

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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MEREDITH SHEEHAN: All right, good afternoon, everyone. My name is Meredith Sheehan and I am the community program manager for the state of Rhode Island for the National Multiple Sclerosis Society. We were very happy to sponsor today's public forum. I want to welcome you all here today. I want to point out quickly before we get started there are accessible restrooms available, should you need them throughout the afternoon. They are right through that door and just to the right. You will see them right there. The purpose of -- I will read a few housekeeping things before I have the panelists introduce themselves. The purpose of these public forums is to identify the concerns of people with disabilities and their families in order to assist the state to develop programs and to improve the quality of the lives of people living with disabilities. To ensure everyone who is here today gets a chance to speak, please keep your comments short and to the point. If you do 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. After the public forums are completed in early August, the sponsoring agencies will review the testimony and prepare recommendations, which will also be posted on the website by the end of November. The recommendations and the transcripts will be printed and sent to state and Congressional offices and to the members of the general assembly. And the recommendations will be used to develop policy and legislative initiatives for the next year or until they are accomplished. The Rhode Island Disability Vote Project, voter registrars are available to register anyone who is a citizen and not currently registered to vote where they live or if you have a change in your address since the last election, we can update that information as well. I'm going to just start with Barbara and we will go down the line here to introduce the panelists to you so you know who is going to be listening to your concerns today.

BARBARA POLICHETTI: I am Barbara Polichetti with public affairs with the Rhode Island public transit authority, RIPTA.

TERESA SCARAMUZZO-DIMATTIA: I work for the office of rehabilitation services.

DEBORAH GOLDING: I am Deb Golding and I work in the office of the special needs in the Department of Health.

ANNE MULREADY: I work for the Rhode Island Disability Law Center. We are the nonprofit federally funded law office that represents people with disabilities in Rhode Island on disability issues

MEREDITH SHEEHAN: Thanks.

CASEY GARTLAND: Can I sit back there? I am Casey Gartland and I am a senior director with Perspectives Program, the adult section

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MEREDITH SHEEHAN: Thank you. Wonderfully talented people on the panel today which can respond. Their job isn't to get into a debate with you, you know, to have this conversation here but they are definitely here to listen to you. If there's anything on the more personal nature, whether they have a break or towards the end of the hearing feel free to approach them individually. So we do have several people who did sign up to speak today. So I will just go down the list as you came in. If you could just -- we do have a CART reporter doing a word for word transcript. So if you could just speak clearly and do state your name at the beginning, that would be helpful. So first we will have Robert Romero.

ROBERT ROMERO: Good afternoon. I will speak as clearly as I can with my cold. Romero, Robert. Two questions. What can you do to improve the RIDE programs

Transportation

 services from my perspective? My son needs to use it and it doesn't seem reasonable to me that he should be riding around on a small bus for two and a half or three hours each way. And if he's starting a program at 9:00, it doesn't seem reasonable to me that the bus should come and pick him up at a quarter to 7 or 6:30. My second question is how does one become a member of this panel, this commission? And I will sit down and listen to your responses.

BARBARA POLICHETTI: I will take the first question since it's for transportation. I am not an expert in our RIDE program but I don't think there your son should be on the bus for two and a half hours. Our times are regulated and monitored by the FTA. So afterwards, I would like to get a little more information from you. We have a very good management team down in our RIDE division. So I would like to get some information to look into that. So, that will hopefully allow us to address that. As to what we can do to improve it, for people who don't know, RIDE is the State's -- RIPTA's paratransit service run in accordance with the Americans with Disability Act. In order to qualify for the RIDE program, you have to qualify under the ADA guidelines and our RIDE administrators are very good at getting people qualified, making sure people that need it are qualified. It's door to door service. It's by appointment. And it's \$4 per RIDE, I believe.

ROBERT ROMERO: Round trip or one way?

BARBARA POLICHETTI: I have to double-check on that. I didn't bring anything with me. So there are very specific guidelines that govern RIDE, A, federally. And then transit wise, I am still learning because I have been at RIPTA for seven months now after 35 -- don't do the math you will get my age -- 35 some odd years in the newspaper business. So I am still learning transit. There are some very specific federal regulations which I find interesting that I am still learning as to where paratransit is offered. So we talk about like what can make it better. Under federal regulations paratransit i.e. the RIDE program is offered only within a certain distance. I can look at you, within our fixed route. The RIDE vans won't run where we don't have fixed route service. That was a big education to me. So

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some of the things we hear that might make it better -- I'm not sure if we can do under regulation or if we even have the finances but one thing we have done recently, that we are excited about and would like to build on this is I think this gentleman knows, you have call and make an appointment. Then you get a pickup window and that window narrows as you get closer to your time. And up until -- I believe it was two months ago when we launched the app in the website, the only way people could find out about the narrow window was to keep calling. And of course people were calling to make an appointment. They are calling to cancel an appointment and calling my pick-up window is 9 to 11 a.m., am I near the 11 or 9 a.m. side? What we just did is we contracted with a private company who developed an app for us. That information can now be -- you can watch it on your phone. If you don't have a Smartphone you can get it on your computer. And if you don't have any of those things, you can still call in. But our hope is, speaking to improving the service, is it will reduce the volume of calls coming in and you will be able to monitor your window, plan accordingly like when you need to step outside particularly in cold weather. One of the things we need to do is continue to build on that technology and use more technology to make access to information about the program more readily available. That would be my -- so we are very happy that we launched that. We would like to expand it and maybe find some other uses to have technology make access to your service and information about the service more accessible

CASEY GARTLAND: I will attempt to answer your second question. The commission is appointed by the governor in terms of three-year terms, if I'm not Mick taken. Chris may know better than I. However you don't need to be a commissioner to serve on some subcommittees. I am a commissioner now but at first I was in the election assistance committee. I was not a commissioner. I was involved in registering people that we provide services to vote. We do have various subcommittees that you are welcome to attend and join if you would like. We welcome all the help we can get from the commission, whether it be in the main commission or the subcommittees. And there is a website you can access if you just type in any search engine Rhode Island Governor's Commission on Disability and it will tell you membership and the committees.

DEBORAH GOLDING: There is the office of special needs brochure right here. There's a number of committees that they run that you might be interested in. There's a brochure right here. You can get one.

MEREDITH SHEEHAN: Did you have any follow-up questions?

ROBERT ROMERO: No, thank you.

MEREDITH SHEEHAN: Okay, thank you. We will move on to Tia Beckman

TIA BECKMAN: I am wordier, I am not as brief. Tia Beckman. I spoke years ago at a forum like this when my son was in school, tears, my heart. Things have not changed, so I am here again. My son

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Education

is now a young adult. He lives with dyslexia, like 20 percent of our school population. Dyslexia means it's putting sounds, two syllables decoding. Some people have troubles with sound, some people have troubles with symbols. My son was with the sounds. It affects reading, especially reading to learn, writing, spelling, speech articulation. It does not go away. It's a specific part of the brain. It does not go away. My son is intelligent. In fifth grade he was 95th percentile in science, across the nation. By the time he was graduating from high school, it was -- we were lucky that he graduated. He did not have a method to learn. Being able to sound out words means you can learn new vocabulary through reading. He could not do that. He never got the treatment in school. He had been diagnosed. He had been identified in -- by Second Grade. He did not learn how to learn. He had to memorize what was said in the classroom. Again, he had the phonological problems. So even that was difficult, keeping up with the classroom lecture. His method of getting through school was memorizing what the teacher said and passing the tests. He could not write quickly enough. He not read well enough to read somebody else's classroom notes. Tape recorders were not allowed in school. So how was he supposed to learn? There are coexisting conditions that might happen with dyslexia that could be difficulty with math, difficulty with the handwriting, there are others. I will probably think of them. Like many others with dyslexia, he would memorize the shape of the words. So if he was taught the material, he could -- the words would jump out at him and he would read from that. So he could pass reading comprehension tests very well because the reading comprehension tests on standardized tests are familiar subject matters. So since he always passed reading comprehension, the school was not decoding sounding out of words was not important. I called up RIDE, Rhode Island Department of Education, and I asked them about due process and they said that the districts have independence where what is important to the district the state will enforce. What is not important to the district the state will not enforce? So many of the districts throughout the state, reading comprehension, fluency is important. Speed of reading. Fluency happens -- can be compensated with extra time but my son had decoding problems. Due process was not going to work for him. So as a parent, I had no options, no recourse. Federal law says that dyslexia should be identified and treated. Since 1950s, there has been ways of treating reading, not the others, but reading, the Orton Gillingham. It started in the 1930s and 40s, we are talking prewar or post World War II treatment and our schools are not doing it. Most districts are not doing it. We have a few really good districts. So what I'd like -- so now my son is not able to attend college. And yet 95th percentile in science. We are missing out on a really smart kid. So what would I like? I would like the state of Rhode Island to determine that dyslexia is to be identified and treated with scientific research, evidence based reading programs. Many districts try others. They don't work. I would like teachers to be taught what dyslexia is. I have asked teachers what is it? They think it's letter reversals. It is not. I would like teachers to be aware of the parts of the brain and the coexisting conditions, how it affects learning, treatment, and how to compensate. I would like parent support groups and mentoring for the students. I would like psych community awareness. Many of these kids,

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you can imagine my son going through school, having difficulty understanding the lectures, having difficulty writing and having difficulty reading and he went through 12 years of school that way. Studies have related it to post traumatic stress. So I would like the psych community to be aware. I'm trained as an occupational therapist. I did not learn about it in school. So we are not just talking about teachers. We are talking about the population. I'm not picking on any -- so I would like -- because there are a lot of practical aspects to dyslexia and I would like the OT community to be aware. Speech pathologists are generally aware now. I would colleges to be aware that students with dyslexia are not being identified and treated. I have spoken with a couple of colleges. They expect the students to come in and identify themselves. And I said, what about these students who come in and say, I don't know how to learn. I don't know what is wrong. Because the students are not being identified and treated in the public school system. And she said, but it's by federal law. I said, it's not being done in the state of Rhode Island and many other states. I'm not even picking on this state. So I would like colleges to be aware and to have recourse. The people that I spoke with said we don't have any tools available for us to identify these students and help them. We have to have them declare their disability and we know what tools to give them. I believe that this is an opportunity and I'm really excited -- I've had this vision for years that there would be a statewide conference. In some states they require teachers to know about all of the learning disabilities, what they are, why they are, how they affect learning, and the compensation and treatment techniques. This is mental health, a specific learning disabilities like dyslexia, autism, ADD, I would love to have a statewide conference and invite other states, have continuing education units for the OT community, the teachers' community, the psych community, the social worker. I think we could -- it could be phenomenal. This is a wonderful time to do it because we have the technology to provide education for the visual learner, which is OT, which is dyslexia, autism and ADD. So I hope that something will happen. Thank you.

MEREDITH SHEEHAN: Thank you very much. Does anybody have any feedback or comments at this point? That was really wonderful testimony. Thank you so much. We will -- just so you are all aware all of the transcriptions do get compiled. We have work groups. We have committees that -- you know, take each issue whether transportation or education. We really are very thoughtful about that process. So you know even if we don't have all the answers for you today just know that, you know, it will be thoughtfully looked at in the months to come.

ANNE MULREADY: Can I just comment briefly. I think there was legislation filed to require that schools use evidence based scientifically based instruction. I don't think it went anywhere. But I think it's been filed for a couple of years. That would be something to visit

TIA BECKMAN: I have been one of the gang. And I have been speaking up there. And the House passed legislation for identification and treatment but the Senate has been dealing with it. And the

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Rhode Island Department of Education's vision is for mostly for culture, race, and economics. But I don't see anything about what I call different kinds of minds so.

CASEY GARTLAND: Well to add on what Meredith said if you look inside the first page of that packet you have, you will see some outcomes that we pursued and successfully worked on in previous years.

MEREDITH SHEEHAN: Thank you so much. Thank you. Okay. Next we have Goldie William.

GOLDIE WILLIAMS: Hi. Goldie Williams. I am with the Chariho school district, a parent with a son who will not give a 504 plan to. I will talk to them about that later. But I was wondering how you can investigate a school district who keeps kicking out kids out of their plans, who need it. And second, I was wondering how you propose a law to fine those school systems or districts.

CASEY GARTLAND: I don't know that our panel has answers to that. Obviously you have two parts there at least and when it comes to laws, that's something you want to work at legislatively. As for oversight for each school district, I imagine that you also would access RIDE --

GOLDIE WILLIAMS: I've tried. But -- I called the legal department. Never got back to me.

ANNE MULREADY: If I can -- this is --

GOLDIE WILLIAMS: And I got the Rhode Island Disability Law Center -- I am filling out the paperwork right now.

ANNE MULREADY: And I just would say that the office of civil rights at the US department of education

GOLDIE WILLIAMS: They turned it down.

ANNE MULREADY: Okay. They look at 504 eligibility issues.

GOLDIE WILLIAMS: They turned it down. They said go to RIDE.

MEREDITH SHEEHAN: Thank you. Bretta Combs.

BRETTA COMBS: Bretta Combs. Thank you. Hi. So, I am here just speaking -- this is also my multiple visits. I have been to a couple of these. I think back in 2006-07 when cuts were made in 2008, I believe about 38 million dollars were cut at that time and then matching funds were also lost and you know that really made, you know, really made our system almost impossible. And now I think Governor Raimondo is not opposing \$91 million in cuts. So my concern is knowing there are some current inconsistencies. I am certainly interested in saving Medicaid dollars and having thoughtful

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conversations about this proposal. But I'm questioning the sustainability and I'm frustrated quite honestly. I do private work in adult services and we have been reinventing Medicaid for over 20 years and you know, families are angry and they are frustrated and our system is acting as a deterrent to us getting good quality services for many of our adults with disabilities and our elderly. So you know, a few things that I hope to accomplish in coming today to speak with you is specific to some of the key initiatives that I see -- I did read the entire proposal many times. But in just thinking a little bit about the key initiatives on the cheat sheet, there were a few things where they make reference to the pilot, the coordinated care program, and the definition, and then also the targeted community based programs for individuals who need intensive services. And I think for myself and some of the families that I work with, it would be very helpful for us to get an idea of like what would that look like for individuals to navigate their way through those two proposals. Can you provide a sample of what that would look like from start to finish? I know for myself, I have one key contact at BHDDH that I can pick up the phone and a dozen of phone calls I can make and I don't reach somebody. That is very frustrating for myself and for some of the families that I talk to. So that is one of the things I am hoping to be very something that maybe you can consider is to maybe provide a sample of what it would look like for an individual to go through one of the few key initiatives like the piloted care program or the targeted community based program. Like what would that look like if I were an individual, young woman 26 years old with you know autism or Down Syndrome, what would it look like for me to go through one of those two programs? What would that look like? That be would a big help for me. Another concern I have is just when we think about reinventing Medicaid and what we want to do in saving dollars, again I am more than interested in trying to do that. But I hear a lot of things in the proposals and how they are saving the money about piloted or expanded or enhanced or improved. And that kind of -- those verbs worry me a little. I don't know how you really define some of those. Like my improvement, what I define to be improved may be different from yours which may also be different from yours. So when we make reference to enhancing the eligibility determinations, what does that mean when we talk about enhancing something versus expanding opportunities. For one individual, expanding opportunity may be stepping outside of their house whereas others it may be volunteering at a pet shelter. That is another concern I have, just wanted to express my concerns. I think the dollars that we are cutting are pretty devastating to our system for both our adults with disabilities and our elderly and our veterans. Thanks.

MEREDITH SHEEHAN: Any comments? No. Okay. Thank you. Okay. We have Diana Juliana

DIANA JULIANO: Diana Juliano. I feel worse than when I came here, honestly. Part of it was for myself but hearing everybody else's story -- when you affect children, you are a decaying society. I was on the beach today and I had spoken to someone at parks and recreation because I couldn't get on the beach because they moved everything. The toilet is over there. This is over here and I almost died on that beach. Thank God the lifeguard, that place was where it was because I couldn't get

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anybody to help me the way it is now. And then I saw a girl come in, about 14 with a family, two crutches, and braces on her legs. Somebody said they have those big things. Oh no there is only one of them somebody has it. They don't bring it back. They take it for the day. It's too hard for the sand, the walker that is why I was sitting at the edge. But I thought this is wrong. My cousin is superintendent of special ed in New York, I mean, I can't believe what is going on in this state. I am trying to move here for six years. I first came here 44 years ago. I got disabled six years ago. And I called everybody you could think of because I said I can't believe, all I get is dead ends. No, there's no bus by you. Charlestown, South Kingstown, so you die. You are in Exeter, so you die? I don't understand it. There's no quality of life. I went to URI, they got so much money, the gerontology department. Had a big thing on active aging or whatever it was. And I couldn't get access to the pool. I couldn't get access to go to Christ Our King. Oh there's no handicapped. You better watch, they tell you. There is a very unfriendly atmosphere. I have been telling that for 20 years and I am handicapped. Well, I mean I am from New York. But besides that, I am a nurse and I would fight for my patients like I want to fight for myself and others there who maybe don't talk. I can't believe what I am hearing. Because I don't think any of you really can address these things. And for myself, it's -- I once read it's better not to have an idea at all unless you can act on it. I have been trying to see how I can get verbal. I get a call when Gina was running. I don't live here all year-round so I couldn't really vote. Oh, the Nat is so good. You should know, write it down. Like here she sat here how many years nag I feel like maybe I am not supposed to live here. You read what is the best place to live. Don't go to Rhode Island because the taxes will kill you. Even on TV, listed don't come here. But if you are here, where are you going? It's a beautiful state but this here has me more downtrodden than anything else about myself. So I try to -- you can't believe what I tried here because so many things happen to me while I was here that I had to try to access everything. And when I was going to this meeting, I must have said to somebody, I have been trying to get someone from the senior place to call me. The woman heard me. She was from there. Afterwards she said, I am going to call you tomorrow. But they couldn't call me because my number wasn't 401. They said they can't make the phone calls if it's not 401. Hello, it's not a long distance phone call. It's a cell phone. And so for two and a half years I am spinning my wheels. Town hall, call over here. I never knew that -- really the senior centers are like little governments. I never heard of such a thing. So I was like no, it can't be. Then when the guy happened to, in the center said I remember you but you don't have a 401 number. Well, what does that have to do with the price effects? The phone won't let them call out to give me any information. She happened to hear me say because here's a place for seniors and URI, parking lot is here. The entrance is down there. And then when you get there, there's stairs, somebody open the door. More stairs and I have a walker. I had picked up a man that I met in a shelter what happened with Irene to get out of the -- and he said don't worry about it. I will fund it. I can walk better than you. So you have a place for people with -- and what's -- where's the access? When I went to the shelter place, the intake guy said I know you. Really? Two years later. He said yeah I picked you up at the beach. He said we just

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finished talking about Rhode Island drivers. They hear the sirens. They don't move. I almost died on the beach. My heart rate went to 14. So I mean I could address every single thing with the story because I don't give up easily. But you know, but you can deal with yourselves. You can't see children deal with it. So I mean I am trying to find out how I can get involved that somebody listens. I don't want to just keep on talking and no one seems to have, oh, you can't -- I can't. I call Whitehouse's office. I just am amazed, amazed. Anyway -- I am frustrated. I am sorry. I want to talk any more --

CASEY GARTLAND: Have you called the governor's commission on specific access issues?

DIANA JULIANO: No, no, because --

CASEY GARTLAND: I was curious.

DIANA JULIANO: Because this was the first -- my friend saw and said you have to go. You have to go to this meeting. So really what I need to do is find out how I could verbalize -- I am an outsider in a way coming in here even though my family came here years ago. I do think I have some valuable things to say and I have been through a lot when I am here. But as I said, I have a full life, children didn't yet. You know, and I use handicap in New York. When they pick you up, there's a half hour window. They are obligated to pick you up on the way back. Not up here. They may not come at all. You are stranded. No such thing in New York. You may have to wait but you say thank you, I got the RIDE and you wait a half hour. If you can't wait and you have the money, you take a taxi and they reimburse you. I am not saying it would be the same thing but like he stayed two and a half, are you crazy? If it's cold -- what are you going to get pneumonia out there? I don't know how the system works. I called RIPTA about this here. There's no way down there. I said well, you have to move. Where? Well you have to give me an address. Oh so I should -- before I buy a house, move -- if I have to do that, I will stay in New York where I have the handicap, I have whatever. I mean, as I said, she knows. I want to move but everything -- something stops me all the time. Anyway --

DEBORAH GOLDING: There's a fairly new brochure, accessible Rhode Island. Have you seen --

DIANA JULIANO: I saw that but you know what? I spent a couple of years calling -- oh my God you have no idea, you name it. And I thought, I'm not going to be eligible for this. I could drive right now but if I can't I have no family up here. So what do you do? At this meeting, they identify two things. Lack of housing, affordable housing in Rhode Island. And no transportation. And suicide, if you don't get that socialization and seniors when they try to kill themselves will succeed. So what's happening? I mean, what's the outcome of that? That was their own conclusion. So you isolate people. Put them in the community. And they can't go anywhere. And Rhode Island, this is just for seniors too, has the most number of seniors over 85 years old. It's a shame what they are doing here. They are so happy about the wind farm. Why don't you show the world that the country what you can do allowing your seniors that healthy. What are they doing that they were able to get like that.

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I'm serious. I have been very impressed with the seniors up here because they are frugal. They are not paying this one to do that, this one to do that. They are good at doing all themselves. I tell my friend, get somebody to pay it. No I can do it. But what I am saying, it's a shame. It's really -- they have another thing that they can be premiering, and they don't. They just are letting it go by. It seems like nobody was watching the shop. You know?

MEREDITH SHEEHAN: And you live in Charlestown?

DIANA JULIANO: I live in South County, across the street is Charlestown.

MEREDITH SHEEHAN: They have a senior center.

DIANA JULIANO: I go to the one in Wakefield because I can still drive. This was years of finding out this trip, that trip, this -- you know? It's -- it hasn't been easy for whatever reason. I could have just let it go but it's not my nature so I kept on trying. I couldn't figure it out. I kept calling the same place. No it couldn't be. It can't be. Well it is. But like she's saying, I'm not hopeful things are going to change, honestly. That's all in God's hands. But I think there's just so much that any committee here can do because that's not what they are focusing on. You know, their priority is the wind, the energy -- which is fine but not when you have the seniors and -- moving or whatever. And cutting and cutting and cutting. It's -- oh my God. It really is too much. And this just reinforced that. Oh my God. Thank God I have to leave early. I don't know how much I can take of hearing this. Honestly.

CASEY GARTLAND: Thank you for speaking up.

MEREDITH SHEEHAN: Thank you so much. Just --

DIANA JULIANO: I will take one of those

MEREDITH SHEEHAN: The resource that Deborah mentioned is actually really good. I know this organization really well. I don't know if you are all familiar with that

DIANA JULIANO: This is not the government.

MEREDITH SHEEHAN: This is called Accessible Rhode Island and it is -- I think they have some state and federal funds that they got to put this together. The reason I know that is because the people who head it up, the woman has MS, so I work with her through the Society. And they actually went -- they had kind of field people who went out across the state to beaches, restaurants, any public place you can possibly think of, and they are all reviewed on this website. And you can read about how accessible they are, how the parking is, if there's a stair to get in, really bathrooms. So you can go on. If you know I am going to go to Matunick State Beach, how does it rank in terms of accessibility? This is a fabulous, really comprehensive. If you want to go out to dinner, it's informational. We have

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them. But it's a really good website. They've done a ton of work putting it together. So it is really good.

DIANA JULIANO: Is that the one that has the evaluation form?

MEREDITH SHEEHAN: I believe so. I think it's on the website. Okay. Great. So Donna Gilton.

DONNA GILTON: It's like the hotel Hilton but it is with a G, Gilton. That's it. Okay. What I want to speak to and I probably won't be long, my brother is -- he's under Perspectives at this time. He goes to what used to be at the LaPlante Center and he lives in a group home in North Kingstown and I live here right around the corner in Peacedale. The reason I want to say something especially after hearing everybody else talk is a few years ago we had the experience -- and my mother was still alive and still relatively well at that time -- this is under governor Carcieri where there was a big attempt for the state to get rid of group homes and we had to go to a series of hearing. And then I remember coming to a hearing similar to this and what was happening was the state was cutting and cutting and cutting and cutting. And LaPlante was -- it had been a good program and it had deteriorated and it eventually Perspectives took them over and seem to be doing okay now. But what concerns me is, I mean, and then I used to teach at the university. And I experienced this in my department and at the university too. It's sort of like where the state is cutting and they are trying to make us do more and more with less and less until we are doing everything with nothing. That's what is going on. And I am also concerned about the lack of coordination between all of these agencies. So those are my two concerns. How long can the state continue to cut before there's really no services left or before we have real poor services. And when do we start cutting? Just cutting cancer can't be the answer. Those are my two concerns and that's it.

MEREDITH SHEEHAN: Thank you. Okay. Gayle Tazwell.

GAYLE TAZWELL: Hi, Tarzwell, Gayle. Thank you. I appreciate the opportunity to address you today. I come as a mother of a 29 year old Down Syndrome woman who receives services, adult services through DDD and also as a local attorney who does a lot of estate planning for families who have children with special needs and who have issues with eligibility for DD funding. So what I particularly wanted to address is the policy of the state, particularly BHDDH concerning paid caregivers who are family members and I've come across this on two different aspects. And other states, family members are eligible to be paid caregivers when Medicaid dollars are involved but our state, especially on the BHDDH side has given a very chilling effect and implicate -- have implemented policies that are anti having family members be paid and I will give you a couple of examples. In the first is self-directed services that are funded with Medicaid, DDD money. And parents, guardians, stepparents and even people who hold powers of attorney for people with disability are ineligible to be paid caregivers for self-directed DDD funding. Totally cannot do it. They are excluded. I'm

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personally not looking to be paid caregiver for my daughter. I am blessed that she's high functioning and that I can have paid caregivers come in and take care of her for enough hours so that I can work as an attorney and also be her mom. But I do have access to other families who will tell me stories. For instance, an elderly mom who is guardian for her Down Syndrome son. She wants her nondisabled son to be co-guardian right now so that when mom passes there will not be a hiatus where the son does not have a guardian. And she went to an informational session on self-directed services. She receives or her funding and utilizes it through Ocean State Community Resources and was told that if her son, her adult nondisabled son becomes guardian, he will no longer be eligible to be paid as an options worker. So that stopped her guardianship proceedings immediately so what do we have, a situation where now we have to wait for mom to pass away and then mom's -- then son without the disability has to race into probate court to become guardian for his Down Syndrome son. Does that make sense? No it doesn't. Even other states -- as I said, do allow Medicaid funding to be used for paid caregivers and even the Medicaid funded personal choice program that's on the DHS side in Rhode Island allows paid families to be paid caregivers. But not on the BHDDH side. When we come to DDD, there's definitely a distrust of allowing family members to be paid. Now I will put on my lawyer hat for a minute and I prepare many special needs trusts for families who have children with disabilities. There's two kinds of trusts. There's the trust with the parents money. We call those third party trusts. I will not address those today. Then there's the ones called first party trust and those are funded with the money that belongs to the person who has the disability. So quite often it will be a person that has had an injury, either at birth or through an auto accident, become injured, become disabled and then they sue and they get a settlement and then the settlement has to go into a special needs trust called the first party special needs trust and it has to have a payback clause. So the deal is you put the money into the trust now. Immediately eligible for Medicaid but when the person with the disability dies, whatever is left in the trust has to be paid back to Medicaid, okay. So that's the kind of trust I'm talking about and I do prepare those trusts for families who have this kind of situation. But what has happened is that we attorneys are being told now from the Executive Office of Health and Human Service when we draft these first party trusts that we shall not put in any provisions in those trusts that allow paid family caregivers. We are being told not to put that in the trust. So -- these are irrevocable trusts. We can't even change them if the policy changes in the future except by going to superior court and asking for a change. So that's having a very chilling effect on having family members being paid like in other states. And we got the very odd situation -- and this is especially with severely involved folks who have big settlements where the family member, like a mother, in my case I know of a mother who has a child and requires tube feeding. Has to be fed by tube. And she can -- the trustee of the trust who is a bank is saying because of this chilling effect, you cannot get paid to feed your own child. We can pay a stranger who has the qualifications but we will not pay you. So we are going to pay more money to have a nurse come in and feed your child but we can't pay you. And this mom says to me, I cannot work outside of the home and even have my own health

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insurance covered because I have to stay home and feed my own child. The trustee won't pay me to feed my child. It doesn't make any sense. I'm just hoping that some of the policies can be changed so that the unpaid hours that parents -- many parents are children with disabilities put in can be recognized and that this perception of abuse -- and I'm sure that there have been abuses and maybe that's what colors the division or BHDDH's thinking on this. But it has to change because it's not right and it's certainly not in the trend of the company. This particular woman that I speak of went to Disneyworld. She saw another mom with a child just like hers and the mom said, I'm being paid in Colorado to take care of my child. The mom came home and said, why am I not being able to be paid for my own child's trust that was set up because of her disability? Why am I not being able to be paid to take care of her? Thank you.

CASEY GARTLAND: Can I ask you a question. Have you ever been shown a regulation of the parts that allude to that? We've heard about that and I have yet to see it.

GAYLE TAZWELL: I have not seen it

CASEY GARTLAND: Wondering if you have GAYLE TAZWELL: I have not. I get my information from David Reese who is the executive director of OSCCR, Ocean State Center Community Resources, one the fiscal intermediaries for the Options Program. My daughter receives her DDD services through an options plan. And we love it. We are very grateful that Rhode Island has that option and as I said, I am not looking to be a paid caregiver there. But you know we have people who are going to secede to be guardians with folks with disabilities then they are categorically denied to be paid caregivers under the present scheme.

CASEY GARTLAND: I want to make sure -- because I would love if you have point to it. They never referred to a regulation that this is based on

GAYLE TAZWELL: No. And it shifts. When we first started options with my daughter, let's see, it would be eight years ago. Siblings who are not under the same roof as the person with the disability were allowed to be paid. But if you were a sibling living under the same roof of the person with the disability, you were categorically denied the opportunity to be paid. Now I have heard that that -- that rule changed. That siblings living with siblings are going to be allowed to be paid employees under a self-directed DDD plan

CASEY GARTLAND: We actually did, within the last year the DD community achieved a minor victory, siblings can be shared living providers. We achieved that. I think you are right. Become more aware with the exception of that area

GAYLE TAZWELL: Okay.

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ANNE MULREADY: I had a quick question about the trusts that you mentioned. Did you mention it was a separate Medicaid policy around not allowing family members to be paid from the trust either?

GAYLE TAZWELL: From the trust, right.

ANNE MULREADY: Is that OHHS.

GAYLE TAZWELL: It's EOHHS legal counsel that has given attorneys who work in this area a checklist of the types of features that the trusts must have or must not have. And one of those features is that a family member may not be paid as a caregiver and they even added as a trustee, which is contrary to Rhode Island law that allows trustees to be compensated. But this is what we are being told to put into the trust and every one of these payback trusts are screened and reviewed by legal hopefully before they are funded. Sometimes they have to be funded ahead of time to keep the Medicaid eligibility. But prudence dictates and this is what they want, and every single year the trustees are requested. Again there's nothing legally but -- requested to provide accountings. So this is where the lawyers at EOHHS are going to say, oh, you trustee, paid a mom to feed her own child. Not allowed. So the trustees are chilled because they don't want to find out that they've paid something and then -- within a year, oh no. You weren't allowed to use the trust money that way. Put it back. Medicaid thinks because of the payback clause and what a payback clause says is that anything that's left in the trust when the child dies, the person with the disability dies, goes back to pay whatever Medicaid tab that person has run up during their lifetime. And they do it just like a hotel bill with your Social Security number at any point in time you can find out what the Medicaid tab is. And the payback -- so Medicaid lawyers think of this trust as Medicaid money. They think of it as theirs already and the trustees account, because they don't want to wait 20 or 30 years and be paying out money under the assumption that it's an acceptable disbursement from the trust and then find out oh no, trustee, you shouldn't have done that. So the trustees are very conservative about how they do this. And thus I get a situation where the mom calling me up and saying the trustee won't pay me to feed my child a tube feeding. Or the trustee won't pay me to do this. You know, you have situations where children need 24/7 care and the money's there. And the parent is willing and the parent can't work outside of the home. I mean, you know, you can't hire people for more than 40 hours or you are paying them time and a half. All of those rules apply. And so you get a parent that says, all right. I will be willing to work but I would like to get paid because I can't work outside the home.

ANNE MULREADY: So that -- and that is just by legal counsel checklists, not a regulation

GAYLE TAZWELL: As far as I know. Yes. Its policy and it's having a chilling effect. It's broadcasting loud and clear to the trustees and to the parents. This is not going to fly. So don't ask and don't do it.

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BARBARA POLICHETTI: This is Rhode Island.

GAYLE TAZWELL: This is Rhode Island.

BARBARA POLICHETTI: That other mom ran into someone from another state Colorado. So -- and I apologize this is not my area but I wanted to make sure I was understanding because it's fascinating and frustrating

GAYLE TAZWELL: Yes.

BARBARA POLICHETTI: So even though this may in some cases involve the disbursement of or eventual reimbursement of Medicaid funds what you are ROUGH ASCII 31 saying is there's a Rhode Island rule or a policy pertinent to -- involving federal funds and that same rule or policy you may go to another state and --

GAYLE TAZWELL: That's correct. In fact I was talking with David Reese yesterday and he said when it comes to this particular issue, Rhode Island is in the minority. Other states -- and the trend is towards paying family caregivers with Medicaid dollars to take care of their own children.

AUDIENCE MEMBER: Usually they cost less if a family member --

GAYLE TAZWELL: Of course, it costs less. Exactly. According to this mom, even a CNA cannot tube feed her child. Cannot, okay. I am bless that had I don't have a child that requires tube feeding. But she said -- it would cost so much more to hire a person who is eligible to feed her child than just to pay me to do it. And I know how to do it. I have been doing it. And of course, she said I can't work outside the home because I have to be available for her feedings. And I don't even have the ability to have a job with benefits. That's what she asked me and I said, I would tell you today her situation and I see it from the parent perspective. I see it from the attorney perspective.

TIA BECKMAN: I will add to it. My father just passed away but during the decline, he had to have caregivers at night. Many times we couldn't count on the caregiver. We hired an agency. We could not count on the caregivers. So fortunately, I was five minutes away and I'm so thankful that I had that special time with him. But it's not only a mother wants to, it's hired help. You can't rely on them.

GAYLE TAZWELL: Thank you.

MEREDITH SHEEHAN: So, on the list I had that was actually everyone who signed up to speak, however I know that a few people have come in since we started the forum today. So if you did come in late and you wish to speak, if you just want to raise your hand. We can have you give your testimony.

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ELLA WHALEY: Ella Whaley. I just -- I am a retired schoolteacher from North Kingstown for 32 years. I served on the school committee in this town for eight years. I just finished with eight years on the town council. Still doing a lot of advocacy, school department in South Kingstown has a lot of -- it's conference calls me. I am a Florida resident now. I am here for four months and Florida for eight, so I don't even know if I have the right to speak. But here I am. Doing a lot of educational advocacy here in South Kingstown as well as neighboring towns. I am just very still concerned about the language based learning disability and I know that there was some legislative acts setting up a committee with dyslexia and I am not sure that that got the traction that it needed. I know there are some recent bills. I want to resurface all of that. I really see a need for the state to take some action and really do some training and process to identify children with language based learning disabilities. So that was my first. I would like to thank Tazwell for bringing her testimony to the forefront and I support all that she has said. I am also the mother of a child with a disability who is 26 and we are trying to transition her into some housing. Kenyon Avenue permanent housing she is number five on the list. So when that gets up and running we are hoping that she is successful and we can realize before we pass away that we have taken care of her. The thing that I really would like to bring, you know, to the forefront is the cuts in the Medicare. I have been blessed also with David Reese and options and very happy with the plan that my daughter has. But I really would hate to see any more cuts, you know, with the Medicare. And I also have many questions -- if somebody could just put me in the right direction for the flex bus. Is there any information that I can get in reference to that?

MEREDITH SHEEHAN: Barbara just stepped out.

CASEY GARTLAND: When she comes back in she can discuss the flex bus

AUDIENCE MEMBER: There is stuff on the internet

ELLA WHALEY: The internet, okay. And I guess my understanding of that is my daughter will be able to call and she will get somebody to pick her up and somebody to drop her off.

ROBERT ROMERO: That is between the flex and the RIDE too.

ELLA WHALEY: There is a difference between -- I know this is probably not like a question and answer thing. I will have to get more information on that. The other thing is as I attend special education meetings for families with children with disabilities and I may have a question, I call and let me tell you I have been doing this for a very, very long time. And when I call up to the Department of Education, sometimes there's not a phone call returned. I used to be able to pick up the phone and call Paul Ponterelli, all of the attorneys up there. And I know its short staffed, but I mean it really is a need that needs to be addressed. And then it's -- again it's a question -- I am just going to throw it out there. I don't expect an answer but if somebody could get back to me. I also would like to know if the state offers the school districts any kind of education to educate and get a baseline for children that

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are nonverbal, okay. I don't see on your list that you have turned, you know, out today that anybody is a specialty on this board for children that are nonverbal. And I really see that there may be something lacking in the schools with trying to address some of the needs with the children. So I don't know if that has an answer or somebody can let me know later.

CASEY GARTLAND: If we don't have the answer here we take these in the notes and someone could get back to you. So make sure -- did you register when you came in?

ELLA WHALEY: I have my name up on this sheet here. To reiterate what Gayle said, I do have a son who now is in Montana. But he was able to get paid to help us out to take care of my daughter. The problem that we had is once we are in Florida and my daughter wants to take a vacation, there's nobody. It's when they leave the state of Rhode Island, again, that that policy that you have. You know, there's no paid worker that is going to be able to take her even to the cape for, you know, maybe a weekend or something like that and I think that people with disabilities are entitled to vacations just as their nondisabled peers. I think that is something to add to Gayle's list. That's it. I thank you very much for having the forum.

MEREDITH SHEEHAN: So, Barbara's with RIPTA. So if you wanted to re-ask the transportation question.

BARBARA POLICHETTI: I apologize

ELLA WHALEY: I am looking for information on the flex bus. My daughter is hopefully going to be successful over at the Kenyon Avenue permanent housing. We are almost into Charlestown and you have been to one mile from a bus line. Like there's no transportation. Even as a town council member I have tried to get our senior van to -- if they are going out to green hill to pick up somebody, and there's a child with a disability. There's another students out there who is at URI who, you know, is blind. She couldn't even get a RIDE to URI. There's just a lot lacking with transportation. So my daughter hopefully is going to be moving into town and I just needed information on the flex bus. If you wanted to fill me in later, that would be fine

BARBARA POLICHETTI: That would be great because I can go back to planning. I can take a look at what is available. And I will get your information and I will get you any information that we have on flex services in this area

ELLA WHALEY: Okay. Thank you very much. Thank you.

MEREDITH SHEEHAN: Anybody else? Anybody who has joined us recently and would like to speak. Sure, absolutely.

CAROLYN MAXWELL: I just ran in so I am not sure.

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MEREDITH SHEEHAN: Would you mind coming over here -- the air-conditioning it's a little hard to hear. That would be great. Thank you so much.

CAROLYN MAXWELL: My name is Carolyn Maxwell. And I am a resident of Kingstown. I have a daughter Emily who is going to be turning 23 soon. We currently have a self-directed plan. To give people an easy grasp, which it's not easy about Emily. I kind of call her my kindergarten kid. We are working at that academic level. And she has a hearing loss, which makes it even more complicated for her to be integrated into the community. Most people cannot communicate with her. And so after looking, knowing that the transition years were coming and looking at programs available and finding none, we found ourselves really needing to be creative about it. The last year of school, Emily's teacher of the Deaf who had worked with her as a consultant in the South Kingstown school system, Emily began her education at the Rhode Island School for the Deaf. But then we moved back to my childhood home when we said six years in preschool. What's the plan? You know? Everybody else was moving on and growing up. And you know, here's Emily. So we created a program with the teacher of the Deaf within the South Kingstown school system. Last year Mrs. Flexure sent home a gift. It was a small collage, little wallet sized pictures she photographed Emily's hands signing LOVE. And of course, I thought it was fabulous. But then when I showed it to other people, you know, their hearts melted as well. So I said, well we might have something here. And we began a business called love letters by Emily. And we are on Etsy and we are kind of around town too. We have been given shop space at Spangles in Wakefield. We are at Bagels in Kingston. We are -- I wanted to see if this was a viable plan. The year before Emily completed school, we started an Etsy shop. And I set it up and she came home and turned on the buttons and turned on the shop. And an hour later somebody in Ankara, Turkey, had posted one of our prints. And from there, her hands are in 41 states and coast to coast in Australia, and in the United Kingdom and Canada. So, with all that said, I haven't worked since Emily was born in my profession of being a teacher. And the four years that I've devoted to this, there have not been any paychecks for me. When Emily was about to turn 18, I started and I called the Office of Rehabilitative Services and said this is a plan, kind of what support can we get? And we were told that unless Emily could really work 40 hours a week in an integrated setting after being supported for a year with a job coach, we really would be referred back to the developmental disabilities kind of department. And of course, now they are saying oh we never would have said that. But I said, well, I am the one person. You talked to hundreds, thousands of parents. But I remember the conversation that I had because it was singular. Anyway, with all of this going on and cleaning off my dining room table every night of the project of the day, and you know, what we put in our bank account is not going into our pockets. It's buying more materials and supporting us in a way to keep it going. So in the second round with ORS, we came in saying everything is on our family computer. I have to kick everybody off when I say I've got Etsy orders to do. Emily always had a communication system in school that consisted of a computer and a printer and an iPad with promo quo to go. And I was saying we need that plus an iPhone which will allow, you know, communication with her support

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staff or if we are sliding credit cards through it at events. This is our wish list. So we approached ORS again and they did a first situational assessment and paid a company \$1500 for it. And they decided they needed more information. And these people, meanwhile we were not given any further, you know, equipment or things. And I felt it was like, well what are you doing with Emily now, with nothing new, nothing provided? And they did a second round of situational assessment for \$1500, and a year's worth of meetings now and then where an interpreter was paid for. So I'm kind of -- going, adding things up in my head saying, okay. We could have gotten everything on our list and been flying now. But all -- and I know there are rules and regulations. But it all came back to she needs to be in an integrated environment, earning a paycheck. Which again won't impact her SSI funding, which is a huge part of raising Emily. So with the requests that I write out paychecks for \$100 a week for her and insure her for workmen's comp because she is working for us in our home, and all of that. I said we don't have \$100 in orders every single week. Where am I going to get this money to pay her and totally rework our SSI benefits? And come to find out they put in an order for \$1500 of technical support, computer support for somebody to come and sit down at our family computer and all. And I said, I can go to the Apple store and ask all my questions for free. You know, you don't have to spend that money. And then the upshot was, well, why don't you go to Goodwill and see if you can find a refurbished computer. So I'm totally beyond frustrated and wondering, you know, where to go on this. And in our self-directed plan we always have unspent money. Emily is a tier D, and even though we pay our workers usually more than the average because they come to us with sign language skills. They have to. And a car to -- she wants to be out and about in the community. They have to have reliable transportation and all. So again, but we would have somebody sitting at our dining room table every night if I filled all the hours that our funding would pay for. And in the meantime, people are telling me we used to be able to write in the computer in one of these plans. Or we used to be able. But the one thing I wanted to say tonight was Emily needs more than people to make this plan work. And if we had any other options for Emily -- I'm not sure I would be doing it. There's so many things about this I love and we call it a mother-daughter business and you know, we are there -- my sidekick and all. But you know, again there are moments when I think, well, what if Emily hadn't had all these challenges. So along with that, we've had people come and go and say things like -- oh, in Michigan my special needs sister can go to school until she is 26. Everyone looks at Emily and wonders why she isn't in school because she's petite. She hasn't developed as most typical kids. And again I said for everything to change at the stroke of 21 and losing all the technology equipment in the school system that is used on a daily basis and not provided unless we, you know, save up our money, you know. Again, ORS says go out and buy a computer or what you need and put it on your credit card. And then, you know, pay it back over how many payments it takes. I'm sorry. I just -- you know, other people seem to get access to what they need or the people who are doing the situational assessment kept saying don't go buying address labels. We want to provide that for you. But you know. And then it was -- you know, the computer that, no, no. We are not going to provide that for you or anything else.

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We would love to. And in the meantime, we have RIPIN. We have the center for excellence and advocacy calling and saying could we use you as a success story? And I said, I don't feel like a success story here. I have been just working as hard as I can for as long as I -- she's been with me that it really -- it really is a difficult stretch now to imagine not to have all the support that we did have when we were in the school system and to really come up with a very creative, very productive lifestyle for her and still it's, what can you provide for your daughter? And I just want to share with you. This is the manual alphabet. I will just use the chair. After I saw her LOVE, I sat her down and took the pictures and this is the alphabet, all Emily's hands. And we've made kind of graphic renditions of the first idea. We just worked with 401 Studios on the Main Street of Wakefield for them to come and vectorize our design, which is another whole area of support of what we could do if we had something to work with. But we bundled our earnings and our money that's come in and have put in our first T-shirt order and are very excited about, you know, again, presenting it on Etsy or some of the events that we've done. We were invited by TechACCESS to be vendors at the New England -- help me out --

AUDIENCE MEMBER: Assistive technology conference

CAROLYN MAXWELL: -- in November. And typically a table fee there is \$450. But it was waived. And we had people standing in line, arms full of prints. And we came up with \$500 that day. But I said, think of it. If we had been the typical exhibitor, you know, we would have come home with \$50, you know? They invited us back and they've expanded it. They decided we loved having Emily there so much that we are going to invite other vendors and it's called "bringing access to life" and we've also been asked for Emily to sign ACCESS and make that a print that they are going to pass out to all 50 of their presenters who come. So again, I could not be prouder of Emily or what we've been able to accomplish. But it's really been on our own. And I just felt strongly enough that I wanted to come here tonight and share with you. This was a local article when we first started out. And this was done by a phone conversation with a reporter and I didn't know how it was going to come out. But for her to come up with the headline or the title, love letters by Emily educates. I thought you know, she got it. She really did. Tia, we went to high school together {LAUGHTER}.

TIA BECKMAN: We went to grammar school together.

CAROLYN MAXWELL: That too. Anyway, my work here is done {LAUGHTER}. I just really wanted to share with you. One last blast is we were invited by the Justice Resource Institute in Massachusetts. They have a program called Full Circle Arts, which is a store front in Natick, Mass, and Westboro. They have clients with a day program and they make a variety of crafts and sell them. But their clients can't produce enough for all the locations and all the farmers markets that they do. So they said, would you like to be consigners. And we took our things up. And then after I saw the shop, she opened the door and it was, you know, a huge kitchen where they were all going to have a meal together and besides the crafting and the store front, they do meals on wheels and a whole variety

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of day programs and I keep saying, oh my goodness. You've figured it all out of what so many people could benefit from or anything that's Warwick or south would be huge. And I said, I've spoken with David Reese at options and he said if you can find the funding, we'd offer options as the umbrella for this. But again, you know, I don't know, you know, it's really hard to have every day go by and think how much time should I be spending and what doors should I be knocking on and who should I share this with. But it's just frustrating that across the state border there seems to be a setup and they've gone to several locations. They are so successful and it just seems to be a really model program that someone could be taking a look at and saying, hum, wouldn't that benefit a number of people and take love letters by Emily off my dining room table. So -- Thank you

ANNE MULREADY: Can I just ask a quick question for clarification. You said you were looking for a computer and some equipment and I assuming the equipment is kind of to make the computer accessible to Emily? So some of this is assistive technology and some of it is a business computer

CAROLYN MAXWELL: Yeah. Well since much of the business is internet driven, it's, you know, plus she has a Facebook page she maintains and it gives her, you know, kind of a connection with -- and you know, we write out the text. She types it in. The photographs, she's involved in. So it's an integral part of it. Or if we need to show her, you know, where we are going. We will print out the picture of the store in Natick and she will have an understanding of what -- but we need these things at our finger tips and again, it's all been family provided in a way. And I've said, you know, I am not asking for any more than our fair share. A lot of our money goes unspent and wouldn't it be wonderful to be able to go down the list or have someone really validate the need for things. Which I am fine with. But it just doesn't seem to be available to us, the way the system is now.

MEREDITH SHEEHAN: Okay.

CAROLYN MAXWELL: Thanks

MEREDITH SHEEHAN: Thank you so much. Great story. Yes

BRETTA COMBS: If I could just piggyback again on Emily's meant -- Bretta Combs. So, again, I do just want to piggyback some of the comments that Emily's mom made regarding how the fundings are allocated. It's all exclusively staffing. So that is a challenge and there are sometimes needs that are specific to the individual with disabilities, where families will attempt to try to seek reimbursement maybe or funding that would support some of the things that some of the adults with disabilities might need. For example, technology or I work with a young woman who uses those Bose noise-cancelling earbuds when she goes out into the community because she has very heightened acuity to certain sounds. Without those she wouldn't be able to navigate her community. And we have tried lots of different devices that have been expensive and the parents essentially have yard sales on Saturdays to pay for it. So you know, some of the families that I've talked to have

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remortgaged their homes so that they can have funds available to buy some of the supplies and assistive technology devices that their children need because -- I know you probably are thinking, no, really? Yeah, really. Like they are remortgaging their homes, refinancing their homes so they can afford to buy some of this. One of the adults I also worked with -- some of the funds at the end of the year do go unused because we have an incredible turnover in staff. We had a horrible winter and staff cancelled. And you know, days and days and stretches and the money goes unused. And it goes back into the pool and I understand. Again, I am completely open to having these thoughtful conversations about saving dollars. I do want to do that. However, there's also other needs that aren't being met with the current structure that is in place. So I just wanted to piggyback on that point that I do think there is a need for us to figure out a vehicle to get some of these other non-staff, non-direct care needs met

MEREDITH SHEEHAN: Thank you. Is there anybody else? Okay. So, it's about 5:30. We are here until 6:00 or a few minutes before. So if you -- feel free. You don't have to stay until 6:00 if you said what you wanted to say. You are obviously welcome to leave. If you did want to have any private conversations with any of our panelists, I am sure they would be willing to talk to you as well. We will -- if anyone else comes in in the next half hour or so, we will reconvene.

DEBORAH GOLDING: I will put these back on the table.