DRAFT

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

July 27 - July 30, 2009

Prepared by

The Governor's Commission on Disabilities

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(date of completion)

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Contact the Governor's Commission on Disabilities.

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 27, 2009 1:30 - 3 pm
Barrington Public Library's Gallery Room, 281 County Road, Barrington
Hosted by the Statewide Independent Living Council

Monday July 27, 2009 4 - 6 pm
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 28, 2009 3 - 5 pm
Warwick Public Library's Community Room, 600 Sandy Lane, Warwick
Hosted by the Ocean State Center for Independent Living

Wednesday July 29, 2009 4 - 6 pm
Neighborhood Guild, 325 Columbia St, Wakefield
Hosted by the RI Parent Information Network

Thursday July 30, 2009 10 am - Noon
Cumberland Public Library's Hayden Meeting Center Rms. 1 & 2, 1464 Diamond Hill Road, Cumberland
Hosted by Rhodes to Independence @ URI's College of Pharmacy

Thursday July 30, 2009 3 - 5 pm
Middletown Public Library's Community Room, 700 West Main Road, Middletown
Hosted by the RI Chapter of the Multiple Sclerosis Society

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 9th 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.

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The Public Forum Sponsors

Brain Injury Association of RI, Sharon Brinkworth, Executive Director;

Community Provider Network of RI, Donna Martin, Executive Director;

Corliss Institute, Mary Wambach, Executive Director;

CranstonArc, Thomas P. Kane, Executive Director;

East Bay Center, Inc., Robert A. Crossley, MA, Chief Executive Officer;

Governor's Commission on Disabilities, R. Timothy Flynn, Chairperson;

In-Sight, Christopher Butler, Executive Director;

National Multiple Sclerosis Society Rhode Island Chapter, Kathy Mechnig, Executive Director;

Neighborhood Health Plan of Rhode Island, Mark E. Reynolds, Chief Executive Officer;

Ocean State Center for Independent Living, Lorna Ricci, Executive Director;

Opportunities Unlimited for People with Different Abilities, Linda Ward, Executive Director;

PARI Independent Living Center, Leo Canuel, Executive Director;

Paul V. Sherlock Center for Disabilities, Anthony Antosh, Executive Director;

Rhodes to Independence @ URI College of Pharmacy, Elaina Goldstein, Executive Director;

RI Commission on the Deaf and Hard of Hearing, Steven A. Florio, Executive Director;

RI Department of Health, Dr. David R. Gifford, Director;

RI Department of Human Services: Office of Rehabilitation Services, Gary Alexander, Director and Stephen Brunero, Administrator;

RI Disability Law Center, Raymond L. Bandusky, Executive Director;

RI Disability Vote Project, Jean Lawlor, Executive Director

RI Parent Information Network, Matthew Cox, Executive Director;

RI Statewide Independent Living Council, Camille Pansa, Executive Director;

The Homestead Group, Dr. Robert Carl, Chief Executive Officer;

TechACCESS of Rhode Island, Judi Hammerlind Carlson; Executive Director;

UnitedHealthcare, Patrice E. Cooper, Executive Director

Part One | Executive Summary

This year, twenty-four agencies conducted a series of public forums across the state of Rhode Island to hear the concerns of people with disabilities and their families from July 27th to July 30th, in honor of the anniversary of the Americans with Disabilities Act (signed on July 26, 1990). This year's forums were hosted by the Rhode Island Statewide Independent Living Council in Barrington on July 27th, the RI Department of Health's Office of Special Healthcare Needs in Providence on July 27th, Ocean State Center for Independent Living in Warwick on July 28th, Rhode Island Parent Information Network in Wakefield on July 29th, Rhodes to Independence in Cumberland on July 30th, and the National MS Society's Rhode Island Chapter in Middletown on July 30th.

An array of issues was brought up at the forums with the main themes being accessibility, employment, health care, housing, services, and transportation.

The most prominent common thread between these themes was the effects of the recent economic downturn. Cuts to services and the fear of cuts to services were voiced during all forums (example 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11). The areas of most concern were with day services, rehab option programs, group homes, and home visits. The homelessness epidemic was also addressed, with speakers calling for action and more organization to combat the spread of this trend (example 1, 2, 3, 4, 5, 6, 7).

In tandem with the budget concerns, many voiced their frustrations with the efficiency of the state government in providing services and information to its service agencies and the public (example 1, 2, 3) as well as the lack of a system by which to file abuse and discrimination complaints (example 1).

Many individuals at the forums also brought up the quality of transitional services in Rhode Island, appealing for stronger and more constructive transitional services (example 1, 2, 3, 4).

Aside from the homelessness issue, the quality and lack of housing was also addressed (example 1, 2, 3). The lengthy waiting lists for housing and the quality of the accessible housing available were two key issues in these discussions.

Comments on the newly enacted medical marijuana program and the already apparent problems it contains (example 1) were made.

In the realm of health care, Medicaid seemed to get the most air time. Some complained about insufficient services allowed by the program (example 1) while most were wary about the Medicaid Global Waiver's vague language (example 1, 2, 3). A recommendation was made for the Governor's Commission on Disabilities to look into demystifying the Medicaid Global Waiver for the public (example 1).

The obstacles that adults and children with special needs encounter when attempting to obtain medical services were also brought up, highlighting the daunting process and the inadequate services provided for those who do obtain services (example 1, 2, 3, 4,).

Accessibility issues were also represented, ranging from barriers to individuals with multiple chemical sensitivity (MCS) (example 1); to providing audible traffic signals (example 1) to curb cuts and accessible/uniform sidewalks (example 1, 2). The process for obtaining or renewing a disability parking placard was also addressed, as the only location that handle it is located in Pawtucket: making it rather difficult to access (example 1).

As for transportation, the need for accessible taxi services was discussed (example 1, 2). However, the biggest source of concern in regards to transportation was the RIde program (example 1, 2, 3).

Another underlying theme that was apparent at these forums was the need for increased awareness of services and resources that could prevent or alleviate many of the issues outlined above.

Part Two | Community Concerns & Recommendations

Accessibility Concerns

ANNETTE BOURBONNIERE: And the other one -- also on walking around, it would be great if we had some audible traffic signals. We do not have a single audible traffic signal on Aquidneck Island. And I know how dangerous it is for me to try to cross the street. I cannot even imagine the terror involved in trying to cross the street if you can't see because those traffic signals are not giving you any information.
See Audible Traffic Signals

SUSAN HURD: I didn't even get to sit down.
Hi. I have some handouts. My name is Susan Hurd. And I am here to represent people with hidden disabilities, including myself. I contend with multiple neuroimmune disorders, including Lyme disease and chronic fatigue and multiple chemical sensitivities.
Multiple chemical sensitivities is a serious issue, especially with housing, that I really believe Rhode Island needs to be paying more attention to. There are simple solutions that could provide accessibility and it's not taking place.
There's over 4 percent of the US population that's disabled with MCS, multiple chemical sensitivities. That's 12 million people. From my understanding, correct me if I'm wrong, there's less than 1 percent that are disabled in wheelchairs. There's less than 1 percent that are disabled with hearing and visual impairments. There is only one HUD MCS accessible housing complex in the whole country. And that's located in Marin, California.
One, that's like providing only one wheelchair accessible housing complex in the whole country, yet there's 4 percent of the population that's disabled with MCS. MCS is a hidden disability and it causes invisible barriers.
Simple things like using zero to low VOC (volatile organic compounds) paints, which are now accessible at places like Home Depot. They are price comparable and affordable exist. That makes all the difference whether I can be in a building or not. It's price comparable. It's not costing thousands of dollars. It's cost thousands to have elevators, wheelchair ramps, automatic doors for those who are wheelchair disabled.
Like those who are wheelchair disabled, those with MCS also need accessibility. I have been struggling now for over two years to find an affordable place to live. I am threatened with homelessness. I am well-spoken. I am educated. And yet I have these barriers taking place. One of the things that constantly I'm up against is places have brand new paint. They have new carpeting. I'm automatically -- that's like for a person with a wheelchair who doesn't have a ramp provided. I can't be in there. If I go into buildings that have new paint, new carpeting, other materials that are out gassing, I get very sick. I become poor functioning. It is causes neurological impairments. The result of it is I cannot often find an affordable accessible place to live. I can't even go into a homeless shelter for the same reasons because accessibility isn't being provided.
It's a serious issue. MCS is just as serious as other medical conditions like cancer or AIDS. It is potentially life threatening. It can cause seizures. It can cause anaphylactic shock, neuromuscular degeneration. I have a close friend who deals with MCS. They had a chemical spray exposure. They live in the south. Three times they have been put in the hospital from chemical spray exposures. Their nervous system for their digestive system shuts down, meaning they need feeding tubes and they can't void. They can't eliminate natural body functions.
Myself, when I get chemical exposure, sometimes because it's a neuromuscular effect, I won't be able to swallow. Therefore food can get caught. Then I could choke. I could have anaphylactic shock. I could have seizures.
Every time things like chemical sprays are used in buildings, on the lawns, that prevents accessibility. The neurotoxic chemicals, they are carcinogenic chemicals. There are safer, less toxic solutions. There's organic and nontoxic lawn care. There is nontoxic pest management available. And it's all price comparable. Yet it's not taking place.
These are simple things that could be taking place, but it is not. So the barriers become -- if there's lawn chemicals outside of this library that can prevent accessibility. If you have a new carpet in here, that prevents accessibility.
I was -- I am a success story. I was able to rehabilitate myself well enough so I could go to school part-time, get my masters, my post masters in holistic mental health counseling in Salve Regina. I also created my own internship at the rehabilitation hospital, the only holistic integral medical clinic in Rhode Island. And I turned it into an independent part-time contractor job. I am still disabled. I am dealing with a whole disability to transition part-time work program. I am very grateful for the assistance that I have been given. Yet even at the hospital, what do they do? They use the high VOC paint.
It's over 72 percent of people with asthma and respiratory conditions are triggered by high VOC paint. The clinic is fibromyalgia, other immune disorders with pain and fatigue. Yet 60 percent of people with fibromyalgia deal with chemical sensitivities.
Over 40 percent of the whole US population is chemically sensitive. Some of you, for example, may have perfume sensitivity. You get headaches. Maybe you get a runny nose or you start getting a little wheezy or asthmatic. Those are all

chemical sensitivities.

Forty percent of the population. When a child crawls on a high VOC carpet, they inhale the equivalent of three cigarettes worth of high VOC's daily. That's -- VOC's contain things like formaldehyde, which are highly neurotoxic and carcinogenic. Yet we are still allowing these things to take place.

Not only that, it's not just those disabled with MCS that benefit. When you have 72 percent of asthmatics, 60 percent of people with fibromyalgia, 40 percent of the population, which increases every ten years, this is benefiting many people, millions, a large percentage of the population.

Since most of these chemicals are not only neurotoxic but carcinogenic, you are adding the percentages of how many people are dealing with cancer daily. Obviously we need to go and start right here. Rhode Island's the smallest state. Therefore, we can more easily have contact and communication organization. It's not happening.

I tried to show up last year for the GCD legislative committee meetings. People were wearing perfume. That makes me sick. I was not able to show up. I wanted to do -- I speak well. I wanted to do what I can and have the information. I suggested a subcommittee because MCS is so complex in itself, dealing with housing, medical issues. I don't really know what to do. But I'm here and I'm speaking out. Maybe through the testimonies being documented, people listening, that somehow some change would happen.

I brought some suggestions that can be passed around. I have contact information, if anyone wants to speak to me later. Thank you.

See Chemical_Sensitivity

CHERYL CROW: I am going to sit here because I'm too fatigued to stand. I thought I'd have a little bit more time to collect my thoughts coming in late. But this lady was I think in effect talking about some gaps in efficiencies in this state. One that we brought up for several years now is about the handicapped placard process. Persons with permanent disabilities per MD and federal government currently have to go through the medical expense to renew application every three years for their placards.

If we are too ill to travel to Pawtucket to replace the placard when it's worn out, we have been told to violate the law. Park in the handicapped parking without our placards and then fight the ticket. A little bit, um, too much effort for those of us who don't have the energy to even stand in the front of a room to give a dialogue like this.

Another gap in efficiency that I think -- well, first of all before I move off of that, we right in town have a AAA and a motor vehicles department where we can go in and show our ID and renew our license and our registration. And there's never even a wait at the AAA. That would be a lot easier than getting to Pawtucket. So that's a very easy fix.

But I think first we should find out why we have to keep going through this, if we have been determined permanently disabled and need a placard.

See Handicap Placards

JOE CIRILLO: I am Joe Cirillo. I came because I'd like to see what is going on and what the issues are. And one of the issues the gentleman just mentioned and also the young lady -- I'm an architect. I have been involved with disabilities about 30 years now. I was a state building commissioner for 28 years.

There's a book out right now that we helped produce. Bob Cooper was one of the members who helped produce it. It's called modifications 101. It's a really well written book. We put it together. And it's all about you living in your house, and modifying it through a checklist so that you can stay there. And what does it take to modify your house. Everything from the ramps and everything. It's really made well. It's the kind of book that you can put in a little sleeve binder, if you -- it's a spiral bound right now. But you can always take that off and copy it. It's available at the state. Elaina Goldberg and Jeanne --

FEMALE SPEAKER: Her organization is Rhodes To Independence.

JOE CIRILLO: Rhodes To Independence. And it's a really written well documented book. It's really nicely done. I was very proud to be a part of putting it together. And I have even introduced it in Washington at some meetings I was at. So now all 50 states have got copies of the thing.

It's one of these things where -- it isn't you. I'm disabled. Back injury and I am a disabled person. But it doesn't have to be. My mom was disabled due to age and other illnesses. And it came through a point where she was in elderly housing. It was accessible. She had to go to a nursing home.

But with this book, it was possible that, you know, I now look at it. How can I move -- change my Middletown house so that it can accommodate me when I get worse? And it's very, very likely I will get worse, if I live longer. I mean -- and this book does a good job of explaining it. I think it just needs to be distributed more. And it is available, as she said.

See Home Modifications

ANNETTE BOURBONNIERE: Okay. I am Annette Bourbonniere. And there are a couple of issues that I'd like to talk about. One is -- we are doing a good job lately. I guess we got some of the stimulus funds. We are putting new sidewalks and curb cuts all over the place. That's wonderful. But a lot of sidewalks are still -- either they are too narrow, or they still have barriers on them that make them narrow. So in those -- in a lot of areas, we are still required to roll down the street, which is really kind of dangerous.

The things that are wrong are the narrowness on a lot of them. The barriers -- some of the barriers are right in the middle of the curb cut or right encroaching on the curb cut. So you try to go up, and I will go right into the telephone pole. And some of us have already done a little damage. That's just not going to help us any.

There are also a lot of hedges that hang over these sidewalks. We are not getting a lot of enforcement on the local -- in local communities to have property owners cut their hedges. So again, if your sidewalk's narrow and the hedges are coming out, we are going down the street like this. And it's a little touchy there.

One of the things that's been brought up at some of the accessibility advisory committee meetings too has to do with people who are blind or visually impaired. On sidewalks, it would be such a help if all the barriers were on one side or another, preferably inside. It would be better for everybody if they were closer to the property line than the street line. But -- yeah, she's nodding her head because you don't know which way -- it's like going through a maze only you have no idea where the maze is.

See Sidewalks

ROGER HARRIS: Roger Harris again. I -- due to my own personal dilemma, I have been in a chair for 15 years. And I was born and raised in Woonsocket. The neighborhood I grew up in does not have one wheelchair curb cut.

I'm also a member of the Paralyzed Veterans of America. And many years I've gone to Washington DC during their advocacy and legislation seminar with the group. And I've actually sat in the Congressman Reed, Senator Reed's office and spoke to him personally about this situation. And his right-hand man took the information down. And they said they would look into it.

Since then, Woonsocket spent some money building -- repairing bridges, building new bridges. On the bridge side, the curb cuts there. When you cross the street from the bridge, there's no curb cut. So, at the time I had a computer and I was on-line. So I would e-mail the senator and say hey, this bridge such and such street. And he would e-mail me back. We will get on it. We will get on it.

That was 14 years ago. And still today, you come to Woonsocket that same bridge is there. The new bridge has a nice curb cut. Across the street, nothing. For me, it's not a big deal. I have learned how -- I mean, hop up on a curb. There's a lot of elderly right there -- lives right down the street in the high rise. They walk down and they cross the street there, talking about busy intersections. But the curb cut is really -- it's interesting. Small example.

See Sidewalks

Accessibility Recommendations:

{To be completed by the Accessibility Working Group}

Employment Concerns

JANE DOUGLAS: I am not on the list of speakers because I didn't see the list. But anyway, I have my spiel that I have said numerous times in the last three years.

My name is Jane Douglas. I have a son Robert who's 51. He grew up in New York in West Chester County. And after high school, which is -- was a special high school graduation; he worked in a workshop where he was trained to do maintenance work. He also worked in the summers in the city park. He comes from a very hard-working family with a strong work ethic. He has no respect for the less ambitious people in our extended family.

After my husband retired, we went to Florida where he lived in a town called Naples. Where they had a very active program for the handicapped. There he had many jobs. Some of them limited by time, dependent on the tourist season. He was busier in the tour season and in the summer. But he always had a job doing maintenance work. At one time the Ritz Carlton hotel, the mall, food court.

And then we lived in a town called Cape Coral about an hour north of Naples. And my husband's health wasn't too good so we had him move to Cape Coral. And there he worked in Wendy's for five years as a dining room attendant.

Then he was in an accident where his father was killed. And my only other close family is in Cumberland, Rhode Island. So I made the decision to move here, feeling that the same services would be available for Robert as in Florida and New York.

This did not prove to be true for him. And every day when I talked with him -- I am going to be seeing him today -- and I know he's going to say, "Mom, I really would like to have a job in the kitchen or doing maintenance work." And he goes to a workshop. One of them, he is allowed to do some sweeping. But he's not allowed to mop the floor, something he was trained very carefully to do.

I don't think that it's going to happen for Robert. However, I think there should be an emphasis on working in the real world and that it fills a social need. It fills an emotional need, a financial need, and it's so important to people like him. Thank you.

See Employment

JEAN CALLAWAY: My name is Jean Callaway, and I go to Hillsgrove House, been a member there for eight years. It's a very good vocational program. It's based on the work order day and we go there and we work, and it channels the symptoms of our illnesses, and I had four transitional employments through Hillsgrove House which is to help you get back up on your feet so you can go out and get a regular job. And it's just; it's just a beautiful program. And we've suffered a lot of cuts, and, you know, we can't even have a, our permanent director right now because of some of the cuts that we've had. It's very difficult to see that a lot of these cuts are being made within the state to all these programs. And I've been dealing with my illness for 31, years and I've never had a program like Hillsgrove House, I mean it's kept me out of the hospital, kept me well. I've kept in contact, I've made all kinds of friends, and it's just very, very sad that all these cuts have to be made to a program like this, and all the other handicapped programs. And this is where we're going to suffer. People are really really going to suffer because they're not going to have a place to go. They're not going to have ways to channel their illnesses. And it's very upsetting, you know, everyday, even reading the newspaper about all the cuts that are being made and I just want to be there at Hillsgrove and continue to stay well and this is what my friends want to feel. And I just, you know, the cuts are effecting everybody, everybody with mental illness and physical illness. Thank you.

See Transitional Services & Hillsgrove House

ELLA WHALEY: And then I just have a few things that I would just like to bring forward. Support for students in high school with transition services is actually a need that I see throughout the whole state. I'm an advocate in this area for students with disabilities. And it's just an area that really needs a lot of professional development and education.

A second one is the support for the collaboratives. We have East Bay Collaborative, Northern Collaborative, Southern Collaborative. Just finding out today that if we can really support them financially; there may be some crisis with some cutbacks with the collaboratives. They do a lot of professional development and they do a lot of support, you know, with families and students with disabilities. So, some support for the collaboratives would be great.

So, transition services, support for collaboratives. My understanding is also -- hi -- that there is funding for post secondary options for students with disabilities. I don't know if anybody on the panel has more information about that or can give us a website. But my understanding is the federal government -- the state is really pouring money into post secondary institutions to support students with disabilities to furthering their education.

And then lastly, I just wanted to bring to the table that Mr. Colin Antonio at CCRI, in charge of the drivers' education program. He really stepped up to the plate. And there was a class -- drivers' education class that's offered with children with disabilities; that because there wasn't an enrollment of eight, that kept getting -- not being able to, you know, run the class.

He really stepped up to the plate and ran the class for some kids that will be taking their test this Friday. So we just wanted to thank him. And if there's any support that you can give to CCRI with their drivers ed, especially for kids with disabilities, it seems as though there are just lots and lots of classes offered for the nondisabled peers and you know, maybe we can run more of those classes with maybe five or six kids rather than having to, you know, have these kids put on hold until we get eight kids. You know, these kids, if they didn't run this class would have been put off from July 7. And then the class started again July 22, and they would have been put off up until the fall.

So kudos to him for doing that. Thank you.

See Transitional Services

Employment Recommendations

{To be completed by the Employment Working Group}

Health Care Concerns

ISABEL: Isabel Pestana, Neighborhood Health. Out in the community, I often encounter families with children or relatives that have disabilities, or adults with disability that, make the comment of -- provide medical assistance and find the whole process very challenging for them, and it almost seems at times that they're set up to create a barrier instead of opening the doors for them to be able to access the health insurance or the services that they need. I understand there's some disabilities, some are more obvious than others, but all disabilities are just as important for adults, at times, to me, it seems so obvious, and I hear often times -- (inaudible), and they stop. I come in and almost let them know they need to go back and advocate for themselves, for their relatives, and I offer assistance in the way of all the information I have from different agencies, or throughout the community. But it's just a concern that I hear this so often when I'm out there about so many adults or children that have special needs that are not really taping into the resources they have because it's very challenging in the beginning process of application and due to the fact of -- or frustration, they stop.
See Availability of Medical Services

Kathleen: Every year with the same problem. Last time I was here I was (inaudible) chair, which -- this is the chair which unfortunately was not given the (inaudible) -- So, has gone to heck, basically. The top side of my body is twisting to the left side so that my (inaudible) -- when I'm sitting. My leg -- because the bottom side of my body is twisting toward the right side, and my right hip has raised up so high that it interferes with my (inaudible), and it's leaking, sometimes twice a day. Medicare/Medicaid says you can only have -- bags a month which is not even close to what I need. Just as I was saying to you, you can't change your underwear every day, you have to change it, every two or three days you can change your underwear. And I have (inaudible) problems and complain about that. I have gotten a doctor's order to get (inaudible) but the main thing is -- more bags. Sister and mother had gone to see -- who recommended (inaudible) – I won't go into everything but they were going to get this handy dandy chair that reclines with my -- it was going to be great, just left me to them, thinking Medicaid is not going to like this, and feeling rejected three times. Once because I wasn't eligible, once because they needed certificate -- something. And then, it was that they needed a prescription; then it was because, this last time, it was because the person I'm seeing is a nurse practitioner and she's not quote/unquote a real doctor. So they had to have a statement from the doctor she works with that said that (inaudible) the organization -- but who saw me, and the one that was – is supposedly working with Medicare to get me permission to get this chair and I didn't know -- just not doing what it's supposed to do, or what's happening, but it's going back and forth. Christina -- blames the nurse practitioner. And it's been going back and forth for two years now, and I just don't know what to do. I do have a cousin who is a lawyer and he agreed to, he wanted to look into it pro bono so we've contacted him. My sister who is real good with day-to-day details sent him all the information that he should get, need. And so we're going to have to go that way, and, really, didn't want to have to get pushy but it's getting to the point where I'm in pain almost all day, everyday, sometimes at night I can't sleep and just I can't do my -- I can't -- any more, I don't know how. They say – if you feel like you're -- tie a knot and hang on, I don't know, I just don't know what to do. Thank you.
See Availability of medical services

ANNE WHITE: I am Anne White and I don't have notes. I don't have notes. And we are battling with these issues on a day-to-day basis in just trying to find an avenue out. My husband is legally blind and he is a patient at Koch Eye. We are in a quagmire between Koch Eye and insurance that refuses to pay for a treatment that has been effectively restoring his vision. It has been a year now that we had that insurance. The vision has deteriorated to the point where he basically -- he doesn't see.
And we can't -- we tried contacting the pharmaceutical company. We've contacted Koch. We contacted Edna. We are presently drafting a letter to Patrick Kennedy. And we just don't know where to go.
But it seems to me if there's a treatment out there that clearly has improved -- he had one treatment and it brought his eye sight 20/400 to 20/50. So clearly it works. And because the insurance company has deemed it too expensive and experimental and not enough clinical evidence, they refuse to treat or they refuse to pay.
The pharmaceutical company agreed to lower the price of the drug. But again, Edna says this: They will pay if the treatment is done in the doctor's office. The doctor's office says they cannot. It's a surgical procedure. It has to be done in the surgical office. And that's where we are stuck.
So every day his eye sight gets worse. And every day we are not making any progress. And I just -- I need to know where we can turn next. Is there any avenue that we have available to us?
See Inadequate Coverage

DAWN: Might I speak to limitation on the -- not The Point and not 211, but on the CEDARR (Comprehensive, Evaluation, Diagnosis, Assessment, Referral and Re-Evaluation) Family Centers. When those centers were designed, I was smack dab in the middle of that so from the get-go in establishing the centers so that families could more readily access services. That's the entire focus of the whole initiative. And the state invested quite a bit of resources, both fiscally and human resources in terms of their staff through the Medicaid agency and some of the other state agencies, as well. And the original intent when those centers were set up were so that any family whose child had a disability regardless of what their insurance status was would be able to enter that doorway to at least get information and be referred to appropriate places, even if they were not eligible for Medicaid, it was a way to go in the door to get some information. Obviously, the first thing was to establish whether or not the child was eligible for Medicaid, because if the child was eligible for Medicaid, that opened the door to kind of the next level of services, if you will, that the family could build a family care plan and really work on the strengths of the family and the strengths of the child. Unfortunately, as it played out, what happened was the CEDARR family centered were really only taking on, if you will, those who they knew to have Medicaid. So, for instance, if I'm a parent and my child has a disability or a chronic illness and we have commercial insurance, we can't get the services, including the information piece, the front door entry piece, if you will, because our child is not eligible for Medicaid. It's not the intent, the original intent of those centers, but unfortunately, that's what the practice became.
See Medicaid

DAWN: I am Dawn Wardyga, parent and program director for Family Voices at the Rhode Island Parent Information Network, and I'll probably be at a few of these, but I wanted this on the record, and I promise I won't speak at every one, but at least it will be on the record. I don't know what came up before I came in, but the area of biggest concern from my perspective going forward, and I think, well, I know impacts all ages from birth to death is what may happen through the Global Waiver process, the Medicaid waiver process. I am very much involved, many of us who work in the system are very much involved in that process, but still, we're all feeling pretty uncomfortable about what the outcome is intended to be, and whether or not our input is going to be taken seriously into what the outcome is. When the state went to the General Assembly to get permission to go forward with this waiver request, I, among many others was one that testified very strongly against going forward with this Global Waiver. We felt as if we could make some positive changes in the same way, using the systems that we had in place. Obviously, we lost that battle. The war rages on, but we lost the battle. Going forward, getting approval to go forward with the Global Medicaid waiver, the first time really the country has looked at Medicaid across, (inaudible), across disabilities and across all ages, which, in concept and theory is a very good thing, it delves in details. As we go forward, I know the Commission will be watching this as closely as we are because we work closely with the Commission, as well. The details are unfolding as we speak, and as one who is, as I say, very invested in the process, and spend a lot of my time, my work time in that process, I'm very much concerned about the outcome, and I worry tremendously about the general public who doesn't have, who don't have the same level of knowledge and understanding of the Medicaid system, and don't really understand how this might impact them in the long run, whether they're Medicaid eligible or not. If they're commercially insured, depending on the outcome of the waiver, it will have impact on the whole health care system of the state. I hate to use their term, but it's a global issue is what it is, and it's something that I don't think we can take our eye off of for a second because, as one who attends many meetings, the landscape changes from one meeting to the next meeting, and that causes me great concern, so I just wanted to be sure that was on the record.
See Medicaid Global Waiver Part One

DAWN: May I make a recommendation in that case? I'd like to make a recommendation that the Commission, the Commission step forward and take that on as a priority area for them. It's tied in with Medicaid Global Waiver, but it isn't only about the Medicaid Global Waiver. And it's so complex to expect the general public to understand it, we're just never going to be there. And in order for us, the general public, if you will, to really have meaningful input into the process, we need to see the big picture, and I think that the Commission has the ability through its Legislative Committee to take a stand in the discussions that are happening in D.C., as we speak on National health care reform. From what I understand, today, the U.S. senate is actually reviewing their bill on National health care reform, so, the time is now. It's one of those extremely urgent kinds of situations, but the Commission ought to be able to, obviously, they're focused on people with disabilities, all people with disabilities, which I think is fabulous because it's across the boards, it's not just isolated populations. But, to have a voice in whatever health care -- whatever shape health care reform takes in the future, that the needs of those with disabilities and chronic illnesses be incorporated into those discussions.
See Medicaid Global Waiver Part Two

LINDA BRADLEY: Good afternoon, my name is Linda Bradley, home access coordinator at OSCIL, and I wanted to just take a minute to talk about the of course the new Global Waiver coming along. Lorna had showed me a proposed overview of the waiver, and had asked for feedback from anyone, and I wanted to make sure, there were a couple of things

I wanted to make sure got registered somewhere. The first one was where it was mentioned that minor environmental modifications were going to be allowed. This was under the preventive need section, and I was curious why they were specifying minor. In my line of work, minor would be putting up a (inaudible), or adding a piece of adaptive equipment, but I wondered if that would allow things like ramps, vertical platform lifts, ceiling traps, all of which are sometimes a crucial piece of equipment to allow someone to stay in their home. I was hoping that ramp they would change it to just say environmental modifications, and not specify the minor. They also mention standing poles, and I wondered whether they were going to allow those. And they didn't specify, if they did specify standing poles whether they would also allow grab bars. Another thing is handrails in stairways or steps. I just thought it would be helpful to not specify something like a standing pole, which to me locks you into one intervention when there are many, many possibilities.

The next section I had a concern about was where they mentioned physical therapy evaluation and services. I strongly feel that this section should include occupational therapy, as well. If PT, physical therapy is the only type of therapies designated, then OTs (occupational therapists) may not even be able to go into homes. Again, I feel that by mentioning something very specific, you may be closing out other professionals who really need to go into the homes. OTs really need to go in there, they are the ones who look at the functional activities that is a person does in the course of a day and can recommend the best interventions. Physical therapists look at the physical reasons for disability and they use physical interventions to improve those abilities. OTs also look at the physical but they go onto look at all the other reasons why a person has limitations. OTs are a crucial member of the team looking at a person's need in their home. I'm hoping that they specify PT because sometimes when people mean therapists of any sort they say, oh, send a PT or they refer to PT as any type of therapy, but it's not. There's many types of therapists. So, if they're, again, going to be that specific and mention a particular type of therapist, I would like them to include OT, PT, speech or other types of therapists.

Let's see, what else? Okay, the next section was under limitations on the availability of services. In the second paragraph they talked about in the event that a waiting list occurred, beneficiaries with high need are given priority access over beneficiaries qualifying for preventive services. And I sent back to Lorna that I can foresee situations where a person has to wait for services and will decline in condition to the point that they can then change from preventive into the high need category. Care givers may be hurt trying to lift or transfer their patient without the necessary equipment. Persons may be trapped in their homes and may have limited ability to get out to go to necessary appointments in the event of an emergency, or just to get some fresh air and sunlight on their faces. So, those were just some specifics that I did want to make sure went on the record. Thank you.

See Medicaid Global Waiver

BARBARA MCCRAE: Thank you for asking me that because it kind of prompts me. Maybe I should be a little careful because I tend to be -- since I have a temporal lobe -- frontal lobe meningioma; I tend to be free a little more to speak openly. I am not afraid of speaking anymore. But I have to watch what I say because to help support change, it's a delicate process. And sometimes I can build up walls.

So, saying that, it seems like -- I just have to tell the truth from my perspective. There is the state working and the illustrious task force and there's wonderful people on the task force. But like you were saying about the amount of people in the system, and the money doesn't filter down to a person. Sometimes sitting there.

It's hard because I look at all the money in the room, first of all. Then the state system, OHHS (Office of Health and Human Services), and the task force are very separate and because the global waiver was pushed through so quickly under George Bush and it's just like created chaos in the system.

And I know people within OHHS are working diligently, trying to come up with a way to provide supports. I hope fairly. I know they are trying to provide supports economically, okay. And I hope it's a just system. But there's -- it's happening so slowly. And the information isn't getting passed in a way that I understand, and I don't have to make an informed decision on my choices.

And it seems like they are pushing the less expensive model, which I understand, if it's right for the person. But it's not always the best model for a person.

And so, do I feel like I am hurt? I stood up and said -- about informed consent and I think I was heard. And I pushed to be on the housing committee within the task force. And I went to my first meeting yesterday. So, I -- you know, they are working on what's available now.

And to be honest, I just don't know what the state's doing. I can't seem to gather -- I mean there's some talk about what's happening with the elderly population and trying to move people out of nursing homes into their home with supports. That's the one thing that I've heard.

But housing, housing there's no housing. People that are on the list that could move out on their own. But where do they go? There's no housing, you know, that's accessible; or they don't have a family member there. Housing seems to me is not only the most important issue to me, and maybe all of us, for quality of life. But it's the most needed thing in our state.

So, that's not about the global waiver so much. But just kind of my feeling when I'm at {inaudible} so.
See Medicaid Global Waiver

ANNETTE BOURBONNIERE: The other thing has to do with -- well, we've passed this Sherlock plan a few years ago so that people with disabilities could go to work and purchase Medicaid so that they wouldn't lose critical services. But we are finding out is that if you tried to sign up for it, they tell you that if you are receiving these critical services, you can't be eligible for the Sherlock plan.
And -- so, you know, where's the work incentive? We really need the Sherlock plan so that people with disabilities can go to work, not lose their personal care assistants, not lose services that are really critical to their functioning.
The Sherlock plan is intended for us to be able to pay a premium for Medicaid based on our income. And, you know, that's okay. We don't mind doing that because we would have to pay a premium for any other insurance. But we do need to be able to do this and not have the critical services removed. So, that's something that really needs to be addressed, I believe, on the legislative side.
See Sherlock Plan

Health Care Recommendations

{To be completed by the Health Care Working Group}

Housing Concerns

CHERYL CROW: Secondly, gaps in efficiencies. Does anybody in this room heard of the CON plan? Anybody know what CON stands for?
It's a state plan, supposed to be consolidated. It's a five-year plan that's supposed to address our housing needs and getting our funding. That plan had a little bit more faith in the process the last cycle around. I spent a lot of time putting in some information about the gaps in the system. And I thought, well, it's just because I'm learning it that I am so late in the process.
Well, but I'd like to know is the agencies who routinely contact us for when they have an interest that they want us to rally for, the disability organizations, the ILC newsletter, the e-mails, you know, the housing agencies in the community development agencies. We get contacted by them when they have an issue they want to promote.
Why didn't we get one notice of the impetus -- some of which has already passed -- for our state CON plan. Not one. Number one.
Number two, we are on the island. And we very much appreciate that every year at least this forum is held here for those of us who can't travel to a Providence centric state. There's not one of the focus groups scheduled on Aquidneck Island, not one. They are scheduled in Providence, Pawtucket, Warwick, and Cranston. I can't get to Pawtucket to replace my placard that you can't read the number on anymore. I can't get there for a focus group. That's a gap. It's inefficiency. It could be handled very, very easily.
Third one, this lady previous to me talked about the crisis that I route out since about time in memorial, the affordable housing crisis in Rhode Island. Now I want to know why we do things like -- let's just use one example -- the fire code legislation that went through.
The representative next to me is a property owner. He rents out the property. I don't know if he got hit with a $3,000 fire alarm system. This is not your Benny's $20, $30 alarm system. It's a $3,000 alarm system in an apartment smaller than this.
What did that do for our affordable housing crisis in the state?
You know, I mean there was a very logical way to start addressing some of the fire safety issues. They have been done in other places for years. Canonchet Cliffs in Hope Valley had a no smoking policy almost a decade ago that would have cost any of the landlords any money. It would have helped open up some affordable housing markets. We keep -- you know, enacting policy that is just inconsistent with anything but economic development {inaudible} and that's wrong. That's wrong.
See CON Plan

MELISSA: I've worked with a number of folks at Crossroads, but, given the fact that there's so much more homelessness now, a lot of these place areas filling up. I've been going around, last month I spent a lot of time going around to the various shelters in the state to let them know about some of the services we provide, and to try to, you know, network,

and make, establish relationships, so when they see our folks, they can give us a call and make a referral, and we can hook them up with a case manager. But I'm hearing a lot of concerns and frustrations from the sheltered community, as well. I think everyone is just feeling the impact of the economy and the lack of resources and the cuts that everybody has felt.
See Crossroads

JOE CIRILLO: I am Joe Cirillo. I came because I'd like to see what is going on and what the issues are. And one of the issues the gentleman just mentioned and also the young lady -- I'm an architect. I have been involved with disabilities about 30 years now. I was a state building commissioner for 28 years.
There's a book out right now that we helped produce. Bob Cooper was one of the members who helped produce it. It's called modifications 101. It's a really well written book. We put it together. And it's all about you living in your house, and modifying it through a checklist so that you can stay there. And what does it take to modify your house, everything from the ramps and everything. It's really made well. It's the kind of book that you can put in a little sleeve binder, if you -- it's a spiral bound right now. But you can always take that off and copy it. It's available at the state. Elaina Goldberg and Jeanne --
FEMALE SPEAKER: Her organization is Rhodes To Independence.
JOE CIRILLO: Rhodes To Independence. And it's a really written well documented book. It's really nicely done. I was very proud to be a part of putting it together. And I have even introduced it in Washington at some meetings I was at. So now all 50 states have got copies of the thing.
It's one of these things where -- it isn't you. I'm disabled. Back injury and I am a disabled person. But it doesn't have to be. My mom was disabled due to age and other illnesses. And it came through a point where she was in elderly housing. It was accessible. She had to go to a nursing home.
But with this book, it was possible that, you know, I now look at it. How can I move -- change my Middletown house so that it can accommodate me when I get worse? And it's very; very likely I will get worse, if I live longer. I mean -- and this book does a good job of explaining it. I think it just needs to be distributed more. And it is available, as she said.
See Home Modifications

DEBORAH: Child right now in our program, severe disability, mom was evicted had to move to different district where the child was eligible for summer services now doesn't have transportation to get to her summer educational program. That's it. She didn't get it. We tried, you know, to work on some things, and I'm aware of the law, but I couldn't even reach the School Departments.
See Homelessness

MELISSA: Hi my name is Melissa Palmer. I'm a social worker with (inaudible) health strategies, behavioral health partner for neighborhood health plan. In response to your question, there are actually a number of our members who are now homeless, either they've had consistent problems with having permanent housing, or we've been seeing a lot more people now who are homeless, and so we've actually been trying to start a new initiative when we're going out into the community trying to connect with some of these folks to make them aware of the services that are available to them. We've identified this population as a group of people who really just have fallen through the cracks, so we're doing our best, but there's so much more that needs to be done.
BRIAN: Are any of these folks that perhaps that are truly ending up in homeless situations getting connected with some of the shelters such as Crossroads, or are they, some of the other places where it's just ad hoc kind of --
MELISSA: I've worked with a number of folks at Crossroads, but, given the fact that there's so much more homelessness now, a lot of these place areas filling up. I've been going around, last month I spent a lot of time going around to the various shelters in the state to let them know about some of the services we provide, and to try to, you know, network, and make, establish relationships, so when they see our folks, they can give us a call and make a referral, and we can hook them up with a case manager. But I'm hearing a lot of concerns and frustrations from the sheltered community, as well. I think everyone is just feeling the impact of the economy and the lack of resources and the cuts that everybody has felt.
See Homelessness Part One

MELISSA: One more comment just to piggy back on the topic of homelessness, one other significant thing I'm seeing is the fact that so many of the homeless folks in Rhode Island have at one time or another been involved in the criminal justice system, and when we try to provide the assistance to get on housing lists and things like that, this history is becoming a barrier. You know, it is a barrier for them, so it's making them, you know, ineligible for a whole lot of resources they might otherwise be eligible for. So, I would love to see more communication between, you know, to try to bridge that criminal justice system and the mental health systems.
See Homelessness Part Two

WILLA TRUELOVE: Can you guys hear me?

Okay. Hello. I am here for myself. I was also a fellow Governor's Commission on Disabilities some years back and I always kind of try to find out what's going on.

And I brought some newspapers that I'm going to leave on the back table and these are from Street Sights. They are from June. We are off in July. But if you guys will please take one of these and read it because the homeless community is a neglected community and it's a population into itself. I'm sure you heard stuff about Tent City or whatever. But within that population, many people have disabilities of physical or mental or whatever. So, I'm bringing these. And that's really all I wanted to say. And I'm happy that this is happening. Hopefully we will see more coordination or talk between all of these different agencies because it's among the homeless community, it's such an issue. Like Street Sights is probably one of the only places where people have a voice. And day-to-day functioning is really, really, really difficult.

So, I wasn't really prepared to speak or anything. I just brought some papers. I want you guys to take one. I want you guys to be aware of the homeless population and not to actually isolate people who are homeless but to be inclusive.

KATE MCCARTHY-BARNETT: Thank you for sharing. And what I'd like it do now is maybe just provide some opportunity for panel members to share a bit on, you know, some suggestions in terms of looking at the population of individuals who have disabilities or special needs who are homeless.

See Homelessness

GAIL JOHNSTON: Are you looking for any more topics?

Again, my name is Gail Johnston. My daughter Sabourin is here. She has been on the waiting list for help to get an apartment for two years. I didn't know if anyone was here from the housing --

LAURA: No.

GAIL JOHNSTON: The issue was she was looking for housing in South Kingstown through South Kingstown Housing Authority. And she was put on the waiting list. We were told that she would -- because she was disabled, she might be able to move up on the waiting list. But they have never done that.

It's been almost three years she's been on the waiting list. They won't talk to me about it because they only will talk to my daughter about it. And I can go in with my daughter. But they don't want to talk to either of us. They just keep saying, "You will have to wait."

And I know people are getting it. But I don't see that she -- maybe she shouldn't get any priority. But if they are going to say there is priority, there should be priority. Otherwise, they can just say wait on the list. That's fine. But I don't like being told one thing and have something else happen.

And then maybe she can get a RIde.

JEANNE: I have a question.

Jeanne Behie responding. Sabourin, is it that you want to stay in South Kingstown, too?

SABOURIN LUSSIER: Yes.

JEANNE: I know there was an ad in the paper a few months ago. There was some housing in Hope Valley and they were looking for people with disabilities to apply for there. But you want to stay in South Kingstown?

SABOURIN LUSSIER: Um, preferably. But I was -- I'm Sabourin. I went to the housing authority a little while ago and they actually told me that they're working on the list. But they're starting from 2006. So those -- all those people that are on the list from 2006 are now getting housing. And so now I have to wait another two years to get on the list; where I should be now due to priority with being disabled.

See Lack of Housing

ROGER HARRIS: I am Roger Harris. I am from the -- I am a member of the Rhode Island Disability Vote Project. And I'm also late -- I apologize -- due to traffic.

And I did not sign up to talk, but I want to speak a little bit more about the lady that was speaking when I first came in -- referred to housing. I have been a paraplegic for over 15 years. And the only housing I'm able to live in is public housing. Fortunately -- I don't know your name --

DARLENE THOMSON: Darlene Thomson.

ROGER HARRIS: Fortunately there was an apartment available for me upon my onset of injury. So I was in a accident. But my choices were limited, and that's what I want to talk about, the choices that we have with disabilities when it comes to finding an apartment or a place to live.

I'm considered a very independent individual with a disability. I don't need the services that are provided for a lot of folks in the state. I can take care of myself very well. I have -- considered a high spinal cord injury. However, I can't stand up at all. I can't climb stairs. But as far as basic needs, I take care of myself. So, I don't need a nurse, a home health aid. But I know a lot of people that do.

The building I live in now has 100 units, one elevator. It also is three floors. It also has one laundry room with 100 people. It has three washers and three dryers.

So you can imagine when the home health aid people come to do laundry 7:00, 8:00, 9:00 in the morning, the struggle they have. People like me who are independent, the struggle that I have. I have to wait in line just to do my laundry. And then on top of that, the management puts a curfew on the time limit to do your laundry, 8:00 at night, one small example. Another one, I lived there for three years. The first year I moved in, the entrance, the very front entrance was not accessible. And I find that since I have been involved with the community, I find that a lot of places, buildings are available for the handicapped are not accessible for the handicapped.

I understand on a state level there's, due to lack of funding, there's only a couple people who work through the Governor's Commission on Disabilities who make sure the access is available and I understand that. However, I think our state is small enough that we can make an attempt to address those issues.

One last thing when it comes to housing. I don't understand how we can't get around all -- bring forth or promote the idea of private owned buildings or private owned properties making availability. For example, there's a lot of HUD governed buildings. There's a lot of investors building these big giant condominium areas. In Woonsocket, where I'm from, our city is selling the old mill buildings to investors, and they are making condos. Why can't they make them accessible? Or why can't the law -- why can't we make a statute in the law that says, okay, if you have 100 units or condominiums, why not make three or four of them or five of them affordable for people like me?

I want to move out of my building. I can't stand it. But I'm stuck. My income doesn't allow me to move, one. Two, there's very little accessible housing for those of us with disabilities. Now I'm a physical -- I have a physical disability. You can see me and tell. But there's so many of us out there that you have to ask them what is their disability in order to find out. And it's disheartening to them to even talk about it, let alone tell you or say or put on the application, I have this -- I can't hold my hand up because I got a problem with my shoulder, okay.

But to go apply for an apartment, to apply for subsidized housing, even with a disability, we get on a waiting list. I think this state is small enough and there's enough resources here enough to really make it better.

See Housing Quality

GAIL JOHNSTON: Gail Johnston again. I heard somebody talk about Oscar, and they were very happy with Oscar. We chose PARI, and we are very happy with PARI.

Some of the other problems that we've had is there's a long waiting list for habitation through the state. I believe its called rehabilitation? And I think there's only 40 slots in the state. I don't know if that's going to change. And that program helps people learn how to -- through repeat -- repetitive things, learns how to cook. Even though they -- you can't just show somebody one or two or three times how to cook. And that program I would think would help a lot of people too. But there's limited slots apparently.

See Rehabilitation

Housing Recommendations

{To be completed by the Housing Working Group}

Services Recommendations

JUDY MCLAREN: I am Judy McLaren. And I am here as a Governor Relations Committee member of the Rhode Island National Multiple Sclerosis Society and I took note to this young lady when she spoke on the homeless because we have people who are not homeless but are in their homes, being cared for, but are concerned about them -- you mentioned this being a concern to you was the abuse to persons with disabilities.

And there is a law in the state of Rhode Island that assigned the Department of Human Services to handle those complaints and police departments throughout the state call into the Department of Human Services. But there had not been any one at the Department of Human Services assigned to deal with these types of complaints.

But people from the legislature have met with -- I will find them in a minute -- Gary Alexander. And he has reassured them that they are putting together a plan of receiving those complaints and a place that will handle them. It may not be right within the Department of Human Services office. But they are going to find a place that will handle those complaints.

So that is something that is being worked on by the state legislature.

See Abuse/Discrimination

ROSEMARY REILLY: My name is Rosemary Reilly. I live in Cumberland, a lifelong resident of Cumberland. And I am here on behalf of my grandson, Nicholas Velwa, 23 years old and has Duchenne muscular dystrophy. For the past two years he has resided in a group home operated by West Bay. This has been a wonderful environment for him, providing him with needed care and opportunity and companionship.

Over the holidays, and in January and February, he was hospitalized at Rhode Island Hospital with pneumonia and returned to West Bay. But last month, he was hospitalized again. Once he recovered the pneumonia and was ready to be discharged, some troubling events occurred. A physician at the hospital felt that he should be discharged immediately to a nursing home. West Bay wanted to accommodate Nicholas but needed to secure a regular nursing care until Nicholas was fully rehabilitated.

At one meeting, a Rhode Island Hospital doctor was so obstinate that he threatened to remove Nicholas' healthcare. This was unprofessional and an inappropriate bullying tactic. His condescending demeanor and hurtful words left Nicholas in tears. West Bay wanted to continue discussions with the hospital. But the physician refused to attend the meetings, insisting he should be in a nursing home. I have all the names of these people too, if you are interested.

Nicholas was transferred to the Jane Brown Unit until his parents could investigate nursing homes. One nurse tried to get him to stand up, not realizing that he couldn't stand. Another nurse yelled at him to "work with me" while she moved him, again, not understanding the severity of his illness.

Presently, Nicholas is residing in the basement floor at Pine Grove Nursing Center. This environment is not good for Nicholas. There is no one he can talk to and no opportunities for social interactions with other residents.

He sits by himself in the television room. There is no wireless internet or other technology. I have been there several times and noticed a strong urine smell in the center each time.

He is bright and articulate, so social interaction and stimulation beyond television is important for his overall being. And I also want to add that he was a graduate of Lincoln High School, CCRI, and finished his first semester at Rhode Island College.

Nicholas needs to be back at West Bay or a similar environment. The events I described are not aligned with the principles and values posted on the developmental disabilities page on the MHRH website. Services are not responsive to his situation. There is no longer the opportunity to develop and grow within a community environment. There were instances where he was not treated with dignity and respect and not allowed to exercise his right to choose. This nursing home is a higher cost for care and is a restrictive environment. I am asking you to be the catalyst and Nicholas' decision to remain at West Bay and provide the needed services.

One bright light according to Nicholas from the beginning is Susan Verone, a social worker at MHRH. And I just heard that you are her boss, her -- executive. So that's great.

So she strongly advocated for Nicholas and continues to do so. Please support her immediately in her efforts to help Nicholas remain in the West Bay system.

And then as of this morning before I came to this meeting, I heard from my son, Nicholas' father Daniel Reilly and West Bay according to John DeMarco, who is the Executive Director of the West Bay group homes. He needs $168,000 to hire and to accept Nicholas and six other residents at their home on Dawn Avenue in Johnston.

It is costing the state $860,000 for the seven people, if they were in the nursing home situation. And if they were at a facility such as West Bay, it would cost $360,000. So there's quite a difference in that care.

I thank you for listening to me. I know there are many other people besides my grandson, who is the light of my life, one of them. I have 12. {LAUGHTER} But he really deserves better. He's an exceptional person. He's extremely smart. The thing is, his body is not like -- so I thank you for your time.

See Abuse/Discrimination

BARBARA MCCRAE: Another one on the way. That's new news to me.

And Rolf -- so Rolf did very well for a number of years. But because it's difficult to understand Rolf when he speaks, and because he's limited in getting around, people make a judgment about who Rolf is. And there is a huge amount inside of Rolf that you cannot see. And Rolf now lives in an apartment program, run by United Cerebral Palsy; which is the way that apartment is set up is they all have their own front door and there's staff, support people throughout it. It's been a wonderful option for Rolf.

He was, however, because of circumstances in his life, when his marriage and different things, it's hard to find housing. And things happen that happen in all of our lives. But because of his disability, where did he end up, in a nursing home. And a nursing home -- how many people were in your room? Did you have your own room?

Five people sharing his bedroom with. And he was young at the -- fairly young. In your 50's, in his 50s?

See Abuse/Discrimination

PAUL: I was brain injured when I was 26 years old, and as a result of that, I have lived my life as a brain injured person for a number of years, and accessing services provided through PARI and Brain Injury Association.

One of the first things that happened to me, I got a scholarship to attend the Brain Injury Center on Cape Cod for six months to learn to live independently, and since then, I've been fortunate to live independently, and through Section 8 housing, and also to work at a local supermarket. Subsequently, I volunteered at a soup kitchen for about 14 years. So, sometimes I still get services, and that's what I'm looking for, services for people who have suffered a brain injury because they happen a lot of ways, car accidents, falling, you can imagine. So, I'm just here to hopefully get services for the Brain Injury Association.

Thank you.

See Brain Injury

DAWN: Might I speak to limitation on the -- not The Point and not 211, but on the CEDARR Family Centers. When those centers were designed, I was smack dab in the middle of that so from the get-go in establishing the centers so that families could more readily access services. That's the entire focus of the whole initiative. And the state invested quite a bit of resources, both fiscally and human resources in terms of their staff through the Medicaid agency and some of the other state agencies, as well. And the original intent when those centers were set up were so that any family whose child had a disability regardless of what their insurance status was would be able to enter that doorway to at least get information and be referred to appropriate places, even if they were not eligible for Medicaid, it was a way to go in the door to get some information. Obviously, the first thing was to establish whether or not the child was eligible for Medicaid, because if the child was eligible for Medicaid, that opened the door to kind of the next level of services, if you will, that the family could build a family care plan and really work on the strengths of the family and the strengths of the child. Unfortunately, as it played out, what happened was the CEDARR family centered were really only taking on, if you will, those who they knew to have Medicaid. So, for instance, if I'm a parent and my child has a disability or a chronic illness and we have commercial insurance, we can't get the services, including the information piece, the front door entry piece, if you will, because our child is not eligible for Medicaid. It's not the intent, the original intent of those centers, but unfortunately, that's what the practice became.

See CEDARR Family Centers Part One

DAWN: That's not the intent, at all. One of the biggest problems in my opinion is when you talk about the connection, if you will, between school districts, serving kids with disabilities and CEDARR Family Centers, it's very, very weak. We haven't gotten the schools to promote the CEDARR Family Centers in general. In general, there are some exceptions to that. But we haven't gotten schools to do that, and in actuality, I've heard of situations with families where a family care plan is developed through a family center, and part of the plan needs to be implemented in the school district. There's a lot of friction between the school district and the family centers, so a lot of dynamics going on back there.

So, they're an operation that, again, I don't think there's any system out there that will be perfect for everybody, but they work for some, don't work for others, and some of the family centers have a better reputation than others. It's common in any line of business, or that sort of thing. But, unfortunately, there's a weak connection between the school districts, and special ed. departments of the school districts, and the family centers, as a general rule, there are exceptions.

See CEDARR Family Centers Part Two

CAROL WILSON: My name is Carol Wilson. I work for Ocean State Community Resources. It's a day program here providing adult day services for ten adults. And my concern is I read the governor's proposed budget, upcoming budget for 2010. And I have one young man receiving services through the rehab option program. And that program is slated to be cut October. And hopefully reimbursed -- we are funded through tax dollars. I am a little concerned that that's not going to happen. And I'm very concerned what his day services are going to look like come October of 2009.

You know, it's the most -- it's not Medicaid waiver. He doesn't qualify for Medicaid waiver through his disability, his work performance over the years. He doesn't qualify. And I'm just concerned. It's the most under-funded support services in the day vocational program. And he receives nine hours of support through -- for a week. But that's his job. So that's his income. That's his daily life. He's a husband of a woman that also receives services.

So as an agency, now how do I divide them to provide their day supports? Yes, we can take your wife. But, oh sorry, we can't -- so I was just wondering if anybody had had any idea --

See Day Services/Cuts to Services

JAMES MCKENNA : Okay, the question is -- okay, the question is about the government, Obama, which I hope he ends all the war that happens and something like that because, and the President Obama is really good, our President -- oh yeah, the Hillsgrove House is popular for me because it's what makes me happy. I'm going there five times a week, five days a week, rather, because I'm very happy, whatever. I have money in my pocket, I can buy, I'll buy snacks like soda and stuff,

and also, being in the business, I'm in the business unit, something like that, and do the best I so -- what else? I wanted to keep being able to go to Hillsgrove house, which is much better than Trudeau because it's more better for me than going to Trudeau everyday. Thank you so much, everybody.
See Day Services & Hillsgrove House

BARBARA MCCRAE: Well, Barbara McCrae -- I just thought well -- what I have the most experience with is vocational day supports, like the old term was workshops for people -- adults with developmental disabilities. And it seems a number of people have been pulled out of the workshops. And they're home now provides day supports to a number of people, which means that the workshops -- which isn't an ideal day program for anybody really. But a lot of people, their parents have told me that their eyes brighten when they know they are going to the workshops on the day that they go. You know, because it's socialization and it's a different place.
So I don't want to put down that sometimes those places aren't ideal. But they still provide some kind of socialization for people that might be utterly isolated.
But because there's so much -- there's a lack of money, I think, going into day supports. It's grouped. And there's not a lot of training, I don't think. Or I don't know what the cause of it is where there's not a lot going on in -- from what I can see. There's some wonderful art programs that have started that are not only social outlets but also creative outlets, like the Artists Exchange and I know Life Incorporated has one. And there's RHG. Some wonderful kind of group day programs that at least are creative and -- but as far as actual work goes, I just -- I am not personally aware of a system of supporting somebody with a job coach that's really working. Maybe I just haven't heard of it or know of it. I don't know. You know, I mean -- I don't know.
Can I say one more thing?
When I talk to people who have day supports, and when I've looked at some real creative stuff going through DDD (Division of Developmental Disabilities), and social workers are really trying to help people have a creative -- even go to three different agencies. I was with one woman yesterday who has three agencies so she's not stuck in one place every day. And that's amazing, you know. But when I heard the amount of money that the agency is getting to provide three days, and this woman wants to do more, I can understand why that agency is limited to what they can provide. And maybe there's some middle management -- I don't know -- that doesn't need to be there, or maybe there's ways to cut. But it just doesn't seem to filter down to providing the individualized direct supports to people.
See Day Services

ELLA WHALEY: I have a letter from somebody who can't be here tonight. So I don't know if you want me to read it or just give it to you?
LAURA: Both.
ELLA WHALEY: I will give you a copy at the end for the stenographer.

This is a man who came to the South Kingstown Town Council meeting, maybe a couple weeks ago. It says, "To whom it may concern." And his name is David W. Frederick and his wife Judy Frederick.

"To whom it may concern, I bring this issue to the attention of the general public and our elected officials, appointed officials not as primary interest for my own economic milieu but to introduce and document what may well be an injustice or at the very least a situation indicating a lack of respect and reverence toward our disabled veterans returning to Rhode Island, following participation in the current global military pursuits.

My grandfather moved to Wakefield upon his World War I honorable discharge in the army around 1918. My father served in the Navy station in Hawaii, honorably discharged at the end of World War II. My wife served in the army, honorably discharged with a 100 percent disabilities rating following 20 years of service, beginning during the Vietnam era and being stationed in the Pentagon in Washington, DC.

The issue first became known to us when we received a vehicle tax assessment notice from the town of South Kingstown on July 10, 2009. We had purchased a new vehicle one year prior to this event but had never been made aware of an additional town tax until this time.

Upon inspection of the document, I noticed that we would be eligible for the totally disabled veterans service connected. My wife has 100 percent disability rating as well as veteran exemption.

I contacted the Tax Assessment Office to inquire as to the proper protocol for achieving this exemption and was pleased to find I would only need to fill out a short form. However, I was then informed that the exemption would take effect next year and would not affect the current responsibility.

I was then informed that the deadline for filling out the form was five months prior to having received the tax bill. When I questioned the possibility of retroactive installment into the exemption program, I was told this possibility does not exist due to state law.

Thus exhibits my association and reason for awareness in this situation. My immediate thoughts and perspective focused on the newly returned disabled veterans who are returning to Rhode Island and carrying with them the hardship of their disabilities to their families who are already struggling with the current economic situation. I picture them having to acquire their -- would require them transportation to and from health centers along with the acquisition of normal necessities and work. They may well need a vehicle that could carry a wheelchair or contain adaptations for missing limbs.

Then one year later, they would find a surprise tax bill added to their expenses and also told they could have been exempt had they met a deadline five months prior to their acknowledge of its existence, with no possibility of retroactive exemption status due to state law.

I also fear that this situation culmination stresses placed upon them may be seen as quite an injustice and promote a feeling of rejection from the country that they sacrificed the rest of their lives so much for. I would hate to see this event as promoting similar feelings as many of those returning from Vietnam.

One point of interest, as a suggestion towards an amenable solution would be that when the vehicle tax assessment is determined, with the transfer of information from the Department of Motor Vehicles, a listing of individuals that have been accepted for handicapped status should also be included. Or at least when given handicapped status, the individual should be given information suggesting they may be eligible for a tax exemption for a vehicle purchase.

I hope that this event will be taken under review to change the legislation which is in favor of those that have truly given exemplary sacrifices towards our culture and lifestyle as the United States of America.

Sincerely, David Frederick.

See Disabled Veterans Services

DAWN: That's not the intent, at all. One of the biggest problems in my opinion is when you talk about the connection, if you will, between school districts, serving kids with disabilities and CEDARR Family Centers, it's very, very weak. We haven't gotten the schools to promote the CEDARR Family Centers in general. In general, there are some exceptions to that. But we haven't gotten schools to do that, and in actuality, I've heard of situations with families where a family care plan is developed through a family center, and part of the plan needs to be implemented in the school district. There's a lot of friction between the school district and the family centers, so a lot of dynamics going on back there.

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PAT: If you'd like information about the CEDARR Centers, it's on the website of the state of Rhode Island Department of Human Services, and you have to look for services for children, so the website, Department of Human Services, State of Rhode Island, then look for children services. And then you should, you know, search for CEDARR, and you should come up with the different -- I want to say 14 locations, but I'm not quite sure.

See Educational Services Part One

DAWN: For starters, its compliance issue if a CEDARR family center has a wait list for entry, that's a compliance issue that I think needs to be paid attention to. There are not supposed to be wait lists for entry into a CEDARR family center. Now, if a family needs a particular service and there aren't providers in the community willing to serve that child, or willing to take the Medicaid reimbursement, which is a huge issue, then, in fact, the CEDARR family centers have no control over that, and the providers, in all honesty, it's my understanding, it's probably been more than ten years, maybe many more than ten years that the provider rates were a little down for any increases through Medicaid. In fact, in the last six to nine months they've gotten clobbered with cuts. So, what was a bad situation before has become worse, basically. So, you have that central point of entry for those able to access it, which is a good thing, but then when you get to certain services, not all services, but when you get to certain services, there's no capacity in the community to deliver the services to the family. These kids wind up in the emergency room, at Butler Hospital, at Bradley Hospital, that's where these kids end up because if they're not safe at home, the rest of their family is not safe at home. I'm familiar with a case that the child had behavioral issues for a very long time, he started setting fires. I mean, they have no choice; they have to go to the emergency room because there are no services. There are child psychiatrists in this state that will only work, and not just psychiatrists, I should be fair about this, there are a lot of specialty services that the providers will not accept your child unless you agree to pay cash, even if you have insurance, they don't want to deal with the insurance company, don't want to deal with the billing issue. So, what happens is, especially in the instance of autism, we all know what a huge problem autism is becoming, and will continue to grow, in my opinion, as we go forward, that a lot of those families, it makes a difference if you're a family that makes a lot of money or you're a middle class money, or, God forbid, you're a poor family, you can't get those services because some of these providers will only take cash, cash only; or no services. That's another issue around capacity, across the board. We can talk about this from the kid's perspective. I don't know as much about the adult perspective in terms of capacity, but the people I've been spending a lot of people lately around the Global Waiver who do represent the older population, capacity is an issue, as well, not as severe, I don't think as the children's

side, but we do have a provider capacity issue, some of it is due to reimbursement, not all, and some of it is due to, we don't have enough of the providers we need to meet the needs of the kids and families.
See Educational Services Part Two

ELSIE MORRISON: We have visited other provider agencies. It seems like in my opinion, the model is what needs to change. Not necessarily, you know, an increase in funding, but people need to be more creative with what they are doing. People need to be more efficient in the use of the funding that they get.
See Efficiency of Service Agencies

SUSAN HURD: I would like to comment on that.
I have been very disappointed with the Rhode Island Disability Law Center. I have called for help. I am grateful that you exist. I know you are well-intentioned people. So I don't -- I don't want to find -- to come across as hard and critical.
Yet I personally have had multiple issues around housing that I have called for help. After the initial intake, I never even got a courtesy call back of saying "Thank you. I'm sorry we cannot help you." I have had that happen multiple times over multiple years.
I had housing for eight years. I was forced out of my place because of ignorance. People insisted they had to do chemical spraying. And because I was forced out of my house, again a barrier, they used a highly toxic stain. They used chemical sprays. I was forced out. I had a place that worked for my living situation.
Yet when I asked for help, I was told, "Well, we can only help mediate." And I had someone I talked to was a legal advocate of the center. He said, "Well, I'm sorry, we can't help you because you are not living in your place anymore." It was like, well, I can't live in my place anymore because I -- my accommodations got taken away.
It was blatant discrimination, according to the Fair Housing Act; the ADA -- owner may not refuse necessary disability accommodations.
I got no help. I had to file with HUD a discrimination complaint on my own to the Human Rights Commission. When I got to the Human Rights Commission, the people in charge of my case were wearing perfume and did not provide other accessibility accommodations for me as well. And the case was handled poorly.
I don't know what to do. There was another -- then I tried to rent a place. The woman lied about toxicity. I lost my deposit. I live on my disability. I'm low income. And a little bit I can make that I earn. I am low income. I lost that -- I asked for help again from the Disability Law Center. How do I deal with it? She lied. It was taken away.
I then went to legal aid. At least legal aid got back to me and said, "I'm sorry, we just don't have the funding to help people. I know it's unjust."
Rhode Island Disability Law Center never even got back to say "I'm sorry; we don't have the funding to help."
I have had this happen multiple times. I can give numerous instances of examples where I heard that from other people as well. Maybe it's because it's an MCS issue. It's not a priority. But I do think I deserve at least a phone call back in saying, "I'm sorry. We can't help you."
I called repeatedly and only leave voice mail messages. I don't know. So if you have any feedback. I have been disappointed. I'm at the point where -- and then I was told referral is for pro bono lawyers. Do you realize that the pro bono lawyer service is $80 an hour? I live on $700 a month. I know plenty of solid middle class income people that are struggling to pay $80 an hour for a lawyer, never mind someone who is low income.
So, I wasn't able to get the help. I tried. I called. I went to Roger Williams Law. Maybe I could get some help with students. I racked my brains out trying to find someone who would do pro bono help. I got nowhere in this state. I am a resourceful person. I don't know what other people are doing.
BARBARA MCCRAE: I heard similar stories that -- the same thing. Oh, goodness. I got to put my thoughts in -- together -- that when a priority is set -- I think is what I've heard is when priority is set at the Disability Law Center that it's hard to get help on something that might not be a priority for that time. And I understand funding and money is always an issue, believe me. But it's hard for an individual to get legal help when they need it for discrimination because of disability.
And if -- they don't have the money, of course, to pay for their own.
See Efficiency of Service Agencies.

CAROLINE BOSLAND: My name is Caroline Bosland, and I have a brother who lives in a group home. He's been in the group home for about 20 years, maybe a little longer. And our family's a little concerned about what the state may have in their plans for an aging population in the group homes and in state facilities that are supported by the state. I understand that there's a crisis going on with the budget and that he may lose some of his transportation, and that's serious.

But his quality of life as he gets older is also important to us. And whether he will stay in the same group home, whether they will move him or what programs they will have for them, I don't know if this is a fairly new issue. But I'm

hoping that can be addressed in the near future. Thank you.
VANESSA VOLZ: I have a question. Is your brother in -- does your brother have a mental illness or developmental disability?
CAROLINE BOSLAND: He's Down Syndrome.
VANESSA VOLZ: Okay.
GAIL JOHNSTON: Is his transportation with RIde or the group home?
CAROLINE BOSLAND: The group home provides the transportation. But we have this feeling with all the cuts that he may not even get transportation to go bowling, which he has been doing for 20 years, 20 plus years, little things that add to his quality of life.
GAIL JOHNSTON: On that similar note, my daughter Sabourin and Seth go to LaPlant. And they have activities which she can't go on because they don't have a handicapped-accessible bus.
See Group Home/Cuts to Services/Cuts to Transportation Services

LAURA: Okay. We -- I did have a -- somebody who couldn't be here today. Her name is Donna -- I get the last name -- Donna Gabriell G-A-B-R-I-E-L-L.

And Donna sent an e-mail saying, "Dear commission members, my sister who's disabled lives with me downstairs. She has chronic pain and fibromyalgia. She is also agoraphobic. Consequently, she never knows how she will feel from day-to-day. It's very hard to make plans for her to get out. As a result, she is very isolated. And even on good day, her agoraphobia makes her highly reluctant to want to get out.

I had South Shore Mental Health coming in here, but their funding was cut. She needs someone to do home visits. She does not want people seeing her in her condition. But she did like the counselor who used to come here. You need to make sure that people like my sister have access to home visits. She needs someone to help her figure out where to go for help, for her various medical needs as they arise.

I work full time and am not cognizant of all that is available. She takes such huge doses of medicine that she should not be driving. She often needs help to get to her doctors appointment and get her medicine. But she cannot plan on going on a bus due to her pain.

Please arrange for home visitation for people like my sister."
See Home Visits

DAWN: Question one -- I think I need to read. One of the issues, and my major concern is that nothing is concrete, it's like, the ground is shifting below our feet as we're moving along, which is very disconcerting because one of the things that we do through my program and through the Rhode Island Parent Information Network is we work very hard to inform the general public, and really, any families that come, about the new public policy issues, and how they might impact them, and, more importantly, for them to get involved in the process. But it's hard for me to even provide concrete information because we're not getting it from the state officials. And so, you know, there is no, to my knowledge, anyway, at the state level, there is no public awareness kind of initiative happening, you know, people are learning as they go, including those -- if I get information that is concrete, and I feel comfortable that what I'm passing on is based in fact versus theory, then I'll pass that on, I keep a mailing list and a, an e-mail list, and that kind of thing. But, to be honest with you, there's not a lot of information out there, and so, so, first of all, to get this out to the general community, I don't even see that as having being made a priority by the state so far, let alone making that accessible for others who maybe have communication barriers or that type of thing, or even language barriers. So, none of that work, to my knowledge, has been happening at the state level. And again, this is a change of great significance. I started out as a parent of a child with (inaudible), he was technology dependant and medically fragile, and we lost health insurance while he was alive, he passed away when he was 19 months old, and I got what I refer to as the education of a lifetime, lost insurance, anything that could go wrong did, and what I do now is my life's work to keep others informed so that it's less traumatic for them in the long run. My son would be 23 years old if he were alive, and I can tell you, in the last 23 years, I know, personally, I have never felt so uncomfortable about the security, if you will, for all populations going forward, but especially those with special needs. Long answer to a short question, but it's very complicated.
See Information

LINDA: And I also -- my doctor actually had mentioned to me about the marijuana program. And so I went up and I got the application. I downloaded it. We filled it all out. And I was accepted and I got a license.
And, typical of Rhode Island, I went up to the Department of Health. And the woman said to me, "Okay. I will take your picture." She gave me my card. And she was ready to send me on my way. I'm like well, what do I do now? I have this license, but like where do I go to get the marijuana or -- oh, you will just find it.
{LAUGHTER}
Wait a minute. I'm just supposed to just walk down the street and find an ounce of pot on --

FEMALE SPEAKER: Go in front of Thompson High School. {LAUGHTER}

LINDA: So I said, what do you mean? And she said, "Well, if you can't find any," she said, "we can get you a sponsor." So I said, well, so you are telling me you are going to like use a snitch on the street to get -- and the biggest part of it is, it's illegal for me to buy it. But it's not illegal for me to smoke it.

To me, that's kind of screwed up. I mean, you know -- so now they are talking about this compassionate centers, which is great, which will probably take four years or whatever to get going. But even that, I have no idea what the setup is going to be for that. But I'm thinking to myself already, and the reason that they are opening these compassion centers is because people are getting mugged. People are getting robbed. And I mean what if I was a 75 year old woman who had glaucoma and I needed it? I am going to know where to find pot? I'm just lucky enough I have a 26 year old daughter {LAUGHTER} who knows people before she -- honestly. I don't know where to go get it, you know?

So, I'm like -- so what kind of security are they going to have at these compassion centers because it can have, you know, lowlife of the state hanging out there. And they know I'm going in there to get marijuana and they know I'm going to be coming out with marijuana.

So, I don't know. There's a whole lot of -- and it's helped me. I haven't gotten any more lesions in six months since I started. But -- it's great. But it's still to the point where I can -- and then they tell you, you can carry -- I don't know, something ridiculous like 5 ounces of weed. If I could afford five ounces of weed, I wouldn't need to be on SSDI because it's like $160 an ounce, and I can grow 12 plants.

So if I go up to you on the street and I buy 5 ounces of pot from you, you are going to jail with intent to deliver for a long time. And I am going to flash my little card and say, see you later, just kind of hypocritical to me. It bothers me.

And I don't know -- like I said, I'm sure it will take them a while to get going because there are all of those questions to answer. And I don't know where they will have them. I read in the paper saying they would have four across the state. But it just -- I don't know. It just seems kind of hypocritical. And I don't know what to do about the heating assistance. Winter's coming up again. Before you know it, it will be up here again. What will I get another dollar? Why bother? You know?

So far it's been working. I do the injections every day. You know, I -- it stinks. You have different symptoms, different days. Some days are great. Some days, you know, like yesterday I fell down three times in Brooks or whatever it's called now. And I have my cane with me and I just -- just trip over your feet.

So, I think it's important that they get the marijuana program running up for those that want to try it or see that it helps. I did it for the last six months, and I just had my MRI come back. It stayed the same. The six months before that, I had grown three more lesions using the Copaxone. So now I am doing the copaxone and the marijuana. And, you know, I mean, I do it at night when I'm not going out driving or anything like that, of course. But I just hope that they get that straightened out so that people won't be afraid to try and get -- to try to use it or that they have access to it.

See Medical Marijuana Program

MARTIN DECKER: I am Martin Decker. I have hearing problems, which are not awfully bad. I just don't hear high sounds. And the problem is if I don't hear high sounds, I don't understand consonants. And so, she will tell you, I keep after her.

But the other problem -- it's associated with aging also. I am -- as the saying goes -- over 50. And that -- even with the hearing aids on -- with this, for instance, I hear the voices well. But when the bottle was put on the table and a tap of the pen on the table was very loud. And it gets a little bit like being in the middle of {inaudible} but this business is I have hearing aids. They are very expensive hearing aids. They don't take care of a lot of things.

Yesterday I was pretty upset. I think my wife and granddaughter were more upset. We were -- I was driving. We were in the middle of a traffic jam, bumper to bumper on Route 4. And I didn't see the ambulance coming behind me. But I also didn't hear it until it was right there.

And it's not severe. It's not severe. It's frustrating. And the other thing, if you talk about aging people, there are a few million aging people with this problem. And the problem is how to get assistance to those people who can't afford hearing aids because it becomes very essential to have. Because even with them, Martha will tell you, I can't respond to questions if I don't see their mouth moving. I lip read. And if somebody in back of me says something or if somebody's chewing gum and says something, all I hear is a bunch of sound. I don't hear words. And that's -- this is not a small problem in our society at this point. And I had no idea how to handle that. Except I know it restricts life for a lot of people. Thank you.

See Services & Equipment for People Who Are Deaf or Hard of Hearing

GRACE: Yes, have I a concern. With the economy being what it is and with the many disabilities that we have in the state, my concern is that the blind would hopefully continue to have the level of services that are presently – I mean, I know for instance at Insight, they don't have people come to one's homes any more the way they used to because of the budget cuts, and layoffs, and so forth of the personnel there. And I just would like to be assured that the blind, because they have mobility issues and transportation issues, slightly different from others, that we could still be, I hate to see the

disabilities be all lumped into on. If human services should lump all disabilities into one as a cost cutting measure, I think that would be terribly detrimental to the blind. I belong to the National Federation for the Blind in Rhode Island, and discuss such issues, and research, what's going on at present, and that's my concern.
See Services for the Blind

WILLA TRUELOVE: There are some serious issues. People who are on SSI (Supplemental Security Income) and SSDI (Social Security Disability Income) and -- the SSI and SSDI check does not allow them to live independently when -- when you put that in perspective with the food stamps. Like there are people who are on SSI and SSDI who only get $60 of food, which is not enough to eat three healthy meals a day, every day for a month.

So, what happens with a lot of people who are on SSI and SSDI is they use their checks so they can't pay rent. So there's this huge vicious cycle that needs to be reanalyzed so that there is a chance for independence because there isn't now.
See SSI/SSDI

LINDA: My name is Linda. I have MS (Multiple Sclerosis), and I was diagnosed about two years ago. And it's -- I go to the support group at the hospital. And it's really hard because people don't -- they look at you and you look fine. So they -- what's wrong with you, you know. There's nothing wrong with you. So, you trip and fall once a while, or your speech is slurred or whatever. I had to give up my teaching job, which was very hard for me to do. I loved teaching.

But I had gotten some forms through the hospital and with all the cognitive issues that go along with -- or a lack thereof -- with MS. I've gotten forms from them for an air conditioner and computers. And I started to fill out the forms. And there's about like 30 pages to each form. And I thought, are they kidding me? They know that all -- most people with MS have difficulty with short-term memory and cognitive functioning and stuff. So I've gotten started with -- I haven't finished them because I just don't know how. It's just frustrating.

And somebody had said something about the heating assistance and stuff. And I applied for that last year. And -- it's funny but it's not funny. It's typical of Rhode Island. I filled out all the paperwork. I sent it in. They sent me a letter back, and they told me that I was eligible for heating assistance.

So I said great, even if it's $50, $100. Oil is $4 something a gallon last year. So I figured even if it's $50, it will help, you know.

So I get a check in the mail a couple days later for $1. And I thought -- so is this the way that Rhode Island is covering their butts by saying yes, we are sending out heating assistance to Rhode Island residents who -- I never cashed the check. I still have the check because I just thought it was so ridiculous. I thought it probably cost somebody that was working $35 an hour to type this check. And then you get to pay for the paper, the ink, the stamp. Now I have to use my gas to go to the bank to cash a check for a dollar. It's absurd, I thought.

And I had checked into -- and where my lesions are, and now I have grand mal seizures where I never had them before, and I have a lot of different stuff. And it happens and then I can't drive for six months.

Now, I have a friend in Massachusetts who is also disabled. Massachusetts, they give them free cell phones for -- I don't know, 80 minutes or something they get, something like that, for emergency kind of thing, not like to call and chat all the time.

And I called the number that he gave me and I tried to apply for one. They said no. It's just in the state of Massachusetts. I just thought that might be something because we are all on a limited income. We are all collecting SSDI, and we all know it's not enough. And we certainly -- at least I certainly can't afford to spend $100 a month on a cell phone. But it would be nice to have one. If something happened and I was home and I fell down or I was if my car -- I got in an accident in my car. I had a seizure over the Sakonnet River Bridge and I got into a terrible accident. So, that might be something that they could look into.
See Support Services

DEBORAH: Okay, my name is Deborah Coury, I work for East Bay Community Action Program Head Start, but also the parent of a 22 year-old daughter with Downs Syndrome, and I'm not sure exactly what the purpose of the forum today fully is, I got the flier, but I would like to say that I do have concerns for my daughter, and for all of her friends and adults with disabilities and challenges. What my concern is, is that after they age out of high school, it seems like the transition process is very stressful for everybody involved, and it creates so much stress that, you know, the whole process is lasting so long, and it's so confusing and complicated, and then, my great concern for my daughter is, I want her to continue to be included in the community, and to have access to the community, and to gain more and more independence. And, this is what she had through school, you know, inclusion was the model, and then she ages out, and all of a sudden, there aren't the supports in place for her to continue that. And so, at 22 years old, you know, I don't want to see people like her sitting

at home, watching television, parents worried about going to work, as I am, when she's at home. You know, what will happen to her when she's home alone. My daughter is kind of in this gray area because we worked really hard toward her independence, and because of that, she is high functioning, but she is she still needs supports. She has an issue with choking, so she needs somebody there when she eats because she has had episodes where I had to do the Heimlich. At 22 years old, she continues to learn, it hasn't stopped just because she's 22 years old, she's still learning to read and write, and she's gaining skills and making progress everyday. So, I just want to see that the supports are there so that she can gain more independence. I think she's very capable of moving forward, and possibly someday living with very little assistance, so I think putting the money and funding into the transition period is very important, and will gain, you know, it will be a good, you know, way to save money in the long run. So, that's all I have.
See Transitional services

Services Recommendations

{To be completed by the Services Working Group}

Transportation Concerns

JUDY MCLAREN: One more.

We at the Rhode Island Multiple Sclerosis Society have also asked legislation to be passed concerning taxi cabs availability for people, persons with disabilities. Currently there are no taxi cabs available. And that also answers your questions. If we had a taxi cab and if it was affordable, you could use that as transportation. But currently, there are no taxi -- handicapped accessible taxi cabs. So there is a law. It has been tabled for study in a committee. But if we all -- we all make mention that we would like there to be one, I think maybe we might get one. They weren't adverse to it. But they want to study it.
See Accessible Taxi Services

STEVE DEANGELIS: D-E-A-N-G-E-L-I-S. I am with the board -- Rhode Island chapter of the National Multiple Sclerosis Society. And I am here today to ask about accessible transportation, mainly taxi cabs. There was a law passed a little over a year ago that mandated accessible taxi cabs. It's not working. There are none. Right now if you do not have someone that can -- if you can't drive yourself, you do not have someone that can drive you and RIPTA's not available in your area, there is no way for you to get around.

I know people in the statehouse worked for two years on this law. It got watered down in the last second, so there was no teeth. There was no mandate for taxi cab companies to -- as they replace their stock, to at least get one or two within their stocks. Something needs to be done about that.
See Accessible Taxi Services

CHERYL CROW: I am going to sit here because I'm too fatigued to stand. I thought I'd have a little bit more time to collect my thoughts coming in late. But this lady was I think in effect talking about some gaps in efficiencies in this state. One that we brought up for several years now is about the handicapped placard process. Persons with permanent disabilities per MD (medical doctor) and federal government currently have to go through the medical expense to renew application every three years for their placards.

If we are too ill to travel to Pawtucket to replace the placard when it's worn out, we have been told to violate the law. Park in the handicapped parking without our placards and then fight the ticket. A little bit, um, too much effort for those of us who don't have the energy to even stand in the front of a room to give a dialogue like this.

Another gap in efficiency that I think -- well, first of all before I move off of that, we right in town have a AAA and a motor vehicles department where we can go in and show our ID and renew our license and our registration. And there's never even a wait at the AAA. That would be a lot easier than getting to Pawtucket. So that's a very easy fix.

But I think first we should find out why we have to keep going through this, if we have been determined permanently disabled and need a placard.
See Disability Parking Placards

STEPH MCKENNA: Hi, everybody. I have a problem. I've had -- this goes back -- I have been trying to find someone in the last 8 years to help me out with this. I get the same answer every time. And it is that that is the rule.

And the problem is this: In 2001, I moved from Providence -- I live in Johnston now. And I had to move because I could no longer get in and out of my house because of stairs. So, I am living on one level now. And before I moved, I checked with RIde transportation, just to make sure that I was eligible for RIde on that route. They said yes, that was no problem.

I didn't find out until later that the rule with RIde is that the bus stop nearest your house dictates when or if you will get service. And the nearest bus stop to me is an express route. So that means I have a window in the morning and one in the afternoon, which allows me to get to work and get home.

But I can't get service any other time, not at night, not on Saturday, not on Sunday. So basically, I can go to and from work with RIde and that's it.

And I -- I really don't know what to do about this. I know that if I were in a different -- if I was able to get to another place where the buses run, I could say, I want to leave from here and go there. And then I could get rides.

But that's not possible because I can't get to a bus stop without transportation. There are no sidewalks. It's a busy street, that kind of thing.

So, anyone I've spoken to -- I've spoken to a lot of people in the last nine years. And there's no answer. It's just that's the rule with RIde.

Some say it's a federal rule. When I checked with an office, they said no. You have to go to constituent advocacy with the state to see if they can do anything.

And I really am at a loss. I don't know what to do. Retirement looms at some point. And I can't retire and stay where I am. I would have to move because I have no freedom, you know. I can't take -- I would have to be dependent on someone. It's bad enough asking for rides, you know, for things like -- for dinner, that kind of thing. I would like to be able to come and go as I please, you know.
See RIde

GAIL JOHNSTON: Here.

Sorry for interrupting before -- in between. But I am concerned because prior my daughter was eligible for RIde and they changed the bus route from going down South Road to going down to 108 and she lost her RIde.

Now I, in particular -- and I'm sure other people have lost the RIde too because it's maybe just a matter of a half a mile difference. I didn't know how to address it. I called the RIde program and they said, "Tough." And I didn't know if there's something somebody can do to either grandfather people in that were -- and we particularly moved to this area -- the area that we live in so that we would be eligible for RIde.

And I don't know if anyone has a solution for that. It's -- I'm sure it's for more the people in wheelchairs. Anybody have any thoughts on that?
See RIde

DARLENE THOMSON: My name is Darlene Thomson. I lost my sight about three years ago. My concerns are the RIde program. That's my biggest issue is transportation. I cannot get to my primary care physician through the RIde program because it does not go on Aquidneck Avenue, even though the new flex bus does. The RIde program does not. So, I have to use friends, family, which means I have to cater to them. I have to go on their days that they are available. And I just had to cancel an appointment with my doctor. And it's now postponed for a month because I couldn't get an appointment that was convenient with a person I could get a ride for.

Is this a huge issue? It could be. I suffer from a lot of different problems. I possibly have multiple sclerosis. I'm a diabetic. I have multiple issues with my eyes that require me to go to specialists all over the state. I'm a severe asthmatic, you know. So, it could have been a problem. It wasn't this time but it could have been.

And it costs me a lot of money to ride the RIde program. It costs me $3.50 every time I take the RIde bus one way anywhere. Now if I go to Providence, that's a great deal. But if I go down the street, that's not such a great deal. That's less than the cost of a gallon of gas. Now yes, it's convenient. It's door to door service and everything. But when you add that up, that's $7 for one trip. Ten times, that's $70. I live on a fixed income, $70 a month for ten trips. 20 trips, you are talking $140.

I don't have that kind of income to spend on travel. But yet, an elderly person only pays $2. So why am I paying $3.50? Why is there a difference?

And with DHS, with the food stamps, an able-bodied person can make -- excuse me -- can make a higher amount of money than a disabled person. Why is that? Doesn't it cost the same amount of money to feed you and me as it does an able-bodied person? I didn't know we got a discount on food. As far as I know, it costs the same amount of money to feed you and me as it does an able-bodied person. So why is there a difference in the system? I don't get that either.

I don't live in subsidized housing. There is no subsidized housing in the state of Rhode Island available at this time. I just had to relocate or be homeless. And I have to pay $850 a month for rent. That's almost my entire check. So, where's the money for the electricity and the water and the heat and the food? Those are just necessities. Those aren't extras. Those aren't anything else, you know. So then you put transportation on top of that.

I just don't get this whole budget. How did they expect us to live -- and I'm willing to move off the island. But there's nothing in this state that's available. It's just not there. And I don't understand why more isn't being done. Why isn't more being done for the disabled people?

That's all I have to say. Thank you.

See RIde

Transportation Recommendations

{To be completed by the Transportation Working Group}

Part Three: Testimony

Barrington | 7.27.09

CAMILLE: Camille Pansa, Rhode Island Statewide Independent Living Council.

MARY: Mary Wambach, I'm with Camille's group, but also Corliss Center.

COLLEEN: Colleen Polselli from the Rhode Island Department of Health.

PAT: Hi, I'm Pat Ryherd from the Governor's Commission on Disabilities.

SHARON: I'm Sharon Brinkworth, executive director of the Brain Injury Association of Rhode Island, and also a Commissioner on the Governor's Commission on Disabilities.

BRIAN: Good afternoon. My name is Brian Adae with the Rhode Island Disability Law Center.

MIKE MONTANARO: Mike Montanaro, Office of Rehabilitation Services.

CAMILLE: I hope everyone has signed in on the sign-in sheet as they came in, if they wish to give testimony. I also would like to tell you there are assistive listening devices if anyone needs them, as well as interpreters for the deaf. And I would like to also 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 develop programs to improve the quality of lives for people with disabilities. I would like to explain that there will be a posting of the transcripts of today's testimony on the Governor's Commission on Disability's website, which is www.disabilities.ri.gov. It will be done, posted, in about two weeks. Later this summer, the sponsoring agencies will review the 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 also like to mention that we will give everyone a chance to speak today. The panel is here to listen and to gain understanding of your concerns. You will be asked to speak in the order in which, I guess, you signed up, if I receive that; if not, we will just start with the first person here. Will you be giving testimony?

FEMALE SPEAKER: No, I will not.

CAMILLE: Is there anyone here who wishes to give testimony? Yes? Then, please stand right up and give us your name, please.

DEBORAH: Okay, my name is Deborah Coury, I work for East Bay Community Action Program Head Start, but also the parent of a 22 year-old daughter with Downs Syndrome, and I'm not sure exactly what the purpose of the forum today fully is, I got the flier, but I would like to say that I do have concerns for my daughter, and for all of her friends and adults with disabilities and challenges. What my concern is, is that after they age out of high school, it seems like the transition process is very stressful for everybody involved, and it creates so much stress that, you know, the whole process is lasting so long, and it's so confusing and complicated, and then, my great concern for my daughter is, I want her to continue to be included in the community, and to have access to the community, and to gain more and more independence. And, this is what she had through school, you know, inclusion was the model, and then she ages out, and all of a sudden, there aren't the supports in place for her to continue that. And so, at 22 years old, you know, I don't want to see people like her sitting at home, watching television, parents worried about going to work, as I am, when she's at home. You know, what will happen to her when she's home alone. My daughter is kind of in this gray area because we worked really hard toward her independence, and because of that, she is high functioning, but she is she still needs supports. She has an issue with choking, so she needs somebody there when she eats because she has had episodes where I had to do the Heimlich. At 22 years old, she continues to learn, it hasn't stopped just because she's 22 years old, she's still learning to read and write, and she's gaining skills and making progress everyday. So, I just want to see that the supports are there so that she can gain more independence. I think she's very capable of moving forward, and possibly someday living with very little assistance, so I think putting the money and funding into the transition period is very important, and will gain, you know, it will be a good, you know, way to save money in the long run. So, that's all I have.

CAMILLE: Thank you. Anybody have any questions?

PAT: Has she been referred to the Developmental Disability Division of Mental Health Retardation and Hospitals?

DEBORAH: Yes, absolutely. My daughter has really good services in place because I started when she was about 18, the process. And I'm really speaking for everyone in general because she has an excellent program in place right now, but what I went through to get that in place, and still go through every single day to make sure that those services are in place and are working well, is, it takes a lot of my time and effort.

BRIAN: If I may ask, you started when she was 18, so you attained eligibility, I assume?

DEBORAH: Yes.

BRIAN: School system provide services until 22?

DEBORAH: 21, she's aged out for over a year now.

BRIAN: Still have programming; did that include the Office of Rehabilitative Services?

DEBORAH: Yes, it did.

BRIAN: Following her attaining the age of 21, did you have any particular difficulties with obtaining adult services after you had your eligibility from the Division of Disabilities?

DEBORAH: Well, it wasn't obtaining the services, which I know now; her friends that are turning 21 are having extreme difficulty. We were able to obtain services. I actually interviewed with eight different agencies. It was really making the services fit her needs that was difficult. And I had to do a lot of work around that, and it still is difficult because I would really like to see my daughter in the community, working, and, even if it's volunteer work, that's where she reaches to her highest potential, and I see it. And she also went to Bristol Community College, and she obtained skills that no one knew she was capable of. So, I really want to say that I think we underestimate a lot of adults with disabilities, and I think there's a learned dependence that goes on. And, we're all about saving money; I think we need to support them in that growth towards independence. So, there might need a little money needed in that area, at least organization around it.

BRIAN: So, if what I'm hearing is correct, it's more in the nature, at least for you, of obtaining individualized services, ones that are a good match, or crafted to her and who she is.

DEBORAH: Absolutely, yes.

BRIAN: Despite what you hear about other things just getting to the age of 21/22.

DEBORAH: I worry about my -- (inaudible) they're the ones that are sitting at home watching TV and their parents are not knowing what to do, and worry about going to work, you know.

PAT: Were you ever involved with the Rhode Island Parent Information Center, RIPIN? Because I know that they have courses in transition.

DEBORAH: I've gone to many of the workshops. I've even participated, and they're very helpful, and there's a lot of information. But it's still; it's a very complicated process, especially in the individualization piece. You know, I wanted very specific goals for my daughter, which I do feel, though, are very important for all adults. I think those needs for independence are across the board, and I think it's the way we look at people, also, and our expectations.

BRIAN: In your view, is it more in the nature of the Division of Developmental Disabilities being able to make those connections, or is the problem with the providers who are able to provide the specialized services that are good for your daughter?

DEBORAH: I think part of it is a way of thinking, a philosophy. And so, like, I found Developmental Disabilities, the social worker that worked with me was wonderful. She went with me to interview all of the agencies. And she was new, so she was learning about it at the same time, but she supported my vision for my daughter. And, you know, we did fine, it was real hard to find the support through the agencies, and I ended up picking an agency I found was the most flexible. But, the challenges, the follow through, and getting things to happen, you know --

BRIAN: So, more of an agency issue, an agency flexibility/creativity, as well as being able to maintain consistency, is that fair to say?

DEBORAH: In my personal experience, yes.

BRIAN: Okay, thank you.

CAMILLE: Any other questions? Is there anyone else who would like to give testimony today? Who is here?

DAWN: I am Dawn Wardyga, parent and program director for Family Voices at the Rhode Island Parent Information Network, and I'll probably be at a few of these, but I wanted this on the record, and I promise I won't speak at every one, but at least it will be on the record. I don't know what came up before I came in, but the area of biggest concern from my perspective going forward, and I think, well, I know impacts all ages from birth to death is what may happen through the Global Waiver process, the Medicaid waiver process. I am very much involved, many of us who work in the system are very much involved in that process, but still, we're all feeling pretty uncomfortable about what the outcome is intended to be, and whether or not our input is going to be taken seriously into what the outcome is. When the state went to the General Assembly to get permission to go forward with this waiver request, I, among many others was one that testified very strongly against going forward with this Global Waiver. We felt as if we could make some positive changes in the same way, using the systems that we had in place. Obviously, we lost that battle. The war rages on, but we lost the battle. Going forward, getting approval to go forward with the Global Medicaid waiver, the first time really the country has looked at Medicaid across, (inaudible), across disabilities and across all ages, which, in concept and theory is a very good thing, it delves in details. As we go forward, I know the Commission will be watching this as closely as we are because we work closely with the Commission, as well. The details are unfolding as we speak, and as one who is, as I say, very invested in the process, and spend a lot of my time, my work time in that process, I'm very much concerned about the outcome, and I worry tremendously about the general public who doesn't have, who don't have the same level of knowledge and understanding of the Medicaid system, and don't really understand how this might impact them in the long run, whether they're Medicaid eligible or not. If they're commercially insured, depending on the outcome of the waiver, it will have impact on the whole health care system of the state. I hate to use their term, but it's a global issue is what it is, and it's something that I don't think we can take our eye off of for a second because, as one who attends many meetings, the landscape changes from one meeting to the next meeting, and that causes me great concern, so I just wanted to be sure that was on the record.

CAMILLE: Thank you. Any comments or questions?

MARY: Hi, Dawn. (inaudible) to explain to the public about the Global Waiver and how this information can be made accessible so people with disabilities will also get that information.

DAWN: Question one -- I think I need to read. One of the issues, and my major concern is that nothing is concrete, it's like, the ground is shifting below our feet as we're moving along, which is very disconcerting because one of the things that we do through my program and through the Rhode Island Parent Information Network is we work very hard to inform the general public, and really, any families that come, about the new public policy issues, and how they might impact them, and, more importantly, for them to get involved in the process. But it's hard for me to even provide concrete information because we're not getting it from the state officials. And so, you know, there is no, to my knowledge, anyway, at the state level, there is no public awareness kind of initiative happening, you know, people are learning as they go, including those -- if I get information that is concrete, and I feel comfortable that what I'm passing on is based in fact versus theory, then I'll pass that on, I keep a mailing list and a, an e-mail list, and that kind of thing. But, to be honest with you, there's not a lot of information out there, and so, so, first of all, to get this out to the general community, I don't even see that as having being made a priority by the state so far, let alone making that accessible for others who maybe have communication barriers or that type of thing, or even language barriers. So, none of that work, to my knowledge, has been happening at the state level. And again, this is a change of great significance. I started out as a parent of a child with (inaudible), he was technology dependant and medically fragile, and we lost health insurance while he was alive, he passed away when he was 19 months old, and I got what I refer to as the education of a lifetime, lost insurance, anything that could go wrong did, and what I do now is my life's work to keep others informed so that it's less traumatic for them in the long run. My son would be 23 years old if he were alive, and I can tell you, in the last 23 years, I know, personally, I have never felt so uncomfortable about the security, if you will, for all populations going forward, but especially those with special needs. Long answer to a short question, but it's very complicated.

MARY: Thank you.

CAMILLE: Is there anyone else who wishes to give testimony? No one? Thank you. It's only 2:00, so we need to stay a while.

DAWN: What role the Commission will take in the National Health Care Reform Committee?

CAMILLE: I'm not with the Commission, I can't answer that, I don't know if anybody can.

PAT: Well, it is a Legislative Committee, and it looks at the issues, and, including the input from these forums, and then decides on the legislative platform that then has to be approved by the full Commission. So, up until now, that has not occurred regarding the federal health care reform.

DAWN: May I make a recommendation in that case? I'd like to make a recommendation that the Commission, the Commission step forward and take that on as a priority area for them. It's tied in with Medicaid Global Waiver, but it isn't only about the Medicaid Global Waiver. And it's so complex to expect the general public to understand it; we're just never going to be there. And in order for us, the general public, if you will, to really have meaningful input into the process, we need to see the big picture, and I think that the Commission has the ability through its Legislative Committee to take a stand in the discussions that are happening in D.C., as we speak on National health care reform. From what I understand, today, the U.S. senate is actually reviewing their bill on National health care reform, so, the time is now. It's one of those extremely urgent kinds of situations, but the Commission ought to be able to, obviously, they're focused on people with disabilities, all people with disabilities, which I think is fabulous because it's across the boards, it's not just isolated populations. But, to have a voice in whatever health care -- whatever shape health care reform takes in the future, that the needs of those with disabilities and chronic illnesses be incorporated into those discussions.

PAT: Thank you.

ISABEL: I have a concern, it's mostly just a concern.

CAMILLE: Can I your name please?

ISABEL: Isabel Pestana, Neighborhood Health. Out in the community, I often encounter families with children or relatives that have disabilities, or adults with disability that, make the comment of -- provide medical assistance and find the whole process very challenging for them, and it almost seems at times that they're set up to create a barrier instead of opening the doors for them to be able to access the health insurance or the services that they need. I understand there's some disabilities, some are more obvious than others, but all disabilities are just as important for adults, at times, to me, it seems so obvious, and I hear often times -- (inaudible), and they stop. I come in and almost let them know they need to go back and advocate for themselves, for their relatives, and I offer assistance in the way of all the information I have from different agencies, or throughout the community. But it's just a concern that I hear this so often when I'm out there about so many adults or children that have special needs that are not really taping into the resources they have because it's very challenging in the beginning process of application and due to the fact of -- or frustration, they stop.

CAMILLE: Thank you. Anyone else?

SHARON: I have a comment on Isabel's comment. We find that a lot with people with brain injuries because a lot of times their disability is not seen. It's not physical sometimes. And one of the things we try to tell them is if they've been denied, they need to go back and go through it again. As (inaudible) as it is, but they need to not just walk away and give up.

ISABEL: I hear it so often that they just give up and walk away, and they're just alone.

SHARON: And sometimes they need help and assistance to fill those forms out, and, unfortunately, we don't have the number of people to be able to take people and help them with that, so, and I'm not sure where they would go to have people help them do that. I understand what you're saying.

MARY: Just a comment, I don't know the (inaudible), I work more with adult consumers, but I do know, it often helps if there's an advocate on the inside, sometimes one who will -- be on the phone or through application, or through a meeting, there are code words and things you don't know, you know what I mean? And sometimes, having somebody that has that information, I'll give you an example. My grandson -- (inaudible) and I would not -- on my insurance because I didn't have legal custody. Four months after I started looking through what to do, somebody who formerly worked at MHRH said that I could get RITE Share/RITE Care, but I had to find the right person who knew how to answer my question, even when I didn't ask the right question. So, maybe some of us need to spend some time finding system advocate either in the system or outside of the system that families can talk to. Because sometimes what you need one thing to a consumer and it means a different thing to a family. When they ask how much available money you have a month, if you don't know that there is -- items and you put all your money you may not qualify because of too much money. There's a lot of different codes in the system, so maybe that's something that would help out in the future for families, when a parent or another person advocates on behalf of someone.

DAWN: I wanted to add to this, we do a lot of work with families and trying to get them access to health insurance through any mechanism whatsoever, and I will personally tell you, I think it's a travesty that the state does not take responsibility for being sure that the consumers are aware of what's available to them. It's almost, like I dare say, a form of rationing, may not be called that, but nonetheless, the end result is the end result. And we do a whole lot of work trying to get families connected to, whether, sometimes they're eligible for commercial insurance, and they don't even know it. So, it's a matter of, again, that inside advocate if you will. We do a lot of work across the state with, we actually have a staff stationed in different sites across the state including the (inaudible) offices, and internal medicine offices, and that sort of thing, and that's specifically what their job is, they're resource specialists, and some are entitled parent consultants, those in the pediatric offices, and that type of thing, but the bulk of their time is spent on helping those families figure out what they are eligible for. I think that the Commission could make a statement and really drive home the issue that the Medicaid agency in this state needs to take responsibility for the public awareness that is needed so that families know how they can access, and so that if the process is too difficult for them, they can get assistance with applications because that doesn't happen now. Again, in my opinion, it's an, I think, unspoken form of rationing.

PAT: I would be interested in whether people find helpful any of these three resources. 211 that the United Way established, it's like an information referral service, you can call 211, and they're supposed to link you up with services. The Point, which is an information referral service, funded by the state and CEDARR Centers. Anyway, I'd be interested in whether those three attempts at providing information and service by different sources are useful, not to replace an advocate, please, not to replace filling out an application, but at least as an entry point in getting information.

DAWN: Might I speak to limitation on the -- not The Point and not 211, but on the CEDARR Family Centers. When those centers were designed, I was smack dab in the middle of that so from the get-go in establishing the centers so that families could more readily access services. That's the entire focus of the whole initiative. And the state invested quite a bit of resources, both fiscally and human resources in terms of their staff through the Medicaid agency and some of the other state agencies, as well. And the original intent when those centers were set up were so that any family whose child had a disability regardless of what their insurance status was would be able to enter that doorway to at least get information and be referred to appropriate places, even if they were not eligible for Medicaid, it was a way to go in the door to get some information. Obviously, the first thing was to establish whether or not the child was eligible for Medicaid, because if the child was eligible for Medicaid, that opened the door to kind of the next level of services, if you will, that the family could build a family care plan and really work on the strengths of the family and the strengths of the child. Unfortunately, as it played out, what happened was the CEDARR family centered were really only taking on, if you will, those who they knew to have Medicaid. So, for instance, if I'm a parent and my child has a disability or a chronic illness and we have commercial insurance, we can't get the services, including the information piece, the front door entry piece, if you will, because our child is not eligible for Medicaid. It's not the intent, the original intent of those centers, but unfortunately, that's what the practice became. What should I say; the intent originally was that commercial insurers would see the value in that component of a centralized system and then kick in to help support that for their commercially insured clients. The only thing that commercial insurance does in regards to CEDARR family centers is for those children who also have Medicaid, because that's the door in, you have to have Medicaid to get in the door, when that care plan is developed and services are required, if it's a billable under the commercial insurance, then, in fact the commercial insurance has to kick that piece in because they're the first player, that's how that works out. And I will say in all fairness because a lot of staff in the state agencies worked very, very hard to make these CEDARR family centers work, unfortunately, the culture in this state is we jump from one fire to the next, and the intent was to stay with that, and to kind of see how it played out and revisit and see where we needed to modify. It was an intent to create a buy-in component so if I was that family that had commercial insurance and my child was not eligible for Medicaid through any mechanism whatsoever, I could buy-in to the services of a CEDARR Family Center. That component was never developed, and in the centers themselves, never got the support from the state to build that component, so that's where it kind of fell short, and now, unfortunately, something that was intended to be comprehensive (sounds like) and accessible to all children with disabilities, children and youth with disabilities, and their families, is really only accessible to those who either have Medicaid, or it's clear that they're eligible for Medicaid, and they only need to go through the eligibility process, so it's kind of a limitation, especially for those kids with disabilities because you think about that.

Family centers work well for some families, they don't for other families. There's a whole variety of reasons, but unfortunately, as the state jumps from fire to fire to fire, you can't get back to see, where is the real issue? I've heard informal proposals, if you will that, under this Global Waiver, we do away with the CEDARR Family Centers, and that makes me a complete wreck as one who went through the process of developing those centers. I wish you guys waited until I died before you start taking that system apart, but, nonetheless, it's become a limitation that was not intended, but because of the priorities, if you will, of the state agencies, and because they've had to shift to other places, those CEDARR Family Centers, in all fairness, never got the level of support that they should have gotten to be effective and efficient and really meet the needs of families.

SHARON: I have a question. Every school district doesn't have a CEDRR center, do they?

DAWN: No, as a matter of fact, there's only one I know of, if it's still in existence, there's a satellite site in the school in Portsmouth, and I can't even think which Family Center they're connected to, it might be Solutions, that's within a school in Portsmouth, there's a satellite site. Other than that, they're in their own locations.

SHARON: Are they basically in lower income --

PAT: They're on the DHS website.

DAWN: That's not the intent, at all. One of the biggest problems in my opinion is when you talk about the connection, if you will, between school districts, serving kids with disabilities and CEDARR Family Centers, it's very, very weak. We haven't gotten the schools to promote the CEDARR Family Centers in general. In general, there are some exceptions to that. But we haven't gotten schools to do that, and in actuality, I've heard of situations with families where a family care plan is developed through a family center, and part of the plan needs to be implemented in the school district. There's a lot of friction between the school district and the family centers, so a lot of dynamics going on back there.

So, they're an operation that, again, I don't think there's any system out there that will be perfect for everybody, but they work for some, don't work for others, and some of the family centers have a better reputation than others. It's common in any line of business, or that sort of thing. But, unfortunately, there's a weak connection between the school districts, and special ed. departments of the school districts, and the family centers, as a general rule, there are exceptions.

PAT: If you'd like information about the CEDARR Centers, it's on the website of the state of Rhode Island Department of Human Services, and you have to look for services for children, so the website, Department of Human Services, State of Rhode Island, then look for children services. And then you should, you know, search for CEDARR, and you should come up with the different -- I want to say 14 locations, but I'm not quite sure.

DAWN: Is Portsmouth –

COLLEEN: Satellite site in Woonsocket, but I'm not sure.

BRIAN: Rhode Island Hospital.

DAWN: There's one there, that's Families First.

COLLEEN: Families First, Family Solution on (inaudible) in Pawtucket, and Power of Families in Pawtucket.

DEBORAH: I was also part of the development of CEDARR, and also referred many families to CEDARR, and although I think the idea of it is very good, one of the things that the purpose of it was that it was like a one-stop shop so that families could go to one place and get all the information in one place, and referrals, and all of that, but what I'm finding is that, first of all, there's a waiting list just to get them to call you. That's what I'm finding from families I'm referring, quite a wait time. And once they do make contact, if they are eligible for Medicaid, if they get that eligibility, another issue I'm finding is, you go on a wait list for all the other services you need. Say you have a child who has a severe behavioral emotional disturbance who is unsafe at home or the classroom, it can be a year or two before they get direct service. They go to CEDARR, once they make the connection and find out about these agencies and referrals, and then they have to go through all the same processes with all the other agencies they get involved with, so instead of minimizing the work on the parent's part, it's just more work. And the paperwork involved, the number of meetings that parents have to go through, and then to relive and retell your story over and over again to different people who have a different understanding or a different take on it, and give you different information, it's so complicated, I think it speaks to what you were talking about, why families give up, and what I was speaking of with the transition process I went through with my daughter, it's just the ultimate frustration for an already exhausted caretaker who is trying to deal with a situation at home that is very (inaudible), so I don't know the whole answer but I just feel like we're putting all this effort and money into all these referral programs an there's no real services to have and that's what is needed. People really need service with their family member or child.

DAWN: For starters, its compliance issue if a CEDARR family center has a wait list for entry, that's a compliance issue that I think needs to be paid attention to. There are not supposed to be wait lists for entry into a CEDARR family center. Now, if a family needs a particular service and there aren't providers in the community willing to serve that child, or willing to take the Medicaid reimbursement, which is a huge issue, then, in fact, the CEDARR family centers have no control over that, and the providers, in all honesty, it's my understanding, it's probably been more than ten years, maybe many more than ten years that the provider rates were a little down for any increases through Medicaid. In fact, in the last six to nine months they've gotten clobbered with cuts. So, what was a bad situation before has become worse, basically. So, you have that central point of entry for those able to access it, which is a good thing, but then when you get to certain services, not all services, but when you get to certain services, there's no capacity in the community to deliver the services to the family. These kids wind up in the emergency room, at Butler Hospital, at Bradley Hospital, that's where these kids end up because if they're not safe at home, the rest of their family is not safe at home. I'm familiar with a case that the child had behavioral issues for a very long time, he started setting fires. I mean, they have no choice, they have to go to the emergency room because there are no services. There are child psychiatrists in this state that will only work, and not just psychiatrists, I should be fair about this, there are a lot of specialty services that the providers will not accept your child unless you agree to pay cash, even if you have insurance, they don't want to deal with the insurance company, don't want to deal with the billing issue. So, what happens is, especially in the instance of autism, we all know what a huge problem autism is becoming, and will continue to grow, in my opinion, as we go forward, that a lot of those families, it makes a difference if you're a family that makes a lot of money or you're a middle class money, or, God forbid, you're a poor family, you can't get those services because some of these providers will only take cash, cash only or no services. That's another issue around capacity, across the board. We can talk about this from the kid's perspective. I don't know as much about the adult perspective in terms of capacity, but the people I've been spending a lot of people lately around the Global Waiver who do represent the older population, capacity is an issue, as well, not as severe, I don't think as the children's side, but we do have a provider capacity issue, some of it is due to reimbursement, not all, and some of it is due to, we don't have enough of the providers we need to meet the needs of the kids and families.

MARY: I have some general comments, but I don't want to take time if there are more questions or comments from anyone sitting here. Did anyone else have questions or comments?

CAMILLE: Yes? You would like to give testimony?

PAUL: My name is Paul Bohac (inaudible), client of, board of --

CAMILLE: Paul, could you stand, please?

PAUL: I was brain injured when I was 26 years old, and as a result of that, I have lived my life as a brain injured person for a number of years, and accessing services provided through PARI and Brain Injury Association.

One of the first things that happened to me, I got a scholarship to attend the Brain Injury Center on Cape Cod for six months to learn to live independently, and since then, I've been fortunate to live independently, and through Section 8 housing, and also to work at a local supermarket. Subsequently, I volunteered at a soup kitchen for about 14 years. So, sometimes I still get services, and that's what I'm looking for, services for people who have suffered a brain injury because they happen a lot of ways, car accidents, falling, you can imagine. So, I'm just here to hopefully get services for the Brain Injury Association.

Thank you.

MARY: The comment I wanted to make, (inaudible) level, also at a state level, those of us old enough to remember before, they had (inaudible), our concept was kind of honor system of, quote, the deserving poor, and then, -- corporations and macro-facilities and other groups who have taken advantage, that most needed it, this is my personal opinion and we have welfare reform. Some good things possibly came out of that. The social security administration -- group called Maximus to begin the Ticket to Work. I was in Arizona when that happened, and Arizona was -- Maximus knew nothing about disabilities, didn't know about people with speech disabilities or how to do TTY. The point I'm making here is that I think we're still seeing a (inaudible) toward people with disabilities, toward families with people with disabilities, towards senior citizens. I don't think it's (inaudible). I think if we look at the demographics, we're changing. We're not all able-bodied young people any more, we're living longer. So, the population is becoming older, and the population is becoming a group of people with more disabilities, not just age-related disabilities, but we're surviving trauma we didn't used to survive before. We're able to provide life saving measures for accidents, for birth defects, and for a variety of things that we didn't have ten or twenty or thirty years ago. But the idea of having difficulty understanding that the larger part of society is not able-bodied young people any more, and I think we're still seeing (inaudible) being made. More populations that's no longer the majority. First of all, Rhode Island Disability Vote Project. Jean Lawlor snuck out of the room, but she's here and has information. Senior centers speak; we cannot change the systems unless we vote. We can't get funding unless we vote. The other thing is I think we need to network better for a lot of reasons, we're all busy with our families, our work, busy with being advocates, we sometimes don't -- other people in groups are experiencing. Just as an example, Dawn had a great -- I got a lot of information from Dawn that I wouldn't know about. But the Governor's Commission on Disabilities (inaudible), I get information from them that I wouldn't otherwise have. I hope that we can all start not just coming together every year when we have the ADA public hearing, but that we can keep working together through the year because through the Rhode Island State Independent Living Council, we've developed a position paper and we try to (inaudible), the Global Waiver from happening, or at least happening so fast, and, in many cases, it's apathetic, people didn't sign it, didn't respond and ask questions. And it's human nature, responding only to what we understand and what immediately effects us, but sometimes we need to trust each other a little bit more. So, I hope that we can start doing better networking. I hope that we can start doing better representation so that it can be clear to people, people who spend a lot of many for things that we can't access, people with disabilities, seniors, and families that have a family member with disability.

BRIAN: I had a question, given the current environment and the economy and newspaper headlines, what looks to be increasing homeless population, I'm wondering if anybody here today has had any experience or heard of anybody with a disability that's had experience either becoming -- (inaudible) as a consequence of being displaced homeless or otherwise or the other way around. We've heard someone here today about difficulties connecting with services in the first place, as a consequence of being disconnected, perhaps becoming displaced, either you or --

DEBORAH: Child right now in our program, severe disability, mom was evicted had to move to different district where the child was eligible for summer services now doesn't have transportation to get to her summer educational program. That's it. She didn't get it. We tried, you know, to work on some things, and I'm aware of the law, but I couldn't even reach the School Departments.

BRIAN: So, this would be a situation where the school had extended school --

DEBORAH: Yes.

BRIAN: Because of change of districts, new district wasn't able to pick it up or older district is washing their hands.

DEBORAH: Basically, the child could still go to the program, but the mom was homeless, staying with a friend or whatever, no transportation. So, now she was unable to get the child to the program, and they were not willing to pick the child up. And they said it wasn't their responsibility. However, I did look up the homeless act, and I know that it was their responsibility, and the district where the child, if I was reading that right, to work together to figure it out. But it was, it's almost over now, and they haven't figured it out, and so the child has missed out, and she's 3/4 years old, and really needy, and time is losing, you know, and when the fall comes, it has to be worked out, as well. So, I'm working on it.

BRIAN: For what it's worth, some of the, if it was some language in the statutes concerning transportation, for school districts, recently, in recent legislature, clarify some of the responsibility for the schools statewide transportation.

DEBORAH: Can I find that online?

BRIAN: I'd be happy to talk to you about it after.

MELISSA: Hi my name is Melissa Palmer. I'm a social worker with (inaudible) health strategies, behavioral health partner for neighborhood health plan. In response to your question, there are actually a number of our members who are now homeless, either they've had consistent problems with having permanent housing, or we've been seeing a lot more people now who are homeless, and so we've actually been trying to start a new initiative when we're going out into the community trying to connect with some of these folks to make them aware of the services that are available to them. We've identified this population as a group of people who really just have fallen through the cracks, so we're doing our best, but there's so much more that needs to be done.

BRIAN: Are any of these folks that perhaps that are truly ending up in homeless situations getting connected with some of the shelters such as Crossroads, or are they, some of the other places where it's just ad hoc kind of --

MELISSA: I've worked with a number of folks at Crossroads, but, given the fact that there's so much more homelessness now, a lot of these place areas filling up. I've been going around, last month I spent a lot of time going around to the various shelters in the state to let them know about some of the services we provide, and to try to, you know, network, and make, establish relationships, so when they see our folks, they can give us a call and make a referral, and we can hook them up with a case manager. But I'm hearing a lot of concerns and frustrations from the sheltered community, as well. I think everyone is just feeling the impact of the economy and the lack of resources and the cuts that everybody has felt.

MARY: I just want to add to your question last year on -- not last year, the year before last year, when the fiscal deficit first came to light among the first known cuts were drivers for the elderly blind program. They got rid of four or five people, and I don't think that was ever restored. For those of us who (inaudible) another one of the first round cuts, health insurance for families and children, day care to families, DCYF discontinued funding to transitional services for youth, so that was a huge impact because young people that would otherwise have been transitioned out have nothing.

People who are leaving school, the law is you go to age 21, there is nothing for them after they get back home unless they can get somebody help them complete an application. I know from working for many years with people who are homeless there are many people who are homeless, if you ask them if they have a disability, they will say no because many people feel that having a disability means being in a wheelchair or being deaf and signing, or blind and using a cane, but there are people without diagnosed disabilities, people with borderline disabilities, many people with disability that is become exacerbated because they can't get medication.

Many who don't have a telephone or home address, and many of us read in the newspapers that the group of (inaudible) on 195 are being told to move. Just get a moving truck and move over to -- where are they supposed to move to? No, Massachusetts isn't a good choice; they're in big trouble, too. So, yeah, there are people with disabilities who are homeless; people who are disconnected from the system and providers, yes, it's true.

ISABEL: ...Kennedy Plaza, I do (inaudible) mostly to try to outreach to the homeless that are in a health partners program but unfortunately due to the lack, they don't have permanent address or get their information from the Department of Human Services or information from Neighborhood Health Plan of Rhode Island or the health plan they were assigned to so they are disconnected from information that could be helpful to them, and often I do find a lot of homeless, I'm trying to tell them to contact 211, or to send them to sometimes Rhode Island Disability Law Center, to your agency, too, it's just that I don't have the transportation, you say where do you live and they don't answer and you say you need to do this and this and this in order to apply you need all the medical records, how do I get there? Or, how do I pay for it because I don't have the health insurance. So, obviously, these are people like you say there's a lot of undiagnosed disabilities, but they get to a point where they're just completely cut off from all services, so a referral would do them very little. It would be infective at that point and need the initiatives of physically going out there and walking them through the system is just my take on that, but to answer your question, yes, there are many barriers, more than one, and unfortunately, the homeless population is increasing in Rhode Island, and it takes a whole community to help them.

DEBORAH: if I can add one -- transportation is a huge barrier, and we just don't have enough bus routes in this state to get from one place to another. I see it with families I work for, and also for my daughter. She would be a lot more independent if she could have access to public transportation, but there's just no buses around. They're not going to enough neighborhoods.

CAMILLE: Pat, did you have something you wanted to say?

PAT: No.

CAMILLE: Anyone else? Jean, register to vote.

JEAN: You can do that right outside.

DAWN: Can you register twice? My argument all the time, just to let you know is, I hear, especially, when it comes to kids that kids don't get the services they need because they don't vote, and my response is always that the parents and grandparents do, and so it's simply a matter of, I'm just being funny when I say I'd vote twice, you know I'd never do that.

JEAN: It's actually something we'd like to do -- through staff, family, friends who care about issues as much if not more than the person effected.

MELISSA: One more comment just to piggy back on the topic of homelessness, one other significant thing I'm seeing is the fact that so many of the homeless folks in Rhode Island have at one time or another been involved in the criminal justice system, and when we try to provide the assistance to get on housing lists and things like that, this history is becoming a barrier. You know, it is a barrier for them, so it's making them, you know, ineligible for a whole lot of resources they might otherwise be eligible for. So, I would love to see more communication between, you know, to try to bridge that criminal justice system and the mental health systems.

BRIAN: Comment for whatever it's worth, in Rhode Island, despite what the, one might have an impression of the population at the ACI, actually, proportionately, we have a large number of people on probation, so if you look at anybody involved in the criminal justice system, or perhaps has been in prison or not, the number of people on probation as opposed to people who are actually serving time is very large, if not the largest in the country. So, it's an awful lot of people who have some sort of criminal record that are trying to get housing while they have a criminal record.

CAMILLE: Is there anyone else who has anything else to say or has a comment?

GRACE: Yes, have I a concern. With the economy being what it is and with the many disabilities that we have in the state, my concern is that the blind would hopefully continue to have the level of services that are presently – I mean, I know for instance at Insight, they don't have people come to one's homes any more the way they used to because of the budget cuts, and layoffs, and so forth of the personnel there. And I just would like to be assured that the blind, because they have mobility issues and transportation issues, slightly different from others, that we could still be, I hate to see the disabilities be all lumped into on. If human services should lump all disabilities into one as a cost cutting measure, I think that would be terribly detrimental to the blind. I belong to the National Federation for the Blind in Rhode Island, and discuss such issues, and research, what's going on at present, and that's my concern.

CAMILLE: Thank you. Anyone else?

MARY: I just want to thank the lady that just spoke. May I get your name, ma’am?

GRACE: Grace Strout (sounds like).

MARY: Your comments were similar to some earlier comments. We're concerned with keeping funding, but there were cuts made a year-and-a-half ago for transportation. I know the people at Insight, they do some great programs and services, so your comments are being noted, and we will give them to the Governor's Commission so that we can see what action might be taken.

CAMILLE: Anyone else? Okay. I think this wraps it up, then, for today. It's just about 3:00. I want to thank everyone for coming, and thank the panelists, and thank you for giving your testimony.

(FORUM CONCLUDED)

KATE MCCARTHY-BARNETT: So good afternoon. We would like to welcome everyone to the public forum here today. I am Kate McCarthy-Barnett. I am a commissioner with the Governor's Commission on Disabilities. And I also work with the Rhode Island Department of Health. The Department of Health is hosting the public forum today.

We would like to begin with a few housekeeping items. The rest rooms are right outside this door and to the left. Inside this room here today, we do have sign language interpreters who are available. And we have assisted listening devices also available if needed. And the purpose of the public forum today is to really identify concerns and issues of Rhode Islanders and their families who have disabilities and bring these concerns back to the commission.

What I'd like to do now is introduce our panelists and have them share a little bit about themselves, their name, and where they are from.

JOANN NANNIG: I am JoAnn Nannig from the Office of Rehab Services.
DEB: Deb Garneau from the Department of Health.
VANESSA VOLZ: I am Vanessa Volz, staff attorney on the Disability Law Center. And I wanted to say we brought some applications for federal registration. If anyone is interested in registering to vote, there are some applications on the back table.

SHELLEY GREEN: I am Shelley Green with the Brain Injury Association of Rhode Island. I am a sister and mother and an ex-wife of a brain injury survivor.

ELAINA: I am Elaina Goldstein. I am the executive director of Rhodes to Independence, which is a federally funded project to help people with disabilities become employed.
PAMELA ZELLNER: My name is Pamela Zellner and I am a program manager at the Rhode Island commission on the Deaf and Hard of Hearing.
KATE MCCARTHY-BARNETT: Great. Thank you. We appreciate everyone taking the time to assist with the panel today.

The process of how the panel and the information works is basically we will listen to testimony and sharing here this afternoon. The actual testimony will be posted up on the Governor's Commission on Disabilities' website and throughout the summer. Samantha who is an intern with the Governor's Commission on Disabilities will be reviewing all the testimony from all the public forums. That will be brought back to the legislative committee within the commission. And we will really begin to review that information to look for opportunities, whether it be policy issues or legislation.

So we are excited to hear your thoughts today and get feedback on some of these critical issues.

So what we would like to do now is we are just going to go through of those who identified an interest in sharing this afternoon. After we've gone through those individuals, we will then open it up, if anyone else is interested in sharing as well today.

I'd like to welcome Willa Truelove from Self and Street Sights. It's Willa Truelove.
WILLA TRUELOVE: Hello. I don't know where to go. Do I sit there?

KATE MCCARTHY-BARNETT: You can stand up there if you'd like. That would be great.
WILLA TRUELOVE: Can you guys hear me?

Okay. Hello. I am here for myself. I was also a fellow Governor's Commission on Disabilities some years back and I always kind of try to find out what's going on.

And I brought some newspapers that I'm going to leave on the back table and these are from Street Sights. They are from June. We are off in July. But if you guys will please take one of these and read it because the homeless community is a neglected community and it's a population into itself. I'm sure you heard stuff about Tent City or whatever. But within that population, many people have disabilities of physical or mental or whatever. So, I'm bringing these. And that's really all I wanted to say. And I'm happy that this is happening. Hopefully we will see more coordination or talk between all of these different agencies because it's among the homeless community, it's such an issue. Like Street Sights is probably one of the only places where people have a voice. And day-to-day functioning is really, really, really difficult.

So, I wasn't really prepared to speak or anything. I just brought some papers. I want you guys to take one. I want you guys to be aware of the homeless population and not to actually isolate people who are homeless but to be inclusive.
KATE MCCARTHY-BARNETT: Thank you for sharing. And what I'd like it do now is maybe just provide some opportunity for panel members to share a bit on, you know, some suggestions in terms of looking at the population of individuals who have disabilities or special needs who are homeless.

So would any panel members like to address -- Deb Garneau from the Department of Health.
DEB: I just wanted to ask, do you know if Street Sights or your organization is involved in the housing work group of the global waiver?
WILLA TRUELOVE: I don't really know too much about that. If you know about that, we'd like to know about that. The hard part about -- the difficult part about helping or being in the homeless community is that there really is no -- there isn't anything like a forum like this. Or if there is, it just quickly falls apart. So, we definitely need to know about that because the grievance process for the homeless is absent. And I guess the office of homelessness is supposed to be responsible for that or the Commission on Human Rights.

But basically people who are homeless and people who are homeless with disabilities do not have a voice.
DEB: Well, the implementation of the global waiver is a community member task force where -- one of the groups in particular is focused on housing. And I know that they are looking at homelessness. But, you know --
WILLA TRUELOVE: There are some serious issues. People who are on SSI and SSDI and -- the SSI and SSDI check does not allow them to live independently when -- when you put that in perspective with the food stamps. Like there are people who are on SSI and SSDI who only get $60 of food, which is not enough to eat three healthy meals a day, every day for a month.

So, what happens with a lot of people who are on SSI and SSDI is they use their checks so they can't pay rent. So there's this huge vicious cycle that needs to be reanalyzed so that there is a chance for independence because there isn't now.
KATE MCCARTHY-BARNETT: Well, I think, Willa, Deb makes a good suggestion in

terms of the global waiver housing working group. Is there a way possibly to connect Willa with that working group?
WILLA TRUELOVE: We would like to know --
KATE MCCARTHY-BARNETT: Great. Right through --

Now I just want to offer up -- any other panel members have any thoughts or feedback in terms of this issue?
SHELLEY GREEN: Yes. I want you -- Shelley Green from the Brain Injury Association. I want to thank you because I know there is a segment of the homeless population that are brain injured, so difficult to get services. I don't know if Brain Injury Association could be a support but they are on Park Avenue. And the number's 461-6599 for any of the population that you know who has a brain injury for services.
WILLA TRUELOVE: Thank you.
SHELLEY GREEN: Thank you again for being here
WILLA TRUELOVE: Because there's a lot of fighting and conflict.
KATE MCCARTHY-BARNETT: Thank you, Shelley. And Elaina Goldstein also had some thoughts.
ELAINA: We had had a housing work group for a number of years on Rhodes to Independence. And a number of organizations within Rhode Island, part of the problem, that do work on the homeless issue. And -- the person who has remained very active with our group and is really -- a person I know the most is her name is Michelle Brophy. She works for the Rhode Island Coalition For the Homeless and does a lot of work and always brings the issue up regarding employment for the homeless, housing for the homeless.
WILLA TRUELOVE: There's huge addiction problems. Addiction problems --
ELAINA: I'm saying, my project works exclusively with people with disabilities. So I'm just saying that she is there advocating, and we are doing a number of different things. So, if you hook up with her organization, I think she might be a really good resource for you because she seems to be involved every where. So I think she knows about everything. So she might be able to be a good mentor and help you out.
WILLA TRUELOVE: Yeah.
KATE MCCARTHY-BARNETT: Great.
WILLA TRUELOVE: Could you tell me, 461-
ELAINA: 6599.
KATE MCCARTHY-BARNETT: Do we have --
AUDIENCE MEMBER: There's a brochure too.
KATE MCCARTHY-BARNETT: Any other panel members who would like to address this issue?

Well, thank you, Willa, for bringing up such an important issue today. We appreciate it. And we will work very hard to link you into the housing work group through the global Medicaid waiver and connect you with Michelle's contact information as well.
WILLA TRUELOVE: Thank you.
KATE MCCARTHY-BARNETT: So thank you.

The next person who has expressed an interest in sharing this afternoon is Steph McKenna. And Steph, hi, Steph. Please feel free to come up.
STEPH MCKENNA: Hi, everybody. I have a problem. I've had -- this goes back -- I have been trying to find someone in the last 8 years to help me out with this. I get the same answer every time. And it is that that is the rule.

And the problem is this: In 2001, I moved from Providence -- I live in Johnston now. And I had to move because I could no longer get in and out of my house because of stairs. So, I am living on one level now. And before I moved, I checked with RIde transportation, just to make sure that I was eligible for RIde on that route. They said yes, that was no problem.

I didn't find out until later that the rule with RIde is that the bus stop nearest your house dictates when or if you will get service. And the nearest bus stop to me is an express route. So that means I have a window in the morning and one in the afternoon, which allows me to get to work and get home.

But I can't get service any other time, not at night, not on Saturday, not on Sunday. So basically, I can go to and from work with RIde and that's it.

And I -- I really don't know what to do about this. I know that if I were in a different -- if I was able to get to another place where the buses run, I could say, I want to leave from here and go there. And then I could get rides.

But that's not possible because I can't get to a bus stop without transportation. There are no sidewalks. It's a busy street. That kind of thing.

So, anyone I've spoken to -- I've spoken to a lot of people in the last nine years. And there's no answer. It's just that's the rule with RIde.

Some say it's a federal rule. When I checked with an office, they said no. You have to go to constituent advocacy with the state to see if they can do anything.

And I really am at a loss. I don't know what to do. Retirement looms at some point. And I can't retire and stay where I am. I would have to move because I have no freedom, you know. I can't take -- I would have to be dependent on someone. It's bad enough asking for rides, you know, for things like -- for dinner, that kind of thing. I would like to be able to come and go as I please, you know.

KATE MCCARTHY-BARNETT: Well --

STEPH MCKENNA: That's my question. Now is there any help anywhere?

KATE MCCARTHY-BARNETT: Thank you, Steph. What I would like to do is open it up to the panel members. She brings up critical issues in terms of barriers with our transportation.

Do any of the panel members have any thoughts or feedback to share?

VANESSA VOLZ: Well, I am from the Rhode Island Disabilities Law Center. Vanessa. And I can't really give you advice right here. But I would encourage you to call our office. I don't know if you talked to anyone in our office before. And there may be a legal issue that we would be able to address. We wouldn't know without more facts and doing research. But we are certainly a resource available to individuals and their families who have disabilities.

So even if we are not able to assist you, we may be able to refer you to other organizations who may have some advocacy help.

STEPH MCKENNA: I checked every where to see what other transportation is available. And there is none.

VANESSA VOLZ: Feel free to call our office. 831-3150.

KATE MCCARTHY-BARNETT: It's the Rhode Island Disability Law Center. We will get that for you --

STEPH MCKENNA: Is that on Allens Avenue?

VANESSA VOLZ: Westminster Street in downtown Providence.

KATE MCCARTHY-BARNETT: Thank you, Vanessa. Do other people have thoughts or feedback to share?

Okay. Another recommendation. And we typically do have someone here from RIPTA. But Bill Inlow is very active within the Governor's Commission on Disabilities on the legislative committee and he is from RIPTA. So, we will also get you his contact information and --
STEPH MCKENNA: I have spoken to Bill.
KATE MCCARTHY-BARNETT: Have you spoken to him? All right.

Well, I think it's excellent that you brought this up. The fact that you brought it up, it's now going to raise the issue a little bit higher based on your testimony. So, we will start to really look at this issue.
STEPH MCKENNA: Thank you.
KATE MCCARTHY-BARNETT: Thank you for sharing, Steph. Thank you.

The next person who has expressed an interest in sharing today is Vivian Weisman from the Mental Health Association of Rhode Island.
VIVIAN WEISMAN: It's actually been addressed. I walked on someone else addressing it. It's the housing issue. It was already addressed.
KATE MCCARTHY-BARNETT: It was the housing issue, already addressed. All right.

At this point in time, those are the individuals who have identified -- expressed an interest in sharing today. But now we would like to open it up to see if anyone else has any issues or concerns or questions as a follow-up to what we've heard to far today?

Yes and your name.
JUDY MCLAREN: I am Judy McLaren. And I am here as a Governor Relations Committee member of the Rhode Island National Multiple Sclerosis Society and I took note to this young lady when she spoke on the homeless because we have people who are not homeless but are in their homes, being cared for, but are concerned about them -- you mentioned this being a concern to you was the abuse to persons with disabilities.

And there is a law in the state of Rhode Island that assigned the Department of Human Services to handle those complaints and police departments throughout the state call into the Department of Human Services. But there had not been any one at the Department of Human Services assigned to deal with these types of complaints.

But people from the legislature have met with -- I will find them in a minute -- Gary Alexander. And he has reassured them that they are putting together a plan of receiving those complaints and a place that will handle them. It may not be right within the Department of Human Services office. But they are going to find a place that will handle those complaints.

So that is something that is being worked on by the state legislature.

The other thing I'd like to bring everybody's attention to --
KATE MCCARTHY-BARNETT: Could I -- before you move on to your second point, could I open it up to the panel members for any feedback on that issue? The issue that has been brought up is the issue of abuse of individuals --
JUDY MCLAREN: Abuse to persons with disabilities.
KATE MCCARTHY-BARNETT: Yes. Some work obviously is being done. But I'd like to open it to the panel members for any feedback that you might have on this issue.

Anything that you are aware of that's being done in this area?
DEB: Deb Garneau from the health department. There is legislation that

just passed in the most recent session that asks the Office of Health and Human Services to look at protective services; so elderly abuse, adults with disability, and also looking at the child protective services.
JUDY MCLAREN: Has that passed or is that part of what is going to pass when they are finished with recess?
DEB: Yes --
JUDY MCLAREN: It has passed, cleared House and Senate and the Governor's office?
DEB: It has passed. And it is part of the budget that is -- we are in the process now starting July 1. And -- but the plans and the workings of it remain to be detailed and identified exactly how -- where is it going to --
JUDY MCLAREN: And we are aware that they are looking at it.
KATE MCCARTHY-BARNETT: All right. Do -- any other panel members have any thoughts on this particular issue?
VANESSA VOLZ: I am Vanessa Volz. I will just say the abuse and neglect of individuals with disabilities is normally a priority for us. And we regularly investigate complaints that we receive about abuse and neglect of individuals. And depending on the issue, it can become a systemic issue undertaking.
KATE MCCARTHY-BARNETT: Thank you.

Any other panel members?

Okay. Then, Judy, you mentioned you had a second issue so please --
JUDY MCLAREN: One more.

We at the Rhode Island Multiple Sclerosis Society have also asked legislation to be passed concerning taxi cabs availability for people, persons with disabilities. Currently there are no taxi cabs available. And that also answers your questions. If we had a taxi cab and if it was affordable, you could use that as transportation. But currently, there are no taxi -- handicapped accessible taxi cabs. So there is a law. It has been tabled for study in a committee. But if we all -- we all make mention that we would like there to be one, I think maybe we might get one. They weren't adverse to it. But they want to study it.
KATE MCCARTHY-BARNETT: Okay, great.
JUDY MCLAREN: It would concern everyone.
KATE MCCARTHY-BARNETT: Thank you, Judy.

I would like to welcome it back up to the panel members for any feedback or comments on the taxi cab accessible taxi cab issue.
SHELLEY GREEN: I just want to make a comment. I thought the same thing about taxi cabs, but then thought also affordability issue. And, you know, because there is the RIde program, I didn't know if there would be any legislation to move forward on that. Taxi cab companies are usually privately owned. But I would love to see that be addressed and provide more opportunity for travel for those that need it.
KATE MCCARTHY-BARNETT: Thank you, Shelley.
AUDIENCE MEMBER: Excuse me. Do you have a bill number? You said there was something.
JUDY MCLAREN: I don't with me. If you want to give me your e-mail?
AUDIENCE MEMBER: Something that Steph would benefit from.
KATE MCCARTHY-BARNETT: So the request was for a bill number. We can actually get the bill number to you from the commission's legislative committee as well.
AUDIENCE MEMBER: Sure.
KATE MCCARTHY-BARNETT: We can ask Samantha to send that out.

All right. Any other feedback from the panel members on the issue of accessible taxi cabs?

From the perspective of the commission and the legislative committee, I do know this was an issue that the legislative committee has looked at and will continue to look at. The need for increased taxi -- accessible taxi cabs is key. So we will be keeping an eye on that as well.

Thank you, Judy.

Would anyone else who is here this afternoon have any other issues to share? Any concerns or feedback that you who like to share or request feedback from the panel members today?

Okay.

Based on the feedback -- based on the concerns and issues that we heard so far, do any of the panel members have anything additional to share in regards to the issues that we've talked about today?

Elaina Goldstein.
ELAINA: Yeah, I just sort of -- Stephanie? Can I ask you a question?
STEPH MCKENNA: Yes.
ELAINA: Again it's always complicated for me to understand the RIde program. But there is a RIde program that picks you up at your door and takes you door to door. Are you not eligible for that program?
STEPH MCKENNA: I am on that program. That is how I get to work every day.

ELAINA: You said your issue was -- there is that issue of that bus route. Some people are not eligible for the door to door pickup. They have to actually get to a bus -- to a regular bus route from their house. You do get door to door pickup?
STEPH MCKENNA: Yes, I do. I guess to work every morning and I get taken home every afternoon.
ELAINA: You don't travel the regular bus. I misunderstood.
STEPH MCKENNA: I don't. It's the RIde bus. But I don't have any other access to that bus, just at those times.
AUDIENCE MEMBER: It's based on the time that closest bus route, closest to a house runs, I think it's --

STEPH MCKENNA: When the big buses run.
KATE MCCARTHY-BARNETT: Can I ask you -- if you interrupt, can you please give your name. That was Jim.

Go ahead, Steph.
ELAINA: You don't have the flexibility in time, a different time that that -- RIde bus can pick up.
STEPH MCKENNA: No.
ELAINA: You are dependent on the regular bus' schedule?
STEPH MCKENNA: Yes.
ELAINA: So that's the issue.
STEPH MCKENNA: That dictates --
ELAINA: I had never heard that before --
STEPH MCKENNA: Believe me, I've called many people.
KATE MCCARTHY-BARNETT: Again, I think we will definitely bring this transportation issue back.

Thank you, Elaina. Any other panel members have any other feedback or thoughts to share based on the issues that have come up today?

Okay.

Just wanted to open it up again to the audience, those of you who are here, if anyone else at this point has anything else that you'd like to share, any feedback, suggestions, comments, that you'd like to have moved forward to our panel members?

Okay.

So I just want to reiterate the overall purpose of the public forums. And just to be very clear that is to identify the concerns of people with disabilities and their families in order to assist the state in developing programs to improve the quality of lives for people with disabilities.

So the issues that have been touched upon today at this public forum include the issue of individuals who have disabilities who are homeless and the need to really look at that issue. We've heard some issues regarding transportation and RIPTA and project RIde and ADA regarding the routes and availability of the transportation. We have heard also some issues regarding abuse and neglect of individuals with disabilities; as well as also looking at transportation, the focus of the accessible taxi cabs.

We have heard some good suggestions today. Ranging from the global medical -- Medicaid waiver, housing working group, also working with the Coalition for the Homeless as well. We've talked about bringing the issues of the transportation and taxi cabs as well as the project RIde and ADA RIPTA back up to the legislative committee as well to begin to look at. And keeping an eye on the legislation regarding abuse and neglect of Rhode Islanders with disabilities.

So in terms of what's going to happen next, just to a reminder that we will be posting all the transcripts on the Governor's Commission on Disabilities website. Later, the sponsoring agencies will have an opportunity to review the testimony. The recommendations and the transcripts will then be printed and sent to Congressional officials and members of the general assembly. And these recommendations will be used to develop all policy and legislative issues from the Governor's Commission on Disabilities.

Brief reminder, the Rhode Island Disability Vote Project voter registration -- registers are available to register anyone who is a citizen and not currently registered to vote where they live to vote. People can also file a change of address and that information is here as well today.

At this point in time, our panelists will remain -- we will stay here for a little bit longer. But just wanted again to open it up if there's any final comments or concerns to be shared.

Okay. Well, we'd like to thank everyone for coming today. We'd like to thank our panel members. And we appreciate the time that you've taken to come out and share today.

Thank you.

Warwick | 7.28.09

JULIE: Welcome everybody. I'm going to give it a couple more minutes, we have one more panel member we're waiting for, so if you could bear with us about four or five minutes, we'll get started then, okay?

(BRIEF PAUSE)

JULIE: Thanks for being patient with us today, we are still missing two panel members, but we are we're going to get started. I'll introduce them when they get in. My name is Julie DeRosa, I work for OSCIL, Ocean State Center for Independent Living. If you can give the panel members your attention, that would be great.

HEIDI: My name is Heidi Showstead, I'm here representing the Rhode Island Statewide Independent Living Council, but I also serve on other boards in the state, and volunteer in multiple capacities, helping youth and families whenever I can.

SUSAN: My name is Susan Eleoff, and I work at OSCIL, I'm the information referral specialist. And if you have any other questions not related to this forum, but related to disability resources, you can always give OSCIL a call.

KAT GRYGIEL: My name is Kat Grygiel from the Office of Rehabilitation Services.

DEB: Deb Garneau.

CHRIS: Chris Butler from Insight.

ELAINA GOLDSTEIN: Elaina Goldstein from Rhodes to Independence.

JUDI: Judi Carlson TechAccess of Rhode Island.

CYNTHIA: Cynthia Brown DDD, MHRH.

KATE: Kate Sherlock from the Rhode Island Disability Law Center.

JULIE: Okay. Thanks everybody. What we're going to do today is we're going to, if everybody, I just want to remind everybody to sign in if you haven't signed in on our sign-in sheet. If you want to testify, you need to sign up on that sheet. We do have assistive listening devices, and you can see the back table if you need one of those. We also have interpreters up here. There is a public restroom right outside; I think it's to the right, ladies and to the left for men.

FEMALE AUDIENCE SPEAKER: They're both to the right.

JULIE: Okay. And there's also public phones located in this hallway. During this meeting, the Rhode Island Disability Vote Project's voter registrars will be available to help register anyone who would like to vote, they're at the back table there. You can also fill out a change of address form if you have moved since the last election. Okay. The public forums basically are followed by a posting of the transcripts of the testimony we receive here today on the Governor's Commission of Disabilities web site, which is www.disabilities.ri.gov. It takes about two weeks to get them all up. Later in the summer, the sponsoring agencies will review the testimony and prepare recommendations which also will be posted on the web site. By the end of the summer, that will take place. The recommendations and the transcripts get printed and sent to the state congressional officials and to the members of the General Assembly. The recommendations that we talk about here today and throughout the forums are used to develop policy and legislative initiatives for the next year, or until they are accomplished. So this is a very important thing we're doing here today. We also do want to give everyone a chance to speak, so if you do want to speak, please make that known to us. Okay. The panel here, basically, is here to listen and gain an understanding of your concerns. They may ask you clarifying questions. So, if they do, if you maybe, say you use an acronym to describe an agency you're dealing with and we don't know what that is, we may ask you just to clarify. We're going to ask you to speak on the order which you signed up on the sheet. And so far we don't have a lot of speakers so, pretty much, we're going to give you about five to ten minutes to speak. We have put note cards on each seat. If you hear something that somebody else has said and it kind of gives you a little idea of something you want to talk about, you can go back to the back table, get a pen, so you can jot it down. I'm going to help move the meeting along so we can end by five o'clock. After the meeting, you will have ample time to talk to any of our panel members or anybody in this room to get resources, information, or any kind of information that you may need. Okay, so with that we'll get started. And I have a Linda Bradley wanted to speak. I can bring it to you if you want to just stand up.

LINDA BRADLEY: Good afternoon, my name is Linda Bradley, home access coordinator at OSCIL, and I wanted to just take a minute to talk about the of course the new Global Waiver coming along. Lorna had showed me a proposed overview of the waiver, and had asked for feedback from anyone, and I wanted to make sure, there were a couple of things I wanted to make sure got registered somewhere. The first one was where it was mentioned that minor environmental modifications were going to be allowed. This was under the preventive need section, and I was curious why they were specifying minor. In my line of work, minor would be putting up a (inaudible), or adding a piece of adaptive equipment, but I wondered if that would allow things like ramps, vertical platform lifts, ceiling traps, all of which are sometimes a crucial piece of equipment to allow someone to stay in their home. I was hoping that ramp they would change it to just say environmental modifications, and not specify the minor. They also mention standing poles, and I wondered whether they were going to allow those. And they didn't specify, if they did specify standing poles whether they would also allow grab bars. Another thing is handrails in stairways or steps. I just thought it would be helpful to not specify something like a standing pole, which to me locks you into one intervention when there are many, many possibilities.

The next section I had a concern about was where they mentioned physical therapy evaluation and services. I strongly feel that this section should include occupational therapy, as well. If PT, physical therapy is the only type of therapies designated, then OTs may not even be able to go into homes. Again, I feel that by mentioning something very specific, you may be closing out other professionals who really need to go into the homes. OTs really need to go in there, they are the ones who look at the functional activities that is a person does in the course of a day and can recommend the best interventions. Physical therapists look at the physical reasons for disability and they use physical interventions to improve those abilities. OTs also look at the physical but they go onto look at all the other reasons why a person has limitations. OTs are a crucial member of the team looking at a person's need in their home. I'm hoping that they specify PT because sometimes when people mean therapists of any sort they say, oh, send a PT or they refer to PT as any type of therapy, but it's not. There's many types of therapists. So, if they're, again, going to be that specific and mention a particular type of therapist, I would like them to include OT, PT, speech or other types of therapists.

Let's see, what else? Okay, the next section was under limitations on the availability of services. In the second paragraph they talked about in the event that a waiting list occurred, beneficiaries with high need are given priority access over beneficiaries qualifying for preventive services. And I sent back to Lorna that I can foresee situations where a person has to wait for services and will decline in condition to the point that they can then change from preventive into the high need category. Care givers may be hurt trying to lift or transfer their patient without the necessary equipment. Persons may be trapped in their homes and may have limited ability to get out to go to necessary appointments in the event of an emergency, or just to get some fresh air and sunlight on their faces. So, those were just some specifics that I did want to make sure went on the record. Thank you.

JULIE: Thank you, Linda. Okay, next on my list I have a Kathleen Podurski.

Kathleen: Every year with the same problem. Last time I was here I was (inaudible) chair, which -- this is the chair which unfortunately was not given the (inaudible) -- So, has gone to heck, basically. The top side of my body is twisting to the left side so that my (inaudible) -- when I'm sitting. My leg -- because the bottom side of my body is twisting toward the right side, and my right hip has raised up so high that it interferes with my (inaudible), and it's leaking, sometimes twice a day. Medicare/Medicaid says you can only have -- bags a month which is not even close to what I need. Just as I was saying to you, you can't change your underwear every day, you have to change it, every two or three days you can change your underwear. And I have (inaudible) problems and complain about that. I have gotten a doctor's order to get (inaudible) but the main thing is -- more bags. Sister and mother had gone to see -- who recommended (inaudible) – I won't go into everything but they were going to get this handy dandy chair that reclines with my -- it was going to be great, just left me to them, thinking Medicaid is not going to like this, and feeling rejected three times. Once because I wasn't eligible, once because they needed certificate -- something. And then, it was that they needed a prescription; then it was because, this last time, it was because the person I'm seeing is a nurse practitioner and she's not quote/unquote a real doctor. So they had to have a statement from the doctor she works with that said that (inaudible) the organization -- but who saw me, and the one that was – is supposedly working with Medicare to get me permission to get this chair and I didn't know -- just not doing what it's supposed to do, or what's happening, but it's going back and forth. Christina -- blames the nurse practitioner. And it's been going back and forth for two years now, and I just don't know what to do. I do have a cousin who is a lawyer and he agreed to, he wanted to look into it pro bono so we've contacted him. My sister who is real good with day-to-day details sent him all the information that he should get, need. And so we're going to have to go that way, and, really, didn't want to have to get pushy but it's getting to the point where I'm in pain almost all day, everyday, sometimes at night I can't sleep and just I can't do my -- I can't -- any more, I don't know how. They say – if you feel like you're -- tie a knot and hang on, I don't know, I just don't know what to do. Thank you.

JULIE: Okay, I have a James McKenna.

JAMES MCKENNA : Okay, the question is -- okay, the question is about the government, Obama, which I hope he ends all the war that happens and something like that because, and the President Obama is really good, our

President -- oh yeah, the Hillsgrove House is popular for me because it's what makes me happy. I'm going there five times a week, five days a week, rather, because I'm very happy, whatever. I have money in my pocket, I can buy, I'll buy snacks like soda and stuff, and also, being in the business, I'm in the business unit, something like that, and do the best I so -- what else? I wanted to keep being able to go to Hillsgrove house, which is much better than Trudeau because it's more better for me than going to Trudeau everyday. Thank you so much, everybody.

JULIE: Thank you.

DEB: Could I ask clarification, is that an adult program.

FEMALE AUDIENCE MEMBER: Adult vocational rehab program through the Kent Center.

JULIE: I have a lot of names on this list and do not have anybody else that asked to testify. If anybody has changed their mind, if they'd raise their hand for me? Back there, okay. Could you just introduce yourself for us?

JEAN CALLAWAY: My name is Jean Callaway, and I go to Hillsgrove House, been a member there for eight years. It's a very good vocational program. It's based on the work order day and we go there and we work, and it channels the symptoms of our illnesses, and I had four transitional employments through Hillsgrove House which is to help you get back up on your feet so you can go out and get a regular job. And it's just, it's just a beautiful program. And we've suffered a lot of cuts, and, you know, we can't even have a, our permanent director right now because of some of the cuts that we've had. It's very difficult to see that a lot of these cuts are being made within the state to all these programs. And I've been dealing with my illness for 31, years and I've never had a program like Hillsgrove House, I mean it's kept me out of the hospital, kept me well. I've kept in contact, I've made all kinds of friends, and it's just very, very sad that all these cuts have to be made to a program like this, and all the other handicapped programs. And this is where we're going to suffer. People are really, really going to suffer because they're not going to have a place to go. They're not going to have ways to channel their illnesses. And it's very upsetting, you know, everyday, even reading the newspaper about all the cuts that are being made and I just want to be there at Hillsgrove and continue to stay well and this is what my friends want to feel. And I just, you know, the cuts are effecting everybody, everybody with mental illness and physical illness. Thank you.

JULIE: Thank you. Is there anybody else that would like to testify? Okay. I want to remind everybody that if you would like to register to vote you can do so in the back. The Rhode Island Disability Vote Project. Also if you've changed your address since the last election you can change your address with them. That's a really great program. They will teach you how to go, they will teach you about the things you want to look for in a candidate, and really kind of explain the process of our government to you. So it's a great program. Since we have.

ELAINA GOLDSTEIN: Can I ask a clarifying question from the two people from Hillsgrove because I'm not familiar with the program, but you've peaked my interest in explaining, and I thank you, Jean, for explaining a little more about what the program is, and if I understand it correctly, it's a voc. Rehab program, and you have been able to get employed in various settings through the work of Hillsgrove House?

JEAN: We have transitional employment.

ELAINA GOLDSTEIN: Can you explain what that is.

JEAN: I sure will. Transitional employment is a job where there's a job coach which is one of the staff, and they teach us the jobs, wherever it is. And at various companies we've had, you know, Sovereign Bank, TJ Maxx, staff teaches us to do the job and it builds our confidence to go out and get permanent jobs. I had permanent jobs after leaving the positions -- transition. I worked for Citizen's Bank, and I worked for the Town of Coventry. It's phenomenal because you have the staff working with you to build confidence; you have the people at the job building the confidence, also. And, I mean, I had two positions at Sovereign Bank and I originally went to establish the jobs with our director, and one of our staff members, and it's just phenomenal. I mean, I love the advocacy, I love being able to, you know, it builds yourself confidence. I'm talking my own family, all right, I've been dealing with my illness for 31 years, after the birth of my daughter, my own family has never, ever seen the supports that I have at Hillsgrove House. And it's totally vocational, there are people that don't have to go out to work, we run the whole club, the members run the whole club, it's called a club.

Clubs are international, all over the world. It's based on; it was originally founded in New York City. And it's just phenomenal. I mean it's a very beautiful program to help keep you well, and, you know, the supports are unbelievable and making friends on the outside. My best friend is from the club. I have to tell awe little story and this was the most beautiful thing that happened to me out of working in a transitional employment position. I met one of my best friends, all right. We worked at Sovereign Bank together, and we worked, the two positions I worked, he worked side by side with me, we're now best friends. You build relationships with the employer, the employees, the staff. I've had staff work side by side just to build my confidence to say you're doing a good job, keep it up. Just the relationship that I got out of working one of those was well worth all that I went through to learn the different things. I mean, I may not have gotten a permanent job at the bank, I got something worth a lot more, I got a real close friend. So, is there anything else you'd like to ask?

ELAINA GOLDSTEIN: No. Thank you very much.

JEAN: You're welcome.

JULIE: You can find out more about the Hillsgrove House on the Kent Center website. Okay, last call for anybody who would like to testify. Okay, we have an hour and 20 minutes left. What I'm going to do is, right now, I'm going to close the testimony unless you have anybody who decides to change their mind, or anybody comes in a little later. So, if you do not want to stay, you do not have to. The panel does have to stay. So, we will be here until five o'clock. So, at this time, if you to talk amongst yourselves, or if you have questions for anybody in the back of the room or any panel members, please feel free. Oh, you want to -- hang on just a minute.

PAT SELTZER: My name is Pat Seltzer, I'm a well nurse, city of Warwick and representative for the – on disabilities. Take time to introduce myself you can find me at the Pilgrim senior center, our commission is due to, having regular meetings starting in September again and we're looking for representatives from the community and from other organizations who would like to participate on that commission. I would be the person in the City if you had issues, concerns, problems, you would contact me and I would take those to the commission and the mayor and we'd try to resolve any problems you have. Thank you.

JULIE: Great, good luck with your position. Okay. I'm going to shut off my microphone, and let you nice people talk amongst yourselves, and if you decide you do want to say something, please feel free to raise your hand and let me know. Okay. You want to say something else?

JAMES MCKENNA: I do. So, we have an hour and 15 minutes? Okay, James McKenna, how you doing. I'm kidding. But I'm happy where I'm at now like five days a week, Hillsgrove House; I've been there since last year, January 2008, January 15th, Tuesday. Okay, so, I'm happy where I am now. So, I just want to let you all know that because I live at Buttonwoods, I've been there for a little over six years at Buttonwoods. Then, before that, I was at CEDARR for over four years at CEDARR. Then, from CEDARR, I used Beverly Lachapelle got me out of Eleanor Slater, on a Thursday in '98, this October 8th coming up which is the same day, Thursday, that will be eleven years I've been out of Eleanor Slater.

Okay. I want to thank you all for coming. Oh yeah, I wanted to do, thank you so much for everything, okay?

JULIE: Thank you.

JAMES MCKENNA: You're welcome.

JULIE: Okay, everybody can get a drink or whatever you'd like to do, until we have somebody else come in. Thank you.

We are going to stay until five, so just hang in there.

(BREAK)

JULIE: It's five o’clock, Ladies and gentlemen.

(FORUM CONCLUDED)

LAURA: My name is Laura Jones. I work with -- for Rhode Island Parent Information Network. I am going to be hosting and moderating today's public forum. Just a couple of housekeeping tips before we get started. If you haven't already signed in, we need you to sign in. And we encourage people to not be shy. If they want to speak, to mark down and -- so that you can get your thoughts down.

Today we are going to be talking about concerns around people with disabilities so that we can take that information back to our legislators and look at getting the voice of the people heard, and the people that have the concerns and what's personal to them to get that message across. So this is your opportunity, and we hope you do take advantage of that.

Just -- also wanted to let you know that when you first came into the building, the bathrooms are at the end of the hall as you walk in. So, you know if you need to use them, just go out and use them.

Also when you testify and speak, please state your name so that we have it for the record. And also panelists, if you could say your name as well, if you are going to ask any clarifying -- answer any clarifying questions -- or ask.

We are going to determine the order of the speakers through the sign-in sheet. So if you came in first, we would have you speak first. We are going to ask that you keep it down to about ten minutes. And that way, we will give a chance for everyone to speak. If your time is over and we have time at the end, you know, you would be welcome to speak again.

If you also are representing an organization, please when you state your name, state that organization as well for the record.

And we are going to, you know, maybe since we are a small group here, we could maybe have people introduce themselves so that we know who's in the audience. If you want to start?
MARTIN DECKER: I am Martin Decker. I live in Narragansett. And I have trouble hearing.
MRS. DECKER: I am his wife.
FEMALE SPEAKER: I am Anne Frank. I work for PAL, organization in Cranston.
FEMALE SPEAKER: Melissa Palmer with Beacon Health Strategies.
MALE SPEAKER: Steven DeAngelis, the Rhode Island chapter MS society.
FEMALE SPEAKER: Carol Wilson, Ocean State community resources.

FEMALE SPEAKER: Caroline Bosland. I have a brother in a group home.
FEMALE SPEAKER: Cynthia Brown, I am a supervisor at MHRH.
NANCY: That's my daughter.
FEMALE SPEAKER: Ella Whaley, parent of a child with disability and South Kingstown town council.
LAURA: Thank you, Ella.

We also have assistive listening devices available. So if anybody needs those, we can get those for you. And we also have interpreters.

And just to reiterate, the purpose of the public forums are to identify the concerns of people with disabilities and their families in order to assist the state in developing programs to improve the quality of lives of people with disabilities.

After -- when the forum is completed, the transcripts will be posted on the Governor's Commission on Disabilities' website, which is www.disabilities.ri.gov. And that will happen in about two weeks. Does anybody need me to repeat that website?

Okay. And later this summer -- just to go over the process -- the sponsoring agencies of the forums will review the testimony and prepare recommendations, which will also be posted on the website by the end of the summer. And the recommendations and the transcripts will be printed and sent to the state and Congressional officials and 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.

Okay. I think we can begin.

Just make sure I covered everything.

Our panel members are here to listen and to gain an understanding of your concerns. They may ask you clarifying questions. You are going -- like I said, you will be asked to speak in the order on the sign-up sheet. And you will have ten minutes to share your concern or idea. And I am going to help the meeting along. And we will end at 6:00.

So, thank you everyone. And we will get started. Yes, question?
AUDIENCE MEMBER: Just to clarify, a question. Can we -- introduce the panels?
LAURA: Thank you. Why don't we start at this end?
GARY: Sure. My name is Gary Brandyberry. I work for Rhode Island Parent Information Network.
NANCY: My name is Nancy Silva and I am here for Rhodes To Independence.

JOAN: I am Joan Gardiner, and I am a board member on the Brain Injury Association of Rhode Island.
VANESSA VOLZ: I am Vanessa Volz, staff attorney with the Disability Law Center.
ROBERTA: My name is Roberta Greene. I am the training coordinator and supervisor at the Office of Rehab Services.
JEANNE: My name is Jeanne J-E-A-N-N-E Behie B-E-H-I-E. And I am a commissioner with the Governor's Commission on Disabilities. And I am a vision teacher at Harmony Hill School, a parent of an adult son with disabilities, and the daughter of two parents who sustained disabilities as they got older.
NICHOLE: I'm the program manager at the National MS Society, Rhode Island Chapter.
COLLEEN: I am Colleen and I work for Department of Health, office of special healthcare needs. And within that office is disability and health.
LAURA: And again I am Laura Jones with Rhode Island Parent Information Network. I work at the Department of Health for -- in the office of special needs and all the Department of Health programs.

Okay. So let's get started. We have Steve -- how do you say your last name? DeAngelis.

Would you like us to spell that?
STEVE DEANGELIS: D-E-A-N-G-E-L-I-S. I am with the board -- Rhode Island chapter of the National Multiple Sclerosis Society. And I am here today to ask about accessible transportation, mainly taxi cabs. There was a law

passed a little over a year ago that mandated accessible taxi cabs. It's not working. There are none. Right now if you do not have someone that can -- if you can't drive yourself, you do not have someone that can drive you and RIPTA's not available in your area, there is no way for you to get around.

I know people in the statehouse worked for two years on this law. It got watered down in the last second, so there was no teeth. There was no mandate for taxi cab companies to -- as they replace their stock, to at least get one or two within their stocks. Something needs to be done about that.

And I'm sorry I can't stretch that out for ten minutes. {LAUGHTER}
LAURA: That's okay.

It's, you know, now it's in the record. And we will bring that to their attention that that's a concern.
JEANNE: Jeanne Behie. I want to respond to that. I am on the legislative committee at the Governor's Commission. And it is an issue that we have been following very closely. And we have been working with the legislature to provide some sort of legislation to support that. So it is something we are aware of and we are definitely interested in pursuing that and getting some accessible taxi cabs in the state.
STEVE DEANGELIS: If you need letters written -- let us know.
JEANNE: That always helps. It always helps writing to the legislature, yes.
LAURA: Thank you, Steve.

Carol Wilson.

Hi. Carol.

You can stand up.
CAROL WILSON: My name is Carol Wilson. I work for Ocean State Community Resources. It's a day program here providing adult day services for ten adults. And my concern is I read the governor's proposed budget, upcoming budget for 2010. And I have one young man receiving services through the rehab option program. And that program is slated to be cut October. And hopefully reimbursed -- we are funded through tax dollars. I am a little concerned that that's not going to happen. And I'm very concerned what his day services are going to look like come October of 2009.

You know, it's the most -- it's not Medicaid waiver. He doesn't qualify for Medicaid waiver through his disability, his work performance over the years. He doesn't qualify. And I'm just concerned. It's the most under-funded support services in the day vocational program. And he receives nine hours of support through -- for a week. But that's his job. So that's his income. That's his daily life. He's a husband of a woman that also receives services.

So as an agency, now how do I divide them to provide their day supports? Yes, we can take your wife. But, oh sorry, we can't -- so I was just wondering if anybody had had any idea --
JEANNE: Is he getting support from the Division of Developmental Disabilities?
CAROL WILSON: Yes.
JEANNE: Perhaps you and I can talk afterwards about something else that might be available.
CAROL WILSON: Okay.

Anything else available --
JEANNE: Family support through Division of Developmental Disabilities. Did he apply for that?

CAROL WILSON: He is -- maybe someone can help me on this. But he -- that's through Medicaid waiver, family supports. And he does not qualify for Medicaid waiver.
JEANNE: Yeah, let's talk a little bit -- when you are leaving, okay?
CAROL WILSON: Okay. Thank you.

LAURA: Okay. We -- I did have a -- somebody who couldn't be here today. Her name is Donna -- I get the last name -- Donna Gabriell G-A-B-R-I-E-L-L.

And Donna sent an e-mail saying, "Dear commission members, my sister who's disabled lives with me downstairs. She has chronic pain and fibromyalgia. She is also agoraphobic. Consequently, she never knows how she will feel from day-to-day. It's very hard to make plans for her to get out. As a result, she is very isolated. And even on good day, her agoraphobia makes her highly reluctant to want to get out.

I had South Shore Mental Health coming in here, but their funding was cut. She needs someone to do home visits. She does not want people seeing her in her condition. But she did like the counselor who used to come here. You need to make sure that people like my sister have access to home visits. She needs someone to help her figure out where to go for help, for her various medical needs as they arise.

I work full time and am not cognizant of all that is available. She takes such huge doses of medicine that she should not be driving. She often needs help to get to her doctors appointment and get her medicine. But she cannot plan on going on a bus due to her pain.

Please arrange for home visitation for people like my sister."

Do we have any other speakers?
SAM: Would you like to speak?
GAIL JOHNSTON: I was waiting for my daughter. She's going up on the elevator.
LAURA: Ella Whaley.
ELLA WHALEY: I have a letter from somebody who can't be here tonight. So I don't know if you want me to read it or just give it to you?
LAURA: Both.
ELLA WHALEY: I will give you a copy at the end for the stenographer.

This is a man who came to the South Kingstown Town Council meeting, maybe a couple weeks ago. It says, "To whom it may concern." And his name is David W. Frederick and his wife Judy Frederick.

"To whom it may concern, I bring this issue to the attention of the general public and our elected officials, appointed officials not as primary interest for my own economic milieu but to introduce and document what may well be an injustice or at the very least a situation indicating a lack of respect and reverence toward our disabled veterans returning to Rhode Island, following participation in the current global military pursuits.

My grandfather moved to Wakefield upon his World War I honorable discharge in the army around 1918. My father served in the Navy station in Hawaii, honorably discharged at the end of World War II. My wife served in the army, honorably discharged with a 100 percent disabilities rating following 20 years of service, beginning during the Vietnam era and being stationed in the Pentagon in Washington, DC.

The issue first became known to us when we received a vehicle tax assessment notice from the town of South Kingstown on July 10, 2009. We had purchased a new vehicle one year prior to this event but had never been made aware of an additional town tax until this time.

Upon inspection of the document, I noticed that we would be eligible for the totally disabled veterans service connected. My wife has 100 percent disability rating as well as veteran exemption.

I contacted the Tax Assessment Office to inquire as to the proper protocol for achieving this exemption and was pleased to find I would only need to fill out a short form. However, I was then informed that the exemption would take effect next year and would not affect the current responsibility.

I was then informed that the deadline for filling out the form was five months prior to having received the tax bill. When I questioned the possibility of retroactive installment into the exemption program, I was told this possibility does not exist due to state law.

Thus exhibits my association and reason for awareness in this situation. My immediate thoughts and perspective focused on the newly returned disabled veterans who are returning to Rhode Island and carrying with them the hardship of their disabilities to their families who are already struggling with the current economic situation. I picture them having to acquire their -- would require them transportation to and from health centers along with the acquisition of normal necessities and work. They may well need a vehicle that could carry a wheelchair or contain adaptations for missing limbs.

Then one year later, they would find a surprise tax bill added to their expenses and also told they could have been exempt had they met a deadline five months prior to their acknowledge of its existence, with no possibility of retroactive exemption status due to state law.

I also fear that this situation culmination stresses placed upon them may be seen as quite an injustice and promote a feeling of rejection from the country that they sacrificed the rest of their lives so much for. I would hate to see this event as promoting similar feelings as many of those returning from Vietnam.

One point of interest, as a suggestion towards an amenable solution would be that when the vehicle tax assessment is determined, with the transfer of information from the Department of Motor Vehicles, a listing of individuals that have been accepted for handicapped status should also be included. Or at least when given handicapped status, the individual should be given information suggesting they may be eligible for a tax exemption for a vehicle purchase.

I hope that this event will be taken under review to change the legislation which is in favor of those that have truly given exemplary sacrifices towards our culture and lifestyle as the United States of America.

Sincerely, David Frederick.

So this was brought to the town council here in South Kingstown. And we are going to be writing to the legislators that there's actually some change in the law so that if somebody does come back with serving our country and needs some kind of, you know, accommodation in a vehicle. And then there's that, you know, that they can get reimbursed, that they not have to wait until the March 15th deadline. So, we will support -- I will submit that.

And then I just have a few things that I would just like to bring forward. Support for students in high school with transition services is actually a need that I see throughout the whole state. I'm an advocate in this area for students with disabilities. And it's just an area that really needs a lot of professional development and education.

A second one is the support for the collaboratives. We have East Bay Collaborative, Northern Collaborative, Southern Collaborative. Just finding out today that if we can really support them financially; there may be some crisis with some cutbacks with the collaboratives. They do a lot of professional development and they do a lot of support, you know, with families and students with disabilities. So, some support for the collaboratives would be great.

So, transition services, support for collaboratives. My understanding is also -- hi -- that there is funding for post secondary options for students with disabilities. I don't know if anybody on the panel has more information about that or can give us a website. But my understanding is the federal government -- the state is really pouring money into post secondary institutions to support students with disabilities to furthering their education.

And then lastly, I just wanted to bring to the table that Mr. Colin Antonio at CCRI, in charge of the drivers’ education program. He really stepped up to the plate. And there was a class -- drivers’ education class that's offered with children with disabilities; that because there wasn't an enrollment of eight, that kept getting -- not being able to, you know, run the class.

He really stepped up to the plate and ran the class for some kids that will be taking their test this Friday. So we just wanted to thank him. And if there's any support that you can give to CCRI with their drivers ed, especially for kids with disabilities, it seems as though there are just lots and lots of classes offered for the nondisabled peers and you know, maybe we can run more of those classes with maybe five or six kids rather than having to, you know, have these kids put on hold until we get eight kids. You know, these kids, if they didn't run this class would have been put off from July 7. And then the class started again July 22, and they would have been put off up until the fall.

So kudos to him for doing that, thank you.

LAURA: Thank you.

Gail Johnston.

GAIL JOHNSTON: Here.

Sorry for interrupting before -- in between. But I am concerned because prior my daughter was eligible for RIde and they changed the bus route from going down South Road to going down to 108 and she lost her RIde.

Now I, in particular -- and I'm sure other people have lost the RIde too because it's maybe just a matter of a half a mile difference. I didn't know how to address it. I called the RIde program and they said, "Tough." And I didn't know if there's something somebody can do to either grandfather people in that were -- and we particularly moved to this area -- the area that we live in so that we would be eligible for RIde.

And I don't know if anyone has a solution for that. It's -- I'm sure it's for more the people in wheelchairs. Anybody have any thoughts on that?

JEANNE: I understand your frustration because my son takes the RIde bus too. I am really glad that you brought that up. And we have Bill Inlow, who

is on our legislative committee and works for RIde. So we -- I will definitely speak with him about it. And it will be in our documents to review.
GAIL JOHNSTON: I would think there's numerous people that are affected by this. I mean, not just in Wakefield but all over. And I can't believe it hasn't been remedied either a grandfather clause or extending the mileage to a two miles instead of one mile within a bus route. It seems like it would be a simple fix.

And I also have -- I am interested in your program for the taxes -- lowering the taxes on a vehicle that is handicapped accessible to get people around.

That's it.

Anything else?
SABOURIN LUSSIER: I think you said everything.
SETH AUSTIN: {Inaudible} I am also brain injury, handicapped -- I moved -- within -- since I am married -- almost a year, very close to a year. I am just getting -- just been told -- the RIde program taken off.
GAIL JOHNSTON: He also is RIde eligible in his old home with his parents and was eligible when we started, and then he lost it also.
SETH AUSTIN: That was in North Kingstown.
LAURA: Can you state your name?
SETH AUSTIN: Seth Austin.
LAURA: Thank you, Seth.

Okay. I think at this point we've had everybody that has signed up to speak has spoke. If anybody has changed their mind, they are welcome to speak. Yes, can you state your name and --
CAROLINE BOSLAND: My name is Caroline Bosland, and I have a brother who lives in a group home. He's been in the group home for about 20 years, maybe a little longer. And our family's a little concerned about what the state may have in their plans for an aging population in the group homes and in state facilities that are supported by the state. I understand that there's a crisis going on with the budget and that he may lose some of his transportation, and that's serious.

But his quality of life as he gets older is also important to us. And whether he will stay in the same group home, whether they will move him or what programs they will have for them, I don't know if this is a fairly new issue. But I'm hoping that can be addressed in the near future. Thank you.
VANESSA VOLZ: I have a question. Is your brother in -- does your brother have a mental illness or developmental disability?
CAROLINE BOSLAND: He's Down Syndrome.

VANESSA VOLZ: Okay.
GAIL JOHNSTON: Is his transportation with RIde or the group home?
CAROLINE BOSLAND: The group home provides the transportation. But we have this feeling with all the cuts that he may not even get transportation to go bowling, which he has been doing for 20 years, 20 plus years, little things that add to his quality of life.
GAIL JOHNSTON: On that similar note, my daughter Sabourin and Seth go to LaPlant. And they have activities which she can't go on because they don't have a handicapped-accessible bus.

FEMALE SPEAKER: Right. It touches everyone.
GAIL JOHNSTON: And if they do, they have it -- for run client --
SABOURIN LUSSIER: One client uses it.

LAURA: We need people to state their name, just for the record.
GAIL JOHNSTON: Gail Johnson and Sabourin Lussier.
LAURA: Thank you.

Because we want to hear what you have to say but we also want to just have it for the record.

Yes?
BARBARA KILCUP: Barbara Kilcup. I have a daughter with autism. And she is in a supported situation with one of the smaller agencies. I've heard rumors that they are looking to -- the state is looking to have the smaller agencies absorbed by the larger agencies. I think that that is absolutely not the right way to go because a smaller agency -- within a smaller agency, you know everyone. You know the staff. There's not as much turnover. I'm very happy with her situation now. Life is good. But it hasn't always been. So, I am hoping that that will be considered.

Again, I think there's something to be said for the smaller agencies that do, you know, maybe take some people that other agencies wouldn't take.
LAURA: Would you be willing to name the name of that smaller agency?
BARBARA KILCUP: I don't know whether -- again, she's with Bridges residentially and she's supported by Oscar during the day. And you know I love both agencies. And I'm just hoping that we will have the status quo and things won't change. Because life -- as I said, life is good right now. But it hasn't always been. I had to pull her out of a bad residential situation.
MARTIN DECKER: I am Martin Decker. I have hearing problems, which are not awfully bad. I just don't hear high sounds. And the problem is if I don't hear high sounds, I don't understand consonants. And so, she will tell you, I keep after her.

But the other problem -- it's associated with aging also. I am -- as the saying goes -- over 50. And that -- even with the hearing aids on -- with this, for instance, I hear the voices well. But when the bottle was put on the table and a tap of the pen on the table was very loud. And it gets a little bit like being in the middle of {inaudible} but this business is I have hearing aids. They are very expensive hearing aids. They don't take care of a lot of things.

Yesterday I was pretty upset. I think my wife and granddaughter were more upset. We were -- I was driving. We were in the middle of a traffic jam, bumper to bumper on Route 4. And I didn't see the ambulance coming behind me. But I also didn't hear it until it was right there.

And it's not severe. It's not severe. It's frustrating. And the other thing, if you talk about aging people, there are a few million aging people with this problem. And the problem is how to get assistance to those people who can't afford hearing aids because it becomes very essential to have. Because even with them, Martha will tell you, I can't respond to questions if I don't see their mouth moving. I lip read. And if somebody in back of me says something or if somebody's chewing gum and says something, all I hear is a bunch of sound. I don't hear words. And that's -- this is not a small problem in our society at this point. And I had no idea how to handle that. Except I know it restricts life for a lot of people. Thank you.
LAURA: Thank you.
GAIL JOHNSTON: Are you looking for any more topics?

Again, my name is Gail Johnston. My daughter Sabourin is here. She has been on the waiting list for help to get an apartment for two years. I

didn't know if anyone was here from the housing?
LAURA: No.
GAIL JOHNSTON: The issue was she was looking for housing in South Kingstown through South Kingstown Housing Authority. And she was put on the waiting list. We were told that she would -- because she was disabled, she might be able to move up on the waiting list. But they have never done that.

It's been almost three years she's been on the waiting list. They won't talk to me about it because they only will talk to my daughter about it. And I can go in with my daughter. But they don't want to talk to either of us. They just keep saying, "You will have to wait."

And I know people are getting it. But I don't see that she -- maybe she shouldn't get any priority. But if they are going to say there is priority, there should be priority. Otherwise, they can just say wait on the list. That's fine. But I don't like being told one thing and have something else happen.

And then maybe she can get a RIde.
JEANNE: I have a question.

Jeanne Behie responding. Sabourin, is it that you want to stay in South Kingstown, too?
SABOURIN LUSSIER: Yes.
JEANNE: I know there was an ad in the paper a few months ago. There was some housing in Hope Valley and they were looking for people with disabilities to apply for there. But you want to stay in South Kingstown?
SABOURIN LUSSIER: Um, preferably. But I was -- I'm Sabourin. I went to the housing authority a little while ago and they actually told me that they're working on the list. But they're starting from 2006. So those -- all those people that are on the list from 2006 are now getting housing. And so now I have to wait another two years to get on the list where I should be now due to priority with being disabled.
LAURA: Well, I think it's good that we are getting this in the testimony. And hopefully it can be addressed, the housing shortage.
ELLA WHALEY: Ella Whaley. Sabourin and Gail, do you know who you spoke to at the South Kingstown Housing Authority?
GAIL JOHNSTON: I have one man who answered me. First they couldn't find her name on the list. We waited a couple years. Then we went in to see how much longer it might be. And they said she was never even on the list. But then we got a call and I kept the call and the person says who he is. And he said that they found her name on the list. But it will be a while. I can get that name --
SABOURIN LUSSIER: Hold on. I think I might have it with me now. But I'm going to look.
ELLA WHALEY: They can give it to me later.
LAURA: Barbara, did you get a chance to speak?

Yes. Okay.

Is there anybody else that has a concern and would like to speak?
CAROLINE BOSLAND: Caroline Bosland. How many cuts -- how many more cuts are they going to make? I mean, I hear transportation a lot. Are they going to make cuts in other areas besides transportation for these disabled people?
CAROL WILSON: That's the proposed budget. Carol Wilson. I just gave her the proposed budget.
FEMALE SPEAKER: You people are very quiet up there.
LAURA: Well, one of the reasons they are quiet is we are not really allowed

to -- we are biting our tongues.
FEMALE SPEAKER: Oh.
LAURA: We are allowed to ask clarifying questions. But this is the public forum. So it's your opportunity to, you know, let your concerns be known and --
GAIL JOHNSTON: Well, I do have to say I don't live in this state anymore. Neither does my husband. And we had full intentions of bringing our daughter with us and assumed that all the states were as good as Rhode Island with benefits. And I have to say, Rhode Island does a wonderful job with benefits compared to other states.

I was always under the impression there was a lot of federal help with state help matching. I'm not really sure that that's the case. But there was really nothing that would be like going back into the ages. No transportation, relatively little day work, day habitation, nothing. There was no help. So that's why my daughter is still here.

So, amongst all the complaints I have, I know it's the best place for my daughter.
LAURA: Okay.
ELLA WHALEY: Ella Whaley. I will add three more to the list. Just support for Division of Developmental Disabilities and also Rhode Island Disability Law Center. My family has been involved. And I just think they are absolutely a great support for families with, you know, children that have disabilities. So if the funding can continue to support Rhode Island Disability Law Center, as well as DDD and the home based, therapeutic services, that still needs continued funding.

And I haven't seen the budget. So when you are done, Carol, if you could pass it. I would like to take a look --
CAROL WILSON: It's on-line.

Carol Wilson. It's on-line, the budget. This is just the proposed budget. It -- I don't know if it's got through, to be honest with you.
JEANNE: Jeanne Behie. I want to say too that it's really important to write to your state legislator. You all brought up issues, hearing aids through insurance, cutting programs. And our legislature really listens to us. So please write -- get family members to write. Get relatives to write. Get friends to write about issues that concern you because that's a way to ensure that the programs that you are interested in don't get cut.
LAURA: And we would also like to hear what is working so we can also pass that down to the legislators, as well as what is not working. So, you have been able to tell us some of that as well today. So that's good.
GAIL JOHNSTON: Gail Johnston again. I heard somebody talk about Oscar, and they were very happy with Oscar. We chose PARI, and we are very happy with PARI.

Some of the other problems that we've had is there's a long waiting list for habitation through the state. I believe its called rehabilitation? And I think there's only 40 slots in the state. I don't know if that's going to change. And that program helps people learn how to -- through repeat -- repetitive things, learns how to cook. Even though they -- you can't just show somebody one or two or three times how to cook. And that program I would think would help a lot of people too. But there's limited slots apparently.
LAURA: Does anybody else have any testimony that they want to include?

Okay. State your name.
MARTIN DECKER: Martin Decker. I just want to say there's a lot of

excellent aid available for those with a total loss of hearing or severe overall hearing. I have tried to get into research programs and other programs that are available. But my hearing loss is not enough. And it's very frustrating because it may not be enough. But it's very, very frustrating.
MRS. DECKER: The cochlear implants they want him --
MARTIN DECKER: They won't talk to me. Or at Brown University said my hearing -- I have good hearing up to about a base voice. And then -- by the time I get up very high, I have no hearing at all. And that interferes with hearing for a lot of people.
LAURA: Well, unless anybody else in the audience has anything else to add, I mean, you may think of something. We welcome your comments.

I wanted to open it up to anybody on the panel who may have some concerns that they want to add into the testimony. You can take off your panel hat and put on your -- either consumer or parent's hat at this time, since we do have lots of time. And just -- I will give you that opportunity since we are all here and we have extra time.

I will start. {LAUGHTER}

Laura Jones. I have a son who has a diagnosis of Asperger's syndrome on the autism spectrum. He is 24 years old. And I know that once children become adults, a lot of the services go away, and a lot of their needs change. And so things like opportunities for friendship and socialization are really difficult for him. Also the need to have skills like job interviewing skills, and such make it really difficult for him as well as some of the mental health issues that go along with that around depression, anxiety.

And I know that there's a lot of young people who are now young adults, who many of them are very well educated, but they're collecting SSI. And they are living with their parents. Many of them in the basements of their parents' houses and not receiving services. And I would just like to see that some attention be brought to that group of individuals.
JOAN: I am Joan Gardiner with the Brain Injury Association of Rhode Island. Everybody is talking about how much things are getting cut because of the crisis in the state. Right now one thing that the Brain Injury Association resource center really benefits from is a state grant that we received a couple years ago for brain injury services. It's through the Department of Human Services, DHS. And it is very beneficial to what we do at the Brain Injury Association of Rhode Island to help people with brain injuries.

I am a survivor of brain injury, traumatic brain injury. And that state grant provides a lot of monetary resource for the Brain Injury Association to keep employees, staffed to help people with brain injuries. And I'd hate to see that being cut.

So, if we could just let everyone know up at the statehouse how important that is.
LAURA: Thank you.

Jeanne?

JEANNE: Jeanne Behie. And I want to attest to the services that the Brain Injury Association of Rhode Island provides because I mentioned that both my parents became disabled as they got older. They both sustained brain injuries, one through a stroke and one through a traumatic brain injury. If it wasn't for the Brain Injury Association, they provided me with information about what to expect when my mother was in a coma. And we wouldn't have been able to make the decisions, the medical decisions that needed to be made without some of the support that I received from Brain Injury Association. So that's really important.

And one of the things I also want to bring up is that a dear friend of our family's has a brain injury. And he's been out of state for three years at a residential placement and is ready to come back to Rhode Island but is unable to come back because there are no group homes in the state that provide services just for people with brain injuries. And that's a need too, to provide the services here in the state so people can be in their own communities and not be out of state.
JOAN: Joan Gardiner again. I thought that they had set up a home --
JEANNE: In Charlestown.
JOAN: Yes.
JEANNE: Because of budget cuts, everything is on hold.
JOAN: Oh really?
JEANNE: Yeah.
GAIL JOHNSTON: Gail Johnston again. Laura, I can sort of understand yours -- there's a lot -- there's no socialization or no groups or no -- nothing for these young people to do. It's -- I know that if you live closer to Providence, I notice there's group meetings for here and there weekly and stuff for the young adults to do. But there doesn't seem to be a lot down here in South County. I didn't know if you were from South County.
LAURA: Yes, I am.

Well -- Laura Jones -- one of the things I always say that I think my son could benefit from is a life coach. And that would be somebody that could just give him some coaching on how to get out there, how to -- sort of what the social rules are, that kind of thing. So that he -- because he's very cognizant of not wanting to be different, not wanting to, you know, really -- he doesn't really want to go out and get services per se. He wants to live a life that's normal that's like everybody else.

And so, I think if he had somebody that could be like a life coach for him. But, of course, there's no funding stream for something like that. It's not -- what he needs is not something that's a medical model, if that makes sense.

MRS. DECKER: Martha Decker. Wouldn't an occupational therapist help him?
LAURA: Could. But I think what he really needs is more of a friend, a mentor, somebody his own age, somebody that could help him. How do you flirt with a girl?
MRS. DECKER: Oh.
LAURA: How do you make plans when you are going to meet up with friends? These are things that seem really easy to us but are very difficult for him.

CYNTHIA BROWN: I can't help you in terms of the interpersonal skills. But the coach center received a grant in terms of folks that weren't necessarily in other programs to work towards resume writing, those interview skills, the interpersonal, how to answer those questions. Sometimes folks with Asperger's have difficulty responding appropriately. It is funded through a grant. So it's not something they would have to be on a waiver for. The contact person is Dana Spencer at the cove center. It's run out of the Coventry -- a building in Coventry.

Cynthia Brown from DDD MHRH.
LAURA: Thank you.
BARBARA KILCUP: Barbara Kilcup. I just want to say there's a group that meets every third Wednesday here at the Guild called Our Voices Count. It's

a self-advocacy group where there's a whole range of disabilities represented. And it's -- the third Wednesday of the month that -- I think its 6:30 to 7:30. They have done a cleanup in town. You know, trying to get more involved in the community. So, anybody that is interested is welcome to come. It meets right here.

LAURA: Thank you.

BARBARA KILCUP: Also they are affiliated with Advocates in Action, which is another self-advocate -- a state self-advocacy group. And a lot of these smaller self-advocacy groups are linked with them. And they provide a lot of social activities as well. And they are on-line -- A and A something. You could look up Advocates in Action in Rhode Island and you should be able to find it.

LAURA: Thank you.

JEANNE: Jeanne Behie. I want to bring up health insurance. And I know people with disabilities, many of them are eligible for Medicaid. But some people, especially people 20 to 30 year olds have been finding that they are not getting health insurance. Maybe their disabilities aren't great enough. They may only be working part-time. So, that's an area of concern.

I have a 24 year old daughter who has asthma. And she's been on our health insurance for the last few years and she will be taken off in November. And she's working part-time, hasn't been able to find a full-time job yet. But we have concerns that she won't be able to get coverage for her biweekly allergy shots.

And also I want to mention adults with disabilities have been eligible for Rhody Health Partners, which is a managed healthcare program through DHS. And they have their choice with participating with Neighborhood Health Plan or a group of primary care physicians with a nurse practitioner as the case manager.

That's been wonderful for my son. He was receiving services through Neighborhood Healthcare, which I have to say is one of the most comprehensive health insurance plans around. But because he has dual insurance -- my husband is a federal employee and he was able to get life coverage for our son who has a number of medical conditions through the federal government because my husband works for the federal government. When Neighborhood Health Plan found out about our dual coverage, we were kicked off -- not we. But he was kicked off June 30th. He didn't receive any letter. I was calling to make transportation arrangements for a weekly medical appointment he had. And Neighborhood Health managed that he was losing his coverage as of June 30th.

It took days of phone calls for one person to another to find out what the reason was. And then I was finally told it was dual coverage.

And I worked at South Shore Mental Health Center up until December. And we saw a lot of children with dual health insurance getting less services than people -- than kids that were just getting Medicaid. And it's kind of hard to believe. You would think that people that had Medicaid and private insurance would get better coverage, but it doesn't work out that way.

That's a concern I have is that it's about time people with dual health insurance get the same coverage as people with Medicaid.

CAROLINE BOSLAND: Caroline Bosland. I can't help but think that perhaps going to retired people that have recently retired from work, have raised families and might make -- they might make good mentors. They might enjoy it as they -- part-time type of thing. That would have to be organized to do that. But there are many out there that are trying to find something

worthwhile to do. And they might opt to do that. Either that or go to the colleges and see if you can get students in their junior and senior years that could get credit for being mentors. That may have been tried. I don't know. But that's another way to go.
LAURA: I think that's a good point. As cuts happen in our state, we are going to need to get very creative.
CAROLINE BOSLAND: Volunteers.
LAURA: At this time, I just want to let everybody know that you are welcome to stay. However, if -- feel free to leave at this point. We are going to be here until 6:00. If -- in case anybody else joins us to testify. But you do not have to stay until 6:00. But you are welcome to stay with us, if you'd like.

If there's anything else you would like to add or -- if you are mulling over things in your head and you think something will come to you, you are welcome to stay. But I just wanted to give you that option that if you are through, we will be staying here to listen to further testimony if people come in. There may be people that come after work and will join us.

I also want to add that if anybody has any further concerns that they think of after they leave, you are welcome to write them down and send them in to us, the Governor's Commission on Disabilities.
JEANNE: They can go to the website.
LAURA: You can go to the website.

Cumberland | 7.30.09

NANCY: Are we ready?

Okay. Hello. Welcome everybody. So, I have to do some housekeeping issues and just go over some basic things first. And then I will introduce the panelists that we have. And then we will open it up for people who signed in and said they wish to speak. If you didn't check that but you feel compelled later on, that's perfectly fine. We just ask that each time that you do speak, that you state your name. Okay? And then if we don't, we will get a gentle reminder.

So, the purpose of the public forums is to identify the concerns of people with disabilities and their families in order to assist the state and develop programs to improve the quality of lives of people with disabilities.

I need to point out the exits and the restrooms. If you all came in the back way where -- down the hall, I think on the left?

Okay. So a few more people are coming in. I'm Nancy Silva. I am actually a native of Cumberland. I lived here all my life. A great place. I'm glad I got to host this one. I will be the moderator for today.

I work for Rhodes To Independence and I also work for a program called Rhode Island Parent Information Network.

So, I will let the panelists introduce themselves. And they will tell you which agencies they work for.
CATHERINE: I am Catherine Sansonetti. And I am a representative of Rhode Island Disability Law Center today.

STEVE: Hi there. My name is Steve Florio. And I am the Director of the Commission on the Deaf and Hard of Hearing and I'm Deaf myself. My agency basically promotes and raises awareness and provides advocacy for Deaf people and Hard of Hearing people. For the most part, we talk about communication barriers, barriers to access, and other laws that cover that issue.

So, if anyone here has a hearing loss, please come and visit us. Tell us about your situation, your family, your parents, your grandparents. We'd love to hear about it.

We are always interested in any situation you may have at work or at school. Have a great day.
ARTHUR: Arthur Plitt, Commissioner Governor's Commission on Disabilities.
ELIZABETH CONNALLON: Elizabeth Connallon, from the Brain Injury Association of Rhode Island.
LEZLEE SHAFFER: And I am Lezlee Shaffer. And I am representing the Ocean State Center for Independent Living.
LINDA: Linda Deschenes, Office of Rehabilitation Services.
NANCY: My little helper over there is Daniel. That's my son. He's taking care of drinks and cookies. Okay.

Yesterday -- I don't know if anybody feels comfortable -- in Wakefield we went through and we gave the audience a chance to state who they are and -- do you all feel comfortable doing that?

Okay.

We will start with you, if you don't mind.
FEMALE SPEAKER: I am Anne White and I too am from Cumberland. And I am here as a concerned citizen of -- wife of a man with disabilities.
NANCY: Okay.

MALE SPEAKER: I am Kenneth White and I am a diabetic and I am legally blind.
MALE SPEAKER: My name is Brian White. And I am here to support these two.
FEMALE SPEAKER: My name is Barbara and I am a stenography student. And I am here to observe Jen Moore. {LAUGHTER}
NANCY: Okay.
FEMALE SPEAKER: I am Jane Douglas. And I am from Cumberland. And I am a concerned parent of my son is at Blackstone Valley.
FEMALE SPEAKER: I am Rosemary Reilly and I am here to advocate for my grandson, Nicholas Valwa.
FEMALE SPEAKER: I am Susan Hayward, casework supervisor. We are the disabilities -- and acting administrator of the division.
FEMALE SPEAKER: Ella Parkinson, community resource at Neighborhood Health Plan for children and special healthcare needs and adults with disabilities.
FEMALE SPEAKER: My name is Lauri, registered nurse at Neighborhood Health Plan Rhode Island. I am a medical case manager with health partners.
NANCY: Go ahead.
FEMALE SPEAKER: I am Kathryn Morrison, a potential -- {inaudible}
FEMALE SPEAKER: I am Elsie Morrison. I am Kathy's partner and also a shared living provider in the city of Providence.
MALE SPEAKER: I am David McMahon. I work for the state of Rhode Island, professional services coordinator.
NANCY: I went to school with you, didn't I? {LAUGHTER} probably a Cumberland thing,
FEMALE SPEAKER: I am Barbara McCrae. I worked in the field for -- since 1978 with adults with developmental disabilities and many friends and I am an advocate for them.
MALE SPEAKER: I am Rolf Justin with UCP. And I worked with the vote project.
NANCY: My name is Nancy, and I work for the Rhode Island cerebral palsy. And I am one of Rolf's staff.
FEMALE SPEAKER: I work under the Office of Diverse Learners in the Department of Administration.
NANCY: Okay. We have some more people I think coming in, wonderful.

I guess I also just need to explain that the postings of the transcripts will be -- of the testimony today will appear on the Governor's Commission website and the website is www.disabilities.ri.gov and that will be in about two weeks.

And later this summer, the sponsoring agencies will review the testimonies 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. The next -- the recommendations will be used to develop policy and legislative initiatives for the next year or until they are accomplished.

We want to give everyone a chance to speak. And as I said, if you changed your mind once the conversations get going, just raise your hand and just state your name before we start.

This is important to understand. The panel members are here to listen and gain understanding of your concerns. They may ask clarifying questions. But as a general rule, we are not here to comment or -- of that nature.

So, we have your names if you wish to speak. We ask that you take roughly ten minutes. But I have been finding that that seems to be ample for anybody. If you need more time, we can come back to you.

And I think that's it. I think I covered all this. Sam, I covered all the housekeeping stuff?

SAM: Perfect.
NANCY: Good to go. Okay.

So the first person I have that looks like they would like to speak is Rosemary Reilly.
ROSEMARY REILLY: My name is Rosemary Reilly. I live in Cumberland, a lifelong resident of Cumberland. And I am here on behalf of my grandson, Nicholas Velwa, 23 years old and has Duchenne's muscular dystrophy. For the past two years he has resided in a group home operated by West Bay. This has been a wonderful environment for him, providing him with needed care and opportunity and companionship.

Over the holidays, and in January and February, he was hospitalized at Rhode Island Hospital with pneumonia and returned to West Bay. But last month, he was hospitalized again. Once he recovered the pneumonia and was ready to be discharged, some troubling events occurred. A physician at the hospital felt that he should be discharged immediately to a nursing home. West Bay wanted to accommodate Nicholas but needed to secure a regular nursing care until Nicholas was fully rehabilitated.

At one meeting, a Rhode Island Hospital doctor was so obstinate that he threatened to remove Nicholas' healthcare. This was unprofessional and an inappropriate bullying tactic. His condescending demeanor and hurtful words left Nicholas in tears. West Bay wanted to continue discussions with the hospital. But the physician refused to attend the meetings, insisting he should be in a nursing home. I have all the names of these people too, if you are interested.

Nicholas was transferred to the Jane Brown Unit until his parents could investigate nursing homes. One nurse tried to get him to stand up, not realizing that he couldn't stand. Another nurse yelled at him to "work with me" while she moved him, again, not understanding the severity of his illness.

Presently, Nicholas is residing in the basement floor at Pine Grove Nursing Center. This environment is not good for Nicholas. There is no one he can talk to and no opportunities for social interactions with other residents.

He sits by himself in the television room. There is no wireless internet or other technology. I have been there several times and noticed a strong urine smell in the center each time.

He is bright and articulate, so social interaction and stimulation beyond television is important for his overall being. And I also want to add that he was a graduate of Lincoln High School, CCRI, and finished his first semester at Rhode Island College.

Nicholas needs to be back at West Bay or a similar environment. The events I described are not aligned with the principles and values posted on the developmental disabilities page on the MHRH website. Services are not responsive to his situation. There is no longer the opportunity to develop and grow within a community environment. There were instances where he was not treated with dignity and respect and not allowed to exercise his right to choose. This nursing home is a higher cost for care and is a restrictive environment. I am asking you to be the catalyst and Nicholas' decision to remain at West Bay and provide the needed services.

One bright light according to Nicholas from the beginning is Susan Verone, a social worker at MHRH. And I just heard that you are her boss, her -- executive. So that's great.

So she strongly advocated for Nicholas and continues to do so. Please support her immediately in her efforts to help Nicholas remain in the West Bay system.

And then as of this morning before I came to this meeting, I heard from my son, Nicholas' father Daniel Reilly and West Bay according to John DeMarco, who is the Executive Director of the West Bay group homes. He needs $168,000 to hire and to accept Nicholas and six other residents at their home on Dawn Avenue in Johnston.

It is costing the state $860,000 for the seven people, if they were in the nursing home situation. And if they were at a facility such as West Bay, it would cost $360,000. So there's quite a difference in that care.

I thank you for listening to me. I know there are many other people besides my grandson, who is the light of my life, one of them. I have 12. {LAUGHTER} But he really deserves better. He's an exceptional person. He's extremely smart. The thing is, his body is not like -- so I thank you for your time.
NANCY: The next person is Kathryn Morrison.
KATHRYN MORRISON: Hi. My name is Kathryn Morrison. And I am a potential provider agency. Some of the questions that I have just for the council, if possible, they could be answered. What plans are there to improve the quality of services for adults with disabilities? And what are some of the possible employment opportunities available to adults with disabilities that may -- that have the potential to work in a regular environment? Thank you.

LINDA: Just one clarifying question. When I hear "potential provider agency," I guess I'm unclear what you mean? Like -- are you talking about employment network or --
KATHRYN MORRISON: Just some of the ideas that we have are just to help further provide a progressive service that will help adults with disabilities not just stay in a day habilitation service but move forward to a sense of independence at their own level.
NANCY: Did that clarify?

Okay.

Yes, no?

Everyone's all set?

Okay.

The next one is Barbara McCrae.
BARBARA MCCRAE: I hope you don't mind if I stay seated. I have a very bad knee.

Like I said, I've worked in the field and have worked for people with developmental disabilities since 1978. Last year I was diagnosed with a benign brain tumor, meningioma, surgically removed last year. I use the RIde van for a year. And better understand the need for some help.

I've always been very supported of people with developmental disabilities and understand how it is important to them that the person that works directly with them affects every day of their life.

And there is a lot of money, I believe in the state already. And our system is not perfect, like you really nicely said, but unfortunately had to say.

And now we are in -- there's a lot of money there. But it doesn't seem to filter down. And right now with the global waiver, starting in January, pushed through very quickly. And there's really nothing in place right now. And it's still July 1. There's information isn't being passed out. It's very much a closed system and people aren't finding out what the changes are going to be.

And when it affects the quality of your life, you know, choices to be made, what you like to do, social interaction, all those things, choice in where you live is like one of the most fundamental parts of the quality of our own lives and who we live with.

And -- let me just check my notes. I remember now. I have a little memory problem.

As information and decisions are made by the state with some help from the illustrious task force, as Gary Alexander describes it, the information and the decisions that are made must be not only passed down to all of us, but it must be passed down to people with disabilities, the elderly with cognitive issues, children in formats that they can understand so that they know what they are making decisions about before you can say or consider them giving conformed consent -- informed consent. I'm sorry.

And that's I guess basically how I'm feeling. And the system for parents and family members, even with agencies -- and though it's more expensive provider support agency, there have been parents in my career who have said to me that they hope they die before their child because they are not sure what kind of supports are going to be in the future for their child. And an agency provides some kind of security, a support agency, they are more expensive. Support some kind of security for parents and for the people receiving that support that those services will continue. So we don't want to just go for the cheaper type of supports, okay. I guess that's it.

NANCY: Okay. Sam, did any -- did anybody want to add or -- you would like to? Could just state your name again?
ANNE WHITE: I am Anne White and I don't have notes. I don't have notes. And we are battling with these issues on a day-to-day basis in just trying to find an avenue out. My husband is legally blind and he is a patient at Koch Eye. We are in a quagmire between Koch Eye and insurance that refuses to pay for a treatment that has been effectively restoring his vision. It has been a year now that we had that insurance. The vision has deteriorated to the point where he basically -- he doesn't see.

And we can't -- we tried contacting the pharmaceutical company. We've contacted Koch. We contacted Edna. We are presently drafting a letter to Patrick Kennedy. And we just don't know where to go.

But it seems to me if there's a treatment out there that clearly has improved -- he had one treatment and it brought his eye sight 20/400 to 20/50. So clearly it works. And because the insurance company has deemed it too expensive and experimental and not enough clinical evidence, they refuse to treat or they refuse to pay.

The pharmaceutical company agreed to lower the price of the drug. But again, Edna says this: They will pay if the treatment is done in the doctor's office. The doctor's office says they cannot. It's a surgical procedure. It has to be done in the surgical office. And that's where we are stuck.

So every day his eye sight gets worse. And every day we are not making any progress. And I just -- I need to know where we can turn next. Is there any avenue that we have available to us?

NANCY: Okay. Susan Hurd. How is that for timing?
SUSAN HURD: I didn't even get to sit down.

Hi. I have some handouts. My name is Susan Hurd. And I am here to represent people with hidden disabilities, including myself. I contend with multiple neuroimmune disorders, including Lyme disease and chronic fatigue and multiple chemical sensitivities.

Multiple chemical sensitivities is a serious issue, especially with housing, that I really believe Rhode Island needs to be paying more attention to. There are simple solutions that could provide accessibility and it's not taking place.

There's over 4 percent of the US population that's disabled with MCS, multiple chemical sensitivities. That's 12 million people. From my understanding, correct me if I'm wrong, there's less than 1 percent that are disabled in wheelchairs. There's less than 1 percent that are disabled with hearing and visual impairments. There is only one HUD MCS accessible housing complex in the whole country. And that's located in Marin, California.

One, that's like providing only one wheelchair accessible housing complex in the whole country, yet there's 4 percent of the population that's disabled with MCS. MCS is a hidden disability and it causes invisible barriers.

Simple things like using zero to low VOC paints, which are now accessible at places like Home Depot. They are price comparable and affordable exist. That makes all the difference whether I can be in a building or not. It's price comparable. It's not costing thousands of dollars. It's cost thousands to have elevators, wheelchair ramps, automatic doors for those who are wheelchair disabled.

Like those who are wheelchair disabled, those with MCS also need accessibility. I have been struggling now for over two years to find an affordable place to live. I am threatened with homelessness. I am well-spoken. I am educated. And yet I have these barriers taking place. One of the things that constantly I'm up against is places have brand new paint. They have new carpeting. I'm automatically -- that's like for a person with a wheelchair who doesn't have a ramp provided. I can't be in there. If I go into buildings that have new paint, new carpeting, other materials that are out-gassing, I get very sick. I become poor functioning. It is causes neurological impairments. The result of it is I cannot often find an affordable accessible place to live. I can't even go into a homeless shelter for the same reasons because accessibility isn't being provided.

It's a serious issue. MCS is just as serious as other medical conditions like cancer or AIDS. It is potentially life threatening. It can cause seizures. It can cause anaphylactic shock, neuromuscular degeneration. I have a close friend who deals with MCS. They had a chemical spray exposure. They live in the south. Three times they have been put in the hospital from chemical spray exposures. Their nervous system for their digestive system shuts down, meaning they need feeding tubes and they can't void. They can't eliminate natural body functions.

Myself, when I get chemical exposure, sometimes because it's a neuromuscular effect, I won't be able to swallow. Therefore food can get caught. Then I could choke. I could have anaphylactic shock. I could have seizures.

Every time things like chemical sprays are used in buildings, on the lawns, that prevents accessibility. The neurotoxic chemicals, they are carcinogenic chemicals. There are safer, less toxic solutions. There's organic and nontoxic lawn care. There is nontoxic pest management available. And it's all price comparable. Yet it's not taking place.

These are simple things that could be taking place, but it is not. So the barriers become -- if there's lawn chemicals outside of this library, that can prevent accessibility. If you have a new carpet in here, that prevents accessibility.

I was -- I am a success story. I was able to rehabilitate myself well enough so I could go to school part-time, get my masters, my post masters in holistic mental health counseling in Salve Regina. I also created my own internship at the rehabilitation hospital, the only holistic integral medical clinic in Rhode Island. And I turned it into an independent part-time contractor job. I am still disabled. I am dealing with a whole disability to transition part-time work program. I am very grateful for the assistance that I have been given. Yet even at the hospital, what do they do? They use the high VOC paint.

It's over 72 percent of people with asthma and respiratory conditions are triggered by high VOC paint. The clinic is fibromyalgia, other immune disorders with pain and fatigue. Yet 60 percent of people with fibromyalgia deal with chemical sensitivities.

Over 40 percent of the whole US population is chemically sensitive. Some of you, for example, may have perfume sensitivity. You get headaches. Maybe you get a runny nose or you start getting a little wheezy or asthmatic. Those are all chemical sensitivities, 40 percent of the population. When a child crawls on a high VOC carpet, they inhale the equivalent of three cigarettes worth of high VOC's daily. That's -- VOC's contain things like formaldehyde, which are highly neurotoxic and carcinogenic. Yet we are still allowing these things to take place.

Not only that it's not just those disabled with MCS that benefit. When you have 72 percent of asthmatics, 60 percent of people with fibromyalgia, 40 percent of the population, which increases every ten years, this is benefiting many people, millions, a large percentage of the population.

Since most of these chemicals are not only neurotoxic but carcinogenic, you are adding the percentages of how many people are dealing with cancer daily. Obviously we need to go and start right here. Rhode Island's the smallest state. Therefore, we can more easily have contact and communication organization. It's not happening.

I tried to show up last year for the GCD legislative committee meetings. People were wearing perfume. That makes me sick. I was not able to show up. I wanted to do -- I speak well. I wanted to do what I can and have the information. I suggested a subcommittee because MCS is so complex in itself, dealing with housing, medical issues. I don't really know what to do. But I'm here and I'm speaking out. Maybe through the testimonies being documented people listening, that somehow some change would happen.

I brought some suggestions that can be passed around. I have contact information, if anyone wants to speak to me later.

Thank you.
NANCY: All set?

Okay.

Yes? You would like to speak, if you could state your name, please?
JANE DOUGLAS: I am not on the list of speakers because I didn't see the list. But anyway, I have my spiel that I have said numerous times in the last three years.

My name is Jane Douglas. I have a son Robert who's 51. He grew up in New York in West Chester County. And after high school, which is -- was a special high school graduation; he worked in a workshop where he was trained to do maintenance work. He also worked in the summers in the city park. He comes from a very hard-working family with a strong work ethic. He has no respect for the less ambitious people in our extended family.

After my husband retired, we went to Florida where he lived in a town called Naples, where they had a very active program for the handicapped. There he had many jobs, some of them limited by time, dependent on the tourist season. He was busier in the tour season and in the summer. But he always had a job doing maintenance work, at one time the Ritz Carlton hotel, the mall, food court.

And then we lived in a town called Cape Coral about an hour north of Naples. And my husband's health wasn't too good so we had him move to Cape Coral. And there he worked in Wendy's for five years as a dining room attendant.

Then he was in an accident where his father was killed. And my only other close family is in Cumberland, Rhode Island. So I made the decision to move here, feeling that the same services would be available for Robert as in Florida and New York.

This did not prove to be true for him. And every day when I talked with him -- I am going to be seeing him today -- and I know he's going to say, "Mom, I really would like to have a job in the kitchen or doing maintenance work." And he goes to a workshop. One of them, he is allowed to do some sweeping. But he's not allowed to mop the floor, something he was trained very carefully to do.

I don't think that it's going to happen for Robert. However, I think there should be an emphasis on working in the real world and that it fills a social need. It fills an emotional need, a financial need, and it's so important to people like him.

Thank you.

NANCY: If I may, could you just give me an example of the services that he received in Florida but yet he wasn't able to get here? Were they employment services or --
JANE DOUGLAS: An agency, which -- that was one of their missions? Find a place to live in the community and find a job. And it was just a case of where would they find a job.
NANCY: So the agency helped him with the job search and --
JANE DOUGLAS: Right, and provided a job coach as long as it was needed.
NANCY: And he was not able to access a job coach or that similar agency in Rhode Island?
JANE DOUGLAS: No.
NANCY: Go ahead.
ARTHUR: I think I remember you speaking last year.
JANE DOUGLAS: Probably.
ARTHUR: And I thought there was an agency that was going to work with you. That didn't take place?
JANE DOUGLAS: Well, he went to Blackstone Valley because of my age and his age. An opportunity came for him to live -- which he had never lived with me for many years. And I didn't have access to -- I had some social programs that I could take him to. And he went two days a week to a day program. But he really wanted to be with a peer group. So, he is now in Blackstone Valley where he lives. He shares an apartment in a sheltered apartment building and he goes to a workshop.

And I don't think that's going to change.
LINDA: Again, I also remember you speaking last year as well, Jane. Again, I know -- you had some exposure with the Office of Rehab Services when you first moved here. But I would highly encourage again, if your son wishes to apply, because then our agency can go back and work with Blackstone Valley on his next step in his goal and go back and kind of connect with the agency he is with right now to help him. I did bring some applications with me. I would be happy to give one to you when we are finished talking. Thank you.
BARBARA MCCRAE: I would just like to say --
NANCY: Could you just say your name first.
BARBARA MCCRAE: Barbara McCrae. That there doesn't seem to be enough money for day supports for people that want to work. And whether the funding that goes with the person for -- to a workshop or whatever isn't -- I don't think -- enough to provide a job coach. And that's the problem I think.

So some people go to a workshop and are either stuck there or doing like the sweeping within the workshop and don't really have true access to employment, unless they can pick up the job quickly and do the job. And their employer -- the job coaching, you do have a lack in Rhode Island.

And also I would like to say one thing that I was kind of emotional because of your story. I'm sorry that I don't remember your name -- about your grandson, right?

And I just want to say that the homes -- I spoke about agencies. And I believe that there's a need for that type of group home or supported apartment living. But I also think there's a full range of other options that can be less expensive too, if that's what a person can be supported using, like supported living arrangements or living with their family with support or finding an apartment on their own with supports coming in; that there's a lot of other types of home support. But it has to be individualized for the person.

And the other thing I would like to do -- I asked Rolf if it was okay if I introduced him and told a little bit about him.

And Rolf, if it's okay, right?

Yeah. Rolf was born with cerebral palsy and he lived with his family for a long time. He went to special schools which he wrote his autobiography. And he always felt -- I don't know -- badly about that term. And he got married, has two sons, has two grandchildren. He just went down to Florida to visit them.
FEMALE SPEAKER: One on the way.
BARBARA MCCRAE: Another one on the way. That's new news to me.

And Rolf -- so Rolf did very well for a number of years. But because it's difficult to understand Rolf when he speaks, and because he's limited in getting around, people make a judgment about who Rolf is. And there is a huge amount inside of Rolf that you cannot see. And Rolf now lives in an apartment program, run by United Cerebral Palsy; which is the way that apartment is set up is they all have their own front door and there's staff, support people throughout it. It's been a wonderful option for Rolf.

He was, however, because of circumstances in his life, when his marriage and different things, it's hard to find housing. And things happen that happen in all of our lives. But because of his disability, where did he end up, in a nursing home? And a nursing home -- how many people were in your room? Did you have your own room?

Five people sharing his bedroom with. And he was young at the -- fairly

young. In your 50's, in his 50s?
FEMALE SPEAKER: Restricted to bed. He doesn't stay in bed.

BARBARA MCCRAE: And somebody went in and met Rolf. Chris went in and met Rolf and knew that there had to be something better for this man and found it.

And now Rolf has like -- you said about your grandson in West Bay. If you are at a place that you finally, through your whole life are at a place that you really feel safe and you have direct supports that listen, and you control what you are doing during your day, it's a wonderful thing.

But right now with the global waiver and the cuts that are happening, even though there are lots of people that aren't getting supports that need them, and Rolf has a nice package compared to them, right?

He is still getting cut in the amount of transportation he has because he's limited to so many miles -- is it -- now because the agencies are tightening. It goes down. And you know who loses a lot of time is the person and their support staff and those two people are the key really to the quality of his life, getting out, doing what he wants, being listened to. And until you are cared for by somebody else, personal care access to family and friends, all those things you never fully understand how important that person is to somebody who's quality of life.

And we would -- Rolf would just like to say, I think --
FEMALE SPEAKER: He goes to church every Sunday. And if they make those cuts with the transportation, that could prevent him from getting to his church, which means a great deal to Rolf.
BARBARA MCCRAE: Anybody else? Is that covered pretty good?

Okay. Thank you.
NANCY: Okay.

There was somebody I think that was a maybe that they might like to speak. Did anybody want to --
FEMALE SPEAKER: I think that was me.
NANCY: That was you, okay.

Anybody else?

Yes?
SUSAN HURD: I am Susan Hurd. I spoke just a couple minutes ago. I just want to go -- also point out that dealing with multiple chemical sensitivities, those of us disabled with MCS, we really need the help of people who don't have MCS. It's an interdependence. We really need cooperation with all kinds of things. It's easy to think by looking at me and hearing me that I don't need that much help. But just like Barbara McCrae was just saying for Rolf who -- how isolated he becomes. That also happens for myself and those with MCS.

If there are events where people are wearing perfume, for example, then I can't be there. There are simple things. Up in Nova Scotia, Halifax, Nova Scotia, the city has banned fragrances, a leading national university, Del Husi University in Nova Scotia. It's 10,000. They have a fragrance-free policy. Every year when incoming freshmen come, we have the We Share the Air Campaign. This model has been taken place all through Canada and into the US at universities.

There are simple solutions that could be taking place. Simple things with people being mindful to refrain from fragrances can make all the difference. I realize it's an interdependent situation. I also understand fragrances are

part of the US culture. But there needs to be more awareness. 60 percent of what we put on our skin is absorbed into the bloodstream. And again these are neurotoxic and carcinogenic products that we are taking into our bloodstream. So thank you.
NANCY: Anybody else?

If I may just ask, you also mentioned day supports. Would you mind clarifying what you meant in terms of day supports?
BARBARA MCCRAE: Well, Barbara McCrae -- I just thought well -- what I have the most experience with is vocational day supports, like the old term was workshops for people -- adults with developmental disabilities. And it seems a number of people have been pulled out of the workshops. And they're home now provides day supports to a number of people, which means that the workshops -- which isn't an ideal day program for anybody really. But a lot of people, their parents have told me that their eyes brighten when they know they are going to the workshops on the day that they go. You know, because it's socialization and it's a different place.

So I don't want to put down that sometimes those places aren't ideal. But they still provide some kind of socialization for people that might be utterly isolated.

But because there's so much -- there's a lack of money, I think, going into day supports. It's grouped. And there's not a lot of training, I don't think. Or I don't know what the cause of it is where there's not a lot going on in -- from what I can see.

There's some wonderful art programs that have started that are not only social outlets but also creative outlets, like the Artists Exchange and I know Life Incorporated has one. And there's RHG. Some wonderful kind of group day programs that at least are creative and -- but as far as actual work goes, I just -- I am not personally aware of a system of supporting somebody with a job coach that's really working. Maybe I just haven't heard of it or know of it. I don't know. You know, I mean -- I don't know.

Can I say one more thing?

When I talk to people who have day supports, and when I've looked at some real creative stuff going through DDD, and social workers are really trying to help people have a creative -- even go to three different agencies. I was with one woman yesterday who has three agencies so she's not stuck in one place every day. And that's amazing, you know. But when I heard the amount of money that the agency is getting to provide three days, and this woman wants to do more, I can understand why that agency is limited to what they can provide. And maybe there's some middle management -- I don't know -- that doesn't need to be there, or maybe there's ways to cut. But it just doesn't seem to filter down to providing the individualized direct supports to people.
NANCY: Yes.
ARTHUR: I was going to mention that if anybody has thoughts afterwards, you can either e-mail them, send them, or fax them. And it's on the front page but its disabilities@GCD.ri.gov.

461-0106 or mail them to Cherry Dale Court.

You are welcome to come to some of the legislative meetings as well.

NANCY: We are here until 12:00. So don't feel like -- yeah? Would you like to speak?

Could you just state your name, please?

ELSIE MORRISON: I am Elsie Morrison. And I am with a company called Dreaming Weavers.

We are considering -- we are in the process of developing our plans to actually become a provider agency within the state of Rhode Island. Some of our biggest concerns right now are, of course, issues of employment for adults with disabilities, housing, people living in the least restricted environments.

I do share living also. The individual who lives with me in the past two weeks -- she goes to a day program in Woonsocket. In the past two weeks, we have kept her home four days because she is so stressed out and has so much anxiety because she has nothing to do. The state is paying for this, you know, facility to provide her with a service that she is not getting and has not been getting at least for the three years she has been living in my house.

We have visited other provider agencies. It seems like in my opinion; the model is what needs to change. Not necessarily, you know, an increase in funding, but people need to be more creative with what they are doing. People need to be more efficient in the use of the funding that they get. -- so this person living in my house at this point -- I mean, it's coming down to just keep her home because the level of anxiety then creates for her behavioral issues.

Well, she will go a long period of time. For instance, she's gone like two years without having any behavioral outbursts. But when the level of frustration comes, the anxiety brings out behaviors. So she's caught in a vicious circle because they will say, "Well, we can't get you a job because of your behavior." Not accounting the fact for two years she exhibited no behavior, tried to maintain herself the best she could, but had reached a level of anxiety in this place. It's unbelievable.

Last week she watched Ice Age, all kinds of movies on that DVD player that one of the other individuals brings to the program. But the state is paying that facility to keep her there.

That's just one example that I see that I know needs to change. But I know that on a broader sense, that there are a lot of people, young and old, disabled who would more benefit from a different service model. Perhaps a model where they have literally more input, not just on paper or when people gather and say, "What do you think we should do?" And then you know, no one goes back and actually takes their word for what it is that they actually want to do.

Granted, we can't create jobs that don't exist. I mean, I get that. But just like you or I in the real world, when you don't have a job, you have the skills or at least the tools of information to keep your mind and self busy so that you don't create this other side effect, which then becomes behavior.

I think that if we provide a lot of our adults with disabilities with the information, the tools, and the support that they need to be independent thinkers, then we'd also be more successful in the services that we want to provide, even given the financial restrictions or whatever, you know, the services may cost. Because personally, I see that, you know, for the amount of money that is spent on this particular individual between her residential program and her day supports program, that it is realistic that the state can provide her with a better service at less cost.

If people really took the time to take a look at what's happening to these individuals that we are serving in these provider agencies, if you take a

look at what is really beneficial to the person and not to the agency.
FEMALE SPEAKER: Absolutely.
ELSIE MORRISON: If we get rid of all of that top heavy, you know -- granted, you need to have, you know, management. You need to have people in place to run these facilities. But you don't need to have all these offices and all these additional add-ons for your management staff and all that in order for the program to function.

Because the reality is that the individual and their direct care person, those two are the key. Those two are the main pieces of the pie in order for things to work. It doesn't take six people to manage one direct care staff person. You don't need all that top-heavy management. I think that's where a lot of the money is going.

A lot of the agencies that I've worked for, have dealt with, and see now are very top heavy. They have facilities that house their offices. Why? You got a computer. Put it on your lap. Sit in your car, if you have to. That money needs to go towards the service that we are supposed to be providing for the person, not towards, you know, how great you want your office to look or how good you want it to appear.

What really should be the focus is what are the individuals that we serve, what are they getting out of the services that we are providing? How can we help them progress from point A to point B?

Again, a woman who lives in my house, you know, and her service coordinator can speak to it; anyone who knows her can speak to it, since she was lived in my house, has made the most progress she has ever made in her house. This is a 33 year old woman who was never given the opportunity to receive enough information to be an independent thinker, think on her own, to be able to make decisions for herself; to a minimum, take every day steps to direct her own life; to understand that no, I'm not going to do it for you; or no, I'm not going to answer for you. You need to speak for yourself. You need to think of what you want. She always waits for you to say what she should do because that's how she's been brought along. You wait for the group. You wait to see what someone else tells you what you want to do.

She's learning to be independent, to be self-sufficient. And my hope is that at some point she will be able to live independently, which, according -- to her records in the state that would be like no way. They won't even let her walk around the block, let alone live by herself.

Information that we take for granted in our lives. Like, you know things that you know how to do; things that you don't even think of. Like I said, when you are unemployed or when you are at home, you can think of things to do. You can think of, you know, an activity to engage yourself in so that your mind is not idle. So you don't bring yourself to a point of anxiety, where other things happen.

You -- we need to inform people. You know, there are tools that we can give people to help them be able to do that for themselves. And I think we are really missing the boat, generally speaking, in that light; that, you know, these people can get from point A to point B, even to point C, whatever those points may be in their lives.

But first of all, let's try setting some goals that are realistic for the person. And move those people progressively from point A to point B to as far as they can go and maximize each individual's potential in life, period. Not just through employment or through, you know, residential services; but in general, look at the whole person and look at their whole life and help them become the independent person that you or I see ourselves as.

I have a lot of concerns about the future for these people if we do not really take a look at the service model and change it. Whether it be employment, residential, whatever service models we are looking at. And then not only change it for now, but plan for future change in advance, because things are going to continue to change. The costs are going to continue to rise unless you can figure out how to get a cap on it, how to handle it.

The number of people needing services, that's not going to go away, it's going to continue to rise. We need to really take a look at how we can be most effective and efficient at the same time.

ROSEMARY REILLY: I'd like to add. My grandson is not able to participate in a work program. He is completely physically disabled. And he is on a feeding tube. He can't even swallow his saliva. But I have to say the people at West Bay where he's been living for the past two years have been exceptional. They take them out. They go to movies. They assist him with whatever he needs. It's a very friendly living atmosphere, and every person that I met there has been exceptional.

That's why now, since he's had these three bouts of pneumonia, he needs some skilled nursing care. And the house -- this Mr. DeMarco has applied for more assistance from the state so that he can have a full-time nurse there to assist not only Nicholas but some of the other residents; and give him something that he can do rather than sit in a basement room, watching TV.

He's extremely smart. He loves to engage you in politics, religion, history. He's -- he is just going to deteriorate in this facility that he's in now because he's in the area where most of the people are ready to die. They are all old like myself, and he has no one to communicate with. And it's such a small area. It's not conducive. He is just going to go. He's very depressed. He was always upbeat. I would have him every Saturday. And I would complain all week long. But when he came, I'd say, he can't even wipe a fly off his nose and here I am complaining and he is so upbeat.

And since he's moved to this facility at West Bay, he has -- in such a change for him and they would take him to school every day. And he had some quality of life. And now it's been taken away from him.

And I would like the state to help these -- especially I'm advocating for West Bay too because they have been so good to him. But you know, we -- some of us look down on people that can't move or speak for themselves, and for the grace of God why. It's just a terrible situation for them, very, very bad.

ARTHUR: I might note that there are a number of resources that are listed in the booklet so that you might touch base with some of those people. And also let's say for those who are in the nursing home, the Alliance For Long-Term Care is the ombudsman. As far as I know, they do a significant job of making sure that people are taken care of properly.

So, you might want to address them as well.

NANCY: There is also to your comment. And we can -- I can give you information after. There is a process called the self-discovery process. And it's relatively new. And I know there are a couple sites in Rhode Island that are using -- it's a new model. But it's about a person's self-worth and that discovery and -- so I can give you more information on that after, okay?

CATHERINE: I just want to add the Rhode Island Disability Law Center, for those who may be unfamiliar with our agency, is federally funded. We provide free legal help for people with disabilities and their families. Each year we set a set of priorities for the issues that have come to our attention that need our help.

We do have limited resources but we are available. So please feel free to contact our agency. Our intake's department will be happy to provide you with a list of our current fiscal year priorities, the cases that we are taking, the projects that we are doing. And if we are unable to assist you, we do have information and referral resources.
NANCY: Actually maybe this -- yeah?
SUSAN HURD: I would like to comment on that.

I have been very disappointed with the Rhode Island Disability Law Center. I have called for help. I am grateful that you exist. I know you are well-intentioned people. So I don't -- I don't want to find -- to come across as hard and critical.

Yet I personally have had multiple issues around housing that I have called for help. After the initial intake, I never even got a courtesy call back of saying "Thank you. I'm sorry we cannot help you." I have had that happen multiple times over multiple years.

I had housing for eight years. I was forced out of my place because of ignorance. People insisted they had to do chemical spraying. And because I was forced out of my house, again a barrier, they used a highly toxic stain. They used chemical sprays. I was forced out. I had a place that worked for my living situation.

Yet when I asked for help, I was told, "Well, we can only help mediate." And I had someone I talked to was a legal advocate of the center. He said, "Well, I'm sorry, we can't help you because you are not living in your place anymore." It was like, well, I can't live in my place anymore because I -- my accommodations got taken away.

It was blatant discrimination, according to the Fair Housing Act; the ADA -- owner may not refuse necessary disability accommodations.

I got no help. I had to file with HUD a discrimination complaint on my own to the Human Rights Commission. When I got to the Human Rights Commission, the people in charge of my case were wearing perfume and did not provide other accessibility accommodations for me as well. And the case was handled poorly.

I don't know what to do. There was another -- then I tried to rent a place. The woman lied about toxicity. I lost my deposit. I live on my disability. I'm low income. And a little bit I can make that I earn. I am low income. I lost that -- I asked for help again from the Disability Law Center. How do I deal with it? She lied. It was taken away.

I then went to legal aid. At least legal aid got back to me and said, "I'm sorry, we just don't have the funding to help people. I know it's unjust."

Rhode Island Disability Law Center never even got back to say "I'm sorry; we don't have the funding to help."

I have had this happen multiple times. I can give numerous instances of examples where I heard that from other people as well. Maybe it's because it's an MCS issue. It's not a priority. But I do think I deserve at least a phone call back in saying, "I'm sorry. We can't help you."

I called repeatedly and only leave voice mail messages. I don't know. So if you have any feedback. I have been disappointed. I'm at the point where -- and then I was told referral is for pro bono lawyers. Do you realize that the pro bono lawyer service is $80 an hour? I live on $700 a month. I know plenty of solid middle class income people that are struggling to pay $80 an hour for a lawyer, never mind someone who is low income.

So, I wasn't able to get the help. I tried. I called. I went to Roger Williams Law. Maybe I could get some help with students. I racked my brains out trying to find someone who would do pro bono help. I got nowhere in this state. I am a resourceful person. I don't know what other people are doing.
BARBARA MCCRAE: I heard similar stories that -- the same thing. Oh, goodness. I got to put my thoughts in -- together -- that when a priority is set -- I think is what I've heard is when priority is set at the Disability Law Center that it's hard to get help on something that might not be a priority for that time. And I understand funding and money is always an issue, believe me. But it's hard for an individual to get legal help when they need it for discrimination because of disability.

And if -- they don't have the money, of course, to pay for their own.
CATHERINE: Thank you both for your comments. They have been noted.
NANCY: Anybody else?

Did you have something?
ARTHUR: No. I was going to ask if any of the people who are here have gone to any of the global waiver task force meetings. And have they been supportive in terms of your input?
NANCY: {Inaudible} public record. You are comfortable. Okay.

If you feel comfortable, go right ahead.
BARBARA MCCRAE: Thank you for asking me that because it kind of prompts me. Maybe I should be a little careful because I tend to be -- since I have a temporal lobe -- frontal lobe meningioma; I tend to be free a little more to speak openly. I am not afraid of speaking anymore. But I have to watch what I say because to help support change, it's a delicate process. And sometimes I can build up walls.

So, saying that, it seems like -- I just have to tell the truth from my perspective. There is the state working and the illustrious task force and there's wonderful people on the task force. But like you were saying about the amount of people in the system, and the money doesn't filter down to a person, sometimes sitting there.

It's hard because I look at all the money in the room, first of all. Then the state system, OHHS, and the task force are very separate and because the global waiver was pushed through so quickly under George Bush and it's just like created chaos in the system.

And I know people within OHHS are working diligently, trying to come up with a way to provide supports. I hope fairly. I know they are trying to provide supports economically, okay. And I hope it's a just system. But there's -- it's happening so slowly. And the information isn't getting passed in a way that I understand, and I don't have to make an informed decision on my choices.

And it seems like they are pushing the less expensive model, which I understand, if it's right for the person. But it's not always the best model for a person.

And so, do I feel like I am hurt? I stood up and said -- about informed consent and I think I was heard. And I pushed to be on the housing committee within the task force. And I went to my first meeting yesterday. So, I -- you know, they are working on what's available now.

And to be honest, I just don't know what the state's doing. I can't seem to gather -- I mean there's some talk about what's happening with the elderly population and trying to move people out of nursing homes into their home with supports. That's the one thing that I've heard.

But housing, housing, there's no housing. People that are on the list that could move out on their own. But where do they go? There's no housing, you know, that's accessible; or they don't have a family member there. Housing seems to me is not only the most important issue to me, and maybe all of us, for quality of life. But it's the most needed thing in our state.

So, that's not about the global waiver so much. But just kind of my feeling when I'm at {inaudible} so.
NANCY: Do you want to --
ARTHUR: There is a housing subcommittee.
BARBARA MCCRAE: And the one thing that I also, while I'm -- I'm sorry -- it's my chance to speak.
ARTHUR: Please.
BARBARA MCCRAE: Is that monitoring. Like when people move out and into an SLA or an elderly person moving in, as we start diminishing the oversight kind of and some of the -- so people have more personal living arrangements and individualized that I am really truly afraid of the vulnerability of that person being in the community without some oversight. And if there's nobody in there monitoring a person in a home, living with somebody, you don't see what goes on. We don't know what goes on in our neighbor's home. We don't know what goes on in my home. It's a very -- for some people who can't speak up, or is cognitively impaired and doesn't understand the scope of it is very vulnerable to abuse, neglect, and mistreatment. And that's the --
MALE SPEAKER: They have to be very careful, very careful.
BARBARA MCCRAE: So the oversight once the changes are made are so, so important to our loved ones.

SUSAN HAYWARD: I am Susan Hayward from the division. If I can just speak to a little bit of what Barbara has mentioned. And thank you for bringing all of your concerns to light. They are very important for us to hear about in regard to shared living. Shared living has been an option for people in Rhode Island for about 20 years through state contracted shared living arrangements. And many of the people who live in those have lived there for about 15 to 20 years very successfully with involvement from the division. And we are supporting our private agencies to also develop shared living arrangements for people and have standards in place to make sure that proper oversight will be provided {inaudible} one of those agencies.

And also if I can just speak to Elsie's comments and the other comments I heard about day support for people and the lack of opportunity for people to receive employment in the community. We do recognize that is an area that we could improve upon. And we are also trying to help insure that people have more access to a larger amount of the funding that's available through opportunities for people to self-direct their own supports by using just a fiscal intermediary to be able to access their funding, but be able to direct the support that they receive for themselves or with an advocate.
ARTHUR: There is also an employment subgroup that is probably accessed best through Rhodes to Independence.
NANCY: And if you wanted to forward those, there's a website and there's information in the back table for Rhodes To Independence. And the director is the head of the employment work group, subcommittee.
FEMALE SPEAKER: Elaine Goldstein.

One of the other groups, there's --
ARTHUR: Dual eligible --
NANCY: Long-term.
ARTHUR: Long-term care.
BARBARA MCCRAE: There's Katie Beckett and they are trying to create a more broad children's group, not just the Katie Beckett, kids that fall under that and what else?

Acute care.
NANCY: They are all listed on the OHHS website. They all have shared -- I think -- I don't know if their contact information is there, but I'm sure it's readily available.

ARTHUR: Or I'm sure if you contact Gary Alexander's office, I'm sure that he would direct you to the right place.

BARBARA MCCRAE: Can I say a positive thing?
NANCY: Of course.
BARBARA MCCRAE: I do want to say that there's some really wonderful people who are working for people -- working for people with developmental disabilities. And I kind of shine the light on the areas that kind of break my heart. But there are some really wonderful times that I see between with people and their staff that are joyful and wonderful and very creative. And it's not all bad, believe me. But there's some areas that we just need to truly focus on.
ARTHUR: I was going to say it is a process. And if you look in the back of this folder, there are many pages of successes that have come out of the public forums for many years. So, your words of frustration do actually come into changes in regulations, legislation, and hopefully movement upward. There is a process.

Unfortunately, sometimes it's a struggle along the way. But again, if you do think of something after the meeting, you can make the call. You can e-mail whatever. We will be meeting let's say for many months.

Perhaps Danny would like to --
NANCY: Share anything?
ARTHUR: Insight?
NANCY: Okay. You may be thinking of other questions. But what we did yesterday was opened it to the panel to share either a little bit about themselves or the agency that they work for so you can understand some of the resources that are available.

We will be starting with you.
CATHERINE: Okay. Well, you heard me just briefly mention an overview of the Rhode Island Disability Law Center. I have been a staff attorney there for seven years. And I can tell you that while I appreciate, you know, the concerns and they have been noted. The seven years that I spent as an advocate and attorney for people with disabilities has been filled with a lot of success stories, including people who didn't have services that got services; people stuck in nursing facilities who went home; people who were inappropriately restrained in school settings; and the list just goes on and on.

So, there have been -- and this is what keeps us doing our work is that there always is a need. And we do have limited resources. So that is why we are required to set priorities every year. We do solicit input from agencies with whom we work, as long as the community providers’ -- we welcome that input every year into our priority setting process. And it's taken very seriously. These are lengthy discussions amongst the management and staff attorneys of our agency. You know, oftentimes these are heated debates about what we are going to do, what we can do, how we can make the most impact for people. Looking as -- sometimes broader than the individual basis. There are things we are -- that mandated by federal law to do every year. So those we don't have much discretion to do.

And we, you know, we've for the most part feel that we provide a good service for people. And I do appreciate the recognition from some of the commenter that having free legal advocacy. Although we may not have been able to help you on a particular issue at a particular time, please don't let that discourage you from re-contacting us in the future as things do change year to year.

So again, and just hearing some of the comments, I have to say I really appreciate all of them. And there are other agencies at this table that just came into my mind thinking, you know, where you might find help.

So, please take a look at the resources in the back. Look at our websites. Contact us individually or contact our agencies and reach out and maybe if we can help in any way to funnel you through navigating the system. I know that all of us at this table and some of the folks from agencies in the audience would be more than willing and definitely would try to help you out.

That's all I have.
NANCY: Thank you.
STEVE: Hi. My agency is the Rhode Island Commission on the Deaf and Hard of Hearing. And our primary focus is -- by the way; we have about 90,000 people in Rhode Island with hearing loss. So it's one out of ten people experience some sort of hearing loss, whether they are born prematurely, whether they are actually Deaf, whether they develop a hearing loss later in life due to an accident or war or whether they become senior citizens and lose their hearing. All of those individuals need some help, whether it's equipment, or resources, information, referral. So anything to do with deafness or Hard of Hearing issues, we have books, videos, and lots of information in our office to help people. We also -- you wouldn't want to go to a public library for that information. They probably wouldn't have such specialized information. But we do have our own library at the Commission on the Deaf.

And we look at different types of issues. For example, what are your rights in terms of your education? What are your rights in terms of having a disability; in terms of which way you would like to communicate, whether it be sign language, whether it be spoken English; whether you would like to be mainstreamed; whether you would like to go to a special school. All the way to the spectrum of senior citizens, many of whom deny they have a hearing loss.

We have information that promotes independence, helps out the family members who complain that their parent may not be able to hear the TV or hear the doorbell. We actually have technology that we offer those families so that elders and people with hearing loss can hear the doorbell, the TV, and so forth independently. And this can be in the home. This can be in the school. This can be at a public location, like a theater, because those places are required to be accessible.

There are lots of barriers that most people don't even know about. So we make sure that we provide access and create access for people with hearing loss and deafness. We try to make sure they know their rights so that they are respected as equals, just like everyone else.

So there are lots of different areas that we work on. We are very much involved in the emergency preparedness issue. If a hurricane, for example, and it's announced on the radio, many of you who drive cars can hear the radio. But for a Deaf person, that's not -- the radio is not a means of access. So we find other ways to inform Deaf people of national and local weather emergencies. Maybe through their pagers, LCD displays, and so forth.

So there are lots of resources and there are obviously lots of issues that Deaf and Hard of Hearing people encounter that we deal with. Also a lot of Deaf and Hard of Hearing people experience discrimination based on their deafness because many of us don't speak. People think that we are not intelligent, when in fact we are. And it's very hard for those individuals to advocate for themselves because they don't necessarily know the laws that pertain to their situation.

So we try to open doors for people. And if we have low income people, we also work on affordable housing issues and accessible housing issues. With low income housing, that's not so much an issue. But the housing needs to be accessible to -- and have visual alarms, visual doorbells, so forth. And that's the responsibility of the landlord. But many of those landlords don't know they have that responsibility. So we provide that information.

We also run an interpreter and CART referral service. We provide not only services in Rhode Island -- not only interpreter services but referral services and CART referral services generally in the state of Rhode Island. So if you are looking for an interpreter, we will hook you up. And then the interpreter will negotiate payment with you. So that benefits the Deaf and Hard of Hearing people and anyone who wants to communicate with them.

We also work with parents, grandparents, and siblings of children who are Deaf and have hearing loss. So please don't hesitate to contact us to find out what kind of independent living services we offer what kinds of equipment, advocacy we can do. I think that pretty well says what we do as an organization.

Thank you.
ARTHUR: The Governor's Commission on Disabilities is actually we are facing a 23 percent cut in our budget. So you can imagine that we are going to be a little bit more innovative this coming year. But we do have a number of committees, the legislative committee, disability business enterprise committee, access, et cetera, which are all noted on the website. You're able to attend any of those meetings. They are all public meetings.

The Commission has been very involved in voting. So hopefully if you haven't registered to vote, there are some voting applications here. And there's also the Disability Vote Project, if you'd like to get involved to help other people register to vote.

And I guess probably the most important thing is you need to make the calls and don't get frustrated and keep calling the Commission or keep calling the agencies in order to access your rights.
ELIZABETH CONNALLON: Our agency was started actually as an advocacy agency by families who had a family member that survived traumatic brain injury and that's the work we continue to do. We provide information to survivors, to their families, and to professionals that work with them. And we are very concerned about those barriers that have been mentioned a lot today. We very much appreciate hearing about those barriers as we continue our work. Traumatic brain injuries are often categorized as one of those hidden

disabilities you don't always know. And access to services has been a problem, continues to be a problem. And that continues to be a focus of our work.

I would say that -- that's what I have.
LEZLEE SHAFFER: Again, I am with the Ocean State Center for Independent Living. And we provide a range of services to assist adults with disabilities to maintain as much independence as possible with their homes and their community.

One of our larger programs, even though there's only one staff person, is our housing program. And we have over the last several years, just year after year seen increases in the number of people that are contacting us for assistance.

We are fighting. But we are dealing mostly with people who have the double whammy of low income and the need for accessible housing. And we have seen the waiting list stretch from a month to three months to a year to two years to three years in some situations. The housing is just not there. We are also dealing with the added issues of working with folks with disabilities that need three and four bedrooms. Some people wait five, six years for that. Some people wait ten years for that.

And we are working with individuals who need some help with working with their property management companies to request reasonable accommodations. We are not lawyers. But we can work with them on how to go about the process, and if need be, draw in some other resources.

We have a very strong information and referral program. Again, we are a very tiny agency. What we do is we have a staff member that specialize in a particular service. We have information and referral specialist that does nothing but take those calls, try to connect people, try to get them to connect to the information that they need. We also have a website and a quarterly newsletter. We have a Deaf services program that provides driver education training and assists Deaf and Hard of Hearing individuals with getting adaptive equipment to meet the needs, whether it's in the community or in their homes.

We also have a small nursing home transition program. What we are seeing over the last six months is probably some issues dealing with what we don't know is going to happen with the global waiver, whether services are going to be available to support people transitioning out of nursing homes. So we are still doing transitioning. But we are doing it with a little bit of hesitation, not knowing for sure that services are going to be available. So we are keeping a close watch on that.

And again, housing plays an important part in transitioning. What we are finding is folks that have been in nursing facilities for a number of years that we are working with, some in their 30s and 40s and 50s that don't have anything to go back to. They don't have family supports. So housing is the number one issue.

One of the things that I'm happy to talk about today, however, is that we have been the recipient of some additional grant funding from the Tufts Foundation. So that we are going to be able to expand what we do in terms of providing some funding for low income individuals that need home modifications to address access issues, whether it's ramps or stair lifts or widening door ways, those kinds of things. We do have additional funds for that and some Assistive Technology to be able to meet the needs of more people.

Over the last few years, we have been working on a wait list that has extended longer and longer. And we are now able to start to address those people on the wait list and do referrals.
LINDA: Hi. I am Linda Deschenes from the Office of Rehabilitation Services. We work with individuals who are disabled, many of the disability groups that are heard here today. We work with as many others. We work with individuals around employment. That is their goal. They want to go to work. And we are the state agency then that, if they choose to work with. It's voluntary on their part.

And then we work with many of the agencies that I heard represented today or maybe alluded to today, even in referring individuals to them. And we are probably one of the funding sources that you alluded to today to these agencies. So we clearly are always interested in hearing the testimony that folks have kindly brought forth today as to how the services are working or not.

So that's very important. But you also need to know -- it is voluntary. Folks can refer to us. But we need to hear from you. If it isn't working -- not to hesitate, as we heard today, to call any one of us if something isn't going right. It's good to hear the good stories too, but also if it's not going well.

I think that's really important. And I think when I was thinking I was going to catch up with a couple of folks I hoped at the end and I heard in yourself and your husband, you spoke on behalf of your husband. Again we are about employment. So we work with individuals who are seeking to move towards employment. But there are other services that might be able to assist -- I don't know if you folks -- I would be happy to talk to you after. We can look at -- some issues with you. I'm not sure or if you have an interest in employment as well. We can work with that as well.

I also -- around folks -- two ladies Kathryn and I think Elsie from dream works?
FEMALE SPEAKER: Dream Weavers.
LINDA: Sorry. I got the work part there because you kept alluding to employment. {LAUGHTER} But again, we also like to look at if you are looking at being a provider of employment services; certainly we also work with an array of providers. So we might be a resource you want to speak with as well.

Okay, about looking at that and what types of services you could provide and how we might work with you, which also then the customers, clients, whichever your term is for that you are working with. So that's really important. We provide an array of services with helping people go to work.

Once they are eligible for our services, it's a very individualized plan. We write an employment plan with them and we look at the objectives and services that are needed. And that is really wide ranging, okay, depending on the individual, okay. It can be from Assistive Technology. Some people might be needing some various forms of Assistive Technology for communication, for mobility, for sight. Other individuals -- it may be training that they are needing to move forward, to go back to work or maintain employment.

So, that's really what we are there for.
NANCY: I will give you a background on myself. I am a parent with a child with a learning disability as well as severe allergies. She requires an Epi-pen and things like that. So I started -- completely out of this world but got involved through my children. And that's how I started working for the Rhode Island Parent Information Network. My concerns were education

related. And they help me navigate through the system.

And from that, I went to Rhodes to Independence. And from there, I work with a really passionate person about removing barriers to employment. So, it's good to hear a lot of these concerns. And I certainly can relate what we are hearing today.

And one of the projects that Elaina worked on was the home modification resource book. And it's very helpful for anybody. And there's lots of information in the back for funding sources and things like that. So, if anybody is interested, I can give you more information on that after, as well, okay.

Does anybody -- we still have 20 minutes to go. Does anybody want to share anything?
FEMALE SPEAKER: I would like to know the dissemination for that resource book for home modifications.
NANCY: Actually that's me.

You can contact me after.
FEMALE SPEAKER: But I'm wondering who has it been shared with.
NANCY: Who has it been shared with?
FEMALE SPEAKER: I know lots of groups could probably benefit from that resource.
NANCY: It is. It's chockfull of resources. We can discuss that after, and I can explain to you. It's also on the website.
ARTHUR: You can download it from the resource.
NANCY: There's an appendix in the back. And that information is on the website. The actual book in its entirety is not on the website. Correct?
ARTHUR: Yeah. I think that there are a number of them at some of the libraries and OSCIL, they may have a copy.
LEZLEE SHAFFER: I have a copy.
ARTHUR: PARI probably has a copy.
NANCY: Right. And I did drop off some to MHRH, I think.

But the way it was designed is that it's a consumer guide. So I do host workshops throughout the state. And the workbook is free to anybody who attends the workshop. If there's a need in your area, I would be happy to come out and do a workshop for you.
FEMALE SPEAKER: What is your name again?
NANCY: Nancy Silva.
FEMALE SPEAKER: Thank you.
STEVE: Actually I do want to say something. I think it is important to note that the individual agencies don't work alone. Oftentimes we work collaboratively with one another on a lot of different issues. Sometimes I work with the Disability Law Center on a specific Deaf, Hard of Hearing issue. I may work with ORS on another issue. So, we all work together. And we do address a variety of issues that way.
NANCY: There are also cookies and water, in case you can prevent my son from eating the entire -- {LAUGHTER}
ARTHUR: Something that people may be concerned about come fall is the flu. There are some flu trainings in September that I think you can probably access from the Department of Health. And --
STEVE: I think just to add to that, September 15 and 17th, there are going to be all day long workshops for the entire community. They will be run from 8 to 4:30. They provide food. Anyone who is interested is encouraged to attend.
NANCY: I think more information for that is on the Department of Health website.

ARTHUR: Right.
FEMALE SPEAKER: What is the website again for these comments? When will it be posted, please?
NANCY: I am under the understanding -- not that you -- correct me if I'm wrong. It's about approximately two weeks. And its www.disabilities.ri.gov and it does take approximately two weeks.

And also if you go into the OHHS website, there is the link for all the global waiver task force groups with the chairs. If you have some other issues you would like to be addressed, you can contact them.
FEMALE SPEAKER: I would just like to say thank you very much for having these. And also I feel very free to speak honestly at this group. So thank you.
NANCY: Thank you for coming.
STEVE: Is that it?
ARTHUR: I think we officially need to stay until 12:00.
SAM: The panel will be here until 12:00. Everybody is more than welcome to stay. But we will be here for another 15 minutes. But you are free to come and go as you please.

Middletown | 7.30.09

GWEN: Good afternoon, everyone. I think we mentioned that we would start at 3:00. So I would like to start on time. I want to welcome you to the 2009 public forums for people with disabilities and their families. And I will introduce myself, and the panelists will introduce themselves. And we will tell you a little more about how the forum works.

My name is Gwen Reeve, and I am with the National Multiple Sclerosis Society. I am the director of programs and services. And our offices are located in Warwick.

So I will just go to my right and have my -- Bryan --
CHRIS: I am Chris Butler, Executive Director of In-Sight, nonprofit visual rehabilitation center.
MIKE: Mike Montanaro, supervisor at the Office of Rehab Services.
BRYAN: I am an attorney with the Disability Law Center.
GWEN: As I notice, we don't have any AV support today. So, if you can't hear us, let us know. We will try to speak up a little bit. And when you have a chance to speak, just remember that we don't have a microphone for you to use.

We do have a CART reporter today, who will record everything for you. So that transcript will be entered in. And I would like to remind you that if you are signed up to speak, to be sure -- this includes the panelists also -- for anyone who is speaking to introduce yourself first. So it might seem a little repetitive because you are saying your name again. But that's the only way we know by the transcript who's speaking at what situation.

Are you guy's all clear?

And we have interpreters here, signing interpreters here. And do we have assisted listening devices here.
SAM: If anyone needs them, I have some up here.
GWEN: Great. Just a couple housekeeping issues also. There are two restrooms right outside the door here. However, they require a key because they are locked and you need -- if you need to use these restrooms, the key is at the front desk in the library lobby. If you don't want to get the key, there are a couple other bathrooms in the library itself, so, just for your information.

Okay. And hopefully everybody signed the sign-in sheet, which I now have. And again, if you haven't checked that you want to speak and you decide you want to speak later, that's perfectly fine.

So, the purpose of the public forums is to identify the concerns of people with disabilities, their families, in order to assist the state in developing programs which improve the quality of life with people with disabilities.

I also want to mention we do have a person from Disability Law Center who is here, who can talk to you about the Rhode Island Disability Vote Project.

So, following the forums, what happens is there's postings -- come in. Sign in there, please. Okay. Following these forums -- and there's a whole series of these forums throughout the state of Rhode Island in each respected area. The transcripts are posted. The testimony is posted on the Governor's Commission on Disabilities website.

Later this summer, the sponsoring agencies actually review all the testimony that's provided and prepare recommendations, whether the recommendations on additional services that are needed or laws that need to be changed. This really comes from you. This is a grass-roots effort. So what people say is important to them, again, to make for a better quality of life. That's entered and truly reviewed and given significant attention.

The recommendations and transcripts will be printed and sent to state and Congressional officials and to the members of the General Assembly. And these recommendations will be used to develop policy, legislative initiatives for the next year or until they are accomplished.

So, the other thing I just want to say is our role as panelists is primarily to listen to you and maybe to clarify your concerns. We are not here just to sit and talk about our agencies, which I'm sure we could do very easily. But our primary purpose is to listen to you.

So, there's only a few people who signed up to speak. And I hope that changes. But in case it doesn't and we are here, we can talk a little bit. But really our job is to primarily listen to you and answer your questions.

So, with that in mind, we don't have a lot of people who signed up to speak. So I'm not going to say there's any time limit for it at this point. And so, we will just start with the list. Is that all I need to do? Okay.

Thank you.

So, the first person I have down listed as wanting to speak is Darlene Thomson. And really you just have to come up and tell your story in your own words and we will go from there.
DARLENE THOMSON: I don't know where I am coming up to.
GWEN: Can you come up to my voice? There's a table in front of me and you can probably turn around right about now.
DARLENE THOMSON: My name is Darlene Thomson. I lost my sight about three years ago. My concerns are the RIde program. That's my biggest issue is transportation. I cannot get to my primary care physician through the RIde program because it does not go on Aquidneck Avenue, even though the new flex bus does. The RIde program does not.

So, I have to use friends, family, which means I have to cater to them. I have to go on their days that they are available. And I just had to cancel an appointment with my doctor. And it's now postponed for a month because I couldn't get an appointment that was convenient with a person I could get a ride for.

Is this a huge issue? It could be. I suffer from a lot of different problems. I possibly have multiple sclerosis. I'm a diabetic. I have multiple issues with my eyes that require me to go to specialists all over the state. I'm a severe asthmatic, you know. So, it could have been a problem. It wasn't this time but it could have been.

And it costs me a lot of money to ride the RIde program. It costs me $3.50 every time I take the RIde bus one way anywhere. Now if I go to Providence, that's a great deal. But if I go down the street, that's not such a great deal. That's less than the cost of a gallon of gas. Now yes, it's convenient. Its door to door service and everything, but when you add that up, that's $7 for one trip. Ten times, that's $70. I live on a fixed income, $70 a month for ten trips. 20 trips, you are talking $140.

I don't have that kind of income to spend on travel. But yet, an elderly person only pays $2. So why am I paying $3.50? Why is there a difference?

And with DHS, with the food stamps, an able-bodied person can make -- excuse me -- can make a higher amount of money than a disabled person. Why is that? Doesn't it cost the same amount of money to feed you and me as it does an able-bodied person? I didn't know we got a discount on food. As far as I know, it costs the same amount of money to feed you and me as it does an able-bodied person. So why is there a difference in the system? I don't get that either.

I don't live in subsidized housing. There is no subsidized housing in the state of Rhode Island available at this time. I just had to relocate or be homeless. And I have to pay $850 a month for rent. That's almost my entire check. So, where's the money for the electricity and the water and the heat and the food? Those are just necessities. Those aren't extras. Those aren't anything else, you know. So then you put transportation on top of that.

I just don't get this whole budget. How did they expect us to live -- and I'm willing to move off the island. But there's nothing in this state that's available. It's just not there. And I don't understand why more isn't being done. Why isn't more being done for the disabled people?

That's all I have to say. Thank you.

{APPLAUSE}

Thank you.
GWEN: Next person is Cheryl Crow.
CHERYL CROW: I am going to sit here because I'm too fatigued to stand. I thought I'd have a little bit more time to collect my thoughts coming in late. But this lady was I think in effect talking about some gaps in efficiencies in this state. One that we brought up for several years now is about the handicapped placard process. Persons with permanent disabilities per MD and federal government currently have to go through the medical expense to renew application every three years for their placards.

If we are too ill to travel to Pawtucket to replace the placard when it's worn out, we have been told to violate the law. Park in the handicapped parking without our placards and then fight the ticket. A little bit, um, too much effort for those of us who don't have the energy to even stand in the front of a room to give a dialogue like this.

Another gap in efficiency that I think -- well, first of all before I move off of that, we right in town have a AAA and a motor vehicles department where we can go in and show our ID and renew our license and our registration. And there's never even a wait at the AAA. That would be a lot easier than getting to Pawtucket. So that's a very easy fix.

But I think first we should find out why we have to keep going through this, if we have been determined permanently disabled and need a placard.

Secondly, gaps in efficiencies. Does anybody in this room heard of the CON plan? Anybody know what CON stands for?

It's a state plan, supposed to be consolidated. It's a five-year plan that's supposed to address our housing needs and getting our funding. That plan had a little bit more faith in the process the last cycle around. I spent a lot of time putting in some information about the gaps in the system. And I thought, well, it's just because I'm learning it that I am so late in the process.

Well, but I'd like to know is the agencies who routinely contact us for when they have an interest that they want us to rally for, the disability organizations, the ILC newsletter, the e-mails, you know, the housing agencies in the community development agencies. We get contacted by them when they have an issue they want to promote.

Why didn't we get one notice of the impetus -- some of which has already passed -- for our state CON plan? Not one, number one.

Number two, we are on the island. And we very much appreciate that every year at least this forum is held here for those of us who can't travel to a Providence centric state. There's not one of the focus groups scheduled on Aquidneck Island, not one. They are scheduled in Providence, Pawtucket, Warwick, and Cranston. I can't get to Pawtucket to replace my placard that you can't read the number on anymore. I can't get there for a focus group. That's a gap. It's inefficiency. It could be handled very, very easily.

Third one, this lady previous to me talked about the crisis that I route out since about time in memorial, the affordable housing crisis in Rhode Island. Now I want to know why we do things like -- let's just use one example -- the fire code legislation that went through.

The representative next to me is a property owner. He rents out the property. I don't know if he got hit with a $3,000 fire alarm system. This is not your Benny's $20, $30 alarm system. It's a $3,000 alarm system in an apartment smaller than this.

What did that do for our affordable housing crisis in the state?

You know, I mean there was a very logical way to start addressing some of the fire safety issues. They have been done in other places for years. Canonchet Cliffs in Hope Valley had a no smoking policy almost a decade ago that would have cost any of the landlords any money. It would have helped open up some affordable housing markets. We keep -- you know, enacting policy that is just inconsistent with anything but economic development {inaudible} and that's wrong. That's wrong.

Finally, there's a group that -- a disability group that has been in the gap since as long as I've been able to see in these forums. It's the disability population that needs protection from secondhand ailments. And what that means is all of our affordable housing because it's a very rare case that it's going to be a stand alone unit. The secondhand smoke, the secondhand VOCs from paint, fragrance, cleaners, dryer sheets, all of that stuff comes right through the walls, floors, and ceilings.

Now I think it's lovely that the health department has now had two years of quote healthy housing luncheons in a country club in North Kingstown. I think that's wonderful. I think that generic healthy housing improvements, like low VOC paint, I think that's wonderful.

But I want to tell you that other states and other countries have been effectively addressing this issue by providing the segregated housing that we need with bylaws and covenants to protect us since the 1990s.

So we are dealing with a non-biblically reported disability. That's got solutions in other places. We further worsened the housing inventory for these poor and terribly dis{inaudible} victims. But now enacting the fire code that allows wireless radiation in their home, their only safety net in society.

There are housing solutions in other areas that protect them from that. And we enacted policy that subjects them to that. That's simply inhumane.

And this is not the first time. I brought this issue up, right up the ladder in this state to any and all responsible for it. And they ignore it and they ignore it and they ignore it. It resulted in violence and personal injury and displacement, not due process of law or disability accommodation.

Thank you.
GWEN: Thank you so much {APPLAUSE}

Anybody else sign up?

We have two people signed up to speak. Is there anybody else that would like to speak at this point?

Yes. Just identify who you are and --
ANNETTE BOURBONNIERE: Okay. I am Annette Bourbonniere. And there are a couple of issues that I'd like to talk about. One is -- we are doing a good job lately. I guess we got some of the stimulus funds. We are putting new sidewalks and curb cuts all over the place. That's wonderful. But a lot of sidewalks are still -- either they are too narrow, or they still have barriers on them that make them narrow. So in those -- in a lot of areas, we are still required to roll down the street, which is really kind of dangerous.

The things that are wrong are the narrowness on a lot of them. The barriers -- some of the barriers are right in the middle of the curb cut or right encroaching on the curb cut. So you try to go up, and I will go right into the telephone pole. And some of us have already done a little damage. That's just not going to help us any.

There are also a lot of hedges that hang over these sidewalks. We are not getting a lot of enforcement on the local -- in local communities to have property owners cut their hedges. So again, if your sidewalk's narrow and the hedges are coming out, we are going down the street like this. And it's a little touchy there.

One of the things that's been brought up at some of the accessibility advisory committee meetings too has to do with people who are blind or visually impaired. On sidewalks, it would be such a help if all the barriers were on one side or another, preferably inside. It would be better for everybody if they were closer to the property line than the street line. But -- yeah, she's nodding her head because you don't know which way -- it's like going through a maze only you have no idea where the maze is.
DARLENE THOMSON: Exactly. And I walked through many poles -- into many poles
ANNETTE BOURBONNIERE: Exactly. So there's that. Plus, again one of our committee members who is blind brought up that many of the like planters that are out there to beautify our city, they are wider on the top than they are on the bottom. Somebody using a cane to determine where they can walk are always walking into these things. And their hips are getting pretty banged up because, again, their cane is telling them it's over here, but it's really up here, and crash.

So we need to really address that, some kind of uniformity on how sidewalks are managed to -- so they are walk-able. So that they are roll-able, so that people can get around without having, you know, more damage done to their bodies. So, that is one issue.

And the other one -- also on walking around, it would be great if we had some audible traffic signals. We do not have a single audible traffic signal on Aquidneck Island. And I know how dangerous it is for me to try to cross the street. I cannot even imagine the terror involved in trying to cross the street if you can't see because those traffic signals are not giving you any information.

The other thing has to do with -- well, we've passed this Sherlock plan a few years ago so that people with disabilities could go to work and purchase

Medicaid so that they wouldn't lose critical services. But we are finding out is that if you tried to sign up for it, they tell you that if you are receiving these critical services, you can't be eligible for the Sherlock plan.

And -- so, you know, where's the work incentive? We really need the Sherlock plan so that people with disabilities can go to work, not lose their personal care assistants, not lose services that are really critical to their functioning.

The Sherlock plan is intended for us to be able to pay a premium for Medicaid based on our income. And, you know, that's okay. We don't mind doing that because we would have to pay a premium for any other insurance. But we do need to be able to do this and not have the critical services removed. So, that's something that really needs to be addressed, I believe, on the legislative side.
GWEN: Thank you.

Anybody else would like to speak?

Even though you might not have signed up. {APPLAUSE}

Yes. You want to introduce yourself --
ROGER HARRIS: I am Roger Harris. I am from the -- I am a member of the Rhode Island Disability Vote Project. And I'm also late -- I apologize -- due to traffic.

And I did not sign up to talk, but I want to speak a little bit more about the lady that was speaking when I first came in -- referred to housing. I have been a paraplegic for over 15 years. And the only housing I'm able to live in is public housing. Fortunately -- I don't know your name --
DARLENE THOMSON: Darlene Thomson.
ROGER HARRIS: Fortunately there was an apartment available for me upon my onset of injury. So I was in an accident. But my choices were limited, and that's what I want to talk about, the choices that we have with disabilities when it comes to finding an apartment or a place to live.

I'm considered a very independent individual with a disability. I don't need the services that are provided for a lot of folks in the state. I can take care of myself very well. I have -- considered a high spinal cord injury. However, I can't stand up at all. I can't climb stairs. But as far as basic needs, I take care of myself. So, I don't need a nurse, a home health aid. But I know a lot of people that do.

The building I live in now has 100 units, one elevator. It also is three floors. It also has one laundry room with 100 people. It has three washers and three dryers.

So you can imagine when the home health aid people come to do laundry 7:00, 8:00, 9:00 in the morning, the struggle they have. People like me who are independent, the struggle that I have. I have to wait in line just to do my laundry. And then on top of that, the management puts a curfew on the time limit to do your laundry, 8:00 at night, one small example.

Another one, I lived there for three years. The first year I moved in, the entrance, the very front entrance was not accessible. And I find that since I have been involved with the community, I find that a lot of places, buildings are available for the handicapped are not accessible for the handicapped.

I understand on a state level there's, due to lack of funding, there's only a couple people who work through the Governor's Commission on Disabilities who make sure the access is available and I understand that. However, I think our state is small enough that we can make an attempt to address those issues.

One last thing when it comes to housing. I don't understand how we can't get around all -- bring forth or promote the idea of private owned buildings or private owned properties making availability. For example, there's a lot of HUD governed buildings. There's a lot of investors building these big giant condominium areas. In Woonsocket, where I'm from, our city is selling the old mill buildings to investors, and they are making condos. Why can't they make them accessible? Or why can't the law -- why can't we make a statute in the law that says, okay, if you have 100 units or condominiums, why not make three or four of them or five of them affordable for people like me?

I want to move out of my building. I can't stand it. But I'm stuck. My income doesn't allow me to move, one. Two, there's very little accessible housing for those of us with disabilities. Now I'm a physical -- I have a physical disability. You can see me and tell. But there's so many of us out there that you have to ask them what is their disability in order to find out. And it's disheartening to them to even talk about it, let alone tell you or say or put on the application, I have this -- I can't hold my hand up because I got a problem with my shoulder, okay.

But to go apply for an apartment, to apply for subsidized housing, even with a disability, we get on a waiting list. I think this state is small enough and there's enough resources here enough to really make it better.

{APPLAUSE} That's it.
GWEN: I'm going to ask the two panelists that have joined us to introduce themselves. And those people who are thinking about maybe speaking who haven't signed up might do that. So, Sharon?

I already introduced them.
SHARON: I am Sharon Brinkworth, Executive Director of the Brain Injury Association of Rhode Island. And we do have a resource center on Park Avenue in Cranston. And I was just down at Vanderbilt Hospital yesterday afternoon. And it looks like we will be having a support group coming to Aquidneck Island for people with brain injuries. {APPLAUSE} And I apologize for being late too. There's all kinds of construction going on.
GWEN: Thank you.
COLLEEN: I am Colleen from the Rhode Island Department of Health Office of Special Needs. And within that department is the disability and health office. I'm sorry I ran into traffic also.
GWEN: I think everyone ran into the same traffic.

I was going to ask our last speaker -- this is Gwen speaking -- if you might, what unit do you live in -- where do you live?
ROGER HARRIS: In Woonsocket. It's privately owned by a property advisory group called Mount Vernon Apartments off of Bernie Street, a block from Mount St. Charles.
GWEN: Thank you so much. That helps us to be specific. Sometimes I know people are hesitant to be specific about their issue. But it also sometimes helps us to be able to follow up a little bit more. Thank you.

Anybody new and then -- anybody who hasn't spoke who would like to speak again? I have two people in the back. The gentleman in the back, introduce yourself?
JOE CIRILLO: I am Joe Cirillo. I came because I'd like to see what is going on and what the issues are. And one of the issues the gentleman just mentioned and also the young lady -- I'm an architect. I have been involved

with disabilities about 30 years now. I was a state building commissioner for 28 years.

There's a book out right now that we helped produce. Bob Cooper was one of the members who helped produce it. It's called modifications 101. It's a really well written book. We put it together. And it's all about you living in your house, and modifying it through a checklist so that you can stay there. And what does it take to modify your house, everything from the ramps and everything. It's really made well. It's the kind of book that you can put in a little sleeve binder, if you -- it's a spiral bound right now. But you can always take that off and copy it. It's available at the state. Elaina Goldberg and Jeanne --
FEMALE SPEAKER: Her organization is Rhodes to Independence.
JOE CIRILLO: Rhodes to Independence. And it's a really written well documented book. It's really nicely done. I was very proud to be a part of putting it together. And I have even introduced it in Washington at some meetings I was at. So now all 50 states have got copies of the thing.

It's one of these things where -- it isn't you. I'm disabled. Back injury and I am a disabled person. But it doesn't have to be. My mom was disabled due to age and other illnesses. And it came through a point where she was in elderly housing. It was accessible. She had to go to a nursing home.

But with this book, it was possible that, you know, I now look at it. How can I move -- change my Middletown house so that it can accommodate me when I get worse? And it's very; very likely I will get worse, if I live longer. I mean -- and this book does a good job of explaining it. I think it just needs to be distributed more. And it is available, as she said.

So, that was --
GWEN: Thank you, and the lady, orange?
LINDA: My name is Linda. I have MS and I was diagnosed about two years ago. And it's -- I go to the support group at the hospital. And it's really hard because people don't -- they look at you and you look fine. So they -- what's wrong with you, you know. There's nothing wrong with you. So, you trip and fall once a while, or your speech is slurred or whatever. I had to give up my teaching job, which was very hard for me to do. I loved teaching.

But I had gotten some forms through the hospital and with all the cognitive issues that go along with -- or a lack thereof -- with MS. I've gotten forms from them for a air conditioner and computers. And I started to fill out the forms. And there's about like 30 pages to each form. And I thought, are they kidding me? They know that all -- most people with MS have difficulty with short-term memory and cognitive functioning and stuff. So I've gotten started with -- I haven't finished them because I just don't know how. It's just frustrating.

And somebody had said something about the heating assistance and stuff. And I applied for that last year. And -- it's funny but it's not funny. It's typical of Rhode Island. I filled out all the paperwork. I sent it in. They sent me a letter back, and they told me that I was eligible for heating assistance.

So I said great, even if it's $50, $100. Oil is $4 something a gallon last year. So I figured even if it's $50, it will help, you know.

So I get a check in the mail a couple days later for $1. And I thought -- so is this the way that Rhode Island is covering their butts by saying yes, we are sending out heating assistance to Rhode Island residents who -- I never cashed the check. I still have the check because I just thought it was so ridiculous. I thought it probably cost somebody that was working $35 an hour to type this check. And then you get to pay for the paper, the ink, the stamp. Now I have to use my gas to go to the bank to cash a check for a dollar. It's absurd, I thought.

And I had checked into -- and where my lesions are, and now I have grand mal seizures where I never had them before, and I have a lot of different stuff. And it happens and then I can't drive for six months.

Now, I have a friend in Massachusetts who is also disabled. Massachusetts, they give them free cell phones for -- I don't know, 80 minutes or something they get, something like that, for emergency kind of thing, not like to call and chat all the time.

And I called the number that he gave me and I tried to apply for one. They said no. It's just in the state of Massachusetts. I just thought that might be something because we are all on a limited income. We are all collecting SSDI, and we all know it's not enough. And we certainly -- at least I certainly can't afford to spend $100 a month on a cell phone. But it would be nice to have one. If something happened and I was home and I fell down or I was if my car -- I got in an accident in my car. I had a seizure over the Sakonnet River Bridge and I got into a terrible accident. So, that might be something that they could look into.

And I also -- my doctor actually had mentioned to me about the marijuana program. And so I went up and I got the application. I downloaded it. We filled it all out. And I was accepted and I got a license.

And, typical of Rhode Island, I went up to the Department of Health. And the woman said to me, "Okay. I will take your picture." She gave me my card. And she was ready to send me on my way. I'm like well, what do I do now? I have this license, but like where do I go to get the marijuana or -- oh, you will just find it.

{LAUGHTER}

Wait a minute. I'm just supposed to just walk down the street and find an ounce of pot on --
FEMALE SPEAKER: Go in front of Thompson high school. {LAUGHTER}
LINDA: So I said, what do you mean? And she said, "Well, if you can't find any," she said, "we can get you a sponsor."

So I said, well, so you are telling me you are going to like use a snitch on the street to get -- and the biggest part of it is, it's illegal for me to buy it. But it's not illegal for me to smoke it.

To me, that's kind of screwed up. I mean, you know -- so now they are talking about this compassionate centers, which is great, which will probably take four years or whatever to get going. But even that, I have no idea what the setup is going to be for that. But I'm thinking to myself already, and the reason that they are opening these compassion centers is because people are getting mugged. People are getting robbed. And I mean, what if I was a 75 year old woman who had glaucoma and I needed it? I am going to know where to find pot? I'm just lucky enough I have a 26 year old daughter {LAUGHTER} who knows people before she -- honestly. I don't know where to go get it, you know?

So, I'm like -- so what kind of security are they going to have at these compassion centers because it can have, you know, lowlife of the state hanging out there. And they know I'm going in there to get marijuana and they know I'm going to be coming out with marijuana.

So, I don't know. There's a whole lot of -- and it's helped me. I haven't gotten any more lesions in six months since I started. But -- it's great. But it's still to the point where I can -- and then they tell you, you can carry -- I don't know, something ridiculous like 5 ounces of weed. If I could afford five ounces of weed, I wouldn't need to be on SSDI because it's like $160 an ounce, and I can grow 12 plants.

So if I go up to you on the street and I buy 5 ounces of pot from you, you are going to jail with intent to deliver for a long time. And I am going to flash my little card and say, see you later, just kind of hypocritical to me. It bothers me.

And I don't know -- like I said, I'm sure it will take them a while to get going because there are all of those questions to answer. And I don't know where they will have them. I read in the paper saying they would have four across the state.

But it just -- I don't know. It just seems kind of hypocritical. And I don't know what to do about the heating assistance. Winter's coming up again. Before you know it, it will be up here again. What will I get another dollar? Why bother? You know?

So far it's been working, I do the injections every day. You know, I -- it stinks. You have different symptoms, different days. Some days are great. Some days, you know, like yesterday I fell down three times in Brooks or whatever it's called now. And I have my cane with me and I just -- just trip over your feet.

So, I think it's important that they get the marijuana program running up for those that want to try it or see that it helps. I did it for the last six months, and I just had my MRI come back. It stayed the same. The six months before that, I had grown three more lesions using the copaxone. So now I am doing the copaxone and the marijuana. And, you know, I mean, I do it at night when I'm not going out driving or anything like that, of course. But I just hope that they get that straightened out so that people won't be afraid to try and get -- to try to use it or that they have access to it.

I mean right now its pretty, you know, if you know somebody, you know somebody. If you don't, you are pretty much out of luck. You know, so I just hope that gets through and it gets -- I'm glad that it was overridden by the governor and that they are going to do that because it does help. At least it helps me. So thanks.
GWEN: Thanks. {APPLAUSE}

This is Gwen speaking from the front. And just to let you know, Linda, that there are -- since I work for the MS Society, very simple two-page form for air-conditioners as well as assistance for utilities that you can apply for.
LINDA: I actually brought them with me. Look how many they sent me?
GWEN: That's pretty unusual. I will look at them afterwards with you.
LINDA: Thank you.

GWEN: Yes?
PATRICIA WHITE: Patricia White, I have never been to one of these before because I was just diagnosed with MS.

But I have a question and incorporated in the budget, it doesn't give a page number, about the cost of the drug, the list of drugs to find -- drugs to include injectable drugs for that that are used in the treatment of MS. Does that mean that it's going to be included or it's been included or we have to call our representative? How does that work?

GWEN: I can answer that. The commission that we work -- the law that we worked on was to allow for co-payment assistance for the injectable drugs. And because for some reason the pharmaceuticals had decided that Massachusetts and Rhode Island didn't honor co-payments -- co-payment assistance. The pharmaceuticals have changed their minds and are now offering co-payment assistance for co-payments on the injectable drawing drugs so -- all four of them.
FEMALE SPEAKER: Four of them.
GWEN: Four drug companies offer co-payment assistance. They all have foundations so that if you are strapped for money, they will give you the drug at extremely discounted prices each month. And I can tell you who to call if you need a particular drug.
FEMALE SPEAKER: So then this has been incorporated into --
GWEN: It was sent to committee for further study. But in the meantime, as I said, the pharmaceutical companies got wind of what we were doing and decided on their own to honor the co-payment system. So we did accomplish what we wanted to accomplish as far as the MS Society.
FEMALE SPEAKER: Where would I find any information on that?
GWEN: On the bill itself?
FEMALE SPEAKER: Well --
GWEN: Or on the --
FEMALE SPEAKER: I guess I could ask --
GWEN: On the co-payment assistance? It would be based on what drug you took and their foundation. So if you were with copaxone, it would be shared solutions.
FEMALE SPEAKER: I am on Betaseron.
GWEN: That would be MS lifelines and I will help you with that.
FEMALE SPEAKER: Thank you.
GWEN: Anybody else want to say something?

Yes in the back.

PETER MARTIN: I am Representative Peter Martin. I was very proud to vote in favor of the marijuana overriding the governor's veto. But I want to ask you what House bill you were talking about that you just referred to because the one that's listed on your document mentions Representative Crowley, who unfortunately passed.
GWEN: That's an old one. The bill we were just speaking about was introduced by Eileen Naughton, and I'm blanking on the number right now. But it was introduced this year, and it was to amend the Patient Protection Act, allowing for co-payment assistance for pharmaceutical drugs. So Eileen Naughton is the one that introduced that bill. And, as I said, I am blanking on the number. But I can get that for you.
PETER MARTIN: Thank you.
GWEN: And that was very positively received. But almost all the bills in the Health Education and Welfare Committee were referred for continued study, which means they are not going anywhere this year.
LINDA: I have a quick question about that too.
GWEN: Linda, you want to introduce yourself?
FEMALE SPEAKER: Linda. Sorry. Once they have the compassion centers up and running is it going to be a certain rate or will it go through Medicare or will you pay for it? Do you know how that is going to work or they haven't gotten that far yet?
GWEN: I'm not familiar with the law in total because the MS Society doesn't take a position on the use of medical marijuana. So I haven't bracket. But somebody else here may know that. Does anybody?

Representative Martin, do you know? Can you answer a question, since you

might be more familiar with medical marijuana law?
PETER MARTIN: I can't answer the question.
GWEN: Okay.
PETER MARTIN: I would be happy to find out to give you an answer.
GWEN: Okay.
ANNETTE BOURBONNIERE: I am going to -- this is Annette Bourbonniere. I am going to tell you that I suspect there are not going to be any medical -- Medicare assistance coverage since even though it's legal on -- a basis, on a state basis, it's not on a federal basis. So we are going to have a little conflict there. So I wouldn't count on Medicare at this time.
LINDA: Well, I didn't think -- I wasn't sure about Medicare. But I thought there would be at least a blanket price of, you know, less than street value price, in other words.
ANNETTE BOURBONNIERE: That I don't know.
JOE CIRILLO: I think the governor --
GWEN: Introduce yourself.
JOE CIRILLO: Joe Cirillo, I think what Governor Schwarzenegger is saying to budget the California on his marijuana crop. I think a lot of these things may work itself out because it will be -- the federal law may change. It's -- it's being used all over the place. And it's just one law is stopping it being legal. And that I think will change.

How fast, I don't know.
CHERYL: I wanted to mention something for Linda as far as the way that I saw the cell phones around the emergency is I bought a track phone at Stop & Shop or Wal-Mart or something for $15. And I buy the cards every three months for $20. So, I don't use the phone. But I just have it for, you know, so that was the most reasonable solution I had.

The other thing about the one dollar heating assistance and this is a gap that I totally forgot about. There are people in the gap that earned too much money in their career to qualify for SSI or food stamps or all of those. But in living on SSDI at a salary that doesn't allow for you to take in effect any of those services, you can't survive. But the heating assistance, there's a qualifier to get other things like reduced electrical rate. I think it's called 860.

Now one of these years I, like you, didn't have the energy to deal with going down and fighting the process to get a small thing. And next thing I know, there is some coordination in this state. Because the next thing I know, my electric bill jumped up to regular rates. And it quadrupled on me.

So, hold on to your $1.
LINDA: I still have it.
CHERYL: If you don't have SSI or food stamps or any of those very low income services that qualify.
LINDA: Thanks.
CHERYL: You are welcome.
GWEN: Anyone else would like to speak?

Yes, is it Linda -- no -- Darlene.
DARLENE THOMSON: Yes. I just wanted to -- was it Annette?
ANNETTE BOURBONNIERE: Yes.
DARLENE THOMSON: I wanted to make a comment about her comments about the sidewalks. I think it should be uniform across the state because when you go from town to town, they vary. And you know, sometimes there's no sidewalk at all. Sometimes they are wider in one place, smaller in another place. And I totally agree about the thing about the planters or the ashtrays or the litter boxes or whatever is in the way. They need to be on one side and one

side only. Because I can be walking down the street and like she said, my cane can tell me its fine. And then I'm banging my head on something, or there's a tree that I'm bumping into, or I am coming to an intersection and I walk into a pole.

If you've ever gone around the corner at Modern Furniture, you go around the corner there. Right smack in the middle of the sidewalk is a pole. And it has a sign on it. It's not on the left. It's not on the right. It's in the middle.

I don't live there. I live at the corner of Vanzee and Farewell, which is a horrendous intersection to try to cross. But that -- going around the corner there, that pole is right in the middle of the sidewalk. It's not on one side, not on the other. And I think it should be uniform across the state.

And I think that in all major intersections, there should be audible traffic lights every where. Because it's very hard to hear and -- because you are using your hearing for everything to try and pick out which area the cars are coming from. And, you know, I try to cross Eddy Street a couple of weeks ago. Don't honk your horn at me. You are not telling me anything. You know? If you are honking your horn at me, I don't know if you are trying to tell me to go across the street or stay where I am at, you know? So I'm not going to respond to a honking horn.

And -- finally, I guess all the traffic stopped and a truck driver honked his horn and said, "It's okay to cross the road, lady." And I'm like, well, that's nice. Thank you very much.

And then I walked up to the Dunkin' Donuts. And I asked the guy if there was a safer place for me to cross than at the main intersection where the hospital area is. And he said, sure. Just walk out the door and go across the street.

And all of a sudden he comes running out of Dunkin' Donuts and grabs me by the arm, which startled me and dumped my coffee all over. Don't come right up behind me to grab my arm and help me. It was very thoughtful and very kind. But don't do things like that to startle me, you know. Just tell me, you know. It's easier to tell me.

Disabled people don't want to be disabled. They want to be as able bodied as they can. And I think this state can make it more able bodied for them. I know, I don't want people doing things for me, not if I can do it for myself.

And as I was told at In-Sight, a blind person is no different than a sighted person. And the only thing a blinded person can't do that a sighted person can do is they can't drive a car.

And I've actually disproved that in my own mind {LAUGHTER} because I have designed a traffic plan that a blind person can drive. But it would mean a major overhaul of the entire road system and design cars and everything else, which I don't think the federal government is willing to put multimillions of dollars into.

But other than that, I can do anything that you can do. But -- people and cities and towns and states put things in my way and in other disabled person's ways too that make life harder than it has to be.
GWEN: Is that Joe? Did you want to speak again?
JOE CIRILLO: Yeah. All of these -- and that's why I really came here because I wanted to listen to some of the complaints. There seems to be a need -- let me stand up. I'm short enough. I won't stand out.

There seems to be a need to funnel things into a manner in which they can be corrected. Like something -- if I go to the Dunkin' Donuts near Valley Road all the time. And when I am pulling out of there, there is a law in the state of Rhode Island that if you have shrubbery and you are pulling out, that shrubbery has to be out of the visible line so that I can see traffic and they can see me.

Little shrubs but they happen to be built up on brick planters and everything. I don't see anybody calling and making sure that they get cut back. And I think the same thing is true with the signage. The roads that are being done now are all -- the Department of Transportation regulations from the Americans with Disabilities Act. We are not talking about major rocket science here.

If there's something that's got to be moved, there should be a process where you call the guy at the head of DOT who's running these projects and say, hey. Look. So and so's hedge is preventing this poor lady from walking down the sidewalk that we just made wide enough for the wheelchair to go by and everything. I think that's what we need. And I think -- they have to respond because their dollars are from -- I mean the federal DOT. That's where all this money is coming from.

So, I think we can complain. But if it isn't channeled well, it's just -- the next time we come to the meeting, somebody else will ask the same question. And I think that's part of the problem. You know?

So that's all I wanted to get across was there are channels. There are places to go. And it's tedious sometimes. But I'm going to talk to this lady here about her dollar because I happen to be on the Governor's Energy Efficiency Committee and I know the guy who writes those checks. I've known him for 20 years. I mean, he doesn't write the check. But you know, he's involved with that. I want it find out who made a mistake and gave her a dollar check from the state. That's a mistake.
MALE SPEAKER: It's an insult.
JOE CIRILLO: It is. Of course it's an insult. And he would want to see the darn thing and try to get that corrected that -- that doesn't make sense. It just doesn't make sense.
GWEN: This is Gwen. I just wanted to tell Representative Martin that that bill that you asked for is H 5656.

Over here.
ROGER HARRIS: Roger Harris again. I -- due to my own personal dilemma, I have been in a chair for 15 years. And I was born and raised in Woonsocket. The neighborhood I grew up in does not have one wheelchair curb cut.

I'm also a member of the Paralyzed Veterans of America. And many years I've gone to Washington DC during their advocacy and legislation seminar with the group. And I've actually sat in the Congressman Reed, Senator Reed's office and spoke to him personally about this situation. And his right-hand man took the information down. And they said they would look into it.

Since then, Woonsocket spent some money building -- repairing bridges, building new bridges. On the bridge side, the curb cuts there. When you cross the street from the bridge, there's no curb cut. So, at the time I had a computer and I was on-line. So I would e-mail the senator and say hey, this bridge such and such street. And he would e-mail me back. We will get on it. We will get on it.

That was 14 years ago. And still today, you come to Woonsocket that same bridge is there. The new bridge has a nice curb cut, across the street, nothing. For me, it's not a big deal. I have learned how -- I mean, hop up on a curb. There's a lot of elderly right there -- lives right down the street in the high rise. They walk down and they cross the street there, talking about busy intersections. But the curb cut is really -- it's interesting, small example.

But my case in point, funneling, forums likes this. The hope is you take our information. I'm speaking to the panelists. You take our information and send it up to the chain of command, if you will, to the powers that be.

Also -- if I remember names, the lady that was talking a little while ago. Ellen? Darlene, call your legislator. I'm also a member of the Rhode Island Campaign to Eliminate Childhood Poverty under the umbrella of the George Wiley Center. We are advocates. And we are strong on calling your representatives, your legislators. Let them know. Let them know how you feel. Don't feel that they are not going to do anything. You keep calling enough, they will do something. But you just have to keep calling. Same with the lady with the marijuana issue. Hold on to that dollar. Let that guy help you there.

The George Wiley Center will also help you with that as well. There's a place you can send that dollar to. Let them know you received it, and they will put you in the program. They will actually give you utility assistance. Okay.
DARLENE: Thank you.

{APPLAUSE}
CHERYL: I think just another comment.
GWEN: Could you introduce yourself again?
CHERYL: Yes. I think another comment that becomes apparent each time we have one of these forums is we need a place locally where we can come together and brainstorm and share, like the architect knows how to refurbish if you haven't gone down the poverty cycle and lost your home already. So he can help you with that.

You know, this gentleman from George Wiley hasn't been worn down by these tedious procedures so much that he just can't do it one more time.

You know, so if we had some place locally with somebody that can still do them right, that can't go 14 years asking a senator or somebody to help, you know. At least it would give us an outlet for our emotional pain caused by not getting things done and addressed, the real serious issues that we have to face and continue to face.

{APPLAUSE}
ROGER HARRIS: Can I respond to what she said? You know what that is? Organizing?
CHERYL: If you have -- just understand if you have a fatigue -- I could have been you a couple of years ago, you know. I come from a six figure information processing executive career. But I'm more than that. I'm proud of that. I fought too many fights. I got too many non-answers. I've gotten too many dumb stares. I don't have 14 more years of fight in me. I don't have 14 more days of fighting for me.

Maybe if I was in a coordinated group with people that still have some energy left for the fight, maybe I could restart. Once you face physical violence and personal injury because of lack of basic human dignity and human rights and accommodation, it really takes the steam out of your whistle.
ROGER HARRIS: It's Roger again. What I was going to get at is organizing. After this meeting, I don't know how many of you live down here. But after this meeting, there's -- everybody signed this list when they came in here.

If you wanted to -- and I would be willing to help you do this -- through the Rhode Island Campaign to Eliminate Childhood Poverty, you can form a committee here.

We have five chapters in the state, and I think the closest here is Newport. I'm not sure. And they meet every month. On August 8 is the leadership committee meeting in Pawtucket where the headquarters is. I know that's a long way from here. A lot of people think Rhode Island is so far -- but anyway, on August 8 at 9:00, two hours every six weeks we have the committee meeting.

And what's your name there again? Joan? Cheryl? You have such great insight, you know. I know you are probably -- you are tired out. But you can bring such great information, informational tools to an organizing meeting. And all it would take is just a few of you.

And what you do with that meeting is you brainstorm what it is you want to do. What do you want to accomplish? You come up with that. Then you take the next step. The next step would be getting the word out there. I want better sidewalks in my neighborhood. I want curb cuts. I want that sound saying I can cross the street now. I want assistance with my marijuana problem. I'm not -- {LAUGHTER} MS problem.

The -- the woman that got diagnosed with MS, now somebody should be calling you already, you know, not just your doctor. It's called organizing. If we don't organize, we are just going to keep complaining.

Thank you.

{APPLAUSE}
CHERYL: Can I just make one response to that? Sorry about the crosstalk. You know, if we had stable housing, stable housing accessible to our disability, not somebody else's disability but our disability, which isn't covered in your architectural book, we could do all -- I would have been head of the disability organization of the state covering all these little MS groups and all these little groups, and I would have solved all the problems here. Without the basic core survival tool of accessible housing for our disability, which is absolutely ignored in the state and continues to be ignored, then we can't go anywhere but down. I'm sorry but that is the truth. I'm glad you have the experience. I'm glad you found the accessibility in the ways that you can manage.
ROGER: One more thing, please. I'm sorry. It's also a choice. You have to make -- those of us with disabilities, you either decide to live with your disability or live through it. I chose to live through my disability. I'm not living in it. I'm not -- you are not going to see me go, oh, I'm sorry. I'm paralyzed. I can't -- I've never done that. The first day it happened, oh well. What's next?

My point to that is, as we -- some of us -- okay. I'm in 15 years. It's seasoned. I'm considered a veteran with a paraplegic. But I met people older than I am and just becoming into their disability and they are lost. So, I think the best way for us to help each other -- I got to keep saying -- is organizing.

And organizing can be anything. It can be just coming together at a hall like this to sit there and we share in our grief. And hopefully in sharing in that grief, you might hear something from me or I might hear something from you that will help me tomorrow or the next day. Or I may not hear something and I may be able to bring it up. I didn't hear you talk about this or that.

Our state -- and the problems we are having in this state are happening in every single state. Trust me. Every single state is having the same problems we are having. We are no different than the rest of the country. My thinking though is we are the smallest state. We should become the -- I will talk to the panelists too -- the model state. We should because we are so small.

But yet those of us who are in agencies or organizations that cater to people with disabilities, we tend to think for ourselves. We don't think -- because I have MS and he is in the blind society, we can't help each other. Or we might lose a little funding if we go help that organization. I don't think that's right. If we choose -- and I think we are small enough to choose to help each other, I think it will be so powerful.
FEMALE SPEAKER: That is such --
ROGER HARRIS: I think it will be so powerful in this state.

There's enough -- last thing. There's enough agencies just in Woonsocket alone. And I've counted 15 different agencies that's doing the same exact thing. They don't come together.
FEMALE SPEAKER: Right.
CHERYL: I think you hit the nail on the head, Roger. And I am going to give you your first assignment besides giving me your business card. I want to find out how we can get input into the CON, the Rhode Island state consolidated housing plan, which is our funding to solve this you know what -- mess that we have been complaining about since before the last five years cycle. I want to know why we didn't know about it. And I want to know what we can do. If it takes putting in a Human Rights Commission complaint or suing them or whatever it takes, I want to know -- I'd like to do it friendly.

But you know what? I'm fed up. It goes -- it happens every single time. So it's a communication problem and it's time that we get it resolved.
FEMALE SPEAKER: You are right.

{APPLAUSE}
ROGER HARRIS: I think I talked enough.
GWEN: Annette.
ANNETTE BOURBONNIERE: This is Annette Bourbonniere again. There are a lot of state councils, commissions, and boards and committees. And I think it's worthwhile to try to get on one that serves what you are looking for. Getting involved -- get involved.

But it is also a big thing that Roger said that we've got to stop fractioning. You know, if we look at the number of people with disabilities all together, there are about 20 percent of the population. That is an awesome force if we were all together.
MALE SPEAKER: 130,000.
ANNETTE BOURBONNIERE: That's a lot of people, roughly, yeah.

So, you know, that's an awesome force. So it is important that we stop fractioning, you know, people with the obvious ones that Roger and I have or the not so obvious ones that others have. People with mental health issues, people with developmental disabilities, people who have disabilities that are hard to define. We really need to all be together. And we shouldn't say, we don't want to be with that group or we don't want to be with that group. We really do need to be together. And we can do things that way.

But it's also important to make a choice and not play the victim. Having a disability is not the end of the world. It is not the worse thing in the world that can happen to you. And you know, being a victim is just going to actually be your disability if you do that. So it is a choice to go forward, get involved. Get on commissions, councils, boards, committees. They are all over the state. They are all over the city. And you can have -- we can make something happen. It may not be everything. But you can make something happen.

{APPLAUSE}
GWEN: Would anybody like to speak who hasn't so far?

Would any of the panelists like to say anything?

All set?

I just want to let you know, again, this is a very informal panel in the sense that if there's no one else that wants to speak, you are certainly free to come and go as you please.

We, the panel, need to be here until 5:00 just in case somebody comes in late and wants to speak or a little bit later. But that requirement to be here until 5:00 only pertains to the panel.
SAM: Did everyone sign the attendance sheet?
ANNETTE BOURBONNIERE: My name is Annette Bourbonniere. We need to have a resource of accessible healthcare facilities. And by accessible, I mean we do have -- there is a website where you can find accessible mammograms, but we don't know where the doctors’ offices are. They have accessible exam tables. Hospitals or other facilities, find a bone density test that is accessible.

Talking about stress tests. Cardiac stress tests. Again what they call accessible is injecting a drug into you to stress your heart, which is not something a lot of people want to have done, you know. Other alternative methods of stressing your heart through exercise, like using your upper body or something, is not available anywhere in the state. So we need more accessible -- not only more accessible healthcare, but we need a directory of accessible healthcare.
GWEN: Thank you. Meeting is adjourned.

Mailed and Emailed Testimony

Dear Governor Carcieri,

My hope is both for you and me. I realize if there is no money in the pot you can't help the Mental Health participants. But I wish we could both prosper.

For your life "As to ours as well"

In any case Good Luck

Sincerely Yours

David E Noel

Warwick

In the State of Rhode Island programs for those with mental disabilities are woefully under funded. RIPTA fees have gone up dramatically; routes have been eliminated .The I.M.H needs more funds. Community mental health centers need more funding. People with mental disabilities are human beings just like anyone else. The Medicaid system should be improved upon.

David Cameron

East Greenwich

I feel terrible. I am concerned about getting another job. I am concerned about people not having a Job including myself. I would like to get a job to make more money.

I am also concerned about the high cost of utility bills.

Richard Allen

Warwick

I like being in the bunsess unit. I think the state should pay to keep Hillsgrove House open so that I can talk with my friends. This is the only place that I have friends and I can socialize. I am presently on SSI and SSDI, and I am concerned that my might benefits be cut back?

James McKenna

Warwick

To Whom It May Concern:

I would like to discuss, how RIPTA can be improved to best serve individuals which disabilities. People using RIDE should be able to obtain transportation to a vocational rehabilitation place of business. Also, it would help lots of individuals if RIDE also would pick-up and drop off people at the YMCA in Kent County or other health club not on the bus line. This is very important to do since it is preventative minded and may improve someone's health while saving the government money in extra medical costs.

It is rather peculiar that all buses lead to Kennedy Plaza, why doesn't the state have an additional transfer station near the airport. Bus 29 could be routed from the Warwick Mall down Metro Center Blvd. and establish a transfer station at the new train station being built in Warwick. Thus, Bus 29 should cover more territory. Bus 20 could also drop off and pick-up at the proposed transfer station near the new train station.

Respectfully Yours,

Louis J. Pinga

North Providence

My concern with the Global Medicaid waver and the overall Mental Health treatment in the State of Rhode Island and Providence Plations. It is thought that the Global Medicaid waiver will save the state of Rhode Island millions but at what cost to the poor and disabled? If services are cut and our health coverage is reduced or otherwise impaired is the Waver justified? Is the growing cost of medical care suitable?...not as the current system is run! Too many people rely on the public hospitals to treat them for the common cold or other common illness. The most serious cases are backlogged because of this. This is the problem with the medical system- not the people on Medicaid! General Assembly Members get free health care at the people's expense! This is insane, why should their get free health care when the people on Medicaid get theirs cut or reduced.

Everyone should get the same health care no matter who they are.

When you have lobbyist and special interest group pushing their own specific goal at expense of our state it will only continue to be lagging other states in Our Great country!!! This once a great place to live. But now I feel I would better off living someplace else where taxes are not so high

And the cost of living is more affordable. Don't get me wrong I love this state my family has fought for it and still does. If it came down to I would still give my life and all my wealth to defend the State of Rhode Island and Providence Plantations, but not if the current state of affairs are not addressed in way that the state take cares of it citizens!! My loyalty is our country not to any self serving goals. I am and always will be an Honorable American and proud citizen of whatever state that I live in. I pray to God that state will be Rhode Island. Thank you for allowing me to share my views they are just that- my views.

God Bless America and God Bless Rhode Island

Josef J Belleville

Warwick