

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



July 26 - July 29, 2010

Prepared by
The Governor's Commission on Disabilities

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State of Rhode Island and Providence Plantations Public Forums to Identify the Concerns of People with Disabilities and their Families

Every year during the week of the anniversary of the signing of the Americans with Disabilities Act (July 26th) the Governor's Commission on Disabilities and over 20 other state and non-profit agencies conduct a week long series of public forums to hear the concerns of people with disabilities and their families.

The forums are open for anyone to come in and speak; representatives of the sponsoring agencies will be there to listen.

It is important for state policy makers and planners to hear from people with disabilities and their families, their concerns about current services, needs that are not being addressed, and suggestions for improving services and expanding opportunities.

Monday July 26, 2010 2 pm- 4 pm

Middletown Public Library's Community Room, 700 West Main Road, Middletown
Hosted by Looking Upwards

Monday July 26, 2010 4pm - 6pm

RI Department of Administration's 2nd floor Conference Room A, One Capitol Hill, Providence
Hosted by the RI Department of Health's Office of Special Healthcare Needs

Tuesday July 27, 2010 2 pm - 4 pm

Barrington Public Library's Gallery Room, 281 County Road, Barrington
Hosted by the RI Statewide Independent Living Council

Wednesday July 28, 2010 4 pm - 6 pm

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

Wednesday July 28, 2010 4 pm - 6 pm

Independent Square (on Rt. 138 just west of URI), 25 West Independence Way, Kingston
Hosted by the RI Parent Information Network

Thursday July 29, 2010 10 am - Noon

Cumberland Public Library's Hayden Meeting Center, 1464 Diamond Hill Road, Cumberland
National Multiple Sclerosis Society, RI Chapter

Comments may be made in person during the hearing, or you can e-mail disabilities@gcd.ri.gov,
fax 462-0106 or mail them by August 2nd to

Governor's Commission on Disabilities

John O. Pastore Center, 41 Cherry Dale Court, Cranston, RI 02920-3049

We ask that you use unscented personal care products. Please realize that what may seem to you to be a mild fragrance can constitute a toxic exposure for a person with an environmental illness.

CART Recorders (real-time captioning) and assistive listening devices will be at all sites, courtesy of the Assistive Technology Access Partnership.

The RI Commission on the Deaf and Hard of Hearing will provide sign language interpreters; contact the CDHH (voice) 222-1204 or (tty) 222-1205 to confirm which forums will have interpreters.

When making the ADA reservation with RIde to get to and from the public forum, tell the RIde reservationist (1-800-479-6902) that this trip is for the Governor's Commission's Public Forums in order to guarantee your return trip, after normal RIde hours of operation. The ADA fare is still applicable.

For more information or to request accommodation needed, please call: 462-0100 at least 3 business days in advance; arrangements will be provided at no cost.

Requests for language interpreting should be made to 462-2130 at least 3 business days in advance.

The Public Forums are sponsored by the commissions, departments, and organizations listed below that provide services and/or advocate on behalf of people with disabilities.

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Public Forum Sponsors

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Part One | Executive Summary

This year, twenty-four agencies sponsored a series of public forums across the state of Rhode Island to hear the concerns of people with disabilities and their families. The forums took place from the week of July 26th to July 29th 2010 in honor of the anniversary of the Americans with Disabilities Act (signed on July 26, 1990). The forums were hosted by Looking Upwards in Middletown on the 26th, RI Department of Health's Office of Special Healthcare Needs in Providence on the 27th, RI Statewide Independent Living Council in Barrington on the 27th, Ocean State Center for Independent Living in Warwick on the 28th, Rhode Island Parent Information Network in Kingston on the 28th, and National Multiple Sclerosis in Cumberland on the 29th.

The public forums are a chance for people to voice their personal concerns for themselves and their families. The main concerns found at the 2010 public forums were abuse and neglect, employment/education, health care, housing, and transportation. The most common reason for each of these issues are the continuing effects of the economic recession. With deficits in many budgets, services and employees are constantly being cut.

The first issue addressed was abuse and neglect. Elders living in nursing homes and RI Veteran's Home seem to deal the most with abuse and neglect. The next issue was how police officers are handling disabled citizens. Many people at the forums wanted to know more about the police sensitivity training process.

On the topic of health care, one of the main concerns for discussion was Medicaid. Medicaid only funds children with special health care needs. This caused many people to complain about the lack of services. Another main issue was Katie Beckett and the trouble in being approved for its services. Many people heard the funding was being cut while others heard it was being eliminated. The obstacles that adults and children with special needs face when trying to get health care was also discussed. These obstacles include the lengthy process in finding services and the lack of help that is provided at these services.

For housing, the main issues were cleanliness and the use of pesticides. Other issues were the lack of housing and its extensive process.

The last issue discussed was accessibility. These issues ranged from curb cuts to buildings that were still not easily accessible. Some of these building included the State House and CCRI. On the topic of Transportation, the overall concern was RIPTA/RIde and their confusing bus routes. Since Rhode Island's bus routes are limited in rural areas, many are left without a means to travel.

Suggestions were made in regards to most of these concerns, but many were still left unsatisfied. The main problem at the public forums seemed to be the lack of knowledge about the services and resources in Rhode Island. Being aware of these services and resources can prevent and eliminate many of the issues outlined above.

Part Two | Community Concerns & Recommendations

Abuse and Neglect

Concern: Complaints were filed in 2004 about the nurses at RI Veteran's Home abusing their patients. The patients who filed complaints on the nurses were given a psychiatric evaluation and threatened to be thrown out. Patients became terrified to file complaints because of this. This issue is being brought up again in 2010 to prevent the abuse from agencies. p. 15-19

Recommendations for action: Back in 2004, the nurses at RI Veteran's Home could view these complaints. Now, The Department of Health prohibits this and only allows certain employees to review the complaints. The complaint process can be found on their website: <http://www.health.ri.gov/hsr/bmld/complaintform.pdf>. Publicizing the complaint process can help prevent future issues. Another recommendation is for the Governor's Commission on Disabilities (GCD) to monitor and respond to implementation of 09 H 5983 Article 05 Sec. 01 the crisis intervention services for abused non-elderly adults (18-64) with severe impaired [need for BCI check for in-home personal care services.

Concern: Respite for the elderly and adults with disabilities is not funded by Medicaid. Medicaid only funds children with special health care needs. p. 21, 80

Recommendations for action: The Governor's Commission on Disabilities (GCD) will monitor Medicaid Reform proposals to ensure maintenance of current services to individuals with severe disabilities. Medicaid is looking at the results of the working group for Respite to assist in determining how Medicaid should consider funding for this service.

Concern: Caregivers and mental health hospitals are not properly handling people who have a disability. p. 20

Recommendations for action: To ensure training is required at agencies, the Governor's Commission on Disabilities (GCD) will receive updates on psychiatric disabilities and the training offered to first responders by Behavioral Health Developmental Disabilities and Hospitals (BHDDH). Another recommendation is to reintroduce last year's legislative package of the protective services bill.

Education/Employment

Concern: The Employment First policy is not allowing the disabled to be first. Employment is being looked at as an option for people regardless of a disability. p. 41, 47, 50

Recommendations for action: The Governor's Commission on Disabilities (GCD) plan to monitor the Sherlock Plan and how well it is being implemented. The Sherlock Plan is a Rhode Island Medicaid buy-in for people with disabilities who want to work, but are worried they will lose their vital health care coverage. The Sherlock Plan helps people with disabilities earn more income without the risk of losing health coverage. To find out more about the Sherlock Plan visit: <http://www.rhodesoindependence.org/docs/09%20combined%20English.pdf>

Health Care

Concern: Children who were once eligible for Katie Beckett are now being denied. If children are not at a institutionalized level of care they aren't eligible. The 2009 legislation suggested a bill to have private insurances cover the costs of Katie Beckett. This bill was put on hold for further investigation and will be reviewed and rewritten after the election in November 2010. p. 70, 73, 77, 107, 113

Recommendations for action: The Governor's Commission on Disability (GCD) will support the legislation for Katie Beckett. Another recommendation is to have a member of the GCD work with the RI Commission on Autism to advocate access to services for children who do not qualify for Katie Beckett. 10 H 7397 Article 19 Relating to Children's Health Account. PL 2010 - 023

Housing

Concern: There is not enough affordable housing and the process to be placed into housing is extensive. People are waiting at least two years to be accepted into housing. p. 48, 79, 99

Recommendations for action: There is already legislation on housing, so the Governor's Commission on Disabilities (GCD) will support these issues and recommendations. The GCD will also make sure that apartment or condos have a minimum of one unit accessible and affordable.

Concern: People with Multiple Chemical Sensitivity (MCS) are reacting to the pesticides their neighbors are spraying. p. 102-109

Recommendations for action: Other states have a law that requires a 48-hour pesticide spray notice to neighbors. It is insisted that Rhode Island follow this law and monitor the affordable, accessible units for people with chemical sensitivities (including inside the apartment, laundry, and other washing machines).

Supports

Concern: Young adults with disabilities are being cut from programs when they turn 22. Finding transitional services is difficult p. 57, 112

Recommendations for action: Monitoring agencies on the support they give callers/clients. Requiring services to have independent peer reviewing as well as monthly surveying to callers/clients about the assistance from agencies can help this issue. Emailing or giving phone surveys that ask people if they would like to receive newsletters about specific resources can help eliminate the frustration in finding services.

Concern: Many people are unaware of the supports and services in Rhode Island. p. 72, 96

Recommendations for action: Publicizing the resource library and updating the agencies name and telephone numbers can help this issue.

Transportation

Concern: The construction on the Tiverton Bridge requires a weight limit for crossing vehicles. RIPTA/RIde buses exceed this weight limit and cannot cross the bridge. Many people who rely on these services are disregarded. p. 10, 24-28

Recommendations for action: With the use of smaller vehicles such as vans, many people can be helped.

Concern: The MS Dream Center provides many supports for people with multiple sclerosis. However, the location of its services is 1 mile from the RIPTA/RIde bus stop. RIPTA/RIde bus law states that the buses cannot travel further than $\frac{3}{4}$ of a mile outside the bus stop. This law limits many people to this service. p. 72, 81

Recommendations for action: Passing a law that gives certain locations, such as this one, an exception to RIPTA/RIde $\frac{3}{4}$ of a mile bus law.

Concern: RIPTIKS and cash are the only way to ride RIPTA/RIde. RIPTIKS can only be purchased at Shaw's or Stop& Shop locations, which limits the access to purchasing RIPTIKS. p. 46

Recommendations for action: Allowing for credit card usage on the RIPTA/RIde buses. Allowing a monthly automatic transaction to a RIPTIK card.

Concern: Rhode Island's bus routes are limited in rural areas. Many are concerned about the accessibility in the state of Rhode Island. Since RIPTA is a public transit service, their routes are only located where public buses travel. p. 28

Recommendations for action: RIPTA is in a deficit with the high cost of gas and health insurance. This has prevented the expansion of routes. RIPTA uses state and federal revenue and the lack of revenue is primarily from the state. The state is only funding capital expenses. RIPTA has plenty of equipped vehicles, but it is their funding that is hindering their services. Redirecting the funding to other sources can help this problem.

Concern: In the 2009 Public Forums the issue on wheelchair lifts failing was brought to attention.

Recommendations for action: RIPTA/RIde have been in the process of replacing these lifts with ramps. The ramps are automatic, but can also be used manually. There are a total of 60 newly equipped vehicles with these ramps. Even though the issue is in the process of being eliminated, publicizing this can ease the concern for many.

Concern: In addition to the 2009 testimony, the need for more wheelchair accessible taxi cabs was discussed. Starting in 2011, 10 wheelchair accessible taxi cabs are available to cab companies. The only issue is the cab companies will need to individually sign off on these wheelchair accessible taxi cabs and will be responsible for maintenance and upkeep of these cabs. p. 11, 88

Recommendations for action: Monitor the wheelchair accessible taxi cabs.

Concern: The last issue brought in from 2009 that also passed legislation is the requirement to have curb cuts on both sides of sidewalks. p. 11, 73, 77

Recommendations for action: To ensure this is being followed properly the Governor's Commission on Disabilities will monitor this legislation.

Part Three | Testimony

1. *MIDDLETOWN PUBLIC LIBRARY, 7/26/10*

LINDA WARD: Welcome, everyone, my name is Linda Ward, I'm a commissioner for the Governor's Commission on Disabilities, and, this forum is a way that the Governor's Commission gets feedback from the public about issues in areas of concern that people with disabilities may have. We use what we gather here to drive our legislative agenda. And, so, we've actually had some real success. We're proud to say that we have passed; the successful taxicab bill has passed. Why are you saying no?

Transportation: taxi cabs

GWEN REEVE: Yes. I'm saying yes.

LINDA WARD: There will be ten accessible vehicles on the road by the end of the year, taxi cabs. So, that's a major accomplishment. We have, what's the other, the sidewalks, curb cuts on crosswalks, on both sides of the road. We could not believe there were crosswalks with accessibility on one end, and the other end was a curb. So, that was really good. We did not have success with passing adult protective services legislation this year, but we will go back to that. So, we do use --

Transportation: curb cuts

Abuse and Neglect: adult protective services

FEMALE AUDIENCE SPEAKER: What is that?

LINDA WARD: Adult protective services was designed, there's a gap in who's covered with abuse, neglect, and mistreatment by a care giver of people who are disabled, but not either in the behavioral health, or the DD world, or elders. So, if you happen to be a 45-year-old woman with M.S., and your care giver is abusing you, or financially taking advantage of you, you have, really, no recourse. There is no statute, I guess, right now, that would give protection. So, this was designed to kind of bridge that gap. And, I have to say, MHRH, now known as has stepped up to the plate to do some of that work in the absence of legislation. So, it's really, we're going to go back to it, I'm sure it will be something on the agenda. So, we take what comes from here, and bring it back. We look at it, we try to compile it into categories, and go after legislation. We bring it back to the full commission. If you want to speak during this, please sign up. And, I'm going to ask the panel members to introduce themselves and their affiliation. We'll start down with Nancy.

Supports: Behavior Health Development Disabilities and Hospitals (BHDDH)

Abuse and Neglect: elders

NANCY SILVA: I'm Nancy Silva from Rhodes to independence in Cranston, Medicaid infrastructure grant.

GWEN REEVE: Program and services for the Rhode Island chapter of multiple sclerosis.

CHRISTINE MARINELLA: Staff attorney for the Rhode Island Disability Law Center, provide legal services to individuals with disabilities, and I want to say that Brian, another staff attorney, is in the back, we have today with us voter information if you're interested to register to vote, and provide accessibility. And, we also have our priority survey which helps us to identify types of cases and areas that need attention in Rhode Island. We have to limit the types of cases we can take, and we use these surveys every year to help us set those priorities and limits. So, if you have a few moments, we ask you take them. If you can fill them out here, and give them to us, great; if not, there are self-addressed envelopes, I believe, or you can pop them in the mail just like this. We appreciate it.

Supports: Disability Law Center

MIKE MONTANARO: Mike Montanaro from the Office of Rehab Services. And, just so you know, I apologize; I do have to leave at 3:30.

LINDA WARD: Yes?

FEMALE AUDIENCE SPEAKER: I want to introduce myself, Janet (inaudible) from the Division of Developmental Disabilities, which is the DD in the VA.

LINDA WARD: It's panelist's job to listen, ask questions to clarify concerns and ideas. If a speaker is not aware of services, the panelist may suggest the speaker meet at the end of the testimony so the panelist can give you information. And, we really, I know, we're here to gather information, we're not really here to, in the course of this conversation, have a real give and take, though we may ask clarifying questions. Again, we're going to ask if you're interested in speaking that you sign up. After everybody who has signed up has spoken, we will see if anybody else has come in. And, we will be here. We ask that you limit, at least initially, your, I want to say testimony because I don't know what to call it, to like five minutes, and after going through everybody, if you have a need to speak again, we'll ask that you do that. And, we will be here until four. So, as people come in, if they want to speak --

GWEN REEVE: Do you want to also mention about, we have the recorder, about saying who you are before you speak.

LINDA WARD: Thank you. Make sure that you introduce, say your name, spell it if it's a complicated one so that she gets it correctly. I think we have listening devices if somebody should need that. And, if you can state, if you are affiliated with someplace. So, do we have a sign up list so far? Nancy, are you going to testify? So, Lauren Blanchette?

FEMALE AUDIENCE SPEAKER: I thought we were just signing in.

FEMALE AUDIENCE SPEAKER: I asked everybody to sign in.

LINDA WARD: Is there anybody who wants to give testimony?

PATRICIA: Concerns?

LINDA WARD: Yes.

PATRICIA: I have a concern.

LINDA WARD: can you just maybe stand up and statement.

PATRICIA: Patricia (inaudible), I'm from Tiverton, Rhode Island, and our biggest concern right now is transportation for kids with disability in the region. My daughter attended Roger Williams in the fall and because of the bridge, there is a constant battle of transportation, getting to doctors. We have no public transportation. As I go to Bristol, I see RIPTA. So, I went to ORS, and I was approved, and everything went well. It was a process and all said and done when I called, to Gateway in Warwick because nobody was available, and they said, we don't do Tiverton, but the application stated Tiverton, Rhode Island, and no one said anything. So, I went, the number to some head guy of RIde, and it said to ask him. And, I've been everywhere, searching, wondering, hoping, what's going to happen. And, not just for doctors, or Roger Williams, but in general. They say the Flex; someone gave me a paper about the Flex program, great. The cut off for buses that can come in, at least five miles away from where Heather lives, so that didn't do good. Been a battle for about two years. I heard on the radio this morning, bridge, they plan on 2012, two years away, and we have no transportation for anyone with disabilities to go anywhere, and it's a constant battle with the school. As long as they're under the school umbrella, it's fine, but, if not, there's no public transportation. It's a big concern, and I know there's more kids with disabilities, and I don't know how they're getting around because unable to drive, and will not drive in the future. I'm concerned for her as far as if I'm not here, how will she get around.

Transportation: RIPTA
Transportation: RIde

GWEN REEVE: Can I ask. Was it because you live off a bus line? What was the reason they gave you, again, for not being able --

PATRICIA: The Sakonnet River Bridge doesn't have buses that go over it, but, apparently, when push comes to shove, through, the school system, they will provide, the bus limits the weight, so they supply one from Portsmouth. I know Tiverton has small buses, and I don't know why Tiverton is not being serviced, why they cannot have, it's like a battle every single year. Children with disabilities from Tiverton to find a RIde. In the summertime, she goes to Roger Williams in the program, and, luckily, I'm off for the summer, bringing her at eight, and pick her up at twelve. I cannot do that in the fall. So, for now, okay, I can manage that, and I know some parents probably can't because their job is all summer, so, now, it's not my battle. But, when the fall comes, they send you to someone else, and someone else and no one know the answer. ORS filled out the form with me to get the service; I was approved, called for a RIde and they said we don't do Tiverton.

Supports: Office of Rehabilitation Services (ORS)

LINDA WARD: RIPTA said they don't do Tiverton?

PATRICIA: Nope. And RIde said we have places we go, but, yet, I see RIde buses in Tiverton, so I don't know where they're coming from, or if I'm getting the runaround. I don't know where to go, or what to do, and it's a big concern because, eventually, she'll need rides that I can't always provide. I just don't know what Tiverton is doing as far as concerns for children with disabilities needing transportation. Five miles away, I can't say, can you walk to park and ride. I can't have her walk five miles in the wintertime to catch transportation because there are no people living toward Little Compton, there's nowhere near the vicinity.

GWEN REEVE: How far from the bus route do you live?

PATRICIA: We don't really have a bus --

GWEN REEVE: Any bus route in Tiverton?

PATRICIA: No bus stops, so to speak. What we've done in the past, she's had programs, they had, like, someone from the program picks her up at park and ride, but that's just an individual. We've always had to find a way. There's no public transportation at all so she has, we got her RIPTA card, she has the no fare, the Rhode Island -- what was it? The state ID, the RIPTA card saying no fare, all that, I went through ORS, and I'm here again. I've done everything I'm supposed to do. I just don't know what responsibility anyone else will do to provide transportation for kids who live in Tiverton, and I know there's more beside my daughter.

Transportation: RIPTA card

LINDA WARD: Over 21 or under?

PATRICIA: Under 21. I know everything changes. She's 18. We had a new set of things to apply for, at 21, I don't know if things change again. Right now 18 to 21 age.

NANCY SILVA: Is she involved in the transition center?

PATRICIA: She'll attend in the fall. My thing is I can't provide a ride in the fall because I'm back to work. Leslie Brown (sounds like), from special ed. of Tiverton will usually find something, but it's the process, the meeting, the whole process again. So, I just want to advocate for her future, that we need transportation in Tiverton for kids with disabilities.

MIKE MONTANARO: Still under the school system? Have you asked?

PATRICIA: She will because there are three people from Tiverton attending the academy, they will when you push. Sometimes people that work at Roger Williams pick them up individualized. And I know that they have a meeting next week, with Leslie Brown in special education, they usually get a small bus from Portsmouth, but I don't know why Tiverton doesn't have their own buses to pick up students. I don't care who picks her up, but I'm thinking beyond Roger Williams, she needs, like, she had multiple doctor appointments. My husband and I maxed out our time out of work that we're in Warwick. So, great, when I was approved, can you pick her up, she has an appointment, they said, we don't do that, so, another day off, and be penalized because there's no. --

LINDA WARD: Sounds like the bigger issue is no RIPTA.

GWEN REEVE: Sounds like you're off the bus route.

PATRICIA: They had a Flex someone told me about, a schedule where the buses -- but it's also five miles from where we live, very limited. So, that would be, you know, I can't expect her to get up at six for an appointment at eight. First stop is at 8:00, if she has an appointment at 8:30, there's no way to get there in time. And, at that time, about eight months ago, we had two or three appointments within a week, and it was very difficult, between my husband and I taking time off. It was challenging. And, I said, we need to do something in the future. If something happens to one of us that can get to her appointments, can't say the Sakonnet Bridge in 2012.

GWEN REEVE: I don't think it's just the Sakonnet River Bridge --

PATRICIA: No, it's not, it's, as far as programs go --

GWEN REEVE: Like the Ride program, is based on they will run special transportation, if it's along the same lines as regular transportation. So, I mean, like, if there's a bus route, if you're within a certain mile from a bus route, then they'll run the Ride program. But, if you're off that, or they don't have rides running at that time, then they're not going to send one, is my understanding. So, it's like, if you live out in the rural area where there's no bus service for anyone, whether they have a disability or not, then you're not going to get special transportation. So that's one of the big problems.

PATRICIA: Yeah. Like I said, it's not just the Sakonnet River Bridge. Overall, in the future, maybe ten years from now, say, living further into Little Compton, transportation is a problem, unless you know someone who drives, or has a friend. But, if that's not available, it's very difficult to get to appointments that need to be get to.

FEMALE AUDIENCE SPEAKER: Have you applied for a transportation for medical insurance for those appointments?

Transportation: transportation for medical insurance

PATRICIA: No.

FEMALE AUDIENCE SPEAKER: I'm not sure what coverage she has, but I work for neighborhood, and I know, here, if you have a doctor's note about a medical disability and you can't get to appointments, and you're over a certain way from a bus line, they can send a taxi there and back for medical appointments. So, it might be worth it to call your insurance company and ask about their transportation benefit.

PATRICIA: Thank you.

LINDA WARD: Anybody else have --

BOB COIA: I'm sorry I came in late, and wasn't really aware of this beforehand, just saw a flier. Is there a specific agenda or purpose for this?

LINDA WARD: It's basically to gather concerns from the community around, concerns of the community around issues that effect people with disabilities, and we use it, it's the Governor's Commission on Disabilities, and we use it to drive our legislative agenda. So, if there are concerns around transportation, housing, medical, anything, we welcome the opportunity to hear it.

GWEN REEVE: It's not as though we're giving a presentation. We're here to listen to concerns of the community. So, concerns are what drives it. And, hopefully, we can try to clarify what the situation is. But, we don't have a presentation to give regarding services.

BOB COIA: And, am I correct in assuming that, Mike Montanaro, you're the only state employee? You're the only one from DHS, right?

MIKE MONTANARO: I believe so.

BOB COIA: You work for URI, right?

NANCY SILVA: Yes.

BOB COIA: I'm debating whether I should bring up something.

FEMALE AUDIENCE SPEAKER: Go for it.

BOB COIA: This is a little ancient history.

GWEN REEVE: Can you give your name?

BOB COIA: Bob Coia. I am a disabled vet, and spent some time at the Rhode Island Veterans Home, and that was a while back, '99 to 2004. There was a lot of mistreatment of patients going on. And, the, in 2007, the Washington Post did an investigative report on Walter Reed Army Hospital mistreating veterans, and not giving them the proper care. As a result of that, there was a domino effect, and, all across the country, the states set up commissions to study veterans' homes. And, the one on the commission that was set up here in Rhode Island investigated the veteran's home in Bristol, and came out with a very scathing set of reports. And, I contributed to that effort. I was there for a number of years, and I basically knew everybody and knew everything. Sort of, just from being there a lot. And, I guess what I want to say is, the commission studied the place for a year-and-a-half, the House, Veterans Affairs Committee studied the place for a year-and-a-half. Quote-unquote, changes were made. They put in a new (inaudible), and yet the vast majority, basically all but one of the bad people are still in that place. And, I want to tell you some of the things they did to us. The president of the resident council was the psychiatrist, was ordered by management to give him a competency test 35 times because they wanted to find him incompetent because he was making waves to stop the abuse, and neglect, and violation of rights that was rapid. And, they were able to get away with that, 35 times, the psychiatrist kept doing it because, I had to follow orders, quote-unquote. How many orders do you follow before it's illegal. The only reason I'm telling you folks this, and I was forced to take medications, which is a direct violation of patient's rights. I'm telling you this just to make you aware of it, and to let you know that it shouldn't happen in the future. It shouldn't have happened in the past, and I'm very concerned it's still going to happen. And, not just there, but any other nursing home in the state. So, they can use psychiatrist diagnosis as a weapon against a patient. That's what I wanted to make you aware of.

Abuse and Neglect: elders

Housing: Rhode Island Veterans Home

LINDA WARD: So, the veterans home, are they covered by a residence, are they covered by the same abuse, mistreatment, neglect, that, the same rights against those things, basic rights, as other nursing homes, or do you have an enhanced one because it's a veterans home?

BOB COIA: I would have to say, I'm not an expert on that, but I would say the enhancement because it's run by DHS, so it has to conform to state law. Plus, there's a lot of federal money, the VA is involved. So, I'm sure there is a lot of VA, federal VA regulations that they also have to conform with. And, I'm concerned about it. After the testimonies, there were a bunch of testimonies at the state house, and everything was, quote-unquote, fine. Six months later, there was a consent decree against the place because of administration of medication problems, and

people not qualified to administer medication. One thing I testified about was it took us almost three years to get a grossly incompetent nurse removed. Virtually, everyday, she was handing out medications to the wrong people. Finally, after making big stink, she got caught red handed handing out narcotics to the wrong person, but it took an incredible effort. And, I have to tell you, the alliance was worthless.

LINDA WARD: Alliance for long-term care?

BOB COIA: Yes. It took Kathy Herren; we had to light a fire under her to get her to do anything. Some people at the Alliance that would send people there, they were kind of okay. But, Kathy Herren, it was horrible. Of all of the zillion complaints we had, (inaudible), because it was that incompetent nurse, and the only reason she acted was because the offense was so egregious, she had to do something. So, I'm just kind of concerned about the Department of Health, and the Department of, and the Alliance, that, you know, they're really going to, when people complain about problems at facilities like that, they take those complaints seriously, and not just, you know --

LINDA WARD: Do you know, is the residence association, or whatever it was called, is that still a viable --

BOB COIA: It's called the residence council, yes, it is. There is also, the last I knew; there was also a family council.

LINDA WARD: So, is your concern about continuing oversight to make sure issues, they don't get out of hand to the point that they were, and people feel they can come forward with complaints, and have them acted on? Is that --

BOB COIA: The difficulty with coming forward with complaints before was that the management style was harassment, intimidation and retribution. So, the staff and patients hesitated to come forward, family members hesitated to come forward. And, so, you know, they put in a commandant in Rick Bakkis (sounds like). One person is nice, but they still left a whole bunch of people in there that are bad people. State employees and whatever.

CHRISTINE: Where did you take your complaints to?

BOB COIA: I don't have the list with me. It was long.

CHRISTINE: Did you start within?

BOB COIA: I started within, then I went to all four of the federal elected officials. Did nothing. The Department of Health, they did nothing. The U.S. Attorney's Office did nothing. The VA Inspector General's Office did nothing. DHS head quarters did nothing. Understand, this is going back to, going back five years. Since the commission hearings, and the hearings of the house veteran's affair committee at the state house in 2008 and 2009, you know, this is, what I'm telling you happened before that happened, but I'm still concerned. And, since you folks are in a position of influence at the state house, I just wanted to make sure that you are all aware of the scandal investigation that went on there, and it effected people. And, some people with both physical and mental disabilities.

GWEN REEVE: So, are you saying, Rick, your first name?

BOB COIA: Bob.

GWEN REEVE: Sorry. Bob, anyway, you're saying, basically, all the things you tried to do didn't work, and it wasn't until, at a National level, when they, the Walter Reed issue came to light, that they finally looked at what was happening --

BOB COIA: That's correct.

GWEN REEVE: ...at the state. So, all of your earlier concerns never got acted on.

BOB COIA: That's correct.

GWEN REEVE: Until --

BOB COIA: Until the Walter Reed scandal happened and the state house, the speaker of the house established the commission to study the veteran's home. In the spring of 2007, and, probably, the reason why is because there's a massive effort, I won't say conspiracy, to just blindly protect the organization and the employees at the expense of family members and residents. There was a lot of, everybody covering everybody else's --

CHRISTINE: Is your experience and complaint specific to veterans hospital and care, or is this sort of something that you have experience with --

BOB COIA: Does Germane Morsilli (sounds like) mean anything to you? In 2005, she died of bed sores at Hillside. There were a series of laws in that cased. I had been complaining about the alliance not doing anything for a couple of years before that. Had my complaints been acted on, Germane may not have died from bed sores, and the state house may not have had to, spend I don't know how much time enacting the Germane Morsilli laws. I think the more the information gets out there, the less that is hidden, the more sunshine there is on what's going on, the less chance there is that misconduct will happen, and people's rights will not be violated, especially disabled people who are already at a disadvantage.

Housing: Hillside

GWEN REEVE: Let me ask the panelists, Linda, do you think the crisis intervention will pass this year, protection of people not elderly, be used in a situation, that somebody could call on a complaint?

LINDA WARD: I don't know because it is considered a nursing home, and, so, anybody in a nursing home is covered by the Alliance for long-term care, so that would be, now could it be another -- remember the issues we had around the legislation with getting the long-term care, having a role in it, I don't know that, I think that they would still be the primary people involved. I think, you know, I think we could probably look at that, and make sure that whatever is supposed to be happening is happening. I know there's a big report that came out, and I had it sent to me, and, unfortunately, never -

Health Care: Alliance

BOB COIA: There were two interim reports, too, that you need to read, too, that aren't included in the final report, and they have a lot of very important information.

CHRISTINE: When you discuss satisfaction with the Alliance, were you told what your next step would be? You said you --

BOB COIA: I was treated like I was stupid, like I didn't know what I was talking about, like it was all my imagination because I had a psychiatric disability, and, basically, told to sit down and shut up. Did I get help from the Alliance? No. One time I was dragged into the nursing, the director of nursing services, the bad nurse, for a meeting, and Kathy Herren was there, Roberta Hawkins was in charge, and, finally, I brought up the subject of the grossly incompetent nurse. That was the one and only time that Kathy Herren didn't blindly side with management against any complaints that we had. So, the resident council, the family council, myself, I used to be on the resident council. And, I guess, trying to think of anybody else. There were a lot of us who beat up on the Alliance at those hearings.

FEMALE AUDIENCE SPEAKER: When you say the alliance, where do the members of the alliance come from?

LINDA WARD: The Alliance for long-term care?

FEMALE AUDIENCE SPEAKER: Yeah.

LINDA WARD: It's an organization. They have, what, state ranks, I believe, to oversight nursing homes, and complaints. I'm not all that familiar with it, but they can investigate, go out and investigate.

Housing: nursing homes

CHRISTINE : I believe they have authority to --

LINDA WARD: So, and a lot of them are nurses. So, it's an entity.

BOB COIA: Maybe you can add to that the lieutenant governor's long-term care -- I'm not sure they work for the Lieutenant Governor and I'm not sure exactly what they do and the relationship between the long-term care coordinating committee and the alliance, I know the alliance goes to those meetings. It's more complicated than I'm aware of.

LINDA WARD: Thank you. Gives us some things to consider. Recently there was an article not that long ago (inaudible)

BOB COIA: I don't think this is limited to just veterans. This can happen at any nursing home or any facility.

LINDA WARD: Sort of just drifting with my voice. Thank you.

BOB COIA: You're welcome.

FEMALE AUDIENCE SPEAKER: Annette Bourbonnierre. As far as nursing homes go, and this is not something I have personally experienced but the question has been brought to me on several occasions and it is about access, actual physical access in nursing homes that people in wheelchairs can't get in the bathrooms sometimes can't get in the doors of the homes and yet the same nursing homes are termed rehab facilities and people instead of going to rehab facilities and hospitals are going here and I'm not quite sure how that can work or even be

allowed. If people can't move independently in and out of a room how can that be considered rehabilitation or even go to the bathroom on their own or take a shower, I think it's scary that would be called rehabilitation. I think that's something the commission should really --

Housing: nursing homes

GWEN REEVE: Have you been getting these complaints or --

ANNETTE BOURBONNIERRE: ...newspaper column and sometimes it's a question brought to me, so that's how I've been informed of that. I have not been to the facilities, people have asked me to go to them but (inaudible) and I think it is something we should pay attention to.

LINDA: As more nursing homes have beds, they're not being filled in the state's global waiver.

ANNETTE BOURBONNIERRE: They really need to keep an eye on it because we'll end up warehousing people that should be rehabilitated.

LINDA WARD: Okay. Is there anybody else who wants to speak at this point? We will be here.

CAROL: I will. Gwen, hi a question for you.

LINDA WARD: Can you just state your name.

CAROL: Carol Crow (sounds like). You mentioned something about a crisis intervention, can you just, I don't know anything about that.

GWEN REEVE: Well, we've been trying, historically in Rhode Island, there was crisis intervention protocol and assistance to, you know, children, so when there was miss, you know, abuse of children on any level there was an agency and protocol to handle it. There has been an agency and protocol to handle people who are elderly through the Department of Elderly Affairs, there's an agency for people who are developmentally delayed who are being abused. And the people that fall through the cracks are adults who are not 60 whatever it is, 62/65, who are physically disabled and who are being abused by the care givers. So there is nothing for them. And the police really didn't even really know how to respond in those situations. This came about four years ago when I received a call from a social worker, one of her clients was being, who was beds ridden with M.S., 35 years old was being abused by her, physically abused by her teenage children and what to do. And even though there was a law on the books saying it shouldn't happen, and passed, supposed to be enacted in 2007 through the department of mental health and hospitals, retardation and hospitals, they did not feel that they were prepared or could really address dealing with people in those situations. So they basically refused to do it. And from that time we have been working with MHRH, now it's BHDDH all these acronyms, sorry, to try to put together a system where they use their expertise and intervention in a situation so that there wouldn't be any, like who is supposed to deal with this, I don't know, not me, you, pass it on. And family never would be supported or helped. And in a way that's still where we're at. There was no designated agency to go with people who are adults who are disabled and fall through the standard systems that deal with that. So I'm hoping that that gets enacted so that somebody, when the police who are usually the first responders get a call about abuse, they know what to do. Because right now they really don't know what to do with those people who fall between the cracks.

Abuse and Neglect: abused
Abuse and Neglect: police

Supports: Department of Elderly Affairs

Supports: Behavioral Health Developmental Disabilities and Hospitals (BHDDH)

CAROL: Well, thank you for giving my testimony. I couldn't have said it more eloquently, only, I'd expand on that. It's not just by care givers. And sometimes the police can actually be abusive in taking the position that the person that called 911 is a problem rather than a victim. I love how you say people who fall through the cracks, I've been saying this for years and almost didn't come today because we never get any feedback or hear there's any progress. We never hear that anyone has heard us. So it's been really wonderful that we've gotten a little of that feedback and we have heard that some things are ready that we we've been raising for years now. Let me give an example. Again I think it's wonderful you're working. It's almost astonishing to me to believe that care givers can cause abuse to people and there is nobody that can help them or help the victims. It goes even beyond that, I'll give an example. A person physically disabled is told by domestic violence experts and an attorney that their having all of the safety issues of a domestic violence victim but the domestic resource center won't help them because the perpetrator is not a partner. It's simply the lands lord that has a key and access into the apartment at any time. No protection whatsoever, no dead bolt, nothing. Two months this went on. Two months, going through the merry-go-round of 211 and the point and the resource merry-go-round. Now it didn't seem like anyone understood that a person in crisis doesn't need to learn, doesn't need to make a million phone calls, nobody can do anything for them. Person, just like this gentleman said in the example of the veterans home and the nursing home only this -- I think a bigger problem, I'm astonished to hear it happens in place that is are supposed to be supervised. But, you know, it's, we're not addressing all of the gaps if we're just addressing institutions. So I guess I came in here with the question, who is the physical disable to -- in this state, who is the person a person in real crisis can call and say I need help, I don't need a million numbers of agencies that I've been to before that have disappointed me because I'm in their gap, I need help. You know, I mean, you well know because you deal with the segment of chronic illness people. You well know that they've got a very limited stamina of resources. If they don't have a wonderful person like this mother from Tiverton fighting their bottom battle, they have to give up because they don't have the strength to go through the resource merry-go-round. So, and we've been asking this for years. Why isn't there one person to call and say I need help. This is serious. I mean two months is a long time for a physically disabled person to be in a physically threatening situation and nobody will do anything. They turn their backs and say it's a police issue, don't bother us.

CHRISTINE: I know this panel is really supposed to be just for us to receive information as opposed to giving information and I know we're all here for the Governor's commission, to receive feedback, we're required to do that, there are specific grants because it's important to our work to figure out what the current issues are. But sort of little bit of information is that, there have been a couple of organizations including ours that work with local police station, so there are other place to say look to, as well. I appreciate the comments that it continues to be concerns because we have worked with several police departments regarding issues with people with disabilities specifically deaf and hard of hearing and individuals with mental illness.

CAROL: Again please address, please start thinking conclusively, the people that look perfectly healthy that deal with this everyday. What's wrong with you? You must be mentally ill because you look fine a lot of bias goes on. When you call 911 in a crisis information and they come and say if you're lying we're going to arrest you. I can't even believe that that's going on in 2010.

LINDA WARD: I can say part of this legislation was that there was going to have to be a lot of work in training with police departments so that they would understand what their responsibilities were. We were modeling it somewhat after what they have at the department of elderly affairs where they have an agency on call after hours who has the ability to go on site with the police and make an assessment so it isn't just the police officer. And then, somebody so dependent on the care giver it's the only way to stay in the house that the people would either be offered the option of somebody coming in and staying or an emergency Respite bed while they figure this out. And I know, maybe Janet knows from BHDDH that there was a posting for a position within the department to do that type of work that it would be somebody that would be a signal point contact. I don't know where it is in the hiring and obviously it will be some time before it's up and running but there is a realization that there needs to be something for that gap. Without doing the training though of the police and all the other, and the domestic violence and all those other.

Abuse and Neglect: Respite

CAROL: Well the gap in this case was the domestic violence agency who wouldn't, wasn't a care giver issue it was a landlord collecting the rents that are here in this state who was violent and threatening. Now somebody should have given hotel money and some advisement. Didn't happen because it was a landlord not a partner.

LINDA WARD: Yeah, and, again, I don't know domestic violence laws but it would seem to me it may not fit into that. But under this other legislation it would have. And so again.

CAROL: But, that's a caregiver legislation.

LINDA WARD: No, it's from anybody. And it can be financial exploitation. If you're rent is 500 and you're visually impaired and your landlord takes 600 and two months later your family realizes you're paying more, that's financial exploitation. So it covers physical, emotional and abuse as well as financial exploitation. So we'll be optimistic that something will happen. But again if you don't do the training to the police departments when they respond what you'll get is what you've talked about which is the bias. And when training has been done with them in the past it's been a good outcome so we know they're not deliberately looking to make it hard for people.

CAROL: But I think my point was perhaps lost. Is why isn't there a state (inaudible) I mean why is there a gap? Why do you have to be 65 to get help in this state?

GWEN REEVE: It's just the way it is right now. It's not right.

CAROL: Is there any other state in the country that has this kind of a situation? I mean I went to one of these disability dinners years ago and I heard the social worker saying we're finally getting the state, disability on the (inaudible) now that was years ago. And so they acknowledged that that's the gap in this state, years ago. And we still don't have one, I don't understand that. The second gap as we're speaking of gaps and I appreciate that that's become a word on the record now and people understand we do have gaps is five years ago we had a special quorum for people that have what we call environmental triggers to their physical illnesses. And one of the things that has been repeated year after year after year is we need to model how this has been successfully addressed in other states and countries throughout the years. These are people who cannot have secondhand smoke seeping into their apartment or secondhand perfume or secondhand fumes, fireplaces; they cannot have electromagnetic fields from wireless fire alarm systems. This needs to be a government protected, it can be a duplex,

it can be a fourplex, but there must be government protection where they will adhere to very strict requirements these people need to protect them from the triggers of their illnesses. And, you know, it's this special forum was five years ago and I have not heard that we have done anything to even consider helping these people. I mean, a roof over your head is the most critical thing that any disabled person needs. Accessible roof over their head. And every time we hear about accessibility it's about wheelchairs. I think that's really wonderful that we address that but it's been addressed in other states and other countries for two decades and I've offered to help and to address this proactively for near a decade now and gotten nowhere.

LINDA WARD: it was identified as one of the five top priorities at the commission for legislative. Unfortunately, for legislative concerns. Unfortunately the state budget and other issues prevented, I think it was as we call shopped to legislators to see if anybody had an interest, and it was identify that had new buildings, every new development would have to have some set aside units that met this criteria. I don't think, Bill, it didn't get any where. So we will again keep it on.

CAROL: But can I just make a point that that would be wonderful in an ideal world to do that but we don't have that many people in the state that are in critical need so rather than go full-blown with an attack like that that's not going to pass because the legislators aren't at the point of recognition of these issues, we need to address it at very, very personally and individually. Who needs this and direct feedback with them, who needs this and how are we going to work with them to address it. Not sit in an ivory office somewhere and fix the problem about feedback. I mean we're talking about a handful. Maybe not even, maybe two or four people, you know, and I'm sure as we get experience with that particular model, it will then be, you know, incorporated into some of the global plans. But, you know, let's face it, in this time frame we've asked for this duplex, we've had housing addressed, affordable housing addressed for workers, police officers and fire people and nurses and even artist communities and we can't get one duplex in the state not in central falls or another polluted area, in a less polluted area to address this critical need for a person who need it is for their very survival and again I offer my service to say assist in coming up with a realistic kind of, and I don't see that it needs to be something that has to go through the legislature. I think it needs to be whoever makes the housing decisions in this state, to get a duplex.

CHRISTINE: Are you talking about additional facilities, or are you talking about policies? Or both?

CAROL: I don't understand your question. I'm saying what's been done in other states and other country is they work with people, the people that are affected to know specifically what their requirements are. I need to be in either a stand alone house in a non polluted area or a duplex where they can't afford stand alone houses and there needs to be no secondhand smoke, no smoke allowed in the place, no perfume, no wireless, no wireless fire alarms allowed in the place. It needs to be specifically addressed and it needs to be under covenant protection meaning it's right in the lease meaning the person loses opportunity to be there if they violate. If friends come and smoke they've lost their opportunity. If you have people so disabled by this, they will respect it because it's their lifeline. They're not going to disrespect it. That's how it's been addressed in other communities for two decades.

Housing: pollution

GWEN REEVE: One more question. Do you know for sure that there is no law that encourages that kind of behavior, that kind of collaboration? Do you think that they're just doing that without a legal basis to do that, or do you think there's a law that suggests that housing agencies or

whoever is working with the individual, work with them to establish a rental property or a property that meets their specification.

CAROL: I don't think it's been done by legislation in other communities. It's been done through the housing, you know, like with the consolidated plan.

GWEN REEVE: Rhode Island housing authority or --

CAROL: It's been done in specific communities where there are people with great needs and it's been worked through whoever develops the housing. So I don't think it's been dictated by legislation. It's been done in one area by, well in another country, it was dictated. I mean I can get you the information. But it doesn't have to be a real complicated thing. It's as simple as getting a duplex and addressing needs, needs to be talked about by the people -- no, I don't think legislation is the way that it's to be done. You know, and a lot has happened in the two decades since they did the initial models. The paints now are all low or know (inaudible) paints. So there has been a lot of improvement. As a matter of fact, a lot of commercial institutions are accessible to people with these disabilities now. But the housing market is lagging behind. And if you're not, if you're just like affordable section 8 person who has to get a regular landlord, you know, I mean there's really, you have no control. Bottom line, it's going to come down to needing to have your special needs met and the lands lord is not going to bother with that, at least this is the experience in this state, and they're going to bounce you out. So you're going to be in a continue wall cycle of (inaudible) and that's very expensive for a disabled person. Or violence if they want to -- violently. And that happens.

LINDA WARD: I just want to introduce one of our panel members who came in. Bill Inlow from RIPTA So, there was a RIPTA discussion.

Transportation: Bill Inlow

PATRICIA: I spoke with him.

LINDA WARD: I wanted to introduce him. We had a big discussion about is there any public transportation in Tiverton.

BILL INLOW: Is there any public transportation in Tiverton? No.

PATRICIA: Somebody gave me your number, so when I saw Inlow, I've spoken to everyone.

BILL INLOW: Once the new bridge is completed --

PATRICIA: 2012.

BILL INLOW: I would think we'll send public transit buses across the bridge again, and provide some modest service, but that would mean probably one trip from little Compton and Tiverton over to Kennedy Plaza. Providence in the morning and one trip back to Tiverton, and Little Compton in the afternoon. Not much, but better than no service. But, right now, we cannot send our RIPTA buses across the old Route 24 Tiverton Bridge.

PATRICIA: Because of the weight capacity?

BILL INLOW: Weight restrictions, the bridge has so much infrastructure of beams and supports are rusted such that our buses weigh too much to send across the bridge.

PATRICIA: Do they have a so to speak for physically disabled or anyone with disabilities smaller RIPTA bus?

BILL INLOW: We send some Rlde vans across to the dialysis center. Some Rlde van goes across that bridge. Again only for dialysis services right now.

PATRICIA: If it's not dialysis, there is no service?

BILL INLOW: That's correct.

GWEN REEVE: Bill, why is that, why dialysis and not --

BILL INLOW: We are legally required to provide Rlde service where ever we provide public transit bus service. Rlde is called a paratransit program . Paratransit means comparable to transit. What that comparable means is where we provide regular RIPTA bus service we also have to provide RIPTA paratransit service. And the same follows, the opposite follows, too. Where we do not provide regular RIPTA bus service, we do not provide paratransit service. Except in the case where it's convenient, more convenient for the customer and RIPTA to provide that service. And since a person who goes from, for example, the southern part of Aquidneck Island, Newport or Middletown, to dialysis, closest is northern part of Bristol and it's closer to go to Tiverton so the advantage to the customer and to RIPTA to send that Rlde van voluntarily across that bridge to the dialysis center.

Transportation: Rlde

GWEN REEVE: So it's not emanating from Tiverton? The patients are coming primary from the island.

BILL INLOW: exactly right. There is no Rlde service in Tiverton, except for, under the department of elderly affairs, if you're 60 or above, you can get some modest Rlde service, only for medical trips in Tiverton.

PATRICIA: That's where a find a huge gap.

BILL INLOW: Heck of a large gap of peep who will still have needs in Tiverton and little Compton and all the things you need for quality of life, grocery store and pharmacy. I agree with you.

PATRICIA: Especially with the new artist community where I live towards South Tiverton, the whole new community development going up. And, I'm sure, you know, the public transportation would be suitable for just that need and amongst everyone else's need. Prior to the bridge did they have it?

BILL INLOW: Prior to the bridge problem, yes. We did send a regular RIPTA bus from Newport up through middle town and ports mouth across the Route 24 Bridge, turned right, went South down to the commons in Little Compton and back un to the Fish Road Park (sounds like) and ride and back across the bridge and up to Providence, in the morning, early, once. And then the opposite way in the evening. It was for primarily people in the community to work from little Compton and Tiverton.

PATRICIA: So, my question would be, I'm not sure how to say this nicely. When they knew the bridge was going to happen did they just say well this is just going to be it for however many years with no plan or something to make up for the fact we do not have it. I just feel like I'm the only one that has an issue with the bridge. I don't want to give up now -- but prior to that, what were they doing, what were they replacing it with? Just nothing.

BILL INLOW: They're no longer getting rides. Sadly, you're right. But, we have no choice.

PATRICIA: But a little bus the bridge would accommodate.

BILL INLOW: That would have been a thought but I will tell you the decision was made no longer to provide RIPTA service across that bridge.

PATRICIA: I guess that's why I'm here.

BILL INLOW: Well, it's a very good point, and I think you certainly should write that down and reflect that advocacy on the part of the.

PATRICIA: I know there are other parents that are just not here with me.

BILL INLOW: Sure. I can tell you there are other places, the whole city of Westerly, no Ride ADA service because there are no regular RIPTA bus in Westerly, which is a lot bigger than Tiverton and Little Compton. There are no regular RIPTA bus services in the town of Westerly, the city of Westerly. It's a city. Fairly big. And, as a consequence, no Ride ADA service. There is a little bit of Ride service down there for people 65 and above, medical trips, but that's it. There are parts of the state of Rhode Island which do not get very good public transit service. We would like very much to provide those services but obviously given the state of the economy at the state and federal level right now that's not going to be expanded in the short run, ideally in the long run, we will. And I agree with you, there ought to be alternative types of vehicles that we could provide that service with.

PATRICIA: Like, the Ride bus for example. I see Ride buses. This is my problem, I see Ride around Tiverton, and see Ride buses here and there, and thinking, not so sure why and not someone over 65 getting on these buses but how these people, I'm trying to figure out how to take care of my own situation, I would love to do it for everyone but how can I get my daughter who will not be able to drive in the future or now to appointments or where she needs to be without me having to, I'm not always going to be accessible to do that, I had adaptive driving lesson that is didn't work out, pretty much, shell not drive. So I'm trying to move forward, okay, what do we do from here.

BILL INLOW: It's a good point. I think the argument you make a good argument as long as people are there in that area of the state, Tiverton, Little Compton who need and will use public transit services then you could make I think a pretty strong argument to RIPTA to try and reinstate RIPTA transit service with a small bus that can go across the route 24 bridge as it is currently existing.

PATRICIA: I know you said something about the economy, that took place with an IEP meeting they said there is no longer services for kids with disability that is fall under the school's umbrella up to age 21 until DD kicks in, said job coach training, we don't have them any more, been at Looking Upwards -

Education/Employment: IEP

CHRISTINE: Can you repeat the beginning?

FEMALE AUDIENCE SPEAKER: She used to attend Looking Upwards with a job coach program and this was the first year when I called for the extended school year we follow longer have that because they're only allowed to do it one year. I said, oh, what is the plan because she was in the extended school year service she said kids with disabilities cannot have twelve weeks off because back to school is so overwhelming. They said we don't have anything so I said what are they going to do she said nothing, budget cut. Miraculously when you put up stink she's in a summer program at Roger Williams, so everything is putting up a stink, and I feel like I'm fighting the world which is not my personality but it's been molded, first of all they have nothing in June, two weeks later, ten to twelve people chosen through Warwick, Cranston, Newport baring ton and she was one out of the twelve because I said what are you doing in place of it. Can't just say kid with disability nothing for you because of the budget plan. Have you to have a plan. RIPTA, okay, don't do Tiverton any more, that's T.

Education/Employment: Looking Upwards

BILL INLOW: To be frank with you, we're human beings, too. We care about people, too. And we don't just say we're not going to serve you any more because of an excuse we have to do that. And at the same time, the federal and state budget is pretty obvious in its challenges. We're trying to struggle and deal with it as best we can. But we're all going to have to advocate for ourselves and for people who we care about. And I think that's just the nature of the system right now. You know, we're listening, we're listening sincerely and doing the best we can.

PATRICIA: I just think a small bus would be such a quick fix, easy. Obviously, I'm advocating, as well.

BILL INLOW: There is always an easy answer to every complex problem, and it's usually wrong. But, I don't know, perhaps, there was an analysis of the number of people that use the bus and if there aren't many people using a bus service, then if we have to cutback some services, we're going to cutback where there is not much of a demand rather than where there is a lot of demand. The problem with that is, and I can tell you some people with disabilities argued it to the RIPTA board just recently, and that is that we shouldn't reduce services if we absolute will I have to based upon just numbers because some people have alternatives. And other people especially those with severe disabilities physical and or mental have no alternative but public transit or the RIde program. And so that they shouldn't just look at numbers. That argument was made convincingly by some people with disabilities directly to the RIPTA board of directors and just recently they made a decision to put off service reductions at RIPTA and told the staff to go back and find another way to find several hundred thousand dollars of deficit that still is in the RIPTA budget. You always have to stand up and speak up and advocate for yourself and others. Just reality.

Transportation: RIPTA

LINDA WARD: that's always an agenda item for the Governor's commission, transportation, without transportation, employment becomes difficult, where you live is a challenge, less choice; access to quality of life things we all take for granted, going to the store or a movie, going to a park, all those things. So we are always working on that. And so we will keep that as one of our, I'm sure one of the things on our agenda.

PATRICIA: Unfortunately, there are many people in Tiverton that do have, I think the same situation, program for her and her friend and the mother is just like, okay, and that was it. Some people don't know, you can't just say okay, you inquire, you search, you advocate and you do your job to get it done because I don't think I would ever be where I am today had I said, okay, because now there are two or three people I know that could really benefit from the summer program.

BILL INLOW: I'm sure it's two or three. Speak up and advocate for yourself and others.

GWEN REEVE: I think that also the taxicab issue we talked about finally getting passed was a situation where RIPTA didn't go to those areas like westerly and or wasn't a doctor's appointment, it was something else. And they are, I mean obviously it's going to be more than the cost of a RIdE trip, but it's not going to be more than a regular taxi to take. So there are accessible taxis also. The other question I have for Bill is that there are those cases where the elderly who get rides to medical appointments, is that written in the RIPTA, how is it that the elderly are pointed out, or, basically have that privilege as opposed to other --

BILL INLOW: The department of elderly affairs has a state funded program through the General Assembly and signed into law by the Governor, part of the state budget to find some money for people along with some federal money from the Older Americans Act, federal, for people 60 and above, federal law and state law, for medical trips and adult -- care and I think some meal service. That's state money and it's a combination of state and federal. It's for people 60 and above. And I agree that's irrational. If you have a need, it doesn't matter whether you're 66 like I am or 56 or 46. At least it shouldn't matter. But that's why there's some money for people 60 and above for medical trips.

Supports: Older Americans Act

LINDA WARD: We'll keep this on the front burner.

PATRICIA: Thank you.

CAROL: I just wanted to ask, I'm going to quote you, I agree that's irrational. I look at other states and I see physically disabled and elderly together. So there is not a distinction and I'm just wondering why we're continuing to set this irrationality for decades. After they're all finally voicing that it's irrational to use Bill's term.

BILL INLOW: I agree. It is irrational.

CAROL: So, we're all in agreement in this room, or, a lot of us, so what can we do about it. You know, not everybody has the energy that this lovely lady from Tiverton has to advocate so who is in charge.

GWEN REEVE: My experience is when I go on the hill to testify, I don't have multiple sclerosis and the way things run at the hill you usually find out a day or two in advance when there is going to be a hearing, you don't get a long leeway and to get somebody out with a disability or in a wheelchair or whatever on short notice is difficult. Second thing that's difficult is the state house is not really accessible. You know, unless you go through the basement but the parking is not accessible. So that's a challenge. But the, our representatives are much more likely to listen to somebody who has the disability than to listen to me. And so you know, I'm always encouraging people, if they can, to, you know, be up on the hill to advocate. If you're connected

with an organization that lets you know when things are going to be heard, that's helpful. But it is a big challenge. And my dream situation is that there would be plenty of leeway so we would know when an issue is coming up, and testimony is needed, and people with disability who this affected, like you, it would be much more persuasive talking about your situation and telling than me talking about it when it's not affecting me personally. Our representatives have a way of listening to their constituents who are affected. So it's an ongoing challenge.

Supports: State House

CAROL: I think there in lies the problem and I'm not directing this directly to you, Gwen, but there in lies the problem, if we had an effective disability organization we wouldn't be anticipating that people with physically disabilities that can't turn on a dime or get up to Providence to plead their case to their legislators, you know, I mean it's to use Bill's term it's irrational so why don't we have an effective, these kinds of conversations, why is everything in the hands of the legislators, you know.

ANNETTE BOURBONNIERRE: They make the rules.

LINDA WARD: Again, there is a great concern that we have attempted to in the last year on the commission look at issues not as you're in this category or this category or this category but more broadly and it's something I think again as we move forward with our legislative agenda for next year that we will look at. I can tell you on a side note stepping out of my role as a commissioner and into my role as part of the disability vote project that one of the things we have talked a lot about is what happens at some of the hearings up at the state house and so, and this happened several times this past session where there was testimony to be taken on, I believe it was the adult protective services, there was this lovely young woman in a wheelchair who had taken a bus to come and testify at house finance, and the hearing was put off, put off, put off, and every other group, every other bill was heard before and she finally had to leave because the last RIPTA bus was going to be running so we want to do some work with whoever schedules those hearings to say, keep in mind how we can involve people in a better way, how can we make these work? Given the constraints that you all have and the concerns going on. So there is sort of a movement afoot in another area to kind of look at some of those and try to have people be sensitive, not that they're not sensitive but realize challenges of somebody in a wheelchair who wants to testify and have waited four hours and taken the time and the last bus is leaving and they have no other way to get home.

Abuse and Neglect: adult protective services

CAROL: I understand what you're saying but I think a model is irrational. I think a comprehensive approach to disabilities and these are general, these are what we know about disabilities and these are what we need to address.

LINDA WARD: And, I think that that's what the commission has been working on and will continue to work on. So we take that and work our agenda from that. Anybody else have anything that they would like to say? If not, we ask if you haven't signed in to please sign in so we know you were here. We will be here until four. And we have a lot of, I think, good information that will help you drive our legislation next year. And just for those who came in late. If you're not registered to vote or you've moved and need to change your address, Brian has the papers.

BILL INLOW: This gentleman here has a comment.

BOB COIA: Couple quick comments with regard to the lady in the back who was talking. I couldn't agree with her more about bias, the whole issue, every time we try to register a complaint we got laughed at or patronized, call this or that office. It's crazy. The sensitivity training, I think that probably goes a long way. But it doesn't go away (inaudible) the second thing as far as the single point of, single place for a person to complain to, I mean, you asked me who did you complain to and I said well there was a whole long list and there really was. The commission that studied the veterans home made that, one of the recommendations was to have a single place to file a complaint. I don't know what happened with that. I do know that there was a lot of foot dragging on the part of a lot of different bureaucrats to, one excuse after another and some of them I'm sure were legitimate. I'm not sure that's the solution either because, you know, watchdogs don't always do their jobs. I mean, the -- management service is supposed to be protecting us from BP oil in the gulf and they didn't, last ten years all kinds of crap has happened on Wall Street but where is the securities and exchange commission so establishing another bureaucracy -- I think it takes people with honesty and integrity willing to work hard and get rid of the people who are just paper pushing bureaucrats, having been one myself.

CHRISTINE: For the people who came in a little after we began. I'm an attorney at the Rhode Island Disability Law Center and we use this forum to gather information about how we can set our priorities to accept cases in the up coming year because our resources like so many other organizations are limited and so we have to narrow the types of cases that we can take every year and we try to choose those types of issues that are most important to our community. So one of the ways we do that is by asking people to fill out what Brian has in the back there are these surveys and they have just different areas where we get grants with different types of issues, you can check off what's important to you. We'd appreciate it. We do ask you to sort of prioritize because that's what we need to do. Instead of picking 20 out of 20, if you could number them that would be helpful and if you can leave them with us today that would be wonderful. If not, you want to take them home and send them back in, there is postage on them already and we would appreciate that. And you can also write in the issue if you don't see it listed on this survey. Thank you.

Supports: Disability Law Center

LINDA WARD: So, we'll be in recess in case other people come in.

BOB COIA: Can I bother you again, real quick. All the years I was struggling with the state veteran's home I didn't realize until three years after I left there when the commission was established that there was a state mental health advocate. The chairman of the Commission, I didn't even realize there was one, if I had known that, I might have called him, too, or written a letter to him. I didn't find out until probably the same time that there was a state child advocate, she's still in the position, is there a state disability advocate?

ANNETTE BOURBONNIERRE: There's the commission and there's the Disability Law Center.

BOB COIA: I don't even know what -- really do, but I just thought I would mention it (inaudible) --

SENATOR LEVESQUE: Chuck Levesque, I'm a Senator from Portsmouth, two years, I like to describe it, voter approved vacation. All of these folks up here I think I've dealt with almost all of you at one point or another and they are I consider very effective advocates for the issues that most of you have been talking about. It is, I think, frequently, for them and myself a feeling like

you're running into a brick wall. And by in large what I will suggest to you is it is because the community is not prepared at this point to support many of the things you're advocating. Now, whose fault is that? I don't know. It is, you know, interesting that this is 20 year anniversary of the Americans with Disabilities Act. Many of you probably recall that that was greeted with some trepidation by everybody, it was going to be a load some imposition on all businesses and I think although compliance has been slow and it has often taken the form of legal complaints aside opposed -- smart people in business recognize right away that access brought in customers and even if it wasn't, the individual there, it was a friend of the individual who needed the access. So we're really limiting your whole ability. And as many of you know and I'm actually facing it in this election campaign and I'm not here running for reelection -- oh yes, I am. But, there is a group of people out there who are critical of something they call compassion. And it is an interesting phenomena, even to the extent of them saying we shouldn't be giving unemployment benefits because they now lack the incentive to go back and work even though it's a compassion at thing to do. Well that's just stupid and it's annoying and it's ignorant. And have I actually never really proposed anything on the basis of compassion. Have I proposed most things in, with a fundamental sense, just like you were saying and like this young lady was saying, ultimately if we take care of these issues and involve everybody in the community and give them all the opportunity to be as productive as they possibly can, we will have a better society. Please understand though in this election I think in particular, about this issue, there are two visions of what this country is or should be. And a lot of the folk in this room are advocating for a, an involvement, activity by the state government which a lot of people outside this room are not. And are advocating almost the opposite. My fundamental suggestion whether you vote or not vote what you need to do is advocate. Not necessarily until the state house because quite frankly at the state house most of them are considering what their constituents back home believe or think or want or need. And most of them are saying keep my taxes down. Do not impose another obligation on me don't do anything like that. And unless in fact those peep am senators and representatives feel from their constituents, either a number of people or a particularly compelling story, many of you remember Paul Sherlock. Paul Sherlock was an advocate for the developmentally disabled for a long time in this state, it was a personal experience that he brought to the state house that was compelling to a loft folks. And that is the kind of thing that can move people but the other thing that can truly move peep until that building is if there is a sense that there is a community behind them willing to support what they're doing and advocate to for it. Whether it's true a TV, radio, newspaper, or just talk to go your neighbor. That's my -- do that and you help us out, a lot of us have tried to work with the folks you see in front of you and get in fights with the folks you see in front of you, too, to accomplish a great deal. Both because we think it's right and because we think it is the best way to advance our state and nation and our community. But without the support of people within the community for what we're doing, you can't get anything accomplished.

Education/Employment: unemployment

ANNETTE BOURBONNIERRE: What about contacting the legislator directly?

SENATOR LEVESQUE: Anybody who has not done that as part of this activity is making a mistake. May seem we fluff you off, but if you get a hold of me, might say you might know (inaudible), I have resources at the state house that tell me, this person looks like they're -- they need to talk at somebody at RIPTA or the center or looking up washeds and so I can get back to you. If in fact, I tend to respond to anybody who e-mails me but simply if you e-mail with an address within somebody's community, they will usually try to find you somebody to talk to. So, I really recommend. I mean, if there's one lesson most of us in the legislature have learned is constituents, don't ignore somebody in your community because the last thing you want is

somebody writing a letter to the papers, I've had it happen to me, and say, he totally ignored me. Well, I remember somebody writing that in the newspaper article about me that I totally ignored them and they weren't voting for me and I said, well, if ignoring somebody meant they wouldn't vote for me then my mother wouldn't vote for me. My best response.

LINDA WARD: Jonathan. Did you come all the way from Woonsocket?

JONATHAN: Actually, class at URI in Newport, I'm going to in two hours. I just realized I was going on Thursday in Cumberland, I live in Providence, but people I recognize here, might as well come in and try to speak. Couple things to point out.

LINDA WARD: If you can say your full name.

JONATHAN: Jonathan Dupre, and I represent the Alive Peer support program, peer support program and peer advocate in Woonsocket. Issues coming up in my population are big one is RIPTA problems, RIPTA issues. The fares are going higher, rates are going higher. The disability -- fare go from like five dollars to 25 dollars or something like that and by 2013. And -- about that in my population, people I represent. And also big deal is access to medications. Housing. Trying to think of a bunch of other things. But, just a lot of issues around basic need from medication to access and funding for treatment, funding for mental health services. Those are some of the main issues that, my members face that they talk about and I wanted to come here and bring them to this hearing and they do effect the mental health population in general not just my membership but also the mental health population in general so these are some of the issues that we're trying to deal with. So, that's why I wanted to bring to the hearing. And if there are any questions, commons.

Supports: Alive Peer

LINDA WARD: Are there specific issues around medication?

JONATHAN: The cost, mainly the federal part D. but there's new regulations for Medicaid coming about and all these regulations for (inaudible) and it goes ongoing issues. For people with disabilities, especially psychiatric disabilities who depend upon psychiatric meds and those medications can be pretty expensive. So that's some of the reasons.

Health Care: Medicaid

LINDA WARD: Housing, what are the specific --

JONATHAN: Just the funding of it, like, not having the funding or the access to housing in the Woonsocket area and northern Rhode Island area. Mental health centers, I don't know if you know but mental health centers are being cut and cut majorly, substantially, and the state budget I guess will be another issue, state budget effects the mental health budget which effects the mental health centers and the in turn the mental health consumer so that's how it would be effected. But that's some of the main concerns I wanted to bring to the hearing. Walked in at this time.

Health Care: mental health

LINDA WARD: Thanks.

GWEN REEVE: I think you answered, I was interested in the problems with the medication.

JONATHAN: Okay. Thank you. I'm going to head off for class.

LINDA WARD: Thanks. Good to see you again.

JONATHAN: Good to see you. Bye.

LINDA WARD: Is there anybody else who has anything to say? They can let us know. Again, if you haven't signed in, please do. If you haven't registered to vote and want to, you can go back there. We'll be here.

CHRISTINE: You can use the time to fill out the surveys

LINDA WARD: Unless there's anybody who has something else to say, we're going to shut the forum down.

2. *PROVIDENCE July 26, 2010*

KATE: Hi, everybody. Welcome. I think we are going to go ahead and get started. My name is Kate McCarthy-Barnett and I am a commissioner with the Rhode Island Governor's Commission on Disabilities. And we would like to welcome you to our public forum today. The purpose of the forum today is to have an opportunity for those of you who are with us to share some experiences or some concerns that you may have, whether it be from, you know, access issues or technology or housing, as it relates to people with disabilities and their family members or care givers. The purpose of the forum is an opportunity for us and the panel members, who will be introduced, to listen to some of your concerns. And that information is then brought back to the Governor's Commission on Disabilities, where we actually sit at the legislative committee and review all of the testimony to identify areas that we might be able to make some changes in. So those could be changes ranging from, you know, policy decisions or increasing awareness, all the way up to really looking at some legislative changes. So we are excited to have you here today and look forward to hearing what some of your issues are. The process -- since this is a public forum, we do have a process that we will follow. And basically, the first thing that we will do in a moment is ask our panelists to introduce themselves and share the agency or organization that they are representing. And then we will be going through the list. As each of you signed in today, you identified whether or not you were interested in sharing some thoughts today. We will go through the list of the individuals who identified. At that point in time, we will open it up to anyone else who maybe has changed their mind and is interesting in sharing something as well. So why don't we begin and ask the panelists to briefly introduce themselves and share what they represent.

DEB GARNEAU: Deb Garneau from the Health Department, the Office of Special Healthcare Needs and we have services and supports for kids and adults with disabilities.

LAURA: Good afternoon. I am Laura Jones. I work for Rhode Island Parent Information Network at the Department of Health in the Office of Special Needs. And we do a few different programs that support individuals, children, families with disabilities in the community.

MEREDITH SHEEHAN: I am Meredith Sheehan with the National Multiple Sclerosis Society in Warwick. We primarily deal -- obviously with clients who have MS. And their symptoms range from you wouldn't know they had MS to severely disabled. So we deal, you know, with many different types of people with many different stages of MS. We are very active with the Governor's Commission on Disabilities to try to promote legislation that we feel we can support. I also serve on the Government Relations Committee as well. So I am happy to be here.

KATE: Thank you.

ANNE LECLERC: Anne Leclerc. I am with RIPTA and the RIde program and also a member of the State Rehabilitation Council.

ANNE MULREADY: I am from the Disability Law Center and we are the federally funded nonprofit law office that represents people with disabilities in Rhode Island on legal issues related to their disability rights.

JOE: Joe Murphy, supervisor for the Rhode Island Office of Rehab Services. In the case of rehabilitation, we work with people with disabilities with employment services for students and adults.

KATE: Great. Well, thank you, panelists, for joining us here today. I think the first thing that we are going to do is -- it looks like Brenda Wilkinson is interested. For the purposes of transcribing, it's Brenda Wilkinson. Brenda, did you have thoughts or concerns you would like to share with the panelists today?

FEMALE SPEAKER: Well, I think the buses should be local hours especially in the summertime when people have to rely on them, like when they work late, and they still have to rely on a bus. I think they should be longer run, different routes.

Transportation: RIPTA

KATE: And you are lucky today to have Anne on the panel from RIPTA. So maybe, Anne, you can provide feedback or thoughts to Brenda.

ANNE LECLERC: We are trying to keep what we have. But because of the situation we are looking at cutting service, night service was going to be affected. Our board has rejected that based on public input, so no services is going to be cut at this point. But the fares will be increased come September 1. So we are still looking at ways -- but we would love to do more. But right now we are struggling to hold on to what we have. Let your representatives know you want to keep what we have and would like more.

KATE: So you are recommending that as consumers and advocates, word should be shared with their --

ANNE LECLERC: It is an election year. People come around to talk to you about what they think, to what you think is important. Let them know you think buses are important. The more people they hear that from, the better.

KATE: Is there anyone else from the panel who would like to address this issue? Already, again, the great thing about this particular forum is that exactly what you just said is going to be shared. And we will look at it as well at the commission to see what we do as advocates to continue to work with RIPTA service -- RIPTA serves on the commission as well -- but to really see how we can start to bridge that gap. So thank you, Brenda.

AUDIENCE MEMBER: You have another one too.

KATE: Absolutely then.

FEMALE SPEAKER: The other one is the lifts should be in better working order at all times.

KATE: And that would be on the buses?

FEMALE SPEAKER: Yes, on the buses.

ANNE LECLERC: Do you have any particular buses?

FEMALE SPEAKER: I ride the regular RIPTA buses. I don't ride the Ride buses.

ANNE LECLERC: Which route?

FEMALE SPEAKER: She rides 72, 99.

FEMALE SPEAKER: Yeah.

FEMALE SPEAKER: A lot of people that take the buses, 99 and 78. They have problems with 78 a lot.

ANNE LECLERC: Um -- we are due to have a number of our buses retire once we get new ones in, which have been delayed. All of our buses going forward will have the ramps not the lifts, which are -- they don't break as much with moving parts. So hopefully within the next six months. We will have that under control better with new buses.

Transportation: RIPTA

KATE: Good. And so then at your level, as advocates in the community, we should keep an eye on that to ensure that as the buses are, you know, turned over. Anne is on the commission as well and the legislative committee and -- multitude -- yeah. Bill Inlow is on it. So we will be able to follow on that.

ANNE LECLERC: If you ever get a bus where the lift doesn't work and someone can't get on, please call RIPTA immediately and let them know because that bus should be taken out of service immediately. That's our policy. Sometimes the drivers don't call the office or call me.

FEMALE SPEAKER: Thank you.

KATE: So just to recap on the issues and concerns that Brenda has shared. The first being transportation and looking at longer hours for the services. And Anne shared that they are looking at different options for that. And in terms of the lifts for the buses, good news that some of the buses will be retired and new buses coming. But as Anne shared, if you come across a bus that does not have a lift working, you should immediately make a phone call so that bus will be taken out of service. All right. Brenda, did you have any other concerns that you wanted to share today?

FEMALE SPEAKER: Yeah. What is the phone number for the bus service?

ANNE LECLERC: 781-9400.

FEMALE SPEAKER: It's on the bus schedule.

ANNE LECLERC: The same number you call that can get you to customer service.

KATE: Great. Any other thoughts or concerns, Brenda? No, all right. Excellent. Thank you so much for taking the time to come today and share those. Those are very good issues.

FEMALE SPEAKER: Thank you.

KATE: I would like to ask -- Charles has also -- Charles Feldman has shared that he is interested in sharing some thoughts today. So again for the purposes of transcribing that. Charles Feldman. So, Charles, you are from NAMI.

MALE SPEAKER: I am representing NAMI Rhode Island, also known as the National Alliance on Mental Illness of Rhode Island and Save Our Mental Health Services Coalition, SOS for short. And I am also on the board of Mental Health Consumer Advocates of Rhode Island. So I get around.

Supports: National Alliance on Mental Health (NAMI)

KATE: Very busy.

MALE SPEAKER: Um -- a few issues I wanted to bring up today are -- one is the importance of peer support in the mental health system. There are some states that have hundreds of what they call peer specialists working in their mental health systems. These are people living in recovery with mental illness, who work along side the other mental health professionals in order to provide an example of someone who has recovered and someone who has been there. So that people receiving services actually get to see that other people, just like them, can recover and go on to, you know, to really provide these services and to really do well in life. And I think it's important for Rhode Island -- we have been talking about it for quite a while now. And it's important to just finally, you know, get going and have a peer specialist system in Rhode Island. They are also known as recovery coaches and a couple of the CEOs in mental health centers have already asked for this. It's just up to the department of behavioral health, disabilities -- you know, behavioral health, developmental disabilities, and hospitals to actually say well, let's get going with this and have a program. That's my first issue.

KATE: Okay. Why don't we open it up to the panel before we move on to the second one. So, Charles raised a good issue in terms of the need for increased peer specialists or recovery coaches here within the system. Would anybody be interested in responding or providing some feedback or thoughts on that?

DEB GARNEAU: The department -- help me with it now -- it has a new name. MHRH. The old MHRH has --

MALE STUDENT: BHDDH.

DEB GARNEAU: -- gave a presentation to the governor's commission on behavioral health and talked about exploring this model and moving forward in this direction of using peer coaches, health coaches within substance abuse and within behavioral health areas. So I do know that they are pursuing it and actively, you know, walking down these paths. The other arm of state government that is pursuing this is the Department of Human Service, when they have reprocured -- which is, they are just signing up again -- insurance companies to work on their -- Rite Care program and Rhody health program have put within their plan that they wanted to use peer navigators, peer resource specialists, whatever. You know, there's a lot of different names that you can use. And that is not necessarily just behavioral health, but it's also physical health and, you know, other areas that they will be using a peer model. So we are excited, you know, to start moving in that --

Health Care: Rite Care

MALE SPEAKER: They are already doing it in the substance abuse side. But in the mental health side, they just haven't given a go ahead yet. And we are just waiting for them to get the go ahead.

DEB GARNEAU: Right. It's been very difficult to do a paraprofessional, somebody without a license to get reimbursed, you know, through the insurers. Although this is definitely the direction that Rhode Island is slowly moving into.

KATE: Okay, good. Basically what we are hearing at least there is some movement in this area. But by getting it into the testimony, again today, it gives the legislative committee at the Governor's Commission on Disabilities the opportunity to continue to review it and ensure that that process is moving forward. And you said you had a second point?

MALE SPEAKER: A couple of points. Um -- one is that I think people might know there are a lot of people who are incarcerated with mental illness that get in a crisis situation that are not receiving treatment. And they get incarcerated rather than getting treatment. One proposal for this is to have crisis intervention trainings for police throughout the state. It's a national model started by Major Sam Cochran of Memphis police department. And it's -- I believe it's a three or four-day training which trains selected officers to respond to people with mental illness in crisis and de-escalate a situation so that no one gets hurt. Not the person in crisis, nor the police officers. And it's been proven to work around the country. We just need to get the will to get it in Rhode Island. A couple of us from NAMI consumers - a couple of consumers from NAMI were part of a training for police. And there's a story in the Providence Journal about a policeman talking about that training; how as a result of that training, he was able to de-escalate a situation with a young man with autism who had a knife in his hand and became friends with the young man. Totally turning the situation around. And he credited the training he got for being able to respond like that in a situation. So, I would say it has to be even more extensive and more widespread. Because in the past few years, there have been a number of killings of people with mental illness by police. And shootings of people, who if they had been trained -- if they had police officers who were trained in crisis intervention training, that might not have happened.

Supports: National Alliance on Mental Health (NAMI)

KATE: I think you made an excellent point and -- I would like to open it up to the panel for some feedback. I can say that we are familiar with some of those trainings in looking at some of the other states. But -- yes? Anne?

ANNE MULREADY: Charlie, I am glad you raised this issue. The CIT model came out of the consensus project that is, AMSA helped to fund. And I know that Providence police have participated in that training. But I think what you are saying is statewide, there has been --

MALE SPEAKER: I don't know if they got the full training.

ANNE MULREADY: Right. But I think -- is that what you were advocating for?

MALE SPEAKER: Yes.

ANNE MULREADY: For all of these departments to have that training, not just sort of pick and choose pieces of the training.

KATE: So really looking at the fact that it's okay if we have some city and towns, but looking at implementing a statewide training of getting this model -- because we have seen successfully that it works. That's another excellent point. Did you have any additional thoughts to share today?

MALE SPEAKER: Yeah. Um -- one is access to treatment in timely appointments when people are first seeking to get into the mental health centers. We get calls at the NAMI office that people are unable to get treatment. They are charged a lot of money for treatment. Or they have a long wait time when they are in a crisis before they can see someone. And I think access to timely treatment is an important issue.

KATE: Okay. That's another excellent issue. Is there anyone else on the panel who would like to address this critical issue? Yes, thank you.

ANNE MULREADY: I had a question, Charlie. Do people have health insurance who are waiting or are these folks --

MALE SPEAKER: Very often they don't.

ANNE MULREADY: Okay. So it's an issue.

KATE: We are looking at --

MALE SPEAKER: Right.

KATE: That was a good follow-up. Okay. So, another excellent point that will be brought up to the commission not only looking at access to timely treatment but looking at the issue of payment and insurance as well.

MALE SPEAKER: Just a few other very brief issues.

KATE: That's fine. We appreciate it.

MALE SPEAKER: Um -- well, transportation was already brought up. I just would like to add to that. What we are hearing is in the outlying areas in the very northern and southern parts of the states, people find it hard to get places. They don't have buses that can go there.

KATE: Anne, would you like to address that from RIPTA?

ANNE LECLERC: Yes. Again, we definitely want to serve them. We do have some service in South County and in Burrillville that people aren't generally aware of. Flex service is another thing we have. Anybody can use it for any reason. But it's a smaller bus that can go into neighborhoods, operates within a zone base. If people have questions about that, I can answer them afterwards. We don't want to take up a lot of the time. That model we would like to expand statewide, if we can get the budget for it. It works in areas where fixed service can't work because there isn't enough population to support regular fixed -

Transportation: Flex

MALE SPEAKER: Are there any limitations into where the flex service works?

ANNE LECLERC: Only within the zone that it operates. The city of Woonsocket is within zone. In Burrillville it operates in the Pascoag area and goes to Slatersville and Pascoag. In South County, we have one that serves part of Westerly that goes to Wakefield three times a day to connect to services and fixture service. We have a zone in Narragansett, southern

Narragansett. Another one in Kingston URI pays us for on the regular Kingston campus. And we have one in West Warwick, Coventry, Warwick line area.

MALE SPEAKER: Thanks. Also housing. I have been to some homeless support meetings. And people are saying they have no place to go during the day so they hang out in downtown Providence and they are harassed by the police. Studies have shown that when -- particularly people with mental illness, when you provide housing, it actually costs less in the long run. People get, you know, services in the community rather than ending up in hospitals, emergency rooms, and jails and prisons over and over again. So, you actually are saving money by providing housing for people. So, I think it's important. Also access to medication, people have full access to medication. That keeps people once again out of hospitals, out of the emergency rooms, out of jails and prisons, and they don't relapse as much. And so, services like that are important.

Housing: homeless

KATE: So what I am hearing from you are two issues. Let's toss the first issue up to the panel first. In terms of looking at some issues, to have additional housing. Does anyone have any feedback or any thoughts on this as to why it's important? That's --

ANNE MULREADY: I wasn't sure, Charlie, if you meant more funding for programs like Housing First, that kind of --

MALE SPEAKER: Definitely. And you know especially giving people their own unit really helps because if they are staying in a shelter, you know, a husband and wife can't stay together in a shelter. That's one example that can be brought up at these meetings I go to. Some people just are afraid to be in shelters. They are in a dorm with a lot of other people. They can get their belongings stolen. If people have their own apartment, then all these fears and objections to being there go away.

KATE: And so you mentioned increased funding for a program such as Housing First? All right.

MALE SPEAKER: Housing First is a program where they just take you as you are and give you an apartment. Then they try to resolve the substance abuse issues, if there are any, or the mental health issues. And they found that that works just giving people -- it's harder to treat these issues if people don't have a place to stay.

Housing: Housing First

KATE: Right. Okay. And I just want to also address your other point that you mentioned. Increased access to medications. Anyone on the panel like to address that? All right. It will just be an issue that once again it's going in the testimony. So it will be reviewed. Just for clarity, we have a much larger group of people who review the testimony and start to look at it in different areas such as transportation and housing and, you know, healthcare. And so, all of this information will continue to move forward. So a larger group can really look at it.

MALE SPEAKER: I just have one more issue.

KATE: That's great, Charlie.

MALE SPEAKER: Um -- that is, at ORS. I feel we have to do away with a certain stigma that sometimes faces people with mental illness. Because we got a call from one person who has bipolar. And he said he wasn't doing well. Then he got on the medication that worked and he recovered, did a lot better. But he was told at ORS maybe he shouldn't try working full time because they felt that there -- as far as I understand, judging him from the way he was before. He recovered a lot more and he might have been able to work full time again, but he was not encouraged to do that. I know another case of a person with schizophrenia who went to a Ticket to Work, workshop, and then he called ORS to ask about that afterwards. And when he mentioned he had paranoid schizophrenia, he was told, well, if you have paranoid schizophrenia maybe you shouldn't work full time. Maybe you should just work part-time. And so, I think there's a certain, you know, underestimation of what people are capable of. I like to point out an example of Robin Cunningham who has paranoid schizophrenia, now retired but with paranoid schizophrenia. He was making a million dollar business deals. He became a businessman, raised a family. So there are people, even with the most severe illnesses such as schizophrenia, who accomplish quite lot. And, of course, we have our own Congressman Patrick Kennedy who - taking quite an immense load in Congress and he has bipolar. So I just encourage ORS to really think twice before underestimating what someone can do.

Supports: Office of Rehabilitation Services (ORS)

Education/Employment: Ticket to Work

KATE: Maybe, would you like to -

JOE: It's anecdotal. But if a person has any kind of issues with ORS, they can contact the Disability Law Center. Hearing that kind of stuff -- they are not happy with what they are hearing, they can contact the Disability Law Center and they can address whatever issue. They may want to come in and review the issue, see what we have, and find out why they are saying that information.

Supports: Disability Law Center

KATE: Do you have any thoughts as to what would be a little more proactive to address an issue like that from the employment perspective?

JOE: Without knowing the cases in particular, I don't know. But I think if a client came to me and said, I think I would like to work full time. I would probably want to look at --

MALE SPEAKER: One of the people is me. I work part-time right now, 20 hours a week. I was just curious to see what my options would be. And I was actually told if you have paranoid schizophrenia, you might want to just stay working part time and not try to work full time.

JOE: Maybe the person was just -- {inaudible} I don't know. But somebody who is not happy with that answer, I think you can bring it up to -- I'm a supervisor and I have people call me all the time. I can be a resource to any of the clients, the contributions I have on them. If that doesn't work, you can always contact the Disability Law Center, a good resource for people.

KATE: So maybe you can -- go ahead.

ANNE LECLERC: The State Rehab Council I serve on is an advisory council that works with ORS. I will bring it up there as well and ask them to see if there's anything to review or any policies that maybe they can provide some input for ORS.

KATE: Arthur?

ARTHUR: On the 28th of October is the Employment First Conference. And perhaps that might be an issue to bring up. There will be a number of agencies that will be there. That hopefully will make the changes whether it's for transportation or dealing with clients to get them employed.

Education/Employment: Employment First Conference

KATE: Excellent. All right. Great feedback. Charlie, did you have any other thoughts or concerns?

MALE SPEAKER: No.

KATE: That was wonderful. You provided great feedback on comments of transportation, other issues looking at mental health as well as employment. So thank you very much for sharing. We -- now I would like to ask Kelly Richards -- yes. Hi, Kelly. You had some things you would like share today?

FEMALE SPEAKER: Two different things. He was talking about the high rises. One problem is lot of the high rises have bed bugs.

KATE: Okay.

FEMALE SPEAKER: If there's anything they can do about that. A lot of them fumigate their apartments. They only do certain areas. You still get them, you know.

KATE: So looking at -- anybody here on the panel like to address this? All right. So probably just an issue we need to make sure is brought up to a higher level to ensure cleanliness and taking care of the high rises.

FEMALE SPEAKER: And I have a couple things about RIPTA. One thing is a lot of the bus drivers in Providence -- I know they don't talk on the phone. But the ones in Pawtucket I know they talk on the phone when they are driving. And I don't really like that because they are not paying attention. And then they tell you not to wear a shirt but they let the little kids do it. That's not helping with the other people. They will start -- pretty soon they will end up wearing no shirt, the guys. They shouldn't let the little kids wear them.

Transportation: RIPTA

KATE: Sorry. Are we looking at --

FEMALE SPEAKER: The bus drivers -- the sign on the bus says, do - keep the shirt on, you know. If they let little kids go on with no shirt --

KATE: So it's a clothing issue on the bus. Anne? Do you have any feedback on that?

ANNE LECLERC: As far as the drivers talking on phones, please call and report them. They are told they should not be -- cannot be talking on the personal cell phones while driving a bus. If we don't hear that they are doing it, no one knows. So call and report them, please. I would bring up that they are letting kids on -- with the weather we have been having if they are little kids, I don't think they will make an issue. But make sure that adults and older kids have shirts.

FEMALE SPEAKER: One thing is the bus drivers have their job to tell people what not to do and everything. People are swearing a lot. And the bus drivers, I guess, they are afraid to say anything to the passengers - I guess the bus driver is afraid to tell them. Stop swearing or get off the bus. They swear a lot.

ANNE LECLERC: Some drivers have high tolerance for that.

KATE: Kelly, any other thoughts or concerns? It's great that RIPTA is here today. So they will bring back the issues to drivers on the phone and looking at some of the clothing and language issues.

ARTHUR: The high rises, is that in Providence or --

FEMALE SPEAKER: Pawtucket.

KATE: Isn't that good.

MALE SPEAKER: They are also in Providence I heard. Providence to -

FEMALE SPEAKER: The one I live in people have bed bugs. People come in and they have bed bugs. They don't make them fumigate their things before they move in. They only spray certain areas in the building; one, two, three sprays.

Housing: bed bugs

ARTHUR: Has there been reporting to the particular authorities? They don't do anything?

FEMALE SPEAKER: The manager I have, she doesn't really do anything, you know. Squirt certain areas, but that's it. But I am -- all my furniture in the middle and I do it myself. I go to the hardware and get the spray stuff. I have to keep moving all my furniture all the time, once a month. I don't want to get any of them.

ARTHUR: No. I wouldn't either.

KATE: Kelly, thank you for sharing today. We appreciate you bringing up the concerns that you have today. Christina Battista. Hi. Christina, you also indicated that you would be interested to share today.

FEMALE SPEAKER: Yes. That's right. Hi, everyone. Thank you so much for being here and listening to all of our concerns. I am here on behalf of the Cross Disability Coalition, which is a newly formed grass-roots statewide organization, as specifically for people with disabilities of all sorts. The coalition is an initiative of the Citizens Advocacy Committee of the Rhode Island Developmental Disability Council. And what our group does is we meet once a month. And we kind of got the priority areas in categories that we feel is most important. And today I would like to share with you the two other members of the coalition, some we identified, and potential

action steps. The first issue that I would like to discuss is better job opportunities for people with disabilities. There needs to be more awareness about available job skills training. There needs to be more resources used from the AmeriCorps . There are not a lot of people that are aware of this program. People need to know that they can work. And they have to address the issue of concerns about benefits. A lot of times people are very afraid to work because they are afraid to lose their SSI or SSDI benefits. There needs to be a central place for people to go to get some good information, such as ORS or other sources of information. Some ORS staff and others have low expectations sometimes about people with disabilities working. So there definitely needs to be some more education on behalf of the ORS counselors.

Education/Employment: jobs skills training
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Supports: AmeriCorps

KATE: Okay. Why don't we take a moment and address the employment issue. So we are looking at increased awareness about programs such as AmeriCorps and job skills and building up a better partnerships with ORS. Can I turn it back to you?

JOE: I think AmeriCorps is a great program. Whenever I see people I am working with that fits that category, I definitely tell them to look into it. There's so many different doors that open, employment, education, job skills. So I really try to stress that. As you know, we have benefits counselors that we have in our agency that if somebody has an employment plan, we can definitely have them work with benefits specialists. And if they don't, we can have them still work with Jeanne Fay or John Stota to talk about benefits. Job skills opportunities. I think we are the central conduit for whatever information people might need. If anybody has any questions, they can give us a call. As far as low expectations, I don't like to hear that. That's something, again, if you have any issues that any of the people you are working with, who happen to have that issue definitely bring it back to the counselor or the supervisor if that doesn't have an issue. And Disability Law Center next to me. Contact them too.

KATE: Okay. Thank you for that. And yes, there are a few of us here who represent actually the State Rehab Council, as well so these issues of employment will definitely be brought up there as well. Did you have additional thoughts, Christina?

FEMALE SPEAKER: Yes, please. Actually, I would like to pass this next issue over to Heidi Showstead who is a part of the coalition with us. And she is going to be addressing better transportation.

FEMALE SPEAKER: I am going to do that. But before I do that, I want to also expand about what Christina is saying about employment opportunity. I wear many hats on boards and on committees all across the state. And I am also here representing the Rhode Island Statewide Independent Living Council. First of all, I think there needs to be more of a general consensus that collaboration across the state, especially when it comes to disability issues, is a wonderful thing. And I think that we need to focus on what are the common goals that all people with disabilities face just being people, as opposed to separating and essentially fighting over the same pool of money. You know, how can we collaborate more? How can we get our needs not only heard and say, that's a great idea, but met. And I think we need to do more things like that. And I think in general, people need to learn how to become leaders. That it's okay to advocate for themselves. That it's okay to ask for help. That, you know, they should speak about their potential. Speak about their dreams. Speak about their wishes everywhere they go because the more people you tell what you want to do for work or volunteerism or whatever, eventually a

door will open and those opportunities will present themselves. I also think that there needs to be more stipend opportunities in the state. And by stipend, I mean not necessarily full- or part-time, per se, work. But stipend for speeches that people could do or maybe some -- Charlie did a wonderful job in talking about the mental health issues and should be very proud of himself. But I think in general there should be a push towards mentoring for children. Children seeing their peers with disabilities succeeding in what they do. There should be more advocacy trainings as opposed to less. There should be more of a fight against budget cuts because it's all about quality of life. And to get back to the transportation, I'd like to commend Anne. I'd like to commend RIPTA in general. And I would love to commend, if could I take this opportunity to just state that Bill Inlow is one of the biggest and best human beings and advocates that this state could have. He does a lot for people. I sincerely appreciate the fact that even though it is temporary, we are not losing the RIde routes because that's my livelihood. And I don't have depression issues. And I think part of the reason I don't have depression issues is because I am able to serve on so many boards in the state and try to help the youth, which is my passion. I would love to hear about more opportunities to help youth and use the RIde program to get there as well.

KATE: Great.

Transportation: RIde Transportation: RIPTIKS

FEMALE SPEAKER: You know, every system is going to have its problems. And I would like to say that RIde, the supervisors, the dispatchers, any issue that I've ever had has been reported and rectified. They are usually very courteous. The avenues do work. And as much as I am grateful for everything that we have in transportation, I'd like to see a couple of things change. I'd like to see the routes expanded rather than reduced. I would like to see, as Brenda stated, I would like to see the hours increased because -- just because you have a disability, especially as advocating for the youth in this country, they want to go to clubs with their friends. They want to go partying. They want to whatever. And if the only way they can do that is through the RIde program and the RIde program says, "Well, we shut off at 10:00." Doesn't give kids much of a, you know, of a weekend social life kind of thing. I'd like to see -- instead of having to go out and buy RIPTIKs or pay the cash for RIPTIKs; to see a system in place where you could call RIPTA or RIde or something like that and have an account number and pay for your RIPTIKs through your credit card. For example, I knew I was going to use \$90 in RIde for the month. And I called and paid on my credit card upwards of \$90. They could swipe that card and say, okay, Heidi's entitled to such and such more rides. Then it's nobody's responsibility but my own to increase my rides as I run out of the money on the card. But I don't have to worry about making the exact change. I don't have to worry about rushing around or not having the right amount or not being able to do something and having to cancel a ride because I don't have the months. That kind of thing it adds to independence. I'd like to see a think tank made on behalf of RIPTA and RIde involving all the disability organizations. Ways to increase the budget. Ways to supplement the budget. Instead of waiting for it to be another crisis and having to stop and threaten all the cuts. Let's all work together to find ways to make things better as opposed to worse. And let's maybe -- if we can, in the future, expand the RIde parameters. Maybe work with Massachusetts or Connecticut, so that if there is a person who say once a year wants to go to a friend's wedding that's in Connecticut, and they are willing to say to RIde, okay, it's ludicrous for me to pay the \$7 and go that distance. But I will pay a price that you quote to me and, you know, have that flexibility. Because the wheelchair accessible cabs are a good thing. But they only accommodate one person. If you want to go with a friend of yours or whatever relationship you had to somebody that happens to be in another wheelchair, you are not able to do that in the

cab routes. You are able to do that in the RIde routes. And I know that there are laws and I don't want to break any of the laws. I simply want to expand as much independent transportation option as possible.

Transportation: RIPTA

KATE: That's wonderful, Heidi. Just to touch upon, you made several excellent points. In the beginning, you talked a little bit about increasing the collaboration. That's one of the great things about this forum, bringing everyone together. I was going to see if maybe Laura or Deb could touch upon - you mentioned mentoring and advocacy with youth. Would you mind sharing a little bit about the Dare to Dream and some other opportunities before we get into the transportation?

Supports: Dare to Dream

DEB GARNEAU: The health department has sponsored for the last two years a student -- students with disabilities with special needs a conference, a student-led conference called Dare to Dream, a one-day event we hold it at URI. The first year we had about 250 students that had come, maybe from 30 different schools. And this past year we had almost 400 people that attended. So it's expanding. And one of the things we want to do is add a Phase II to that, to do more of an ongoing mentoring that can happen on an ongoing basis within the schools rather than having it a once a year kind of event. So, we are meeting with some of the teachers that are able and well and trying to, you know, pull these resources together, helping us to pull these resources together. We are meeting with them later in August and hoping to start off like this, more of a mentoring -- you know, having every district having some sort of a mentoring type program for the youth that are in their schools. So we are with you on that one. And really seeing that there's a big need, and we've seen a lot of data and a lot of things that talks about how students with disabilities are really doing risky behaviors and being pushed into making bad choices, and, you know, on and on. So we are trying to really change, you know, that whole area of providing more of these mentoring programs.

Education/Employment: mentoring

KATE: Great. Thank you, Deb. It's a very exciting opportunity, Heidi. So it's great that you are bringing this up. And then moving on to the comments you mentioned about transportation options, about credit card, and also looking at the issue of the cabs and only being able to maintain one person at a time. Did you want to touch upon some of the questions there?

ANNE LECLERC: Yes. I agree with everything you said. Thank you for a lot of what you said. I will pass it on to Bill with his comments. I would love to see the system expanded, hours increased. We need advocacy efforts to do that for the entire system. I will recommend anyone interested in expanding transportation, whether RIPTA or RIde, look up the Coalition For Transportation Choices. It's an advocacy group that started with environmental groups, but they are adding a lot of other groups. AARP has joined on. They really do need a stronger contingent, in my opinion, of people looking at accessible transportation.

Transportation: Coalition for Transportation Choices

FEMALE SPEAKER: Excuse me. Anne, do you happen to have a phone number or a contact person for that, that I could steal from you?

ANNE LECLERC: Um -- not with me, but I can get to you.

KATE: Maybe afterwards you and Anne can swap phone numbers.

ANNE LECLERC: Um -- I have been advocating for a bank account for RIde for years. And I am still going to. I think we need to get there for people who can have an account. I think it would help RIde as well, as helping the passengers. The think tank, I think that's going to come within the next year that some group is going to happen. But I also think the Coalition For Transportation Choices and having a collaboration of all the groups, not just groups with disabilities looking at increasing transportation options, it's very important. The only one I am negative on is expanding to other states. We have been trying for federal permission. Federal regulations -- three different federal departments that we need approval from. That's going to be a long uphill battle to try to get something. We are trying to get some input into the next preauthorization of the federal transportation law to make it easier for public transit agencies to cross state lines into contiguous commercial zones. It's unbelievably onerous to do. It is something we would like to do. We can't go to the South Attleboro, which is a quarter mile over the state line.

FEMALE SPEAKER: Would a -- as I said, I represent the Statewide Independent Living Council. And their role is slightly changing due to how the state is ever changing. And now we are basically going to conferences and collecting needs assessments and helping to collaborate with other organizations. Would a perhaps position paper or letter writing campaign help with these issues?

ANNE LECLERC: A position paper might because we can use that to try to talk with our federal legislators to help with the reauthorization issue because there -- it's just inconsistently -- the three federal departments are inconsistent in their application of some things that could make it easier for public transit agencies to cross state lines. So expressing the need and the fact that public transit is not the same as a freight hauler. Some of the rules they apply to over the road trucking they try to apply to public transit. It might help, yes.

KATE: And I think also getting your voice heard and in the testimony, it's going to be brought back so we can start to really look at it.

FEMALE SPEAKER: I apologize. But I would like to say one other thing and I'd be absolutely remiss if I did not. It is essential that all people with disabilities are able to have fulfilling lives whatever their choice range may be. And in order to do that, there needs to be unity with making sure that budget cuts to whatever services people need for help to get up to live daily lives does not happen. I mean, if you have budget cuts, and you lose the staffing that you need for eating or socialization or family activities, you are losing a big piece of your life. And I'm speaking in general on a humanity standpoint, and also friends of mine and myself that always have concerns about what happens when the services that people with disabilities rely on are on a chopping block.

Education/Employment: workers cut

KATE: I think that's especially a good point today as we celebrate the Americans with disabilities act. So, Heidi, thank you very much. We appreciate it.

FEMALE SPEAKER: Can I ask her one question? How come the Massachusetts buses are able to come into Rhode Island?

ANNE LECLERC: We don't ask them because we are not sure they --

FEMALE SPEAKER: They come to where the railroad tracks are. I'm glad they do but--

ANNE LECLERC: Sometimes private carriers have a little more leeway than public carriers. They could have gone through and -- like I said, it's inconsistent. Sometimes the exemptions and regulations are applied. Some of them have been coming since the 60s. So, as the federal regulations got more stringent, they just may have been grandfathered in. We don't ask because we don't want to open a can of worms if they haven't - put everything, all their ducks in a row.

KATE: So we will continue on. There are two more people who are also interested in sharing their thoughts today. So thank you very much.

FEMALE SPEAKER: Could I just elaborate on two more issues really quick?

KATE: Back to Christina. Sure.

FEMALE SPEAKER: Just to touch on better job opportunities once again. We feel that it's very, very important for the word to get out about the Sherlock plan. A lot of people with disabilities don't know about this program. And even in the past, I mentioned it to a few of my friends and they are like, "What is that? We don't know about that." So the fact to get out a little bit more to the public. As well as something called PASS people achieving self-support. People with disabilities to run their own businesses, small businesses. And a lot of people have so many potential qualities to run their own business and be self-employed that can also help the community in a lot of ways as well. And just real quick, just to mention about state budget cuts. We, as a group, are aware of the fact that there are a lot of concerns with this. But if it could be looked at in other areas, besides disability areas, a lot of the effects will change the way people with disabilities live. They won't be able to have personal care attendants. They won't be able to maintain their employment that they have now. So if we could just kind of figure out what we could do with that issue. And also we need to have people be more involved in public policy. We need to talk to government leaders. And if this is to be the most number one priority for myself as an individual with disabilities, need to establish -- excuse me -- Individual Development Account, IDA program, for people with disabilities in Rhode Island. I believe Rhode Island is the only state that does not have this program. So if you could explore that option, that would be fantastic. The last issue covered by Jeffrey Ovaginian talking about affordable safe housing.

Supports: Personal Assistance Services and Supports (PASS) Supports: Individual Development Account (IDA)
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KATE: Before I move on, Christina, did anyone have any comments to the additional points that Christina made?

DEB GARNEAU: What was the last one you mentioned, individual --

FEMALE SPEAKER: Individual development account, which is the IDA program.

KATE: Great. All right. So we will look into that. Thank you very much. And that's a nice segway over to Jeff. You were next on the list. So, Jeff. That would be Jeff Ovaginian.

MALE SPEAKER: Thank you. Basically some of the main points that we would cover under affordable safe housing would be needing more properties built for safe housing, expanding on Section 8 housing vouchers, providing more homeowner vouchers in all public housing authorities. Helping people to build credit and open bank accounts. Get on waiting lists for apartments. Going to classes for -- on how to be a home buyer. And there is some money available for closing costs and identifying tax credits for people with disabilities.

Housing: affordable housing

KATE: All excellent points regarding affordable and safe housing. Do we have anybody on our panel today who could speak to those points? We don't have anyone directly representing housing. But once this testimony is reviewed and written, there will be a group that will just be focusing in on housing. So these are excellent points to be made.

FEMALE SPEAKER: And can I submit this into the testimony? It just states who the disabilities coalition is and how to gain more access about our group, if that would be allowed.

KATE: Absolutely. We will take it before you leave.

FEMALE SPEAKER: Thank you very much for your time. We appreciate it.

KATE: Thank you. And Jeff, did you have any other comments?

MALE SPEAKER: I think that about covers it. Thank you.

KATE: Thank you.

ANNE LECLERC: I just think Heidi had mentioned the accessible cabs. I want to explain it to the people who haven't heard about it.

KATE: That would be wonderful.

ANNE LECLERC: The Federal Transit Administration had some money that the states were to spend new freedoms, services for people with disabilities. In our state a lot of that money was just awarded to buy ten accessible cabs for cab companies. And the state -- we actually had a prior award that was for another car. We have money for 11 accessible cabs. Right now our state has none. So the cab company is getting together to decide on what vehicle they want. And they are leaning towards a new vehicle, with a ramp that is going to start to be manufactured in the fall. So, if they get that one and they get on the waiting list for the start of manufacturing, we would have them probably next spring. Depends on how long the waiting list is. But we do have -- we currently don't have any in the state. So Heidi's point they only fit one wheelchair doesn't even help right now because we don't have any. But hopefully by next spring we will have 11 throughout the state for people.

Transportation: taxi cabs

ARTHUR: That's the same --

ANNE LECLERC: But they -- they might be able to fit two. Depends which vehicle they go with.

KATE: Great. Thank you, Anne, for providing that overview. Okay. I have one additional person who has identified an interest in talking. Gary, did you have some thoughts that you would like to share today?

MALE SPEAKER: No.

KATE: Okay. All right. At this point in time, we have asked all the individuals who have identified when you came in with an interest in sharing. Now we would like to open it up, if there is anyone else here this afternoon who has additional thoughts or feedback that you would like to share? Okay. Well then just to recap where we are at and some of the issues that have come up today and our next steps. Obviously transportation was a big issue that we talked about. We talked about increasing our transportation hours and expanding the services. We looked at some issues in terms of lifts on the buses as well as some issues with the drivers in terms of talking and looking at some clothing and language. As well as looking at the wheelchair accessible cabs. And the idea for the account number. So several issues that came up. And that will be brought back not only to the commission, but with Anne here, will be brought back directly to RIPTA for further review.

FEMALE SPEAKER: May I make one more comment that I think is very important? I think that with so many organizations in the state that do the best they can but leave some things to be desired, the organizations that work very well deserve a lot of kudos and to that end, I sincerely cannot say enough positive things about the Sherlock Center on Disability at Rhode Island College. They listen to people. They put people's thoughts and questions into action and future plans. They are all over the state helping in multiple realms and they are just a wonderful, wonderful resource. And I'd love to give credit where it's due. An organization that not only talks the talk but walks the walk absolutely is the Sherlock Center on Disabilities at Rhode Island College.

Supports: Sherlock Center on Disability

KATE: That's wonderful. Thank you, Heidi, for mentioning that. And I think you are right and that goes to some of the points shared today. And then moving on, in addition to transportation, we looked quite a bit at some of the mental health issues. And NAMI has brought forth increasing peer support specialists and coaches here in the state. Also looking at some crisis intervention strategies for law enforcement. Looking at the issue of access to treatment. And also moving on to housing, ensuring that we have housing available for individuals as well. We've also talked about having additional safe and affordable housing and some of the issues that come with that. We then looked at the access issues of increased access to medication. And also issues brought up in terms of employment, also looking at some of the stigma with mental health issues and employment. And increasing awareness of job skills training opportunities and other opportunities such as AmeriCorps to continue to build that relationship. On the budget issue and big picture issue, we talked about being and increasing advocates for budgets to ensure that all services are maintained. We also looked at the importance of the Sherlock plan and the PASS plan and also a new concept of the IDA which will be looked into as well. We then talked a bit about the issues of collaboration and having common goals across the state. And I think that's a great point. As we sit here together with so many organizations and agencies, you can see the commitment. And we just need to continue with that. And also increasing opportunities for our youth. We have great programs such as Dare to Dream here in the state. But looking at increasing internships and stipend opportunities, as well as increased

mentoring and advocacy training for the youth. So we can continue to increase their awareness of the importance of what their rights and responsibilities are. And -

Supports: National Alliance on Mental Health (NAMI)
Supports: job skills training
Supports: AmeriCorps
Supports: Individual Development Account (IDA)

FEMALE SPEAKER: If I could just make a clarification. I think the stipend opportunities are not only vital and essential to youth, I think they are vital and essential to all people. A lot of people are on the cusp with their benefits. And if they make a certain amount of money, the benefits they need to function and live will be drastically decreased. And where stipends are, you know, simple pocket money where you can do what you choose to do with the money and not be so much over a barrel. I think they are important to people at all stages of life.

KATE: It's an excellent point. And yes? Charlie.

MALE SPEAKER: I just want to add that there is a coalition called the Campaign for Rhode Island's Priorities, which is the Ocean State Action which tries to bring about a better budget for Rhode Island each year. And we could use more people with disabilities in that coalition. They provide what they call the better budget, which is not to cut these services. And they go the whole realm, including state employees, all services provided by the state budget. And if people with disabilities have more representation on that coalition, we might, you know, we are going to have some representation, but we could use more.

Supports: Ocean State Action

KATE: That's wonderful. Thank you, Charlie. So at this point in time, if we do not have anyone else who has official public comment, our panelists will be here for a little while to just -- if there's anything additional you would like to share with them directly. Again -- Arthur?

ARTHUR: I was just going to mention if somebody remembers something later on, they can send a note.

KATE: You read my mind. Yes. As Arthur is sharing, if someone remembers something in additional, we do have public forums going on throughout the week. But you can send at any point in time to the Commission on Disabilities e-mail address. And I believe that was on all the papers in the forums. And we can make sure you have a copy of that. And -- yes. So the next steps in terms of this information, the testimony, as we talked about, will be transcribed. It will be reviewed by the commission's legislative committee. Based down in priority groups and based on the sharing tonight, you can see all the different areas that we touched upon, even in this brief period of time. And then that information is looked at either from a public policy standpoint, advocacy or awareness, or a legislative standpoint. So, on behalf of the Governor's Commission on Disabilities and Department of Health, who hosted the forum today, I would like to thank you for coming. If you have any additional information, please let us know. And we will be here for a little while if you have anything else you would like to talk about. So thank you for coming.

3. *BARRINGTON PUBLIC LIBRARY, 7/27/10*

CAMILLE: I'd like to welcome everyone. My name is Camille Pansa, Executive Director for the Rhode Island Statewide Independent Living Council. I'd like to begin by having members of our panel introduce themselves, and the organization that they represent.

NANCY: I work for Rhodes to Independence.

JOHANNA GOMES: Johanna Gomes.

NICOLE: Nicole Aguiar, Multiple Sclerosis Society.

BRIAN ADAE: Staff attorney with the Rhode Island Disability Law Center.

SHARON: Sharon Brinkworth, Brain Injury Association of Rhode Island, and commissioner on the --

MIKE MONTANARO: Office of he Rehabilitation Services.

LINDA WARD: Opportunities Limited, and also a commissioner on the Governor's Commission.

ARTHUR PLITT: Commission on Disabilities.

CAMILLE: Has everybody signed in the attendance sheet when they came in? If not, I'd appreciate if you could do that. I'd also like to mention that there are restrooms outside this door, in the hallway. I'd also like to tell you that the purpose of these public forums is to identify concerns of people with disabilities and their families in order to assist the state to develop programs to move for quality of life of people with disabilities. These public forums, at the end of this week, will be followed by a posting of the transcripts of the testimony on the Governor's Commission for Disabilities website. And that website is www.disabilities.ri.gov. That will be in about two weeks. Later in the summer, the sponsoring agencies will review testimony, and prepare recommendations, which will also be posted on the website by the end of the summer. The recommendations and the transcripts will be printed, and sent to state and congressional officials, 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. I'd like to give everybody a chance to speak. We should have plenty of time. Although only one person has checked off that they wanted to speak, I hope more people will as this goes on. We are here, on the panel, are here to listen to you about your concerns. We may ask you for some clarifying questions, but we're mainly here to listen. I just want you to understand that. So, having said that, we can begin. And the first person on the list is Julie DeRosa.

JULIE DEROSA: We don't, I'm not going to (inaudible). I am here today because, although I'm an advocate on several different committees in the state, I am here to represent the Ocean State Center for Independent Living. And, basically, I wanted to talk to you today about the home access program that we have there. I work for the home access program, I've been there exactly a year as of today. And, my job there is as an administrator to support the program director. In the year I've worked there, I have seen so

m Housing: home access program e run. I guess we serve about 30 to 40 individuals a year, helping them with access in their homes, to get in and out, or with access to the bathroom,

or access in the kitchen. We install BPLs (sounds like), we do stair lifts, and ramps. So, I think the most important thing is to understand that we really are very appreciative of the funding that we receive from the state, and from the federal government, and just to state that we really want that to continue, and we see that so many lives have been transformed just by, you know, that funding. And, you know, it's a really good thing to watch people all of a sudden have independence, and be able to remain in the community, rather than in institutional settings. So, that's basically about all I wanted to talk about. Thank you very much.

CAMILLE PANSA: Thank you. Anybody have any questions?

ARTHUR PLITT: Do you run out of money for the --

JULIE DEROSA: Well, money gets tight. We are a funder of last resort. So, yeah, sometimes things, we have a waiting list. The waiting list can run anywhere from a year to two years. So, it depends. Sometimes it's a good year, sometimes we get money from an unknown source, a grant would come through. So, you know, it kind of, it's changing all the time.

CAMILLE PANSA: Anyone else that would like to speak?

MALE AUDIENCE MEMBER: Jack Walter (sounds like). I'm a parent of a 31-year-old man who has Down Syndrome, and physical problems beside his mental problems. I guess, my wife asked me to come today, and I certainly wanted to come, because she saw it in the paper. We're getting older; we're not sure, Michael lives at home with us right now. We're not sure what's going to happen when we're either not physically able, or whether we're not even here to take care of Michael. We try to follow up and talk to everybody we can to get ideas. Sometimes it gets confusing. Also, we have legal questions, and we've consulted several different lawyers, whether it be about power of attorney, estate planning, everything like that, seems every time we talk to someone, they say what we have isn't right, or good, or whatever, and they'll have their own opinion. And, we're just looking for somewhere to go to get, not only information about his future living, but also some legal help from someone who may specialize in estate planning and what have you, for people with disabilities. And, basically, that's why I came today.

Supports: legal help

LINDA WARD: Just as a resource, there is a (inaudible) trust in Rhode Island now that allows families to put money away for the future, and I can give you some information.

MALE AUDIENCE MEMBER: Thank you.

CAMILLE PANSA: Any comments or questions?

BRIAN ADAE: Yes, when you indicated you were looking for legal advice, or assistance, have you tried the American Bar Association referral (sounds like), or --

Supports: American Bar Association

MALE AUDIENCE MEMBER: No, we haven't. We basically asked people, this person is great, you know, we've pretty much done it by word of mouth.

BRIAN ADAE: The yellow pages are not necessarily the best place to find a lawyer, sometimes word is mouth is probably the best bet. The kinds of issues you're looking at, estate planning, power of attorney, is there anything else you were concerned about?

MALE SPEAKER: Well, we're concerned about that, and, I guess, our biggest concern is care and guidance for our son after we're gone. Whether that be a group home or some other kind of setting, just really not sure, you know, where to go, how to proceed.

Housing: group home

BRIAN ADAE: Depending upon, one thing to, maybe, if it's not apparent what I'm driving at is, a lot of the legal-based questions or areas are issue-driven. So, it's the specific issue you're looking at, whether it's estate planning, it sounds like what I think you are asking is where do we set up an estate, so we know he is taken care of. And part of that purports to knowing what resources are going to be there, as to who is taking care of or other folks that may be in a similar situation are at home or being assisted or taken care of by a family, as the family ages, what next, is that about correct?

MALE SPEAKER: Yes.

BRIAN ADAE: If you would like to see me afterwards, at minimum, I could discuss a little bit with you about the general areas, as well as give you a phone number to call. We do have referral lists at the Disability Law Center on attorneys we're aware of. Not necessarily recommending attorneys, but attorneys we're aware of that do concentrate their practices in particular areas such as guardianship or estate planning, especially where Medicaid comes into play, and you might be able to get you some general information and legal information, as well.

Supports: Disability Law Center

Health Care: Medicaid

MALE SPEAKER: Just as a follow up, also be able to get advice on actual living arrangements? You know whether it's a group home, or, an apartment, or some kind of help?

BRIAN ADAE: I think, I saw a gentleman next to you, that's where we get into --

LINDA WARD: David McMahon from what is now Behavioral Health Developmental Disabilities and Hospitals, which was MHRH, is right next to you.

MALE SPEAKER: I'll just grab him, I'll see him.

BRIAN ADAE: Maybe helps to explain it, and without getting into your particular situation. Depending on whether or not out of school, after education had been referred to, or if individuals had been referred to the division what was known as the Division of Developmental Disabilities, am I correct, it's still DD? Used to be known as MHRH, and there would be a question of DD eligibility. And, I'm sure the gentleman sitting next to you can tell you a little bit about that, but what we used to know as MHRH at the Division of Developmental Disabilities, if there is eligibility, there is a caseworker or case manager that's assigned, and they look at various resources that might be available, make some suggestions to you, as well as advise you as to what funding might be available. Did I get that about right?

DAVID MCMAHON: Let me add a piece. I don't think families always realize the first step is to make application, a lot of families think it's (inaudible), there is really no automatic referral. You must fill out an application for services, eligibility is determined if the person is found eligible -- and that social worker helps you navigate the system. So, the first step really has to be getting in an application, and that application can be made (inaudible) at the house, you don't necessarily have to make (inaudible) feel free to do that, go to our web site.

CAMILLE: Any other comments? Someone else has just joined our panel, I'll have him introduce himself and go from there.

BILL INLOW: I'm sorry I'm late, I'm Bill Inlow, a member of the Governor's Commission on Disabilities, and also the disability services coordinator at RIPTA and RIde.

Transportation: Bill Inlow

CAMILLE: Is there anyone else now that wishes to give some testimony? Your name, please.

MALE SPEAKER: Good afternoon, I'm not sure that this is a disability in a technical sense, but I'm struck by the conclusion that ignorance in the public of all your organizations, and what in fact is now out there needing to be solicited is in fact a real issue for people in the public. They just don't know, and they don't know, once they get a motivation for learning, how to go about becoming informed. And I wonder, maybe this exists already, but is there a handbook already that you could get, or buy, or have in the library which would amplify the kind of information very usefully presented today in this handout? As you all know, probably better than I, some of these disabilities arrive in an instant, and others arrive gradually over many years. People out there who are experiencing them and in some ways in our house have experienced both kinds. Have zero time to think about them before they have to deal with it. And, in other cases, they have decades to think about it. A situation that can vary, from family to family, and person to person, but it would be nice if it doesn't exist already, maybe it does, if there were a handbook at a local library, or you could call in, and have it sent to you for a price, to help navigate the offerings already out there. But, the public don't have adequate knowledge of it.

LINDA WARD: Interesting, there used to be a book a few years ago, it was a little blue binder, and it had every agency, and every organization, pretty much, on a variety of disability and elder care issues. And, I'm not sure who it was funded by, but it kind of went away, and it doesn't exist. People would say that 211 is a resource, or the Point is a resource, where you can call somebody up and have a conversation with them about what you're looking for. But, this is similar to what we heard yesterday at the forum in Middletown, is there a central place to get information for the public when they're confronted with it. So, I think it would be something that will probably emerge as a critical need area for the Commission to look at, so, thank you for bringing that up.

ARTHUR PLITT: One of the other problems, unfortunately, with the internet growth and changes in agencies and changes in information, the information is constantly being changed. So, probably, calling 211 would give you the best update on the information. And, generally, I think if you call any of the agencies, they will probably help to refer you to the right agency for the information. But, we do need to get the word out more and more. I think 17 percent of the state is considered people with disabilities.

JULIE: It's not complete or comprehensive in any way at this point, but maybe a place to start, you can go to the library and get on the Governor's Commission on Disability website. There is

a link to several resources. We're still working on building it, and adding things, but it's a place to start getting some information. It will at least get you to their website, and you can always access that at the library if you don't have internet at home.

CAMILLE: Anyone else?

SHARON: I was going to add to that, I represent the Brain Injury Association of Rhode Island, we're a nonprofit organization, and we, too, sometimes experience that, people don't know if they have somebody that's all of a sudden in the hospital, in a coma, like you said, happened in the blink of an eye, that they don't automatically think we need to call the Brain Injury Association because they don't know we're there, but after about ten years now, we're beginning to be more well known. So, sometimes we suffer those kinds of things, too. But, we have published, we're on our third rendition of it now, over the last, I'd say about eight years, of a brain injury resource guide. And, it covers several different areas, like, for children, or elders, and then all of those in between. But, it has a lot of resources in that book, and we have distributed, probably, in the first two printings, about 10,000 throughout the state. And, they've gone to the libraries, to every library, and we're waiting right now from the printers for our third update.

Supports: Brain Injury Association of Rhode Island

MALE AUDIENCE SPEAKER: Would that be true of all your organizations that something about your organization is in the library now?

LINDA WARD: Probably not.

BRIAN ADAE: Honestly speaking, at least my organization, the Disability Law Center, I'm not aware of any publication we have in the public libraries. And, as mentioned earlier, since the converging of the web, internet, we do have a web site as many of the organizations do. Often times, they have links from one organization to the other, and we're in the process of updating and expanding our web presence so that we'll be able to do things like, one of the things in here today, one of my -- from the Disability Law Center Kate Bowden has our annual survey that we used to mail out, trying to get a sense from the general population of what it is we should prioritize with limited resources we have for the upcoming fiscal year. Formally, we mailed these out, we found that we had a dismal return rate by mail, so we're now looking at putting it on our newer version of our website so that we can get more response. So, that's a way of explaining what's been happening. In fact, I encourage you to grab one of these and fill it out as long as with some of this vote information. So the resources like this that we have, that we do that are available on our web site and even more so in the coming months, weeks and months. And I'm sure that, I know that brain injury association has a web site, I've seen a lot of positive nods here from the panel. I don't know if you or someone you know does have internet access; I believe they do have internet access available here at this library. Most libraries do. So that might be a potential to begin looking. I'm not aware of a centralized location that has all of the links, the Governor's Commission for Disabilities has a web presence, and they do have some links available there. Perhaps that's a way to start in lieu of what we used to have the blue book.

ARTHUR PLITT: And giving credit to the library most of them have great reference librarians who are able to access information they may have in their files, information on disability organizations.

Supports: local library

CAMILLE: Anyone else like to give testimony?

MALE AUDIENCE SPEAKER: We have here in Barrington, an organization called the Friends of the Barrington library; both my wife and I are members of that. And it occurs to me that through that organization we should lobby the Barrington library and implicitly all libraries in the state to somehow get together and promote this idea. And here again, if people don't know about it, it doesn't do them any good. So, libraries can publicize the availability through the library of this kind of information. I'm a teacher so I worry about ignorance as a general -- and seems to me that that's fairly easily remedied if you recognize it as a problem.

ARTHUR PLITT: We have, can I -- we have elections coming up this September and November. And folks might be interested to know that if you do have a disability, there is an alternate way of voting at the polls. And it's accessible for all to use, whether you have a disability or not.

MALE AUDIENCE SPEAKER: When does the infirmity of age become a disability in the sense of which your organizations use that term?

BRIAN ADAE: Maybe, if I can, I'll take a shot at this. Being, at least nominally the lawyer on the panel here. Disability has differing definitions depending on the application. Generally speaking, it doesn't matter what it is, whether it's a physical, emotional, mental disability, whatever that is, generally speaking, most people think of disabilities they're thinking of the Americans with Disabilities Act, which this week is the anniversary and the 20th anniversary of the signing of the Americans with Disabilities Act. That definition basically says the physical or mental impairment that affects one or more of major life activities. So, if you're having difficulty voting because of a disability, whatever that disability may be, then you come with the gamut of the ADA and are eligible to request an accommodation if necessary in order to enable you to vote, as an example. So, am I doing that right, Kate?

Supports: Americans with Disabilities Act

KATE: So far.

BRIAN ADAE: A little more knowledgeable source in our office, and, actually, when it comes to voting, another shameless plug for our vote project is Kate has a ton of information on that as well as if you or if you know of someone or some agency that would like some assistance in voter registration, we're certainly available, Kate can explain that. And we maintain a presence during voting season. We have a hot line open to be able to answer questions regarding what needs to be done. In the ADA, definition applies to just about any major activity that you could think of, as far as life goes. There are some limitations in private sectors whether it be church or a private home, but public areas, even condominiums that most people think of as private, ADA modifications or accommodations can be made and are required by law, federal law and state law. We have state law on this issue, too. So when you think of that definition, that's probably the best one. When we get into school education issues, it may be a little broader, what we're looking at, public schools, and IDEA is the name of the act that talks about special education in schools. Jobs, housing transportation. That's what Mr. Inlow's role is at RIPTA as to be able to work with accommodations in doing various things so that RIPTA is available to folks with disabilities. Do I have that right?

Education/Employment: Individuals with Disabilities Education Act (IDEA)

BILL INLOW: That's correct.

BRIAN ADAE: Thank you.

BILL INLOW: We don't do that just because of the law requirement. We want to do that because we want to serve all of the citizens of the state of Rhode Island as best we can. Whether or not they have mobility issues. Brian does help explain some of the --

MALE AUDIENCE SPEAKER: Yes.

DAVID MCMAHON: Incredibly valuable way to get information in the State of Rhode Island today, we put a lot of resources into The Point, which is 211, the number you can call to get information about human services, Medicare and Medicaid services, remarkably skilled people. You can listen to guidance toward the correct -- I'm not sure it's the replacement for the blue book, the blue book is an excellent resource as well but this may be an easier way for people to speak at a person at the end of the line and get some good guidance as far as which resources are available.

Supports: The Point

ARTHUR PLITT: And, if there are more changes that need to be made, you'll note on page 11 of the handout that a lot of enactments of legislation have come as a result of the public forums from two sides of the street for accessible crosswalks to wheelchair accessible taxis. Some of these seem to be no brain errs but sometimes we need to get the legislation or policy or regulations revised.

Transportation: taxi cabs

LINDA WARD: If anybody is not registered to vote or needs to change an address, there is a table setup with voter registration materials.

CAMILLE: Anyone else like to give testimony? No one? Okay. Well, we'll be here.

MALE AUDIENCE SPEAKER: What is the interface between your collective concerns and the Department of Elderly Affairs?

BRIAN ADAE: There are often times, that's an excellent question. Again, our roll is here to listen, actually, so, my first question would probably be in response, answering a question with a question is have you run across the problem that we should be aware of or the panel should be aware of? But I can tell you that it's not uncommon that the particular agency that I work for that encompasses legal aspects in disability rights issues, may agency role is to represent rights of individuals with disabilities, so often times somebody may go an entire lifetime without a disability as you pointed out, develops a disability and if there's rights issues that involves legal based rights issue, my agency may be involved if it is within our priorities within our mandate. And it's possible that the department of elderly affairs may also be involved. There are other agencies that overlap with that, as well. If you've read the newspaper this morning there was an article about the mental health advocate interestingly enough representing or trying to represent a family member to retain a guardianship over an elderly gentleman who apparently has dementia and allegedly is being taken advantage of by someone so that's an example of probably I think what's not a newspaper story, but if not the Department of Elderly Affairs the alliance for better long-term care may have been involved with that and requested advocate assistance in trying to do something, the mental health advocate looks at it, and says, well, here

is somebody who is having mental health issues, dementia, and needs assistance and step in to do what they felt is the correct thing for their agency needed assistance.

Supports: Department of Elderly Affairs

FEMALE AUDIENCE SPEAKER: I have a question about guardianship, over an adult, 18, with autism, high functioning autism. At what point, or how difficult is it to acquire guardianship over a child who has a low IQ but can function somewhat.

BRIAN ADAE: it's really impossible to address specific or individual situation without going into a whole ream of information, in particular medical information. Generally speaking what's involved in the process of guardianship is a petition in the local probate court. So there is state law that concerns or rather that is applicable to all guardianships throughout the state but it is actually in the performed at the local level at the local municipality for example here in baring ton at the (inaudible) when a petition is presented, Rhode Island state law is actually very restrictive about guardianships. They try to maintain the if not complete autonomy, the rights of the individual involved, you've probably heard this. And what it requires is a medical opinion by a doctor. And there is a particular tool that the doctor uses that's referred to as an assessment tool, it's part of the statute, when talking about guardianship, what we're talking about as opposed to something like less restrictive alternative to guardianship, there is mention here of powers of attorney and an individual at age 18 could execute a power of attorney. And that would give power, for example, if I gave power of attorney to my friend Ms. Brink worth she would have the power to do those things enumerated in the power of attorney on my behalf. I would still retain my ability to do those but in the event I couldn't or in the event of my absence, she could do those things. A guardianship, if she had a guardianship over me she would make all of the decisions. She would have to give her consent; I would have no ability, no rights. If I ordered ice cream tonight, she would have to consent to that. So, it gets to be a little ownest. Bottom line with guardianship, you're talking about in some ways total ownership of another person and that's why we advocate less restrictive alternatives at the disability law center because we are about and what we do are the legal rights of folks with disabilities. What you're talking about, I think, and in general, is how do I go about get ago guardianship? I think I need to have a guardianship, like many folks when they may have a child coming of age in the school system, they are told by the school or by other agencies that you should get a guardianship over this individual in order to take care of them. The reality is, is there are very few situations where guardianship is absolutely necessary that there is not a less restrictive alternative that would work just fine.

Supports: legal help

Abuse and Neglect: guardianship

FEMALE AUDIENCE SPEAKER: I think in my experience, there are adults or over 18 individuals whose IQ is to a certain level that, yes, they can make some decisions, and I understand what you're saying about the autonomy. However, how clear those decisions are made and how good of a choice that they make is sometimes, come news their safety.

BRIAN ADAE: yeah that's what you're talking about. This is where it gets into that gray area where we're talking about judgment. Now, Sharon is my guardian, Sharon thinks I'm about to do something impulsive, I'm going to go out and buy a car rather than put money in a 401K. she knows this is a bad thing, no way he's exhibiting bad judgment, I have guardianship, I'm making a call here that I don't think he's competent to make this decision because it's bad judgment in

my opinion and most people's judgment it may be bad. How many times do we look at parents shaking their heads over their child's decision over who their mate, wife, spouse will be.

FEMALE AUDIENCE SPEAKER: But, that's a person who has a cognitive ability to make those choices.

BRIAN ADAE: Interesting area. I do. What you're talking about is competence. This is where it goes across the scale and you're talking about medical opinions and you're talking about competency of any of us to make a decision. And it gets down to voting, it gets down to is somebody competent to vote or not competent to vote because they're nonverbal? Is somebody competent to make a decision about ice cream or broccoli? It's an individual choice decision and it can get pretty interesting. I would submit to you that any of news this room at one point or another on a particular topic, any of us may not be competent on an isolated issue. May be times we're totally competent. I remember times in college on a Saturday night and a good portion of the freshman class may not be competent to make a lot of decisions.

FEMALE AUDIENCE SPEAKER: But, you're competence outweighed your incompetence is what I'm trying to say.

BRIAN ADAE: That's not the way it works legally.

FEMALE AUDIENCE SPEAKER: What I'm trying to say is what you're saying we all can make inn competent decisions and I know I have, I know what you're saying but when the majority of the decisions that you make are not competent decisions, it's, I think you're dealing with a different.

BRIAN ADAE: Decisions about what?

FEMALE AUDIENCE SPEAKER: Drug rehab when you need it. Walking out of or going into an area that's dangerous, crossing the street when there's cars coming. Anything.

KATE: Guardianship won't fix that, it doesn't stop a person from crossing the street if it's unsafe, only a care giver or loving person can stop that.

FEMALE AUDIENCE SPEAKER: But if you have guardianship over someone that they can be put into a group home, that's what I'm talking about. Because if you don't have guardianship then you can't put them.

BRIAN ADAE: I'm going to our friend in DD.

LINDA WARD: ...service provider, they're volunteer. Doesn't matter if they have a guardian or not. We can't, you know, unless someone is in imminent danger, you can't stop somebody from leaving a home and that's part of what we do as risk assessment. But as a provider, I don't feel the need for anyone to have a guardian. We involve the families in those decisions to the extent the person allows us to but guardianship has historically actually slowed down the ability to provide really good services because there's another layer of formal it that has to happen. So, I think, you know, we have never experienced a time when guardianship made anything easier. It hasn't. We've had people who will have refused to take meds and people say get a guardian. Okay but we're still not opening their mouth and shoving a pill down their throat, we're not going to I.M. (sounds like) them because they refuse. There is a limit and there are alternatives over money and medical decisions beyond just sort of taking away of all of those rights.

BRIAN ADAE: Let me apologize to you. I'm kind of putting you on the spot, and I shouldn't be doing that.

FEMALE AUDIENCE SPEAKER: It's fine.

BRIAN ADAE: Here, there's an illusion out there if you obtain guardianship over someone you can control their life's totally and put them where they need to be but what guardianship means is you have the legal authority to consent to something. So if you take somebody to the hospital and I say I want to put them in a hospital, the doctors, nurses, are going to have to admit them to the hospitals to determine whether or not there is a basis to do that and the guardian can provide necessary consent and medical consent to treat, even if the person is not able to give that consent or doesn't have the mental competence to give the consent. However certain kinds of treatment for example medications inn volunteer or intrusive medical procedures, that's something where even with a guardianship, the guardians say I want you to make them take the medication. The doctors and nurses are not going to make them take it inn voluntarily even though the guardian says so. It's not quite the same as if it is a child under the age of 18 where a parent is the natural guardian or guardian by law when they are anticipate under 18 where you can say you're going to take your pill or you don't get your dessert, or, you know, with a child being tide down and make ago child take it forcibly, would they do this to an adult? No. It's a specific type of proceeding of a different nature to do an inn volunteer medication or an inn volunteer (inaudible) an oh a guardian could provide consent but if an individual doesn't want to do it they can't control that. If then want to walk out, they will walk out, there's nothing making them stay at that group home unless there's potential danger to them selves or other and there's been adjudication involving DD, as well as (inaudible), so, controlling the person, it's only indirect control like providing consent for something. It's something where you can say you're doing this because I'm your guardian you have to do it or else what? Call the police, it doesn't work that way. Have I said way too much? I think so.

KATE: Yes.

BRIAN ADAE: Let me ask you this. I think really the appropriate way too look at this, I'm not clarifying, I'm explaining. Do you perceive that this is an issue, is this something that the governor's commission should look at.

FEMALE AUDIENCE SPEAKER: I think so. I think there's a population, I'm just generally speaking about kids on the spectrum, where at 18, what do you do? And I know personally for my son, if he walks out tomorrow, he needs somebody there to take his meds, to help him cross the street, to get dressed and do laundry and all those things. I understand what you're saying, having guardianship over him can't, he has enough intelligence to know he need to say take his medication. Would I force him to take it? No. But I remember erratic behavior living on his own, what is the answer to that then?

Housing: autonomy

BRIAN ADAE: I think, looking at this as helpful, is, we're looking at positive interaction that is do not necessarily require guardianship, put guardianship aside. It sounds like if I'm reading this correctly is he's not going to remember to take his medications or appreciate that he need to say take his medications.

FEMALE AUDIENCE SPEAKER: He's not going to remember to cross the street.

BRIAN ADAE: ...danger crossing the street unaccompanied. So what we're really talking about is a prompt, an aid, somebody there, as you have been as his mother. And I apologize for making it personal.

FEMALE AUDIENCE SPEAKER: It's okay.

BRIAN ADAE: But, an aid in doing that. This is where when we talk about coming into an adult hood and I know our friends other over from DD, and the system somewhere we're in the process of 18 to 21 we begin to look at as they phase out of school and into the adult system, there is a system there, and they can look at the kinds of supports that are needed. Talking about exactly the kinds of things that may be needed to do what has been done before by family or other agencies which is the prompting and the aid to get from one place to another. Somebody being able to monitor. There are probably, I don't know the numbers but there still are a good number of folks who used to be inn city constitutionalized -- some were nonverbal, never had or needed a guardian. Yes they have a lot of assistance, yes there may be a decision every once in a while they may or not be able to make a decision about, an intrusive medical procedure, that is where there is a one time court proceeding and their competency to make that decision is reviewed and if it's found they're not competent to make that decision, there's a substituted judgment process by the court oh oh made on their behalf.

KATE: I'm Kate Bowden, colleague of Brian's, and I think this discussion sort of speaks to something we've seen at the law center which is that there is a gap that we've seen for eligibility for people on the autism spectrum. The eligibility criteria that was developed for people with developmental disabilities was really geared towards population that we once referred to as M.R. with mental retardation and so some of the higher functioning folks in the autism spectrum are not deemed to be found eligible for service that is may assist them for some of the services that you have. So maybe you can think televisé as a concern for how we address this population in light of what our current landscape is for services.

DAVID MCMAHON: I wanted to go back to sort of beginning and you say, thank you very much for your question, I think it's very important to discuss this stuff and the issues that you have will very real. But what you're describing is sort of the final step in the process. The first step needs to be application to the agency formally known as MHRH. The social worker will be assigned and will assist you with the proper treatment of your child. We have some wonderful programs out there that deal specifically with the issues you're articulating this afternoon. These programs are tremendously successful in dealing with specifically the needs of people. Guardianship is a tool in a toolbox that we have. It's a very intense tool, very complex tool, and not the tool that you go with first. So there are times we use a piece of guardianship for instance a guardian ad item, complex medical issue, a temporary thing, what you're describing is a guardianship in entirety which is the big piece. There are many many things that we can do to help a person who needs some assistance taking medications, or a reminder in bathing and this type of things. Programs that are specifically designed and have proven to be tremendously successful. The first step is to apply to the program.

FEMALE AUDIENCE SPEAKER: What is the web site?

DAVID MCMAHON: You could Google MHRH, and that would come up. You may be able to get it, our e-mail, which is only a month old, keeps coming up Buddha.

LINDA WARD: Leads to you weird sites, so be very careful.

MALE AUDIENCE SPEAKER: I think if you Google MHRH, that will bring you to Behavioral Health Developmental Disabilities and Hospitals, which is our new name. Behavioral health developmental disabilities and hospitals. Once the social worker is assigned, you can start to look at appropriate treatment goals and programs. Many of which are specifically geared towards the things that you're looking for, assistance with hygiene or medication. Some of the decision making processes you are describing are things that these agencies specialize in. Not only in group homes.

Supports: Behavioral Health Developmental Disabilities and Hospitals (BHDDH)

FEMALE AUDIENCE SPEAKER: Like, right now, he is in Paths, he has a Paths worker, and they work on goals such as like you said prompting and things like that. He has goals and dreams he wants to be on his own at 21 and he wants to do all these things but it's that prompting piece, is he going to remember those things when he's out there on his own.

BRIAN ADAE: If I can, maybe --

FEMALE AUDIENCE SPEAKER: You're talking way too much. I'm kidding.

BRIAN ADAE: That's why I want to apologize for commandeering, but, obviously, you hit a nerve inside my rights advocacy role, so I got up on my soapbox when we're really here to do is hear your concerns. I was going to suggest a number of referrals. If we are still in school are a lot of the agencies out there if not have been contacted. Looking at other agencies that links that would be nice oh know, RIPIN, the Rhode Island Parent Information Network.

Supports: RIPIN

FEMALE AUDIENCE SPEAKER: That's where I work.

BRIAN ADAE: CEDARR, a number of things.

FEMALE AUDIENCE SPEAKER: He is involved in that. It's long-term, when he's 21 and wants to move out because cognitively he's not able to go to college so ORS will be get ago phone call pretty soon so it's all these things and it's the scary thing of I don't know want to prohibit him to be independent but yet as a mother and my social work background, it's a pull and yes I'm his mother and yes I understand what you're saying about taking away his autonomy and things but it's very hard to be in that situation when you're worried about giving his autonomy but are you putting him at risk at the same time.

BRIAN ADAE: we have a gentleman here earlier who had a son that's -- age and was talking about his concerns about what happens as we age and our ability to care for him. And we're talking about this if I'm correct, not even there yet, but more likely as he gets older, autonomy concerns are basic safety concerns and what's out there to guide him through this process.

Housing: autonomy

FEMALE AUDIENCE SPEAKER: Yes.

BRIAN ADAE: On a day-to-day basis. What do you perceive for him and others like him that you may be aware of, is what those needs may be and if they're being met and what is unmet, if anything.

FEMALE AUDIENCE SPEAKER: Right now or later.

BRIAN ADAE: As this process goes on that you're expressing concern about.

FEMALE AUDIENCE SPEAKER: I think my concern is, so, if he does go into, say, an apartment that has assisted, like, a person that would go in, caseworker to go in and check on him, make sure his meds are being taken and things like that, what happens if is absent minded sometimes because he gets distracted, he can cook himself macaroni and cheese, but he turns on the stove, and, oh, look, there's a wild life planet show on he likes and that stays on, it's those kinds of things that I'm afraid of and then my mind goes to he needs to go to a group home because there's not going to be someone living with him there every minute of the day and he doesn't want to live with me forever.

Housing: group home

LINDA WARD: you could have a roommate, a roommate with a disability or a roommate without a disability. There are so many different options and way to say address a loft those concerns. I mean nothing is a hundred percent but there are a lot more options than there were 20 years ago. Sometimes being in a cluster of apartments within a complex where there's a lot of staff around because there's a lot of people living there. So there's a whole variety of things. But I think getting the eligibility determined and then trying to figure out with him and with the social worker what are those dreams and is it at 21, he wants to move out?

FEMALE AUDIENCE SPEAKER: The door is closed.

LINDA WARD: Anyway. But, that's, you know, does he realize through working with the social worker that there's a process to it and there are certain things have you to do and maybe certain things he has to demonstrate whether it's being able to use the phone or to recognize emergencies, some of those things that are critical criteria for being in your own place.

DAVID MCMAHON: That's really the beauty of the system in Rhode Island, to make sure that people have options. So once a person is found eligible they can have a social work err and they sit down and talk with brilliant people like Linda and say this is what I need and Linda can put together some options and if she can't she can help direct you. It's a system that works together and comes up with ideas to address the specific concerns of families. And the success with these programs is phenomenal. Many many parents have come to me over the years and Linda over the years, as well, with very similar concerns, and (inaudible) and so we come up with what where he think are good and common sense answers like maybe if a staff person is there at mealtime or maybe we could have a roommate or maybe we could have an environment with more supports. The maybes can go on almost forever. As long as you can, you know, discuss the issues with the social worker and the team that's built and the good thing about it is that plan isn't a ten-year plan or a hundred year plan. It can constantly change as the person changes. So as you're working with, you know, great organization, you can sit down and say a change has occurred and look at modifying -- what's most important? Maybe bedtime is most important, maybe combine bed and mile time and have a staff person there at that time so those things are dealt with, eligibility, social worker, meet organizations, have you some choices. Quite a few choices in the state of Rhode Island. To develop a treatment plan that best meets the needs of the person that you're working with, your loved one, family member.

BRIAN ADAE: may I ask, at what age is division taking applications at this point in time?

MALE AUDIENCE SPEAKER: Well I'd like to say 21 that doesn't always happen. Some families, we don't get an application until the person is 35 or 40. I just met last month with an 82 year-old woman completing her first application. In a system that continues through a person's life, hope any, after children services they move to adult services with us but in many situations the person doesn't need the supports until something changes at which time.

BRIAN ADAE: as we know there is an 18 to 21 year-old range.

MALE AUDIENCE SPEAKER: Gray area.

BRIAN ADAE: that area where they may be in school, we would hope they're in school continuing education under IDEA until age 21 but if they're not in school and not receiving school services.

Education/Employment: Individuals with Disabilities Education Act (IDEA)

MALE AUDIENCE SPEAKER: That's a policy issue. I'm not here to answer -- we would like at age 21 the School Departments to be involved until their 21st birthday.

BRIAN ADAE: Perhaps DCYF prior to --

MALE AUDIENCE SPEAKER: Sometimes.

BRIAN ADAE: If it's done before age 18.

FEMALE AUDIENCE SPEAKER: It's like a way ward that is.

BRIAN ADAE: Depends.

MALE AUDIENCE SPEAKER: There is a variety.

BRIAN ADAE: --/way ward.

FEMALE AUDIENCE SPEAKER: That's the sad part between that 18 to 21 that you have to get involved with DCYF.

BRIAN ADAE: is that a problem?

FEMALE AUDIENCE SPEAKER: I think, I just think that, I think it is. I think it doesn't, that piece needs to be tweaked.

LINDA WARD: we will definitely put that issue on commission's agenda.

ARTHUR PLITT: Interesting discussion. Thank you.

MIKE MONTANARO: ORS can assist but assist with employment, not assisting with a lot of other issues you're talking about. So a lot of times there is a misconception with parents or agencies that want us involved in that time period and they think we can do independent living issues and all that other stuff and we really can't.

Supports: Office of Rehabilitation Services (ORS)

FEMALE AUDIENCE SPEAKER: It's employment.

MIKE MONTANARO: It's employment, exactly.

FEMALE AUDIENCE SPEAKER: One more question. Are you ready to talk? Just to go back to what you were talking about, you know, guardianship and you wanted to buy an ice cream cone, or.

SHARON: He's not getting one.

FEMALE AUDIENCE SPEAKER: Good, and the car, good. What happens when you, you know, my son is extremely generous, so he moves in with, you know, Joe, and every night he wants to buy Joe pizza, and buy Joe a new suit. By the time you know it my son's money is gone because it's his money and he can do what he wants because there's no.

BRIAN ADAE: Are you asking about a less restrictive alternative as opposed to guardianship with what happens with his money? A lot of folks, in adult hood may be recipients of SSI and manage their cash benefit. And everyday of the week, I don't know what the percentage is of folks on SSI that receive their own check or folks on SSI, who a representative payee, but there's an entire program with social security and the representative payee program, (inaudible), so, if there's a family member or mother or father may be a representative payee. There are organizations that can be rep payees. If there's a group home, they could be the rep payee. As a matter of fact, may need to be because their monetary contribution to the group home aside from other sources of money are required. Representative payee means in social security the SSI check, the cash benefit check goes to the representative payee. So the rep payee will pay the rent, will pay the heat, pay the cable bill. And, is in charge of the money. So, there is no guardianship, it's already there. By the same phone the person is employed, it is possible that they could have a, could execute a power of attorney for monetary. Yes they would still have the right to their own money but it may be limited how much they have. Or if you get into more restrictive environment, it could be a limited guardianship, strictly on finances. So, somebody to have control of finances but they can could, you know, still be totally autonomous otherwise. There are a variety of tools. Part of it though is, without getting into individualized situations, may like to spend his money on some of that. And it's as simple as just with anybody else, maybe a small amount of money, checking account, trying to see how it works with money, trying to work with the concept of money, it might be possible. That's something that certainly happens in certain kinds of occupational therapies or O.T. assistance and sped programs in school sometimes, I'm aware of clients, where they're talking about, I don't know if ORS does anything like that. But, a lot of the adult DD providers or folks that are representative payees or that type of situation where they're in control of something, may give them a small amount at trying to work with them where they're allowed a certain amount, they find out, when the 25 buck social security gone, it's gone. Spend it in one night or maybe they won't. Maybe it's blown and it's blown. It's one of those facts of life. Does that answer the question?

Supports: legal help

Education/Employment: school programs

FEMALE AUDIENCE MEMBER: Yes.

BRIAN ADAE: In too many words?

FEMALE AUDIENCE SPEAKER: No, it was great. Thank you.

BRIAN ADAE: Let me ask you this. That's an area that you're concerned about. I don't know, I'm aware that certain agencies can act as representative payees, or, you know, power of attorney. There are certain folks that may be adults who do not have family available or close friends, maybe live in their own apartment so there's not a group home or case manager or a certain agency in a position to be a representative in that normal position. There are agencies like vet vs. a particular agency, veterans, for a nominal fee per month. I don't know if that's something you perceive or other folks perceive as a need. More of a need for an independent representative payee agency that's at a nominal cost.

CAMILLE: I'd like to move on if we could. And Jean Lawlor from the Disability Vote Project.

JEAN: if I could have your attention for a moment or so? My name is Jean Lawlor with the Disability Vote Project, and, one of the things we try to do is sign people up as voters who will be collected on a database and then through a process, get back a list, we can share with our elected officials that indicates who has voted, what district they voted in, all public information. But, what we're doing is just collecting your home address; it's as simple as that. If you don't mind. If you do mind, no hard feelings. But that's what this is. If you can just take one and pass it down. So, really, one thing that this will help move forward is the chance to work with our elected representatives at no time state and can say, hey, you know, we have 30 people voting in your district and we care very much about this issue and we hope you do, too. That's powerful when you've got a block of voters. So that's our mission to mobilize the disability vote. Does anyone on the panel want to -- thank you. Thank you very much.

CAMILLE: Is there anyone else to give testimony? Okay. Why don't we take a five-minute recess and see if anybody else comes in.

CAMILLE: I don't think anyone else is coming so if you don't want.

KATE: You don't have to stay here until four?

CAMILLE: I can, I will, but if folks want to leave --

ARTHUR PLITT: I think you can leave if you want. I mean if they haven't shown up in the last 45 minutes, probably not.

(FORUM CLOSED)

4.

WARWICK LIBRARY, 7/28/10

LORNA: Excuse me. We'd like to get started soon. Before we get started, I hope everyone has signed in. If you haven't, if you could take a second to go to the front table and sign in. Whether you are going to testify or not, we'd like to know who is here. And I'm hoping everyone got a 3 by 5 card. And we have a pen if you need one. This is just for you. It's not going to be handed in. This is a way for you to jot down something you might hear today that you agree with. Perhaps there's someone that talks about accessible transportation; and you are sitting in your chair going, "Oh, I agree with that testimony." Just jot yourself a note. When we are done with the testimony, I will say, "Does anyone wish to add more? Anyone with cards wish to add to the testimony today?" You can come forward or just from your seat say your name, where you are from, and that you agree with this person, that person, whatever issue you feel strongly about. This is really good to do. And I encourage you to do so. All of our testimony is being taken down by our CART reporter Jen. It will be written up and available at the Governor's Commission on Disability on their website. More importantly, it's printed and given to our legislators. So, the more things that are mentioned, if -- it's kind of a good way to let the legislators know how important some issues are. So I encourage you to jot down some issues that you absolutely agree with, and we will have a moment at the end for you to testify. And if you are nervous, you don't have to be. It will be very quick. I guess we are all set to go now. I would like to welcome you to the Governor's Commission. There are five over the state. It's an opportunity for people with disabilities and their families to present issues of concern to folks, like the panel that's up here, as well as written testimony that will be shared with legislators. I -- just so you know, all testimony will be reviewed by the Governor's Commission, prioritized with a summary page that is then actually shared with the legislators. I think they have privy to the whole thing. But they do definitely get the summary page of issues that are mentioned by the public. So, anything that is said here today keeps going. You have a concern. Someone will either hear it today or see it later. So it's a wonderful way to get your voice heard. Today we have with us Representative Eileen Naughton, just a hi sign. There she is. {APPLAUSE} She recently won an award for her work with working with people with disabilities, and we congratulate her on that. Very deserving. And also from Congressman's Langevin, we have Kristin Connors with us today. Kristin. {APPLAUSE} Okay. Just a few housekeeping kinds of things. If you would like a cold drink or something munchy, there is the shop around the corner that you can go to and it's pretty reasonable. Lavatories are out this door to the right, and they are right there. And I think there's also a bubbler out there. The procedures for today, basically I am going to be getting a list of people who are signed up. I will call your name and you can come forward and give -- please state your name and your city. Why your city? Because legislators want to know who their constituents are. So your name, where you are from, and then please present your testimony as brief as you can. In fact, if you would like to, even at this time, kind of take notes of the first, second, third issues that you would like to testify so that it can be pretty precise. The panel is here to hear your concerns. They are not here to discuss, only to listen. This isn't a debate. They can ask clarifying questions. Really only if -- let's say an acronym is mentioned and we are not sure what the acronym stood for, like OSCIL, Ocean State Center of Independent Living. A way to get a plug in. It would be only to clarify something that is said. I'd like to introduce our panel, very distinguished panel. Please give a hi sign. I think everyone is here. Bill Inlow from RIPTA. He is our bus guy. Vanessa Voltz. Linda Ward from Opportunities Unlimited. Rory Carmody. Not yet. She is coming. She's from Cranston Arc. Jenn Fiske is here from ORS. Elaina Goldstein, that's URI, Rhodes of independence, URI pharmacology department.

ELAINA: College of Pharmacy.

LORNA: Monica Tavares from Rhode Island Department of Health. And what else? Nichole Aguiar. Nichole Aguiar from the MS society. And Robert isn't here and Sue Eleoff. I think we can get started. Is there anything else I need to say? We are good. Okay. I need the list. Thank you. The first person to testify is Pauline DeFalco. I can come to you if you like.

FEMALE SPEAKER: My name is Pauline DeFalco from North Scituate, Rhode Island. I am here today because I have a five and a half year-old son with autism spectra disorder. Sorry if I get a little emotional. My son has been denied Katie Beckett twice. It has been stated, although it is clear he would benefit from the home based services that they can provide to him through Katie Beckett. And CEDARR he doesn't qualify because in their terms he doesn't need to be institutionalized. I don't think any child needs to be institutionalized in this day and age. It's because of the level of criteria that the state has in place for these children to meet the criteria for Katie Beckett. I was told by the DHS representative, the Department of Human Services representative that autism is not a disability. I was told that my son will never have friends. He will never be able to communicate because he has autism. All of this is completely untrue. And for her to say that to me is completely absurd and it's demoralizing. She needs to spend a day with an autistic child to see what we go through. My family does not qualify -- or meet the criteria for Rite Aid or Rite Care. We have private insurance. It doesn't cover the therapies my child needs. In this state, if you are above the poverty level F a child has been diagnose with a developmental disability and you have primary insurance, you cannot access the services. Sorry -- during the past year, I've contacted numerous agencies. To name them would be -- we would be here all night. One after another I have been told without Katie Beckett or Medicaid, they cannot help me. I'm sorry -- to obtain these services on your own is almost impossible. If you are lucky enough to find someone to provide them, the cost is so high that most cannot afford them at all. Although I have been lucky enough to find two people who are qualified to help my child in the home, I don't know how much longer I can have these services provided to him because the cost is just astronomical. I don't work any more. I left my job because my child needs me at home. I need to be there for his appointments. I need to be there for him to get services. So I can't -- I can't be in two places at once. The state of Rhode Island really needs to readdress their level of care criteria and to include the children with autism. Without Katie Beckett, our children do not have access to services because commercial insurance does not cover the services. Our current system requires eligibility for Medicaid to access these crucial services and supports, which include CEDARR, out-patient services, ABA programs and social skills groups. Without these supports, my child or any child with autism will not be able to progress and reach his full potential. The state of Rhode Island and the Department of Human Services need to look at these children as human beings and not a case number and not just a name. They are little boys. They are little girls. They have disabilities, and they need to be given the opportunity to thrive just like everyone has that opportunity. If something is not done to help us parents get the services that they so desperately need for their children, these children will fall through the cracks. And if that does happen, then shame on the state and shame on this country for not giving these children a chance to thrive. I'm not going to -- I am going to continue to fight for my child's rights and for the rights of all the children and any person who has a disability, especially autism because they deserve the right to have a productive life and to thrive in the community because they can, if they get the services. And that's it.

Supports: Department of Human Services

Health Care: Katie Beckett
Health Care: Rite Care

LORNA: Thank you, Pauline. Marie Perna is next -- after, Marie.

SUE ELEOFF: Lorna, I want to clarify please. Has there been a change in the criteria for Katie Beckett? Or have these children previously been covered and are no longer being covered?

FEMALE SPEAKER: My child himself has been denied choices. He's never had it. I was told by the same person who told me my child would not have friends that next year the children with autism are the first to be taken off the services because they -- it's not a disability in her mind.

LORNA: Thank you. Marie.

FEMALE SPEAKER: Thank you. My name is Marie Perna. This is my husband Don. We are both from Cranston, Rhode Island. And we are about to open up an MS dream center, a day facility in September for people with MS. We are surrounded by a large group of people with MS, care partners with MS, and many other support people. We are going to help see us get through to this. We are here today to let you know that we are very happy that we have a RIPTA to fall back on. It is a wonderful service to our state. One of few in the nation, and we can be very proud of that.

Unfortunately, sometimes things just don't go far enough. Our center is going to be located two and a half miles outside of any route that RIPTA or Ride can offer. That's just the way of things. But because so many of the people we hope will be coming to our center are going to be people who are in wheelchairs, are going to be people perhaps coming from nursing homes, who have not had the opportunity for the services that we hope to provide at our center. What we are here today is to ask for RIPTA to please consider extending some of the routes where possible. I know I ask that in the worst of times. But we have to ask anyway because we don't want to deprive people of a better quality of life because they can't get to where that quality of life can be improved. Thank you.

Supports: MS Dream Center

Transportation: RIPTA

LORNA: Thank you, Marie. Anna Liebenow.

FEMALE SPEAKER: Right behind you. Thanks.

LORNA: Do you need me to hold it?

FEMALE SPEAKER: I think I got it. Every -- both people that spoken were so articulate. And, Marie, some of what you were saying about RIPTA, I will second that. I really am very thankful for the fact that RIPTA is able to do what it can do so well. And -- but I really want to -- I just really am concerned about there being any kind of changes to RIPTA that would make it even less than it is because even as it currently stands, it is great. But there are plenty of places that you simply can't go to with the buses. And this new MS center is one of them. So, in getting over to the library here is a little confusing in and of itself. And earlier today I was trying to go to an appointment in Warwick. And I couldn't get to it taking the buses. So, I think that's something that I really want there to be continued work towards there being, not just maintaining where things are at with RIPTA but being able to increase. And then another piece also is that there are lots of sidewalks that the corners, the curb cuts aren't -- they are not consistent. You can't rely on it. So even this morning when I was out, it was here in Providence. And I was looking -- trying to figure if it wasn't 100 degrees out how would I have gotten home from here. And I was looking at the sidewalks and they just -- you don't know until you get to the end really if you are

going to be able to get off of it. In two places in particular that I'm really -- I think it's really unfortunate that more work hasn't been done for the curb cuts is over by Rhode Island Hospital. Sort of by Dudley Street, crossing the street there is very difficult because of the fact that the curb cuts are so poor. And also over by the mall. The downtown mall. I was over there recently and just crossing the -- whatever the main street is there is -- it's just hard because the curb cuts are really poor. And they need attention. So, that's it. Thanks, Lorna.

Transportation: curb cuts

LORNA: Thank you, Anna. Bridget. Hi, Bridget. Do you want to come up?

FEMALE SPEAKER: My name is Bridget Hjerpe and I live in Cranston. I work for the Ocean State Center for Independent Living. I am the nursing home transition coordinator. Our nursing home transition program is also known as the community living option. And I am a little nervous. And I am here today because my concern is that a lot of our potential consumers and a lot of service providers aren't aware of this program and the option for people to live in the community. A lot of people have been placed in nursing homes because they - they had a medical condition that landed them there. That initial placement was considered medically necessary. However, once people become medically stable, they might remain in the nursing home simply because they lack the knowledge of programs like mine. Programs like ours help people identify their individual needs and concerns to help them be able to live in the community. A lot of the tasks that need to be accomplished for people to be able to do that can be confusing and somewhat overwhelming. These tasks can include establishing community connections, finding accessible housing, coordinating community support services; for example, home health agencies, Meals on Wheels, adult daycare, other day programs that people, you know, might need to be able to remain independently in the community. Accessing public transportation, like the RIde program and other programs through RIPTA. Securing home safety devices, like assistive technology, tub benches, alerting systems, things that will help people remain safe in their homes. And assisting people with accessing appropriate home adaptations, home modifications. Maybe somebody might need a ramp or they might need doorways widened so a wheelchair can fit through. We will assist people with any service that they need to get back into the community. Many studies have shown that people, even with very significant disabilities, can live safely and comfortably in their own homes with the right supports. It's been my experience that these people report being happier and healthier when they have their independence and their own home environment. In addition the cost of a nursing home level of care is about \$83,000 per year per person. That comes out to \$415,000 over a course of five years. A one-time cost to allow someone to modify their home or get the equipment necessary to live independently and safely can cost up to 10 or even \$15,000. The savings is still over \$400,000 when you look at a period of five years. That being said, I think programs -- nursing home transition programs like the one that we have at OSCIL is a win-win situation for everyone involved. In conclusion, I hope that the word will get out to service providers and other potential consumers of ours and that that will be continued and even increased funding for programs like this.

Transportation: RIde

Housing: nursing homes

LORNA: Thank you, Bridget. Susan Baylis. Susan Baylis.

FEMALE SPEAKER: Right here. Hi. My name is Susan Baylis. I am the parent of two daughters, Juliet and Emily, 14 and 11. Both my girls are profoundly autistic. So I am one of the

lucky parents who have a child who actually meets the criteria that Katie Beckett has for institutional level of care. Without Katie Beckett, my kids would not be in my home with me. I have services through CEDARR, CBTS, PASS, and Respite And this level of support and training that we all get allows my kids to be as independent as they possibly can be and allows them to stay at home with me while they are children. I am also a RIPIN parent consultant at the Autism Project. And many of the families I am dealing with now are no longer getting Katie Beckett. We just heard from Pauline earlier the devastating effect of not being able to have these services for our kids to have. The criteria for Katie Beckett has not changed. It's always been that the child has to meet an institutional level of care -- which there are no institutions in Rhode Island. So I'm not really sure what that means - or at risk of hospitalization. I think in the past, most of our kids were always approved for Katie Beckett, whether they had severe autism like my kids, PDD-NOS or Asperger's syndrome. What I have seen in the past year and a half working with families is that kids who have Asperger's syndrome are no longer approved for Katie Beckett. And kids who had Asperger's syndrome and had Katie Beckett are no longer getting renewed for it. So, the systems that they have in place to be successful and independent, which for a lot of our families are not a lot. It's not a lot of services, and the kids are thriving. Those services are now being pulled for them. I am now seeing the middle kids, PDD-NOS kids. Those applications are now being denied and they are no longer --

Health Care: Katie Beckett

Supports: CEDARR

BILL: What is PDD --

FEMALE SPEAKER: Autism is a spectrum disorder. So can you have kids who are severely and profoundly impacted with autism, all the way up to high functioning children with no cognitive impairment but have major social and communication. PDD-NOS is Pervasive Developmental Disorder - Not Otherwise Specified, and it's kind of in the middle. They have some of the criteria for severe and profound kids. They can't have cognitive impairments. But they have a lot of good skills.

BILL: Is Asperger's below or --

FEMALE SPEAKER: Asperger's is high functioning, no cognitive impairment.

BILL: Where are they on that continuum? Where is that person who is diagnosed with Asperger's on that continuum?

FEMALE SPEAKER: They are considered high functioning.

BILL: So they would be low on the spectrum?

FEMALE SPEAKER: Depending which direction you are coming from, yes. My kids -- I call my kids severe and profound, so they are on the lower side. And then we go PDD-NOS and Asperger's. Kids with Asperger's academically are fine. A lot of them can go to college. 80 percent of kids with Asperger's syndrome will never be able to hold a job because communication impairment and social impairment is that significant that they are unemployable. So that is why the services early on are so really, really important to our kids. And what I've seen with the families that I am working with is that we are having a whole bunch of kids that are being kicked off of Katie Beckett. If we don't have Katie Beckett, the only other way we can get Medicaid is for me to start an income criteria. A few of my families have been lucky enough to

meet that income criteria so their high functioning child is able to access services because they meet the income criteria for Medicaid, where another high functioning child can no longer get services, you know. I think we are going to see a huge increase with the higher functioning kids and hospitalization at Bradley and Butler because the supports that they have in place right now that are helping them be successful are being removed from them. And I want to share a quick little story with a plea from a family I am working with who lost Katie Beckett when they went up for renewal. The mother was very, very upset. When their son went to sleep -- he was an 8 year-old boy. He went to sleep. The parents were talking about how could they possibly afford their PASS worker. This is a kid getting two social skills groups and ten hours of PASS and being extremely successful in school and home and community. He overheard the parents talking, and he overheard how upset they were. The next day he went to school and he brought a knife in his backpack. And he told his friends that he had a knife in his backpack. And mom got called down. He got suspended. When she asked him "Why did you do that? Why would you bring a knife to school?" He said, "Maybe if they know I need help, they won't take away my PASS worker." I think we are going to see an increase in hospitalization. And I am really concerned for the families because we can't access anything without Medicaid. We can't access the CEDARR Center. Without the CEDARR Center, we can't get services.

Health Care: Medicaid

Supports: Personal Assistance Services and Supports (PASS)

LORNA: Thank you, Susan. Victoria Hay. You want to come up?

FEMALE SPEAKER: I will sit.

LORNA: It's fine.

FEMALE SPEAKER: Hi. I am here today to say that I do agree that ADA is a great opportunity for people who are disabled. But it's very hard to implement. It's very hard to get the services. I have been legally blind all my life. I have had three children that were all legally blind -- sorry. They were learning disabled. And one is dyslexic. My ex-husband was dyslexic. I am handicapped. I was handicapped. My whole family was. And it was up to me to try to get the school to understand my kids. And it was always like, well, that means another class. Well, we don't have the money, you know. Well, put it with -- they do well mainstreaming. I'm a person who came from a two classroom. From first grade to fifth grade I was in one class with one teacher who taught on five different levels. From then, I went from six to eighth grade with another teacher. And then when I got to high school, I was thrown out in the mainstream. And I got to tell you, I sat there because I couldn't see what was on the board. Everybody else was doing work. If the teacher referred to anything on the board, I was lost. I sat there like a big thumb. Kids would say to me, what class do you come from? So, my point is that when I was in those two classrooms, I was an apple with the apples. When I went out in class, I was an apple with oranges. Today this is what they do with people who are handicapped. And I will say to you -- or disabled -- from whether or not you are legally blind or whether or not you have a learning problem or whether or not you've got Asperger's, you are in a big classroom where nobody's helping you. You know, I had a home room teacher we could bring our problems to. She would get books that were large print to help with whatever we were studying. But most of the time we had to fend for ourselves. And it wasn't socially helpful. So, the other thing I have to say is that as far as RIPTA goes, I have figured out their game. Here's the game. Threaten that

you will cut the routes. Threaten that you will stop the time. And they have a five-year looking forward to negative things they are going to do to this bus company, which I can't understand why you would take a commodity where you are making money out of people getting on a bus. They are going to pay you, and you are shrinking those services. Shrinking them. It's the disappearing bus. So, I say this. What happens is people get scared. People say, "Oh, we will take the fare. Don't cut the routes." So every year they get a jump in their fares, you know. And I feel that it's very misappropriated the money in that company. I feel they have a heavy office. I don't know if they're telemarketing there or what. But you are taking -- RIPTA is taking away the freedom and independence of people who really need it, you know. And I think it's a shame. And we are all here now saying we need help for our children, for ourselves, and everything is cut, cut, cut. But oh boy, people are six figures sitting on boards. Within the town, whether they are a politician or what, everybody's grabbing the money. But when it comes to the people who really need it, and our children are our future. You know, it's not there for them. You know, and I have spent my life for my kids going to school and asking them for help and getting the remarks. The only time I got help was when I brought lawyer. Then all of a sudden my kids were disabled, and we will put them in resource class. We will do this. We will do that, you know. Why do we have to go that far? And I got to tell you, accessibility. Try Main Street in Warwick. No curbing for wheelchairs. Now maybe there's nobody there on that street who wants to take their wheelchair out. But if they do, they will have to go down a driveway, come out in the middle of the street to get back on to the sidewalk over the next block, and probably get killed because you know Main Street. There's no margin for walking. That's for sure. And then there's CCRI. This has been going on for years. If you are in a wheelchair on the fifth floor and there's a fire, forget it. There's no ramps. There's only an elevator. For years, CCRI has got away with not complying. And nobody pushes it. So, the ADA law is wonderful. But why don't we see it do what it really has to do. And to think that Mr. Langevin finally got a seat so he can be a speaker. It took that long. So, I got to say that, you know, one hand gives and the other hand takes away. And there's been too much taking away. And you've seen too many people say how much help they need and how much help they are not getting any more. So I think everybody needs to step up and start throwing the money in the places where it needs to be. Thank you for listening to me.

Education/Employment: learning disability
Education/Employment: CCRI

Transportation: RIPTA
Transportation: curb cuts

LORNA: Thank you. You brought up many interesting, good issues. I would like to have you spend a little time after the session, maybe meet with Bill Inlow.

BILL: I would be glad to talk to you.

LORNA: After the session, he would be glad to speak with you, if you would like to stay. Next will be Robert Alessandro.

MALE SPEAKER: Here.

LORNA: In the corner.

MALE SPEAKER: What did you say?

LORNA: What would you like to say? Speak right into it.

MALE SPEAKER: I was at a meeting a long time over here -- a meeting. Thanks for coming.

LORNA: Okay. I am so glad you are here. I will shake your hand. I am glad you are here, Robert. John Medeiros. John.

MALE SPEAKER: Hi. My name is John Medeiros. I work for Cranston Arc. I am a PASS worker, and I work with my friend Dylan here. I am not prepared to be -- I didn't find out about this meeting until 9:30 last night. Dylan's mom called me and asked me to come by and to talk about my experience with Dylan. Um -- I've only known Dylan since November. And he's grown quite a bit in that short amount of time. And I work with him and he has another worker too. Two of us work with him separately. And if he could speak for himself -- I don't know if he wants to or not. It's up to him. I think he would agree that the PASS worker program is very beneficial to him. And his hours are getting cut 20 percent. And at this stage in his development, that's not beneficial to him. And I do my best with him. I teach him manners. I teach him what a respectful society would want from an adolescent. And I'm concerned for the people that are going to be cut and are not going to be able to have anybody to help them. And I hope everyone can see what is happening when our services are being cut. But money is being spent in places where it's just wasted. And it's the needy that keeps getting cut. The seniors and disabled that keep getting their services cut. Thank you for--

Education/Employment: workers cut

BILL: Could you tell us what PASS means? What does that stand for? The letters.

MALE SPEAKER: To be honest, I don't --

FEMALE SPEAKER: It's Personal Assistant Services Supports.

BILL: You told us what it really means, and that is a good caring person providing good solid services to this young person. You want to say something, Dylan?

MALE SPEAKER: Not really.

BILL: Thanks. Thank you for being --

LORNA: Thanks, John. And thanks, Dylan. Melissa Rosenberg. Is she here?

FEMALE SPEAKER: I am here. Hi. My name is Melissa Rosenberg and I live in Cranston. I am the Assistive Technology Specialist at Ocean State Center for Independent Living or OSCIL. Everybody knows it. There are two issues I would like to discuss today. The first one is I want to stress the importance of assistive technology and the funding for it. There are many pieces of durable medical equipment that are not covered by Medicare, private insurances, and Medicaid. These pieces of equipment can make the difference between someone being more independent versus someone who has to rely on a care giver for assistance. AT, not only improves the quality of lives for our consumers, but it also increases their independence and safety throughout their homes and communities. Agencies like ours depend on government funding. We are a funder of last resort. And some of these pieces of AT that we provide for people give them dignity and independence, and they are able to provide for themselves and do more. And it's simple things. Little things that people take for granted every day, putting their socks on to taking a shower. There's another issue that I wanted to bring up. Something that's been brought

up to my attention recently regarding Deaf consumers. If somebody who is Deaf has been arrested and are brought down to the police station, there has been issues recently with them having interpreters available to them. With my experience, I feel that a video relay phone, if they were installed in the police departments, it would be possible for the police officers to communicate with the hearing impaired day or night. In conclusion, I would like to see funding continue to assist people to remain independent longer. And I would like to see the installation of video phones seriously taken under consideration. Thank you.

Housing: assistive technology

Health Care: Medicaid

BILL: That would be in each police department? Municipal station?

FEMALE SPEAKER: Each town.

BILL: Every town and city would --

FEMALE SPEAKER: Absolutely.

BILL: A video relay phone. That's a very interesting idea. Thank you.

LORNA: Thank you, Melissa. Dawn Wardyga. Where is Dawn?

Health Care: Katie Beckett
Health Care: Medicaid

Supports: CEDARR

FEMALE SPEAKER: I wasn't going to speak, but you guys who know me know I probably had to. {LAUGHTER} I came in a little bit late. But Sue was speaking when I came in. I'm Dawn Wardyga, and I am the director of health and public policy for the Rhode Island Parent Information Network. And I actually come at my work as the parent of a child who had significant disabilities, and have been working with families like mine for many, many years in this state. I recently met with Bob Cooper and other members of the Commission regarding not only the Katie Beckett issue. The Katie Beckett -what's happening with Katie Beckett is a symptom of a much larger problem in my opinion. That the -- we are -- our agencies working with the Department of Human Services to try to come up with solutions for what's happening with Katie Beckett. Some of the kids that are actually being denied Katie Beckett -- some, not all -- probably don't meet the strict criteria that we currently have in place and actually that's in fed the law. What we did several years ago, the advocacy community put together a system of services and supports through the CEDARR Family Centers It was built around Medicaid eligibility because at the time that it was built, we didn't have the eligibility issues that we are currently seeing. And it was also built as a pilot program. Call it a pilot program with the intent being that over time once it had proven itself, its efficiencies and actually the best practices for kids and families, that commercial insurance would hopefully kick in and pay for those kids who have commercial insurance. And just for the record, 94 percent of the kids that are on Katie Beckett in the state of Rhode Island have commercial insurance as a first payer. So we are only -- there's only 6 percent of these kids that are 100 percent Medicaid. So there's quite a bit of commercial dollars already going into these services. The issue that -- the bigger issue -- and I'm not saying Katie Beckett is not an issue because it is and it's been a problem for the last four or five years. Because somewhere along the line someone decided that it was one of those,

and technically in law it is an optional population under Medicaid. Although you can talk to any parent whose child has relied on services who's eligible by way of Katie Beckett, they will tell you how optional it's not. How mandatory it is. So having said that, there was always a group of kids that met the Social Security disability criteria but did not meet the institutional level of care, which is required under Katie Beckett. So they couldn't qualify for Medicaid under any mechanism whatsoever. Those kids were not able to access services through the CEDARR Family Centers. We always had that gap. They were always what we call the gap kids. Well, that gap is becoming a gorge is what's happening. That with the increased -- with the application of the criteria being applied more rigidly. Because I will tell you, I specifically ask the question and got an official answer from the state that there has been quote-unquote no change in policy. So having said that, and knowing the numbers of denials that are happening both at recertification and new applications that are getting turned away, that group of kids that couldn't access services before is getting larger. Those kids that have been accessing those services, as you heard earlier that are losing access to those services. So the bigger issue is access. This is not just a Medicaid issue. This is a much bigger issue than that. This is an issue about access for all kids with disabilities, whether they are Medicaid eligible or not. The original plan with CEDARR Family Centers was that we were going to talk about building in sliding scale fees and buy-in mechanisms for those families whose kids did not -- were not Medicaid eligible and again sliding fees based on income and who had the means to help contribute to those services. That particular piece of the experiment never got continued. So, now we've created a system that quite frankly is discriminatory. That unless these kids can find a way into Medicaid, regardless of how severely disabled they might be, they have no access to services. This is more to me - the Katie Beckett issue is always a hot button issue and we continue to work on that. But that's only a symptom of the larger problem. We have an access issue here, and it represents discrimination. And in my opinion, it's only a matter of time, if things don't change before it winds up in a courtroom up for discrimination.

Abuse and Neglect: discrimination

LORNA: Thank you, Dawn. I don't have anyone else signed up. What I'd like to do -- Dawn did come a little late and didn't hear the testimony earlier of a number of people with concerns that folks may want to talk to you. I'm thinking of a young lady in the back and a few folks that testified -- the first few that testified. What I'd like to do perhaps is give a break right now. Have our CART reporter cool off her fingers. And if the folks perhaps could meet with Dawn that would like to talk with her for a few minutes, that's good. When we come back, I would like to hear from folks who have written on the cards. The card folks, we will hear from you. So how about five minutes -- yeah, just five minutes. At five of we will come back.
(Return from break)

LORNA: Hi. I guess we are back. I think there's some great conversations going on. Some nice connections that have been made. Please feel free, if you would like to step outside and continue the conversation. I think it's really important that we have some peer support and some folks that are finding services right here in the room. And that's fantastic. So feel free to keep talking. I would like to continue for those folks who wish to continue before we end at 6:00. And I think I heard from -- oh my gosh. I forgot her name. There was a young lady that wanted to speak first, and I forgot your name. What was your name? Leah. Leah? Babbot.

FEMALE SPEAKER: Hi. I am Leah Babbot, a case manager at Fellowship Health Resources. We work with people with severe and mental illness and disorders. I have been with the agency a little over three years now. And something that I have seen now that I think would be so important is more housing, not only affordable housing but housing in a timely manner. Several

places, the waiting list is two, three, four years. And a lot of the people that we work with are ready to go out in the community very quickly and would benefit from the sense of independence that housing could get them. And then secondly -- sorry. I'm a little nervous. Housing First is a program. It's been a pilot program in a couple of cities. And actually Riverwood has done a program here in

Rhode Island, which is you give housing to people, no matter what, without any criteria. You don't make them take their meds or stop drinking. They get a house, an apartment, a place to live. And it has showed immense success. And I think developing that in a into a bigger program for more people in the state -- because we have seen a lot of people come to us who have a history of being homeless, not taking their meds. And they get into the group home and they become real success stories and they get back into the community. They get friends. they get jobs. They got all these things and just because they have somewhere to live. And just my last point is we do have people with us who because of their illness and not probably caring for by taking medications have criminal histories. And what happens when they are ready to go on their own into an apartment, they are denied. So, we get them stuck. Even though they have shown -- we lived here at Fellowship for two years with no problems. And they get denied, denied, denied. So I think housing would be a great issue because that would allow more people to get into the group homes and supportive apartments for treatment. And you know, overall you save the state money. That's it. Thank you for letting me speak.

Housing: affordable housing

Supports: Riverwood

LORNA: Thank you so much, Leah. Anybody else has a card that has some -- has agreed with some of the folks that have spoken already?

FEMALE SPEAKER: Hi, everybody. My name is Ellen Kreutler. I am with the Parents Support Network of Rhode Island. And I am so happy to be here among you folks today because we are trying to make everybody aware of a new program that's coming around to provide Respite to care givers so they don't get burnt out. They need a rest. All the populations here, there's -- right now there's programs with one of our programs, the Department of Elderly Affairs. There's programs with Diocese of Providence that covers basically the elder population. But we are putting forth this Lifespan Respite Act that went through Congress, partly through Langevin. And it's covering people all the way from childhood through life. And we are trying to see what's in Rhode Island already. We are trying to grow access to Respite in Rhode Island. It really needs to be done. We are having a luncheon on Tuesday to talk about it. We are forming a coalition, publicity campaign, getting public awareness out there. The exciting part is we are growing our volunteer Respite force. People will be earning what is called time dollars through a program called Time Max. There's no money exchanged. Families are in time dollars. I will be happy to talk about that later. It's a whole presentation in itself. But this is a way of getting more Respite housing to Rhode Island. So if anybody wants to talk about that, that would be great. Thank you.

Supports: Department of Elderly Affairs
Supports: Lifespan Respite Act

Abuse and Neglect: Respite

LORNA: What was your name again?

FEMALE SPEAKER: Ellen Kreutler from Parents Support Network. I am from North Scituate. I am a neighbor.

LORNA: Neighbors have found each other. That's great. And anyone else have an issue they would like to bring up?

MALE SPEAKER: My name is Don Perna. My wife Marie spoke earlier. I am here wearing two hats. One as a member of the OSCIL board. I can't reiterate too much about the testimony from the people speaking on behalf of OSCIL because they do a wonderful job. And it's so important, the work that they do, the dedication of that staff. And one issue about OSCIL is, to be on the OSCIL board, the board is comprised of more than 50 percent of persons with disabilities. Now my second hat is -- as the chairman of the board of the MS Dream Center, which is a new operation. We are just opening in September. Our board is composed of 16, 6 in wheelchairs and 3 care partners; so more than 50 percent of our board is composed of people with disabilities that have a concern, a specific concern with people with disabilities. I spoke briefly with Bill Inlow before. And I know his dedication to the community, the disabled community. And I know the importance of RIPTA and RIde and it's affecting us right now. But I asked Bill the question. And he said he would check it out for me. But I don't believe that a single person with a disability sits on the RIPTA board. And I'm wondering since it's a state operation, at least partially funded by the state, why that is? And other than Bill, who really -- who really is looking out for the community of the disabled? Thank you.

Supports: MS Dream Center

LORNA: Thank you, Don. Anyone else? I don't see -- nobody? Yes? Anyone else like to say anything? Well, I thank you all for coming today. Wonderful testimony has been presented. Know that your voices have been heard. And I thank you so much for attending. And I will see you, same time, next year -- same place next year. Thank you. And thank you to our panel. The panel has to stay here until 6:00? Yes, we do -- Who is saying yes? The Governor's Commission guy says we have to stay. Well, I guess we have to stay. Feel free to talk among yourselves. Go get coffee. I guess we have to stay for a little while longer.
(Return from break)

LORNA: We have Nichole Aguiar, who would like to speak.

NICHOLE: I just want to stress the importance of the crisis intervention bill that was introduced and stalled in committee this past legislative session. It will be brought up again next year, and we hope it has the attention of the legislators.

LORNA: And that's it. Thank you.

5. *KINGSTON, INDEPENDENT SQUARE 7/28/10*

LAURA: Okay. I want to be sensitive to people's time, so, the forum does go from four to six. But we can get started. My name is Laura Jones, I work for Rhode Island parent information network. Welcome to the public forum for concerns of people with disabilities. And I'd like to introduce our panelists. Each panelist will state your name and talk a little bit about what they do at their organization. We can start with Rhonda.

RHONDA O'DONNELL Hi, I'm Rhonda O'Donnell, I have multiple sclerosis. Been on the committee for over twelve years and self help group leader in Warwick for about ten years. And down South county for about two years.

DEB: Deb Golding work for the Rhode Island Parent Information Network, working at the department of health in the office of special health care needs and focus on adolescent health care transition, helping to support communities and providers and parents and people, adolescents with healthy development and transition into adult hood.

BRYAN HUDSON: Bryan Hudson, attorney with the Disability Law Center, and for those who don't know, the Disability Law Center, we are federally funded nonprofit, helps advocate for rights of individuals with disability disabilities. And every year we actually set our priorities based on federal law and we ask that if you are willing to fill out a survey that we have back there, actually, attorney Brian Adae has the surveys. And our voter hot line this year if you see issues with voting specifically, if you have difficulty accessing the polls to give us a call and we'll see if we can give you some assistance.

NANCY: Nancy Silva, Rhodes to Independence, working for independence for individuals with disabilities.

FEMALE AUDIENCE SPEAKER: Can you speak up, please?

NANCY: Gosh, this is the first I've ever been told that. I'm Nancy Silva, I work for Rhode Island Parent Information Network at Rhodes to Independence in Cranston, and it's a Medicaid infrastructure grant for employment, focusing on employment for individuals with disabilities.

JEANNE: I'm Jeanne Behie and I'm with South County Community Action Program, also a commissioner with the Governor's Commission. And in South County Community Action, I work in a homelessness prevention program working with families that are being evicted from their rental, helping them access resources and temporary funding.

ROBERTA: I'm Roberta Greene, (inaudible) at the Office of Rehabilitation Services, state and federally funded program helps people with disabilities obtain employment and also I run the assistive technology -- and (inaudible) to help people understand if you're receiving Social Security disability how to access (inaudible).

TIM FLYNN: Good afternoon, everybody. My name is Tim Flynn, I am Chairman of the Governor's Commission on Disabilities and I have for the last five years been, up until last year been Chairman of the legislation committee. I don't know if Laura mentioned but these forums are extremely important and how we develop our legislative package. Every year we listen to concerns of you guys, the public, we take those concerns and formulate, we look at them, and we formulate the legislative package, and then advocate for their passage at the state house.

So, really, you have a real opportunity here to speak to this panel, to have an impact on the life of people with disabilities and your own lives. We're here to listen and hear what you have to say and I really appreciate you taking the time out of your busy schedules to come and help us out. And with that, .

LAURA: So, welcome everybody. Just to let you, give you an idea, some guidelines about how this works is, those of you who came in and signed in, some of you checked off that you would like to speak. You will have your opportunity to voice your concerns. That information that you give to us will be captured by our stenographer/recorder here and so that testimony will then be brought back to the governor's commission and will be part of, like, Tim said, the legislative committee will look at that, and that's how we bring back the information so thank you all for coming. And, so, what I'll do is the people that checked off that they wanted to speak, we will start with those folks first. And then after that, I'll open up the floor. If there's anybody else that would like to, who have changed their mind and would like to bring up a concern, we'd be happy, we would be happy to have you speak. So, with that being said, let's start out with, now I'm having to read your handwriting. J.G., somebody's initials. Could you state your name for the stenographer?

J.G.: I'd rather not.

LAURA: Okay. So, we welcome your opportunity to speak at this time.

J.G.: Let's see. I don't know where to start, actually. I wasn't sure if I was going to testify here, but, last minute, I decided to.

LAURA: We're glad that you did.

J.G.: Even today, myself and a friend were, I would say abused, by a very agency that is supposed to be helping us. It's called the drop in center for those with a, I won't name names because I prefer not to, because there's so many, I'm not here to get anybody in trouble, quote-unquote, in trouble. I don't want to jeopardize anybody's job. I know I may or may not have a -- demeanor, but I don't even know what they call mental illness now a days, they seem to change the terminology every so many years. But I think, all right, that's what really pushed me over the edge today, was to show up. -- to a drop in center and had a very negative, funded by the state, and MHRH, both had a very negative experience and we never want to go back there. My friend was integrated, what is your diagnosis, are you sedated, how do you expect to work if you're agoraphobic, and that can be dealt with with medication and she may or may not be able to return to work, she was an R. N., she was a victim of domestic violence, so she now has PTSD which is a very difficult illness to treat. For example, there's something that is a little bit out of, it's not usually considered, from my point of view, regarding housing, South county community action program, may help someone if they're losing an apartment. This person was an R.N. and bought a house. She became, she, I don't know what to call it, she has PTSD after a domestic violence situation where her, the person that almost killed her, almost murdered her is in prison for the rest of his life, but, she can no longer do her job as an R. N.. So she is being foreclosed upon. Her house is being foreclosed. I don't know the correct grammar. And I don't even have a clue who can help her. That's not a usual, she lost her job, the factory closed, there's an oil spill and she can't go shrimping. Whatever it is. I have no clue as to who to refer her to.

Housing: South County Community Action

Abuse and Neglect: abused

TIM FLYNN: If I might interrupt you and I certainly don't want to, my question to you is, you've described certainly a tough situation. I wonder if in your own mind have you thought about this as an idea, a recommendation.

J.G.: No, I haven't had time to think it out. We've been working on immediate things like how to get food. There's another thing that a lot of people, basically I wrote an outline, and the main thing is, one of the main things is for the mentally ill, adults. Age 18, going into even elder years. Hand in hand with mental illness is poverty. Unemployment. Isolation. Shunned by family and friends. Fear. I've been told when my kids, when my friends had children, people didn't want me to hold their babies because of the stigma of mental illness yet I had a part-time job baby sitting where people didn't know I had, I was on medication, no problem. Family. Families, a lot of times do not understand, psychiatrists don't understand why people with various diagnoses act or say or behave the way they do. A lot of times the very agency that is supposed to be helping make the situation worse. They just, they prescribe the wrong medication, dangerous medication. Or you could be on medication for ten/twenty years and end up with -- the movements of your face, or whatever, are disabling, humiliating, but the psychiatrist convinced you that you need that medication. Another issue is safe, affordable housing. That's an issue for people without, quote-unquote diagnosed mental illness. A diagnosis of mental illness does not mean that half of the population in Rhode Island are not mental ill judged by their behavior. I would say driving drunk, there's mental illness, child abuse, there's mental illness there but it's categorized in a different manner, elder abuse, there's a mental illness there, but they're just not diagnosed. Drug use, drug addiction, I don't know what they call that. A lot of times, that poverty means you're going to live in a substandard house, the lands lord is going to take advantage of you.

Education/Employment: unemployment

LAURA: I would like, if I can interrupt you just for a moment because I would like to summarize what you've --

J.G.: I'd like to finish. As far as the substandard housing. If you're low income, your appearance, you're humiliated, especially in South county, you don't have Pandora bracelets or have your hair done or drive a fancy car, it's very noticeable that you are, one, you might go to food pantries and get fat because of what they give you but you're taking advantage, you're accused of taking advantage of the system. Getting food stamps, what are you worried about. It pits one group against another. The working poor, the working middle class, well I don't get free skippy peanut butter but you people are getting all of the free food. Regardless, if you notice with the mentally ill and I don't know what they call it, the developmentally disabled, Down syndrome, have a weight problem. Nobody is helping them with that. It's difficult enough for somebody without mental illness to control their, to keep their weight at a healthy weight. Another problem is Medicare/blue chip. Take Medicare, they charge us 30 dollars per visit, everyone is a specialist, therapist, counselor. I can't get counseling because I don't have the extra \$30 once or twice a month, once a week, whatever I would need. So go to the library and get a self help book, watch P. B.S. and watch Dr. A -- I'm name dropping. I was even told by your agency, I wasn't going to -- I've been told by agencies we're not federally funded so we can't help you, we're a private nonprofit so we can't help you. Lied to. I guess you want me to sum it up. Privacy issues. Mentally ill do not have any process, for example, life planning, when I become n elder person and I'm shunned on by family and most mentally ill people do not have children. Studies say they do not reproduce, they do not have children to help care for them in their senior years. This level of neglect when you're functioning, I'm really petrified as to what might happen when somebody can't care for them

selves any more in their 70s, 80s, 90s, whatever, whatever disease might afflict them. So again I think stigma is a very serious problem. The poverty issue. Yes, discriminated against on the job but you can't hire a lawyer, an attorney, and the disability -- the agencies that are set up to help you, successful you off to the EEOC or some other commission or this commission. Bottom line is you end up not working. So it does pit one group against another.

Health Care: Medicare

LAURA: you've brought up some very good concerns.

J.G.: Last thing, my landlord, no washer, no drier, I can't complain because I have no place else to move, I'm low income, I don't have money to move. So, I guess I wash clothes out by hand and I look like a slob half the time, further stigmatizing. Unless you can really, really fake it. When you're younger you might be able to fake it. Or if you're older and, you know, you've, you're well off, you're eccentric, people look up to you, people elect you.

LAURA: I'm so glad that you have come today and you've expressed your concerns. I think that, you know, just to summarize, I think that you brought up a lot of really important concerns that do face people that suffer from mental illness. I think it's concerns around human rights, human dignity, stigma, all of these things that are really important and I'm so glad that you brought them up and you were able to capture that. I would like, Jeanne Behie to respond as a person who works at community action. You might want to say a few words.

JEANNE: I just want today summarize. As Laura said, you brought up some issues that face many people with disabilities. Affordable housing, abuse, I'm just summarizing some of the issues.

J.G.: Does that include laundry?

JEANNE: Let me talk right now. Affordable housing, abuse, the need for case management, the need for job training, health issues including weight gain, discrimination and prejudice, not being able to afford medical copayments, privacy issues, and life planning, again, case management. So that's kind of what I heard of your concerns. And what you and I can do after the meeting is talk a little bit and I can address some of your specific questions about where you get food and also about some job training so I'll be happy to meet with you after wards if you would like or you can take down my number or supervisor's number and give us a call if that's better.

J.G.: I'm aware of South County Community Action Program. It's so pervasive.

JEANNE: We can talk after wards about this, I think. I think probably other people might want to speak.

J.G.: People get, ORS might help you try to go to college, but there's no accommodation at college for a lot of disorders for like PTSD, for example. So even at the universities or the colleges, people need, may need help, and even now when so many children are put on these psychotropic medications, they end up, later in life having substance abuse problems.

Supports: Office of Rehabilitation Services (ORS)

JEANNE: I really think we should allow some other people. I think you bring up some valid concerns and we'd be happy to speak with you after ward if you like.

LAURA: Thank you so much for coming and expressing your concerns. Our next person is Gary Brandyberry.

GARY: My concerns are with RIPTA. Most people can come and go wherever they want to by driving their vehicle. Those of us that are in a chair or have some sort of a disability depend upon the RIdE program in order to get us where we need too long. If you don't live within three quarters of a mile of a bus route, you're not allowed to use the RIdE program. It's a real issue for a lot of people, luck I will for me, I'm on a bus route, but, for, even someone on the panel like Rhonda, she lives too far away and she can't use the RIdE program. I also happen to have M.S., we are opening a new center for people with M.S. in Hope, Rhode Island. The center is 2.1 miles, I believe, past the last stop on the run that goes out there and so they will not service it. So, a lot of the people who have M.S. are not going to be able to go to the M.S. center because of this. So, you know, spending thousands and thousands of dollars to be able to make this happen and the people who need to go are not going to be able to access it. And it just doesn't seem like our human rights are being valued as much as peep who will can drive them selves. So I have some real issues with that portion of RIPTA.

Transportation: RIPTA

LAURA: Well, I'm glad that you came here today, and voiced that concern. I think that it's, I wish that somebody from RIPTA was here on our panel.

TIM FLYNN: I'd like to ask you, when you were planning this center, was there RIPTA service that would have, what I'm asking is, have there recently been cuts in the routes?

GARY: Not to this location, no, this is a temporary location -- church.

TIM FLYNN: So what would you, if, you're asking, would you like to see the rules changed?

GARY: Well, of course, I would love for Rhonda to be able to take the RIdE, or anybody who needs to be able to take the RIdE, but I understand there's only so much money in the state, as well. I'm not ignoring that issue. But we've even offered to pay a premium to RIPTA to go that extra two miles.

TIM FLYNN: Just for clarification, how did you sort of make that offer?

GARY: In writing, to the guy who runs the RIdE program, I can't think of his name.

FEMALE SPEAKER: Bill Inlow.

GARY: Yep. All the way up the chain, or whatever, and got no response.

TIM FLYNN: You would like to see sort of expansion I guess to the corridor. Instead of just three quarter miles on this side.

RHONDA O'DONNELL: It would be temporary because this is a temporary spot.

GARY: You've got to be three quarters of a mile from the bus route and absolutely that needs to be expanded. I mean how can you hold people to that.

TIM FLYNN: I understand. I'm trying to, if we're going to put together an effort, I'd like to know specifically what we can do, how we can meet the needs of people.

GARY: I use the Ride program in Boston and the system is so much better there. There are no restrictions like this. No matter where you are within the greater Boston area, you're allowed to use the program.

JEANNE: I understand your frustration with the Ride program, I had my son affected at times depending on the day of the week as the bus routes change. But, I'm just wondering, since, dealing with RIPTA and getting them to change their whole policy which might be based on federal policy, what about working with the M.S. society and finding a place that's on a bus route so that it wouldn't be a travel issue.

GARY: First of all the M.S. society has nothing to do with this center. M.S. society focusses on getting a cure. That's their only issue. This is being done by a private group of people who are putting this center together.

JEANNE: Okay.

GARY: And we are looking for a place that will be on a bus route, this is a temporary location until that happens.

NANCY: I want to comment, and I'm sure Tim can elaborate more. By spring, they will have ten, RIPTA will have ten handicapped accessible taxis to help accommodate some people. Again, it's not a fix but it was the result of all of the work performed so it's important to bring those topics up again and again.

Transportation: taxi cabs

GARY: Are those taxis going to be wheelchair accessible?

NANCY: Yes, they are, and environmentally friendly.

TIM FLYNN: The problem is we couldn't find, the way the legislation is set up there are five cab companies in the state of Rhode Island who agreed to participate in the program, each company has to pay 20 percent of the cost of the cab, RIPTA would use federal funds to pay the extra 80 percent and these cab companies will operate on a, pick up the phone and say I'm on in a wheelchair, pick me up. The vehicles are MV1 (sounds like) taxi cabs. Brand new, just introduced this year and can accommodate two wheelchairs each but can also be used for the general public as well so they're not dedicated to people in a wheelchair, the companies can use them for other, for regular clients. The issue is we had no bidders from South County. So, South County and Westerly, we sort of announced it to all of the cab companies in Rhode Island put out an RFP, had five companies come in and say they wanted to participate. We tried phone calls, can't make them participate. I hate to say this. But we couldn't find anybody in South county. Kent, Aquidneck Island, Providence, Barrington area and northwest in Woonsocket. So, but money is still available (phone ringing) as the system gets put in place, I think this should be happening somewhere around the turn of the year, we get evaluation and if the cab companies show it's profitable we'll then take that information and try and talk to people in South County, to the companies down there, and see if we can make it make sense for them on a fiscal basis. That's sort of where we are.

GARY: Unfortunately that doesn't do us much good.

TIM FLYNN: Yeah, we tried.

GARY: Well, we appreciate that.

LAURA: I did see your hand up, however, we do have one more person that signed up to testify and after that person testifies.

J.G.: Can you remind me? It's a Ride and his issue.

LAURA: Yes, then I will open it up and I will remind you. Thank you, Gary, are there other concerns you wanted to bring up today?

GARY: That's it.

LAURA: We're glad you came out and brought that to our attention. The next person who is signed up to testify is, Tia Beckman.

TIA: I'm here. They brought up some good points, too. I'm here regarding learning disabilities and education. I'll give a little background so perhaps I make more sense. Sorry about wordiness. There's one student who tested 95 percent aile in science across the nation in 5th grade. He's always been smart, in elementary school he was labeled the physicist by the teachers. He is now a junior in high school, getting a D-minus in algebra, D in science, teaching himself to not care about education. Being a very active effort for him to be able to teach himself not to care because he loves to learn.

LAURA: I know it's hard.

TIA: Okay. The process, ever since elementary school, he has had outside neural psyche evals saying he needs reading assistance, he needs his hearing looked at, and that he has an emotional component. The emotional component is post traumatic stress. He came from an orphanage in Belaruse, and has learned inadequate coping strategies. During the summer all of these years, he has been fine, even when put into areas of stress like sailing with the South land, learning how to sail with the South land and staying out of the way. Very stressful. He coped fine. In school, he would come home, you know what it's like with post traumatic stress, families are blamed, children are blamed, I helped him too much at home, he's supposed to fail. As a sophomore in high school there is finally the diagnosis of language based learning disability, dyslexia, temporal auditory processing, possible attention deficit, hyper activity. Many of these, and post traumatic stress. Many of these diagnosis get confused. If somebody does not process what they are hearing they are automatically looking around and jumping around to see what the hearing is. They look ADD. There is a sensory integrative problem also he does not feel with his fingers, information he gets, so the balance has been difficult so somebody who fights and want to say move around looks like hyper activity. He's been tested, has great attention span. The school system says because he comprehends what he reads from their testing that there is nothing the matter. He tells me he can read novels because he recognizes what words look like. He's memorized what they look like. And he reads them in context. He does not have smooth reading, he has, he recognizes the words, he puts together an idea of what the words are saying and if the word, if what he identifies as a word fits in, great, if it doesn't, he changes the word. He's not sounding out the words by syllables. This is typical of somebody with dyslexia. So he can read English, he can read social studies. Science gets to be

less words so he has difficulty in science. And math is even worse. He has difficulty with concept of time because it's a language based learning disability. That is words like 15 minutes of, quarter to, 645, quarter, you know, that kind of thing. So those concepts are difficult. He has difficulty with organization because he does not have the concept of time. He has difficulty with finger writing because he has to visually monitor his fingers to form the letters. He has had the state from what I understand has grade level expectations. I have said that he is not meeting elementary school grade level expectations for reading because he is not able to sound out words. He is not I believe. He visually memorizes. They don't care. His comprehension is fine. I've said the speed of his reading is not fast enough for him to keep the idea of what he is learning in his head so he can learn new material. He cannot learn new vocabulary because he cannot sound out words. He just through private tutoring learned about syllables this year. The school will not provide private tutoring. The state does not. I called up the state and the state said they look at only what the school district looks at.

Education/Employment: learning disability

TIM FLYNN: You called the state, who did you call.

TIA: They referred me to this parent advocate.

TIM FLYNN: Okay, but prior to that you called the state, the department of education?

TIA: I believe it's disabilities education.

DEB: The office for diverse learners?

TIA: Yes, thank you.

LAURA: Were they able to tell you about what your rights were when you disagreed and what that process looks like, what your options were?

TIA: They said that I could go to due process. What they also said is in due process that the state only looks at what the district looks at. And I said, the district looks at only reading comprehension and through the testing that they do for reading comprehension, my son succeeds, there is enough context for him to figure out what is there. Somebody with dyslexia, does not necessarily have a reading comprehension problem, especially if there's a context. So-

LAURA: I work for the Rhode Island, for Rhode Island Parent Information Center. And I don't know if you've ever contacted our organization?

TIA: I have.

LAURA: But, we have a resource call-in center.

TIA: I've tried to work with you. I have chronic fatigue and fibromyalgia, limited opportunities. I called the network several times especially when he was in elementary school and I pleaded. I said I am not able to process information well I am not able to drive far. I need somebody to come to me and hold my hand and help me through this process. And I was not able to get that so it's a double disability we're talking about.

LAURA: I would like to, I'm one of the directors at the Rhode Island Parent Informers Network, but I like to give you my card and have you give me a call and we'll see what we can do to assist you as far as getting you some support around meeting your needs. I would like to offer that out to you.

TIA: Thank you. For the state, for recommendations.

LAURA: Please.

TIA: I would like to see, 1, the state has wonderful grade level expectations, all written out, absolutely wonderful. They talk about fluency, decoding, wonderful. I would like to see all of them enforced. The nation is going with nationwide standards. The same thing, the state has already put it together, and this is wonderful, enforce it all. Don't go with the comprehension because you lose 20 percent of our population, one out of five students have problems with reading. And so I think to myself, four kids in everyone of your classes has the same problems as you. The next thing I would like is recognition of the medical background. I used to be an occupational therapist, and we have so much knowledge, medical knowledge now, that can combine with the education system and be a wonderful process. Language based learning disabilities, parts of the brain biological, it's medical, emotional disabilities, biological, medical. We need to bring it together and help our teachers understand it. And then our teachers can be a lot more supportive and be able to recognize. Half of the problem is the teachers don't understand language based learning disabilities in the symptoms the kids show with that. The other thing I would, and so, that is an education process of combining science and education. Another thing I would like brought together is post traumatic stress. We are going to have more and more of it. It's not going away. I don't know the statistics but with soldiers being gone, both parents working, drugs and alcoholism, it's only going to increase. My son has been hospitalized, I believe that his learning disabilities contributed a great deal, going to school and faking it with all of the shame that goes with faking it contributed to it. I nearly lost him again a year after. The school was teaching him in English class. I went to the education program, the individual education plan and I said to my son what's going on in school? They didn't know. I finally called all of the teachers together. This is my son's background, what's going on? And a wonderful English teacher spoke up, and said, I am teaching from a book. This is the book, I can't remember the title, it was about children, a child, true story about a child being put into orphanages and foster care because his parent couldn't take care of him and it was all triggers and I nearly lost my son again. My son is being seen by a therapist in the school. This book is taught every single year. And the therapist knew, she knew my son, she didn't put it together. I'm the one, I was not notified of the book list. In 9th and 10th grade, I did a big advocacy once he got to the high school and it took me six months to say post traumatic stress need to be careful of what he is going to read because it's very powerful. It took six months to have his reading list modified. The way we modified his reading list was in 9th grade he missed half a school year of English. He sat in the guidance office because they could not change the books. He missed a half a year of English and this is a learning disabled kid. The second year he went through three different English classes so he bounced from class to class to avoid the books.

TIM FLYNN: So what you're asking is, you know, more flexibility in IEPs, or, more parental input into IEPs?

Education/Employment: IEP

TIA: What specific recommendations would I like?

TIM FLYNN: Yes.

TIA: I would like a recognition of psychological issues in book lists. Even normal kids have come to their parents because I've spoken a lot about this and have said the books we are reading every single good person dies. It's always deaths. The first story in English that they were to read was, I don't remember the name but it was about, this is 9th grade going into a big school and it was about this hunter who was.

TIM FLYNN: I don't mean to cut you off, but I think we understand.

TIA: Okay. But I would like positive roll models in the reading curriculum rather than a pervasive negative and it's statewide it's not just South Kingstown.

LAURA: I don't want to interrupt you, however, I'm thinking to myself, I really think the Rhode Island Parent Information Network could assist you with some of this because it sounds like you're a great advocate, you have, your son is so lucky to have you as his parent. But I can tell you're very frustrated. You're trying to help him the best you can and you're frustrated, you're running up against barriers and I can see it in just your eyes and that you're really frustrated and you don't know where to go from here and I really believe that if you give us a call, we're going to be able to help you to advocate, to direct you in the place you need to go to address some of these issues because I think sometimes it can be very complicated. You can advocate for something in the wrong place, and you can spend a lot of energy there and it's not going to go any where, and our organization has many years of experience helping families with a variety of issues and many of them are issues that you just brought up. So I think that we would like you to learn off of us and to, we're all parents of children with special health care needs, learning disabilities, chronic care conditions, and so we've had to advocate at the school, we work very closely with our partners at RIde, we work very closely with specific, with each of the school districts. We know the laws around this. We have an expertise in it, and we would like to share that with you.

TIA: Again, I tried RIPIN and RIPIN wasn't available. And also RIPIN talked about the individual education plan and goals and what I found with that is I am not able to even get the goals in because the school does not recognize language based learning disability and dyslexia.

Supports: RIPIN

JEANNE: so he doesn't have an IEP.

TIA: He does for writing mechanics.

BRYAN HUDSON: Would you mind telling us what district?

TIA: Kingston.

NANCY: You said you had an independent evaluation, and brought it back to the school, the school didn't accept the evaluation? Or did they take pieces from it?

TIA: They have read, at their meeting, they read it out loud. They never used the words language based learning disability or dyslexia, they would not have that come out of their mouths. When something trigger add thought she said oh that fits his profile, and then it was, oh, ADHD, because they want accommodation. They don't want to help him to learn.

LAURA: and I could tell you, I could sit down right now and explain all that to you, where they're coming from and what their perspective is and why they reacted the way they did but I don't think this is the place to do it but I absolutely hope that you will give RIPIN another shot at assisting you because I really believe that what you're telling us is not uncommon and we've been able to help other families and I hope that you can give us another chance to assist you.

JEANNE: Are you saying she should call RIPIN, or you directly?

LAURA: I'm going to give you my card, you can call me directly and I will give you the information, direct you, triage you where you need to go and I will make sure that the person receiving your call will be able to assist you.

DEB: Can I add something? We're working on to help adolescents develop, we're working on the youth leadership projects for students with disabilities and special health care needs, coming at it in a couple angles, we have for the past two years a conference called dare to dream in the spring. South kings town is not participate in dare to dream, but, I'm pretty sure they didn't, I know the independence academy here did. But RIde is very aware and very supportive of it, this is one of their adolescent transition things they're working on and we're working with youth leadership organizations and groups, support groups for all sorts of different kids with different needs, to help built a statewide youth leadership congress, and maybe this is something that your son might be able to get involved in for his own process of self determination. So again if you were to talk to Laura, we could, and..

TIA: Is your program at South Kingstown?

DEB: Pretty sure South Kingstown didn't go this year, but a lot of schools didn't go, it's new.

TIA: Is that a program for parents?

DEB: For students, to help students understand their disability, understand who they are, built their self determination and their self advocacy skills to take them through high school and so they can become successful adults.

TIA: That would be interesting since the school can't even say what his diagnosis is let alone help him what understand what it means to him now.

DEB: What this program does is it brings all different youth together and they see that they're not alone, they see that there are other kids who might have similar things going on, whether it's the same diagnosis or not, it's about becoming who you want to be, so it's very, it's exciting.

TIA: So, with the state, I would really like them to follow up with the grade level expectations. And not just go with what the district because it's pervasive. And the district is only with comprehension and not with fluency and decoding. The last idea that I had is when I went to B. U. the students put together a conference and it was bringing nationwide people together and the students attended. And the National OT Association has conferences. I would love to see the state start having conferences, and that is bringing, I have spoken with top-notch people all across the nation regarding learning disability. They love to speak, they love to be an advocate and I would love to see a conference in the state of Rhode Island for families, teachers, and, I will call them paraprofessionals, the social workers out in the community, to talk to, educate, and put together more, what auditory processing is, what language based learning disabilities are,

what nonverbal learning disabilities are. Teachers get very little education in college regarding the specialty areas.

Education/Employment: learning disability

LAURA: You're right, so more professional development and conference with speaker to say bring people into our state I think that is really, we could always use more of that.

NANCY: I do know that there is that going onto some degree, memorial hospital, teachers are being offered credits, they come in and speak about autism and what it looks like in the classroom and classroom management and things like that so there are organizations out there doing that, probably needs to be more of it.

TIA: I think more. There's technology, also. Universal design for learning. In Texas, they have internet classes for those with dyslexia to supplement the curriculum. It's observation, it's auditory plus reading. Which is excellent. It would be nice to get tape recorders, computers, the dragon, all of this stuff, it's not being put together.

LAURA: So, it sounds like you're very frustrated and even though you're putting forth a lot of effort and energy, you're frustrated and so hope any we can get you the help that you need. I do want.

TIA: The last thing, I don't want it one-on-one, I want statewide because even in Connecticut they have centers for districts that have people who specialize in it, and so the school sends the kids to the centers and the centers can write up a program. What happens in this state is that each individual family fights for their kid. And basically overall loses. Loses family life, loses years, loses so much. Statewide.

LAURA: Great. Thank you.

TIA: Thank you, I'm done.

LAURA: I don't want to cut you off, but I also want to just open it up to the floor now. I think we've addressed everybody who checked off that they did want to chance to speak so I'm opening it up to the floor. Would you like to --

J.G.: Yes, two other things, the police department, Narragansett police department, South Kingstown police department do not know how to, and I guess statewide because I have seen people in the state get murdered, shot by police because they were acting out. Either on the wrong medication, or whatever it was. So, the place need, and this could be legislative. This is an idea, a brilliant idea. Can we, can you somehow get this over to the commission, you all are on the commission.

LAURA: this will all be tracked.

J.G.: I think the police department need to have some training when somebody with a, whether it's a mental illness, like they call it bipolar, they throw everybody into that category, bipolar or alcoholic, drug addiction, whatever it is, they have some PTSD. When your son acts up when he's 19 and with other kids and gets in an argument that he not be, that somehow the police be aware that the child, the young adult, or the adult, has a problem and he's not just creating a disturbance or a crime, -- for example, a girl, two of us were at the bus stop. A girl was smoking

cigarettes, a woman, said could you please not smoke, it's right near me and got punched in the nose, blood everywhere, I'm screaming, I'm crying, I said call the police, call the police. A woman just attacked me. Police show up 20 minutes later I'm screaming, I'm crying, therefore what they see is somebody screaming and crying and yelling. The girl, they knew her, she said I'm bipolar and -- they arrested her even after she told them she was bipolar. I have a diagnosis of -- they arrest me like a criminal, you know, and the two of us, now she has a record, I have a record. I can't volunteer, I cannot move to another apartment because that is on my record, disorderly conduct.

Abuse and Neglect: police

LAURA: So, what would you suggest, are you thinking like sensitivity training?

J.G.: Absolutely -- she even came out and said she has bipolar; and I didn't give the policeman my diagnosis but I did not need to be treated like a common criminal. Now that's on, what's it called, permanent, police record, went to the FBI and call this other -- I cannot volunteer with children, because of that disorderly conduct, I cannot work with elderly, I simply did not want to stand next to somebody smoking.

LAURA: I would like this gentleman back here from the disability law center to just respond to you.

BRIAN ADAE: I'm a staff attorney with the Rhode Island disability law center. Are you able to hear me sufficiently?

J.G.: Yes.

BRIAN ADAE: If it helps to have this information, and also, I'd like to add, I'd be delighted to speak to you afterwards about some of the specific individual things that you mentioned, there had been for a period of time, some specific training as minimal as it was at the municipal police academy, the statewide municipal police academy. Understand two things, all police departments in this state receive their initial rookie training at the statewide police academy as well as the municipal police academy is responsible for ongoing, what's referred to as in service training. Providence police department and the State Police are separate. There had been some, without getting too far into my personal opinion, but some minimal training involving how to respond to folks with disabilities. All kinds of disabilities. Specifically mental health issues. Some of it was in response to a number of, unfortunate, incidents, some of which were legitimated, monies were paid by municipalities, it was patterned on what's referred to as the consensus project which was an ongoing National project addressing specifically these issues with folks in the criminal justice system who may have had mental health issues and how they're responded to. Some of that training, actually, that training was taken over in a more intense fashion on a particular, I believe it was a grant by had a we used to know as MHRH what we now know as Buddha recently, I'm not sure specifically what was going on, I know the target was to make it more like a crisis -- team more like the municipalities across the country namely there would be a social worker that could be accessed, if not an actual ride along social worker to address something if they're aware there's an issue they need to address going in the door.

J.G.: They called it a cat fight, ha ha ha, a cat fight.

BRIAN ADAE: Which, to me, would not be an appropriate response but something perhaps the commission in looking at this could make a recommendation do more of the kind of training or expand the kind of training that's been started.

LAURA: Thank you so much.

J.G.: You cannot, accepting this agreement, in court, I had to go to court three times with a letter, blah, blah, blah. Saying that you have no recourse, this has to stay on your record for a year. And the other person that punched me, I didn't want to hurt her, I didn't press charges, I could see anybody that goes around punching people has enough problems. You know. She's on probation.

LAURA: Thank you for bringing that really important issue up because.

J.G.: Do you think it can be, do you think, I don't know where the status of this program is now.

LAURA: we will follow up on it.

J.G.: These policemen totally mishandled the situation and I don't know how often they do that but I assume it's quite often.

Abuse and Neglect: police

LAURA: okay. Thank you.

J.G.: And, as far as the RIde program goes, it needs to be legislative. It needs to be legislation that people with M. S. get to that center whether they're 1 or 2 or twenty minutes out of the way, get them to that center, period. No question about it. And doesn't have to be a personal fancy cab, those RIde vans have room for wheelchairs. This have a is willing to take a RIde van. But to keep somebody away from that because of, she doesn't, we don't have to assume you're going to redo the whole RIde program. Another thing is those RIde things are not monitored. There's no car-pooling, they'll send a private van from Woonsocket to pick somebody up in South kings town and drive them all the way back -- the ride costs \$250, where is the car-pooling, it's not good for the environment and it's not good for the RIde program in general.

LAURA: Thank you for bringing that up.

J.G.: That's obscene from those people not to let them attend a program. Thank you.

LAURA: Brian. Just state your name again.

BRIAN ADAE: Again, I'd be happy to talk to you individually after wards about some of the issues that you've raised. The other part that was mentioned from the audience member concerns the experience that apparently happened to you before. There is what's referred to as a pretrial diversion services at the 6th division district court that see a tremendous amount of volume. I know there's been discussion of trying to expand the pretrial, I said diversion, sorry, pretrial services but they do divert a number of these cases out of the court system if they happen to find them selves in court despite whatever has happened at the police department. In efforts, I believe, that are trying to be expanded throughout the district courts throughout all of the states requires obviously funding, grants, other things, perhaps that's something else that can be added to the recommendation.

LAURA: Thank you. I know some people came in a little bit later after I picked up the sign-in sheet. Was there anybody else who had signed up to testify that I have not called on? Okay. I would like to open it up again. If there's anybody else that has some concerns that would like to bring that up now. Can you state your name.

JULIE: Julie Ramaro, son 19 years old with traumatic brain injury from an accident when he was almost five years old, so, I've navigated the system a long time met Laura on several occasions. He's approaching the transition time and in addition to trying to navigate getting his social security and so he'll have adult services when he turns 21, the services I have now that enabled me to go to work with HBTS and paths workers that work in the home so I can go to work and he can get off to school and the same when he gets home. When I first started receiving HBTS services he was a student in the kindergarten in the next room to here, and Oscar was across the hall and for over a year I've done everything by myself and I really did need help and I got the HBTS services. I dealt with that office because miles was eligible for Medicaid that made him eligible for HBTS, and I had one or two people in that office to talk to. Now, everything has changed. And I'm trying to navigate the system that the state has setup that CEDARR is involved, and has one set of rules, and Oscar has their own different set of rules and now we have pass with homestead and they have a different set of rules, little detail rules not the big umbrella things but it's frustrating, I'm exhausted and now I want to try to get Respite and I have to do a huge application, everything all over again and probably work with a third agency to get that Respite help and I'm frustrated and also feel like there is no way that this new system of doing things is saving money for our state. I just can't see. So that's one thing. The other thing I wanted to mention is the only reason I came here is at quarter of four I got an e-mail that told me about this forum. I had no idea and I think if it was better advertised, there wouldn't be enough seats in the rooming.

Housing: Home Based Treatment Services (HBTS)

FEMALE AUDIENCE SPEAKER: I called Langevin's office, they didn't know where it was.

JULIE: I'm glad I opened my e-mail.

NANCY: Can you make some suggestions as to where we might better advertise next year? I know we put adds in the local newspapers, I believe.

JEANNE: I didn't see them, usually I see them. Usually they're in the times and the Providence Journal.

JULIE: I go to Belmont's market all the time, someplace public like that or the library, I don't go every week but I go fairly frequently, buy probably would have seen it there. When smiles in public school a lot of times when things like this came up a notice came home from school but he's attending sergeant and those things are slower to get home sometimes, I could get a notice tomorrow from sergeant. I don't fault them they do a lot but this is important also.

LAURA: Thank you forgiving us feedback on that and we will try to do better.

JULIE: One more thing, the state has also taken over the transportation for out of district students. It's not going very well I really hope you examine it more closely because I think probably the triage you end up doing because of all of the problems, the whole thing isn't saving any money, I really doubt it so I would really examine that.

LAURA: Can you expound?

JULIE: Miles was at camp so the change came July 1st for South Kingstown students and so he just started last week and he left sergeant at 2:30 last Tuesday and got home at 4:30. We live down the street from here, Sergeant is in West Warwick. So I called the state office about the transportation, I drove him myself in the afternoons until today, and today, they started a bus just to transport him from sergeant to our house, no other students because of that. And, you know, so it's two extremes. I hope there could be a middle. I like him being on the bus with other children, I have no problem with it but two hours to take a drive that in my car takes thirty minutes. I could see an hour.

LAURA: I believe there is a law around a specific amount of time that kids, it's one hour that can be on the bus.

JULIE: There is an exemption now if the student goes out of district that hour does not hold and you can ask your lawyer friends to look it up but I got a notice from the state stating that. And if that's not true, then the state transportation office lied to me.

Transportation: bus laws

LAURA: Brian, would you like to speak to that?

BRIAN ADAE: there is a law saying one hour, a law changed I believe last year regarding out of district transportation, I can't say definitively whether it provides an exemption. But sometimes there's been a part where we're not going to transport, the school district says we're not going to transport somebody completely out of district, in district is one thing, it's statewide now so that's been clarified. But accepting the hour, I don't know, I can't say for sure.

JULIE: I believe it's accepted, and what is acceptable is vague in what I was given as their policy.

BRIAN ADAE: I don't know. It's something we can certainly look at, maybe it can be changed.

JULIE: Because I was the squeaky wheel, my son, but that's not right either. You know, there are plenty of children that don't have a parent that will do that and they're suffering.

LAURA: I think, Julie, I'm very glad you brought that up. That's going to be in the testimony and that's something that we can look at. However, I will suggest that you call the RIPIN office and call the call center because they will be able to help you find out what that law says and actually bring it back to a higher level as well as, you know, they keep track of all of the families that call and they have data, report that data back to the state.

JULIE: The morning was an issue too but not as bad but missed several therapies this week because of the issue.

LAURA: If you hear it from one parent, and another parent, and another parent, it has more impact when we find that there's a lot of families being impacted by this. And that we, you know, we -- things to happen.

JULIE: That's important, you need to call.

JEANNE: Jeanne Behie. With the Governor's commission. Brian, I can tell you, I'm very interested as I think a lot of the members of the governor's commission would be interested to hear if there's an exemption to that law so I'm wondering if the disability law center could find out and clarify that and let Bob Cooper know because I know when we look at this testimony it's going to come up that we want to know if there's been a change.

BRIAN ADAE: I'm wondering myself and it is something we can look into. I know I saw Ms. Greene shaking her head like maybe she knew something. She might.

ROBERTA: I don't know definitely, but I had heard.

BRIAN ADAE: I know there was a change two or three years ago but.

ROBERTA: Have a lawyer take a look at the interpretation.

BRIAN ADAE: I'd be happy to do that.

JEANNE: if you would let Bob Cooper know at the Governor's Commission, that would be great. Thank you.

TIA: My name is Tia Beckman. With regards to the learning disabilities, back to finances, if the district had recognized and been willing to address reading disabilities back in elementary school, two years of reading assistance, that's the average, and if they worked with the family, there are places that provide tutoring for a nominal price. If they worked with the family, and helped out in the school, they would not have had to pay for resource teachers all of these years, they would not have had to pay for individual tutoring to compensate for an English class, it would have saved the school a lot of money so addressing problems doesn't necessarily cost the state money.

LAURA: Thank you. Is there anybody else that would like to bring up a concern? Okay. The forum will, we will all be here until six o'clock. In case some people are coming after work. However, you're welcome to stay, but at this time, we're going to close the testimony unless anybody else wants to speak. And I thank you very much for bringing your concerns to our attention. And

JEANNE: and you're welcome to speak to any of us individually if you'd like.

LAURA: Absolutely. Thank you.

LAURA: So, Carol Anne, you have a concern about Katy Beckett?

CAROLANN: Carolann Guilmette. Yes.

LAURA: And the home based therapeutic services?

CAROLANN: Right.

LAURA: Why don't you tell me what your concern is.

CAROLANN: I heard through rumors they are possibly going to cut it or cut hours.

LAURA: And, how does the home based therapeutic services help your family, and what would cuts mean to you?

CAROLANN: Safety issues, life skills they're helping him with. Let's get back to, he has autism and he has been diagnosed with slight M.R., so it would help him in the fact that safety issues, flight risks, some behavior issues, him fleeing the home, teaching him to safety skills to learn that you need to be careful crossing the road. He is 7 years old. I'm just trying to think off the top of my head. He has social skill problems, too, as well as inappropriateness saying pulling down his pants if he's in public and has to go to the bathroom he'll pull his pants down prior to walking into the bathroom, so these are the skills the HBTS is working on with my child.

Housing: Home Based Treatment Services (HBTS)

LAURA: Right now, have there been any cuts in the services he's currently receiving?

CAROLANN: Not at this point in time.

LAURA: You've heard rumors, and came here to voice those concerns?

CAROLANN: I just happened to be with speech right now, he's with my husband at this moment. But I knew this was going on because I got an e-mail so I decided to come in.

LAURA: Okay. Is there anything else you would like to add, Carolann?

CAROLANN: Not that I'm aware of.

LAURA: Any other concerns?

CAROLANN: I'm sure there will be soon.

LAURA: Well, if you think of any, we're here. Okay.

ELLA: Ella Whaley. I'm a parent of a child with a disability, but I'm also a teacher for 32 years, and educational advocate, and I'm get ago lot of phone calls with children, parents of children that have language based disabilities. I mean I'm, was at a meeting in baring ton with a family I didn't do, there's one in Burrillville I'm working with and there's a whole group from South kings town and it's just a need that the School Department is not addressing. So, at some point if there could be a subcommittee formed to take a look at that, maybe with the new commissioner, or, make recommendations to the board of regents, there really needs to be.

JEANNE: Do you feel this is as a result in the change of the speech therapy?

ELLA: There needs to be something that is addressed, sorry.

JEANNE: Any relation to the change in receiving speech therapy students from years ago, no?

ELLA: I don't think that it's kids getting dropped with speech when they turn age 9. ASHA (sounds like) put out some new guidelines for speech and language pathologists servicing kids in the districts and speech and language pathologists according to ASHA should now be implementing literacy goals some districts don't want them involved in any reading programs, no literacy programs and speech language pathologists are the ones that understand the neuro

development of the brain and they are really the key to breaking the language piece apart in the classroom. So, school districts need to recognize that and act upon that.

Education/Employment: learning disability

JEANNE: Okay. All right. Thank you. I work in a homelessness prevention program at South County Community Action, and we have many families that are looking for affordable housing in South County, and are unable to find it. So, there's a need for more affordable housing, all over the state, but specifically in South County.

ELLA: At the last session, last year, at the Guild (sounds like).

JEANNE: The 2009 public forum.

ELLA: A man brought a concern about the date for a motor vehicle tax exemption for veterans. And, the South Kingstown town council wrote a resolution and it got passed in the General Assembly that the date was done away with so that we could exempt people, you know, people from applying.

JEANNE: Veterans.

ELLA: Taxation.

JEANNE: Everybody gets hit with. That's great.

ELLA: That did happen.
(FORUM CLOSED)

GWEN: Excuse me, did everybody sign in? And if you signed in could you mark testify if you want to testify or make comments. If you haven't, just please come up and sign in. I think we're going to the started with the forum. I'm going to introduce myself and tell you a little bit about the forums and I want to apologize that we don't have something more formal for a sign in today. This is part of the public forums which is an opportunity for people with disabilities in the community to come forth to voice their concerns about what issues they feel need some attention, some resolution. It is our opportunity as panelists to listen to you. So, we will not be giving you a presentation. That's not our role today. Our role today is to listen to your concerns, clarify what your concerns are, and if we happen to have an answer or know of something that might be helpful to you, we certainly will share that with you. So it's your opportunity to get whatever you need to get off your chest off your chest today. Okay. So, we have that sign-up sheet and again if you mark that that you wanted to testify, we'll just call on you. If in the process of listening to other people, you think, oh, I have something to say now, then we'll certainly, whether you checked that you want to speak or not we'll certainly ask you to speak up, too. So that's kind of the purpose. From the information that we gather from you that drives our legislative agenda. So that in the past, people have complained that there weren't any wheelchair accessible taxi cabs in the state of Rhode Island and after four years of working on that, every year in the legislative session, this year, we got that passed so there will be wheelchair accessible taxis in the state of Rhode Island. But that bill was generated from public forums. Just like this. Another thing that was generated from public forums was accessible sidewalks for people in wheelchairs out and about in the community. They frequently run into situations with a curb cut on one side of the street and not on the other side of the street. Well, this year, it was passed that sidewalks needed to have curb cuts on both sides of the crosswalk. And so again that was generated from testimony gathered in public forums. So that's what we do with your testimony. It's recorded, and because it's recorded, it's important to, when you speak, say your name, spell your name so the recorder can get that correctly. If you want to speak again or comment on something that somebody said, just please say your name again. Sometimes that's easy to forget but if you can remember to do it helps the recorder over there. So, I'm going to introduce the panel, have them introduce them selves and as I said our primary goal today to listen to your concerns, clarify your concerns and again if we have an answer for you, we'll provide that for you. So, I'll start. My name a is Gwen Reeve director of programs and services for the Rhode Island chapter of the National multiple sclerosis society and I serve on the Governor's commission of disabilities legislative committee.

NANCY: I'm Nancy Silva I'm with Rhodes to Independence which is Medicaid infrastructure grant designed to look at employment issues, concerns barriers for individuals with disabilities.

LINDA DESCHENES: ...with the office of rehab services working with individuals with disabilities looking to go to work.

BRIAN ADAE: Attorney with the Rhode Island Disability Law Center, which is the Rhode Island part of the National disability rights network. We provide legal based advocacy and representation on issues of disability for folks with disabilities. Unfortunately I have another one of the attorneys from the office here today, Catherine, separate and apart from this forum has our annual surveys where we assign priorities. So, if you happen to have a moment, after wards, we would be delighted if you could assist us in completing a survey. Catherine is also available to answer questions about voting rights or accommodations or things of that nature.

MONICA TAVARES: I'm Monica Tavares with the Department of Health under the Office of Special Health Care Needs, and I work with traumatic brain injury program.

BILL INLOW: Hello, I'm Bill Inlow, a member of the Governor's Commission on Disabilities, and I'm also the disability services coordinator at RIPTA/RIde.

GWEN: Okay. Just to mention, there have been a few people that have come in after I made my introduction. If you would like to testify or speak today about your concerns, there is a sign-in sheet up here and just fill in your name and put a check that you would like to speak. And, if you didn't get a chance and want to raise your hand later and say I'd like to speak that's fine, too. Do we have, let me see the list. Okay. We've got Linda Nedderman-Eaton. Can you just, she'll be able to record, she needs to record your voice.

LINDA NEDDERMAN-EATON. : Linda Dugas, and myself have what's called multiple chemical sensitivity, extremely sensitive to chemicals to the point of life threatening reactions and we're here to talk about the possibility after law for pesticide notification when neighbors spray pesticides on their lawns they are not giving us notification. We have no 48 hours, there are some states that obviously do. Linda has a printout from the internet from New York, which talks about their pesticide notification law. I think it's just common sense. We're sitting herewith a thing from Pawtucket about keeping your waters clean and talking about keeping pesticides out of waters because this is not safe and yet they're allowed to spray it right next to your lawn without any notification whatsoever. Some states are adopting pesticide notification laws and we would like to see Rhode Island adopt one for health and safety for us and everyone else.

Housing: pollution

BILL INLOW: Did you say you had a copy of a statute from other we'd be glad to have a copy of that statute.

LINDA DUGAS: I don't have them for everyone, but you're all from the commission, anyway.

GWEN: Do you want to speak now, Linda and then we'll go back to the other Linda's husband, I guess.

LINDA DUGAS: My name is Linda Dugas, from Pawtucket diagnosed with environmental illness, I was chemically poisoned eleven years ago. The reason I'm here today to express my deep and immediate concern regarding residential pesticide application. Many counties within states already have what is called pesticide neighborhood notification, I'd like to see Rhode Island follow suit. If I may I'd like to read part of had a New York's citizen campaign for the environment has to say on the subject. Each year hundreds of thousands of pounds of pesticides are used on residential lawns in counties in New York state. That's an amazing figure. This is all of the United States of America, this is just New York state. Mostly for aesthetic purposes. Science continues to uncover links between pesticide exposure and health problems including acute impact such as headaches, dizziness, nausea, seizures and respiratory -- hormone disruption, reproductive disorders and cancer. Infants and children, the elderly and people with compromised immune systems are especially vulnerable to these risks. When commercial ap indicators spray pesticide, the chemicals drift into properties potentially putting natures at risk as well as pets and property at risk to exposure. The public should have advance notice when pesticides ap indicators are coming to spray near their home. This allows it's public to take precaution to say avoid exposure such as keeping children and pets inside closing windows and closing vegetable gardens and grills. The notification law says pesticide applicators must give 48 hours written

notice before spraying on abutting properties within a hundred fifty feet. Reality to remembers post signage to let customers know that they are required to post warning signs on their lawns when applying them selves. 2006, eared county legislation passed legislature passed a permanent pesticide neighbor notification law but Nan muss decision, went into effect 2008. June 14th 2005 Monroe county legislator passed the law 21 to 8, went into effect January, 2006. There are other states, Maine included, I think 21 states have adopted some type of law like this. Excuse me, I'm a little nervous. And also of the eleven years I've been chemically poisoned, this is the first time I've been able and not well to come to these sessions because it's toxic. I called before I came to see if this place had been pesticide, painted, was under construction, cologne and things make it difficult to be here and bathrooms with sprays like this one here make it awfully difficult. I think it's imperative for some form of legislation to be adopted that require advance notice to be given to any person who resides in an adjacent property. Not limited to just the owners but represent errs should be included. It should also not be limited to only commercial lawn care companies, often homeowners them selves are more lethal with their application when taking lawn care into their own hands. I personally would like to see all of these toxic chemicals to pollute air I remember rad indicated but people have a love affair with their perfect weed free lawns and, they put -- above -- I ask for the moon but I setting for one nontoxic piece of it. You may have the right to enjoy tee roses on your property but I should have the right to know when they're spraying them under my grandchild's open bedroom window. Imagine that your six year-old's birthday party in full swing in your backyard to have from you green show up spraying a few feet away or come home from the bank to find laundered clothes in the breeze now having a lay err of pesticide. It happens all the time. I invite you all to go to the yahoo site, green canaries, hundreds of people on this site, it's a message of people desperately looking for solutions to toxic problems because organizations can't help and a lot of this is not recognized. And so it's things like my car, I can't buy a car because it's been shampooed, there's so much. And you don't have to be a member to read the message boards to get an idea of what's going on. When you have MCS and diagnosed and are chemically poisoned your life as you knew it is gone. I was a normal person, pretty normal. Look at me, I had nice teeth, I have broken teeth now, there is no such thing as non-chemical safe dentistry, I used to go to the hairdresser, now I cut my own car. You have old clothes. You don't buy new furniture, it has stain resistance and I was chemically poisoned when my husband and I who is the interpreter today bought a house eleven years ago which had all kinds of toxic chemicals, I was never able to move in, I lost my job, I was an interpreter for 22 years, I interpreted for the Governor's commission at the time hand capped, known Bob Cooper for years, OSCIL, PARI, ORS, all these organizations. You can't work any longer. Your relationships are compromised, no more trips, no getting on buses or planes, no buying new clothes, none of that. You lose your income. This is a small thing and I have a neighbor right now who doesn't give a rat's ass about this, goes out and sprays, no notice. He has had lawn care companies and I've asked him for 24 hours notice, they've tried to comply but when they don't they're afraid, they just say there are no safe chemicals so they would rather not do the lawn then compromise my health. We could move, took us five years to find this house. People in apartments are subjected to all kinds of chemicals. If you have any questions, I'd be happy to answer them and I appreciate that you have these forums. And thank you for, also, having interpreters available.

Housing: multiple chemical sensitivity (MCS)

LINDA NEDDERMAN-EATON. : Linda Nedderman-Eaton, also have multiple chemical sensitivities, right now we live in a house in Cranston where the land lady also has M. C S. but I have live in an apartment building and almost lost my life more than once because of no notifications and stuff drifting to other apartments. So not just homeowners, people in apartments, we can't stop the use but we would at least like notification. That's the least I think

any state could do for anyone. Considering they already know regardless of MCS, have long-term consequences for everybody. For us to ask for pesticide notification is a very small, I think it's warranted, I think it's warranted. You don't know what people go through and you don't know your M. S., multiple sclerosis, you don't know you're M. S., you look into studies, you'll see connections to Parkinson's disease, this stuff is not safe so to just ask for notification I think is quite warranted. We can't stop the use, we wish we could but to give 24-hour notification so people can get out, it's just, I don't see any reason why the state can't do this. It's just common sense, plain common sense.

LINDA DUGAS: One other comment, Linda Dugas, it's not like we're going into a hotel, we sit in parks for hours, can't go into friend's houses because of the chemicals they use. It's not like you seal up your windows, you get the heck out. And whether it's the heat or whatever you try to find a safe haven for hours at a time. Often times we can't go into each other's houses because multiple chemical sensitivities is not one size fits all, some of us are allergic to different things with different reactions. I am very allergic to animals. But like every cancer is not the same, everybody with different disabilities, it's not the same, necessarily. Thank you.

GWEN: I was just wondering, this is Gwen Reeve, giving the notification so that you can leave, but how long is it before you can come back. I mean I would any if something were sprayed the results of that will be around for a bit.

LINDA DUGAS: My neighbor did it, you know, five feet from my, you know, bedroom window, all the windows open. And took us 20 minutes to get the heck out. And you're right, it does linger, however it gives you the opportunity if you have 48 hours notice that you know to have windows shut, no clothes on the line, you'll tape up windows and make arrangements to do something for at least several hours if not the entire day, if it means sitting on someone else's porch or spending time in the park or whole foods, it doesn't do that direct exposure that effects my central nervous system. I'm here to tell you it's headaches and nausea, and brain fog and central nervous system. Everything from that to seizures. Just because somebody wants a green lawn. So, yeah, it would be ideal to go away but to be out of your house anyway whether this should be a safe haven, and it's like you have to leave, have to get out and protect yourself, it's not safe to come back early, I can still smell it after a week.

Housing: multiple chemical sensitivity (MCS)

BILL INLOW: but the notification would at least minimize.

LINDA DUGAS: I've thrown out clothes on a line. Buy new clothes, put them on the line, neighbors think we're crazy to put them on the line so the rain will take toxins out. I just throw them out.

LINDA NEDDERMAN-EATON: What about normal people with kids.

BILL INLOW: You're arguing interests of a lot of people not just those formally diagnosed with multiple chemical sensitivity, it's a good argument.

LINDA NEDDERMAN-EATON: Laws in New York for multiple chemical sensitivities, somebody sprays all over your lawn or you're in the middle of a party with your kids, little kids, this is a public health issue as well .

FEMALE AUDIENCE SPEAKER: My mother-in-law was having mother's day so I can't go to those events any longer she's a hairdresser, so, forget it, but mother's day with the family and planning an outdoor thing, her own lawn care people came that morning and sprayed the lawn and so she had to like have everybody inside. I forget if she changed the venue and it was like who thought on a mother's day, Sunday, her own lawn care company didn't give notice.

BRIAN ADAE: Brian Adae, question, the advocating you're demonstrating today, have you had the opportunity to take this to your legislature, local representatives or municipality, perhaps, or the state department of environmental management to hear these issues.

LINDA DUGAS: I've talked to Bob Cooper before, I've talk today my state Senator, Peter, and Jamie, both running for other offices right now, I've brought it up, it's difficult for me, I'm not on the computer rings grateful for the library I can now go into for brief periods of time but until recently I haven't been able to do these things. I certainly have conversations; I like to take it to the next level. A lawyer deals with me for other matters as far as my parents have passed away, because he's from Cumberland and he's a classmate we talked about it, he works for the Governor's commission on human -- human rights commission and he suggested that I speak in greater detail with Bob Cooper who I've known for years and see what can be done in terms of introducing legislation. Did I answer your question?

BRIAN ADAE: yes, you did. Thank you very much.

GWEN: Chris is in the back, can you introduce yourself, where you're from and make a.

CHRISTINE: Chris Rancourt, I work with Bob. You reference a couple states that passed legislation, how successful had they been with people complying with that legislation.

LINDA DUGAS: You know I don't know, have I no idea because I have limited use of the computer, some people had tried to look up certain things for me, I was using this as an example, I don't know if it has, recently, Pawtucket passed an outdoor burning, fire pits and whatnot, and it's like, you call and they, you know, and that's another whole area, toxic for us, can't open windows, how effective they are, I don't know. How effective are they when you're supposed to pick up after your dog, not very. So I don't know that answer. It's a great question.

NANCY: Because have you done your homework so well, down the do you know percentage of citizens in Rhode Island effected with this.

LINDA DUGAS: Some have died, but it's varying degrees. In Pawtucket one month with fifteen, twelve or so people who can't work any longer, really severe like we are, but you know you talk to people and say I can't go down the deter gent aisle any longer or can't breathe when people use Glade air freshener, so there are varying degrees. A lot of people, there's an antiwar activist, Joyce -- she's a guitar player, Joyce Katsburg (sounds like), she developed chemical sensitivity and had an ongoing battle with having people around her to do nontoxic things so there are people trying to be in the work force yet are sensitive. So I don't know a number.

LINDA NEDDERMAN-EATON: Probably around 50 that I know of and probably much more that don't know.

NANCY: Have you collaborated with other such as asthma

LINDA NEDDERMAN-EATON: Yes, people with asthma have problems.

LINDA DUGAS: Have we collaborated, no. Things in bathrooms are unbelievable, can't wash our hands bring stuff with us. And let me tell you, it hits our bladder so we're always looking for bathrooms.

Housing: multiple chemical sensitivity (MCS)

LINDA NEDDERMAN-EATON: We don't want to take up the whole thing, the point I want to make here is, if you have the law you have some clout. She has no clout with her neighbor at all and he's retaliating because she tried to do something. Because people don't understand what we're dealing with so unless you have a law you don't have any defense whatsoever for yourself and this is just a very reasonable law other states have instituted for public health reasons and we think we should have it too.

LINDA DUGAS: Last comment, unless there are other questions, to try and make a comparison, if you were having a party and using, cooking something with peanut oil or you had peanuts, there are so many allergies that can go into shock, you call them and say gee, there are things at this picnic, they can make the decision at to either then want to eat it or be any where near it. That's what it's tantamount to for us and other people with the problem. Just give us notification, still means we have to get out of our home, our immune system will be compromised but we won't be continually poisoned. I had blood work done that they said and this was several years ago in March, they said when did you do pesticide applications, your blood is loaded with it and I said I don't do it but it's in my system and because of what everybody else is doing. Thanks so much.

GWEN: Robert, did you want to speak?

MALE AUDIENCE SPEAKER: I cannot emphasize how much I believe in informed consent. Little bit of background, why I feel this way. I was deployed in Vietnam three different times and my biggest memory is once a week is Air Force planes kept flying over our base and spraying. Too many people I'm getting letters from telling me, friends I was stationed with who were in the country less than I was are dying off with lymphoma, leukemia and in one case suicide having two children with spin a bifida. We had no choice and this is years down the road problems with pesticides and herbicides is just coming to light. I check my blood plates four times a year, maybe eight, possibly. I hope you can understand why I feel very strongly that we should do legislation, and possibly even with other subjects, people being just informed to they can make a decision rather than having that deprived of that. Thank you.

GWEN: Thank you. Kristen -- okay. Monica Tavares.

MONICA TAVARES: No, I'm here.

GWEN: Okay, no. Is there anyone else who would wish to speak about any kind of issue that they have concern about? Would you like to give us your name and also the recorder can make note of it.

HOLLY PFEIFFER: Holly Pfeiffer, I'm here because my son has special needs, and, as I understand it, Katie Beckett is being cut off. I've spoken with other parents about that who are no longer able to utilize outpatient services that are available. I just feel that some of these services are really necessary to keep the kids at home instead of hospitalization. Services like therapeutic sports, HBTS, social skills groups, play therapy, counseling, so on and so forth. Without those our kids would probably have to be hospitalized and there are only so many beds

available. I think that would be very detrimental to the family itself, to pull the kids out of their home to -- you would have lack of unity and bonding. Because kids would not just once have to be hospitalized but numerous times, over and over if we don't have the services available. Because I know for one, I cannot handle my son all the time, and without help, and the constant learning that I have to do, I won't be able to help him. And get him to be a positive person in society instead of a burden on society. And as I believe I said, only so many hospital beds are available and they're full all the time already, I happen to know this; I'm very involved with Bradley and some of the other hospitals around. And I don't want to admit my son because I can't handle it. I think that's it. Thanks.

Health Care: Katie Beckett

BILL INLOW: Thank you, we appreciate your comments. We pick up your sincerity and the evidence you've made and all you're looking for is continued assistance that has been provided under Katy Beckett for you and your family, right?

FEMALE AUDIENCE SPEAKER: Yes. There are services now that some of the parents have, they can't continue with those services because they don't have the money, and private insurance, I've got to tell you, they're no help whatsoever, none. I mean, I can't even get a weighted blanket for my son because the deductible is \$4,000. Health care is \$2,000 deductible we have to meet before I can get any help. So Medicaid is the only thing that is keeping us going. I have my son in every single thing that I can have him in because I don't want to put him in the hospital and I want him to be a positive influence.

NANCY: Can I ask a clarifying question. The services that you receive that are, they are results of the level of care criteria that's been instituted.

HOLLY PFEIFFER: Yes. His is going higher and higher and less and less people are qualifying, obviously. And that's not fair. Involved in a lot of events with these kids and they want to learn and they want to be positive people in society.

GWEN: How old is your son?

HOLLY PFEIFFER: Seven. He's a wonderful boy.

GWEN: Thank you for sharing that. I don't think there's anybody else that signed up to speak. But, again, if you would like to speak and you haven't signed up, you can certainly, take your testimony.

LINDA DUGAS: May I ask a question? Do you think these panels will continue?

GWEN: You mean next year?

FEMALE AUDIENCE SPEAKER: Good.

MONICA TAVARES: I believe it's held on a yearly basis the whole week, too.

FEMALE AUDIENCE SPEAKER: With low turnout sometimes, I only found out, I get OSCIL and PARI's newsletters but I don't think I saw it in there and I didn't see it in the newspaper. So I just knew because my husband was interpreting for it so I went, wait a minute, so, but I just wondered what, other than the newspapers, is there anything.

GWEN: I don't know what other agencies do, but I put it out in an eblast and put it out on our website, usually. But, I'm not sure what other agencies do.

LINDA DUGAS: Like a radio or TV public service announcement. I just didn't know if that was a possibility.

LINDA DESCHENES: I don't know, it's a suggestion worth looking at.

GWEN: My understanding is they were supposed to be put into the local papers so the local, whatever your local Cumberland paper is or local Warwick paper like the beacon, or, to notify that these forums were happening. I think it was a addition not to put it in the Providence Journal because a lot of people don't read the Providence Journal and it's very, very expensive to put it in that and a lot --

MALE AUDIENCE SPEAKER: John with the Governor's Commission on Disabilities, we actually did, we put the advertisement in the papers all through the east bay, the westerly sun, the Cranston Harold, papers like that that would target certain audiences in certain cities and we also geared it towards the forums that were close to that area such as Cranston had the Warwick forum so anybody from Cranston could go down there so if you want to look out in small newspapers like that.

FEMALE AUDIENCE SPEAKER: Valley breeze?

MALE AUDIENCE SPEAKER: Yes.

LINDA DUGAS: Thank you. (L. D.)

CHRISTINE: It was in the Providence Journal on Sunday. This morning, I couldn't remember the address of this and it was in Cumberland, so I looked online and Googled governor's commission public forum and they were all listed there .

FEMALE AUDIENCE SPEAKER: That's great.

MONICA TAVARES: Usually have the schedule for the entire week, so you could attend more if you like.

FEMALE AUDIENCE SPEAKER: Do you have a web site?

GWEN: Governor's commission has a web site, .

RON MCMINN: My name is Ron McMinn. I'm a commissioner on the Governor's commission on disability. I have attended several of these forums, and believe me, they're an eye opener. Problem with the governor's commission is our funding keeps getting cut and cut and cut. So we cannot provide all the services that we would wish. You've talked to Bob Cooper, Bob Cooper has mentioned on several occasions in a commission meeting about chemical.

LINDA DUGAS: MCS.

RON: Right. And I had a very good friend who later in her life developed it. I know it's expensive but what we did on her house was put a negative system in. And had a this does is it doesn't

take from the outside, it blows inside, out. So it's negative pressure. It's expensive, but it works for her. The agent orange that the gentleman talked about, the government is finally realizing that it was a problem. Once again, governor's commission, this isn't the first time I've heard about it in the forums that we run. We wish we could do everything possible for everybody. School system, that your son would be in, what school system?

Housing: multiple chemical sensitivity (MCS)

HOLLY PFEIFFER: Cumberland. That's another issue all together.

RON: They cut back on their.

HOLLY PFEIFFER: He's not supposed to regress in the whole month of August. There are no more services after tomorrow. He has the whole month of August to do what? Home teach him to try not to regress. The system is really, I'm just trying to get more active with everything. I spent last Wednesday at the School Committee meeting because along with the ESY program being cut there is, last three weeks we had tremendous heat and no one seem to say care these kids are having to learn in a building that's 95 degrees with a hundred percent humidity, nobody cared from the School Committee, superintendent didn't care.

RON: Dr. Morrel (sounds like)?

HOLLY PFEIFFER: Yes, please. Again I'm just trying to work with the system more, but I've gotten nowhere with that issue, I don't know where the other parents are, I'm disappointed on that. The state has no rules on that which I find amazing because they have rules about everything else and regulations about everything else.

BRIAN ADAE: if I may ask, have you been in the contact with the Rhode Island Parent Information Network, RIPIN.

FEMALE AUDIENCE SPEAKER: Absolutely.

BRIAN ADAE: I had a question, too, for Ron. You were mentioning the individual that you were able to help and the negative system, I assume same kind of system sometimes employed when painting or bridgework is being done where it's tented and then there's.

RON: Blowout system -- and the negative pressure and it exhausts from the inside out, instead of the outside, in. That's why they call it negative pressure.

BRIAN ADAE: Are you aware of where the resources for that came from or where they might be-

RON: You're talking Cindy died, almost 20 years ago.

BRIAN ADAE: Some time ago. Okay.

RON: So, it was her son who found the system. Because he was in New York. And they had it installed. She was not even able to go out of her house because of the chemicals so a bunch of us would do the grocery shopping, stuff like that that she needed. And it's kind of tough to see someone that was very active being completely shut in her own house. So I understand what you're saying about people with chemical sensitivity, it's, not only her but involved her family and her friends.

BRIAN ADAE: thank you. I apologize, I saw some hands.

NANCY: I had a question for you because your issue would be almost twofold because you're losing your services through Katy Beckett and then not getting adequate support through your school system because of cutbacks and so I wonder if the commission would, I guess what I'm saying is the education piece and the extended school year issue versus, and all these other supports you're getting through Katy Beckett is now compounded, correct?

HOLLY PFEIFFER: Absolutely. I'm trying to go to all this, you know, I'm not, actually, I wasn't here at ten o'clock because hi to bring my son up stairs, they're doing a special program. And so I apologize for not being here and not maybe understanding everything. I understand from some of the people here they're from the commission, and I'm not sure I understand, do you report to the commission?

GWEN: No, our role here is primarily to listen and to get your concerns and to clarify your concerns. They are recorded and the testimony is compiled and then the legislative committee gets together and looks at all of it to see which issues have a legislative solution or need some legislation to solve, which ones are other types, maybe there is already something available that people just aren't aware of or it's not being advertised well enough so that people don't know about the services. So we take all that testimony and from that testimony is how we develop our legislative agenda. So, next year, when bills are introduced, they're introduced taking into consideration what people said. Or we can advocate for it.

CHRISTINE: Sometimes things brought up in a session may not come to resolution until several years later. So I think we can all attest to that.

GWEN: Yes.

RON: Taxis is a terrific example.

GWEN: So our system, and if you haven't had the pleasure of working within the legislative system, does not move quickly. And so you may feel you have a really justifiable, common sense why don't we have this situation, and introduce that bill that would, you know, solve the problem, and it still may take several years. And because of the financial situation in the state of Rhode Island, we pretty much could not introduce anything that had what they call a fiscal note, something that would cost money. Every time we introduced something that would cost additional money, it was kicked out. So we are in a very lean times and of course your experiencing the results of that through cut services. I mean that's the consults of a lot of financial difficulty. So, most of us just keep ongoing back and back and back kind of like pounding our head against a brick wall but sometimes it actually does move, but it moves slower than what we would like it to move.

MONICA TAVARES: I know you may not see the results right away but it's very important to stay active and attend all of the forums you can so you can be heard. The more you bring up your concerns, the more they hear it and the more inclined they are to do something about it so keep up the good work and keep doing it.

HOLLY PFEIFFER: I will. I understand that part. I guess my question is or my concern is, these kids if they don't get help now where will they be when they're adults. The ACI is full. There aren't many mental health places to put these people if they need help. And as far as the cooling system issue with the schools, and I was not, like this lady here, I was not able to find out the information on how many other towns have this issue, whether or not they are sensitive to these kids trying to learn in temperatures that are way too high. They're already special needs, and for them to try and learn in those situations, I find is very difficult. I've gone through RIPIN, I went to the deputy director and superintendent in Cumberland, the department of education in Cumberland, the health department in the state, and they don't handle that. It's a health issue; they don't have any regulations on that. Neither does the department of education. I wrote to Commissioner Gist and got a call back had a it's a local issue. So I go to the School Committee meeting and they knew nothing about it. And there was nothing said about it. And I even had somewhat of a solution, in Cumberland schools in the winter, the heating is way too high so again the kids are learning in, not in a healthy environment, so, my solution was lower the temperature in the winter time to save a little time in the heating cost so that you can fund some air-conditioning costs or cooling costs in the summer. My son is fortunate due to some personality issues with the deputy director who quote-unquote, it's not his responsibility or the town school's responsibility to keep these kids cool. He said to me unless your child has a note from a doctor, we will not supply fans or air-conditioners in the room. So I went out and got a note from my doctor. His room in the school is the only one with an air-conditioner. And even with that air-conditioner running full-time, it's still 80-some degrees in his room. Other than lowering the temperature in the winter, which is very high. I volunteer at the school, and all winter long I wear T-shirts and so do all the teachers. I'm not even able to dress my kid in warm clothes because it's too hot in the school. So the electricity it or the cost is an issue, but.

Education/Employment: funding air condition

MALE AUDIENCE SPEAKER: Which school.

HOLLY PFEIFFER: BF Morton (sounds like).

MALE AUDIENCE SPEAKER: They renovated that school a few years ago, there was an issue with the heating and the hvac they call it, the heating and air-conditioning, they were supposed to put in air-conditioning.

HOLLY PFEIFFER: There is none. Again I would get a note and have an air-conditioner put in his room but now he has one, well summer, the school ends tomorrow. But it wasn't substantial enough to school off the room. From what I understand from OSHA the optimal temperatures 65 to 74. So it's not a healthy environment for these kids to be learning in. And I took this to the School Committee, yeah the School Committee and the only one that said anything at the end, came over to me and said I'll go to the school myself and see how it is. Well Monday as you all know, Monday was a nice, dry, cooler day. So, if he went to the school that day, he was not going to get an example of what these kids are going through everyday. And I'm shocked that the teachers don't speak up. Well no I'm not shocked because they don't want to lose their jobs, most of them are temporary employees. I also feel like they pay dues into a union why isn't a union saying anything about them having to work in an un healthy environment, they have to teach in this kind of environment and why have the ESY.

NANCY: Can I offer another resource, I know you've been to RIPIN, and you may have done this, Cumberland has a great special ed. advisory committee, if you're not a member, but they

do talk a lot about these issues you're talking about and they are, they do work hand in hand with the both Lisa and the other gentleman, Fred.

HOLLY PFEIFFER: I'm very aware of them, unfortunately they don't offer child care which is a major issue for me. I had to beg to get someone.

NANCY: They used to be able to have high school kids watch and I don't know what happened.

HOLLY PFEIFFER: They have trouble, even for the PTO meetings, getting child care. I had to beg, because it's open ended, too. These School Committee meetings have lasted until twelve o'clock at night and I can't have my son out.

NANCY: The advisory committee meetings usually meet here, small group and they're receptive if you bring your children, as well.

HOLLY PFEIFFER: You don't want to see my son here, he's very disruptive. We went to the state house, I don't remember, to support a bill that was going through. Well, he was himself, and the legislators and the people around the building, seemed to have distain for his behavior and the way he couldn't help being. We were there to support the bill. I don't get the feeling anyone cares about special needs kids, they are throwaway kids. That's what I get the sense from superintendent more rel. Unfortunately, I'm trying not to be somebody say a doubting Debbie, I heard that the other day but it's getting harder and harder not to be. I only knew about this because of the autism project, we're involved in that, as well. I've tried to get him involved in as many things as I can. But without Katy Beckett or Medicaid, we're going to be stuck at home and that's not a way to treat a kid with these issues. And it's not fair to him, either. Thanks.

Health Care: Medicaid

GWEN: Thank you.

BILL INLOW: anyone else care to speak at this public hearing?

GWEN: I just wanted to let you know that we are obliged, the paneling is obliged to be here until noontime, just in case somebody comes in, or decides to speak. But that obligation does not effect you at all. So, you can continue to be with us and think about things that were said or if you want to get up and move around or go to the rest rooms, they're over here. Up to you.

7. **EMAILED TESTIMONY**

7/28/2010

To Whom it may concern,

Unfortunately, I cannot attend one of the public forums on The Concerns of People with Disabilities and their Families. I am writing about my son, Paul, who has ASD. He is a Boy Scout. Just last week he went to Camp Yawgoo with his troop. Because of his disability, my husband had to take a week off (unpaid) from work to be with our son during this trip. (My son sometimes has violent screaming outbursts, may hurt himself and others, sucks his thumb, soils his pants, and takes things literally) We should be able to send him to an appropriate facility where he can get the most assistance. My husband had no choice but to volunteer to work with the other campers, also. It was costly to send my son. There should be affordable programs in Rhode Island for him and others with disabilities. He has not been offered ESY (Extended School Year) in a couple of years, although he does regress every summer. We do not qualify for cash assistance. We do receive Katie Beckett but it is not enough. We are far from wealthy with 3 children. We do not qualify for anything but medical assistance. We don't even qualify for reduced school lunches for our children.

My youngest son, Ryan, is 4 years old. (He has yet to be diagnosed with Autism.) He lost many pre-learned skills around the time he was 2 years old (stopped eating, stopped talking in sentences, stopped potty training, stopped recognizing his colors, shapes, numbers, and letters amongst other things) For two years, I have been looking for a neurophysiologist to evaluate him. We have been turned away from some psychologists because of Ryan's age. (Even though over the phone they say they can help) (My insurance company, United Health, is no help at all, either) Yes, we did Early Intervention but once he turned 3, everything was turned over to the West Warwick School Department. Although he does get Special Education services, it is not enough. I want to see him improve drastically. He should be able to get all the services he needs. The school department refuses to pay for an evaluation. I do not want to go the Hospital Route (RI hospital/Hasbro) because there are many hidden fees. He has been to Meeting Street school for a hearing screening, Occupational and Speech evaluation. At one visit there, the person who handles the insurance claims came out of her office and demanded money from me. I told her that I did not have an upfront co-pay but she said that they have had bad experiences with United Health. (My co-pay ended up being less than what she was asking for) It's embarrassing and frustrating to be put in these situations. My children deserve better. I need an evaluation to get a diagnosis for Ryan and also so he can continue to get the services he needs in school. Also, in order to get Katie Beckett, he needs an evaluation. (Catch 22 situation) These evaluations can cost upwards in the thousands of dollars. Please help in addressing these issues.

Health Care: Katie Beckett

Thank You for your time,
Mrs. Sherry Goodrich

8/2/2010

To whom it may concern:

I was unable to attend any of the forums that were held this past week. However, I do have one concern. I have recently found myself on disability due to mental health issues. After some research, and discussion with my treatment team, I have found myself interested in pursuing a psychiatric service dog. The issue with this is that the RI laws do not specifically address this,

they mention service dogs for physical/sight/hearing assistance, but not psychiatric/mental. I do not want to proceed until I know that the law will be on my side and support me in taking my fully trained service dog into public places. I have done my research, and although PSDs do offer emotional support, they are also task trained like any other service dog.

Housing: psychiatric service dog

Thank you for your time,
Heather Oliver