER: She's going to give you a card so you can call her. Remember, I'm long-term care, I'm not disability. So I got it all mixed up. Kate was good enough to tell me that.

FEMALE SPEAKER: Kathy didn't really get it mixed up, it's just that there are different names for different things. And when you are a client of the division of developmental disabilities, you can go to an agency, or you can do, like Deanne and Karen described, there is a different waiver, which there isn't supposed to be anymore, there is a different waiver called personal choice. And that is a waiver that was started by the independent living movement years ago. This is people waved the right to have / care and decided to have less than / care and hire their own staff. It's a different waiver. (Inaudible) client of the division of developmental disabilities probably doesn't need to go in that direction, but maybe does, so you can explore it. But options like Deanne described and like Karen explained would be a way to choose your own staff and stay as a client for developmental disabilities.

FEMALE SPEAKER: Remember, if you're a certified nursing assistant, are you a certified nursing assistant or a nurse?

FEMALE SPEAKER: (Inaudible).

FEMALE SPEAKER: How many times have I spoke to you on the phone? (Laughter). What you can do, Karen, is this: You can also take my card when you leave and you can contact her. So we'll do something to be able to help, because that's a tough situation. It's nice to put a face to the name.

FEMALE SPEAKER: This is just a little suggestion, because it sounded to me like you're saying you can't find a person, not like -- so somebody in the same circles, care.com is one place that has people that posts positions, I'm looking for this person to do something with my brother, or there's people that post what their jobs are. I posted things on Craigslist. Maybe outside of the regular circle. I think we all go to ABC, but maybe if we think outside the box.

FEMALE SPEAKER: You're the director of nurses, you have certified nursing assistants that are (Inaudible).

FEMALE SPEAKER: (Inaudible).

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FEMALE SPEAKER: Everybody? But, I mean, sometimes, like she said, things will come up and you'll be able to think of something. There's a lot of people that are advertising in Providence that are looking for jobs. Get a copy of the Providence (Inaudible). Who else?

FEMALE SPEAKER: This is crazy, because the other night I was watering the flowers in my yard. And there was a gentleman down the street who had a stroke. He has a personal care attendant. She parked near my house and got out the car and started conversation with me, left me her card, and said if you ever need child care or elder care, I'm an extra set of hands. And I found it a little strange, telling you the truth, and I snapped a picture of her business card just to have it, because I said, gee, you're never going to know when you're going to need this. After this I'll give you her number, and she's right in Burrillville. I don't know if that will help you or not. This is very odd.

FEMALE SPEAKER: Anybody else on the panel that would like to do something to address? No more? Come on, somebody has another question. Somebody has a problem we can help you with. Somebody has a challenge that you need help with. The voted ID card, she answered that question, right?

FEMALE SPEAKER: If I haven't, you can call us.

FEMALE SPEAKER: You can call the Disability Law Center. You have that, I think, with one of the handouts she gave you. Okay? Give me one just in case. Have your social worker work -- who's your social worker? Shannon, Shannon will help you with that. Okay. But you got Kate's number there. You can call and ask for Kate. Kate will remember. Nobody else?

FEMALE SPEAKER: Does the disability (Inaudible), do they have a plan, maybe someone could tell us what the plan is (Inaudible) what is the plan for the commission about disability changes (Inaudible)?

FEMALE SPEAKER: She wants to know if there's any plans for the upcoming year on changes that you're working on.

FEMALE SPEAKER: The commission takes the information from the public forums and (Inaudible) based on the issues that have come out of the forums. Every year we try to highlight those with legislators. We monitor legislation, (Inaudible) right now the things that we're looking at are housing, transportation, access to health care, and employment. Particularly, (Inaudible) persons with disabilities because Rhode Island is lacking in our ability to get jobs for people with disabilities. Percent, folks with disabilities in Rhode Island (Inaudible). That's pretty much the plan. Public access for buildings, state buildings, public buildings, have good access for people and (Inaudible), all of those things. (Inaudible) issues with people from all walks of life (Inaudible). We're really looking for direction from the public. (Inaudible) we encourage as much participation as possible. We try to do a lot of advocacy, training of legislators. There's a lot of new legislators this year. There's a lot of new people. We have a lot of people in the state capital. (Inaudible).

FEMALE SPEAKER: Okay. We're going to end the formal part of this session, but we will wait around in case anybody wants to come up to us personally and ask the question if you're too shy. And we'll

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try to accommodate whatever your need is. I thank you for coming up today. I thank you for your participation. I hope this helped. I hope we can get some answers for you. Thank you, very much.