

## 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  
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### July 27, 2015 South Providence Public Library

CASEY GARTLAND: Welcome, everybody, to the public forum to identify concerns of people with disabilities and their families. I want to mention before introductions that there are bathrooms right outside here, to the right. And in a moment, I'll have the panel introduce themselves individually. First, the purpose of these forums is to identify concerns of people with disabilities and their families in order to assist the state develop programs to improve quality of lives for people with disabilities. To ensure everybody who wants to speak gets a chance, please keep comments short and to the point. If you have a critical problem that needs to be addressed, panel members will be available at the end of the forum to direct you to the proper agency for help. After the forums are completed in early August, the sponsoring agencies review testimony and prepare recommendations, which are also posted on the web site by the end of November. The recommendations and transcripts will be printed and sent to state officials and members of the General Assembly and recommendations will be used to develop policy and legislative initiatives for the next year, or until accomplished. If you picked up a packet, on the inside cover, there are what past forums have done. The Rhode Island Disability Law Center's panelists are available to register anyone who is a citizen and not currently registered to vote at the end of testimony. People can also file a change of address if they moved since the last election. At this point, I will have the panel introduce themselves, and identify who they are affiliated with.

MEREDITH SHEEHAN: ...for the National Multiple Sclerosis Society.

CARMEN BOUCHER: I am at the Rhode Island Department of Health, at the Office of Special Health Care Needs.

CHARLES MESSINA: Attorney with the Rhode Island Disability Law Center in Providence.

KAREN RUSSELL: I am a vocational rehabilitation counselor for Office of Rehabilitation Services.

CASEY GARTLAND: I want to ask that you register in the back, and there are assistive listening devices if needed. We ask that you speak slowly and clearly so the person transcribing can get correct spelling for the notes. Identify not only your name, but which city or town you live in. So with that, we're going to start with the first speaker, if anyone has decided to speak, anyone want to say something to the panel?

MEREDITH SHEEHAN: I wanted to mention for the transcript, at the MS society, I do a lot of advocacy work for people, we have about 2000 people registered in our chapter location, we do Live with MS, and an issue, we're consistently hearing how challenging it is to pay for home modifications, and they need to, make a bathroom accessible, a ramp into their house, lower their kitchen counters, anything that would be necessary for someone with MS or any disability, or an aging population to stay in the house they own without needing to move, and be able to stay safely and independently. So one of the pieces of legislation we did submit this year through the national MS society was what we call the

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Rhode Island liveable home tax credit establishing a tax credit program within the state, on your state income taxes that would allow you to deduct expenses paid for certain home modifications, your basic ones would be included in that. And we did, it didn't pass, obviously, so we'll continue to work on it this year, but I wanted to be sure it was brought up as an issue, how hard it is for people to stay in their homes and pay for home modifications, to keep them safe as opposed to being prematurely admitted to a nursing home if they fall, or have to leave their home for some reason, they don't really want to do so. So I'm hoping, I've met with some people with the Department of Health, and working with AARP and OSCIL and other agencies like that, for a host of people, like I said, with disabilities or the aging populations. I just wanted to be sure I got that in the record.

CASEY GARTLAND: Any questions from the panel about that? For those of you who are going to speak, if you wish to speak, the job of the panel is to listen and ask questions to elaborate, to be sure everything is in the notes. They might interact only as much as you have questions. With that, is there anybody else that would like to come forward and speak, anything for the record? Well, we're here until 5:45, we might have people come in and out, so we can reopen.

MR. MARTINS: So, my name is Antonio Martins and I live in North Providence. And something I was thinking about while listening to the forum is about my own personal story in regards to my father recently diagnosed with Alzheimer's. One of the things we experienced as a family is the concept, in order to get him any services we basically have to strip him of his rights and thinking about the progression of the disease, he's not completely incoherent, he does have input into his own care, things he likes and does not like, and they have a direct effect on his health overall because whenever we try to force him to do something he is not in agreement with, it doesn't go well, delays services, all kinds of things. One of the issues we experienced as a family overall is finding any, it was easily enough to find providers but to find somebody who could advise on just whatever the process is, because the doctors would make this referral and then we would talk to this one, and then they would make a referral to a different one, and then it was like you could do this but you have to collect all of this paperwork ahead of time. And one of the things we are finding as a family with dementia and Alzheimer's, they are not very good record keepers and it's something that starts a long time ago to trying to find the back story and figuring out what happens, it's a little bit as a family, difficult, and then, it's difficult also to rally the different providers so one of the things we had to do, my father had lost his social security card so we had to go down to the office and apply for a new card and they wanted to speak to him directly and they were asking him a litany of questions, he's not going to respond to you, and at the end, it's all the same anyways so it's just kind of like that sensitivity and having somebody who could guide families through the process overall, so this is what's coming next, these are things you should start to think about. My parents are first generation in this country, so long-term planning, all of those kinds of things are not things that were in their ideas about what they wanted for themselves. We have tried, I think its service called the Point, you had to call and tell your story, and they were helpful, I think everyone tries very hard to be helpful but there is no direct path where you just fall into this path and these people will take you through. That's one of the things I have done in my profession, I work for early intervention, so once you are qualified for the program and we're connected with a family we take you through the process and one of the last things we do before a child turns 3 is finding the person to take them through the next steps in their journey for

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finding services for their children if still required so I definitely found that was something lacking for my own family and people in the situation one way or another is to find a dedicated, I don't know if the right term is service coordinator or social worker, whatever it is, to help a family, these are the things you need to start thinking about next. Because it's difficult, my father has Alzheimers, my mother has mental health issues so it's difficult for each one of them to help the other and as a family the only services, thing, we have been able to find is basically putting them each in their own different home which doesn't help either one of them per se but my father has a nice place to go during the day now but my mom can't go with him because she has a different diagnosis, she offer today volunteer but she has to pass background check that is she won't pass because of background checks so keeping older couples together in older age with competing histories is something we haven't found a solution yet. So that's just one of the things I was thinking about as sitting in the back and thought buy bring it to the attention of the panel. So that's my own personal story. But my professional story, working with families with young children, what we're find ago lot of, as well, is just access to really pointed and good mental health services. It's something we are finding that it's hard for families to find. Particularly in Rhode Island, they're pretty good about making the initial phone calls and they have been able to establish quite a few agency that is our families can pick up with, but, I mean as we all know, people with mental health issues at the time they need them most are also the time when they're less stable so we're find ago lot of issues in regards to, you miss an appointment, back at the bottom of the list and really getting agencies to talk to each other so that's something we find a lot in our work and also I find that for families that enter into the DCYF process, having really good professional help for parents and their own parenting skills because these parents have a lot of requirements sometimes to get their own children back, rightfully so, but at the same time with a high level of requirements does not come a high level of support. We try to do the best we can to act as a stopgap but we're find ago lot of these nonprofit organizations that existed in the past like parents as teachers and a couple of the different ones, there was a great program who were older peep who will had raised several children would volunteer to come in and work with these parents to impart some parenting and coping skills which is really in essence what they need. It's just harder to find these kinds of programs and we make a lot of referrals so the agencies out there but they are not always the best fit for the families that we deal with. The majority of the families who get involved with DCYF and have children removed, almost inevitably they had the same thing happen to them so they didn't grow up with great examples or someone to impart to them coping with stressors of life and managing high need. So it ends up being kind aftercycle over and over. So those are just the things I was thinking about while listening to some of the concerns you brought forth so I figured I would share them today.

CASEY GARTLAND: I have a question in regard to your first situation, did your family contact the department of elderly affairs?

MR. MARTINS: I find more of an issue with timing sometimes, called the point, someone was on vacation, left a message. I know in our case our father was refer today a place in Woonsocket, they were great but he quickly out grew their ability to support and then needed something specific for families or for adults with memory issues. And by the time the point got back to us we had already found a different place. So it was really kind of, it's just the quickness have you to deal with things

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sometimes. The other thing I am finding in regards to work, for my father, is that you can quickly outgrow a facility and there isn't necessarily a mechanism to have the next facility ready and the people are really helpful like if I wanted to put him in a nursing home, like 24/7, people have that idea about it but I don't feel that is the thing we need or want for him as a family right now and that's the part that's harder is figuring out who can help us maintain him at home. Because when we first got in diagnosis my father started attending places during the day, because of his diagnosis, my mom's diagnosis got kicked off so she ended up in butler for a while, they are very happy as a couple, lived together for 40 years, so that sudden switch of now he goes elsewhere, those that was really difficult for her. I imagine even apart from their diagnosis, I'm sure it's something couples and families deal with. With my brother and myself, extended services, 7:30 in the morning until 5:00, basically my work schedule so I have to leave early to pick him up at 5:00 and if my brother can't in the morning or myself in the afternoon so extending existing services to be more friendly towards families with a traditional work schedule. I can't even imagine if you have a second shift or something where it would be hard to find care for a family member. But like I said everyone has been helpful, it's just the transition of taking you onto the next set of people. I feel all the people we have dealt with are very well intentioned and knowledgeable, it's just figuring out all of this working together. I know how to be a good son and take care of my dad, per se, but not like necessarily a doctor or social worker for that population and they come with their own set of rules and even in regards to like for social security in particular, they have missed deadlines for applying for Medicaid and for this and that, and it wasn't something I was thinking about in terms of having to manage for them. And even this past October when it came time to renew by the time we figured out what had happened all of the agencies that were willing to work with you to figure out the best augmentative insurance, they were all booked up, sorry, we filled up months ago. So I know they are now like in that Medicare, that doughnut hole and quickly going through the little resources that they have. So it's just kind of hard, I feel the pre-emptive work where you get on the wait list sooner rather than later is what's missing and it may be particularly in my family because of the way we figured out what was happening for them, but even in regards to the doctors, we got lots of referrals to other doctors, not any referrals to social services.

MEREDITH SHEEHAN: Has the Alzheimer's association --

MR. MARTINS: We haven't contacted them, I didn't know there was one.

MEREDITH SHEEHAN: There is a wonderful -- MS society, we have case managers on staff who kind of help people in similar situations but with MS obviously but I can, actually, I can give you the number, my girlfriends works there. There is a national Alzheimer's association but then there is a local branch as well right here in, at least, in New England but I think there is a Rhode Island office, as well. And in fact I know about them because I have seen lists of, like, series like educational series that they do, there was a four part one but some is for a caregiver to go to, as well. For support and things like that, but did he feel reach out to them. If the structure is similar, to the MS society they probably can offer some help.

MR. MARTINS: For us, it was primarily finding him someplace during the day, get doctors setup then

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concentrate on what long-term would be. My brother took time out of work, I did, which is open to us as a family but putting everything on hold is difficult. So, I thank you.

FEMALE SPEAKER: So it's located on Waterman Street in Providence. ALZ.org. You can Google Alzheimer's association of Rhode Island and you'll be able to find it.

MR. MARTINS: Thank you so much.

CASEY GARTLAND: Last four or five minutes.

MS. MONROE: I'm not even from the state.

CASEY GARTLAND: That's okay.

MS. MONROE: Okay. I am Milly Monroe from Seekonk, moved there from Rumford. The reason I am here, I have disabled children. But one in particular, my youngest daughter in particular, is in such a crisis right now because of the state funding situation. And you can understand all the issues all you want, but when you're actually dealing with it, it's heart breaking to see. I know I am not the only parent going through this. There are hundreds of them. Like I was saying, my youngest daughter, she has lived in semi-independent, in an apartment, geez, for well over 20 years. The apartment that she is living in she's been there for 14 years and how I know that exactly is because she was told that her agency is no longer going to support her staffing at night. Because she has to take medication, she needs 24 hour supports. And they -- that SIS thing makes me crazy. She consistently, over the years, has been on tier C. She is able to be in her own apartment like I said, but with supports. Well, they just came out, lowered her to a B. How convenient was that? Nothing has changed. She is brain damaged. And as far as I know, brain damage doesn't go away. Nothing about her has changed. She has gone through breast cancer, that whole journey with her. And she goes to work, she works on the base, she works part-time, but she is always saying, you know, I'm going to get 20 years, I'm going to retire, I'm going to get a check and that's all she thinks about. So even on a bad day, when she thinks she is having a bad day, I'll say, but, Donna, you can't quit, what's going to happen if you quit? She goes, yeah, I won't get that check. But she does beautifully with a little support. But now because they've cut her, the SIS has put her to a B, they're saying they can't support her any more like that. Now they want her to go into shared living and, well, let me back up a little. She has been totally unbearable to be around because she does not want to lose her apartment. So she is still, she's still in turmoil, and so I did the what if thing, but what if, what if you had to live somewhere else, where would you like to live? And she said, well, I just want to stay here. I've been here for 14 years and I do good and when the state comes to check my apartment, they say it's good. And she's all so happy about that so, trying to redirect her, it's difficult because, like I said she's acting out, I'm scared to death she's going to runaway so when I mentioned shared living, she goes, mom, that's foster care, I'm not going to go in foster care. And you can call it what you like, but, it's her perception, she knows that it's foster care, you can call it any fancy name you want. But it means, to her, she's not going to have an apartment. It just tears me up to think that all these years and years and years of making these kids be the best, their personal best, of what they could be, that it's all being just...thrown away.

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And it's not right. And she cries and cries and says, it's not right, mom, it's not right. Now I have my other daughter, Denise, that you know, she keeps saying, mom, what are we going to do? Saying that she can't go again to a group home. The funding. And it's trying to find another apartment situation where there's staff available. She has always lived all by herself. So I don't know where all of that is going to end. But, it's not right. It's not fair.

CASEY GARTLAND: And have you spoken with her DDD social worker, you said?

MS. MONROE: Yes, I have. I have spoken to Jodi. Jodi is great with me. But it's just so hard to get your head around because all their life, the goal, we always worked on and they always went along, went along, went along. To get as far as they are and through no fault of their own, it's all just being demolished, it's not right.

CASEY GARTLAND: Any questions from the panel?

MS. MONROE: That's my two cents.

CARMEN BOUCHER: You identified you don't live in Rhode Island but do.

MS. MONROE: They all do, all of my children.

CARMEN BOUCHER: so you are testifying for the adult children that you have that are residents of Rhode Island and those are the issues.

MS. MONROE: Yes, and they vote, by the way, they all vote. Keep that in mind. I wish, you know, I wish I could vote in Rhode Island, but I moved just down the street, just over the line. And so -- that's it. That's what I have to say.

CASEY GARTLAND: Thank you, very much.

MS. MONROE: Thank you for listening.

CASEY GARTLAND: So I guess that's the conclusion of today's testimony. Thank you very much for coming. And we have four or five more the rest of the week, there is a list if you want to get one as you walkout.