

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



**July 21-25, 2008**

**Prepared by the  
Governor's Commission on Disabilities**

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**State of Rhode Island and Providence  
Plantations  
Public Forums  
To identify the concerns of people with  
disabilities and their families**

**Monday July 21, 2008 1:30 3 pm**

Barrington Public Library's Gallery  
281 County Road, Barrington

**Tuesday July 22, 2008 3 - 5 pm**

Independence Square II, Independence Way,  
Kingston, Route 138 just west of the URI campus

**Wednesday July 23, 2008 2 - 4 pm**

Warwick Public Library's Community Room  
600 Sandy Lane, Warwick

**Thursday July 24, 2008 10 am - Noon**

Cumberland Library's Community Room  
1464 Diamond Hill Road, Cumberland

**Thursday July 24, 2008 3 - 5 pm**

Middletown Library's Community Room  
700 West Main Road, Middletown

**Friday July 25, 2008 4 - 6 pm**

RI Department of Administration's Conference Room B, 2<sup>nd</sup> floor  
One Capitol Hill, Providence

Comments may be made in person during the hearing, or you can e-mail [disabilities@gcd.ri.gov](mailto:disabilities@gcd.ri.gov), fax 462-0106 or mail them

by July 31st to: **Governor's Commission on Disabilities**

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

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"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 hearing, 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.

**Donald L. Carcieri, Governor**

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

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

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

**In-Sight**, Christopher Butler, Executive Director;

**J. A. Trudeau Memorial Center**, Mary Madden, President/CEO;

**Looking Upwards**, Carrie Miranda, Executive Director;

**Multiple Sclerosis Society, RI Chapter**, Kathy M. 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 Differing Abilities**, Linda N. Ward, Executive Director;

**PAL**, Doreen McConaghy, Director;

**PARI Independent Living Center**, Leo Canuel, Executive Director;

**Paul Sherlock Center for Disabilities @ Rhode Island College**, Anthony Antosh, Executive Director;

**Rhodes to Independence @ the University of Rhode Island, College of Pharmacy**, Ronald Jordan, Interim Dean & Elaina Goldstein, Director of Public Policy;

**RI Commission on the Deaf and Hard of Hearing**, Travis R. Zellner, Chairperson;

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

**RI Department of Human Services** Gary Alexander, Director;

Frank Spinelli, Acting Medicaid Director Division of Health Care Quality Financing and Purchasing  
and

Stephen Brunero, Acting Administrator Office of Rehabilitation Services;

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

**RI Disability Vote Project, @ Community Provider Network of RI**, Jeff Christie, Moderator;

**RI Governor's Commission on Disabilities**, John J. MacDonald, Jr., Chairperson;

**RI Public Transit Authority**, Alfred J. Moscola, General Manager;

**RI Statewide Independent Living Council**, Donald Phelps, Chairperson

## Chapter A Executive Summary

Twenty one agencies conducted a series of public forums to hear the concerns of persons with disabilities and their families during the week of July 21 to July 25, 2008, the Anniversary of the signing of the Americans with Disabilities Act (July 26, 1990). The forums were hosted by the Rhode Island Statewide Independent Living Council in Barrington on the 21<sup>st</sup>; Roads to Independence @ URI's College of Pharmacy in Kingston on the 22<sup>nd</sup>; Ocean State Independent Living Center in Warwick on the 23<sup>rd</sup>; PARI Independent Living Center in Cumberland on the 24<sup>th</sup>; Looking Upwards in Middletown on the 24<sup>th</sup>; and the Rhode Island Department of Health in Providence on the 25<sup>th</sup>.

A variety of issues of concern were voiced at the forums; transportation, home care agencies, employment, affordable housing, health insurance, state services, and education.

The Medicaid global waiver raised a tremendous amount of concern regarding its impact on transportation, appropriation of funds, shortages of medical services especially for children, etc. Many in attendance had issues not only with the vagueness of the legislation but with the trust of the state's legislators to make the right decision for the most vulnerable persons whom this plan will affect. There were concerns with the commitment the state will be making with the federal government. The five year cap with Medicaid was seen as a huge gamble. The loss of guaranteed dollars will have a big effect on this waiver. Who determines how much funding is needed and what are the criteria used? Who will distribute the funds? What happens if the funds are depleted in three years? Will the waiver cause a human crisis far more severe than the financial crisis we now face? Is this global waiver based on the projections of decreasing health care cost and a declining enrollment in health insurance? Are we giving up the entitlement of medical coverage? Will this waiver cause some agencies to close only to have other agencies burdened with the closed agencies workload? What will be the effects of this waiver especially for those in need of long term care? How will this waiver effect the agencies that concern themselves with the transition of consumers from nursing homes to independent living situations, do home modifications and offer technical assistance?

Employment opportunities for persons with disabilities, especially young adults,

Environmental issues such as excessive exposure to radiation caused by wireless smoke and carbon monoxide detectors placed in larger housing complexes as well as multiple chemical sensitivities and the housing dilemma for this disability.

Health care concerns, in addition to Medicaid reform, ranged from home care agencies and the lack of quality care, staffing problems and scheduling; affordable health insurance and expensive co-payments.

Housing concerns regarding how state budget cuts affect home modifications, there is a two year wait for home modifications for such items as a ramp. Why can't the local high schools, colleges or universities have a community service program and use it to help with this waiting problem?

Special education, the transition from children to adult services and the lack of information about work incentives.

Transportation related concerns included: the lack of wheelchair accessible taxi's, RIPTA buses not having ground level ramps for persons in wheelchairs; Ride ADA service availability with bus routes being streamlined, the fare charged for ADA patrons along with the scheduling practices and the Flex Plan.

Several suggestions were made concerning the forum meetings themselves. There weren't any meetings at a time when a working disabled person could attend. It was suggested that a meeting be held at night or on a Saturday so that such a person could attend a meeting without taking time away from their employment.

During September and October, representatives of the sponsoring organizations met, reviewed the testimony and developed recommendations for action. A listing of their recommendations (see Chapter B) were presented to the Legislation Committee on the Governor's Commission on Disabilities, in October. The Legislation Committee selected some of the recommendations for inclusion in the Commission's 2009 Legislative Package, which was revised and adopted, by the Commission on November 17, 2008.

1. Ensure implementation of the crisis intervention services for abused non-elderly adults (18-64) with severe impaired (Public Law 2006 Chapter 275 Assault on persons with severe impairments or mentally disabled - penalties - services for adult victims with severe impairments of abuse, neglect and/or exploitation);
2. Mandate the purchase of accessible taxicabs – the Commission’s legislation enacted in 2007 providing tax incentives to purchase accessible taxicabs has not resulted in the purchase of a single accessible taxicab;
3. Ensure the continuation of RI Public Transit Authority and RIdE (paratransit) service statewide;
4. Monitor and respond to Medicaid Reform proposals to ensure maintenance of services to individuals with severe disabilities and seek Commission membership on the Global Waiver Advisory Committee; and
5. Support the consolidation of school districts, to improve special education & transportation services.

## Chapter B Community Concerns & Recommendations

Concerns	Recommendations	Testimony on:
<b>1. Education</b>		
Information regarding transitioning to independence questioned by several parents.	<p>The Commission and RI Department of Education should promote consolidation of districts to use scarce resources for better use and earlier transition plans for better success.</p> <p>The New Individualized Educational Plan (IEP) forms should assist young adults with disabilities and their parents with transition planning.</p> <p>At the Division of Developmental Disabilities, the loss of personnel and the direction that the approval of services will entail without the social workers to do the work. Not sure there is a policy solution, but perhaps more advocacy and resource education of parents and individuals.</p>	Pgs. <a href="#">15</a> , <a href="#">47</a>
Intellectual resource education, post high school “adult learning / personal development” (for those with limited abilities) has been dropped from adult basic education in Bristol/Warren.	The Commission and RI Department of Education should encourage all districts especially Bristol/Warren to include programs with their ESL and GED and Adult Education programs to challenge all people in continuing education	Pg. <a href="#">103</a>
Resource lists vary and sometimes are not available to parents and students.	Send a letter to the Commissioner for Elementary and Secondary Education and the Interagency Transition Council urging dissemination of information about 211; on websites and on handouts to all people involved in education from students, parents and teachers and other staff	all
<b>2. Employment</b>		
At the Office of Rehabilitation Services	Meet with Office of Rehabilitation	Pg. <a href="#">110</a>

Concerns	Recommendations	Testimony on:
there are long waiting times for services, staff out on leave are not setting up call forwarding.	Services Administrator to address these concerns.	
Social Security Administrations cuts people off benefits, once they have a job but were eligible for work incentives.	Meet with Social Security Administration’s RI Administrator to address the need to provide accurate information on work incentives.	Pgs. <a href="#">25</a> , <a href="#">28</a>
<b>3. Health Care</b>		
Process at RI Department of Health (interns only), timeframe for appointments and lack of information.	The Department of Health and the Peer Assisted Health Initiative should focus on assisting with the process to make connections with other resources.	Pg. <a href="#">110</a>
People with disabilities must wait 24 months after being enrolled into the Social Security Disability Income program before they are eligible for Medicare.	The Commission has addressed this concern in the past; suggest reexamining the role the Commission can take in making changes within the system.	Pg. <a href="#">56</a>
Uncertainty regarding services under that Medicaid Global Waiver.	The Commission should continue to follow-up on this issue as it impacts Rhode Islanders with disabilities.	Pgs. <a href="#">18</a> , <a href="#">29</a> , <a href="#">35</a> , <a href="#">36</a> , <a href="#">38</a> , <a href="#">60</a> , <a href="#">68</a> , <a href="#">69</a> , <a href="#">90</a>
Chemical Sensitivity	Identify next steps to address this issue	Pg. <a href="#">105</a>
<b>4. Housing</b>		
Are people with post polio syndrome issue eligible for home modifications. Is anyone tracking their housing needs?	<p>The Commission should determine if:</p> <ul style="list-style-type: none"> <li>• data is being collected on number of people with post polio syndrome?</li> <li>• their need for housing modifications is covered under any existing law, bind, statute etc.?</li> </ul> <p>If data is not being collected then:</p> <ul style="list-style-type: none"> <li>• the Health Department should collect data for future planning needs and</li> <li>• legislation should be drafted to insure access to housing modifications.</li> </ul>	Pg. <a href="#">46</a>
Shared living (also shows up on numerous pages throughout the document and at many of the forums that were held).	<p>A variety of living options needs to remain available within the service system.</p> <p>The level of oversight of shared living arrangements must be heightened to insure health and safety, prevent victimization, abuse, mistreatment and neglect.</p>	Pgs. <a href="#">48</a>
There is a long waiting list for home modifications.	The Commission should work to insure state budget includes money to address long wait for home modifications. Also formalize relationships with colleges and universities and maybe Habitat for Humanity to address need for home	Pg. <a href="#">56</a>

Concerns	Recommendations	Testimony on:
	modifications if money is not available that is sufficient to address waiting list.	
Many smoke detectors affect air quality, especially for people with chemical sensitivity.	Education around chemical sensitivity should be available to housing developers and property managers. New housing projects should set aside units for those with chemical sensitivity – legislation may be needed to address this.	Pg. <a href="#">85</a>
There is a lack of housing that is both affordable and accessible.	The Commission should maintain relationship with RI Housing and development corporations to insure accessible housing are included in new housing stock as it is developed.	Pg. <a href="#">108</a>
There is a waiting list for home modification and adaptive equipment.	Current program is working well, don't cut but rather expand program.	Pg. <a href="#">111</a>
Adults with disabilities are having trouble maintaining their own home with a limited (financial) resources.	A pool of money should be set aside to maintain properties. Local entities (like a bank charitable trust) should be tapped to address this. Home modification money should be expanded to allow for routine maintenance like roofs, paint, etc.	Pgs. <a href="#">108</a>
<b>5. Support Services</b>		
Information & Referral		
It is difficult finding information about services.	Information & Referral, 211 & the Point need to be better publicized and assisted to make sure they refer to proper agencies.	Pgs <a href="#">50</a> & <a href="#">93</a>
Lack of information available to parents and young adults with disabilities about the adult service system.	Improve information for kids transitioning to adult services (see Education above).	Pgs. <a href="#">15</a> , <a href="#">26</a> , <a href="#">73</a>
It is difficulty providing input to policy makers, if meetings are held during the work day.	The Public Forums should be conducted in the evening, 6 – 8.	Pg. <a href="#">79</a>
Quality Control and Quality of Life		
The habilitation waiver services are needed, so people can stay in “community” rather than at the Adult Correctional Institution.	Retain the habilitation waiver services, as part of any Medicaid Reform.	Pg. <a href="#">14</a>
Services need to match needs of individuals (with disabilities).	The Medicaid system must include various levels of care that coincide with the varying levels of disability.	Pgs. <a href="#">47</a> , <a href="#">49</a> , <a href="#">60</a> , <a href="#">67</a> , <a href="#">69</a> , <a href="#">89</a> , <a href="#">90</a> , <a href="#">97</a>
There is a lack of training, licensure, and quality of home health care staff.	Improve licensure, quality control, and require national Bureau of Criminal Identification check of employees in health	Pgs. <a href="#">11</a> , <a href="#">14</a> , <a href="#">54</a>

Concerns	Recommendations	Testimony on:
	care services.	
<b>6. <i>Transportation</i></b>		
The impact of cuts to RIPTA and RIdE ADA paratransit services.	Support increasing by \$0.03/gallon the state gas tax devoted to public/para transit services.	Pgs. <a href="#">43</a> , <a href="#">54</a> , <a href="#">57</a> , <a href="#">94</a> , <a href="#">98</a> , <a href="#">113</a>
The lack of accessible taxis.	Require taxis companies to purchase accessible vehicles, as vehicles are replaced.	Pgs. <a href="#">61</a> , <a href="#">65</a>

## Chapter C Testimony

### 1. *Monday July 21, 2008 Barrington Public Forum*

CAMILLE PANSA: Good afternoon. It's nice to see so many people here. We will to speak up and give testimony. I am Camille Pansa, Executive Director of the Statewide Independent Living Council. I'd like to begin by having our panel members introduce themselves. I'll start with the lady on the right here.

KATHLEEN SAMWAYS: I'm Kathleen Samways with the Rhode Island Developmental Disabilities Council.

KATIE LOWE: Hi. I am Katie Lowe, I am with the Commission; on the council.

BRIAN ADAE: Brian Adae, staff attorney with the Disability Law Center. I'm here with my partner, another staff attorney, Kate Bowden, who will be registering people to vote. If you have not registered to vote, please see my friend Kate. For those of you who may not be familiar with the Disability Law Center, it is part of the National advocacy system for folks with disabilities. We are the state designated protection and advocacy system for Rhode Island, and operate on a variety of different issues, legal based advocacy and independent representation, and, in fact, these forums come at an opportune time for us, we're in the process of preparing our annual priorities. So Kate is also going to have some questionnaires am I correct?

KATE BOWDEN: Yes.

BRIAN ADAE: You can indicate that you think we should be focusing our attentions upon. And I would ask, if you could, to take one of those surveys and complete it for us. Thank you.

TIM FLYNN: My name is Tim Flynn, Governor's Commission on Disabilities, and Chairman of the Legislation Committee on the Governor's Commission. These are important to us, we take what you guys say, take what we hear from you, and formulate a legislative package. We have hearings all over the state as you know and take the information we get from you guys and we create a legislative package over the next two or three months, go over the testimony and formulate what issues are important and we want to pursue, and formulate and create laws and create a package, and then we take that up to the State House and lobby for its passage. So I'm glad you're here, and it's important to hear what you all have to say. Thank you much.

BECKY BOSS: My name is Becky Boss, MHRH, Administrator within the Division of Behavioral Health Care.

PAT RYHERD: Pat Ryherd from the Governor's Commission on Disabilities.

KEN PARISEAU: Ken Pariseau from Neighborhood Health Plan.

SHARON BRINKWORTH: Sharon Brinkworth, Executive Director of the Brain Injury Association.

MIKE MONTANARO: Mike Montanaro, representing ORS.

CAMILLE PANSA: Has everyone signed the attendance sheet that wishes to speak? I'd like to just go over the purpose of these public forums to identify concerns of people with disabilities and their families in order to assist the state to develop programs to improve the quality of life for people with disabilities so today is

important. I would also like to explain what happens here, what happens after the forums. And that is that there is a posting of the transcripts of the testimony on the Governor's Commission on Disabilities web site, and their web site is [www.disabilities.ri.gov](http://www.disabilities.ri.gov). We will prepare recommendations which will also be posted by the end of the summer. The recommendations and transcripts will be sent to congressional and state officials and to members of the General Assembly and the recommendations will be used to develop policy and legislative initiatives over the next year, or until they are accomplished. I would also like to review the process today that we will be following, and that is, we want to give everyone a chance to speak, and the panel members here are here to listen to what it is you have to say. You will be asked to speak in the order in which you signed in. And based on the number of people here that wish to speak, we're going to have to limit your testimony to approximately ten minutes. We will give you a two-minute warning when you get close to the end so that happen everybody has a chance to speak. Having said that, I'd like to begin and the first person on the list is Helen Carr. Would Helen like to step up? Or we can give the mike to you.

HELEN CARR: Really I just have a question I have a disabled daughter and she has aids that come from Medicaid: Home care services two different agencies and there are some days when she has nobody come in and she is completely disabled. It seems like either they don't have enough coverage or instead of the agency telling the aids what they're supposed to do at work, what hours they're supposed to work, the agency will if the girl can only work four hours then that's the four hours Paula gets. If she can only work two hours in the evening then those are the two, even though she's entitled to more hours. For instance, Fourth of July, there was absolutely nobody assigned. I don't understand it, since I worked in nursing, we had to work whatever hours were scheduled for us. And we may have had every weekend or every third weekend off but I don't think it's very fair of these agencies to not have the family and the disabled person know who is coming and when they're coming. I don't know which I can only tell you the names of the two agencies that I know that cover her. One is Home Health Care and one is Bay Side. Thank you.

CAMILLE PANSA: As I said before, we're here to listen and to take down the information, not to comment at this point. I don't know if any panel members have any questions or anything they would like to say?

FEMALE SPEAKER: Do you know the source of funding for it in other words is that through one of the waivers, DD waiver or aged and disabled waiver.

HELEN CARR: I don't know I don't. Beverly Lamaner (phonetic), she's the nurse but she is not the social worker and he's the one that works with the two agencies that I'm talking about.

FEMALE SPEAKER: Maybe we can talk after wards.

MALE SPEAKER: Excuse me if I mispronounce –

ANNA CORVI VELLECA: I'm not quite sure why I'm here except I have a disabled grandson. And he is on SSI. Now he's not mentally capable of holding down a full-time job. He's all gung-ho for a month and then he doesn't work any more. So he has no health insurance except for SSI and I am very concerned about what the Governor is going to do about his health insurance. As it is, I can't find a dentist who will take him because he's on SSI. There are very few psychiatrists who will deal with him because he's on SSI and he has OCD severely. No one at Butler will see him because he's ON SSI but even if he loses SSI, what will I do with him? I want him to work because all he does ask sleep in bed, depressed if he doesn't work. So, it's I'm very concerned about what the governor is planning on doing about health care for people who can't work.

FEMALE SPEAKER: I think I can. Generally speaking, we can't provide legal advice here, even though I am a lawyer from the Disability Law Center, but I can tell you generally speaking that the governor's cuts as far as what the state is doing have no bearing on the funding directly from SSI. Supplemental Security Income is a federal program and the insurance that comes along with that is federally based so there should not be a concern as far as the Governor's cuts at least with that particular provision. I'm sure that make Becky

might be able to provide general information if she thinks is appropriate in terms of what the Governor's budget may address.

FEMALE SPEAKER: Again, the Governor's budget wouldn't have anything to do with the SSI as indicated. If you would like to speak with me afterwards about some of the eligibility for psychiatric care where an individual might be able to go with Medicaid, I might be able to help you with that.

FEMALE SPEAKER: Next is Patricia –

Mental illness: Monitoring medication

PATRICIA PROVENZANO: Thank you. I have to begin by apologizing that I'm going to have to leave as soon as I speak because I have to get back to work but I'm here because I wanted to address the needs of the mentally disabled in this state. I have particular knowledge of this, I have a 26 year history of a daughter with mental illness, and for many of those years, I, as her family, have spent countless hours, days, months, trying to get some type of agency that would listen, that would give us some direction. Although great strides are being made I believe with children with mental illness and diagnosis and treatment, I think the stigma of mental illness still is alive and unfortunately well in our society. Often times these people are left to be discharged to the street or to shelters with no follow through, no consistency and everyone recognizes the one thing they need most is consistency and structure. Often times compliance with medication has grave consequences and as, again, with knowledge of mental illness being what it is, one of the biggest problems is getting someone to be compliant with their medications. I feel that the communication between agencies and hospitals is lacking in this state. I feel that we need to balance the right to privacy of which everyone has I'm not disregarding that. But it has to be balanced with the level of cognitive understanding that the patient has. So often we have experienced firsthand where our daughter, though an adult, 38 year-old adult, was given more rights to her right to privacy who willed any of her family members from helping her. And in the end it wound up costing us approximately \$20,000 in legal fees to try and keep a particular place to discharging her to the streets. I was told that was the first time in Rhode Island history that a private party has done that but I worry for the people who don't have \$20,000 to spend. We know where they go, they go to the streets and fill our shelters. Thank you for listening.

CAMILLE PANSA: Thank you.

MALE SPEAKER: I have a fast question. I'm just thinking, in your mind, I guess from what you said, you want to see more monitoring after discharge and a problem is people with mental disabilities, they have trouble complying with the treatments.

PATRICIA PROVENZANO: Yes.

MALE SPEAKER: You've been thinking about this for a long time. Do you have a solution, any answers in your head that might be.

PATRICIA PROVENZANO: Actually, I have researched, of course the internet can be our worst enemy or best friend. But there is a law for instance in the state of New York, called Kendra's Law and I don't know if anyone is familiar with it or not but Kendra's law came about in response to a case of a, an adult male who was discharged on his own, who was felt to be okay to live on his own. Again, compliance with medication taking was a big issue for him. He stopped taking his medications. He in turn, because of no follow through, became psychotic. He happened to be at a subway one day, saw a random woman waiting for the subway, pushed her in front of the subway and of course she was killed. After that, a law was enacted in New York called Kendra's law in memory of this woman and in essence, it requires some agency of the state to be responsible. If someone is discharged on their own, to be responsible to say, look, you have to report so many days a week. You have to take your medication, we have to be sure you're taking those medications. If you are not, you will be institutionalized and I know that's a hard pill to swallow, but, again with the hard core mentally ill, they need to have that structure and perhaps with some of them, not all of them, but with some of them, the threat of having to go to an institution would be enough to make them compliant.

FEMALE SPEAKER: I would add, in Rhode Island, there is mental health court and I don't know if you're familiar with them.

PATRICIA PROVENZANO: I am.

MALE SPEAKER: I'm sure you'll appreciate that I certainly cannot get involved and will not get involved in discussing any particular case, but as it sounds like you may be aware of, there is in this state a mental health law and there is a mental health court that is available to involuntarily commit such individuals and there is an outpatient commitment where court orders have to be complied with including medication and medication compliance. That is something that does occur on a regular issue. Then it becomes an issue of the providers, generally speaking, there are community service providers in this state and amongst community service providers there are mobile treatment teams that go to the individual. Sometimes there is a lot of controversy as to the extent of rights many individuals feel that the rights of the individual patient may be? Excess of what they should be to help that individual, however, I think if we had a mental health advocate here who could explain that system in more detail but it's important to know there is a system outline there at present however it functions. Does that help?

FEMALE SPEAKER: May I rebut that quickly?

FEMALE SPEAKER: First hand knowledge of that with my daughter, she was discharged under the care of a mental health agency in this state. Within four days of her discharge, she was broke, had gone through almost a thousand dollars worth of cash. She was homeless, and thankfully, that agency did pick her up and bring her to a facility where she remains now. So, I'm not questioning the efforts. I know there are many caring individuals and many great efforts being made, however, I am saying that there are a lot of cracks in that system and perhaps if that system could be insured up a little bit better so that these people do not, are not allowed to fall through those cracks and not allowed to be discharged to flounder. In those four days anything could have happened. Thank you.

CAMILLE PANSA: Thank you. Next person, Antonette Stanzione.

ANTONETTE STANZIONE: I'm not sure if this is where to bring it up, I'm recently been having a problem, I had gotten a letter they were going to change to Neighborhood Health Plan, I was on Medicaid. I called and said I didn't want to, they said it was a computer glitch, I was changed to the neighborhood health plan and right now I am almost out of the medical supply need I have, I only have two-and-a-half days left, I was on the phone with them this morning of the they're in the process of trying to work it out that I will get this need taken care of. I'm supposed to be back on they're saying we can't put you back on Medicaid until August 1st and meanwhile my doctor doesn't take it so have I an appointment with him on July 31st, I don't know what will happen when he puts the bill in. They don't seem to be meeting my needs. Well the computer says you can't do this and that and meanwhile you're a person sitting there with needs not being taken care of. That's about it.

Medicaid: Prescription services

FEMALE SPEAKER: Thank you.

MALE SPEAKER: Can I ask a question. Are you talking to people at neighborhood or at DHS?

FEMALE SPEAKER: Both. I'm her daughter and will be the next person she calls.

MALE SPEAKER: So you talked to somebody at Neighborhood about the medication?

FEMALE SPEAKER: It's not a medication, a personal need.

FEMALE SPEAKER: It's something through Vanguard and they're saying that they need a form and they need 30 days notice and she won't even be on the program for 30 days so how will that be met? There's no way to do it. What's annoying, she put in through the Medicaid system she didn't want to switch originally and then what we got back was the computer says you can't do it so our hands are tied. Well what's running the state, a computer or people?

MALE SPEAKER: I'm thinking at this point, it is at DHS and in terms of making sure you can get into a system, however, we do have someone at neighborhood who can work with DHS to make that happen and what perhaps what I'll do is give you my card with this person's name on it because I know July 31st is we have about ten days to work this out.

ANTONETTE STANZIONE: DHS said I'll be back on Medicaid as of August 1st but in the meantime I need my services and they're not getting taken care of.

MALE SPEAKER: So what services do you need that aren't being met.

ANTONETTE STANZIONE: Doctor's appointment on July 31st, he doesn't take it. Might be a way to pay him but the medical supplies I need, I need in two and a half days. When I first got put on neighborhood I told them, they're like we'll take care of the paperwork just call us closer to the time you need them which I did and when I called today they're like we're still waiting for this and this and I'm like what do I do in two-and-a-half days.

MALE SPEAKER: We have a member whose job is to work out these problems. You are a neighborhood member through the 31st so it's our obligation to be sure you get your needs met, so I'll take your name and number and have this person get back to you this afternoon.

ANTONETTE STANZIONE: I talked to a lady this morning Sue I talked to a lady this morning who said you still need this paperwork done but what do I do in the meantime.

MALE SPEAKER: We have ways of facilitating that so we'll talk after wards to work this out for you.

FEMALE SPEAKER: Thank you.

DAWN STANZIONE: I actually do have another point not about Neighborhood to make. I'm Dawn her daughter. When first on the Medicaid member not first but when she started needing home care because I work full-time hours Medicaid system has a program they it was covered by the Medicaid system, the first person they sent to our house, first day admitted and I quote, I just smoked a bone on the way here. Why do they hire drug addicts to work with some of the most vulnerable. My mother has mental faculties but someone with Alzheimer's or mental disabilities, no way people like this should be hired. We ban child molesters from schools, we should ban people who have broken the law and could pose a threat of abuse to take care of handicapped, disabled, various things. We're hooked up with the PARI program where a client would be in charge of hiring people and they work much better than the Medicaid system because we had no control. I through out the lady the first day she showed up, I'd rather have my mother alone but there's no way that should be I realize they're trying to help people back into the work force and they also mothers trying to enter work and that's snot a crime, have I no problem with that but drug addicts, there's no reason. That's something I want to see addressed.

Medicaid: home care services

CAMILLE PANSA: Thank you. Paul would you like to speak?

MALE SPEAKER: I am a member of the Brain Injury Association of Rhode Island. I'm with the I suffered a brain injury 22 years ago and suffering a brain injury affects your cognitive and mental way of life, you're a different person. I was in a coma for 3 weeks, when I woke up out of the coma for three weeks, you need occupational therapy, physical therapy, psychological therapy and thankfully after my accident I was able to live in my parents home for a while and then I was able to obtain a Section 8 voucher to find an apartment any where in the country and so with the support of the PARI organization, I have an aide that comes to my house to help out with daily living activities. They take me shopping. I need to go to BJ's today or if there's a function for the brain injury association they take me there. It's important to have there are other peep who will have suffered a brain injury also who need services I get and so that's why I'm here today, to advocate for services for people with brain injuries so they can maintain a normal life, that's basically my function here today, to advocate for aids for people with brain injuries.

Community Supports:  
Brain injuries

CAMILLE PANSA: Thank you. Next person. Mary Genko.

MARY GENKO: Hi. I'll try and articulate what I need to say. My children and I have four children and one is multiply disabled. I can't even call her a child, she's 19-and-a-half years old so getting into the gap of children services to adult services and I'm not liking what I see thank Rhode Island disability law because they have represented this poor child more in her years of schooling than they can possibly imagine and so we have found every pit fall in the school systems when it comes to children with medical disabilities as well as cognitive disabilities to go along. She spent many years not in school and in other at home with mom who has had to give up her career to stay home and take care of this child. She is now 19 and a half and they're telling

me to go out there and start looking at what's out there and I'm realizing that I believe she's a group of, one of the first waves of individuals who were not institutionalized when they were young because of the severity of her disability. She's had a wonderful quality of life, she's gone to the public schools until just recently. Her family and her parenting's and those around her have made her life wonderful. We continue to here from the neurologists what a tremendous quality of life she's had, what she's been able to accomplish, et cetera, et cetera. So now I'm out there and starting to look at the adult service piece and I'm not finding a place that she's going to fit. She's one of these children who has had a one-on-one teacher assistant her entire career, shall we call it?

Transition: Children to Adult services

School career. She walks, she runs, she climbs, she's troubled. She's trouble on wheels. She has daily seizures and needs to be monitored, she's non-verbal, not toilet trained. So you look at one side of her you have this, another side of her, you have that. I've gone to some of the agencies and looked and it's not going to work. You talk to the providers and they say, well, I'm sorry, in adult services they can't have one-on-ones. There is no place to put them. She's a child who has been out in the community everyday of her life, when she wasn't in school she's been in the community, goes to school and to field trips, goes to the mall, she did you see everything with her parents and to think that when she graduates from Meeting Street which is where she's gone for the last year, plus, prior to that she went to the Cranston public schools, that there's no place for her to go. There is no peg for her to fit into and so I see this grouping of children that I now see are many of my daughter's friends and younger who have lived at home, who have gone out, who have many, many connections with the community around them which is la we have wanted, which is what we had hoped for but now they're getting into those adult years and I'm not getting any younger, I can't imagine what she's going to be like if she has to sit home with her mother 24/7 once she gets out of school. What is out there, what are we looking for these individual who is had these wonderful experiences through childhood and now go and look at I don't know what up want to call them, sheltered workshops. She's not a child or young lady, an adult who will be able to work. When I look at some of the agencies, unfortunately, she's not going to sit still. She's going to cause trouble. It's like having a 7 year-old running and climbing and going and going with the brain of a 9 to 12 month old. So she's going to cause trouble and like I said, most of these kid who is now trouble with one-on-ones, what are they going to do? Where are they going to go? What agencies are out there? Services are being cut. I was talking to someone at the Sherlock Center and they said even with the level of funding she would get from DDD she might be able to get a day and a half a week and that would be inclusive of nursing services. That's a joke. It's a travesty for someone like her so I bring forward to you that there is this growing population of medically fragile and developmentally disabled individual who is will lived at home and been supported throughout the years by their families whose families are getting older and there's no place for these individuals to go out and spend their days, spend their evenings. My daughter has had, besides not being in school, qualified for every service known to mankind. The agencies are wonderful. Everyone says she's eligible for paths, respite, nursing, don't ask me the last time I had those people in my home because as these people said, there's nobody qualified to do it. I've had nurses come to my home and say, she walks? I have to follow her around? I'm sorry I'd rather take care of the tube feed where I can sit and read my book but yet she has to have these services so her mother, her father, and her two remaining brothers take care of her when she's at home, when she's at school, the school takes care of her. If you were to see her, she's the happiest child known to mankind but that's because her needs have been met. So as a parent I ask, what services are going to be out there for this up and coming medically and developmentally fragile population. Did I articulate it okay?

KATIE LOWE: So, if you want to call the Commission on Disabilities.

KATHLEEN SAMWAYS: First of all, thank you. You've done a great job it sounds like and you're an amazing advocate so thank you for that and I invite you to call the council. We have some wonderful stories coming in from all over the place from folks with very individualized plans for their children who are transitioning from very dense services as children to the adult world where the density doesn't end.

MARY GENKO: It won't happen because she won't survive. The first day she goes to a setting like the ones I've seen, you will find her hit by a car in the middle of the road.

KATHLEEN SAMWAYS: So you need individualized planning and those kinds of plans are being made and you need to hear about them so we invite you to give us a call.

BILL INLOW: If I could just add I think I understood Katie, thank you for speaking up, Katie. Katie knows about getting good quality support and services when she was a student and will face the same challenge and I think Katie was saying that's a really good point you were making and you should call the Governor's Commission on Disabilities, right?

KATIE LOWE: Right, correct.

BILL INLOW: And the Developmental Disabilities Council, right Katie?

KATIE LOWE: Yes.

BILL INLOW: And finance to make input on that issue. Thank you for speaking up, Katie.

KATIE LOWE: You're welcome.

CAMILLE PANSA: Thank you. Is there anyone else who wishes to speak? I would also like to remind people that there is someone here if you need to register to vote.

KATE BOWDEN: I put together packets with our materials, there are a number of them. Gives information about what the law center is doing, with all programs including the voting program, if you need assistance with helping people register to vote.

KAREN KANATZAR: Hi my name is Karen Kanatzar, with Parent Support Networks, we have a few brochures with me today. We are all parents with children with special needs and we're here to help you in any way we can regardless of the age of your child. I don't promise miracles, but you will have a listening ear and we'll do whatever research you need to find what you need for your child. So, I hope you'll feel free to call on us. I do have a child approaching adult hood who needs 24/7 and I adopted him as an old what hed and I'm getting older faster and I'm just not always going to be around for him and I'm very, very concerned about how to plan for him as an adult to make sure that his needs are met when I'm not here. So I can appreciate some of the issues that you have.

CAMILLE PANSA: Thank you.

LUCILLE STRING (phonetic): My name is Lucille String, and this is my husband, Bob. We came here

Medicaid: Global waiver

today, thank you for the opportunities, our concerns are regarding Article 17 of the 2009 budget. We have deep concerns about the whole thing. Especially for the changes that will affect persons with developmental disabilities who require long-term care in the community. A very frightening to us as parents, takes us back to the years of being without help and without choice, years of division of developmental disabilities rejecting our daughter's needs, years of being on our own for all aspects of their lives A daughter born with cerebral palsy, left 33 of her 48 years, we were our daughter's only support for she was never deemed eligible for services. When born, there was no early intervention, no HBTS [home based treatment services], children in a wheelchair were barred from neighborhood schools. She spent six-and-a-half years in an institution setting in New Hampshire for her education. We traveled every weekend to bring her home. Intrusion and transition were only words to be found in the dictionary. Our daughter at the age of 21 found herself at home with no training, nothing to do, no future. Today, we are proud and most grateful that after many years of struggle and determination, our daughter is living in the community independently of us in her own apartment, made possible by daily supports through you knighted cerebral palsy Rhode Island, shell continue to need long-term care for her natural life. Our concerns as her family regarding a capped waiver. I have question that is follow these statements. I know I'm not here to receive answers but I want the questions out there for people to know our concerns. The five-year cap on fund social security a major gamble, loss of matching federal dollars, a loss of federal payments guaranteed on an as needed basis. If capped funds are exhausted in say 3 years, what happens to our daughter's services and supports? Where will the additional money come from? How can this be resolved without added unrealistic burden to Rhode Island taxpayers and an increase in the existing debt problem? Determination amount for the five-year period rests on assumptions such as projections of health care costs and an un anticipated enrollment increase. My question is, how can Rhode Island even begin to project a

fixed financial amount to public one year, let alone five years for children, adults, and seniors requiring long-term care? All control for the capped waiver will begin to the executive branch of government to choose the spend the dollars as they see fit without accountability. My question, how can we be guaranteed that the funds will be appropriately dispersed? That there will be no borrowing from Peter to pay Paul? My husband and I support

Medicaid reform that will include participation by the individuals and families affected by the changes state agency staff, community providers with expertise in providing services. We need to work together with the current waiver system to initiate positive reform. And last statement is a human crisis will be far more costly to this state than any fiscal crisis. Lives will be in peril. And I thank you.

CAMILLE PANSA: Thank you. Is there anyone else –

GINA WALLACE (phonetic): Thank you. My name is Gina Wallace, I wasn't planning to speak but as a learning process five year-old who was a victim of shaken baby system, has traumatic brain injury, cerebral palsy, has seizures and needs full-time care. Happened when he was five months old, and I had to leave my career and my husband and I stood strong and, we take care of him and I'm getting quite a bit of services. It's a full-time job just trying to get the services. The services have been amazing, early intervention, Cedar, I have paths and also some nursing in the home to help me care for my son. It's not what I'm authorized because there is a shortage so I definitely can relate to people who said the quality of the care is a little lacking. It's hard to trust someone. Once your child has been abused and this was by a licensed day care provider I don't get into

it. But I just wanted to say that, you know, it's just very, it's hard. This is a day-to-day process, it takes so much time. I'm trying to use every service. I have, you know, every phone number. It's been helpful but it sure would be nice if things were just a little bit easier, if things were maybe put in more of a layman term when you're explaining certain laws and I just, you know, I'm an educated person but sometimes I'm just lost on the process. And I just wanted to say that, again, he's five years old, the services are wonderful. We are very, very grateful for Katy Beckett which has helped with our medical bills and allowed me to stay home and take care of him so I just wanted to say thank you.

CAMILLE PANSA: Thank you. Is there anyone else?

GWENN: Hi. I just wanted to introduce myself. My name is Gwenn with the Multiple Sclerosis Society. I know we sent out an invitation for people with M. S. to attend these forums I want to say if you're here, we'd be happy to meet you. Thank you.

BOB: As my wife said, my name is Bob, and you heard about our daughter. I would like to say a little something about this waiver. This has to be they will amend the federal social security system. This is the beginning of privatization of social security, I would like everyone to know that, especially parents. Parents right now should be right in and do all they can to get to their legislators and to see if this can be stopped. Once this is in, as my wife said, money to pay Peter from Paul and the whole bit and once you start doing something like this, the state now receives 52 cents on every dollar from the federal government. When this is eliminated, say they don't make the five years with their projected amount. What happens? It rests once again on the state. Once again we go to five more years or however they do it again. This is what everyone has worked for over 30 and 40 years from when there was nothing for people with disabilities, no matter what type of disabilities and now this is the beginning of shooting it all down. This as I mentioned before is the administrations, federal administrations beginning of privatization of social security because, the Medicaid waiver is right where it come from. Thank you very much.

Medicaid: Global waiver

Social Security:  
Privatization

CAMILLE PANSA: Anyone else?

KEN PARISEAU: Can I make a comment? I'm sorry, I didn't catch your name, the mom in the back. Raising a child with special health care need social security challenging and a full-time job and I know of a lot of parents who have children with special needs who spend a lot of time coordinating all the care across multiple system that is their children need. Whatever health plan you belong to, should also have care

coordinator who is should know those systems of care and should be providing system assistance to you in accessing your need. I know you probably get some care coordination through Cedar but I'm assuming you're also part of a health plan and the health plan care management department should also have fairly experienced care coordinators who should provide assistance to you also so I would challenge your health plan whether Rite care or commercial, particularly if it's a commercial health plan because they tend to not always fulfill their obligations to their members, but all health plans have care coordinators so you certainly deserve to get assistance from your health plan.

FEMALE SPEAKER: Thank you.

CAMILLE PANSA: Anyone else?

BILL INLOW: I'm Bill Inlow, on the Governor's Commission on Disabilities Legislative Committee and I would like to congratulate this couple and you for wonderful testimony as well as others but the three of you are speak being a critically important issue and that is something that you'll read about and hear about in the next couple months in the paper and in other parts of the media, radio and television, called the medication global waiver. Is that right, Ken? That's how you'll hear it most of the time.

MALE SPEAKER: Yes.

BILL INLOW: The Medicaid global waiver. We have an attorney here, it's my understanding the Medicaid

Medicaid: Global waiver

program is called an entitlement program, part of the social security act, title 19 chapter 19 of the federal social security act. Isn't it right that it's an entitlement program? Citizens of this country are entitled if they need meet certain

conditions, if they meet.

BRIAN ADAE: We've always, at the Disability Law Center, in answer to question, is it an entitlement program, our interpretation is that this is an entitlement program although that's not universally accepted.

BILL INLOW: If a citizen of this state under that federal law which is really a jointly funded state and federal program for health services, about 60 percent federal or 50/50, whatever the ratio is, if a citizen of the state meets certain conditions of income and health care needs, they're entitled it's a civil right, they're guaranteed by this federal law a certain level of health care services, is that a fairly accurate statement? Because it speaks to the point that you're making. My understanding is that a part of the hundreds of pages of details contained in this thing called Medicaid global waiver is a waiver, small w, a giving away of, an entitlement of Medicaid services. And at least that's my understanding. So that if it doesn't work, this plan they have, to save money, by making significant changes, there will no longer be a federal guarantee that you will at least get some level of health care services under the Medicaid program. Ken, is that your understanding that we are in effect giving away the entitlement rights of the citizens of Rhode Island under the global Medicaid waiver if for the five-year period, or beyond the five-year period? If that's inaccurate tell me because I think it's a major misunderstanding on my part and a critical point to the point you folks were making.

KEN PARISEAU: The waiver application is still being written. The waiver is still being written so the application has not gone in. The basic concept of the waiver is that under this global cap, or this five-year cap, the state would agree to accept a certain amount of money covering the five years and they could only get that amount of money so it essentially looks more like a block grant than it does an entitlement program because once the state uses up the money and as you pointed out, if the muffin is use in three years, what happens for years 4 and 5 and I think those are the concerns raised at this point about the global waiver. As you pointed out, I think there's consensus that Medicaid does need significant reforms to T I think people today have mentioned the lack of home and community based services that care for adults. I mean the state historically has been geared towards hype end expensive services to the detriment of quality home and community based services. There aren't enough qualified nurses, there aren't enough qualified home care providers, that's because the state has tended to spend its money on hospitals, nursing homes and high end institutions. So the global waivers intent is to get some more flexibility so they can begin to shift some of those dollars away from some of the high end services and invest those dollars in the home and community based services. That's the intent to be able to provide more home community based services than exist now but as you point out there are certain risks

to that because you give up the entitlement to settle on a five-year amount of money which requires doing some pretty good prongs projections. While there's agreement there need to be reforms, there are question about a capped waiver because once the money runs out, the feds won't give you any more.

TIM FLYNN: I just wanted to say, I don't think that for people with disabilities that there is an increase in eligibility. So I think the people receiving services now will still qualify for services later on. But will there be money for the full five-year as soon as I think that's important.

FEMALE SPEAKER: If there's no money available, it's a moot point.

MALE SPEAKER: I won't take up much more of your time, just a knew things. The state of Connecticut first ever all, turned this down. Some states have portions of it. Vermont, the federal government of years ago gave them a bundle of money to try it but there's a small state, a very small population of disabilities and they tried it there, I don't know how it made out but I know Connecticut turned it down and we're going to be the first state if this happens to go under this waiver. I don't think, and I know in five years, for five years there's no way that they will ever come up with a proper amount of money and it's going to put the state as a disadvantage once again. We're trying to clear up a budget deficit that was made out over a period of years, we can't do it in one year. That's all I have to say, thank you.

BILL INLOW: Couple quick things. One, my understanding, the global waiver does have some advantages, more control by the actual peep who will are receiving the care, the client, the family member. Some more flexibility, those are good things. But it's my understanding also that the absolute mandate from the governor and General Assembly to save 67 million dollars per year, actually starting this year, the fiscal year that started July 1, between now and July 12008 and June 30, 2009, that waiver is supposed to save 67 million dollars. Now I am not aware of the fiscal challenges at the federal and state level, we face it everyday when one of us pays four dollars a gallon for gas and those of us who know what it's like to purchase our gas, many federal and state officials don't because they don't pump their own gas, somebody else drives their car around. If you think you're detecting a bit of sarcasm and anger in my voice, you're right because the peep who will pay the risk here are the frailest most vulnerable most health fragile peep until our state and that's a big risk. Administers trying to work out these details and they're not bad people, they're trying their best, they work under a mandate from the governor's office, they'll be embarrassed if this doesn't work, maybe they'll retire. The Governor won't be around if this doesn't work, he'll probably feel bad about it, I hope he does but the peep who will pay the risk are the family who is worked so hard to keep their loved ones in their homes for these years in cooperation with the state. I think there's a loft danger. I'll make one suggestion, I'll give awe toll free number. If you want to express your opinion to the General Assembly members or to the governor you can call this toll free number and they'll hook you up with the Governor's office or to the speaker of the house's office or to the president of the senate's office or to the chair of the finance committee's office, Stephen Costantino. Any of those people, the chair of the house finance committee, Costantino, you can get a message to them through this number if you have an opinion about this global waiver avenue about what you'll read about in the newspaper very, very much 1-800-547-8880. 1-800 it's up on the board. 1-800-547-8880 and you can get a hold of any of those people, get a message and tell them what you think. It's important that you do that.

FEMALE SPEAKER: Do you really think Governor Carcieri cares? I don't really think he cares. I'm sorry but I don't think Governor Carcieri cares. I think he's going to leave office and we're stuck. We're stuck with Governor Carcieri, we're just stuck with him.

MALE SPEAKER: He still works for us, folks.

FEMALE SPEAKER: Does he really?

MALE SPEAKER: Technically he does.

FEMALE SPEAKER: I don't think so. I'm sorry but I just don't like Governor Carcieri.

CAMILLE PANSA: Anyone else that would like to testify today?

KEN PARISEAU: Can I make another comment about the waiver? Just as this public forum today is a really outstanding opportunity for us to hear about what your concerns are about programs and services and needs, part of article 17 which is the budget amendment that deals with the global waiver, part of what that

requires is once the state negotiates a deal with C.M.S. which is the federal agency, that deal has to come back to the General Assembly, which is required to hold public hearings on that waiver. So you should can tracking the web site both DHS and executive office of health and human service to learn more about those public hearings and those public hearings will also be announced in the newspaper, also. But that will be an opportunity for the public to respond to what the final deal ends up looking like. So those of you who are concerned about what this may eventually turnout looking like in terms of impact upon our state, the public hearings would be a good time for you to add some comment to that.

FEMALE SPEAKER: Thank you. Hi I'm Linda, Executive Director of Opportunities Unlimited and Commissioner on the Governor's Commission. The other thing about the waiver, before it gets submitted to CMS, it has to be submitted to the two finance committees, house and senate. They have ten days to look at it before it's submitted to CMS. They have a group of people across many spectrum who is have sent a letter requesting public hearings in that ten-day period so we can hopefully kill it before it's even submitted. The other thing to add, most people believe what the Governor wants which is to improve home based services can be accomplished under the existing waivers and that control by the people who get services of their funding already exists in many of the systems that are in place. So,-- and the notion of saving 67 million dollars in one year, my concern is who ends up on the street or dead this year. There's no way to cut 67 million from a system and not have something like that happen.

SENATOR DAVE BATES: Hi, I really came to listen this afternoon but I'm not trying to hide either so I wanted you to know Senator Dave Bates from Barrington and Bristol. As I said I didn't want people to think I'm sitting here hiding, I'm proud to be in the Legislature, but I pressure comments and certainly will be listening. I'm not finance in the house or senate so I won't be in the hearings but many of us watch this very closely as well.

CAMILLE PANSA: Anyone else?

FEMALE SPEAKER: This is mostly a question is that why they're putting us on different health care plans does this have anything to do with that? Because, frankly, since I've been put on this health care plan with neighborhood health, the services are just immensely hard to get. They're not responsive to my needs. I was on

Housing: Home  
modifications

Medicaid and I'm on PARI, PARI had been a tremendous help. They've gotten me the care I needed and helped me get a lift for my elevator, I live in a house with seven stairs, I could not get out of my house. I was stuck in my house for a few years before I heard about PARI. It's not known to people. I found out about PARI by accident. My daughter works at Shaws and had gotten laid off and they gave her a stacks of papers and there was a little paper saying if you're disabled and you need help you can call this organization. No one had ever told me about it. I was literally home bound, stuck in my house for almost 3 years, could not get out F there had been a fire, buy have died. There was no way for me to get out of my house but once I found out about PARI, they took over and I'm on waivers so, you know, to get the lift in and this is one of my PAs here with me, my personal assistant. She works more than full-time to help, because I'm on SSI and I'm home alone a lot of times but now with PARI I'm not and they got me the lift but with this new thing they put me on. The lady I talked to this morning was responsive but up until now I was getting and I still don't have answers, she was very nice to me today but I still don't have the answers as to what I'll do about my doctor or my medical appointment. They put me on this and I'm like, I don't want to be on it and they have a record of my call because I said I called and oh, it's a computer glitch. Well that leaves me, you know, floating in no where land.

FEMALE SPEAKER: I'll comment on that also. When I found out about this PARI organization, what happens, I was laid off temporarily from my job, I it was illegal and I ended up with a small settlement. They gave out papers with more information than my mother's social worker ever did including free food program, not the food stamp fund but it's a shelter she was on the programs five years before we knew about that. I was basically supplementing the food out of my own pocket to take care of her. And the state just didn't I know now and I found this out actually about six months ago, there's a little yell owe handbook about different programs they can get into, nothing was ever mentioned by her social worker at the time. I don't want to get into that because I don't remember any names but nothing was mentioned about any of the programs. I know this book

has some. These are programs I know offhand, and how is someone elderly or physically handicapped or even mentally handicapped supposed to be able to have access to these things? I work a little more than full-time with my mother have trouble getting through the system because she can't do it. The place we pick up the food is not' handicapped accessible. She can walk a few steps on crutches but there's seven stairs where she picks up the food and no access. There are so many things like that, if you don't have if you don't have a bull dog fighting for you, you won't get any where with the systems in place and then want to make it more stringent, it makes no sense.

CAMILLE PANSA: Thank you.

FEMALE SPEAKER: I probably don't need the microphone. Following up on her question on what the qualifications are to work for these agencies, I just happen to think a friend of mine said not too long ago a new worker her home and dismissed after the worker said to her, if I lose this job I'm breaking my pa roll and have to go back to the ACI, she called the agency and said her check hadn't come back yet. What was she going to do work in people's homes for three or four days and do what to these people? The way the conversation came about is the woman walked in and said, oh, this is a pediatric home, someone is here? Because shed been sent to take care of a child and that was the response from the agency, well, the BCI check hadn't come back item. So how does one find out what the hiring protocols are for people who work for these agencies before you do leave them in your homes with the most vulnerable of individuals?

FEMALE SPEAKER: I know PARI we just hired a new PA for my mother. A 127 page application and two background checks. This is through PARI not through the state run organization but maybe they need to impose stricter background checks on the people they're hiring because with what she said and I experienced myself and even the second woman we did I say missed, hers wasn't drugs but she was bragging about how violent her son was. There's no way I'll let these people stay with my mother. There needs to be some regulation.

FEMALE SPEAKER: The PARI organization, I don't know in you're familiar with them at all, you pick who you want to work in your home. I pick the people and I give the application to them, they do the background check so I was the way my life work ised I do have a lot of good friends that I was able to hire through the PARI waiver that I knew were trust worthy but on top of that from my own judgment but PARI does the background.

FEMALE SPEAKER: But everyone in the state can't go through PARI, they go through multiple agencies so you have to have some form of minimum regulation.

FEMALE SPEAKER: Yeah, should be more like that because before I found out about PARI, I was terrified in my own home.

BRIAN ADAE: I can't speak specifically to the situations you describe but if it helps to clarify it a little bit, there are two different kinds of employment that we're talking about, there's the general agency employment where the agency is responsible for screening the individuals and we do know that generally speaking, speaking they do screening the criminal background it may not be uncommon that someone with a criminal background, here the question, what is the nature of that, are they rehabilitated, somebody may have had a drunk driving case from years and years ago, any number of situations you can imagine if you've known somebody personally who may have had a brush with the law at some point in time and is still looking to be able to be gainfully employed and contribute to society. The PARI program which is administered or the PARI waiver is one where the individual, in other words, the consumer can employ somebody directly and then the paperwork, the money, is handled through PARI. So I see in that situation there are folks more familiar with the PARI waiver or it has another name now is it Tritown or OSCIL as well.

FEMALE SPEAKER: Personal Choice waiver.

MALE SPEAKER: The Personal Choice waiver. Correct me if I'm wrong, I believe there's a certain amount of responsibility on the consumer to screen that person as well.

FEMALE SPEAKER: Yes.

MALE SPEAKER: So those two different things and my suggestion would be obviously, like any employer or if you are receiving service from an agency that if there's an issue going on with the particular individual who is providing the services, you may be able to discuss it with the agency first and pass it back or if it's an individual you've employed then you know what you need to do if it's someone working for you.

FEMALE SPEAKER: Can I just say one more thing? I just want to say, I had to let those agency people go I went for years with no help because there was nothing else to fall back on until I found out about PARI. I complained to them and they said that's who we hire, we're trying to help these people and I'm like, I can't be in a house alone with someone like this and they offered no other way out of the situation so I was stuck with no help until I accidentally found out about PARI a few years later so I was home alone for a number of years with no help because they offered nothing else.

FEMALE SPEAKER: The gentleman in the front row with the white shirt on right in front of you.

MALE SPEAKER: I'll take that. Hi, I'm a deaf person, but no, I have nothing to say, but thank you for the opportunity.

CAMILLE PANSA: Again, is there anyone else who wishes to say anything.

MALE SPEAKER: I'll say something now I guess. Just a brief comment. The assistants that I work with, they have some technology, it's really wonderful gas and I've been working and I'm actually living, doing well, with some assistance that has helped with some gas, I've had gas assistance with my house and that's helped me live more successfully and that's all. Thank you.

CAMILLE PANSA: Anyone else before we conclude today? I wish to thank everyone for your comments. I appreciate your being here and for what you had to say. Thank you.

## **2. Tuesday July 22, 2008 Kingston Public Forum**

FEMALE SPEAKER: We have more people than we do in the front, this is great. We will wait for my watch says 10 after 3. What does everybody else have? Okay.

AUDIENCE MEMBER: Can I pet your dog?

FEMALE SPEAKER: You should come up here because we are running late. We need you to fill out your name.

AUDIENCE MEMBER: I am just an observer.

FEMALE SPEAKER: I have you on my panel.

AUDIENCE MEMBER: You did? I prefer to be in the audience.

FEMALE SPEAKER: Are you serious? Really? Okay. All right. Did everybody who is in the audience sign-in sheet and if you wanted to speak, indicate that you would like to say something on the sign-in sheet? I think it says if you want to say something. We are feeling the budget crunch of the state government. So we are

evidently making our own name tags. So we are going to make this all work. All right. I don't have a full handout.

MALE SPEAKER: What do I have? I have the announcement. That's it.

FEMALE SPEAKER: Are you Elizabeth? Good. We have a couple of people from I think we are pretty set. Okay. Good. Frank is coming. Could you make him a sign? Okay, folks. All right. You know hi. Is Jean

FEMALE SPEAKER: I'm right here.

FEMALE SPEAKER: How many of you have been here in previous years? Anyone ever been to one of these? Great. Not great but I'm glad that you are here today. Let me give you a little bit of an overview of how these forums are run. Basically the objective here is that we are to listen to all your concerns. So it's not like we are here, the panel, and you are giving us the concerns, to give you an answer. But what the commission does and Tim Flynn here is from the legislative he's the head of the legislative committee on the commission. Much of what happens from these forums general outcome from a lot of the concerns and issues that are brought up in this forum are generally dealt with legislatively within the governor's commission on

disabilities. I run a program called Rhodes to independence. And I work very closely with the governor's commission on disabilities. So sometimes if an issue is one that really doesn't have a legislative remedy or we can do it without legislative initiative, I will work to try to get the issue or the concerns taken care of in a non-legislative way. And so, that's that has sort of become the role of Rhodes to independence. I am going to have everybody else on the panel introduce themselves. ? And if you could just introduce yourself, where you are from, and sort of so that you will know that if after this forum you would like to get people's cards or you have other questions specifically that you think they may be able to help you with, you will know who to go to, okay. Because again, the process here because we do have so many people here today we want to make sure we get everybody on the record and get all of the concerns you have on the record so that we can then make sure that we address everything for everybody that is coming to all of the hearings throughout the state. Okay. Why don't we start, Charles.

MALE SPEAKER: I am Charles Messina, a staff attorney with the Rhode Island disability law center. I have although not a panelist, Vanessa. She can register you to vote.

FEMALE SPEAKER: We also offer trainings to organizations and individuals about voting rights

FEMALE SPEAKER: Can you hear her? Talk up a little bit.

FEMALE SPEAKER: We are also offering trainings to organizations about voting rights. So if that is something that interests you, you can speak to me during or after the program or contact our office. We have a grant to do trainings on voting rights so we are happy to assist you if you are interested.

FEMALE SPEAKER: Elizabeth Connallon. I am representing the brain injury association of Rhode Island and we advocate for families and survivors of traumatic brain injuries.

MALE SPEAKER: I am Tim Flynn and as Elaina indicated, I am Chairman of the Legislative Committee on the Governor's Commission on Disabilities. The process we want to hear from you. We take what you say to us. And we bring it back and we sort of categorize it all and we have some legislators who are very friendly who are friendly to what we are doing. And we will then if they are good suggestions and we take these forums, we will then craft a law. We will lobby to get the law passed at the state house. That's really that's what our mission is. We also monitor really pretty much every law that goes through that goes through the House and the Senate. We look at them all. Try to be beneficial to people with disabilities or harmful for people with disabilities or harmful with disabled unless amended to include a particular change in the law. And we sort of see ourselves as a watch dog legislative watch dog for people with disabilities in Rhode Island.

FEMALE SPEAKER: Okay. Again I am Elaina Goldstein. I want to just a couple other things about Rhodes to independence. We have a brochure in the back which is a brochure talking about your choices, why should you have to choose between healthcare and working. The goal of the project is to help people with disabilities to become independent and competitively employed. So that is our main mission is to help people get into good paying jobs and making sure they have healthcare. There's a program called the Sherlock plan, which will allow people to make up to probably \$50,000 and buy into the Medicaid program. It's a program that has had fits and starts and needs a little bit of a modification. But it is a great program to be able to actually get out of poverty and be able to be working and still not lose your healthcare. You can call our office if you think that you or someone you know that would benefit from this program, and we would be happy to give you some counseling on that. The other thing is that we have an advisory board that consists of employers in the state, consumers in the state, and people from the different agencies in the state. And if you go to our website, which is Rhodes to Independence. org and you see that there are some issues that you are interested in working on, if you would like to be a consumer rep, we are always looking for new consumer reps to be participating in our project. And that would be great.

FEMALE SPEAKER: Hi. I am Janet Spinelli. I work at MRN the division of behavioral healthcare services and I am also on the legislative committee for the governor's commission on disabilities. And at work, I work a lot with nursing facilities and mental health centers, complaints and monitoring behavioral healthcare.

FEMALE SPEAKER: I am Deb Golding. I work for Rhode Island parent information network, better known as RIPIN. I am the parent of three children. My youngest has autism and I have two older kids with

various older kid issues. I am placed at the department of health in the office of special healthcare needs. Our office works on four core priority areas right now. Emergency preparedness, data and surveillance, health promotion, and adolescent health transition, which is what I do mostly. So we are really working with the schools, I work with the goals, RIPIN and our organizations to help kids transfer from pediatric into the adult healthcare world.

MALE SPEAKER: My name is Ron Racine, debut administrator for the blind and visually impaired. We oversee with people with visual impairments become employed or work independently or as a whole primarily goal is to work with people that have disabilities in order to help them get back to work or maintain their employment.

FEMALE SPEAKER: Okay. I am supposed to ask this. It is probably kind of weird to ask now. We have assistive an assistive listening device if anybody needs that. Anyone? Good.

Okay. There are rest rooms I believe right over around the corner. After you go out the door, there are the rest rooms. We did mention that you have some voter registration forms for people.

MALE SPEAKER: Yes.

FEMALE SPEAKER: I don't know if you are representing there's a project called the Rhode Island Disability Vote Project. And it's been in existence for what? About two, three years now?

MALE SPEAKER: Probably about three years.

FEMALE SPEAKER: About three years. And their main goal is to get people, especially people with disabilities to register to vote. So just so that you know, if you are not currently registered, you register. People can file a change of address form, if they moved since the last since the last election. As long as they register by August 9<sup>th</sup>, they can vote in a September 9<sup>th</sup> primary. Or if you register by October 4, you can vote in the November 4<sup>th</sup> general election. July 28 is the last day for requesting Braille for the primary on September 9. Requests should be made to the elections division this is a lot for somebody to know. Is any of this is there a handout?

FEMALE SPEAKER: It's all in this packet.

FEMALE SPEAKER: It's all in that packet?

FEMALE SPEAKER: All the deadlines.

FEMALE SPEAKER: Okay, great. All right. After we have these forums as I said, your comments are then going to be here is what is your name? Jen Moore is our transcriber here today so this becomes the holy grail, the transcriptions because this is where all of your testimony will be reviewed by various committees with at the commission. Later this summer the sponsoring agencies will review the testimony and prepare recommendations for the commission. And they will be posted on the commission's website at the end of the summer. Recommendations and the transcripts will be printed and sent to the state Congressional offices as well as to the members of the general assembly. And the as Tim has said, its recommendations will be used to develop policy and legislative initiatives for next year. Okay. All right. How about Jean as far as the names of the people who want to speak because I need to then can you just bring those up and we will get going with the most important part of this whole procedure. Nobody wants to speak? Okay. Well, this is going

AUDIENCE MEMBER: We would like to ask some questions, obviously. We would like to ask questions. We are not here to make any statements.

FEMALE SPEAKER: Okay.

FEMALE SPEAKER: They need to identify themselves before they speak so that the translator can get their information on paper and their names spelled correctly.

FEMALE SPEAKER: Okay. Who has questions they want to ask? I need to get a sense of how many people want to say something so that we can, you know, use our time wisely here. Okay. Nobody all right.

AUDIENCE MEMBER: I will say something.

FEMALE SPEAKER: Did you have a question also?

AUDIENCE MEMBER: I guess. Context to ask the questions

FEMALE SPEAKER: The context is I'm sorry. I thought the purpose of the forums is to hear from consumers about what your concerns are. That's it. And the we are really just supposed to listen. We have been advised every year that we are not supposed to really be too responsive, you know. So what I'm trying to do here is if there isn't a lot of people who want to testify, and there are a handful of people who have questions, then I could maybe we could modify our charge by trying to answer some questions if we could. I just want to make sure that everybody who wants to speak and is going to give that is given that opportunity because that's the main goal of these forums. Okay? Yes?

AUDIENCE MEMBER: Do you need my name?

FEMALE SPEAKER: Yes.

AUDIENCE MEMBER: It's Mary Roth from Wakefield and I am an advocate for a person with disabilities who wants very much to work full time and is capable of working full time. But when we speak to other advocates, other disabled people, or people from agencies that care for disabled people, we get a very strong message that it's a bad idea to work too much. And this upsets me. He is dependent on a large amount of medical care each month, probably over a thousand dollars. And it's very difficult to figure out how to keep him working and keep people taking care of him. Even though people I can read the brochures for the Sherlock plan, et cetera. The how to get into the system and make everything come together is very elusive for me and I have been working at it for four years.

Employment: Social  
Security benefits

FEMALE SPEAKER: Who has been the who did you say was suggesting that he shouldn't work?

AUDIENCE MEMBER: Almost everybody I speak to.

FEMALE SPEAKER: I'm trying to get what realm? The healthcare realm?

AUDIENCE MEMBER: I was told that I don't really want to name names.

FEMALE SPEAKER: I'm trying get a general

AUDIENCE MEMBER: I was told from a lawyer. I have been told that by other disabled people. I have been told that by other parents of disabled mostly parents of disabled people.

FEMALE SPEAKER: Really?

AUDIENCE MEMBER: And two people who were representing agencies that we had spoken to in terms of services.

MALE SPEAKER: Which agencies are you talking about?

AUDIENCE MEMBER: I would rather not

MALE SPEAKER: You are not naming names. I want to know what agencies we are talking about.

FEMALE SPEAKER: See, in order for us to figure out where our problems are with and fixing them, we need to know where misinformation is coming from. Not the individual person, I hear that. But we need to understand where the misinformation is coming from.

AUDIENCE MEMBER: Everybody.

MALE SPEAKER: Again, I ask you a question. What agencies are you talking about?

FEMALE SPEAKER: Medicaid? Did you deal with ORS? Did you deal with Department of Labor and Training?

AUDIENCE MEMBER: ORS, yes. Since I'm giving you my name, I would rather not make it real obvious who I'm talking about.

MALE SPEAKER: If I can comment on behalf of ORS, we do have a benefits counselors on staff.

AUDIENCE MEMBER: The benefits counselor who I spoke to, I had questions about disabled adult child, dependent adult child. I had questions about that and the benefits counselor didn't know the answers to any of my questions about that.

MALE SPEAKER: Did it have to do any with the new regulations coming up?

AUDIENCE MEMBER: No.

MALE SPEAKER: I know the two benefits counselors we have on our staff were recertified recently. One of them scored the highest in the country or second highest. The other was right up there as well.

AUDIENCE MEMBER: Okay.

MALE SPEAKER: So it's a very extensive training they have to go through to become a benefits specialist. They couldn't get it if they didn't know about the program, the supervisor, the person who works for me and that is something. I can talk to her if you want to talk to me afterward. I can get you in touch with her. She is very knowledgeable. If she can't get the information, she can go nationally for you. But we are trying to obviously our agency tries to promote people going back to work. That's the purpose of benefits counseling is to show people how they can work and still maintain their independence and the benefits and healthcare. So it's we try to refer most of the clients that we work with through the benefits specialist.

FEMALE SPEAKER: I think maybe some nomenclature may be a problem too. I think benefits counselor is a generic name. But then there's also these "expert" for lack of a better word benefits counselors, okay. And I'm not sure if you got an opportunity to speak to the expert benefits counselors. And that's who he is recommending that will get you in touch with.

AUDIENCE MEMBER: Okay. I went to an office in Providence. To say the street

MALE SPEAKER: 40 Fountain Street?

AUDIENCE MEMBER: I don't know. Fountain yes.

MALE SPEAKER: That would most likely be our building.

FEMALE SPEAKER: Okay. So, all right. So you have been getting across everybody not ORS.

MALE SPEAKER: If there are problems or gaps in the services they receive, I want to hear about the problems. We want to hear about them so we can fix them. It's not like you are going

AUDIENCE MEMBER: My questions were about disabled dependent adult child criteria. And (inaudible)

Transition: Child to Adult services

FEMALE SPEAKER: The other thing would you like to discuss I know you are here for the Department of Health?

FEMALE SPEAKER: RIPIN

FEMALE SPEAKER: RIPIN. The issue may be as far as getting you connected with parents who are very much advocating for all of this the movement of getting people back especially children and young adults back to work, for sure RIPIN. So you maybe want to address some

FEMALE SPEAKER: Just a couple of questions. You don't have to answer them if you don't want to. This is a young

AUDIENCE MEMBER: A young adult, yes, who did not go to school in Rhode Island. We moved here.

FEMALE SPEAKER: So didn't receive any kind of transition services or any kind of through schools just curious to see.

AUDIENCE MEMBER: No. Because we moved and right. We moved here at the time he would have been transitioned.

FEMALE SPEAKER: Okay.

FEMALE SPEAKER: Were you getting services where you were before? You are.

AUDIENCE MEMBER: But not transition services because they knew we were moving.

FEMALE SPEAKER: Right. That was tricky. So he is over 21?

AUDIENCE MEMBER: Yeah.

FEMALE SPEAKER: Have you contacted the Rhode Island parent information network, have you spoken to

AUDIENCE MEMBER: I didn't know you did anything for people past age 21. I did when we first moved here, but I thought after 21 it was

FEMALE SPEAKER: There are lots of parents who have children, who work there who are individuals who are over 21. Yeah

FEMALE SPEAKER: They are actually just to put a plug in for RIPIN, the transition issue is it seems like everybody is trying to work on that now. So, I think that

FEMALE SPEAKER: It's a national movement.

FEMALE SPEAKER: Right. So she will get you who to contact, RIPIN so that should help you in that front. We need to address one other front, or would that and if you want to talk about the Sherlock plan, you can certainly call me at my office. And I will be happy to go through that with you.

AUDIENCE MEMBER: Okay.

FEMALE SPEAKER: Okay? Pick up the little brochure back there.

FEMALE SPEAKER: Can I ask is your son why didn't he come here today with you?

AUDIENCE MEMBER: He's in a program today.

FEMALE SPEAKER: Okay, good.

AUDIENCE MEMBER: He also doesn't like crowds. He does okay one to one. He doesn't do okay in a panel or a forum or auditorium.

FEMALE SPEAKER: Still a lot of jobs for people that like to do computer loads of jobs.

AUDIENCE MEMBER: He was worked full time.

FEMALE SPEAKER: Great. I'm excited I hope you call me soon because I would love to get you in the Sherlock plan.

AUDIENCE MEMBER: One of the problems is the economy as it is.

FEMALE SPEAKER: Hard to get a job.

AUDIENCE MEMBER: He lost his job and does very poorly interviews. So it's been hard to get him hired. But once hired, he is great.

FEMALE SPEAKER: What about mentorship programs and friends? (Inaudible)

AUDIENCE MEMBER: My complaint is there is sort of a culture of don't work.

FEMALE SPEAKER: Yes.

AUDIENCE MEMBER: There needs to be a culture of work.

FEMALE SPEAKER: Absolutely.

AUDIENCE MEMBER: That's my message is

FEMALE SPEAKER: I think just to tell you from my own perspective, that's what this whole Rhodes to Independence is a grant. But it's become sort of an entity in the state now. And our mission, you know, we are out there. We work with all of these different people who want to work with us. And our mission is to say, yes who is it that we need to be who is it that we need to be saying this to. And

AUDIENCE MEMBER: Everybody.

FEMALE SPEAKER: You know, I've got me and two other people. You know what I'm saying? That's why the advisory board and getting consumers who are interested on the advisory board, one of the things that we are doing with the department of health, hopefully starting this year in November is to do seminars with providers, doctors, nurses, people in the healthcare profession who tend to be a first contact for lots of people with disabilities. We started out with employers. But people with disabilities, if you acquire a disability, the last person they are going to tell is the employer. So it took us a little while to figure that one out. So we know we need to be targeting providers and who else and to be fair to the state system right now. The state system is in crisis. They're losing so many people who were, you know, institutional front line people, institutional memory, know how to do this because of retirements, because of all that is going on; that there is a huge gap that really didn't exist let's say maybe three years ago. You know, and that is a that's a reality we have to deal with. The other reality is if we can get some training out there and seminars out there to some key people. But who are those people? Who should be the key people that we need to be talking to? That's where it really helps us to have consumers say, you know, I need I think you need to be getting some one-on-one's with this group,

these groups. And so, that would be helpful to get that feedback. Because you are right. It's this attitude that people can't work and don't understand the new laws that have been put into place.

AUDIENCE MEMBER: Outside of my comment then, can I ask a question?

FEMALE SPEAKER: Sure.

AUDIENCE MEMBER: Is there a certain number like if a disabled person works for like four years or five years, at some point is there and collecting Social Security because they are making enough money. Is there some point where they are no longer going to be eligible or where they are going to no longer be considered disabled because they have a work history?

Employment: Social Security benefits

FEMALE SPEAKER: I believe again, I'm the Roberta's people will be able to give you the changes that have been made to the law, especially with Medicare. I don't know if your son's on Medicare or not.

AUDIENCE MEMBER: Medicaid.

FEMALE SPEAKER: He is on Medicaid but not Medicare? Okay. Medicare is where there's the issue of a certain amount of work. But that's been extended, extended, extended. And if you are off, you get off all together, they have a I don't know, a quick

AUDIENCE MEMBER: (Inaudible)

FEMALE SPEAKER: You said you are not considered disabled any more. If you are off and you have been off and then you can't work anymore because something has happened, what is it called?

MALE SPEAKER: Expedited reinstatement.

FEMALE SPEAKER: Which is relatively new to the program.

MALE SPEAKER: Everybody person who received SSI or SSDI generated a specific individual case. So most of the times there's no single generic answer to that we can give you. Because what we have to could it contact for example what I do. I represent people with disabilities on Social Security or SSI who have work and have difficulties with employment, which includes overpayment. And every case I get, everyone gives me the question. It's like I can't answer that until I talk to Social Security. So I'm very happy to talk to you later. But the answer to your question is as and Elaina was mentioning, there is a Social Security rule that is referred to as expedited reinstatement known as EXR. What it does is allow a person who has gone off benefits because of work to go back on to benefits, if that same disabling condition prevents that individual to work. The only trick is it's a five-year window. So

AUDIENCE MEMBER: It has to be about five years.

MALE SPEAKER: Five years when Social Security says you are The answer to that is yes. If you don't qualify for EXR, expedited restatement as Mr. Racine said, you can file a new application for new benefits.

AUDIENCE MEMBER: One of the fears is he is out of business for five or six years. The business closes. It could take him three years to find another job. And is he going to be without benefits for those three years?

MALE SPEAKER: I think at that point I would refer him over to ORS or some vocational rehabilitation, for one. But for two, also to talk to a benefits specialist. CWCIS because that's a multipart question actually.

FEMALE SPEAKER: Okay. Did you have

FEMALE SPEAKER: She may be interested in the job fair.

FEMALE SPEAKER: Okay. You want to talk a little bit where we can go ahead.

FEMALE SPEAKER: Jean Depipo from ITI. We are having a job fair for with disabilities October 3 at the Marriott in Providence on Orms Street. A collaborative effort we are working with several different agencies throughout the state. And all of it will be posted on our website in the next coming months, as well as the other agencies' websites. But it will be there's generally 30 agencies there that are open to employing people with disabilities as well as agencies such as ORS and

FEMALE SPEAKER: Employers 30 employers.

FEMALE SPEAKER: 30 employers. Sorry. There are 14 agencies as well. And there are generally 14 schools that come in for training and development. So that again will be October 3. And it will be running

from 1 to 5 at the Marriott on Orms Street. It's on four bus lines that will also be posted on the websites. And there is plenty of parking. It's first level, lower level and easily accessible.

FEMALE SPEAKER: Okay. Frank, you didn't get to introduce yourself.

MALE SPEAKER: I know. I came late. I apologize. I am Frank Spinelli. I am the acting Medicaid director for the state of Rhode Island. I work with the Department of Human Services. (Inaudible)

FEMALE SPEAKER: A smile.

MALE SPEAKER: I am trying my best these days.

FEMALE SPEAKER: Okay. Did you have a question, sir?

AUDIENCE MEMBER: No really

FEMALE SPEAKER: You didn't, okay.

AUDIENCE MEMBER: My general concern I think is this very simply

Medicaid: Global waiver

FEMALE SPEAKER: Can you tell us who you are?

MALE SPEAKER: I am Glenn Kumekawa. The general question is the governor's proposal for cutting Medicaid or getting authorization to have a little more freedom for the formulae dependency on Medicaid for the federal side, which who is providing the kind of advice for differential impacts like diminution of Medicaid and how do you who is making the recommendations for the universal disabilities. Otherwise what you are going to get is different constituencies coming to the state, promoting for their own constituencies. And I'm asking for a general kind of council, legislative and to the executive with a total universe of the disabled because there are differential impacts by diminution of Medicaid funds. The question is, who has the responsibility? And is the governor's commission the one that provides the kind of leadership and/or advice to the legislature and to the executive? Otherwise it's going to be automatic program by program, is that it?

MALE SPEAKER: That's a we that's not our job, really. I guess

AUDIENCE MEMBER: Who's job is it?

MALE SPEAKER: The people who are designing the Rhodes to independence

AUDIENCE MEMBER: Then it has to be programs

MALE SPEAKER: Excuse me are you talking about the global waiver that is happening right now?

MALE SPEAKER: I think that is what he is referring to.

MALE SPEAKER: I would refer to the gentleman on my left.

MALE SPEAKER: All public policy for the Medicaid program as to who's covered appropriations are generated by the general assembly. The governor is responsible for administering the program as seems fit based upon the authority given to him by the general assembly. So each in the current Medicaid programs we have and the ones we are proposing a waiver that the legal authorities of each department, programs that they administer are going to stay in tact. So if MHRH, for example, will still be administering the DD program and the behavioral health programs. The department of health provides programs for people with HIV. DCYF has responsibilities for children's behavioral health, et cetera, et cetera, et cetera. What determines that appropriation really is the general assembly. They give us a budget. And within that budget we operate. The waiver proposes is that the departments or the Medicaid program gets an amount of the federal government to manage under the authority of the general assembly. Puts some flexibility in terms of benefit designs so you can make changes that will be more based upon people's needs. So the important thing is you get advisory councils. You get into working with your legislators, if there are areas. They have input as a Medicaid director. I don't have the authority to move like half a million dollars into a program. I have to operate that the general assembly has given us so much money to operate a certain program, so much money for our rite care program, so much money for pharmacy, so much money for long-term care communities support services. So the voices of the public to the legislators are help set the large numbers. Then what happens is in essence we go forward and we establish rules. There is a public process, administrative procedures act where policy is promulgated, posted. And people can react to that in comment and input to the department, where it gets to involved service

deliveries are not happening, what restrictions will be implied. So it's as open a process as you can. And it's not left up to us as an agency to decide if, for example, Rhode Island I don't know if any of you know, our total spent last year was 1.676 billion dollars. We don't have 1.7 billion dollars. You get to a table and help me divide it up. It's come through the legislature the appropriations. I don't know if that answers your question but

AUDIENCE MEMBER: But there's different formulae responsibilities and matching grants and all the rest. Someone has to advise the executive or the legislature what the opportunity costs are. Because there are some programs that will be hurt more by diminution of federal funds or the lack of matching funds from the state funds. So the question I'm asking is, who's got the overview to suggest who are the different constituent disabled population? Who's going to get hurt the most, whether it's the residential program or whatever it may be in reference to the diminution of Medicare funds or sorry shouldn't be that. The actions of the state under the new freedom from formulae

MALE SPEAKER: It's the same process we operate now. I'm not and I don't really believe that the model being proposed is going to hurt anybody. What's going to hurt is if this economy doesn't turn around and we continue to spend more than what's coming in. And that's reality we are faced with last general assembly. And people came forward. And the process is each agency makes recommendations to the governor as to where their cuts are going to be. The governor comes out with a budget and says, all your agencies. You are spending more than you got. We have to make some changes. What are your changes? So each make a recommendation to the governor. Each director, his cabinet and policy office sits around and decides what gets put into the budget. And then it becomes part of the general assembly discussion. That determines what sector gets hurt. Last session, there were cuts in terms of children who are state only undocumented children. The decision was made to cut 1500 off the table. A decision was made to reduce eligibility for a thousand parents. That's recommendations because there weren't enough cash to continue the program. Governor recommended. The general assembly debated it. Passed the budget. That's the process. In the global waiver, that process still is going to continue. If there's not enough money to go around, there have to be significant cuts. A lot of what's in, in services that people receive are in statute regulations and you can't arbitrarily change it. You have to go through a process to make that change.

AUDIENCE MEMBER: You are describing the current procedures and that is either the governor or the legislature is going to make a formulae 10 percent cut and everybody that's it. Or for those who are proponents of specialized programs are going to win. And that's the name of the game. And I'm suggesting that either the governor's council, disabilities council, has a larger responsibility. It seems to me, to suggest who will be the component populations, who's going to get hurt, and what are the opportunity costs if you don't put it in now, you are going to pay later. And some that kind of council ought to come out of your commission or all of the disabilities council or somewhat.

Medicaid: Global waiver

MALE SPEAKER: Frankly, it does.

AUDIENCE MEMBER: Otherwise

MALE SPEAKER: We do it all the time for every law.

AUDIENCE MEMBER: Tell me it's going to be the same thing over and over again. An arbitrary 10 percent cut, 15 percent cut off all programs.

MALE SPEAKER: We can make a recommendation. We can render an opinion under an issue. Whether it's listened to or adhered to is beyond our control. You know, so, we took a position on the global waiver. We submitted testimony. We submitted our opinion and recommendations vis-à-vis that type of legislation. And that's really all we can do. And whether or not it's listened to is beyond our control. I can't really say much else. We are not just sitting there, you know, meeting for the sake of meeting. We a lot of people on this legislative committee, who spend a lot of time going over these laws and making thinking about and making recommendations. I feel like I have to defend what we are doing.

AUDIENCE MEMBER: I see. But you know the agencies, the DA's of the world will want programs that are responsible and that try to reduce it, which is possible, sure. But that's not where what I'm suggesting. I'm

suggesting that there ought to be a council or governor's council on disabilities council that provides an overview so that the public can understand what is the nature of the game, who is the ones that are going to get hurt because there will be differential impact when you have cut off federal and the requirements in terms of matching grants.

MALE SPEAKER: Can I maybe speak

FEMALE SPEAKER: Go ahead.

MALE SPEAKER: Within the article 17 of this budget, the general assembly has sided that they want that oversight role

AUDIENCE MEMBER: Of course.

MALE SPEAKER: As it relates to the Medicaid

AUDIENCE MEMBER: That's their responsibility.

MALE SPEAKER: They are going to set up an advisory commission for I think they call it a committee that we have to, as a Medicaid agency has to report to them, the nature of the proposal, the changes in the law they are making, and of course that becomes the check and balance on the executive branch with the legislature come in. But you are right on target that it's incumbent upon all interest groups make their voices heard. It's not just the governor's commission on disabilities. There are segments of this commission and there are other agencies that need to speak up, let their voices heard. Both us as the executive, them on the general assembly. And hopefully we can partner and make this as smooth as possible in troubled times.

AUDIENCE MEMBER: That's across the board of all the allocation for the entire budget. And I'm saying isn't there those of you who represent the universal disabilities have an advocate position to suggest what the impacts are and whether there's diminution of either state or federal requirements. And in this case, what the governor's asking for, as I understand it, is a little more freedom in order to be able to allocate the federal funds in such a way as to to somebody's view of what maximizes the major services. I'm asking, is there somebody in the world of universe of disabilities that would advocate what the impacts may be as those funds are diminished?

FEMALE SPEAKER: I think one thing that I am going to share with you. I'm relatively new to the state. I have been here ten years. And

MALE SPEAKER: (Inaudible)

FEMALE SPEAKER: I know. And I have been working on this project for eight years. And what surprised me and I had worked in Washington DC and had worked with a lot of interest groups. What surprised me coming to a state and watching what happens in the state level is that there's many different segments of disability community. And those segments advocate for their specific issues.

AUDIENCE MEMBER: Of course.

FEMALE SPEAKER: And what has happened in law is that certain segments of disability community have received more generous programs than other segments. So when you are asking the kind of question you are asking, and if certain segments don't have any don't have as much, they have a lot less to lose than the segments that have a lot more. Because the segments that have a lot more than are the segments that tend to be targeted because that's where the savings are, if another segment doesn't have anything. So that's sort of the reality about the system. Our project, as this commission on disabilities, is supposed to look at all people with all types of disabilities and what is good for everybody. And that's wonderful to think about it that way. But the problem is with the current system is such that it's not an equal playing field to start. So, what happens is when you try to offer up a new program, the people who it's the have's and the have-not's. And the have's don't really want to work with you because they are afraid that if we put something forward, that there will be stuff taken away from them.

AUDIENCE MEMBER: But then the problem is there's a huge data base. If you look at any of the websites, you will find just tables and tables of federal programs. How much have been advocated and state funds. There's an old model that says what is the impact if you start to reduce federal or matching funds in this particular area and how does it impact. You don't have a model. So you can't even answer that question. What

is the total effect of diminution of any federal or local matching funds for Medicaid and as it impacts the service delivery. You don't have a model to do that. You have a huge data base. But anybody trying to figure out how what the impact would be by any diminution of federal funds, it can't be done. I'm just telling you it can't be done except by program and program. And that's the way it always ends up. You know, I'm saying that's a lousy way of doing it.

FEMALE SPEAKER: Well, if you have a suggestion on how you would model this to do it the way you are recommending

AUDIENCE MEMBER: Something like an all body it's a dynamic model. You just put inputs and outputs. It's very simple.

FEMALE SPEAKER: Maybe you should contact Frank.

MALE SPEAKER: A model and then you say what happens if you do this. And what happens if you because you have variables like matching grants, formulaic items, they are not all equal. That's the point.

MALE SPEAKER: There is modeling going on. It's programmatic by programmatic. I will give you a good example. One of the proposals that was made in a budget was dealing with a reduction in nursing home labor costs. There was a model ran. It estimated that by reducing it, the facilities in order to reach the target would have to layoff so many people. There was another model taken from that to say what does that layoff mean in terms of care? And as a result of it, we made some recalculations that didn't go to exactly what we were originally proposed. But then again, as much as you get to a goal you want it achieve, the bottom-line was we still that particular area had a hit of 5. 5 million dollars in savings. So at some point, you know, that's your line. You don't really have you can't go below or above it because there's an exportation you need to take that much money out you do kind of the analysis. But you are right. We don't have and I think a lot because of the complexities and the area of disabilities and the services they get. What impact hospitals have, nursing homes have, community placed services, on the labor force, each of the entities and how does an impact by another funding like Medicare will have on shifting the monies and it's very complicated because it's all intertwined. Different screens, not just state and federal. There's Medicare, Medicaid, private insurance, state money, local money, private money. And it's a very complicated model. If you have any suggestion, we would welcome to analyze them.

AUDIENCE MEMBER: The point is the disabilities council, or the governor's council or somebody, has been given the responsibility not only to track those things but I would assume to try to draw some conclusions on the impacts. And I don't see it. And then that's the name of the game, again. It's going to be 15 10 percent, 15 percent across the board. Or some programs can save and others don't. It's nuts.

MALE SPEAKER: In defense, they do some of that because I receive a number of correspondence from the commissioner, executive director Mr. Cooper articulating that a decision was made. What they perceive to have this kind of impact on these individuals, what they are expected to do. And they do, do that. I just want it does happen. It's probably not visible. It's not published. There are letters not going out.

AUDIENCE MEMBER: Let me tell you what the impact happens to be for our society. You don't deal with early intervention in mental health. You end up with people in (inaudible) you don't do it there, you will end up in homelessness and then what happens is the enormous cost to society to pay, to deal with homeless as homelessness, prison 100,000 a year for one person incarcerated. It's nuts. And what does it do for the individual?

FEMALE SPEAKER: Can I share with you something? I worked in Congress and I don't know how the economists work here in the state when they do an analysis. But I can tell you how they do it in Washington. They would not take into account those kinds of issues. The only issues that the economists in Washington take into account let me give you an example. If you were to include in the Medicare program a test to determine whether or not you had cancer, okay. So you are going to do a mammograms or you are going to do colonoscopies. Every time they want to put in a preventative test to see if you are going to get a disease, those are scored by the economists in Washington as costing the Medicare program money because if we find out and we are able to extend your life beyond because you didn't get the disease. That costs the Medicaid program --

Medicare sorry Medicare program money. That is how healthcare economists operate. It's very frustrating to see that kind of thing. And then if you want to come in and say, well, wait a second. If we do this because I've done it in Washington where we came up with programs and we said if we put this program in, it will save money in this area. It will save money in this area. Their concern is does the federal government spend money in that or is the savings going to be, as you said, a society savings. Because what they work on is they work on the actual federal government budget and will this impact and will the savings help the federal government. My guess is that the state government does something similar, although I don't really know because I haven't been there. But that's part of this problem is that from a logical standpoint, you would save from a society from a general society. But when you are looking at these programs and the costs that the government has, it doesn't save the government money and it could potentially cost the government money. And that's sort of a very frustrating reality. Did you want to say something about RIPIN or did we pass it?

FEMALE SPEAKER: Somebody mentioned something. But we kind of passed it. But I can still say something. Just about family voices as part of RIPIN and what they do is take some of these issues that are happening and they kind of make put it out so that people can understand what everybody's saying. They will take these issues and these cuts and they will put it in language so that a lot of people can really understand it. And then they often rally families and people together to go to the state house or to go to different things. I just want to put that plug in because it's very complicated when you are trying to listen to the folks sitting over there. That's what I would say.

AUDIENCE MEMBER: Deb, could you just say how somebody gets in touch with family voices or accesses

FEMALE SPEAKER: RIPIN. org is the website. And the number is I always forget the number. I have a card.

FEMALE SPEAKER: Okay. Anybody else? You know, if anybody wants to sort of introduce yourself and say why you came and what you were hoping to get out of this forum so maybe we could address that. Would anybody want to kind of share why you came? Okay.

AUDIENCE MEMBER: Well, transportation for people who don't drive is also a barrier to employment.

Employment: Transportation
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And I wish there was someone from RIPTA here or

MALE SPEAKER: I work for RIPTA (LAUGHTER) I have to respond to anything you have to say.

AUDIENCE MEMBER: Okay.

FEMALE SPEAKER: You what?

AUDIENCE MEMBER: It's as far as I can tell, there's not an easy system for people who have a job but can't drive themselves to get there short of me hiring a driver, which is what I've done or drive him myself. And my son is not disabled enough to require a wheelchair van or anything. And I think sometimes I wish he was because it seems like it would be easier, if there was a real obvious problem with transportation. But there's not. It's just been difficult.

MALE SPEAKER: Can you send him on a regular RIPTA transit bus?

AUDIENCE MEMBER: Yes. But we don't live he can actually walk to the bus stop. You know, I guess I wish there was an ideal world where there were more of us as more buses there every hour. But yes, for him to for me to not hire a driver would involve him a two-hour commute for him to get some place that is like ten miles away.

MALE SPEAKER: I see. Well, I you know, RIPTA's in the news recently. You are not

AUDIENCE MEMBER: You are cutting, I know. I wrote a letter.

MALE SPEAKER: Every one of RIPTA's vehicles we serve about 3,000 people with disabilities a day in RIde, people with very severe disabilities. We serve many more times that number of people with disabilities every day with regular RIPTA transit buses. Far more people who have disabilities use regular RIPTA transit buses than use RIde. And every day RIPTA does many things pretty poorly. We make mistakes every day with the RIde vans and our regular fixed route transit bus services. Every day we make mistakes, without a doubt.

Every day we also do a lot right. And I'm not trying to avoid taking responsibility. Our general manager Allen Mascola for the things we don't do as well as we should every day. But we are also proud of the things that we do well every day. Every one of our 350 regular long stinky 40-foot long fixed route transit buses is run on diesel fuel. Every one of our 125 RIder vans, small white vans with a red stripe on them runs on diesel fuel. Diesel fuel is already over way over \$4, \$4.50, \$4.60, \$4.75. We are having to renegotiate our contracts right now we buy a lot of our diesel fuel and we have a solid contract now, just under \$4 a gallon. But as Frank can tell you and other major administrators, Ron and others, when you renegotiate a contract to purchase a lot of material, whether it's fuel or other items necessary to provide your service, obviously the company that you buy it from is going to want to get a fair price. Well, the fair price for diesel fuel in the future is going to be \$4. 50. Even in some parts of this country it's over \$5 a gallon already. That's not excusing poor service, which we do provide sometimes. But it is to say that we have a fiscal imperative, a challenge to meet financially as well. So, I would tell you that I don't see RIPTA expanding its services. We are trying our best to maintain this current level of services. And unless we develop more revenue somehow, we will be cutting services in the state of Rhode Island for everyone, for people with disabilities and everyone else who depends on RIPTA services. Let me say parenthetically I'm not in any position to stand here and defend the kind of salaries that some of you might have seen that some of the higher officials at RIPTA get. I'm not one of them. In fact, I wear a tie. I am not one of those seven assistant general managers who make about \$100,000 a year. I'm not defending them. That's our board of directors and other people to make comments on. It doesn't look good for public transportation unless more revenue comes from the federal and state government. We have a current administration. Our general assembly has refused to raise taxes in the state of Rhode Island. Since costs go up, since the number of frail elders and people with disabilities is increasing dramatically, it's easy to count the number of people who are going to be 65, 75, 85 years of age and above. All you do is count them now. Project out five, ten, 15 years. The fact is the number of people who need long-term help and social services care is going to increase dramatically. Right unless they all move out of the state right, Frank?

MALE SPEAKER: That's right. We got people moving back in.

MALE SPEAKER: So there are fiscal imperatives and we are working in terms of your son, again, I don't anticipate public expanding. We would like it to expand, very much.

MALE SPEAKER: Interesting. Bill, one thing

MALE SPEAKER: I don't see it expanding unless the general population conveys to the governor, its executive, financial, and the members of the general assembly how important public transportation is. And I will be glad to work cooperatively with the general assembly and administration to expand our services.

MALE SPEAKER: Didn't mean to interrupt. It's interesting actually, Bill, you were telling me the other day. A large part of your funding comes from a gas tanks in the state of Rhode Island.

MALE SPEAKER: That's a good point. In addition to the cost of diesel fuel, most of our revenue, about 85 million dollars revenue, about 40 percent of it, almost half comes from gas tax. And it's about four cents per gallon that you pay for gas, gasoline at the gas pump is a gas tax that's called revenue yield to us. We get four cents for every gallon that people use. That's great except as the price of gas goes up, people use gas less. We get less money. And they use gas less because they are riding more on our RIPTA buses. So the costs go up and our revenues coming down, right? Costs go up, revenue coming down. That's tough.

MALE SPEAKER: (Inaudible)

AUDIENCE MEMBER: As ridership goes off, it doesn't offset

MALE SPEAKER: When ridership goes up, we spend more because we have to put more buses on.

AUDIENCE MEMBER: Even though people are buying tickets?

MALE SPEAKER: While more people move from their car to the public buses, which we want them to do, they use less fewer gallons of gasoline. We get fewer little four pennies per gallon of gas into our revenue.

AUDIENCE MEMBER: So the cost of a bus ticket is artificially very low?

MALE SPEAKER: Oh, absolutely. Public transportation is just that. It's funded by the public. The cost of a full bus ticket right now for regular public transit bus trip is \$1.75. It just went up from \$1.50. But that only

represents about 25 percent of the total cost of that bus trip. The other three quarters comes from the federal and state government taxes.

AUDIENCE MEMBER: Okay. I didn't know it was that low.

MALE SPEAKER: So, we are anxious to expand our services. We are prepared to do it. And we would like to do it. But unless revenue comes from either the federal or state government, I would anticipate RIPTA not expanding, in fact, cutting services. Because we, just like the state government, have to meet our budget, mandated by state law and by reality to balance our budget. The amount of revenue that comes in has to match the amount of money we spend. That's a long response to your concern. But I would just advocate with your general assembly members and with the executive branch, the governor, to remember and focus on the importance of transportation to all of us. And certainly we encourage people to use the bus, public transportation as much as possible. It's the most efficient way to get people from one place to another, even though it takes a little longer, an hour or two to get somewhere. I ride a bus from Middletown where I live to where I work in Providence. It takes me an hour and a half from the time I walk from my house to the bus stop. Get on at 7. And I get off at about 8:30 and in my office. I can drive it in about 35 minutes. So it's a trade-off. I think we all need to work on being more efficient with the resources we have. I we are doing the best we can. It's not defending everything we do. Every day we make some mistakes and we are certainly open to some criticisms.

FEMALE SPEAKER: Thank you, Bill.

MALE SPEAKER: We want to work with everybody.

AUDIENCE MEMBER: What is your last name?

MALE SPEAKER: Inlow. Bill Inlow, disability services coordinator at RIPTA. And I can show this other gentleman here that we are trying to advocate for people with all types of disabilities, persons with vision impairments, persons who use assistive devices like wheelchairs, people with cognitive disabilities, across the board, both on fixed route buses and through the RIDE program.

AUDIENCE MEMBER: Okay. Can I make a comment then to the commission?

MALE SPEAKER: Please.

AUDIENCE MEMBER: That it is unfortunate and ironic that the short-term savings from not supporting public transportation will have a much far greater long-term cost as a barrier to people with disabilities increase.

MALE SPEAKER: That's what this gentleman next to you was emphasizing.

MALE SPEAKER: That's the first time I heard that today.

MALE SPEAKER: That certain decisions at one point, they are going to come up at another point. But there is a fiscal imperative that Frank knows and the general assembly knows and the governor knows affect federal and state level. You can't spend money some ways and expect to still have it to spend other ways. And sadly, I would like to comment on not Frank's agency and its imperative that came from the general assembly and the governor. It seems to me that the business of state government is not just to save money. It's to provide services to the citizens of the state. And I'm really sad that most of what I hear about the global waiver under the Medicaid program is incredible determination to save 67 million dollars or some amount of money, right, Frank? This year, 67 million? Again, I think the business of state government and federal government is to take care of the citizens of the country and the state.

Medicaid: Global waiver

FEMALE SPEAKER: If I could respond to that, because I have been working on long-term care reform for the full ten years that I have been here in the state. And Frank's been working on it longer than that. And I have to tell you what was put forth was after processing it and processing and processing for years and reprocessing what was recommending to the general assembly, to the various governors ten years ago, eight years ago, five years ago. And the reality was if put into place, this type of system reform, which is really what it is, it's a system reform, would have always saved the state money because, to be honest with you, when you create

a better more efficient system, it is it's better for everybody. You got better quality. You get better services. And it saves money. And that was the message that we kept saying year after year and year. And when this terrible crisis hit the state, it really was the first time that people said, so do you really think you can save this much money if we changed the system? And since we had been working on it for all these years, we said yeah.

Well, you guys said yeah. And there was a lot of support from both the senior community and the disabilities community regarding that because it really provides for greater autonomy of the individual, provides for the

services as needed when needed because the assessment system would change from what it is today. So, I don't know how it sort of happened that it became about the savings. Because it was something that we have been

talking about system change. And this was really the first year that people looked at the fact that it really could had a savings and because we were in such a budget crisis I think that that for some reason was the message that got out. But that wasn't the impetus behind this. Now I don't work for Medicaid. But like I said, I have been involved in many different grants. And I don't know anybody else who has also been involved in this, if anyone else also wants to share. That's unfortunate that this message became about how much money this is going to save versus all the benefits by doing it. Yes?

AUDIENCE MEMBER: My name is Barbara Kilcup. I have a 40 year old daughter with autism. And I'm involved in various advocacy groups in the state. And I think I disagree with what you are saying. I think there's just too many if's about this Medicaid waiver. We don't know how what the impact is going to be. And it's scary. And I think a lot of the advocacy groups have come out against this proposal or looking for more information because it's something that we don't have, as this gentleman said, a model to look at and say, well, this has worked for this state or that state. I think is it Vermont that it's been I don't know I'm not that familiar with

Medicaid: Global waiver

FEMALE SPEAKER: I want to tell you the Northeast Medicaid programs and again I've worked with the Medicaid programs across the country. The Northeast section of this country has more optional services in the Medicaid program than any other part of the country, except probably California. What would have to happen is a state is only required to cover the mandatory services in Medicaid. So what would happen is instead of doing what sort of you were saying, across the board, 10 percent cut, the cuts that would have to be made would all of these optional services that are not required by the federal government would be taken away. And that's what they would have to do if they didn't move towards something like this, where a lot and they have done you have done analysis on all of this. I thought you had they had two consulting maybe three consulting firms come in and do this modeling, this analysis on what the options are here. And the options for the state are we are not required to have optional state services. And when you look at the list, there were meetings that (inaudible) there were meetings that they had public meetings where there was a really nice charts that you guys put up about here's like a quadrant. Here is the optional services. Here is the optional categories. And the option for the state is to get rid of those optional categories, which a lot of the states in the south and in other parts of the country don't even have. So I think that right?

AUDIENCE MEMBER: That's not what also what I don't know that much about very honestly the Medicaid issue because I don't know what kind of impact it would have on my daughter. Right now this is my concern. And this is her concern. She is non-speaking and she types. She uses supported typing, better known as facilitated communication, which is a dirty word in this state. We are having a lot of trouble finding people to help us with her speech production device. Tech access says no to facilitated communication or supported typing. They are trying to improve the image. She has presented using her speech production device in a number of different venues around the country, not yet in Rhode Island. Hopefully with the advocates in action conference in the fall. But you know, she her concern is that right now and we have had to fight long and hard. I had to pull her out of a bad residential situation recently. Right now life is good. She says she loves her life. She is concerned about cuts and how that will impact upon her. And she's also concerned for other people

MALE SPEAKER: Is she

AUDIENCE MEMBER: who can't get into the system who are coming up. We are very fortunate that she's in this situation now, which, you know, which is good. She doesn't want to lose that. And she wants other people to get what she has.

MALE SPEAKER: Excellent. Is she home now? Is she home with you now?

AUDIENCE MEMBER: No, no. She's in she's supported by ridges residentially and she actually works at the cafe here at independence square. She's supported by Oscar during the day. It's a good balance of situations. The only right now the only impact that it's had is that while there's each agency has had to cut has had to tighten their belts. There's no longer one manager for her situation. The manager has more than one residence that they are responsible for. And it's caused some minor glitches. So far, it's been okay. And, you know, again there's just a lot of concern and feeling I'm sure you've heard this statement before that the budget is being balanced on the backs of those who are the most vulnerable. This is a statement that's been said time and time again. I think there are places where other cuts could be made, you know. I'm a former special ed teacher. I'm retired. And again, you hear a lot of issues about the retirement system and how I paid into the retirement system. My school department did. There are people who are benefiting from this retirement system who didn't pay into it. You know, the things that need to be looked at, instead of cutting services for I substitute now. And there was a woman who was a teaching assistant. And I'm hoping that her situation has been rectified by now. I don't know her except for having met her in this situation. Her she has a son with severe diabetes and her Medicaid was cut so that she has to make she's working three jobs, she said. And she has to make a decision whether to put food on the table or get expensive medication for her son. And I'm hoping that, you know, that there have been that this has been resolved for her because I'm sure nobody would let that I would hope that nobody would let that happen.

MALE SPEAKER: Do you know why your friend's son's Medicaid was cut?

AUDIENCE MEMBER: I think it was her I don't know whether it was her salary battle

MALE SPEAKER: Well, if I may, the proposal we put forward, other than I mentioned the parents is not seeking to cut any individuals off the program nor is it eliminating benefits. What we are asking to do is look at how we provide benefits. Rhode Island is atypical in the sense that we have a tremendous amount of individuals that are utilizing high end services. And there are states that have moved to provide these services in other settings, which is why we use the concept "the right services at the right time" in the appropriate settings. A good example. For us to put a person in a nursing home, it costs us \$68,000 a year. To put them in assistive living is about \$35,000 a year. To keep them in their own home, it's about \$16,000 a year. This is whether they're aged or disabled. We don't use a lot of consumer rep services. We found that when consumers and families have opportunities to manage their own benefits, they make choices that are different than the choices we have as organizations and bureaucracies and that drives down costs. A good example. We have parents who have RN's to help take care of their children. They have to get it through an agency. They get it through an agency I'm not trying to minimize the agencies because the agencies will cost anywhere between \$60 and \$120 an hour. Yet they can have a friend next door who is an RN, licensed in good standing who may be able to provide that service for \$30, \$40 an hour. We don't allow that. You can see if you start changing how you think and how you purchase services, and who you can have access to, gives families and consumers more opportunities to make innovative choices in moving from the high end. This is what we are banking a lot of that savings on. The savings of the DD world is predicated by more consumer directed services. The same in the institutional world is talking about moving people out of institutions into lesser services. Not saying they don't get the services. They need nursing services. They need home care, personal care. They are still going to get them. But they're going to get them differently in different settings. And when you start doing that, you start saving money. And by saving money, you are able to maintain the current environment we have. In all honesty, as a manager of the program, if we don't if we were not able to come forward with this recommendation, our only opportunity because we make cuts on provider rates, which is why those of you who have service providers out there, you find that they are laid off their direct service workers or whatever. We can't go there any more. We go there. We take two or three percent off their rates. They will lay off more people. Then none of you will get service capacity as an issue. You would have to stop messing into

eligibility, which is why I asked somebody about the friend. Their income went up. We are talking about dropping the income limits because we only can provide what you have and what you get. Decisions about how you get it is decisions the general assembly make in terms of whether they want to spend it on education, on cities and towns, RIPTA, or Medicaid or whatever. That's what the public process is about. They make decisions. And unfortunately they don't fund everything we need. And we are left with providing benefits and services at the best possible way with the dollars we have. And those dollars again are tighter and tighter and tighter every year. And they are hard decisions we are making. I understand that there's concerns because it's not clear, because this is a culture change infrastructure we are trying to change. We are not out there usual, go out and budget an issue and say, we are going to reduce, you know, 10 percent of residential payments for X and Y. Everyone sees that. They know who they are. They can rally around them and against it. We are saying, we will give families opportunities to make more choices. We will use more voucher systems if they want, more consumer directive, more personal private PCA's instead of using homemakers, putting people in different living arrangements instead of traditional ones we have. All of those will save us money over the long run. That is what this waiver is really all about.

AUDIENCE MEMBER: You had some wonderful people come in you know, I attended a lot of forums where you had consultants come. And I just hope that you listen because I know a number of these people that you listen to what they've had to say because there have been savings and there have been good things happening for people in other states.

MALE SPEAKER: We will continue to listen.

MALE SPEAKER: No one can argue against least restrictive care, more flexibility, more home based care. Every frail elder person, every disabled person I know would choose to get the care in their home versus in a nursing home or even a boarding or an assistive living facility. Who can argue with that? Do we have to trade off our entitlement rights as citizens in the Medicaid program to get that? And you know what I think you know what I mean by that. In the four or fifth year, if we don't say (inaudible) we are going to really face some very, very harsh decisions because the budget is going the amount of money we get from the federal government is going to be capped. Then we have to go not in a matching ratio but straight state dollars. Why can't we do the kind of thing that does no good to say why haven't we done them? But why can't we do some of those increased flexibilities, least restrictive care, consumer choice, all those very desirable things without taking this huge risk that neither you or I are going to suffer from but frail elders and disabled people depending upon the Medicaid program in year four or five? There's a hell of a risk there. And I want to know why we can't could some of those desirable things without selling our soul to the federal government and taking such an incredible big risk for the frailest most vulnerable citizens of our state in year four and five?

Medicaid: Global waiver

MALE SPEAKER: I'm not sure we are selling our souls yet. But the answer to your question is very simple. To draw down federal money, you have to spend state. You have to put up the state dollar every federal dollar you bring in. People want to believe this. Rhode Island does not have the dollars. So, you can talk the talk and do what you want. But at the end of the day, you are in the same place. Rhode Island does not have the tax base or the willingness to put additional money on the table to draw down the federal money. This is why we made the decision to go the model we are going with. Because the states who belong to that like Vermont

MALE SPEAKER: Why can't we do that without this global waiver contingency?

MALE SPEAKER: Vermont went and did the same thing. The principle we saw the concepts we did. They ended up putting another 150 million dollars of their own money on the table to get it. We don't have we don't have a million dollars, Bill. You don't get federal money unless you spend state money. That's the dilemma. There is no state money. People don't want to believe that. Go down to the general assembly. Sit there. There's nothing left. That coffer is dry. And if there is money to have, I'm not sure that we are in the front of the line. You have the cities and towns who are up there saying wow, our property taxes are off the roof. Our tax payers are beating us down. We are laying off firemen, policemen. We can't pick up garbage. I have cities and towns in the state charging for fire now, garbage delivery, everything else. We have the

education department saying we need more money to educate our children. We have a lot of different entities as Glenn was trying to tell us pressure points on people going after the dollars. I'm not even sure if they sold what's that place in Lincoln Twin Rivers tomorrow, you got 100 million dollars from that, I'm not sure how they would distribute it because I know RIPTA would be one of the ones in the front of the line saying we need money. So you have to spend money under the model that the federal government has right now to get money. That's why the decision wasn't to do it this way.

FEMALE SPEAKER: Why don't you explain a little I have been privy to a lot of could he explain how they get the money with

MALE SPEAKER: I don't need to know the details. I know next year

FEMALE SPEAKER: I think it's important.

MALE SPEAKER: Next year Don Carcieri will still be governor, but we may be dealing with a new CMS leadership, namely a new democratic administration in this country. And I just wonder why are we cutting a deal with the current administration and the leadership that's in the department of health and human services and particularly CMS when we might be able to cut a hell of a better deal next year might. I from a

MALE SPEAKER: That's the operative word, might.

MALE SPEAKER: Might.

MALE SPEAKER: Might.

MALE SPEAKER: Well I don't know about you, but we are making a major decision. And it's a public policy as this country is making a major public policy decision in November. And I'm not just saying the new administration, democratic or republican will change things immediately. But we will be dealing with some different I think it could be argued, Frank, couldn't it from the secretary right on down to CMS. Secretary of HHS we will be dealing with some different kind of people, not totally different, same fiscal imperatives and maybe some projected changes.

MALE SPEAKER: The proposal we put forward has been a bipartisan proposal. There have been democrat governors for five years who advocated for what we have. One of the most liberal part in the country being Vermont, Howard Dean.

MALE SPEAKER: We would like to get the kind of deal they got, Frank, but we know we probably will not. Oregon has made some changes that wasn't dependent upon the deal that was cut with the Medicaid changes.

MALE SPEAKER: The issue is that the opportunity rests at by putting a proposal together and factoring in your growth rate and your caseload growth that there's an opportunity where there may be more federal money coming to Rhode Island as a result of this than under the current arrangement. And I'm not sure we are in a position to walk away from that, knowing what our resources are in Rhode Island right now. Because again, we we had 67 million dollars in the state money that are on the table right now; that if we went and got the flexibility that we are asking for, we would have to come up with about 35 to 40 million of state revenue to draw that other

MALE SPEAKER: To match it.

MALE SPEAKER: And there's it's not there.

MALE SPEAKER: Let me finish by saying I know you and Greg and Gary and other people, good decent people. I know that. You care about human beings just like the rest of us do. But I know who you work for right now. And I'm not blaming it all on Don Carcieri. But he is your boss and that's very clear and you are under a mandate. And you are trying to meet that mandate and I admire the way you are trying do it. I just think there might be some other alternatives. So other good people making some comments not about you, Frank, or the other people I mentioned as people because we know you are decent people trying your best. But I think that the governor has to take some responsibility for being so incredibly stubborn about the tax basis. General assembly as well. But thank you for trying to do the best you can with an incredibly difficult job. Sorry to be out of line, madam chair person.

FEMALE SPEAKER: There are certain ways that the money's distributed so whether it's not that there's no money left (inaudible)

MALE SPEAKER: That's true. The a lot of people I know, Representative Constantino was concerned about using all the money up. We are proposing that we get allocated the money that these savings be banked. We have to talk to the general assembly because there is budgetary process. There's no way of banking money for fiscal year to fiscal year. And what we are proposing is, for example, say we are saving 67 million. Instead of that not being spent, it goes into a pool that would build up a reserve. That some of the money we are seeking from the federal government is in a reserve. So it minimizes some as the fifth year gets out there. Again looking at the infrastructure we have in the state, if we really believe that there's opportunity to reduce people going into nursing homes, of the benefits of consumer directed services, that we are going to save a significant amount of money in those models. I think anyone who runs those models will admit there are opportunities there. And what this is we can't we can't spend the federal money to build bridges or build, you know, schools. It's going to go into healthcare. So if we work hard and save more money, we will build a reserve to minimize some of the concerns that people may have in that fourth and fifth year that the money might not be there. But you are right. None of us really know what the future may be. It might be \$10 an hour.

MALE SPEAKER: If it doesn't work, we are not going to pay the price. You and I aren't family members and the children that we are talking about here, they are going to pay the price. That's the big fear

FEMALE SPEAKER: We are paying the price now. I think that's the frustration that I have. We have a 450 million dollars, maybe 500 million dollars deficit now. So we are in the process of paying the price now. That's the reality of it. We are paying the price now. For years and years of money being misspent, we had lots of money coming in with certain things. And where the general assembly, where the governor, who's pointing fingers to who, where that money was decided to go and how it was going to go, certain decisions weren't made that probably could have been made earlier to prevent certain things. That is relevant because that's where we are today. And I think the frustration, at least from somebody new to Rhode Island, is that you don't for such a small state, you don't get a 450 million dollar deficit overnight. It's not an overnight thing. It's years and years and years. And what do you do? And I have to tell you that, you know, everybody thinks that we should be increasing taxes. But don't increase the taxes on me. That's sort of one of those kind of things where people are pretty frustrated to see where their tax dollars is going. And if you live in Providence, and you don't live in Providence. We pay the highest property tax in the state.

MALE SPEAKER: I will tell you what, I will take a tax increase to avoid cutting off what 300,000 children that just don't happen to be children of parents born or legal citizens. We already cut human beings off of healthcare in this budget savings. So no, Elaina, I don't agree with you. I will take a tax increase.

FEMALE SPEAKER: You might. But people of Providence can't take a tax increase.

MALE SPEAKER: Cut healthcare we have

FEMALE SPEAKER: I understand.

MALE SPEAKER: They are human beings that don't happen to be citizens.

FEMALE SPEAKER: But you have to understand there are people who are living on the edge. If they get another property tax increase

MALE SPEAKER: So make it tax a progressive tax increase. Increase a lot, assistant general managers taxes at RIPTA and I will take some too.

MALE SPEAKER: Well, these are all legitimate concerns. None of us are (inaudible)

MALE SPEAKER: We already cut people off of healthcare.

MALE SPEAKER: That's the beauty about America. You express your views. Elaina and I express ours. And eventually people get elected and they vote. Hopefully they make the right decision. And we may not like their decisions. But this is a good country. We have to abide by them because we are loyal citizens. Otherwise we can have somebody making decisions that none of us would like. So I'm uncomfortable with a lot of things I do on a day-to-day basis, but I do it because it's the law.

MALE SPEAKER: I'm glad you are there.

FEMALE SPEAKER: I know I can say working for RIPIN, the families that work at RIPIN have made changes, policy changes, changes in schools, just by banding together. It's called the network. And I my motivation for being there originally was for my son. And I saw that I needed to work on his future. And that's why I got involved. I can't say enough about an organization. People everybody really needs to get involved. Sit back and that's how things can change. Just by being involved and

MALE SPEAKER: Speaking about getting involved, my legislation committee, you don't have to be is open to the public. So anybody can join. And I welcome anybody to contact me and sign up and participate in what we do because it's important.

MALE SPEAKER: Can I tell you? We a lot of our (inaudible) demonstrate that we are listening to what (inaudible) will say, but we do. We talk about it a lot. We have staffers at meetings.

FEMALE SPEAKER: We go we march right into those meetings and sit there and our voices are

MALE SPEAKER: We may not always agree. At least it's important to voice your opinions and concerns and be persistent because a lot of times situation may be warranted. We can sit there and just say nay, nay, nay. I myself have had my mind changed on a number of occasions because people make good arguments, put faces in there, and appeal to your passion and commitment and it works. But unfortunately, it doesn't work all the time.

FEMALE SPEAKER: I'm working at the department of health. I'm kind of like doing this adolescent health transition thing. I'm like doing it. I'm doing what I thought like I have a job that I wanted to do. It's like bizarre. It's like here I am doing what I really want to do. Here I am. So, I mean, that's what I say to people. Just do it.

MALE SPEAKER: Excellent. Great. Thank you for the good dialogue.

FEMALE SPEAKER: We still have some time.

MALE SPEAKER: A glass of water.

FEMALE SPEAKER: You want some water

MALE SPEAKER: Anybody else want some?

FEMALE SPEAKER: You want some water? You want to say something?

MALE SPEAKER: Oh, no. I waved to say no. I am all set.

FEMALE SPEAKER: Okay. Anybody else? We have like a whole

MALE SPEAKER: I am not jumping in this conversation.

FEMALE SPEAKER: We have people that may want to say something.

AUDIENCE MEMBER: I just want to put in for one of the advocacy organizations I'm on the board of is PAL, and they work with RIPIN. There is a RIPIN person on our board. And that is if the various groups pull together, I think that's important. And also PAL goes across the board. Historically it's been mostly adults that they have helped, my daughter being one of them. However, as I said, RIPIN, we are all part of that network.

FEMALE SPEAKER: Let's say some positive things about so instead of or actually quite a lot of positive things that are happening that unfortunately, because they are being done by people that are just sort of doing it, they don't get a whole lot of press and they don't get a whole lot of information. For example, there's a couple of projects that I know Rhodes to independence is going to be collaborating with your department. Why don't you talk a little bit about that. It's kind of exciting.

FEMALE SPEAKER: Nationally the big movements are because of dropout rates, which are they have just been recalculated how dropout rates nationally and in Rhode Island, dropout rates are horrendous.

AUDIENCE MEMBER: High school dropouts?

FEMALE SPEAKER: Indicators in Rhode Island, it's like 70 percent. It used to be calculated at 89 or something. But when you really redo it and some school systems in Rhode Island it's 50 percent. Kids entering 9th and nationally the indicators for these dropout why kids they say are going to dropout because you can pinpoint kids in kindergarten these are kids with disabilities, without disabilities, it could be economic,

whatever. Anyway, reading and math ability in kindergarten, 8th grade and 9th grade are indicators that a child isn't going to make it. And then one of the big things with that is whether they have a disability or a learning disability or physical disability or their parental involvement and parents really feeling uncomfortable going in, helping the kids at school or being involved in their schools and the teachers. So, we are working on two projects. One of them we are working with Rhodes to independence. We want to model after New Jersey, which does this thing called dare to dream. And they take kids, high school kids with all sorts of disabilities. It could be anything. And kids don't want to think they have disabilities. So it could be a kid with asthma, a kid in a wheelchair, all sorts of kids. They work with transition teachers to understand their disabilities and teach classes come up with little classes and seminars. So they go to the middle schools to help teach those kids about understanding their disabilities. And then they have these regional conferences where all these different groups a big regional conference and the schools hand pick kids to go to these conferences and parents can go too. And New Jersey has had the dropout rates have changed because the kids understand their disabilities. Graduation rates this has been going on for ten years there. So we are really working with the department of education and the department of health and Rhodes to independence to try and start that here in Rhode Island. It's one of the things we are starting. And another thing is a real parent involvement. Georgia does something called parent university. And we are hoping maybe this is early, but we are hoping we can really help with the parent involvement. RIPIN does a lot of it now with the schools. These are things that we are hoping will come from the bottom and eventually make things better.

FEMALE SPEAKER: Are you familiar with what we are doing next year, that project where you were working with this is actually kind of a healthcare connection where they did this for kids that you have peer navigators.

FEMALE SPEAKER: Right.

FEMALE SPEAKER: Health plans.

FEMALE SPEAKER: That's the other thing. RIPIN has pediatric practice enhancement project where they have parents in pediatric settings in health centers to help parents who come in, navigate the system's healthcare. They do all sorts of things, getting an air conditioner for a kid to helping them find parents find they just do everything. So now we are working on piloting doing an adult version of that where you are going to get an adult family member or a person with disabilities employed in adult primary settings to help adults with disabilities navigate. So that's coming up.

FEMALE SPEAKER: It wouldn't be expert it would be peer to peer.

FEMALE SPEAKER: What they do part of what RIPIN does so well is everything is within your community. Trying to really find out what resources are right in your community.

MALE SPEAKER: Within the last couple of minutes, don't you think we ought to listen to see if anybody else wants to say something in the general community?

FEMALE SPEAKER: Well, I wanted I have been saying that all along. So I just thought we would give some positive examples

AUDIENCE MEMBER: The bus passes are very nice.

MALE SPEAKER: Since we only have a few minutes, I want to see if anybody else from the general community wants to say something.

FEMALE SPEAKER: I just wanted her to give an opportunity to say some of the things that people most people that are sitting here right now have asked about six times who would like to say something. I think a lot of people are here because they want some information. If I'm wrong about that I don't know why everybody came. But I want to give some information about programs that might be helpful or useful to know about, positive things.

AUDIENCE MEMBER: What about programs for say I'm an employer and I'm willing to hire a disabled person. Are there some incentives or assistance that I can get?

FEMALE SPEAKER: There's loads of that. First of all, they have a business leadership network that Rhodes of independence helps support employers working with other employers.

AUDIENCE MEMBER: Is there a website?

FEMALE SPEAKER: Rhode Island business leadership network. And it's a group of businesses that are working to help each other learn how to hire people with disabilities. And many of them come to our job fair. We do the job fair every year. There's also disability commission yeah, commission on disabilities you have

MALE SPEAKER: I think it's what's the name? If you go to our website, which is I'm not going to remember that. Google governor's commission on disabilities. We have a it's not in my head right now. But I know it's I believe what it does is it facilitates hiring people with disabilities. And it also and it works with employers that want that use like supportive employment and I am going to remember as soon as we leave the room. But I don't have it in my head.

MALE SPEAKER: From ORS, what I would like to add what we can do for employers if you are looking to hire somebody with a disability. We can pay actually double the person's salary for the first two weeks that they are working as an incentive to both the employee and the employers for a tryout. We also have an OJ team where we can subsidize half of the person's salary up to three months because we understand that an employer is taking away either their time or the employee's time to actually train the person. So we can help that business out. In addition we have a work force

Employment: Employer's benefits

AUDIENCE MEMBER: That's what I wanted to know. Go ahead.

MALE SPEAKER: Also we have a work force supervisor. I remember you mentioned earlier your son has difficulties when it comes to interviewing, some soft skills. We have workshops pretty much every month. We try to have them throughout the state. But we have them usually in Providence. But we have had them in south county, east bay as well. And the purpose of that is to actually teach the person, you know, behaviors on the job, dressing, interviewing skills. We actually bring in employers so they can have a mock interview, a test interview with that person to get feedback from an actual employer. They can learn what the employer is looking for to help them out to be more comfortable.

AUDIENCE MEMBER: OJ team?

MALE SPEAKER: On-the-job training.

AUDIENCE MEMBER: Subsidizes half of the salary for the first two months?

MALE SPEAKER: Usually it's three months. Depending on the nature of the job, it can be longer, sometimes less. There are also tax credits available as well. Sometimes we educate them. There are tax incentives for businesses to hire somebody with disabilities.

MALE SPEAKER: I remember what it was. Disability the disability business enterprise initiative. And really it mostly focuses on people with developmental disabilities. And they do things like go around and it's for disability owned businesses, usually associated with a lot of art associations for retarded citizens, a lot of the arts run state. And we provide sort of leads and business plans and that sort of assistance to these organizations.

AUDIENCE MEMBER: Okay. So that's a link on your website?

MALE SPEAKER: Yes.

AUDIENCE MEMBER: Thanks.

FEMALE SPEAKER: We have five more minutes.

Transportation: RIPTA

AUDIENCE MEMBER: How does flex work? Is that the one that just goes within the zone? Is that the one that has the zones?

MALE SPEAKER: RIPTA has some other services that look like RIPAN's but there are areas where there's not a lot of public transportation. It's called the flex program.

AUDIENCE MEMBER: My daughter uses the RId program to get from Newport to here. And sometimes she's picked up by I guess when the van the time is such and the vans are unavailable. One time she was picked up in a limo. I think they used taxi --this was just recently. I think they used the taxi service when so that if they have

MALE SPEAKER: That's right.

AUDIENCE MEMBER: Whatever vehicles they happen to have.

MALE SPEAKER: If we don't have a ride van or flex van.

AUDIENCE MEMBER: The ride is \$2. 50 each way.

MALE SPEAKER: The good news is flex program is an idea that sort of took people from where they lived to the regular RIPTA buses. It's such a great idea. It was an experimental program by the federal government. And this is probably one of the last years it's going to operate. It's worked so well. We think it might be defunded. That's sarcastic. It has worked well in some underserved areas of the state, rural areas. And we are working hard to try to keep it going. But it's difficult because it's an experimental program. It's worked well. We have data to show it. But it costs money to provide services to people.

AUDIENCE MEMBER: So flex may be dropped?

MALE SPEAKER: It might be in the future. We are working to try to keep it going.

MALE SPEAKER: That's a particularly important service to south county where there's not that much transportation. I have a counselor in south county. That was the number one issue every year for people looking for jobs.

MALE SPEAKER: In Westerly, for example, the whole city of Westerly has no regular RIPTA bus service and a little bit of Ride service. But it has a nice flex program that brings people here to south county hospital and Wakefield and (inaudible) Westerly. We are working on trying to keep that going.

FEMALE SPEAKER: I would like to say one last thing before we go is we are we have been working on a home modifications 101 consumer guide. And we have had architects and builders and PT's and OT's and people from the various state agencies all involved with this. And it's going to be a really pretty comprehensive consumer guide on how you actually get a home modification made done. And we are going to be holding various seminars for people with disabilities, senior citizens, across the state. And there is going to be hopefully some changes in the Medicaid program about home modifications. All towards the end that you are advocating for people to be able to stay in their own homes as long as possible. And how we can help facilitate that from happening to happen is to help empower the consumer to understand how exactly to go about this. So we are pretty excited about that. I hope to actually have all of this completed in the next month, ready to roll in September. There's also on our website an interview guide that was actually created for kids with disabilities, but it can actually be used for anybody. It's another good document that in case like especially your son on how you interview. What you should be doing. Little tips, how to do all that. DOH has also a new get ready, get set, go. Is that what it's called?

FEMALE SPEAKER: Checklists.

FEMALE SPEAKER: Checklists on how you move forward. So there's a lot of really good comprehensive documents that have

FEMALE SPEAKER: On our website.

FEMALE SPEAKER: On their website.

AUDIENCE MEMBER: We got something about that

FEMALE SPEAKER: So anybody else? Because it's now two minutes before the bewitching hour. I want to thank everybody for coming. And hopefully you got something out of this.

And hopefully we've gotten something out of this too. So thank you very much.

AUDIENCE MEMBER: Consumer directed is the latest feature.

FEMALE SPEAKER: What a lot of states have been doing is consumer directions because it's been demoed in a lot of places but not something so broad that it's the way to go. Consumer directed is not for everybody. But

it is for a lot of people.

### **3. *Wednesday July 23, 2008 Warwick Public Forum***

LORNA: We are going to be starting soon. We are waiting for our panelists. If you are here to listen but you truly have a concern and you are just afraid to testify, we are really nice. We are here only to listen. And

it's a great way for you to voice your concern or your praise of a service here in Rhode Island. So please don't be nervous. We are taking your name at the back. You just have to check that you wish to testify. And please, even at the last moment you are a little nervous and maybe somebody else said exactly what you wanted to say, it's okay to say my name is I'm from such and such a place and I agree with that person who discussed a similar issue. It's fine. So if you haven't signed up, if you wish someone to come to you, just raise your hand. We will get you on the list.

LORNA: Hello. I am going to do a little commercial break here. We have someone here from the project vote project. If you are not registered, and you wish to register to vote this November it's an important election --give a hi sign.

FEMALE SPEAKER: I am Kate Bowden from the Rhode Island disability law center and the vote project. I have materials here on the back table with voting related deadlines, voting rights. If you need trainings, we can let you know. And we can also register you to vote.

LORNA: Thank you. I think we are going to get started. We've had some people who did arrive just before 2 and we are still waiting for a few panelists. But as they arrive, we can just have them get seated. I welcome you all to the governor's commission on disability public forums. This is one of several happening across the state this week. And it's a wonderful way for you to testify, to give to put in writing any concern that you might have. I need to read exactly the reason for today's meeting. The state government and the sponsoring organizations want to hear from people with disabilities and their families regarding concerns and issues and ideas for improving the lives of Rhode Islanders with disability. I'm Lorna Ricci, the executive director of the ocean state center for independent living. And I am today's moderator and your host. I will try to keep things moving along and hopefully give everyone a chance to testify today. Our panelists are here. And if you could give a hi sign as I read your name. With us is Roberta Greene from the office of rehabilitation services. Also Kate Sherlock from the disability law center. Kate. Linda Ward is not here

FEMALE SPEAKER: I'm here in the audience.

LORNA: Linda Ward is in the audience from opportunities unlimited for people with differing abilities. Would you like to come up and be a panelist?

FEMALE SPEAKER: Bob asked me to sit out here because there are too many

AUDIENCE MEMBER: Heidi is here. Go ahead. Down we have Gwen Reeve from the muscular sclerosis society, Rhode Island chapter. Laura Jones from Rhode Island parent information network. Heidi Showstead has just arrived from the statewide independent living council. We also have Deb Garneau, office of special healthcare needs. Deb.

FEMALE SPEAKER: Rhode Island Department of Health.

LORNA: Rhode Island department of health. And I'm not sure if someone from the Paul Sherlock center's here.

FEMALE SPEAKER: I'm here. But I am not a panelist and I don't plan on being one.

LORNA: Okay. Someone is in the room to listen to your concerns. We also have Tom Martin from the division of behavioral healthcare services. Lisa Onorato from the brain injury association of Rhode Island. She might be arriving a little later. Michelle Amoto from the Division of Human Services. And last but not least at the end we have Tim Flynn, who is the chairman of the legislative committee of the governor's commission on disability. Also members of the governor's commission members that are with us today are Arthur Plitt and Rory Carmody. So we are all here to be able to hear your testimony. I would like to thank our Court Reporter, Jen Moore. Our interpreters Carol Fay and Yvette Johnson. If you do need an interpreter services and wish to come up a little closer, feel free to. Also if you have any difficulty taking part, hearing, or seeing, any kind of difficulty, please feel free to move forward. You can move around the room as need be. Just so you will know, the rest rooms are out as you leave the building and then to the right. Men's room and ladies room are right there. The phones are as you leave this room to the left, right near where you came in, the backdoor. Should you want coffee, hopefully things will be you won't be falling asleep. But it might be warm in here. Coffee can be purchased right as you passed a little cafe. So feel free to get coffee and even pastries

sold over there. I ask that you do please take your cell phones out and please turn off the ringers. It could be very disturbing for people who are testifying, many of whom probably are a little nervous to begin with and don't want to be disturbed with ringing phones. Has everyone signed in? If you haven't, if you would like to raise your hand and have someone sign you in, if that's more convenient. We need to get everybody listed. Now today's procedure. When your name is called, please come forward. There's a chair right here. We will give you the microphone. And we wish you first to state your name, nice and clear and if you could, please spell it for our Court Reporter. That would be much appreciated. Also if you could give the name of your agency affiliation, if you are representing an agency, and also please list your town, the town that you live in. The reason being, why do you think? This goes to legislators and legislators are very interested in their own constituents. So please make sure you give us the town that you live in. We ask that you be concise. We are going to limit your testimony for about four minutes. So if you could even be thinking ahead of time the subjects you wish to touch upon and try to organize it so it's pretty clear and quick. We like to have everyone have a chance to speak. Our panelists are here purely to listen to what is being said today. This is not a debate. Panelists are not going to challenge you. They are here only to listen. The only time they may ask a question we have a mike for them is only for clarification. If you say something that's just isn't clear, they may ask you to repeat a sentence or two in another way just to clarify what you are trying to say. That's about it. Oh, also if panelists do ask questions, we ask that you also say your name first for our Court Reporter.

AUDIENCE MEMBER: You have another panelist.

LORNA: Another panelist. Elaina Goldstein is with us from Rhodes to independence. Okay. Let me just go back. Oh, all the testimony that is going to be presented today by the will be reviewed by the sponsoring agencies and compiled into a document that will be available to the public and shared with legislators. This document can also be viewed on the governor's commission website, not tomorrow, people. It takes a while to combine compile the Court Reporter's manuscript and it probably will be another month or so. But you may want to check it. And you can see the testimony verbatim on the governor's website. The website is [disabilities@gcd@ri.gov](mailto:disabilities@gcd@ri.gov). All this information is there. Written testimony is of course accepted and we encourage anyone who's a little timid, if you hear something today and you really wish to testify still, you can testify in writing. It needs to get to the governor's commission before July 31. You can send it via e-mail or fax it. It's 462-0106. Again that information should be on your handout. So I think that's it. Let's get started. We ask that you keep your testimony to four minutes. Eileen Naughton is here okay. And just regarding time. Since she's here, Leslie is our timekeeper and she's tough. So watch out if she if you get I think there's a yellow a bright pink folder she has to catch my eye when four minutes is up. So, if I begin to say like this. I will probably go four. And please that means for you to please wrap up your testimony. Again, it's only to allow everyone else to have a chance. If by chance we didn't address all of your issues, wait. I'm sure by the end we will have time for people to come forward at after everyone has signed up, if you have additional things you wish to testify or comment on. I'd like to announce that representative Eileen Naughton is here. I would like to recognize her. Thank you for coming. (APPLAUSE) She's been a wonderful advocate for people with disabilities and we thank you tremendously. And representative Frank Ferry is here. (APPLAUSE) Thank you for coming. Okay. Let's get started. First to testify will be Eleanor Hassell.

AUDIENCE MEMBER: Good afternoon. My name is Eleanor Hassell. I'm a resident of Warwick. I

Housing: Home modifications
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contracted polio as a child of 8 and now suffer from post polio syndrome. I am permanently confined to a wheelchair. And I am here to testify for the desperate need for funding for home modification to help people like myself live independently. I want to remain with my family in our home. And it is becoming increasingly difficult for all of us. I am unable to use my own bathroom without the help of my grown son. My wheelchair does not fit through the door. They support me as I take steps, holding on to the door knobs and towel bars. This has result in a number of severe falls on to a tile floor. Over time, these falls have made my condition worse in causing pain. The cost to put people in assisted living is more costly to help us in our homes. Linda Bradley of OSCIL has spent a great deal of time and effort in guiding me in the issues. She has prepared modifications to make my bathroom accessible. I have copies of those with me today. She's also given me products to help me be

safe. Since I am on Social Security and unable to pay for myself, I am asking for funding that we may all live with the dignity and independence to which we are all entitled. Thank you. (APPLAUSE)

LORNA: Thank you, Eleanor. Sharon Terzian.

AUDIENCE MEMBER: T-E-R-Z-I-A-N. Hi. My name is Sharon Terzian. I live in the city of Warwick.

Medicaid: Global waiver

I work at the Sherlock center but I am not here at all on behalf of the Sherlock center. I have a child at Katie Beckett and she's 14. And my concern is the global waiver that's about to be developed, passed in whatever you want to call it through the state house. I had serious concerns about the way the state has handled money in general over the years. And I just am very concerned. They are going to run out of money if they don't estimate right. Or in general, even if they do estimate correctly, I just have this fear that in three years, there's going to be no money at all and there's going to be then what happens to our kids and other people that rely on Medicaid and the services that go along with it? My daughter is independent because of the services she's had through Medicaid over the years. She gets the pass program which helps her with independent living skills. And hopefully, you know, she will maybe be able to live on her own some day. But I also look at this realistically that when she turns 21 in seven years, I don't honestly believe she will qualify for anything. And that's a scary thing as a parent. The only other thing that I would like to bring up is special education funding. There's a lot of

Education: Special education

problems with funding of education in general with the way it's calculated throughout the state. It's different in different places and my daughter has always been included. It costs a lot more money to be included than to not be included, but it works for her. And once again, our goal is for her to be able to live independently when she's 21 and we are not here anymore for her. Those are my two concerns. Thank you.

LORNA: Thank you, Sharon. Kenneth Simas.

AUDIENCE MEMBER: Okay. Good afternoon, panel. My name is Kenneth Simas. I live in Warwick. I am a little new at this. I was born with cerebral palsy 54 years ago. I have been independent all my life. I worked all my life. I worked for Blue Cross Blue Shield for 30 years. And now my department of the IT division moved to Texas Prosystem. So I worked at home until last year when I injured my right ankle, which is my good side. My left side got more cerebral palsy than my right side does. So I had major surgery done in June. And unfortunately so I really have to get around in my scooter a lot has happened within the past year. I couldn't work. I lost my home that I had in Cranston for 14 years. And I got accepted to on total disability as

Medicare: 24-month delay

recently as December. But I'm concerned about medical. Now they told me that I had to wait a year before I could get on Medicaid. And I'm married. This is my wife Cindy behind me. I don't know what the answers are. I'm trying to find out I contacted Medicaid and they told me that they couldn't really help me because I would have to pay the first three or 4,000 dollars out of my pocket every year before they could help me because of my income is a little higher than the normal person that's on SSI because I guess I worked for a long time. I'm mainly concerned about health insurance, if I can get it, where I can go to get it, and you know, until I can get on Medicare. So that's why I'm here today and thank you for listening. (APPLAUSE)

LORNA: Thank you, Kenneth. Kenneth Sundberg.

AUDIENCE MEMBER: Good afternoon, panel members and Representative Naughton. Thank you very much for joining us this afternoon. I may recognize you from the House finance committee. I testified twice there. I just want to say that we have a 42 year old developmentally disabled daughter who lives in a group home. And she lives there with six or seven other young women. She's lived there for 14 years. And it's

Medicaid: Supported living arrangements

become like a family with them. They are very supportive of one another. And there's a lot of safeguards and security measures built into and support built into the group home model. I'm very concerned about this global waiver in that they've stated in the original proposal that they want to start moving people into SLA's [shared living arrangement] with privately contracted families, which in my simple definition this would probably fall under the umbrella of a foster home. And I think that it's just unwise to think of doing this. And I'm very concerned about that. They've

Housing: Shared living arrangement

stated in the waiver also, in the original proposal, that there's no case too severe or medically involved that wouldn't fit the model that OHHS has in mind. I just want to say that I'm very opposed to this. It's probably good for some people, but not for everybody. And I would ask that the legislature maintain some hand in the administration of all of this and give families and people who need help a forum to protest and placement in such a living arrangement. That pretty well wraps up what I got to say. That's the one thing in the waiver that I particularly picked out. There are a lot of other things. But this was the one that is nearest and dearest to my heart. Thank you. (APPLAUSE)

FEMALE SPEAKER: Gwen Reeve, with the Multiple Sclerosis Society. I just have a question and maybe you know the answer, maybe not or somebody on the panel does. If they are moving your daughter out of the group home into, it looks like a private you are concerned that would happen?

AUDIENCE MEMBER: That it might happen.

FEMALE SPEAKER: A private living situation. What is the difference between doing that and moving them back into the original parental home because it's the same issue of at least to me the concern would be whether or not they're living independently or in a home setting. And why not back into the family of origin setting as opposed to foster situation?

AUDIENCE MEMBER: My daughter is 42 years old. And she has multiple impacts. She is developmentally disabled and she has physical and medical issues as well. My wife and I are approaching 70 years old. And to bring a 42 year old woman like that back into the house, we are not capable of dealing with this anymore. And the group home arrangement, there are multiple staff members and they can spread the responsibilities out. And it's a (inaudible) thing. They are not there 24 hours a day. In an S LA, this family in the community would deal with it 24 hours a day. And I don't know that people really realize the burdens that (inaudible).

FEMALE SPEAKER: Thanks for the clarification.

AUDIENCE MEMBER: Thank you.

LORNA: Thank you, Kenneth. Laurie Archambault.

AUDIENCE MEMBER: Hi. My name is Laurie Archambault. And we live in Chepachet. This is my son Jared Taylor in the third row in the end. Some of you may be familiar with our story. It ran in the Providence Journal last May. I have a few copies for those who may have missed it and are interested in reading it. To be brief, Jared was born with severe mental retardation and complete blindness.

Self advocacy

He has a complex medical history that includes seizures, severe osteoporosis, and hormone deficiencies. He possesses autistic like tendencies and behavioral issues. He has the cognitive ability to a two or three-year old. His vocabulary consists of 50 words. He requires assistance in even the simplest activities including using the bathroom. Jared can never be left alone. Jared cannot express his needs effectively and will never be able to self-advocate, direct his own services, vote, or live independently. In 2005, I had no other alternative but to remove Jared from the group home where he had lived for three years to protect his health and safety. Through no fault of her own, another client living in that group home sat on Jared's head while he lay sleeping on the couch. A few days after removing Jared from that home, I applied to MHRH for new residential and day services. I am still waiting. Jared is not receiving the intensive services that would allow him to flourish. Jared isn't receiving any services at all. The current movement toward self-advocacy, choice, independence, and responsibility is wonderful for those people who want it and are capable of self-advocating, making choices, and handling responsibility. My son cannot do any of these things. If pushed too far, this movement will totally eliminate necessary services for Jared, who requires intensive services that would keep him healthy and allow him to live the most fulfilling life he can in the face of his disability. During my research of the current system of services for the DD population, I estimate that there are about 500 people with severe to profound mental retardation. Who advocates for these people who cannot advocate for themselves? How many of these severely profound retarded people said, "I want to live independently" or "I want to vote"? The answer is none of them because due to the nature of their disability, they cannot do these things. Individuals with severe to profound mental retardation have no choice but to depend on the understanding and compassion of others, to design and

complement an array of services that would not only include them but meet their extensive needs. It is my opinion that the state of Rhode Island wants to hide behind this new global waiver. I feel the state of Rhode Island is working toward shedding their responsibilities to the DD population. With the cap on funds, services will be spread very thin. And people like Jared who require intensive long-term care will continue to go without necessary services. Waiting lists will grow. I would like to ask the self-advocates to acknowledge that there are many people served by this system who cannot advocate for themselves, cannot make choices, and cannot handle responsibility. A comprehensive system of services needs to be in place to ensure that all people with developmental disabilities receive the services that they require. I think the system should include various levels of care that coincide with the varying levels of disabilities. We need hospitals, nursing homes, group homes, intermediate care facilities for the mentally retarded as well as shared living and foster care. I do have one question for the governor and that would be what has happened to the governor's committee on mental retardation? I understand that that is supposed to be a permanent committee that has 14 members. And there have been no appointments to this committee for 18 years. The only members at this point are MHRH. Thank you. (APPLAUSE)

LORNA: Thank you, Laurie. Jolene Thomas. Jolene.

AUDIENCE MEMBER: Hi. My name is Jolene Thomas. I am just going to speak from the heart. I was going to write something but I just chose to speak from the heart. I was diagnosed with MS in 1995, 13 years ago. And I must say it's been a long road. I have done a lot of things backwards because I had no one to help me to show me which way to go. I discovered OSCIL a few years ago due to another friend that I have that has MS. And he told me about OSCIL. And they have helped me tremendously. OSCIL for me is like the internet. I can call them up. If I don't have the answer for something, I call them up. Either they give me the answer or they provide the answer or they set me on the right path to get the

Medicaid: Global waiver

Accessibility: Automatic doors

answer. They have helped me as much as from driving lessons with the hand controls. They provide the hand controls for me. As big as that, until the littlest thing, like a button, a button I button my clothes. They provided that. So it goes from the biggest thing to the littlest thing. And what baffles me when the state wants to cut programs like this, they always start with the needy. They always start at the bottom with the people who need it the most that don't have any money. I don't understand why they want to always start at the bottom. They don't start at the top. And I'm quite sure if someone went to the governor and said he wasn't going to get a bonus, he would do everything to make sure he got the bonus. So, it just baffles me how they always want to cut programs. But they always want to start at the bottom with the people that need it the most. So that was one question I had. The other question I have and I was so surprised this is my first time at the Warwick public library and I was so surprised to see sliding doors. I was so happy because medical buildings, especially medical buildings, doctors office, hospitals, you all know. Most of them don't have sliding doors, automatic door openers. And you have to struggle to get the door open. And I can give you a perfect example. Coastal medical, 400 reservoir avenue. If anybody knows how that building is set up, you know what I'm talking about. The door, the handicapped door is not where the main door is. So there's no people coming in and out to see you to help you. So either you are going to have to have somebody with you or just wait until somebody opens the door. It's I don't know who designs these buildings. And I guess because no one knows until you get to a situation. And I didn't know until I got hit with MS. Now that I'm in this situation, I can see different things that people don't pay attention to, if you are quote normal. And now that I am in this situation, I see all the things that I go, hum. Things that make you go hum. Like why do you go into a bathroom and a handicapped bathroom is the last one? Why can't it be the first one? You got to go all the way down to the last one. I mean, things --little things like that. And people don't know little things like that. It bothers me. I think it bothers a lot of people. At first I skipped over. I want to thank Linda Bradley of OSCIL. I also want to thank my daughter for bringing me here because I kind of goofed up. I was supposed to get the RIdE program here. I forgot to call. So my daughter brought me here. So I want to thank you. She is just such a godsend. She doesn't get thank you enough. And (APPLAUSE) (inaudible) the other thing I want to say I kind of got off

track is that as far as a cut in the program or whatever they are going to cut, not giving enough money. Like I said, OSCIL is like the internet for me, personally. And it just helps me. And to one day with these cuts, it's just like a disease. I have progressive MS. I wasn't always in the wheelchair. Slowly, slowly, slowly. I walked. I walk with a cane. And from the cane I went to a scooter. Then I still can walk, just a little bit with a walker. My balance went. Once my balance went, you know, that was it. But you know, just like the disease slowly took my independence, I still have it. That's why me and my daughter argue so much because I'm so independent. I believe that OSCIL and the state is cutting OSCIL and it's taking away our independence. And with them every year, cutting, cutting, cutting. Pretty soon one day I'm going to call and they are going to say, OSCIL's not here any more. Then what? It's just like the disease. You know, and all I'm asking is don't take away our independence. Whether no matter what disease, you know, disability that you have, you know, we are still independent.

LORNA: I'm sorry. The I got the four.

AUDIENCE MEMBER: Okay. I'm sorry. But that's all I have to say

LORNA: Okay. Jolene, that was wonderful. Thank you. Thank you very much.

AUDIENCE MEMBER: You are welcome.

LORNA: Just a little sidebar. I know you are all enjoying the Warwick public library. And when it was being built, this wonderful place actually called advocates at OSCIL. The Warwick commission on disability had us all come and help design this building to make it accessible. So they get and applaud. Thank you.

FEMALE SPEAKER: I just want to sorry. I forgot it's here. Hi. It's Gwen from the MS society. Jolene, thank you for sharing that. I think you gave a very accurate description of what happens with multiple sclerosis and the people that have it and needing the services. I want to let you know if you leave before, that the local chapter does have financial assistance programs and a few other things like that. So, I just want to let you know that you can access that.

AUDIENCE MEMBER: Okay. Thank you.

LORNA: Thank you. Thank you Gwen. Next is Lucille Gallagher. Lucille.

FEMALE SPEAKER: Good afternoon. Lucille Gallagher and I live in Warwick. Actually I'm here on

Information

behalf of my daughter, Jennifer, who happens to be a person who is blind, was blind at birth. And recently, the last three years received developmental disability support, despite the fact that we had applied at least 12 years previously and she was rejected at that time. And I still haven't figured that out at all. Nothing changed in her whole history, et cetera. In fact, I reapplied with the same paperwork 12 years later and she was accepted. So mom thinks there is really a problem there. I was told that her blindness was looked at when she was finally accepted. But I hope to be brief today. And I kind of chuckled to myself saying that my former college students would really laugh at that and understand that I am fully retired because I was never brief. But I am also concerned that the state has 42 agencies that parents or individuals can opt into. That was my last comment. I may be in not correct with the amount of agencies. Personally, I think that many of these agencies are redundant. So I feel that that is a problem; that expenses are going to all of these agencies that could be better utilized. I also have been very concerned at the price tag that is given for an hourly rate with a person who has a disability and the staff person. I just feel that finances could be better utilized within the state to better betterment for tax payers as well as for a person who has the disability. I also, when we did receive support from developmental disability, I was given a list of these agencies. And I was told to go for it. Now that was an awesome task for me to finally select an agency. I really think some sort of booklet or pamphlet should be printed with all of these agencies filling in their name, address, and the people that they deal with. I actually made phone calls to agencies that were not related for my daughter. So those are the few statements that I would like to make. I really feel that tax payers could be better utilized in the taxes that they pay and with that by slenderizing these 42 agencies. I feel a person with a disability would have an advantage. The funds wouldn't be redundant. And I thank you for your time. (APPLAUSE)

LORNA: Thank you, Lucille. Is there anyone else? Elizabeth McLaughlin.

AUDIENCE MEMBER: Elizabeth McLaughlin, M-C-L-A-U-G-H-L-I-N, and I am from Cranston. And I decided after hearing a gentleman speak a while ago that I needed to put my two cents in as well. Since my sister died in January, I have been the primary care giver and guardian of my niece who is 21, just turned 21, and is disabled with a number of disabilities. She's developmentally disabled. She's hearing impaired, mental health significant, significant mental health issues. One of the things I'm very much interested in, as I look to the future, is group home. I am 71. And it's a strain at this point. And I won't be able to keep it up much longer. The situation with group homes in the state, as a gentleman referred to earlier, is there's just nothing available. There are no openings. And there's no movement in that area. And I just want to speak to the need for that. My niece would not function well in a foster home situation. She needs the care around the clock care of a group home situation. But that situation right now is not very promising. There are some people who might function well repeating a little bit there with other types of situation. But we need a good group home situation. Thank you. (APPLAUSE)

Medicaid: Supported living arrangements

LORNA: Thank you. I would like to also announce we have a new panelist with us. Jenny Goodrich from the Paul Sherlock center is here with us as a panelist. Thank you. Next is Marie Perna.

AUDIENCE MEMBER: Marie Perna and I am from Cranston. I also have multiple sclerosis. And I also coordinate along with some wonderful people, members of my support group, as well as many of my family members, accessible Rhode Island. They are in the back. I'm here to talk about some of the good that's going on today for those of us with disabilities. I'm here to say that in light of all of these terrible things that are happening around us to people with disabilities, we have undertaken over eight years the task of outlining and defining clearly what handicapped accessibility is in Rhode Island. We've done it for galleries, for restaurants, for theaters, for libraries, for recreational centers. My daughter and I just got back from south county. We were a little late because we have been doing beach assessments and campground assessments throughout the state. It will be a new section in our next guide and it will be on our website very soon. I'm here to say that we with disabilities can enjoy what's here in Rhode Island. And it doesn't have to cost money. So, I want all of you in this room to know that this is for us. It will continue to be for us. And when time's are so bad and we can't get services for our loved ones and for ourselves, we do know that there are places in Rhode Island we can visit for free and have a good time. Thank you. (APPLAUSE)

Accessibility: Guide

LORNA: Thank you, Marie. Ruth Peasley did I say your last name right?

AUDIENCE MEMBER: Hi. My name is Ruth Peasley. I'm from North Kingstown. P-E-A-S-L-E-Y. The reason I'm here is I have a 30 year old son Matt who's profoundly retarded, developmentally disabled, and autistic. He has been living in a group home since he was 21. Prior to that, he lived at New England Center for Autism and the Groden Center. The things that are scaring me that I have been hearing going through hearings and meetings since last November are the global waiver cap, which I understand is going to be a tradeoff for Social Security. One of the things I don't like about it, probably the scariest thing is they can take up to 25 percent of it to use for other purposes, like balancing a budget or paying future salaries, whatever they feel like. It's not going to go it doesn't have to go to recipients that right now we are getting X amount of dollars in the state for social services, Social Security. That money can be used for something else, you know, to pave a parking lot, whatever. The other thing is the supported living arrangements or shared living arrangements. Right now Matt's in a group home. He has been there for a number of years, both through the Groden Center and through Gateways to Independence. What I hear is that they're thinking that they will take the people that are everyone, elderly, handicapped, whatever. Put them literally on an auction block and people will have a chance to bid as they okay. Matt is profoundly retarded. He has seizures. He has this disability. He's worth \$40,000 a year. This person here might not be as severe or profound. He might only generate \$30,000 in income. And people, foster parents, whatever you want to call them, will be able to decide which person they want to take. And that's how they are going to generate their income. And that's where the folks that are in group homes and nursing homes will be allocated, if there's not an apartment or something. What I don't like about that is well, is

Medicaid: Supported living arrangements

that right now Matt's in a secure environment. There's safety precautions in place. He has locked med cabinets, things like that because he is on a whole host of medications. If he goes out into someone else's home as a foster parent are they going to have the training and the expertise to go and give him his meds because there are extremely like class IV, whatever volatile medications. I know the interactions and everything. Are they going to have the training for that? Are they going to have the safety measures in place? Is every house going to be retrofitted so that they have the alarm systems to go off? Or if they need anything in the bathroom, any kind of accommodations, are they going to be there? And suppose somebody does leave a group home setting and go into one of these shared living arrangements, then the people find out that they don't like it. One, the state has spent all the money to modify that house. They are not going to do it anymore. How are they going to recoup the money they spent? And two, when Matthew or someone goes into one of those arrangements and it doesn't work, he's lost his group home placement. He's back on the bottom of a list that might take ten years. And I don't like that either. Oh, as far as independence, right now and it was hard for me to let him go into a group home setting. But the way I look at it is Matt is no different than any young 20, 30 year old man living with his friends. He has an apartment. He needs structure. He needs someone there because he can't be left alone. But it's no different than my other son, who lives with a couple of guys when he was younger before he got married. They had their own thing. They would go out and do whatever. So does Matt. They go to the ball game. They go swimming. He does meals on wheels. They do their own cooking with supervision. So he is at, I believe, the best place for him at this point in time. That's about all I have to say. I probably forgot something. But that's it. Thank you. (APPLAUSE)

FEMALE SPEAKER: Hi. I fortunate but there's a stakeholder meeting that the department of human services has been holding every couple of weeks. I have been working on a number Perry Sullivan legislation and the implementation of it and long-term care so the people who have been working in this group, which is people with disabilities, senior citizens, providers, working for like the last two years. So we kind of debate, bring us in every couple of weeks to go over some of the details, as much as with the global waiver and where we are going. And we got to ask pretty tough questions to try to get answers. I'm just curious as to and I don't feel real competent or that I should be the one responding to your concerns about the global waiver. But what you had to say is just so far from what I do know is allowable under Medicaid. They cannot use money of Medicaid money to just pay for other things. They just can't. It's a federal law. State cannot do that. So I was curious as to where you got your information.

AUDIENCE MEMBER: I think it's (inaudible) I did go

FEMALE SPEAKER: What concerns me is to have information that's that misunderstood distributed out really makes me upset because I if I heard what you heard, I would be really upset too. But I'm just saying what I do know about Medicaid and I have been at working in policy for a while. But I do not work for Medicaid. I work pretty much as an advocate at Rhodes to independence for people with disabilities. So I would hope that somebody from Medicaid at some point will be able because it really that really is not accurate.

AUDIENCE MEMBER: I have it back in my chair. It's from one of the meetings that we also had down at the Trudeau center. That is the case

FEMALE SPEAKER: Maybe find out who is saying that and to try to get them to understand so they don't give out the misinformation.

FEMALE SPEAKER: I can give you my name and number also.

LORNA: Thank you. Next is Mary Harlow.

AUDIENCE MEMBER: Good afternoon. My name is Mary Harlow. I live here in Warwick. But I'm here on behalf of my sister who belongs to the Cranston arc. They we had a meeting with her social worker and another person last Monday who told us that she would, may be moved out of her group home that she has been in since she was 18 years old. She's been in different group homes and under the auspices of Cranston arc. But we had an incident a few years ago where she was moved out of the group home and moved in with a woman who supposedly knew how to take care of a mentally challenged person. She has down syndrome. She has a lot of mental she's very social and people think that she's more able than what she is. She has the intelligence of a 12

Medicaid: Supported living arrangements
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year old. She's 53 years old now. But this woman was leaving her alone for long periods of time. There was no supervision in the house. And she had a mental breakdown. And then they moved her back into a group home and didn't have 24-hour staff. And she again had another mental breakdown and ended up in St. Joseph's hospital and all on all kinds of psychotic medication. We had to fight to get her 24-hour staff. We had to get a psychiatrist to sign a piece of paper saying that she needed this help. Now they want to move her out of the group home again and put her with a family. Our question was, who's going to take care of her 24 hours a day? My oldest sister and I have tried to take care of her. We take her on vacations with us. And it's a very daunting task to take care of this woman. She's a wonderful person. We love her to death. But we just couldn't do it. If you take her away on vacation, you end up with taking medications. You have to practically be a registered nurse to make sure that she gets her medication, gets it on time, and in the way it does. And my question is, what family is going to do this? And how are they going to do it? And are they all going to be trained to do it? Is it going to be just one person that's going to be with her 24 hours a day? Is it going to be the whole family involved? So, we are very much against this global waiver and moving them out of the group home. And without even any provocation or anything, last Saturday we had her sitting at the dinner table. And she says to me, "I'm very happy where I am. I don't want to move. "And I have no idea where that came from unless she overheard staff talking or somebody talking. But she said it at least three times. And then when my son came in, she said to my son. "Hey, you know, I don't want to move. I want to stay where I am. " She also has a very hard speech impediment. It's very hard to understand her. And a lot of people just don't understand what she's saying. And I don't understand how a family is going to do this. Thank you. (APPLAUSE)

LORNA: Thank you, Mary. Sharon Fielding. Sharon Fielding. Did she leave?

AUDIENCE MEMBER: Do you have a mobile mike?

LORNA: Yes. Hold on.

AUDIENCE MEMBER: Hi. My name is Sharon --

LORNA: Excuse me. We may have to push up the there you go, Sharon.

AUDIENCE MEMBER: Hi. I am Sharon Fielding. I had a stroke four and a half years ago. Compared to where I am now, I have been doing pretty good. I'm at home with my husband in a rental apartment. And the thing I have to ask you is, I ask my husband to help me on a ramp because I can't get out of the house by myself. And I want to do things for myself. But because there's no ramp, I have four to five steps to get in and out of the house. My husband will finish.

AUDIENCE MEMBER: Hi. My name is Larry Fielding. I am Sharon's husband. And we have been living working with OSCIL, trying to get ramps installed for our apartment.

Housing: Accessibility

And it's just it just seems like there's a big run around about the whole thing. They are asked for information and they send the information. Then they ask for more information. Then they send the information. Then they are asked for a whole bunch more information. And it just goes on and on and on. In the meantime, it's Sharon's kind of stuck. I've got bad legs and a bad back. And I do the best I can. I help her. I get her in and out of the house the best I can. But she is at the point where she really needs her mobility so she can go in and out of the house when she pleases and if there's an emergency. Right now, if I'm not there and there's an emergency, she's in trouble. She can't get out of the house. So I understand that there's a financial problems in the state but there's also things that need to be done. This I believe is one of them. I think that's about all I have for now. Thank you very much. (APPLAUSE)

LORNA: Thank you. Anyone else signed up? One more person just came in? Is there anyone else that would like to testify?

AUDIENCE MEMBER: I didn't sign up --

LORNA: Hold on. What is your name? Brenda.

AUDIENCE MEMBER: My name is Brenda Myette. We have a son who is 38 years old. He has down syndrome. He again is very social and is able to do a great many things but could never be left all alone 24 hours a day. He lives with us at home. We are

Medicaid: Supported living arrangements

getting on in years. We were considering establishing a place for him to live for when we are not able to do it anymore. We wanted to do it while we were still around so that he could come home weekends and he would settle in to another kind of setting. Looking at the way things are now, there's no way that this is going to happen. I have great concern for all of the folks who are in group homes now. I would just like to remind everybody on the panel to think about this system that the state has for foster children that they cannot do a good job. The foster children are in most cases of normal intelligence without disabilities. They have come from home situations that the state had to take them out of their own home. If the state can't do something with foster homes for children who are going to grow and graduate from school and leave the home and get a job, how in the world are you hoping to get foster parents that will take care of people who are never going to leave that home, who are never going to be able to be independent? How long are those families going to be able to support a person with great needs? We have been supporting our son for these number of years. And fortunately we have been able to do it. But how many families are going to support somebody for 20 or 30 years? And how many times are the people that are already disadvantaged going to have to move out of the setting that they are in? I don't believe any family knows what it's like to do 24/7, especially for families of or for people who have great needs. 24/7 is a great commitment. And I cannot believe that this state is foolish enough to think that they are going to get the number of people that they will need to do 24/7 for our disadvantaged folks. (APPLAUSE)

LORNA: Is there anybody else that would like to testify?

AUDIENCE MEMBER: There's one in the middle.

LORNA: Hold on. Anna is it?

AUDIENCE MEMBER: My name is Anna Liebenow. And I have so many things that I'm thinking about.

Transportation: RIdE

But right now I'm very concerned about the fact that the state has this huge budget crisis. And I'm very concerned about what's going to happen for people with disabilities. I look at many issues. One of them is transportation. And I think I saw someone here from RIPTA . And right at this moment, there are wonderful ways that people with disabilities are able to get around using the Ride program, using the bus. I am very concerned about cuts that are happening to that and what will happen to those services. And like Marie

Transportation: RIPTA

Perna, I agree that right now there are wonderful things that are available for us to do here in the state. But we need to be increasing that to open up the doors for people with disabilities. And if we have this huge budget crisis, I am very weary that things instead of improving, like curb cutouts to bring us up to the ADA standards of the amount of curb cutouts that were expected to happen, supposed to happen. Then instead of improving that, it's only going to get worse. And when I'm listening to all of the stories of people talking about themselves or family members trying to find just basic ways to be living that are not only safe but also support

Housing: Subsidized housing

them to be able to do what they want and need to be able to do. So I think about myself also working, or subsidized housing has a one to five-year waiting list. And then wanting to be able, through the Medicaid waiver, to be able to have somebody come in and help me who's a wheelchair, to being able to have somebody come and help me. And I am very concerned about that, that support being cut. So, those are some of my more than two cents about where life is

Medicaid: Home care services

right now. And I feel like I don't want to lose ground for people with disabilities at this in this very financially scary time. Thank you. (APPLAUSE)

LORNA: Where are you from?

AUDIENCE MEMBER: I'm from Providence. My name is Anna and my last name is Liebenow.

LORNA: Thank you very much.

AUDIENCE MEMBER: Lorna --

LORNA: I'm sorry.

AUDIENCE MEMBER: That's okay. Hello. My name is Arthur Bourassa. I'm from Providence. I do have muscular dystrophy. I am one of Yuri's oldest boys. Last night I was walking on Atwells Avenue. And you know Atwells Avenue has quite a few restaurants. But there's a new deal. They are putting tables on the sidewalks. And it's very difficult to walk right from one end of Atwells Avenue to the other without having to go in the street. The tables and chairs take up most of the sidewalk because the sidewalks were not made for outdoor eating on Atwells Avenue. I think there should be a rule that sure, they can have tables out there. But there has to be enough room left for people to walk continuously, enough room for an electric wheelchair to go without a problem. And this is something that can be done statewide. And I'm sure that it's not costly to the state to regulate this. And we should regulate this so that I can walk on a sidewalk without any problems. Thank you very much. (APPLAUSE)

Accessibility: Sidewalks

LORNA: Thank you for testifying. Anyone else? Hold on.

AUDIENCE MEMBER: My name is Pat Carne and I am from East Greenwich. And something that has always perplexed me about what goes on here is I'm very curious why there can be no link established between high school and technical schools and college groups who send groups of people off to places all over this country, out of the world, to build homes and do repairs for people. But there doesn't seem to be a way or I don't know what it is to link those same types of people who want to help, people who need a ramp built, who need some help, to work with the service agencies that are also working with the state department of purchasing to supply material. Why we cannot overcome the labyrinth of bureaucracy that is established here that prevents that from happening so that instead of people having to raise money to fly down to wherever to put a roof on somebody's house or build a ramp, which is not saying those aren't good things because they are. But those things need to be established here too. People have instilled community service requirements for high school kids as a way to get them to touch other people's lives, realizing that their lives get touched too. They shouldn't have to leave the state to do it when there's so many people here who need the help. (APPLAUSE)

LORNA: On this side of the room before I go to the other side of the room? Kristen comments next.

AUDIENCE MEMBER: Hi. My name is Kristin Connors, C-O-N-N-O-R-S. And I am actually here just to speak to you in regards to an event that I was able to go to this past Saturday night in downtown Providence during the Providence water fires. I'm not sure if anyone is aware but they do have now accessible boats that people with disabilities who use wheelchairs for mobility can get on the boat and go down the into water place park and watch the water fires from the water. And it's a program that they've had for a couple of years now. And they are looking for it's free for anyone who is disabled and a companion and a donation for anyone else. Any time there is a full water fire in downtown Providence, then the boats will run. And they are being very lucky with the Shiners donating some money for them. But they are always they are looking for more help so they can get another boat so there can be more than two boats there and that people with all kinds of disabilities will have the opportunity to see the water fire from a real different perspective. So I just wanted to make everyone aware of that. (APPLAUSE)

Transportation: Accessible

LORNA: Anyone else? Linda Bradley, Linda.

AUDIENCE MEMBER: Hello. My name is Linda Bradley, B-R-A-D-L-E-Y. I am the home access coordinator at OSCIL. I have a couple of things that I would just like to mention today. I want to thank everybody for coming out. Yeah. I am very concerned about the growing number of consumers that I need to put on my waiting list for home modifications. I currently have over a two-year waiting list. These modifications are essential to these people's ability to stay in their homes and to live in the community. Whenever possible, consumers are directed to alternative funding sources. We screen requests. And I always look for the most cost effective solution. There have been rising costs. Funding has been sketchy to waiting for verification. This past fiscal year, I was only able to provide home mod services to 28 consumers. That's down from 45 a year before and 67 the year before that. And I really looked at it and it really, really tracks with the funding and the rising costs. This list just keeps growing and it's getting stretched thinner every year. I'm appealing to the

Housing: Home modifications

grantors to ensure continuous funding for these projects, which will allow these folks to stay home and not have to move into institutions. Another concern I'd like to raise involves a recurrent confrontations that I'm running into with some landlords or management companies. When modifications are requested for their tenants, in this case OSCIL is not providing the actual modification but providing education and advocacy to the consumer. I've worked with the governor's commission on disabilities on some of these cases. But it seems to me over the past year or so the problem has been increasing. Many tenants, many of my consumers are actually afraid to ask management for even minor modifications, such as grab bars because they fear retribution. I wondered if anyone can speak to do you know if management of subsidized housing is mandated to be educated about the fair housing laws, et cetera? And if not, could we put together perhaps an education event addressing reasonable accommodations that would educate not illegal landlords and management companies but the tenants as well? The other just little thing I wanted to clarify was and I did speak to Sharon and her husband. And this is okay with them. I just wanted to clarify my involvement with helping Sharon with the ramp. She is on a DHS waiver and OSCIL goes in to do assessments to help to identify the best intervention, again, to be most cost effective but to also meet that person's needs. And the assessment is given to a vendor, in this case a company that's going to build the ramp. That then gets processed through the Medicaid. And this is where the problem has been is it keeps coming back and coming back for more detail and more detail. I know the vendor left me a voice mail yesterday and said that they're pretty upset that it's they feel like it's being stalled. And in the meantime, you know, the person has to go without a very necessary modification. So I just wanted to clarify that. That's about all. Thank you. (APPLAUSE)

LORNA: Anybody else? You may you may also agree with something that has been said. And this is your time to go on record. All it would mean is your name and the town you live in and reference to one of the issues that's been mentioned that you also agree. And I tell you this because when the organizations review all the testimony, when there's a lot of the same kinds of testimony in one area, it's definitely paid attention to; that in fact many people agreed with a certain topic that was discussed. So if you agree, that's all I have to say, even if you are a little timid. Your name and where you are from. Or if you raise your hand, I will be glad to take it for you that you agree. Anyone want to talk about an issue that's been raised or something new?

FEMALE SPEAKER: Me right behind you. (LAUGHTER) Hi. I am Gwen Reeve and I'm with the Multiple Sclerosis Society. And I think that what I wanted to do was speak a little bit about some basic issues that our consumers have difficulties with. One of them is the fact that and I was relating to the woman that had a stroke. The problem is that most of our clients or consumers are diagnosed with multiple sclerosis as adults after they've put in a pretty good work history, a working history, which means they have the ability to collect Social Security, if they are determined to be disabled. And what happens is they if they are no longer able to work, they do file for disability and that's a process that takes a number of months. But once they are determined to be disabled, and or beginning Social Security Disability Income, they don't have any means of getting healthcare insurance. The fact is that they have to wait two years from the time that they are determined to be disabled to the time that they can use Medicare. And for most people by that time they are not working they don't have an income and they are not able to purchase healthcare, which is incredibly, incredibly expensive, as most of you know. So, I know on a national level, the Multiple Sclerosis Society did some advocacy to eliminate the two-year waiting period for Medicare. And that's a real big price tag ticket to do that. And some states have filled the gap and have means of assisting people with healthcare during that waiting period. And I know we are in a financial crisis right now and it would be highly unlikely that we could get something like that passed this year. But that's a real, real big issue for us and for our consumers. The other one is just the general lack of services that are there for adults over 21 and under 65. I always felt that we do a pretty good job with the elderly. DEA is pretty good. There's a lot of services for people over 65 and services for kids, although that sounds like they are drying up. But there's really very, very little for adults with physical disabilities. It's incredible. And we all go searching for things and try to come up with mandates. Lastly, and I'm glad Representative Naughton is here and maybe she can speak to this. I've had several clients who again are in their 40s, who have experienced physical abuse from family members. And there was a law that was put on the books that would deal with that.

Medicare: 24 month delay

And again, the elderly services has a method of addressing abuse of the elderly. But when they fall through the cracks, they are not elderly. The question is, what agency is really designated to go out and investigate and assist these families? They are under a lot of stress because, you know, if you are caring for somebody 24/7, it causes a lot of stress. And there is potential for physical abuse. And nobody wants to report a family member because that's who's taking care of them. So, I'm still getting the call. And one of the consumers that I've been following up was abused by her teenage daughter. Now her children are being removed from the home. Which as a solution, I don't think it's a real good solution either. So, again, I would just really, really want to advocate for better services for people, for adults with physical disabilities to meet their needs from healthcare insurance down to just basic safety needs. Thank you. (APPLAUSE)

LORNA: Thank you, Gwen. Anybody else? A hand.

Health insurance:  
Affordability

AUDIENCE MEMBER: My name is Nell Poisson and I want to reiterate what Rose was talking about. My daughter is 33 years old, a single mom. And she's very productive in society today. We don't know what's going to happen later on. And giving you an idea of cost factors, how many of you go for an MRI every year? My daughter has a relapse. She has to go for an MRI. Her copay is \$130. Whenever she is on medications, although the MS Society try to help as much as they can, there are co-pays that are killer for the pocketbook. Someone else said it before, despite our economy and the state of Rhode Island is tough. But I think it's morally wrong for our government to go after the weakest links, those that can't speak for themselves, the young children, or the elderly, or those with chronic disease. My daughter wants to be a productive part of society as long as she can. Continuing to force these people to pay the co-pays to survive is just unfair, unfair completely. Thank you. (APPLAUSE) my name is Nell Poisson.

LORNA: Anyone else? Any hands? Ah --

AUDIENCE MEMBER: Hi, Laurie Archambault. I think this DD population needs their own ombudsmen. They have them for the children and they have them for the elderly and they have them for mental health. Where's ours? Thank you. (APPLAUSE)

AUDIENCE MEMBER: I am Ken Sundberg. I just wanted to add that you heard a lot of information from real people about real cases. And you know, taking care of people with handicaps is very time consuming and can be very stressful. And I can't imagine what the governor and OHHS are thinking of when they say that they have planned to put even the most severe cases and family relationships in the community. As I said before, there are some that could benefit from that. But in large part, that's not going to work and I can't imagine where they are coming from. Thank you. (APPLAUSE).

LORNA: Thank you, Ken. Anyone else?

AUDIENCE MEMBER: My name is Joyce Nelson. I am from West Warwick. My son is in a group home with CranstonArc. He has been for about 14 years. The thought of the state trying to move him out and into a family scares me to death. Jerry lived with me. I've taken care of him and his behaviors. He's retarded. He's physically handicapped. It is not a situation that I want to see happen to him or to many of the others that we service, because I also work for CranstonArc. I don't think these individuals are ready for that. And I don't think the population in the state of Rhode Island is ready for it. Look at our foster care system for children. And you are going to put our individuals there who can't speak for themselves? I don't believe it will work. I believe it will hurt them more than it's going to help. And I think the Governor and the Commission need to look at this. Thank you. (APPLAUSE)

Medicaid: Supported  
living arrangements

LORNA: Anyone else?

AUDIENCE MEMBER: My name is Rosetta Desrosiers. I am a resident of Warwick. I am a voter of ward 2. D-E-S-R-O-S-I-E-R-S, okay. And I don't have any problems myself. But I have been hearing lately that people who rely on transportation to go to doctors appointments are finding that the RId schedule is much too short for them. I have a friend who has an appointment. The audiology clinic in Providence. And she said it's 8 in the

Transportation: RId

morning and there's no way that she can go there. And I guess the bus is not available until 10: 00. That's it for me.

LORNA: Thank you. Anybody --

FEMALE SPEAKER: I don't know if the director of DHS is going to be upset at me for going to this, but I am really upset about hearing so much misinformation and real stress that a lot of you people have out there. I tend to be the only person that goes to this meeting that's every other week, Amie Forand building on the third floor in the Sullivan conference room, which is a very little conference room. But I would really recommend that you come to this meeting. There's going to be a meeting this Friday at 10: 30 and they have a meeting every other week at 10: 30. Frank Spinelli, the acting director of Medicaid is there. Gary Alexander, the director of DHS is there. And whenever new people come and they have questions, they are very forthright about the issues, about the answers. And they have been saying in their forums that they've had I guess there are three of them to invite people to come to this meeting because there really is I'm because I have been going to these meetings for all this time. I really do feel like I have better information than a lot of you guys have. And it's really making me very upset to hear you guys so upset for reasons that you shouldn't be because it's not what you it's not going to be what a lot of you think it's going to be. And they've had all of these people involved. Assessment it's just I think it would be really good to come and to hear exactly what it is. And again, they have been very forthright. They have information that they can share. It's too bad that it's not getting out somehow. I don't understand why. But there is this meeting that is open to anybody who wants to come every other week. And the people who are involved in this are doing it. So I would highly suggest that if you want to come, to come.

LORNA: Could I repeat where and when? What is it?

FEMALE SPEAKER: It's in the Amie Forand building.

FEMALE SPEAKER: 600 New London Avenue.

LORNA: The rusty bucket over in Cranston. What room?

FEMALE SPEAKER: Third floor, Sullivan conference room. 10: 30 to 12. It's every other Friday. This Friday happens to be where it's going to be.

LORNA: So this Friday, the rusty bucket, third floor, Sullivan conference room, for those who are writing it down. And maybe you would like to attend. As Elaina has said it's very small so don't think it's a room this size. And you may not all want to go. But maybe you could talk among yourselves and decide who would fit in the room and be a good place to get some correct information, as correct as it can be.

FEMALE SPEAKER: Right.

LORNA: I need to say that the whole global waiver, it's in draft form. I don't think anybody knows exactly what it states, even the powers to be don't know exactly.

FEMALE SPEAKER: But they have what they want it

LORNA: This is the time to be there to speak, just as you have today. Be able to present your own cases and try to assure that cuts won't happen to the programs that we are very much aware of and that affects your families.

FEMALE SPEAKER: Hold on.

LORNA: I see I don't see a hand

FEMALE SPEAKER: Heidi.

LORNA: I'm visually impaired.

HEIDI: Okay. I'm here on the panel representing the Rhode Island statewide independent living council. And I've heard a lot of testimony from a lot of powerful folks about independent living, wanting to be active, and wanting to be involved. The Rhode Island statewide independent living council is a volunteer organization, always seeking new participants to serve on the many committees. If anybody is interested in volunteering or wants further information as to who to contact, please see me at the end. I'm here until about quarter past four. But if interested, I will give the information.

LORNA: Thank you, Heidi. Anyone else? At this end two over here.

AUDIENCE MEMBER: I just want to ask the person on the panel that had spoken about MHRH and being able to go to the meeting there.

FEMALE SPEAKER: It's DHS, not MHRH. The Medicaid agency.

AUDIENCE MEMBER: Right. I don't know if you were present at many of the previous meetings that many of us have attended. One is at the Shrines.

FEMALE SPEAKER: This is the DD issue. I hadn't been to that.

AUDIENCE MEMBER: At that time we were asked for suggestions on what we thought needed to be done. And I believe at that time there were a much larger group than is in this room now. And I think that they presented their cases even better because the idea was given to us that the reason this is going to be changed, the system the way it is had nothing to do with money. It had to do with making things better. Now every single person in that room, every single person at that time spoke to the group about things couldn't be better. Things are wonderful the way they are working. There's not enough for a lot of people. But to change what's already working is absolutely insanity. And that was spoken over and over and over again. And to go to another place and start all over again telling everybody what you are doing is insane. It has to do with money. It has nothing to do with making things better. Things are as good as they can be with the amount of money that we presently have. And when we have less money, changing everything around. One thing that every one of us knows that deal with people with disabilities, stability is the most important thing in their life. The people that they see day in and day out, no matter how severely handicapped they are, that makes a difference in their life. And having this all I can picture is the bag people going to a different hotel every single night. And who's going to watch them there? That's what they did with the children. And this is just absolutely insane. And I just I hate to have to go to another place and speak about it again because the numbers of us are dwindling. We are tired of it. We've told it over and over again. And clearly and it's just not it's not sinking in.

FEMALE SPEAKER: If I can follow up with what the lady from MS

LORNA: One minute. We need to take the testimony.

AUDIENCE MEMBER: Thank you. My name is Dawn Martin. I am the director for the community provider network of Rhode Island, and I just wanted to say a couple of things. First off in support of all of the parents that are, you know, really taking the time out of their day to come here and to be heard about their concerns. From their perspective, their concerns are extremely valid. And I think part of the issue is that we have been working and working with information from at least two different departments over a period of about nine months. Most of us have seen the draft waiver documents. The material that's in there certainly causes concern. Families are certainly concerned about the restructuring of the levels of care, of how the funding will be metered out. And there has not been a forum for these questions and concerns to really be directed in the context of the global waiver. Last year under a different administration, we went through a very elaborate process with MHRH around reshaping services. It's what Mrs. Myette was just referring to and now that initiative has essentially ended. And the conversation now is really sort of housed and centered within DHS in the development of the waiver. We have asked repeatedly for opportunities to participate in these work groups that are developing the content of the waiver. We have not been have not received information on where those meetings are happening, are being held. Elaina, I thank you for that feedback. I'm sure there will be people at this so-called stakeholders meeting because there is tremendous concern. We have on numerous occasions testified before the house finance committee, the senate finance committee. The people of Rhode Island really need to be heard about this the development and the process around this global waiver as its moving forward.

LORNA: Thank you. Your name --

AUDIENCE MEMBER: Donna Martin. I am a residents of Cranston.

LORNA: Thank you. Anyone else testifying? Are we doing good? Anybody else? I thought I saw Ken?

AUDIENCE MEMBER: I just want to address the concern that this woman at the end of the panel has

about misinformation. Have you read the global waiver proposal that was submitted, I believe, on March 28?

FEMALE SPEAKER: I've not only read the global waiver proposal, but I have been involved in meetings that I've gotten specifics the proposal was pretty sketchy in my opinion. And there was a lot of unanswered questions. And so that's what these meetings have been we have been meeting to get more detail about what was meant by certain things in that March there's many documents that have come subsequent to that. And there's been more clarity. And again, I have been involved in I still don't I honestly am not thrilled about the process either. But at least I do know that every two weeks we go. And when we hear some rumors going on, we have them at the table. And they answer the questions. At least --

AUDIENCE MEMBER: I'm not referring to rumors. If you read page 33 and 34 of that document, and it defines what an SLA is. And on page 34, it defines who is eligible for it. And any subsequent information that I've seen come out since then basically says the same thing. And it says that they plan to find private families and communities to under contract to place people with. And regardless of the severity of the developmental disability, behavioral disorders, medical issues, et cetera. It's right there --

FEMALE SPEAKER: I would be happy to respond to that issue. There was this work group I was not part of it. But there was a work group with consumers and nurses that have developed this assessment. The issue I think that you are addressing, if somebody from what I understand, and again, it's better to come to this meeting on Friday. From what I understand, if somebody needs 24/7 hour care and they need a group home setting, they will have a group home setting. What I've been working on for most of my career here is working for people with physical disabilities, senior citizens, who basically do not have the kinds of services that the DD population in this state has. And that for the people with physical disabilities, for people with senior citizens who do not have the kind of services, this global waiver and what they've been asking for is they don't want go into nursing homes. They want to have independence. They want to be able to stay in their own homes. I have been working very heavily on home modifications and changing that in the Medicaid program and elsewhere. So we have been working to do that. So for a segment of the people in Rhode Island who do not have the strong amount of services that the DD population currently has, believe it or not this is a move forward. I hear that for the DD population --

AUDIENCE MEMBER: I want to say I agree with some of what you are saying. And I said in my testimony earlier that it's good and beneficial for some people.

FEMALE SPEAKER: Right.

AUDIENCE MEMBER: But you know I would like to see it in black and white. And it's not in black and white right now.

FEMALE SPEAKER: That's what please come to this meeting on Friday. Please come. They have other documents. You can get other documents. There has been a lot of movement forward that have been developed by people ombudsman at Roberta Hawkins group is the one who elderly she doesn't work for elderly affairs.

AUDIENCE MEMBER: Long-term care.

FEMALE SPEAKER: She was very involved with this assessment process on who is going to get what. The whole point of this was that people who want to be able to live independently in their own homes with appropriate home modifications and things like that should be able to be able to do that.

AUDIENCE MEMBER: I agree with you, but put it in black and white. The way they've stated it, it's good for everybody.

FEMALE SPEAKER: I hear you --

AUDIENCE MEMBER: I have been told by the people at MHRH and I agree. They told me it's not going to happen to these people. But it doesn't say it in the waiver and I think it should say it in the waiver.

FEMALE SPEAKER: Their waiver right now it's gotten so much more detail. But it's not done yet so they don't have it out. They have to get I don't know the finance committee has to get a copy of the actual waiver that's going to go to CMS. And I believe when the finance committee gets that waiver, it becomes a public

document. And I'm telling you. It's much huger than that other document. They have been working on all of this. I haven't seen it either. So, but there is a lot more flesh on it.

AUDIENCE MEMBER: I will pass the mike to Donna.

AUDIENCE MEMBER: I just want to comment that it's great that the proposals that are being developed are meeting the needs of the elders and people with physical disabilities. But DHS, representatives and the members of the panel need to understand that there has not been stakeholder involvement from the DD community.

FEMALE SPEAKER: I hear that.

AUDIENCE MEMBER: That's it.

AUDIENCE MEMBER: I just have one question. When it comes to this

LORNA: You need to say your name

AUDIENCE MEMBER: Joyce Nelson. When it comes to this possibly moving our individuals into homes (LAUGHTER) I don't need the mike anyway when it comes to this, are we as guardians and parents going to have any right to say, no, we don't want that.

FEMALE SPEAKER: Yeah. But come on Friday. Please come on Friday I'm telling you. I don't want to be the only one

AUDIENCE MEMBER: Elaina, I really have to cut you off. I really need to say the panelists are not supposed to engage in active conversation with the members. They are supposed to ask clarifying questions. And I really think if you guys want to have a conversation about the global waiver after, I would suggest you do that because quite frankly, it's your perception of what you are doing and

FEMALE SPEAKER: I'm a stakeholder in this whole thing.

AUDIENCE MEMBER: You are a panelist member. And I quite honestly don't see it as your role to engage. And I know it's not your role to engage in an active conversation. So I would ask for other people who might want to talk about something else if they could have the opportunity. And if you want to chat one-on-one afterwards, that might be a better way of using the remaining time.

LORNA: What I would like to do at this point, we have about 15 minutes 20 minutes. I would like to go back to our original testimony about other issues. If anyone has something right now they'd like to discuss, other than the global waiver. We could actually end in five minutes and then those who are interested in leaving could. Those who wish to stay could and you can have your discussion. But we need to continue the hearing right now as far as any other issues that need to be discussed. Is there anyone else that wishes to talk about anything?

AUDIENCE MEMBER: This is Anna Liebenow again. I read something in the MS Society last night, the

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Rhode Island MS society, that it was from one of these forums, one of these hearings a year ago, two years ago that the legislation that companies excised fully needed to have wheelchair accessible lifts; that that legislation sort of came out of one of these hearings. And I haven't heard of any wheelchair or any tag (inaudible) that have wheelchair lifts.

GWEN: Yes. My understanding is that it passed. And there was some guidelines for the carriers that if they had a fleet of a certain number that when they needed to replace a vehicle, it would be replaced with an accessible cab, a wheelchair accessible cab. Now what which leads that is and if that's happened, I'm not privy. And you know which PU what is that public utilities. But do you know do you know which carrier has an accessible one now?

AUDIENCE MEMBER: I will check on that. I don't know the exact carrier. But I know the PUC is in charge of that.

GWEN: Thank you. And it did come out it actually came out of written testimony of somebody who came to Rhode Island, landed in TF Green.

FEMALE SPEAKER: I can tell you who that was. That was Katie Beckett herself.

GWEN: Some of the adult people don't know who Katie Beckett is though. Adult disabled people don't know.

AUDIENCE MEMBER: She was responsible for the first is this on? Katie Beckett was responsible for the first Medicaid waiver in the United States. President Reagan was compelled by her lifestyle living in a hospital away from her family and decided it didn't make sense nor was it economically the right choice either. So he provided exceptions for that. Representative Waxman provided changes in federal law that provided the same options for all the children in the United States. So, Rhode Island has a Katie Beckett program. We've worked very hard with many of the people in this room to make the application and I think maybe that's why 12 years later when you applied, hopefully it was a little better to be able to get services from the state. We continuously monitor. The legislature does not do the work. We create the statutes. We do oversight. And I depend on your remarks here. For instance, when mentioned about abuse. We did pass legislation that address this. The department of elderly affairs has legal jurisdiction in this area. As to why they have not acted, that is a question they need to be responsible for that answer. Many of the testimony I've heard here today, I believe Rhode Island has coverage for some gap conditions. We have the Sherlock plan. It's going to be something I will take up certainly this Friday at 10: 30 as to why I have been hearing cases where ramps haven't been installed, where people haven't had access to Medicaid, and why we aren't helping people live more independent. So I really appreciate you all coming here today. And I certainly have been taking copious notes about what I've heard and hope we can get some remedies. But primarily, what I'm hearing is that there isn't trust with the system we have today. So that makes everyone very anxious about any changes. (APPLAUSE)

LORNA: Thank you, Eileen Naughton.

AUDIENCE MEMBER: I'm Arthur Plitt from the governor's commission on disabilities. Partly as a result of the testimony in the last couple of years, people have had an elderly, disabled individual who they needed to have as part of their home, but yet have a certain amount of independent living. That legislation has been passed this year. So you don't have to go through the big variance process. And you know, before the person, let's say, has spent thousands of dollars, you can make accommodations for their housing.

LORNA: Other testimony? Other testimony? Wave a hand.

AUDIENCE MEMBER: I just have a question. Jolene Thomas. I live in Providence. The question I have is home care providers. I don't know (inaudible) she lives with me. And basically you know, she does everything that someone that from the outside would come in and do. Yes, I can do most not most some of the stuff. But as far as cooking or if I fall, she puts me back up. You know, she helps me with getting dressed sometimes. I is she qualified to get to fall under a home care provider? That's what we are trying to find out.

LORNA: I think there's some agencies here that could probably help you get in touch with the right agency.

MALE SPEAKER: I can talk to that.

LORNA: Can you address that? I will bring you the mike, Tim.

TIM: Sure. I certainly know you can contact PARI. And they have a personal choice home care waiver, which means that you can hire the people that you like to hire to provide the care for you, as long as it's not your spouse. So

AUDIENCE MEMBER: But will she as my daughter, would she if I didn't want to hire someone to do that, could she be the home care provider?

TIM: I believe so, yes. I think you can.

AUDIENCE MEMBER: Okay. PARI is in Pawtucket?

LORNA: 275-1966.

AUDIENCE MEMBER: Anyone particular to speak with?

TIM: Probably Heather Sprague.

FEMALE SPEAKER: Jolene, are you currently on a waiver program for DHS? You would want to call your local office and ask about the waiver program. Personal choice is a waiver program. I can look it up. What city do you live in?

AUDIENCE MEMBER: Providence.

AUDIENCE MEMBER: You have to be Medicaid eligible though.

LORNA: Can you two talk after? Jolene talk to Michelle before you leave today to get numbers. Anyone else? Anyone else? Does anyone else wish to do a ditto with something that's already been said? Ditto? Panelists? I think we are are we complete, 15 minutes to go. Wait a minute.

AUDIENCE MEMBER: I would just like to do the ditto with the --

LORNA: Okay.

AUDIENCE MEMBER: the facilities that are not available to handicapped people, the sidewalks.

LORNA: Okay. Facilities that are not handicapped accessible. And your name is --

AUDIENCE MEMBER: Brenda Myette. The doors that slide open, everything that she said.

Accessibility: Automatic doors

LORNA: That's good. Accessible public places, which should be under ADA. Anything else? A hand on the other side of the room? Where's the hand?

AUDIENCE MEMBER: Hi, Laurie Archambault again. I would like to say Mr. Sundberg is very correct with how tired us parents get taking care of our loved ones at home. I think caring for Jared for three years and I need to do every single thing for him. I'm exhausted. But I just learned I need to go for a little medical, a little surgical thing. And I don't have any help for Jared. I called the department to ask for specialized respite care.

They don't have a clue what I'm talking about. So I'm not sure what's going to happen from here. Maybe the governor wants to baby sit. Thank you. (LAUGHTER) (APPLAUSE)

LORNA: Respite services in Rhode Island. Anyone else know of service? Specialized respite services. Specialized respite services?

FEMALE SPEAKER: I can try to get back that's not my area.

LORNA: Laurie, talk to Michelle. You talk later

FEMALE SPEAKER: Hi. I am Jenny Goodrich. I am the central project coordinator in the Sherlock center in disabilities. What that means is I am the chairperson of our consumer advisory committee. And I just wanted to let you all know that what you expressed in this room is what I hear every day from the families that I'm advising and working with. So, you are not alone, first. And if at the end of the meeting you'd like some more information on how to become more involved in the conversations we are having at the Sherlock center about sort of what works and what doesn't work and how we'd like to see things how we'd like to see things change or not. If you'd like to sort of have another place to sort of have your voice heard, you can see me after the meeting and I can give you some information on that.

LORNA: Thank you, Jen. Anything else? Another commercial break. Jenny has also been involved in youth leadership forum. This is young people with disabilities who let's see, juniors and seniors and they get together. They have to demonstrate leadership ability and there's a wonderful program. I think it's pretty full for this summer. But you may want to ask about that too, if you get a chance to talk to her or Sue Shapiro, who is at the back of the room. Couldn't resist. I have to tell them about a great program. Anyone else? Anyone else? Do you feel comfortable ending it now? Or is there anybody out there that may be coming in late? Ten minutes to go. Everyone who's wanted to testify has testified. I will then end the program, since there's been so much interest and other discussion. I'm a full believer in taking these opportunities when you are all in the same room to connect. Again, there's people up here who know great stuff. Disability law center is present. Paul Sherlock center. MS Society. Office of rehab services for those who are looking for work. Michelle Acoto has been very generous in offering her time, if you would like to talk to her about DHS services. Please take advantage of the wonderful knowledge we have in the room and I'd like to end the forum now. Thank you so much for coming. One minute one more?

HEIDI: I just want to reiterate if anybody is interested in volunteering for helping legislative issues and leadership type of things, talk to me about the statewide independent living council. I would be more than happy to give information.

LORNA: Thank you very much for coming. Hope to see you next year or at the state house. Wonderful testimony. Keep in mind there's always chances you can testify at the state house.

#### **4. Thursday, July 24, 2008 Cumberland Public Forum**

LEO CANUEL: We're going to get started in about three minutes. I just want to remind people, make sure they sign in, even if you don't plan on speaking today, if you just plan to listen, we'd like your name so we can count how many people were here. And we'll just get settled and started. All right we're going to get started. My name is Leo Canuel, I am the executive director of PARI independent living center and the host for this forum today. I welcome you and thank you all for coming. And beating the rain, hopefully we won't have a storm like we did yesterday. But, we will go forward anyway. We will be here for an hour and a half so we have plenty of time to take your testimony. My role here today is to host and moderator to sort of control the flow of the conversation and have the panel hear your concerns and bring them back to the governor's Commission on Disabilities so they can take those issues, put them together with the issues from other forums and develop a strategy as to how to work with those issues. Couple of housekeeping things. First of all, I need to make sure that everyone has signed in. We have a sign-in sheet on this table over here, there is a sign-in sheet at the back table. Also, please take the handouts. Even if you're not testifying I'd like to you sign in just so we know how many folks are coming and your affiliation would be great. We also have assistive listening devices I don't think they're here yet because I thought Bill Inlow was bringing them, anybody need an assistive listening device this morning? No? Okay. We have a CART reporter for recording this forum as well as a sign language interpreter because we only have one sign language interpreter today, is there anyone using the sign language interpreter this morning? I'm going to ask the sign language interpreter to rest her arms. The easiest one she's had in a long time I'm sure. Again, some housekeeping items, if you need to use the bathroom go out the front door to your left, two bathrooms out there, they are both male and female so just pick which ever one you choose. Check out, see which one is cleanest and use that one. What I will do is have the panelists each introduce themselves and tell their affiliation. We also have a couple panelists that are too chicken to sit up heaver and are in the audience, we'll ask you to introduce yourselves as well and we'll then start with the forum. Starting to my left.

FEMALE SPEAKER: I'm Joan Wood from Neighborhood Health Plan of Rhode Island.

CLAIRE ROSENBAUM: Claire Rosenbaum, Sherlock Center on Disabilities.

TIM FLYNN: Tim Flynn representing the Governor's Commission on Disabilities and I chair the legislative committee. I want to you know what you say here is important because what we here in these forums enables us to formulate a legislative package for the next legislative session in order that we can, you know, take your concerns into mind and bring them to the attention of the legislature and the Governor.

KATE SHERLOCK: Kate Sherlock from the Disability Law Center. I passed out a little packet to most of you and to those of you who didn't get it, it's over there, we're also here to represent the Rhode Island Disability Vote Project and we're available to help anybody register to vote who need that is assistance today. There's a form in the packet. If you don't need our assistance, you can do it yourself.

TOM MARTIN: Tom Martin from the division of behavioral health from MHRH.

LEO CANUEL: And those panelists out in the field.

LINDA DESCHENES: Linda Deschenes from the Office of Rehabilitation Services.

ARTHUR PLITT: Arthur Plitt, Governor's Commission on Disabilities.

ELIZABETH CONNALLON: Elizabeth Connallon from the Rhode Island Brain Injury Association.

LEO CANUEL: Did I miss anyone?

FEMALE SPEAKER: I was on one yesterday.

LEO CANUEL: She's not one of us today. Okay. Just to state how I intend to run these forums. I hadee like them to be as comfortable as possible. You may come up to the table and give your testimony or you may sit right at your seat and give your testimony, as long as we and the CART reporter can hear you. I will explain that what the CART reporter is doing is taking down word for word as a court stenographer would do and

documenting everything that is being said here today and these documents will become part of the testimony and entered into as testimony and kept on file. So, the commissioners can go back and actually read word for word what was said. And then they pull from that information and put a report together so actually I as a host of this event get a copy of everything the reporter put together and sort of a synopsis of everything and it gets distributed to the legislators, the entire thing. So when giving testimony I ask that you give your name, the town that you live in, and your affiliation if you have one, and then go forward. I ask that we only speak one at a time. The panelist's role to listen however panelists are allowed to, if you have any feedback, feel free at the end of testimony, to provide feedback but our role here to listen. Okay? On one of the sign-in sheets, the first person up to give testimony is Gwen.

GWENN REEVE: That came very fast. My name is Gwen Reeve, I live in Bristol Rhode Island but I'm here representing the National Multiple Sclerosis Society, Rhode Island chapter, and I serve the legislative advocacy group that takes these testimonies into consideration and forwards them to the legislators for hopefully some action. What I want to talk about is something I learned last night. A couple years ago we worked very hard on getting an accessible taxicab, wheelchair accessible taxicab here in Rhode Island. It was brought to our attention that there were no wheelchair accessible taxis in the state of Rhode Island which I think is deplorable. We have people coming into our state that require taxicabs to get to their destinations and people with multiple sclerosis that need to go to weddings, church, a variety of things that public transportation does not address. So we worked very hard to get a law passed, developed and passed that would mandate accessible taxicabs to taxicab carriers that have a certain number of, in these fleet. And I just was informed yesterday that at the very last moment, the word mandate or requirement was removed from the legislative bill that passed and the word volunteer, it became a voluntary request that these large taxi fleets put in a wheelchair accessible van and I think we should go forward this year and amend that law back to the original wording which required taxicab companies with large fleets to actual will I have accessible vans. They don't have to have a lot but they need to have some. Because I think that I said, there are many peep 8 coming into the state and many people within the state that need transportation at times when, and for times and situations where RIPTA or the RIdE program would not be able to address. So that's my pitch for the day.

LEO CANUEL: Comments or issues from the panelists? Just happen to see Bill Inlow, is he still here? Bill, this is Bill Inlow from RIPTA, I'm wondering RIPTA's perspective on this law and any position RIPTA took regarding this.

MALE SPEAKER: Rhode Island public transit authority is definitely in support of the legislation that was just talked about. Taxicabs are controlled by the public utilities commissions because taxi service is a public utility, owned by the public. Cab companies are private businesses, can do what they want, make a profit and continue as a business but they have to purchase the right from the public utility, they have the right to provide taxicab services at various places like the airport or downtown Providence. As a result of being covered by the public utilities commission, we as the public have a right to tell some of the businesses some of the things they have to do to earn that right to provide the public a service. I'll give you an example, in the city of Louisville, about the same population as Rhode Island, there are 7 wheelchair accessible taxicabs, 7. The reason being the chief executive officer, the mayor, helped pass legislation that mandated each taxicab company have at least one wheelchair accessible taxicab, and it happened. So in my judgment, it's just a failure of leadership on the part of our chief secretary stiff, the Governor, and our General Assembly to not mandate the taxicab, require that each of them as part of their privilege they get to make money from serving the public, that they have at least one wheelchair accessible taxicab. I spoke to three of the owners of those cab companies in Louisville and each said we wish we had done this before the city required it because we found a market pitch, we're actually making money selling taxicab services to people who use wheelchairs so sometimes good business can also be good service to people with disabilities even though we conveyed that to Bob Cooper, the executive director, and I and Arthur over here, we all conveyed that, went to the General Assembly, they chose not to honor that information I guess and change it had to voluntary and as a result there are none. And the suggestion is a good one and I suggest you sell your representatives, house member or senate and the Governor as you have an

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opportunity to convey that information to change that law to make it mandatory so people who use wheelchair also have an equal right like everybody else to take their money and buy a taxicab service from the airport or any where else in the state of Rhode Island. Long answer, I apologize for taking so long.

ARTHUR PLITT: I just wanted to check with the commission, but it is mandatory as the larger taxi companies replace their fleets, it is not a voluntary thing except for the small mom and pop taxi companies.

LEO CANUEL: Point of clarification, only when they replace their fleets.

ARTHUR PLITT: Correct.

GWENN REEVE: Point of clarification. So, Arthur, this is Gwen again, you're saying when the law was passed about two years ago and went into effect in January, there have been no large taxicab services that have replaced any of their.

MALE SPEAKER: I assume so because you're saying there are no accessible taxicabs currently, correct?

MALE SPEAKER: There are none.

ARTHUR PLITT: I don't know who the largest unit, I believe it was 30 or 40 units in the taxi fleet that they had to have accessible taxis but maybe we need to follow up.

LEO CANUEL: A question in the back.

LINDA McMULLEN: Linda McMullen(phonetic), parent consultant Rhode Island Parent Information Network, and I have had guests come to a conversation who needed to have a taxi pick them up, bring them around. I had to call a few limousine companies, I could not find anyone I did get a shuttle from the airport because that's what was available a van shuttle. I even called the School Department to get one of the smaller buses. The prices were outrageous. It was a lot of money and I didn't have a choice so I just wanted to say as someone helping families and even out of town, people coming in, it's extremely expensive. A limousine is hundreds of dollars so I am all for, definitely supporting the taxicab, at least one or two.

GWENN REEVE: Gwen Reeve again, if what Arthur suggests is true which means it's mandated when they need to replace their vehicle, I would again amend it to not until they replace the vehicle, that they do it now.

LEO CANUEL: Any other comments or concerns regarding this particular issue? We have no one else who checked off that they wish to speak but we definitely have about an hour and 5 minutes left to go here so we can all stair at each other or we can open it up to the floor and see if there are if anyone else in the room has any issues that they would like to bring forward at this time.

FEMALE SPEAKER: I'm kind of new to these forums so I really don't know what I'm able to discuss but I have some real issues with the Governor's Medicaid reform.

LEO CANUEL: Can we have --

MARY MARTINO: Mary Martino, Lincoln. I have a daughter who lives in one of the group homes in Cranston. And it's my understanding that the governor is looking to take some of these children with disabilities or adults with disabilities and place them into foster care. Then I heard, well, it's probably not going to happen to those who are already in group homes but to those individuals who have, who are not in group homes and who do not have, whose parents are, you know, elderly and so are they. They're going to have nowhere to go. I just thought I would throw that in.

Medicaid: Supported living arrangements

LEO CANUEL: Can you just express your concerns. Why do you feel opposed to that.

MARY MARTINO: I'm opposed to it because, well, I can look at it from my daughter's point of view. She's been in a group home now since she was 8, she's 32 now. And she has just, you know, the people that work with her, they're like her family and to rip these people up from wherever it may be, you know, a parent's home, or, is, would be traumatic for these kids if they have nowhere to go.

LEO CANUEL: Okay.

MARY MARTINO: And, you know, if they ever tried to remove my daughter from the group home she lives in, I would throw myself across the door. I just wouldn't let it happen.

LEO CANUEL: comment from the panel.

TIM FLYNN: Question. What are your fears about what is good about the group home and what is.

MARY MARTINO: My fears about foster homes are that, you know, there are good people out there that really care for individuals and then there are those that, I believe, are in it for a profit.

TIM FLYNN: The group homes you're talking about.

MARY MARTINO: No, I'm talking about foster care. I am all for group homes. Our system really doesn't have the capability to keep up with the case load that they have now. How are they going to, you know.

TIM FLYNN: If I could just ask you further, what are the services that your daughter receives in the group home setting that are vital to her lifestyle?

MARY MARTINO: Well, she's non-verbal, she's developmentally disabled, she is, needs watching 24 hours a day, can't be alone, she's autistic, like, she's fully mobile, she can get around but she has to be cared for 24/7.

TIM FLYNN: Cared for, meaning supervised?

MARY MARTINO: Yes.

TIM FLYNN: Given medication.

MARY MARTINO: Yes.

TIM FLYNN: And the like, outings, that --

MARY MARTINO: Yes.

TIM FLYNN: Thank you.

LEO CANUEL: We had a hand in the back. I'm sorry, the gentleman --

GEORGE NAZARETH: My name is George Nazareth from The Homestead Group, I'm totally opposed to

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any foster care type my daughter is went into a group home at eight and now she's 44. And the foster system here in the state is fraught with a lot of abuse. And to put a handicapped person into a situation like that, and there would be more money attached to this than there would be to a regular foster child or

foster person, it would be fraught with abuse, that's for sure and we don't need that as parents. So, we have created in Rhode Island a wonderful system that works fabulously well, maybe it's somewhat costly but I would rather pay more taxes than to destroy something we're doing very well and let it go down the drain.

LINDA McMULLEN: Hi again, Linda McMullen, I'm also here as a parent, I have a child with Aspergers, a form of autism, receives direct services from a cedar center and I have a paths worker that helps me as a single mom be able to work. My child can function in school, homework, helps with her daily social skills. And I'm very concerned because I work full-time, I pay taxes like everyone else, and I have a home that I care for, and

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another child with special needs and I'm very concerned with this global waiver and this Medicaid because I'm afraid I'm going to lose those services that I have as a paths worker even though they're not as involved as in residential care but without it, my child could end up in a Bradley Hospital or Butler Hospital so

I'm saving money by having a paths worker be part of my family right now and without her I would be struggling and would probably have to work part-time which I don't want to do, I enjoy the work that I do, so I'm very concerned that because my child is not highly involved that I will be one of the cuts that happens, or the changes. And I agree with what this man said, it's working. Don't ruin it, it's working. Look at the stuff that's working and let's come up with other solutions. I'm all for trying to come up with solutions, invite the public to come up with money saving solutions but not to forget that it is keeping some of us afloat and it will cost more money in the long run.

MARY MARTINO: I just want to say that I've been where you've been and it was very difficult, I was a single parent and if I didn't have the help of these people, I wouldn't be able to survive either. My other concern about foster homes is, my daughter has come full circle but when she was, it took her about 30 years to get there. She was behaviorally involved and I can't see a foster parent taking on a child like that and saying, oh

yeah, we can do it, and then all of a sudden, I didn't know it was going to be this difficult. I didn't know it was going to be this difficult. So what do we do then, what do we do with these kids then? Create another Ladd school?

TIM FLYNN: Excuse me, so what you're saying is that in taking people out of the positive environment they're in and putting them into a different environment would cause difficulties, would cause regression or something.

MARY MARTINO: Regression and the person that agrees to take care of this child finds it far more difficult than what he or she thought in the very beginning. So then you've got no group homes, you know, and you have to create some place for these people to go. And we're going to go right back to where we were, you know, 40/50 years ago.

FEMALE SPEAKER: Just a comment on that, too, I mean group homes are good in a better sense because there's socialization happening. There's lots of other people living there and lots of other families that come to visit and isn't the goal for them to become more socialized and be involved in everyday community life as much as possible and I was a foster parent before I became an adoptive parent and it is a very different atmosphere than a group home. A group home has activities and bring people in and there are other family that is visit that become extended families. I'm not at that place, I hope I don't have to be at that place but someday I may be with my daughter so I think it's very important to stress and you need to look at the person's disability. You know, this is not just a number. These are people who have certain needs and I think individual needs need to be heard before big decisions are made. Because it is going to come around where this person may be hospitalized, how much do you think it will be behaviorally to hospitalize this lady's child than it is for her to be in a stable environment that's he is in right now function? In a lot more money in the long run.

MARY MARTINO: Not only that, these are, these people have choices, you know. And if what they want to live in a group home, they should be able to do that. It helps them to become independent. I mean I serve on a human rights committee and I know that, you know, we carefully look at every situation, you know, and provide support for them. It wouldn't be that way if they were in foster homes. I mean the case load for social workers in the state of Rhode Island are like 50 people each. How can you service these people? You can't.

LEO CANUEL: There were two things mentioned that I wanted to clarify. If I have it correct because we're talking about foster homes and then the global waiver through Medicaid was mentioned. And one as I see it really doesn't have anything to do it with the other T they are two different proposals on the table that the legislature and the Governor are looking at. The foster care system is one option because the Governor is trying to save money for the cost of group homes. The other one is the global waiver which is a Medicaid program which would impact everyone on Medicaid from children through adults through seniors, and it basically takes away all the current Medicaid programs that we have now and wraps them all up into one waiver. And it's just the way that the federal government disseminates moneys to the states for how to provide Medicaid dollars. So, other than providing health benefits to folks that are in either group homes or foster homes, the global waiver wouldn't have an impact on the foster care setting as I see it.

FEMALE SPEAKER: I think it has a huge impact.

CLAIRE ROSENBAUM: I think the residential cost of the group home is paid through Medicaid so the global waiver would have to my name is Claire Rosenbaum, work at the Sherlock Center, so I'm trying to clarify this issue here. The issue of residential support, also seniors, is Medicaid and it would be impacted by the waiver. So the savings that the legislature and the Governor hope to achieve, one of the mechanisms that's being discussed is moving folks with high residential costs to a less expensive residential model such as shared living or, some foster care. So the proposal is for the Medicaid global waiver will impact residential service for folks with disabilities and seniors.

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MARY MARTINO: What the global waiver does to is it caps Medicaid costs. If somebody gives you, you know, 50 million dollars for five years and you run out of money, what do you do then?

FEMALE SPEAKER: Just to piggy back what Claire said, it does impact because my child is not a high cost right now, she is on the lower spectrum so if they do look at the cost and her daughter has much more high intensity needs than my daughter does, I will possibly lose my paths worker and I'm not saying you should get it more so than I should but they will look at the more high functioning the more needy families and so it does, it all wraps around and it's connected and like you said, Claire, it is paid all by Medicaid and if it's in one giant pool of money, then I'm also concerned with the decision making of that pool of money. Who will be the decision maker to decide what programs to cut, which programs not to cut? And unless they hear from everyone, I don't think they can make a real good decision so I'm very concerned about how much money they're going to spend, who is going to spend it and say, oh yeah, let's get a new program in here and it will impact lots of people.

BILL INLOW: Bill Inlow again, not speaking as a representative of RIPTA but as a citizen and taxpayer of this state and a person who is willing to pay more taxes to provide services to people. My understanding of the global waiver is that, it's an important issue that this person spoke to and that is it caps the amount of money under the waiver the Medicaid program. Medicaid for your information was passed originally in 1968, for 40 years, each of us as citizens of this country and citizens of this state have had what's called an entitlement, a right as a citizen for health care services if we meet the legitimate healthcare needs and our income is at a certain level, we have a right under the Medicaid program, federal law, for health services. It's an entitlement. Citizen's right. The state of Rhode Island is proposing to give away that right in a contract, a deal with the federal government. The major motivation of which to save money. I would remind the Governor and the General Assembly that they exist as our representatives to provide services to the citizens and not just save money. And I spoke with Frank Spinelli, the Medicaid director, a good and decent man, works for the Governor, he's under clear mandate to make changes to the Medicaid program that will save money. And my judgment, Don Carcieri's major motivation as our governor to balance the budget without increasing taxes. And that's an important thing. See, they start off with the assumption that we will not increase taxes on the citizens of Rhode Island and as a consequence, we have to in order to balance the budget, we have to cut costs. But the primary purpose of the Medicaid to provide services to legitimately needy people. Certainly we have to face fiscal reality that somebody has to pay for those services but you're right, part of that this global waiver is very relevant to each and everyone of us in the state of Rhode Island, not just taxpayers but people who might need and know people who might need health care services.

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MARY MARTINO: I don't know if anybody has had the opportunity to read it, but it's very, very vague, very vague. It I mean, the way it's written, anyone can interpret it anyway they want.

LEO CANUEL: The problem with the global waiver is, the state now has an obligation to write a plan that is going to be submitted to the federal government for approval. Other states have done a form of the global waiver in smaller ways, effecting just a variety of programs. Rhode Island so far is the only state looking at using the global waiver for the entire Medicaid program.

FEMALE SPEAKER: You're talking about Vermont which is much smaller.

LEO CANUEL: Vermont, much smaller and New Jersey New Jersey, I think.

FEMALE SPEAKER: Florida did a little bit too.

LEO CANUEL: other states did pieces of it but not the entire Medicaid program. And the way the global waiver works and I'll just state this for the record but the state has to develop a plan and it's a five-year plan, they have to decide how much money they're going to get from the federal government over the next five years and that's all they get. So if the costs go up, guess what? The other thing is, unlike the current program the current waivers that we have do have limited caps on some of the waivers, meaning that only so many amounts of waivers can be given. In the past whenever Rhode Island has approached those caps, all Rhode Island has done is contacted the federal government and request an increase in those caps and the federal government has always granted those increases because, basically, the state is saying, this is why we need to do it. This would be the only time with this particular waiver that Rhode Island would not be able to request an increase for five years. So they would have to wait five years and then request the increase which means that the way I

understand it, folks that are on programs now will continue on programs, but anybody new coming aboard may not be eligible for services, may have to wait for five years or whatever the time period would be before they could get services no matter what the condition is. So, what, as I see it, it would mean that that person would have to go and stay at a hospital level of care until they would be eligible for services. So, they would have to stay at a hospital because by law going to certain hospitals, you would have the hospital has to provide them with services no matter what. And I don't understand why the hospitals are not screaming about this. Because that's what it means. If you're not on the waiver, there's no more spots, someone gets into a terrible accident and becomes a quad, they're staying in a hospital until something is available because that's the only place they'll get services.

FEMALE SPEAKER: Then you get the insurance companies.

MALE SPEAKER: If I can interject, I'm not certain that's the case. I think eligibility for Medicaid programs remains as it is now. We're talking just in terms of service delivery, what services will be available to any given individual. I think the debate we're having here underscores really what's going on in the state. This whole implementation of article 7 of the budget which encompasses this waiver has been very vague. You know, the Medicaid in the state of Rhode Island is asking, you know, the process has been so far is they've come up with a proposal merely a proposal that they are going to submit to Washington. They came up with it, it's supposed to be submitted at the end of July which is where we are now. Medicaid in Washington will then look at this waiver and approve it or not approve it. Then the legislature in the fall when they reconvene will have hours, not reply, I think the finance committee will have hearings and so that will be an opportunity for all of us and all of you to go in and listen and hear and perhaps testify on the impact this bill will have. I think it's very important that you pay attention to that. Also, I've been to every public forum that we've had, four so far, and this is clearly the number one issue that everybody is talking about. So I really would urge you, really, to talk to your legislators, pick up the phone, call them, let them know how you feel. It's not necessarily a done deal yet because it does need legislative approval. So I would I wanted to offer that for your consideration.

FEMALE SPEAKER: I would just like to say that I have been to the hearings and have testified and they ask some very important questions. I was surprised that the legislative people there will did ask important questions. So I think they do have some concerns themselves. So if you do have that chance, please keep an eye out for article 7 and testify or even send in a letter in regards to that. It is important. We have made many changes by bringing people to testify bring your daughter or your son for the day to that testifying so they can see what exactly it is you're talking about.

MARY MARTINO: I too have testified years ago. I've written, I've called. In fact I've called the Governor's office to try and get an appointment to see him.

LEO CANUEL: He still does the last Thursday of every month or something like that.

MALE SPEAKER: Friday I think no I'm talking about something different.

LEO CANUEL: I think the last Thursday of every month or whatever, he still has those office hours.

FEMALE SPEAKER: You have to be cleared by the State Police and wait about six months.

ARTHUR PLITT: Also wanted to mention Gary Alexander, stakeholder meetings tomorrow at 0: 30, Sullivan conference room so if anybody would like to show up the rusty bucket, yeah.

MALE SPEAKER: Do we all know where that is, in Cranston.

FEMALE SPEAKER: What time?

MALE SPEAKER: 0: 30.

MALE SPEAKER: And these are held every two weeks so if you can't make tomorrow, you can go in two weeks. Frank Spinelli will be there, Gary Alexander.

FEMALE SPEAKER: Where do we find this information?

MALE SPEAKER: Have you to look for it. I actually found out about it yesterday.

JANE DOUGLAS: I have sort of a different type of problem. I'm Jane Douglas from Cumberland and my son Robert and I moved here from Florida two years ago. And we moved here

because my husband died suddenly and I had the daughter and grandchildren here and I understood that Rhode Island was a wonderful place to access services for the handicapped. Wow. It has been an absolute nightmare. The main problem is, my son wants to work. He was raised with the attitude that work is good. And when a school didn't teach him things, his father and I taught him. He was employed in New York before we were tired. He was a handy man in the summer and in the winter he worked in a museum as a cleaner. Then we retired to Florida where he was employed in various jobs, the longest was doing maintenance as a dining room attendant at Wendy's for five years. And my daughter is an educator and someone she spoke with, she talked to all of the agencies, she said they're all wonderful. And they say the job is the easy part. Well, everyday, I have a discussion with my son. Well, mom, you know, I could do this, I could wash dishes in a nursing home. I could clean bathrooms, and I couldn't help but think when I read about the illegal immigrants, I was once an immigrant but I was a student and I know that they face their own problems, however, they said, we do the work you don't anticipate want to do. Well I'll tell you, my son want to do so that work. He just wants a chance and I don't know, maybe I have made errors, maybe I've been going down the wrong road but I contacted everyone who I felt could help me. He's now with an agency who supposedly has been helping him to get a job. Does anyone have any answers?

MARY MARTINO: (Mary) have you tried the local supermarkets.

MALE SPEAKER: If I could ask when you do speak, please identify yourself so the stenographer can --

MARY MARTINO: Mary Martino.

FEMALE SPEAKER: The agency I feel is in a position to do that, because that's their job, that's what they do, they know the advantages of employing a handicap, they know there are incentives for employers. I don't know that sort of thing. And

LEO CANUEL: Can you say, which agencies have you worked with --

FEMALE SPEAKER: Proability.

FEMALE SPEAKER: Developmental Disabilities Agencies.

FEMALE SPEAKER: He did have one opportunity but it wasn't workable. He is going into a semi independent living situation soon which I am very, very grateful for and so is he. That is with black stone valley ARC and I think it's probably one of the best places available.

MARY MARTINO: Mary Martino. My daughter goes to the day program there.

FEMALE SPEAKER: I am very grateful for that, however, he was offered something which would have been great, it was with Homestead in Woonsocket, working with a work crew that went from there each day to do maintenance work at the airport. They seem to have a contract with the government somehow to get this type of work. But, because he's going South, they wouldn't transport him that far north. But he will do anything, he just loves the idea of work. He has no respect for anyone who is lazy and he does not want to be considered lazy.

LINDA DESCHENES: Linda Deschenes from the Office of Rehabilitation Services. Sounds like your son might be I don't know if he's ever been referred to the office of rehabilitation services or if he's currently active with a counselor there.

FEMALE SPEAKER: I just didn't get any response from them.

LINDA DESCHENES: I would like to follow up with you before you leave today and be able to see if we can make that link.

LEO CANUEL: Yes?

GEORGE NAZARETH: George Nazareth again. I'm sure if this lady went to Bob Carl the CEO of the Homestead Group he would make sure that that, her son, got a job that he wants. I mean that's ridiculous to want to work and not be able to get the job. I know that Bob Carl is a guy who gets things done and I think that it would be ideal if she went to see Bob Carl and that's in Woonsocket.

FEMALE SPEAKER: Well, I have had good feedback from homestead.

LEO CANUEL: Identify yourself.

JANE DOUGLAS: Jane Douglas from Cumberland. My husband had talked to the people at Homestead. He died suddenly, I did not know of this. When I finally got around to talking to the people they remembered very well their conversation with him and they took a big interest in my son. However, by that time, we were being offered this living situation which is ideal for him and I'm not at an age where I can say, oh, I don't think I want to accept that, I think I want to look around for another two years. So it just doesn't seem to me it should be so difficult.

LEO CANUEL: Where is this living situation.

FEMALE SPEAKER: It's in Pawtucket.

SUSAN HAYWARD: I'm Susan Hayward from the division of developmental disabilities, caseworker supervisor there. I just wanted to offer Mrs. Douglas an opportunity to speak with me after this meeting about her son and what we might be able to do differently. I am familiar with the difficulty agencies have in finding employment for individuals. It is not a simple task. It's much more difficult than filling out an application with a direct care staff and then following it up with a phone call. Generally it involves a support employment coordinator to go out into the community and pave the way and do networking. So it is something that I appreciate you bringing to my attention and we certainly need to do a better job and I would like to speak with you after.

LEO CANUEL: Bill again.

BILL INLOW: Isn't it important to know that the office of rehabilitation services, for example, state employees who know about getting people jobs, one reason you might have to wait longer and not get as good a quality, there's a freeze in employment and as people leave the office of rehabilitation services, part of the department of human services, they're not being replaced right now. And that's because, again, of a failure of leadership in my judgment as a citizen of our chief executive officer Don Carcieri, he argued five and a half years ago when first elected that job creation, big corporations coming into Rhode Island is very important and he's right, more jobs, more families getting more income. Well the fact is that the six states in New England there's only one in a recession, one whose economy is shrinking and that's Rhode Island. The other states at least are still growing somewhat. Highest unemployment in New England, Rhode Island. So, the Governor needs to confront the reality that perhaps we need to increase revenue a bit and I know he says not to raise taxes because it discourages economic development. But especially hasn't for five years and we still haven't grown. So, we're going to get fewer service from people with legitimate needs like this wonderful person here who is doing most of the work caring for her son and only asks for a little bit of help from state government to help him get a job. We should be embarrassed as a state not to be able to help this person out who can't last forever, right? I'm 64.

FEMALE SPEAKER: I'm not going to tell you how old I am.

BILL INLOW: You've done a great job caring for your son. But we're going to do less good a job, right Linda? Because those jobs aren't being filled because of the stubbornness on the part of our governor and our General Assembly and the failure to at least consider --you know you balance a budget two ways, cut costs or increase revenue. The Governor and General Assembly are stub born about increasing revenues in the best ways in my opinion to increase progressive taxes. I feel people making 50 thousand or more in this state should pay more. I'm one of them, I would be willing to do that in order to provide good and decent services or at least to help out in continues to provide decent services to our citizens. And so I think that the governor and General Assembly need to think about increasing revenue so as to continue to provide at least a moderate level. I also think the global waiver should be waived, wait for a year and negotiate a better deal with the officials at the federal level with the new administration coming in with the federal level. Not all the problems will be solved with a new administration but one way or the other it's new people in the federal Medicaid system in a year and right now, it seems to me we're dealing with our state representatives who are trying their best, we're dealing with the most stubborn obnoxious people you can imagine in the federal government. Their only thought to reduce costs. If we waited a year we can get through this for a year, I think we should table the whole Medicaid global waiver, do the best we can to balance the budget even if it require a modest increase in the progressive income tax in the state of Rhode Island. I just think they're making some commitments for us, five-year

commitments and you're right, Leo, what happens in the 4th and 5th year if we run out of money? That's the deal, if we spend too much in the first 3 years, what's going to happen to people in the 4th and 5th year? I really think it's time to urge the Governor and General Assembly to do the best they can to balance the budget which they're mandated by state law to do this year, wait a year, have more discussion, negotiate with stubborn people to deal with in a year, a new administration, and not break something, not try to fix something that's really not broken, and especially in a way that might in fact end up breaking it. So my opinion is you should call the Governor and General Assembly members and urge them to do whatever they have to do to balance the budget this year and to think about some of the good things that are talked about under the global proposal but for God's sake not make a commitment for five-years in a very, very uncooperative environment that we have at the federal level right now.

LEO CANUEL: Just one other thing if I could add to what Bill was talking about. A major concern I have as an executive director working the Office of Rehab Services as well as Department of Health and Human Services or Medicaid, is, we have a major problem in this state of brain drain. A lot of experienced workers are retiring. And a lot of them are not retiring because, gee it would be nice to do so. They're retiring because, I'm escaping the sinking ship. And not to say that younger newer folks are not skilled or qualified but there are a lot of workers that have been there, our state employees that work very hard. The folks I work with work very, very hard and are very passionate about their jobs, not people leaning on a shovel as people think of state employees, hitting the time clock. The folks I work with are not those folks. And a lot of them are leaving and a lot of them are retiring and I think if I was in their position I would be doing the same thing but it scares me because that means the younger, less experienced folks are going to be dealing with a lot more issues that they don't have the experience to deal with and the folks that they had gone to get the answers are no longer there. So it's a major concern that nobody in the administration is even dealing with; if anything they're happy that all these retirees are taking their golden parachute which is much tarnished. I think we had a question on this side that I want to go to.

THERESA SNOWDEN: Theresa, Department of Developmental Disabilities. Before he went off the subject of services and jobs, it's not that they're not enough jobs outstanding there, one of the biggest problems that some of the parents I work with and run into is transportation. I think this lady hit it on the head when she said her son had a position in Newport but because of the transportation where she lived they couldn't get him back and forth so I think hopefully that will be a big part, we need a lot of money for transportation because people need to get from Point A to point B. So I would just encourage the legislators to, you know, put some extra funds for especially with gas costs the way it is.

MALE SPEAKER: Last name?

FEMALE SPEAKER: Snowden.

MALE SPEAKER: You're right about, in order to make intelligent decisions, you need to have perspective of what went on. My perspective came from being president of the Rhode Island Association way back in 1969-1973 when we passed, the state of Rhode Island, the people of Rhode Island passed three straight bond issues for the creation of group homes. Now the people knew there was a need and they overwhelmingly were passed and that was a time when a lot of things weren't getting passed but ours got passed because there was a need and the people of the state of Rhode Island are compassionate. But the people coming don't know that history and after I'm gone probably a lot of people will never know it. But that perspective is important.

SUSAN HAYWARD: Susan Hayward. Supervisor with the Division of Developmental Disabilities. I just wanted to speak briefly in regard to the SLA [supported living arrangements] that people were eluding to earlier and terming it foster care. There is a directive to open up the opportunity for shared living arrangements for adults with disabilities. And it is being approached by the division in a very thoughtful and planful manner. Mr. Nazareth speaks to the long history of changes in Rhode Island for adults with developmental disabilities and how Miss Douglas speaks to how services in Rhode Island have typically and historically been viewed as very

forward thinking. And the division as I said is under a directive to have more opportunity for living in the community and environments that are not group homes but they are very aware that it is something that needs to be a person's choice and not something that is dictated by finances. So it is being addressed very thoughtfully and slowly. The division is attempting to certify numerous providers and have already certified many of them to be shared living providers and as part of that they need to do background checks on all of the persons looking to be providers and they need to provide ongoing training and they need to have clinical oversight and that is just a very small piece of this whole idea. I am very appreciative to the parents here who are speaking up about this and speaking very passionately because it's important for those of us who are trying to provide more options for adults with disabilities to hear not only the positive side of that but also the concerns.

ARTHUR PLITT: Arthur Plitt, commissioner. Interesting let's say that I was at several of the meetings earlier and people talk about three and 5 year waits to get into group homes and get services. So, it's really interesting also that the state is turning back, I believe 40 million dollars to the feds this year because we don't need it. We have too much money. They're not filling certain positions at ORS and other divisions of state government because the state doesn't need these services. So, I guess let's say, people just have to wait until the state is ready to take care of the people with disabilities and hopefully we'll all be around at that point in time.

LEO CANUEL: Other comments or issues?

JOAN WOOD: My name is Joan Wood, yesterday I was a participant in the Warwick forum, I don't know if the handout is here today of the governor's address and Representative Costantino's address because I haven't seen if that's over there or not but there was a recent article in the paper that Representative Costantino who I believe is the head of the senate finance committee is very concerned.

MALE SPEAKER: House.

JOAN WOOD: House, sorry who is concerned about the global waiver so he might be a very good person to put a letter out to. I just wanted to mention that.

TIM FLYNN: I might just say my name is Tim Flynn, excuse me, Leo it is important that you also, in addition to contacting the Chairman of the can I, it's important you contact your local legislators that might be committee members. You can find that information by going to the secretary of state's web site, I don't have the exact title but you can find it if you go to [state.ri.state.com](http://state.ri.state.com) because your local anybody on that committee who happens to be your representative will listen to you and they all have a vote on the committee. The Chairman doesn't have the Chairman probably settings the agenda but each other is important. So I behoove anybody looking into this issue to take that step and contact your own legislator but I also think in addressing what Susan said, I think there really has been a lack of transparency and a lack of communication to the public, what exactly this waiver entails and I think that, as I say, I've been to all these meetings and this is clearly the number one issue everybody is talking about. I will say this, it's intentionally cloaked in secrecy but there have not been great efforts to let the general public know what's going on. It's also important you talk to your legislators and say we want to know what's going on.

LEO CANUEL: Yes? Name again, please

GEORGE NAZARETH: George Nazareth. When I first got involved in the leadership, volunteer leadership with the disabled, I requested to go to Ladd school. I left Ladd School and I left and I saw the horrendous degradation of human beings that I could ever imagine. What they did in Germany in World War II could not compare to what was going on there and I went directly to Governor Litch's office and would not leave there until he saw me and that was the start of the demise of Ladd School. I would not let up and others thought I was nuts but I didn't, didn't stop. And so, it took from the early 70s until the 90s to clean it out and we became the first state or close to the first state to eliminate state institutions. We don't want to go back to that kind of stuff but you have to remember that the past is relevant because you don't want to repeat the sorry mistakes of the past. Well, we don't want the legislature to repeat any sorry mistakes either. We want to go forward with the great system that we have. And we're noted for our great system.

LEO CANUEL: We have a question on this side of the room.

FEMALE SPEAKER: I'm Dawn from Woonsocket. I was raised in foster care, long-term foster care for a long, long time and many people really honestly thought that people with disabilities would never get into apartment setting but I kind of outsmarted them, I told them I knew what I wanted and I wanted to be in my own apartment living at that point with a roommate and down the road on my own and I finally did get what I wanted just recently and it's something that I really toll told myself I had to work forwards.

FEMALE SPEAKER: Good for you. (APPLAUSE)

LEO CANUEL: We have about 20minutes left. I don't want to rush people but I just want to make sure that everyone has an opportunity so if we hear from new voices.

ELIZABETH MURPHY: Elizabeth Murphy, I live here in Cumberland and have a son about to turn nine who has been on the Katie Beckett program for the last six years, about to lose that in a couple weeks and I'm here because I am concerned about what's going to be happening with him in the next couple of years; how he needs to advocate for himself because I am quite a pit bull when it comes to advocating for him but legally that's his job now and my son is minimally handicapped. We don't deal with many of the issues you're all talking about. And one of the problems I've run into over the past only been handicapped for six years is he's not handicapped enough. And when he gets better, he started out completely paralyzed from the waist now, now walk with canes and ankle braces, as he improves and gets better, he's less qualified for anything and as his parents we feel it's our responsibility to care for him the best we can, but it took 3months to go through our entire life savings. There were when he came home from the hospital, we were recommended to apply for this grant and that grant because we had to redo the house over. We applied and they said it's nice you applied but there's no money so you'll have to do it yourself and as he has improved and as he has grown he's become less eligible for just about anything and my concern for him is going to be how does he advocate for himself on just the small things he needs but are just there are things not covered by he's still covered under our Blue Cross right now because he's in college. There are things that Blue Cross does not cover that in two weeks we will have to pick up on, which, that's our job. I'm not complaining, but, my concern is for him in the future, in other8months, he's completely on his own, he won't be covered by Blue Cross any more and he is basically un insurable, you know, I have a six inch thick file for Blue Cross. The battle royal is waged every year with them. It's been a difficult process and so I need to learn who do I direct him to, where does he go, how does he advocate for himself and how does he demand, okay I only have smaller problems but I have needs that need to be met and, you know, it just seems as though he's just not considered important enough, you know, and, in the grand spectrum of things, he might not be but he's my son and I think he is. I've made phone calls, I've contacted the state. I don't know if you all know this but there are no sidewalks out hereon route14. My son has not been able to walk down the street or use his wheelchair for six years to go get an ice cream at Josies (sounds like) down the street from our house. And that has been an issue I've been raising for six years, making phone calls for six years, things like that seem so small to some people and, you know, I have to admit ashamedly that over six years ago I thought, we do such a good job for handicapped people and when you're put in a position where you see all these little things and how difficult it makes life for the individual, for the families of the individual, so I'm just very concerned. I'm here because I'm very concerned when he needs to advocate for himself where he turns and what he does and I'm very concerned about this waiver and how it's not going to just affect him but, you know, so many other people in the states. So that's what I'm here for and I'm open for any information that's here and available to us. I realize compared to so many needs I'm hearing about that his need are so small but they're still needs and financially he is not going to have the means of meeting those needs. Once he's finished with our insurance and leaves our home, hopefully, although his older brother hasn't done that yet, so it may be a while, you know, he needs to know where to go, what to do. And we have been in contact with people over the years and, you know, I can't complain. People have been terrific about trying but we just keep getting, he basically just isn't handicapped enough.

LEO CANUEL: I think one of the problems in Rhode Island is there's such a sort of a division between youth services, adult services and elder services. For a variety of reasons. So now you're in a position where he is now moving from youth services to adult services. Have you ever heard of an independent living center.

Self-advocacy

ELIZABETH MURPHY: Yes.

LEO CANUEL: Maybe you and I could talk when we're done here because I think we may be able to provide some support.

ELIZABETH MURPHY: Okay.

LEO CANUEL: Okay. Before is there anyone who.

TIM FLYNN: When you talk about, your son needs services and you said you've talk today people, I would like to know specifically.

FEMALE SPEAKER: The job issue was one.

TIM FLYNN: But in terms of what kind of medical care that he needs.

FEMALE SPEAKER: It changes drastically.

TIM FLYNN: What is his.

FEMALE SPEAKER: Transversemyelitis (phonetic) best way to describe, like having MS all at once. He's a mire Cal, he's not supposed o do any of the things he does. He has a job right now training youth how to lift weights. He's a weight lifter. Starting working out for his upper body at the YMCA and that's a job he got on his own after being in touch with a couple state agencies that really kind of just.

TIM FLYNN: Which agencies.

FEMALE SPEAKER: Office for Rehab services put us in touch we went through the Sherlock Center, there really just wasn't anything for him, you know. He's a very capable person, so my concerns are, you know, when he leaves my home he still will need a handicapped bathroom and issues like that can in his life. And medically advocating for himself as Medicaid changes come up. His medical status changes every 3 months or so, he has a big leap forward and two big leaps backwards. There are things medically that he needs that believe it or not does not cover.

MALE SPEAKER: Specifically.

FEMALE SPEAKER: Catheters, and he uses several a day.

MALE SPEAKER: Anything else.

FEMALE SPEAKER: His leg braces, they cover only a particular type of leg brace. The leg brace he uses right now is fairly new, we pay for that out-of-pocket. It was 4500 for the pair and going up to \$6,500, we have to pay for that within the next month, because they're not F.D.A. approved, they're been used in Europe for over ten. We decided on these particular leg braces because he has so many issues with skin and issues that are covered by insurance.

MALE SPEAKER: Good point. I understand. What's approved is causing more problems than

FEMALE SPEAKER: Exactly. After he finally got to the point where after two years, when they started talking about amputating his foot because the infection on his ankle bone, I said no way so we opt today pay for these things out-of-pocket. I can scream I'm good at screaming and yelling but, you know, he's not and he needs to learn how to do it. So, you know, it just seems as though the more improvements he makes in his life, the less there is available for him, you know. And we're grateful for every improvement and I would love for the day to come when he can just be someone who pays taxes and helps out everyone else and doesn't have to use any of these services. So that's, those are my issues. I'm just concern about, as he continues on into the adult world of disabilities.

TIM FLYNN: Thank you very much.

LINDA DESCHENES: Linda Deschenes from the Office of Rehabilitative Services. He was involved it sounds like with our agency, probably when he was in school.

FEMALE SPEAKER: About two years ago when looking for a small part-time job.

FEMALE SPEAKER: Not involved now and some of the needs can't go backwards but going forward there might be some things we can step in and help out because he's going to school to be self sufficient, there might be some things we can so we encourage that he look to reapply, I can give you I brought with me an orientation list and so forth.

FEMALE SPEAKER: I would just encourage, Teresa from DDD. Just, nobody is ever alone in their struggle. I don't know if up went to the just to think outstanding the box for a minute and not to think that the state has the answer to all of our problems, but, sometimes you know there are other people out there who think that, who may be facing the same difficulties you're going through. I don't know if you can start a web site or, you know, just kind of get your name out there somehow because that's a how a lot of the ARC agencies were started, by parents who had nothing in the beginning and they kind of got together with four or five of their friends with children with some of the issues and some problems and now look at the system that is built around them today. So I are would just say, I'm sure you have, but, I'm sure that there are other resources out there that perhaps you could --

LINDA McMULLEN: The answer to that question my name is Linda McMullen work for Rhode Island parent information network and I'll leave cards for our resource center. Anyone, please feel free, we can help this mom to navigate the system and find supports and we do them in unusual ways sometimes. We have a big network, family to family network and this very situation, this family's needs could be posted and you would be amazed at the answers and solutions we get. There are a lot of resources out there. We could help her so I'll leave cards if anyone wants to grab them on the way out.

LEO CANUEL: last chance before we close the meeting today.

ARTHUR PLITT: Just wanted to remind people that the disability law center voting package and voting for people that you think are going to support the areas that are of concern do make a difference, don't be afraid to quiz some of these candidates. And there is also a plug for disability law center but there is a request for priorities for the next year so fill them out, send them in.

MALE SPEAKER: Please.

JEAN CAVANAUGH: Gene Cavanaugh. Resident in Providence. I just want to say it's our privilege as a society to take care of people who have, who need to be taken care of and I think that's how we want to present it to the legislature, that we the people, as Bill says, you know, willing to pay more for taxes but that people get served. And it's our privilege as taxpayers to know that, that people are being serve withed what they need.

LEO CANUEL: I think unfortunately the community does think that people with disabilities are being cared for. I can't tell you how many people have come up to me and said to me, why do you work for a living? Don't I pay taxes so the government can pay you? Or, I've also had people say to me, don't you have someone that follows you around and helps you all day?

JEAN CAVANAUGH: That would be me.

LEO CANUEL: But the government doesn't pay you, I do. So there is and other people have said, now that the Americans with disabilities act has been passed, aren't you guys all set, don't you have everything you need now because the world is completely accessible? And I usually like to remind people, yeah, the civil rights act was passed in the 60sand of course we know that solved all of our problems too, didn't it. So, our work is not done and your testimony here today, I thank you for. The Governor's Commission will take it back and PARI, as well, will create our legislative agenda and our work for advocacy for the coming year. So it is very, very useful. And it does not fall on deaf ears. So thank you very much and thank you very much for coming. We willing now close the hearing. And any written testimony that you would like to submit can be submitted to the Governor's Commission, probably by Friday

FEMALE SPEAKER: Longer than that.

ARTHUR PLITT: Also the e-mail and fax number.

LEO CANUEL: Okay. I believe on one of the handouts so feel free to grab any of the handouts. Thank you.

## **5. Thursday July 24, 2008, Middletown Public Forum**

ANGELA: We are going to get started. I want to welcome everyone and introduce myself. I am Angela Semonelli. And I work with looking upwards, an organization over here in Middletown, Rhode Island, supporting people with developmental disabilities. And we will introduce the members of our panel. If you could introduce yourself and the organization that you represent, please, starting, Barbara, with you.

FEMALE SPEAKER: I am Barbara-Ann Borden, rehabilitation specialist with the office of rehabilitation services.

BRIAN: Good afternoon. I am Brian Adae. I am an attorney, staff attorney with the Rhode Island disability law center. I am here this afternoon with another woman from the office, Elizabeth Hubbard. If I may do a shameless plug, Liz is here helping out anyone who needs to register to vote and she's you can take care of that. As a matter of fact, this is a shameless plug, that we do voter registration. We have a voter registration project. If there are any organizations out there that would like some assistance, we would be happy to assist with that. And if I may also add, I love this time of the year when we have the public forums because it also coincidentally is when we put out our annual surveys to hear from the public on what they think our priorities should be on issues we address. We are the protective and advocacy system for persons with disabilities for the state of Rhode Island, part of the national protective and advocacy system for persons with disabilities. We are a service agency and we provide legal based advocacy, individual representation, a variety of things. Thank you.

LINDA: I am Linda Ward. I am a commissioner.

FEMALE SPEAKER: I am Colleen Polselli from the Rhode Island department of health, office of special healthcare needs, and located within that office is the disability and health program.

MARIKA: Hello. I am Marika Terlecky. I am from the brain injury association of Rhode Island. I'm also a brain injury survivor. And I'm on statewide independent living council as well. And not to toot his horn, but the disability law center for any of you who haven't worked with them, they are a great bunch of people who have helped a lot of people, including myself there, and really support your efforts. You have been great to work with our organization. Thank you.

BRIAN: Thank you.

TIM: I am Tim Flynn. And I am a commissioner on the governor's commission on disability. I am also chairman of the legislation committee. What I would like to say to you, we have been holding these public forums all week now. The input we get from the public is taken. We create a legislative package that we then we take all the transcripts and we separate them by category: Transportation, education, a lot we have been hearing about this new waiver that's going on. What we do is we put together a legislative package. And we then distribute it to the senate and the assembly. And we advocate in the fall. So really what you say here really directs what we do and it's really important. So I really thank you all for coming.

ANGELA: Okay. Thank you to our panel members. We have a sign-in sheet over here. We have some materials. If anyone hasn't signed in or grabbed some of the materials, please be sure to do so before you leave. There are assistive listening devices. If anyone needs an assistive listening device, if they could just let Karen know. And the purpose of these public forums is to identify the concerns of people with disabilities and their families in order to assist the state to develop programs to improve the quality of lives for people with disabilities. The Rhode Island disability vote project registers are available, as Brian Adae mentioned, or someone here can help. If it is important to be registered by August 9 in order to vote in September 9 primary. Or by October 4 for the November 4 general election. July 28 is the last day for requesting Braille ballots. And let's see. The 28th July 28 is the last day for requesting Braille yup. It should be made to the election division at 222-2140. That's for the primary. The deadline to request a Braille ballot for November 4 is September 22nd. And the public forums will be followed by these transcripts being posted. The transcripts of the testimony on the Governor's Commission on Disabilities on the website, [www.disabilities.ri.gov](http://www.disabilities.ri.gov) in about two weeks. The sponsoring agencies will review the testimony and prepare recommendations which will also be posted on the same website by the end of the summer. The recommendations and transcripts will be printed and sent to state and Congressional officials and to 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. We want to give everyone a chance to speak. The panel members are here to listen and to gain an understanding of your concerns. And they may ask clarifying questions. You will be asked to speak in the order on the sign-up sheet. And you will have five to ten minutes to share your concern or idea. And I may help move the meeting along so we will be sure to end by 5. Okay. All right. Those are the things I have to read. So, check. And is

there anybody who has something right now pressing that they want to be able to share or ask before I look at the sign-up sheet?

AUDIENCE MEMBER: The rest rooms are to the left and right of the door. That is pressing.

ANGELA: A little information.

AUDIENCE MEMBER: Priorities.

ANGELA: The rest rooms are to the left and right outside the door.

AUDIENCE MEMBER: In order to get the key, you have to go to the library and ask.

ANGELA: The library likes a visit to get a key to the rest room.

AUDIENCE MEMBER: First you have to hold your hand up and be recognized.

TIM: Say your name first.

ANGELA: Oh, that's right. If everyone who has something to share or to ask, if you when you raise your hand and are called on, if you will state your name first, including the spelling of your last name.

TIM: And the town you are from.

ANGELA: And the town you are from. Thank you. Okay. Can I see the sign-in sheet? Thanks. Okay. Emily Allen, okay.

AUDIENCE MEMBER: I am usually first because of alphabetical. But I am first because I signed in.

ANGELA: Why should it be any different today?

AUDIENCE MEMBER: I am Emily Allen, A-l-l-e-n. I work as a team leader for Newport County Mental Health Services, children intensive services, and early child treatment program that we are just starting, which are programs for severe, mentally disturbed children. And I think what some of our concerns are, mostly coming from the state budget, being able to provide the best quality services that we can to

Medicaid: Mental health services
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children with the severe problems in such a limited amount of time or limited amount of modalities that we are able to provide. So we are finding ourselves doing the best we can, short amount of time. And realizing that our children are our future and you know we really want to invest as much as we can. We then find what we need outside of what we are able to provide and coming out kind of short. So you know finding it all difficult to make sure we get all our children's needs met. That's basically in a nutshell where our concerns for the children's program.

TIM: Can I ask a question?

FEMALE SPEAKER: I'm Janet Spinelli from MHRH. Maybe you can elaborate a little more on specific areas you are talking about, the shorts –

AUDIENCE MEMBER: The children's intensive services that we've provided at one point used to be six months, with the ability to have extensions. And it's the program's changing to be limited to 16 weeks. That doesn't include group therapy. It's family, individual therapy, community based with case management services. And up until around this point too, psychiatric services was also a component of that program, which no longer will be part of the program. It will be billed separately.

TIM: What type of services?

AUDIENCE MEMBER: Children's intensive services. The psychiatric services will be a part of the program, will be billed separately. So there's a little more limits on what we can actually provide in our program. And we fortunately have a psychiatrist available in our agency to have partial be able to be seen by him. But we are finding that many of the children that we see, who have severe problems, once they are completed with our program, we are not sure if how many programs there might be to still address their needs because they continue to have such severe emotionally, behaviorally disturbed issues that what we provide might not be enough; or at least over time that we are allowed, authorized might not be enough time. And we are hoping that we will be able to provide the best that we can (inaudible).

CART PROVIDER: Can you please speak up and repeat what you just said?

AUDIENCE MEMBER: The best that we can, period.

TIM: I have a question for you. When you talk about step down services, what does that mean? I don't understand.

AUDIENCE MEMBER: Following our program, many of our clients end up going to an out-patient provider where it's mostly office based. And many of the—

TIM: Go to an out-patient provider?

AUDIENCE MEMBER: An out-patient provider who does therapy and most of that service would be office based. And many of the clients that we see have access to transportation and our program is community based. We go to their home so there aren't many programs that are home based or that will provide so much time, therapy at a time for each client as we might. So, going from an intense three, five hours a week in the home to a period going to an office, seems to me difficult transition. So we are hoping to make a better transition, better program to help with them still get their needs met.

FEMALE SPEAKER: Maybe after we can talk about the eligibility for reapplying and re-established eligibility.

AUDIENCE MEMBER: Yeah. It's from what we've been told, the benefit is will be a 16 week per year benefit for it's now going to be called CAITS, children adolescent intensive treatment services. And it will be a 16 week, no extensions program. So, we have been told that they aren't able to reapply until their year is up. And many well, all of our children, the criteria to be in our program is to have a severe emotional, behavioral disturbance. So chances are it's going to last more than 16 weeks. That's (inaudible) TIM: Just one question. In a perfect world, in your mind, I'm sure your clients have different varying needs of service needs. Have you thought of what will be the ideal solution? You know, if we are trying to create trying to find a solution to this problem. Is it more money? Is it you know

AUDIENCE MEMBER: I think being able to have the home based services for a longer period of time or leaving it to a clinical judgment of how long someone really needs to be in there, and not say, well, you stay at 16 weeks. Clinically maybe they really need that much more in a year and not have it very time limited.

TIM: You would like to see more clinical judgment, decision made by your staff?

AUDIENCE MEMBER: Unfortunately it does amount to money, but being able to have clinical judgment to say this child needs much more than 16 weeks.

TIM: How many of your how many percentage bases (inaudible) particularly accurate but ballpark figure. How many of your clients you think fall into that category that are thrown out after four months and could use the six month model?

AUDIENCE MEMBER: I'd say a good 80 percent. We have quite a few that return to us because they have been able to return to us once we have determined they are able to go and step down but then sometimes feel the need to return to us, and seeing a trend in whether or not someone will start using the emergency room hospitalization as another solution while I don't have anything else intensive enough and I'm in crisis. I can't go back to, you know, this intensive program. Maybe I need to (inaudible).

TIM: Does that happen a lot?

AUDIENCE MEMBER: We have a decent amount at our agency is actually the gatekeeper for many insurance companies. So we are the ones that see clients coming out of the hospital. And there are a decent amount that we try to before they get to the hospital to have a crisis visit with them. For the most part, many of our clients feel pretty comfortable calling our emergency service line so that we can hopefully offset them before they even get to the hospital.

TIM: Sort of ballpark figure, I'm just sure it's more expensive to deal with in a hospital based setting. I'm curious to what that number might be.

AUDIENCE MEMBER: Right. I'd say probably a good 75 percent could

TIM: Of all your clients?

AUDIENCE MEMBER: of being able to benefit from longer than 16 weeks or something else could happen: Justice system, hospital, at home placement, if we are not in place longer. And I think a lot of them really would have a lot more problems if they didn't have something in place.

FEMALE SPEAKER: What are the age groups that you serve?

AUDIENCE MEMBER: 2 to 18.

MARIKA: 2 to 18. And approximately how many people are you serving at this time?

AUDIENCE MEMBER: Right now about 40. It's slower in the summertime for us. For us in particular, our program has had up to 70, 80 clients, a little slower in the summertime.

MARIKA: I know it may seem silly. But is there any type of prevention program particularly with the earlier age children that you are serving or minimization program

AUDIENCE MEMBER: Yeah. I know that we have a pretty good collaboration it seems with early intervention. That's through looking upwards. We try to talk with them. So there's some of their programs that end at three years old. So we are trying to get a working relationship to help them out if they need (inaudible). We will pick them up after that. And we have a program, like I said, a team that works just with two to five-year olds, two to six year olds within the intensive services, as much as we can prevent. We try to be unfortunately, most of the time someone comes to us, they are already you know in crisis it's already been an issue for a while.

TIM: I just want to go back to the point you were talking about before. You are talking about the clients or others that wind up in a hospital, in an emergency room. And I just if you can give me a ballpark figure as to how many people that might be per year, if you feel comfortable. If you

AUDIENCE MEMBER: I'm not sure that I would have an accurate number with that because I don't work particularly with the- our emergency service department.

TIM: More than ten?

AUDIENCE MEMBER: Yes.

TIM: More than 20?

AUDIENCE MEMBER: You said within a year?

TIM: Yeah. AUDIENCE MEMBER: We get several calls in a day. Trying to think of just children. Well, I don't know if I'd know

TIM: Thank you.

AUDIENCE MEMBER: I don't want to throw a number out there that may not make sense.

TIM: Thank you. I appreciate it.

FEMALE SPEAKER: I just wanted to add that there are many CIS because this new CAITS program used to be CIS. There are many CIS programs in the state. Many agencies have a CIS program. So you can multiply this times how many people. Probably give you more of an idea.

TIM: And these cuts are happening to everybody?

AUDIENCE MEMBER: Statewide.

TIM: Statewide.

FEMALE SPEAKER: All of the CIS will now become CAITS and will affect all of the agencies providing CIS services, which is hospital diversion program.

FEMALE SPEAKER: And just a ballpark, how many of these CIS ballpark exist in the state?

FEMALE SPEAKER: I'm not sure. Do you know how many?

AUDIENCE MEMBER: Nine in the state.

MARIKA: Nine.

FEMALE SPEAKER: But we are not sure each of them (inaudible)

AUDIENCE MEMBER: Yeah. There are some that are definitely many more than us.

TIM: Is there a way we can find out what those numbers are; isn't there?

FEMALE SPEAKER: Yeah.

AUDIENCE MEMBER: I think in the state what are 2400 in the state have been served by CIS.

TIM: Since?

AUDIENCE MEMBER: In this past year, this past fiscal year.

FEMALE SPEAKER: The symptoms that clients served on this program present with a very serious

FEMALE SPEAKER: Very serious?

FEMALE SPEAKER: Very severe.

TIM: Can I ask another question just you know, no agency is perfect.

AUDIENCE MEMBER: Right.

TIM: How often do people sort of find themselves, you know, in the court systems? You know, and subsequently maybe in jail?

AUDIENCE MEMBER: We have a couple of middle school aged children that we're have collateral contact with probation officers. I want to say at least four of our teenagers that are some have a probation officer or somehow involved in the family court system. And again right now we have about 40 clients.

TIM: That's ten percent.

FEMALE SPEAKER: I think it might be more than that, that are involved in the court system and what really got them there with mental health issues.

TIM: Thank you.

ANGELA: Thank you very much. And J. John Pimentel.

AUDIENCE MEMBER: That would be me. Hi. I am John Pimentel. I am from Portsmouth. And I think

Public forums: Meeting times

these forums are a wonderful thing. I have attended in the past and I hope I can continue to attend in the future. I think they serve a great purpose. But I do have one concern regarding the forums themselves. And that is that the timing of the forums is not really conducive to allowing someone who is actually working to attend. I feel almost that there's kind of a stereotype assumption there that folks who have disabilities are also not employed, and therefore, can be free during the daytime to attend these forums. I question why we don't have at least one of the forums set up for a later time in the evening or for a weekend where disabled people who are also employed would be able to come and express their opinions without taking time off from work. Of the six forums that are being held, the latest that's being held and there's only one that's being held starting at 4: 00, which still means that someone has to take time off, find a way to take time off or take a vacation day or whatever in order to attend. So, if anyone has any comment on that, I'd love to hear it. Other than that, that's my comment.

ANGELA: Thank you very much. I don't know if there are any comments.

TIM: You know, we can certainly you now the commission actually works with the sponsoring agencies. So it's a matter of the timing when rooms are available and the like. But certainly, I agree with you. I think there could be there should be at least one night. I think the best we can do we did this year, as you said, was 4 to 6 p. m. tomorrow. But it's also good to space them throughout the day because other people can't certain times that people can come. If it's (inaudible) personal care needs or whatever. We want to make sure that we offer a variety of times. But I think you are probably right. We probably could have one from 6 to 8 p. m. or something like that. We will try to do that in the future.

ANGELA: Thank you. And there's someone sorry. I can't read your first name but Nick the last name is Davis.

AUDIENCE MEMBER: Yeah. Me.

ANGELA: If you could state your name and spell your last name.

AUDIENCE MEMBER: My name is Liz Davis, D-A-V-I-S. Sorry you can't read my handwriting.

ANGELA: That's okay. And what town are you from Liz?

AUDIENCE MEMBER: Newport.

ANGELA: Thank you.

AUDIENCE MEMBER: Can I?

ANGELA: Absolutely. Go ahead.

Medicaid: Mental health services

AUDIENCE MEMBER: It's just something that I wrote. Okay. Hi. My name is Liz Davis. I have received mental health services with the Newport county since 1992 and it's helped make a big difference in my life. I have learned many things about myself and overcome many challenges. It's helped me to have a place to be with people who understand me and help have help me and have the same challenges. The services that I receive help me to keep my life together. They keep me out of hospitals, for mental health hospitals. I'm proud of my recovery. I am I have concerns about the changes that might happen soon, changes with my finances financials and medical benefits. I am doing the best I can. But I don't know how I could afford some of the changes the state and government are taking are talking about. I'm worried about the co-payments for my medicines. I don't know how to afford those either. I am here to ask my representatives and the governor to listen and to stop and think about me when making those changes because what I hear makes me feel afraid and makes me worry what could happen. Thank you for listening to me and have a good day. Thank you.  
(APPLAUSE)

ANGELA: Thanks, Liz.

AUDIENCE MEMBER: You are welcome.

ANGELA: And Cheryl Grove.

AUDIENCE MEMBER: Is there anyone that can go before me because I'm still trying to cut my words down to ten minutes?

ANGELA: Sure.

AUDIENCE MEMBER: Is there anyone else on the list?

ANGELA: Did you have something to say?

MARIKA: Yes. Liz, is it? Was your name Liz?

AUDIENCE MEMBER: Yes.

MARIKA: Thank you very much for speaking. I don't know if you are aware, Liz. It may not help in the immediate thing with payments on the meds or with mental health services. But Congressman Patrick Kennedy has introduced at the national level legislature to give equitable weight to the insurance companies so that people receiving different mental health services that fall under mental health will be able to get better less like co-pays. So if you are physical or mental, you are one person. It treats the whole person not just a piece. It's going to take a little time but they are making good progress. On that bill there's a good chance of passing. Probably won't see it in September or October. But it is moving along. And there's some nice updates that were given by Congressman Kennedy at recent meetings. And some of the work groups that some of us have worked with him on. So, it's on its way to try to keep mental services not only alive but to make them more equitable to what's considered physical services.

AUDIENCE MEMBER: Can I add one other thing if you don't mind? Can you put this back out there? Tell them that I am still I talked to him one time. He was at a thing before. Once we were talking one to one that I have 25 years of a mental institution. And I'm planning on doing another ten outside of it. I'm giving it my best. (APPLAUSE) Thank you

ANGELA: Okay.

TIM: I want to ask a fast question. Ms. Davis, what kind of services are you getting right now?

AUDIENCE MEMBER: I'm getting counseling one-on-one. I'm seeing Dr. Clang (sounds like), a psychiatrist what do you call it occupational whatever you call it.

TIM: Occupational therapy.

AUDIENCE MEMBER: That. Voc rehab. I go see a what do you call? The doctor that is all kind of doctors. So all the way around.

TIM: So you are worried about the co-pays. I imagine you are seeing all these doctors.

AUDIENCE MEMBER: Yeah. And some of my medicine the state doesn't cover that I have to come out of my payments.

TIM: About how much is that total? Can you give me a guess?

AUDIENCE MEMBER: One of my medicines I have to pay for it costs \$200 that I have to pay for.

TIM: A month?

AUDIENCE MEMBER: Yeah.

TIM: Really?

AUDIENCE MEMBER: But that's okay.

TIM: That's a lot of money.

AUDIENCE MEMBER: Well, you got to do what you got to do to survive, you know. Like they say, you got to do what you got to do.

TIM: I thank you.

AUDIENCE MEMBER: But I thank you.

FEMALE SPEAKER: Thank you.

ANGELA: Thomas Kelly.

AUDIENCE MEMBER: Hi. I am Tom Kelly from freedom apartments, which is part of Newport county

Accessibility: Crosswalks

Newport Mental Health as well. I come more with a local concern and that is traffic safety at West Main Road or on West Main Road. In particular, where our site is located at 1409 west main road, the traffic lights that are situated right outside our main building next to McDonald's if you can picture that and across the street do not give our residents which we have a ton of residents in our program enough time to safely cross the street. I've personally witnessed several occasions where these our residents have nearly been struck by the oncoming traffic. The light itself just does not give enough time. And on top of that, we have traffic that converges on to them from both sides. The Stop & Shop Plaza and McDonald's. And I'm just here today to share that concern. And I don't think it would be an expensive problem to fix. But we do I'm sorry?

MARIKA: It's a very good point. It's a major problem.

AUDIENCE MEMBER: As we help people have been killed on west main road considering the population at hand. And anyone with a disability, I believe it's I haven't timed it. But it's you know ten seconds to get across a street. And that with McDonald's traffic and Stop & Shop traffic. There's cause for concern. So, that's what I have been here to share with you. That's why I'm here.

TIM: Have you shared this with is that Portsmouth?

AUDIENCE MEMBER: Sorry. Middletown. We have written a letter, a petition signed by our residents. And also we are in partnership with church community housing. And a couple representatives from church have signed on as well. And we passed them along to I don't remember the gentleman's name, but a representative from Rhode Island department of transportation. I haven't heard more on where that stands.

TIM: I wonder if you called the police department and asked them, if they can extend it. I'm not saying

AUDIENCE MEMBER: I believe we have brought that up in the past. Not while I was coordinator, but as it still stands today, that traffic light I do believe actually now I'm thinking about. They have tried to reconcile that but it's still not giving the residents enough time. I think maybe the bigger problem is the traffic that converges from Stop & Shop. They don't have to adhere to a light. Or if they do, the way it's set up is they are turning into potential pedestrians. When they are given the okay to cross, they are also given the okay to turn. So

TIM: Maybe we request talk about it later. Maybe we can talk to the mayor excuse me. I don't know I forget what kind of political system you have in the town of Middletown. Is there a chief

AUDIENCE MEMBER: I'm not a resident of Middletown. There's a mayor.

TIM: There's a mayor?

AUDIENCE MEMBER: I'm assuming.

AUDIENCE MEMBER: A town manager.

BRIAN: Tom, if I may suggest, I would like to speak to you; or if you would like to speak to me afterwards, I might have a couple thoughts on that.

AUDIENCE MEMBER: Thank you.

ANGELA: Okay. And I think we have Gary Brooks.

AUDIENCE MEMBER: I'm a refugee from New Orleans from Katrina. And we got caught with our tail end down. I am concerned what Tom said about us crossing the sidewalks. It's very, very dangerous. Our petitions first of all, let me say I am on the directors of freedom housing. It's an honor to be a refugee. I represent the staff. I represent people living there. And I also represent people at 65 daily road. I am your spokesman. And believe me, we are all concerned with this. (Inaudible) somebody killed before the light is changed. It's ridiculous. That's all I got to say, you know. I thank you very much. I am very honored and very pleased and proud to be on a board to serve these people because they are good people and they have the best theme. And my purpose Liz or this young lady here or Tom Kelly. They are all doing the best they all have faith for me to be their spokesman and I appreciate that.

Accessibility: Crosswalks

MARIKA: Thank you.

ANGELA: Thank you very much. I'm not sure that I'm going to get the first name right. Rhonda Romanelli.

AUDIENCE MEMBER: Yes. Well, the electronic lights at the crossings are a very good thing. And they work pretty well except that the time span in between the time the light flashes and the time you have to walk is too quick for prohibits safe crossing of people, pedestrians crossing at the stoplight. And I have almost been hit a couple of times when I crossed the highway. And people with shorter legs than me could be hit. And I'm a very educated person. I went to the University of Connecticut and Roger Williams college and west New England college and southern New England college. And it is something said when you are just being used I took psychology and organizational behavior and advanced thinking. And they have a psychiatric medications and when you are just being used at there's something to be said I'm not a psychologist. I'm not smart enough to be a psychologist. But my needs haven't been met. So that's why I haven't gotten married and had children.

Accessibility: Crosswalks

FEMALE SPEAKER: I understand, Rhonda. It's so good that so many of you came out to speak on this important issue. And I think we've all taken note of it. And we are glad you are here. We are sorry that you have to go through this. We will be trying to

AUDIENCE MEMBER: But other people too. (Inaudible)

ANGELA: Thank you very much. Okay. Cheryl Grove?

AUDIENCE MEMBER: Okay. Hi. Cheryl Grove, Middletown. In 2005, the governor's commission on disability held a special forum at the American lung association for persons significantly impacted by air quality barriers. The better breathers, COPD group indicated over 50 percent of voided respiratory irritants from common consumer products by significant life alterations. The most clinical survival priority has been accomplished in other places by state funded segregated housing for the susceptible disability population in low pollution locales within forced pollution protection covenants since the 1990s. In December and another state, a foreplex was completed after ten people testified in person. The problem for this susceptible disability population has been exacerbated by another environmental barrier with the allowance of 24 by 7 wireless radiation without consideration of susceptible populations: Children, pregnant women, elderly, the ill, and the disabled in multiunit housing by the fire code interpretation. The department of health, department of radiation indicated in December that they had no knowledge of this type of radiation. I will share but a little of an appeal from

Housing: Chemical sensitivity

medical doctors in 2002. "Out of great concern for the health of our fellow human beings, do we as established physicians of all fields, especially that of environmental medicine turn to the medical establishment and those in public health and political domains as well as to the public. We have observed in recent years a dramatic rise in severe and chronic illnesses among our patients, especially learning concentration and behavioral disorders, attention deficit and ADD, extreme fluctuations in blood pressure, ever harder to influence with medications, heart rhythm disorders, heart attacks and strokes among an increasingly younger population, brain degenerative diseases, Alzheimer's and epilepsy, cancerous afflictions, leukemia, brain tumors: "More over, we have observed an ever increasing occurrence of various disorders often misdiagnosed in patients as psychosomatic. Headaches, migraines, chronic exhaustion, inner agitation, sleeplessness, daytime sleepiness, tinnitus, susceptibility to infection, nervous and connective tissue pains, for which the usual causes do not explain even the most conspicuous symptoms. "Since the living environment and lifestyles of our patients are familiar to us, we can see especially after carefully directed inquiry a clear temporal and spatial correlation between the appearance of such disease and exposure to this radiation. "We can no longer believe this to be purely coincidence. For too often do we observe a marked concentration of particular illnesses and correspondingly radiation polluted areas or apartments. Too often does a long-term disease or affliction improve or disappear in a relatively short time after reduction or elimination of radiation pollution in the patients' environment. Too often are our observations confirmed by on-site measurements of radiation of unusual intensity. "On the basis of our daily experiences, we hold the current mobile communications technology to be among the fundamental triggers for this fatal development. One can no longer evade these pulsed microwaves. They heighten the risk of already present chemical, physical influences, stress the body's immune system, and can bring the body still functioning regulatory mechanisms to a halt. "Pregnant women, children, adolescents, elderly, and sick people are especially at risk. Our therapeutic efforts to restore health are becoming increasingly less effective. The unimpeded and continuous penetration of radiation into living and working areas, particularly bedrooms, an essential place for relaxation, regeneration, and healing causes uninterrupted stress and prevents the patients thorough recovery. "In the face of this disquieting development, we feel obliged to inform the public of our observations. What we experience in the daily reality of our medical practice is anything but hypothetical. We see the rising number of chronically sick patients, also as a result of the irresponsible safety limit policies, which fails to take the protection of the public from the short and long-term effects of this radiation as its criterion for action. Instead it submits to the dictates of a technology already long recognized as dangerous. "

TIM: Can I ask you a question, Cheryl? I think we understand sort of is there I think we understand where you are going what you are saying here. Are you talking about cell phones and cell phone usage?

AUDIENCE MEMBER: No. I'm talking about the wireless radiation devices that have been put in by mandate of the fire code into large condominium complexes. We are talking over 150 wireless devices when it's not necessary. There are hard wired alternatives.

TIM: I am unfamiliar with these sensors. What are they? What are they there for?

AUDIENCE MEMBER: In the large condominium complex that I live in, in July, a hard wired smoke and CO 2 alarm was installed with no problem. That's more than adequate for a state that has this level of residential fire safety. One of the highest in the country.

TIM: I'm trying to

AUDIENCE MEMBER: I'm answering you. Then they came in against the wishes and requests for some consideration for susceptible populations and put in wireless heat detectors in the kitchen, which are for property protection. This is in addition to the hard wired smoke and CO<sup>2</sup> detectors.

BRIAN: May I ask? It appears it sounds like you are reading from a particular article or piece in there. Perhaps if we can get a copy of that or get it incorporated into the testimony, would that be of assistance?

AUDIENCE MEMBER: Sure. I have about you can have this article. But I have about this much information on additional articles since then. In addition to that, this wireless technology that has exploded it's in our libraries. It's everywhere. You can't escape it now. There are now libraries across this country and in Europe. As a matter of fact, in June, Paris just stopped wireless. They took out the wireless that they installed

in late last year because of the reports of health effects from it. And they went back to the hard wired connections.

BRIAN: So what you are suggesting is that an accommodation be made that these be removed and hard wired versions be put in, is that

AUDIENCE MEMBER: I don't know that they need a heat detector for property protection. The reason that they did that wireless is because they claim it's half the price of the hard wired units. I don't know if that's true or not. They added \$2800 to each of these 150 condominiums. I don't know what that does to our affordable housing stock in the state. But I mean, if you take a state that had one of the highest safety records in residential safety and you just do the no-brainer things that are known to improve fire safety, like disallow smoking, okay, or do these hard wired smoke and carbon detectors. That's enough. You don't have to go to this

BRIAN: I think that if we have an illustrative article that we can put in to testimony and just give it a time limitations so we can allow other people to testify. If we can put that in so we can understand it a little bit better. Would that be satisfying?

LINDA: I have to say I have no idea what you are talking about, even after you just explained it. So I think an article that I can read and if you have

AUDIENCE MEMBER: You are not going to understand this. I translated it for you. Bottom-line, there's two ways to do electronics now. The hard wired that you are used to, plugging into the wall, or the wireless. The wireless is an extension of the microwave radiation. We all know what happens when you have an old microwave and it leaks radiation, okay. This is in the same realm of radiation. Okay. But it's going everywhere. Now my contention is how can you put that into my home that I am being as a sick and disabled person exposed 24/7? How can you add that additional stressor, with no dialogue and no alternative? I mean you have to move me somewhere where I can get away from this radiation.

BRIAN: If I can ask you, do you have an extra copy of that article? If not, perhaps we might be able to make a copy here at the library. And we can put that in, to the next person on the list.

TIM: Thank you.

BRIAN: If we could take a look at the article, I think we can do that in the library.

TIM: I just want one further question. You thought about this, obviously, quite a bit. What would you like to see? Would you like a regulation or a law or

AUDIENCE MEMBER: No. They have to take the wireless listen. I went to the health department in December

TIM: Please tell me

AUDIENCE MEMBER: Since December, I the health department said they don't know anything about this radiation. I said, how can you put that in my home?

TIM: I understand that.

AUDIENCE MEMBER: So it's got to be out of all whatever the location that is affecting me. I don't know if that's the entire 150 units. If it's just the unit in the condominium underneath me, if it's the unit in the attic. That needs to be taken out or I need to be given housing

TIM: So I think like you said before, that you should be able to if this affects your health, you should be able to not have it in your apartment.

AUDIENCE MEMBER: It's not in my apartment. But in multifamily housing, it could be right there. It could be in the next person's apartment. It goes right through the walls and floors.

TIM: Okay.

AUDIENCE MEMBER: So in effect, they made every multiunit housing apartment, which in this case is all of the affordable housing, all the HUD qualified housing. They have made it inaccessible for me. Where am I supposed to go?

TIM: I think we understand your concern. I think we are at ten minutes anyway. So thank you. And we can talk later if you want to get sort of further figure out how you know the governor's commission, how they can come up with a reasonable solution.

Transportation: Disability parking placards

AUDIENCE MEMBER: The other question I have is about the placard. This came out last year. What do we do when our placard is completely broken apart and completely taped together and the letters are the numbers are fading, actually not readable on one side?

TIM: I think you can contact who

FEMALE SPEAKER: Contact the registry of motor vehicles. If there is a reason you can't get there and it's you are in jeopardy if you send it in, you can talk to them and they will try to work something out with you.

AUDIENCE MEMBER: Well, I read your article in the that describes that. But the problem is what do I do in that interim? I was going to do that yesterday. And I had to park in a handicapped spot and I got a \$100 ticket.

FEMALE SPEAKER: I don't know that answer. They will try to work something out with you.

TIM: I'm sure you can (inaudible)

AUDIENCE MEMBER: I can't pay the ticket.

TIM: I said, I'm sure you can appeal.

AUDIENCE MEMBER: I am.

TIM: You can explain it. I would certainly you know set start the process. I'm not going to tell you what to do, but do what makes sense to start the process. If you do get any tickets in the interim, I'm sure you can get them dismissed.

ANGELA: Does anybody else have anything that they want to share? I don't see anyone else on the list that has indicated that they want to speak. I have already called Emily I think was on that.

TIM: Somebody.

AUDIENCE MEMBER: I have a question. Nora Royles, and my question

TIM: And you are from?

AUDIENCE MEMBER: I am from Newport. But my question is a lot of the agencies provide transportation to and from jobs and to the workshops and to some of the recreational activities. And I know with the global waiver, from what I understand of it, that it's a five-year commitment. And if you run short of that money, then you are kind of out of luck or there has to be some serious fund-raising for people. But what about a catastrophe like that? The cost of fuel and things happening that we didn't expect this time that just came upon us? Would that affect the global waiver? Would that take a big chunk of the money because they know particularly I'm thinking of the Maher center that transports people all over this state to the base jobs and at home again at certain shifts all shifts, I believe. I'm just wondering what happens if that falls short within the five-year span?

Medicaid: Transportation

TIM: If you are

FEMALE SPEAKER: Yeah. I guess there's a couple of things you are talking about. One thing you are talking about, the issues of transportation and we've discussed that quite a bit how there's hardships right now in transportation. We have somebody here that can testify a little more on that. And the thing with the global waiver and you are asking questions about what happens in five years from now. You know, there's a lot of things going on. You are talking about the price of gas going up. The price of gas may continue to keep going up. We really can't control that. And the global waiver does have some provisions in there to try to control costs. But we can't control how much money we have in taxes. We can't control how much money we have available for new programs. It's all part of the legislation and part of what is developed.

ANGELA: Yes?

AUDIENCE MEMBER: Hi. I am Nicole Pelletier. I live in Tiverton, Rhode Island. I work for the Maher center. I just have a comment more than a question. I think right now it's important for everybody to remain really positive. That's what I do with my staff. All the things that are going on right now. The thing about human service workers I think that's very special is I think we are all magical people in a sense. Our tolerance levels are amazing. And that's what I tell my staff. And, if anything, I think once again, with the recession and whatever we are going through right now, whatever you want to call it, I think it will bring us once again closer together. And I know by what's taking place, Governor Carcieri knows that we are not going to let anything happen to any of our people. We are going to take care of each other. And I believe that in this system, even when it's very negative at times, and I just think it's important for us to remain positive. And I think that we are going to get through this. And we are going to come out even stronger in the long run. So that's all I wanted to say.

FEMALE SPEAKER: Thank you.

AUDIENCE MEMBER: I have one more question. There the savings another thing that I understand is if there is a savings with the global waiver, if that does get passed, suppose that there is another crisis, not anything to do with the waiver but with the state. Will that money that's saved to put aside for the provisions, will that be rated by the general assembly to place it somewhere else?

Medicaid: Global waiver

TIM: I can answer that question. No. By law by law, any Medicaid funds that come to the state have to be spent on services. Cannot be diverted to anywhere else.

LINDA: However the state funds could be taken.

TIM: State funds could be. But any federal money that comes in can't be diverted. I would also like to say, you know, there have been I have been to all the forums. We I have been to five four now. This is my fifth. And you know, this Medicaid waiver has been a major topic of conversation. Everybody's asking questions about it. There really is I think what's happened is the department of human services has put together a proposal, this global waiver, which I guess you've seen, read about. There really it is still a work in progress. Nothing is codified. Nothing is permanent. What happened is they put together they put this together asking Medicaid for sort of wiggle room to sort of create new programs so that they can save money. What has happened is they set they are still working on it and actually there are no budget numbers yet. I haven't seen them yet. And when they get this proposal together, they are supposed to send it down to Washington, as I said a month ago at the end of July. Well, here we are. The proposal will go down to Washington. It will get reviewed by the center for Medicaid services. It will either be approved or denied. There's no definitive answer on that question either. If it gets approved, it will then get sent back to the legislature, to the finance committee in the House. The House will then hold hearings sometime probably early in the fall. So I suggest that we all contact our legislators and state our concerns to them, especially anyone on the finance committee. And then what I would and then certainly make an effort to keep your eye out to make sure that you can find out when those committee hearings happen and show up. And you will find out more about it. It is still very convoluted it's not a complete it's not a done deal yet. And so, I think it's really important that you will understand that, and that the public does have a more say, and there will be sort of a more forum for us to make our opinions heard.

AUDIENCE MEMBER: Thank you.

ANGELA: Yes?

BILL: I am Bill Inlow. And I am on the Governor's Commission on Disabilities Legislative Committee. I also work for RIPTA and I'm closely aligned with the RIDE program and the Maher center and we watch the transportation. And I also live near that intersection up the street. These good folks living in this group home near the Stop & Shop, and I will work with you folks on that issue as a personal thing as well. One thing Tim said I see a little differently, Tim. The current state budget that went into effect on July 1 has in it a savings of 67 million dollars in the Medicaid program. So, the state of Rhode Island, the general assembly, the governor already made a commitment to save 67 million dollars from the Medicaid budget between July 1, 2008, and June 30,

Medicaid: Global waiver

2009, in that year period. So there's already been a big commitment made, whether or not Medicaid go ahead, Tim.

TIM: You and I don't have to debate. I agree. You are right. I do have to mention that is really one of the purposes for this new global waiver is because the state is mandated and Bill, the point is you are saying this is all in draft form. Well, it may be. The document but the fact is the financial commitment the state of Rhode Island is required by law to submit a balanced budget. They are supposed to talk about how the revenue that comes in matches the expenses that go out. There are two ways to balance a budget. Two ways to balance a budget. I held up one finger, but it's two. Increased revenues or decreasing expenditures, right?

BILL: Well, the governor, Don Carcieri in my judgment has failed the citizens of the state of Rhode Island by not supporting any tax increases during his tenure of five years. And as a result, he's made a definite in my judgment stubborn decision to not seek any new tax increases. And as a result, the only other way to a balanced budget is to cut costs. So he has given his employees, the department of human services, many good people including Frank Spinelli, who is the Medicaid director, a mandate to come up with a plan to save 67 million dollars this fiscal year that we are already in, started on July 1 up to June 30 in the Medicaid program. And one way to do that is to cut services to people. It's already occurred. It has already occurred. My understanding is 1,500 to 3,000 children who happen to be children of undocumented so-called undocumented aliens, people who are not citizens of this country have been cut off of health insurance. Isn't that accurate? Somewhat of so if you don't think the state government will cut services to people to balance their budget, you are wrong. They already have. Children have already been removed from health insurance coverage starting on July 1. To me that's immoral. It's despicable. We should all be embarrassed by it because we are all citizens in this state. Just because a child doesn't happen to have a parent who is a citizen of this country doesn't make that child not a human being and deserves healthcare. It's also irrational because they will get sicker, go into an emergency room. And then we will end up paying more in a hospital. And in addition, that child is going to be sicker. And it's our responsibility, all of our responsibilities. First of all, we don't know that. We ought to tell our governor and our general assembly members that that is not something that we want them to do. The global Medicaid waiver will change there are some good things in this plan, this global Medicaid waiver. More flexibility, more individual so-called consumer choice or choice of individuals to get care where they wanted, if they get those choices made. It reduces the number of elder people hopefully that go into nursing homes. Rather they will go into assisted living or get their care in the home. Those are wonderful things. But the proposed global waiver also trades off some commitments on the part of the federal government to provide care to people who need it through the Medicaid program. And the trade-off is we get more the state of government will get more flexibility. But the trade-off is if they don't save money in the next five years compared to what they would have spent, if we hadn't made all these changes under the global waiver, then in the fourth and fifth year we may not get near as much federal money as we currently are or we would if we did not make all these changes. So there's a lot of risk involved in it. If it works, and we save money through all this flexibility, then people will have more flexibility. They will get more home care. They will get more services that they choose and they can manage. And we will have a balanced budget too. But the fact is some decisions have already been made. Some children have been removed from health insurance roles. The budget is already reflecting a savings of 67 million dollars; that good people like Frank Spinelli who is in charge of the Medicaid program have been directed by the governor to save between now and June 30th. So there are some things that are going on. I think it's very important that we all express to the governor, who's our chief executive officer, and for whom all these other people involved in the global waiver work and under his direction they work, what we think about some of these ideas that you will see in the paper. Because as this good person here just said, you know gas went from \$1.35 to over \$4 a gallon just in the last seven and a half years, just in the last seven and a half years. And part of that, in my judgment has been done because of a failure of leadership at the federal level. The failure of leadership, so really dependent upon quality leadership especially from the governor. And so, I have a green sheet over here that has the name and address obviously the name you know. Don Carcieri is our governor, his phone number, his address, his e-mail address. And it also has the name and phone number and e-mail address and snail mail address, as well of another gentleman who is very important in this global

welfare proposal development, and that is a man named Steven Costantino. He is the chair person of the house finance committee. Steve Costantino is a good and decent man. He knows about running health programs. He used to be the director of a community health agency. He is very smart. And I believe, my assessment of him, he's a decent and caring man. And he is working with the state governor to try to come up with ways to control costs but still provide quality care. If you have input to make to those two individuals, I certainly hope you will make it. It's on the green sheet. It looks like this. And again, we need to give our input as citizens. But the fact is change is already being made. Commitments are being made. And I think it's very important that we all speak up as citizens and articulate our opinion about this all the changes that may be in fact are being planned in the Medicaid program. Thank you very much.

ANGELA: Thank you. Are there any comments from anyone on the panel? Would anybody else like to speak?

MARIKA: Can I add a comment? I think it falls if it doesn't, tell me to be quiet. I think the points that were just raised are very important for all of us to pay attention to as voting citizens, as people who represent the different disabilities that we do, and certainly those who live day-to-day life with those disabilities. We all know what that's like. And I think where we could do our part to write to our Congressmen, write to our governor, is that's what's in the state and how the budget's handled. There's a direct correlation to the federal monies that will come in or not come in to this state because the feds have changed they're looking for matching funds from the states. So where programs are getting cut within the state budget, even those of us my organization for one has been vetted from state money as well as federal money. But if we get cut at the state, we will also get cut at the federal. And this is happening not only I'm not speaking here at brain injury. I believe this is happening across what we know as human services and mental health. So what becomes critical as citizens and people who participate or try to get as many services, because God only knows we need more and they are not here, for many is that we need to speak up and voice our concerns as best as we can. Because if the programs that do exist it's one thing to get cut. But if there's going to be if they are going to be cut out of the budget, they are not going to get their matching federal funds. It will go to the states that are providing services. So the ones who are bigger will get more money because they have more services to begin with and larger budgets. We are a small state. And I think it becomes quite critical for us. So when we lose 100 or \$500,000 or whatever, we are going to be losing not just that here. I don't know if I'm saying this clearly or not. But I know within our organizations and the organizations and boards I sit on, where we try to get our constituency to speak up or to write is there's there's a double problem there. One will affect the other. And if the first one gets solved, one will help the other. So, thank you for listening to that. But I just have gone to so many things in the last year and a half. I think it's very critical what's coming up in the next two fiscal years.

ANGELA: Okay.

AUDIENCE MEMBER: I'm for gas coming down and I like transportation (APPLAUSE) mostly for I'm mostly for the working man, the guy out there pumping gas and moving gas, and the guy out there farming some vegetables for us, and the guy out there cutting meat for us, and the guy out there fishing for us, and the guy out there working McDonald's for us or Burger King for us.

ANGELA: Thank you very much.

AUDIENCE MEMBER: I'm for the working man.

ANGELA: Thank you.

TIM: I would like to make a quick point of order, Bill. The are you with the program you are talking about where the cuts were made was part of rite care. That's not the same waiver that we are talking about.

BILL: I'm not saying it is. State government

TIM: They are making the cuts, right.

BILL: State government this governor and our general assembly is willing to stop providing care to some people in order to save money. So, the illusion that the global waiver will increase the quality of care for more people and save money, and it's worth the big risk that in year four and five we may run out of money.

TIM: That (inaudible)

BILL: It is an illusion that government it's an issue of trust. Are we going to trust the governor and the general assembly to make a commitment for us for five years, with a great assurance that it's not going to result in dramatic cuts to people in year four and five? The same general assembly and governor who through the rite care program removed human beings, children, from health insurance already on July 1? No, I don't trust that at all. So, quite frankly, my recommendation is to ask the governor and general assembly to not make a five-year commitment under great distress. We've already made a commitment to save money on July 1. They are making it like we have to do this or all hell's going to freeze over. Well, the fact is, I don't think it's the world's going to end. If the governor excuse me my recommendation is that we urge the governor and general assembly to think about this global waiver in a much more thoughtful careful way. Aim for it to go into effect next July 1, not this year. For two reasons. One, we will get much more chance for people to think it over with before we make a five-year ever risky proposal. And second, we will be dealing with hopefully a different administration. Well, we will definitely be dealing with a different federal administration. Hopefully we will be dealing with people at the center for Medicaid and Medicare services and in the whole federal department of health and human services who are easier to negotiate with. I cannot imagine a group of people after seven and a half years of George Bush and the federal government controlled by republicans I can't imagine a group of people less open to making caring, thoughtful, logical, rational, humane decisions in the leadership at DHHS and the center for CMS that are there now. So I'm not saying that in November when we elect the new president that everything is going to be perfect. But I sure think we will be dealing a year from now with people at the federal level, including those that have something to do with Medicaid at the federal level who are much more open and more focused on human need and not just saving money and avoiding tax increases. Thank you.

FEMALE SPEAKER: Bill, I would just like to add, you are making a very good point that the it's important for people to voice their concerns. And the global waiver is not decided on yet. The legislature is going to be reviewing both the pro's and the con's of what of your proposal has been whether there's beneficial to go now or to wait a year or other options. And it's important for everyone that's why we are here to all let the government know your concerns so that we can voice them and let them know.

TIM: And we certainly will, you know, report on what we are hearing here today.

ANGELA: Anybody else like to speak? The panel will be staying until 5: 00. So we certainly can

AUDIENCE MEMBER: I'd like to make a public service announcement for Newport Hospital, the

Chronic disabilities

Department of Health. They've recently been offering a free program for six weeks on living a healthy life with chronic conditions of heart disease, arthritis, diabetes, asthma, and COPD. And I tell you what. Even if you don't have the funds to continue the one-on-one's for the six weeks, if you can just make this book available or tell people that this book is available, it would save so much turmoil in adjusting to living with a chronic condition, without any support from anywhere. It was written by Stanford University. And it's I mean it's not perfect. But it's a lot better than what we had. So, they are going to be doing it it was done by an occupational therapist, which was good because she has a broader perspective than someone with just a mental illness background and a nurse. I think they are going to be doing another one in the fall. So, if anybody, you know, you should call Newport hospital and ask them to get on their list.

ANGELA: Terrific. Thank you.

AUDIENCE MEMBER: You are welcome.

ANGELA: Okay. We do have some other people.

FEMALE SPEAKER: Just back here. Hi. I want to introduce myself. I am Gwen Reeve. I am with the multiple national sclerosis society and we have a newsletter. If anyone who has MS, I am back here in the back.

ANGELA: Thank you. Thank you for your attendance. Thank you for braving the elements to make it out here. I hope you get home dry. And if you want to stick around, certainly feel free to do that.

## 6. **Friday, July 25, 2008 Providence Public Forum**

KATE McCARTHY-BARNETT: If we can begin. On behalf of the Department of Health, the sponsor of this public forum, I would like to welcome you this afternoon. The purpose of these public forums is to identify

the concerns of people with disabilities and their families in order to assist the State develop programs to improve the quality of lives of people with disabilities. Panel Introductions.

TIM FLYNN: Timothy Flynn, commissioner, Chairman of the Legislation Committee on the Governor's Commission on Disabilities. Very important for us to listen to what you have to say today because what we hear here and at forums throughout the state is the basis for our legislative package that we will be pushing for lack of a better word next fall in the legislative session. So, we'll take what we hear today, review it, and consolidate all of the opinions and what we hear and then formulate a package and present it to the entire state legislature and the Governor in the fall. So thank you very much for coming.

KATE: Thank you, Tim.

ANNE MULREADY: Anne Mulready, attorney at the Rhode Island Disability Law Center. I'll echo what Tim says, and also tell people we have a package in the back, this is a very important forum for us, as well. We also use it to help us figure out what our legal priorities should be next year, both in terms, systemic issues we should work on and also what kinds of individual cases people might need help with. Liz from our office is in the back with packets and also a survey if you could take the time to fill it out, but otherwise we use the testimony here.

KATE: We'll have an opportunity at the end for panel members to share a little more about their agencies and organizations.

CHARLES WILLIAMS: Charles Williams, chief of prevention and planning at the Department of Mental Health, Retardation and Hospitals.

KATE: Thank you.

ELAINA GOLDSTEIN: Elaina Goldstein, Director of Rhodes to Independence, basically long-term systems change grant from the federal government on helping people with all types of disabilities become as independent as employable as possible. And we also have a pamphlet in the book there, on why choose between work and health care, about the 1619A and B and the Sherlock plan. So pick that up.

KATE: Thank you, welcome.

DEB GARNEAU: Deb Garneau from the Office of Special Health Care Needs, Health Department.

FEMALE SPEAKER: Office of Rehab Services, voc. rehab agency.

KATE: For those of you who just came in, if you're interested in speaking today, if you could sign up on the sign-in sheet. The process will be, we'll go through the individuals who have identified themselves as having something to share. The panel members are here to listen and provide feedback and as Tim Flynn said, the information shared today will go back to the Commission on Disabilities and it will be reviewed in the legislative committee for looking at legislative issues and policies that need to be developed. So we would like to keep our remarks fairly brief, about five minutes each and we'll go through the different people who have identified as having an interest in testifying and then open it up to everyone else on the floor.

BETH MAROOTIAN: I'm here from Neighborhood and I was supposed to be on the panel.

KATE: Do you mind just would you like to introduce yourself.

BETH MAROOTIAN: Sure. I apologize for being late. My name is Beth Marootian from Neighborhood Health Plan of Rhode Island.

KATE: Thank you. And if you have identified yourself as speaking, please state your name clearly so that we can get it for the record. So we'd like to begin, first with Anna Martin.

ANNA MARTIN: Hi, my name is AnnaCamille Martin. I'm very they're going to change my health care, not my health care, my agencies, they're going to be putting them all together. Sometimes when they start to change things, they think they should I have a brain injury, anyway, I think they should really talk to people and see what's going on. Sometimes, like the Governor wants to cut there and cut there and cut there, but for disability people, like people in my situation, I think we should really think about it.

Medicaid: Providers

KATE: Okay, Anna, thank you. Would someone from the panel like to share some thoughts?

ANNE MULREADY: Could I ask a question for clarification? Is your current agency being changed, is that what you're saying?

FEMALE SPEAKER: What they're doing is they divided the regions up, and people that, family, they get one and another one is a different region, people that live by themselves. What she's worrying about, if they close down the regions, if the same people will work. Because we're hearing things that they're closing agencies down and going to make it into one. And she's worried about that, losing her staff and what's going to happen.

TIM FLYNN: Can I ask another question who is they?

FEMALE SPEAKER: I've heard from workers and from CNAs from different places and they had said some agencies are going to close down, put it into one. Close like three of them and then put all of those people that were in each one of those and put it into another place.

ANNE MULREADY: May I ask one more?

FEMALE SPEAKER: Just giving off names, like if, let's say they close, say like I kind of told her, what they told me, if they close UCP (phonetic) and they close options and they'll take those people and put them in another agency, that's what she's worried about, they'll close UCP down and the other ones and put them somewhere else and people won't --people that do work for her won't be working with her any more, will they all be supported by people of another agency.

ANNE MULREADY: I think you answered my question. You're concerned that maybe some agencies that provide DD services won't be there and their staff might your staff might change, is that right.

FEMALE SPEAKER: Yeah.

ANNE MULREADY: Okay.

KATE: Any thoughts from anyone else on the panel?

FEMALE SPEAKER: I think our role is just to be sure we understand the question.

KATE: Okay. All right, thank you very much Anna for sharing that. Next person who has requested to share today is JAY PADROFF. Thank you.

J. PADROFF: Thank you. I'm honored to be here and I want to say that I have hoped that these meetings

Housing: Accessibility

would take place in Providence since I first heard about the Commission when I lived in Rhode Island in 2001 and 2002 and at that time I understood from the Commission that there was no desire to hold the meet cans outside of Cranston and then when I moved back to Rhode Island about a year and a half ago, I looked into the situation by contacting Providence city haul and they said they would look into the situation and they never did get back to me on it but eventually I found out that occasionally meetings are held in places other than Cranston and as I told City Hall, I would expect that Providence being the capitol city would host meetings of, government meetings of this kind of significance. And as a handicapped person from birth, I've experienced considerable discrimination and difficulties in housing and other areas of my life when I'm in Rhode Island, that I do not experience or do not experience to the same degree when I've lived in, for example, New York city or Los Angeles. I've had atrocious situations herewith Rhode Island housing and mortgage company. I've had considerable problems with RIPTA, everything from the non handicapped stairways on the RIPTA buses to their demanding freezing cold temperatures in the summertime on the buses and to tropical heat on the buses in the winter time and as someone with fibromyalgia and blood clots, I have altercations with difficult bus drivers because of not wanting to experience a fatal blood clot during my ride on RIPTA. Some of them are not temperature sensitive as well as sensitive about the fact that the bus stairs are supposed to be working if the bus has stairs so that they can go up and down. And I was kind of rejoicing that the trolleys going to be discontinued because the steps on the trolleys were even more difficult but now I hear that the plan to keep the trolleys and change the engines and I was hoping that they would get mini buses on the order of the Key West Transit system because those mini buses don't have any stairs, they just come in level with the curb. So, that's the problem that I've had with RIPTA in terms of the buses. I've also had problems with the RId service and

Transportation: RIPTA

Transportation: RId

that their scheduling is not, does not facilitate what I need for my life activities and they're over priced compared to what I pay for RIPTA services. I think a person with disabilities should not pay more for a RIde service than they do to ride a bus or subway. Aside from that, there have been other problems with the RIPTA bus stops in that I've reported at times that the, in Providence, I'll stick to Providence in this, that the Thayer street bus stops were being blocked out by the businesses that, that were proximity U.S. to the bus stops and they ended up moving the stops over to the tunnel which was even more difficult and hazardous to wait but made the business owners pleased and in downtown Providence, there have been issues with the seating being taken away such as at Washington and Matthews street. And of course we all know about the dismay goes of Kennedy plaza that took place within the past decade and turned it into something horrendous for everyone, especially for handicapped people and the condensation of the buses into a tiny mite area in Kennedy plaza with the iron bars and the difficult curbs and uneven paving that exists that the buses are always going on and --it's very bumpy, it's very easy to fall. I fell on Halloween avoiding the piles of horse shit that have cropped up there since Mayor Cianci left office and the Providence police department was able to bring in horses and, crapping on the Kennedy plaza enormously everyday. I've reported that to the police department, to various local organizations but it doesn't seem to make a difference but Kennedy plaza seems to have been turned into the circle of hell from the relatively nice place that it had been when I first came here in 1985 and until the ruination happened in the mid 90s and of course while the ruination was taking place, the construction, the bus riders were sent all distant points everyday to a different point to get your bus. So I think overall the disrespect that RIPTA has shown for bus riders, in particular for handicapped bus riders is phenomenal. The other one or two points.

KATE: Could we take a moment and touch upon the RIPTA concerns.

Transportation:  
Accessible

BILL INLOW: My name is Bill Inlow, with disability services coordinator at RIPTA. I certainly will convey the comments that this gentleman has made to the senior managers at RIPTA who make policies in those regards. In response to one thing, it's a policy of RIPTA that all future RIPTA buses, each and every bus purchase in the future instead of having a wheelchair lift that is prone to failure,-- instead of that, all future regular RIPTA transit buses will have wheelchair ramps in the front of each of the regular fixed route buses. Each of these new buses, we have about 50 now out of a total fleet of 250 these new low floor buses, the floor of the bus is lower to the curb and again, instead of a wheelchair lift, it has a ramp that goes out in the front of the bus and the wheelchair position in those vehicles are located in the front of the bus rather than the rear, closer to the driver and in the front which is in most vehicles, a more comfortable position for a person in a wheelchair to ride rather than there are of the bus. But the main thing is these ramps that are literally just 4 by 8 pieces of aluminum that flip out into the curb and through which a person in a wheelchair or a parent pushing a child in a stroller or elder who has a cane can enter the bus more conveniently than going up two or three steps. That is, I think progress, and will represent better service to all of our customers, especially those with disabilities. The other details this gentleman described as I said, I'll be glad to convey to the policy makers at RIPTA.

KATE: Thank you. Did you have anything else you wanted to share?

Accessibility: Sidewalks

JAY PADROFF : Just as far as RIPTA, it's my hope that Kennedy Plaza should be restored as much as possible to the way it was in 1990 which was much more preferable in terms of the space and the lack of hazardless and lack of iron bars and police horses and the numerous waiting kiosks, like the ones at main in Pawtucket that existed over the whole area over at better than side park and maybe past better than side park. Those were good waiting areas and didn't force people into condensed spaces and then you have the mayor and police complaining that the high school kids and whatever creating too much criminal activity because they're in too condensed space but that's what RIPTA created. RIPTA created that hazard. And it's not something that the people or the bus riders would have ever wanted and it's just a horrendous situation. And really much more thought needs to be placed in terms of the waiting areas because the removal of the benches is not a good thing. The moving of the bus stops like they did on Thayer street into the tunnel isn't a good thing and the scheduling of the buses is done with a complete lack of common sense. For example the buses that take you into Olneyville square, the 27 and

28 are timed to come at the same time so you can wait 30 minutes and then the 27 and 28 will come for example, instead of spacing them out 15 minutes apart so you don't have to wait so much. That's consistently happening. I've noticed the buses that take know East Providence. Thing these are of course things that effect all bus riders but especially the handicapped. More and more difficulties on our plate everyday. Also, just to reiterate about the RId service. It's my belief that RId should not charge a bus rider more than they pay on a regular bus.

The other matters more serious matters I've experienced in Rhode Island is the ditz with the Department of Human Services, adult service department or adult service division. I've reported that to the old Governor's office because I've had these problems since 2001 or 2002. And it's, as a person who qualified for Title 20, homemaker service, which is administered through adult services, I find enormous difficulties and discrimination with the various agencies that are given the contracts and there are other agencies that are not given the contracts and there seems to be quite a bit of at least restraint of trade to use the legal term, if not outward on a graph or something that's going on. But I'm being forced to link up with agencies that don't speak my language, that don't know how to do the basic requirements of shopping for me, which are included in the requirements and on the other hand when I'm in Los Angeles, I get to choose my own workers and the government pays them. Where as in Rhode Island I have to go through these particular agencies that are selected and most recently, I've been told that I have to use nursing agencies even though I'm not receiving nursing services. I'm just receiving title 20 homemaker services and it doesn't make the slightest bit of sense to me whatsoever and I strongly recommend that they shift over to whatever is the system in Los Angeles currently, as soon as possible and they also investigate the charges of corruption that I submitted about the adult services department years ago to the old governor.

Medicaid: Homemaker service

KATE: If I could intervene, we do have someone from our panel today. Frank, do you have anything to share from DHS.

MALE SPEAKER: We'll look into it. It's not nursing agencies, it's home health agencies qualified as a title 20 vendor. Probably half, about 70 percent, but there are a couple who just provide home health homemaker and personal care services. That network is open, so I'm kind of confused by your comments but I'll check into it because any home health agency that participated and services title 20 individual. The issue you say about language and culture is one that's across the enterprise because trying to match workers to culture and language of the participants is a difficult challenge and we can see if we can do something to that effect.

JAY PADROFF : Currently there were two languages available, Spanish and French, and it's my own needs require English and Yiddish and Hebrew. The workers that they send are inappropriate in that respect and in appropriate in many other respects, as well.

MALE SPEAKER: Like I said we'll check your comments about personal care attendants, our title 20 program is very limited and only does use certified agencies. If you, if an individual did meet a nursing home level of care, which, puts you in the situation, a lot more personal care needs, we do provide that option to individuals in that category. As a matter off act we have close to I think 400 people available as personal care attendants. I guess California does it across the board for the title 20 program.

JAY PADROFF : I'm not talking about personal care, I'm talking about home making which is laundry, shopping, cleaning the apartment and those sorts of things. And I find nothing but trouble with the agencies that are given to me and one of the people this past year, one of the workers was highly insulted that I called him a homemaker and not a nurse but he was working as a homemaker not a home health it's a miss begotten system here that doesn't work and it's in tremendous disarray and it's just easier for me to wall owe in my own disabilities than to have the stress and in sanity of dealing with these non workers that come to me sporadically when they feel like it and the agencies, they give me nothing but sass and grief.

KATE: Thank you for sharing and thank you Frank, we'll move on for the sake of time to a few other people.

JAY PADROFF : One other thing briefly --since my article strike that. Since my letter to the editor appeared in the Providence Journal criticizing the Providence public libraries for not being responsive to handicapped needs, I think that was in 2001 or 2002, the Providence public libraries have done everything they

can to make me feel un welcome, used security mechanisms to communicate with librarians to minimize the help they give me and make me feel particularly un welcome, not put out chairs for handicapped people near the desks, to disappear when I go to reference services and the situation has escalated since I went to city hall last October to complain and there are now severe legal ramifications that I will be bringing to the government offices within the next two weeks.

KATE: We'll have an opportunity to share with our panel member a little letter. Thank you very much for sharing. Next person who has requested sharing today is Laurie Archambalt.

LAURI ARCHAMBALT: Can I speak like this? Okay. My name is Laurie, this is my son Jarrod Taylor (phonetic), he is 28 years old. Some of you may be familiar with our story, ran in the Providence Journal last May. Born with severe mental retardation and total blindness, complex medical history that includes seizures, severe osteoporosis autistic like tendencies and has behavioral issues. Jarrod has the cognitive ability of a two or three year-old, a vocabulary of 50 words, requires assistance in the simplest activities including using the bathroom. He can never be left alone. He cannot express his needs effectively and will never be able to self advocate, direct his own services, vote or live independently. In 2005, I had no other alternative but to remove him from the group home where he had lived for 3 years to protect his health and safety. Through no fault of her own, another client living in the group home at on his head while he lay sleeping on the couch. A few days after removing him from that home I applied to MHRH for new residential and day services. I am still waiting. He is not receiving the intensive services needed to flourish, not receiving any services at all. The current movement towards self advocacy, choice independence and responsibility is wonderful for those people who want it and are capable of self advocating, making choices and hand willing responsibility. My son cannot do any of these things. If pushed too far, this movement will totally eliminate necessary services for him who requires intensive services to keep him healthy and allow him to live the most fulfilling life he can in the face of his disability. During my research of the current system of services for the DD population I estimate that there are about 500 people with severe to profound mental retardation. Who advocates for these people who cannot themselves. How many of these people have said, I want to live independently? Or I want to vote? The answer is none of them because due to the nature of their disability, they cannot do these things. Individuals with severe to profound mental retardation have no choice but to depend on the understanding and compassion of others to design and implement an array of service that is would not only include them but meet their extensive needs. It is my opinion that the state of Rhode Island wants to hide behind this global waiver. I feel shedding the responsibility to the DD population. With the cap on funds services will be spread thin and people like Jarrod who require care will go without services. Waiting lists will grow. I would ask the self advocates to acknowledge there are many people served by this system who cannot advocate for themselves, make choices or handle responsibility. A comprehensive system of services needs to be in place to insure all people with developmental disabilities receive the services they require. I think the system should include various levels of care to coincide with the varying levels of disability. We need hospitals shall nursing homes, group homes intermediate care facilities for the mentally retarded as well as shared living and foster care. A few points I need to stress. His seizure disorder is unpredictable. Also appear to occur more frequently. A few months ago we were heading out for errands after a 30 minute ride to our destination he had a seizure as I was attempting to get him out of the car, I managed to break his falling to the ground, we were force today return home, he just want today sleep. That's his usual routine after a seizure, sleeping a few hours. It was a struggle to get him into the house safely. Few weeks after that, he had a seizure while shopping, he feels pushing the carriages he always did you see, I was holding my grandson, took all my strength to get him and my grandson to the floor safely, there was no one around to help. I don't take Jarrod shopping because he enjoys it, I have no choice. I don't have anyone to watch him. Just recently, he was swinging on his ham mock, had a seizure, bruising and cutting his needs. Sunday night during Jarrod's shower, he had a seizure, unfortunately, I was unable to catch him as he fell from the shower and hit his head on the porcelain part of the toilet, next five hours amount emergency room trying to obtain X-rays and an MRI for which he was helpfully sedated. He was helpless but not

Self advocacy

Medicaid: Global waiver

completely harmless. He is self injurious as well as aggressive behaviors. In January, I was walking him through the yard to his swing, he was kicking and ended up tripping me, I sprained my ankle. Just yesterday, July 24th, 2008, he was taken for his blood work, two nurses and I restrained Jarrod, he bit my breast and left teeth marks. Anyone want to see it? Since Jarrod is totally blind, he is apprehensive walk not guilty unfamiliar places especially when forced to walk up or down steps. Behaviors in these situations include kicking pinching, biting, and screeching. Someone like this with these issues is not appropriate for a shared living arrangement, adult foster care. How long do you think a stranger will put up with this situation like those I have just mentioned before becoming frustrated and possibly assaultive with him. I have a fuse questions for the Governor. I want to know where his services are and why I have to wait so long for them. What happened to the committee on mental retardation referenced in the statutes? This is supposed to be a permanent committee to address the needs of those mental retardation. There have been no appointments to the committee in 18 years. The only member at this time is MHRH. I would like to become a member of this committee, please forward an application to me. Where is the advocate for group homes, children have an advocate and there is an advocate for mental health. I am due to have a surgery by the end of August, I need at least two-weeks to recover. I do not have anyone to care for Jarrod. When I ask department staff about respite care no one had a clue what I was referring to. Maybe the Governor wants to baby sit. Thank you.

KATE: Thank you for sharing. I would like to open it up to the panel if anyone has any thoughts to share?

MALE SPEAKER: We'll bring your comments back to the department of mental health, retardation, and hospitals and look into the commission.

FEMALE SPEAKER: Thank you.

KATE: Did you want to introduce --

CHARLES WILLIAMS: Charles Williams.

FEMALE SPEAKER: Nice to meet you.

KATE: Karlton.

KARLTON BONTAGGER: I had indicated interest in discussion with the transportation issues so I want to

Transportation: RId

piggy back on some of his comments. Mine are more towards the RId program because that's what I my name is Karlton Bontagger. So, one of my primary issues with the RId program, I think RId is wonderful because it gets me all around the state for my education, for employment issues, therapy issues.

RId is very helpful and I try not to complain much but there are just too many issues that it's hard not to complain he had talked about scheduling and one issue with scheduling is that I have a hard time, when they pick me up for a two-mile adjournee even pick me up for example, today from my home in East Greenwich to this meeting at 4: 00. They picked me up at 3: 00 with a taxi. Only takes less than a half an hour but they give me a full hour to make this journey. It's a frustration when this impacts my daily rituals or what I need to be doing with my life. Suddenly I find out there's a bus waiting for me because they decided to pick me up an hour early. So scheduling is just one thing I want to talk about. Another issue I wanted to bring um is the fact that RId parallels very closely the regular RIPTA bus schedule. So when I was studying at Providence college this past spring, I had a, 3different classes that ended at 9: 00 at night and o the RId bus would not bring me back to East Greenwich so I had to devise a way where the RId bus would take me to TF Green Airport and I would call my mom and she would pick me up at ten o'clock at night and drive me home. This is a woman who is a Providence school teacher so shed to be up at 5: 30 or 6: 00 everyday. So this is another n a sense, a scheduling issue but one example of how it really impacts my life on a daily basis and I was hoping that perhaps somebody in the RId or RIPTA program, I know Doug Wood is not here but if someone could address this and hopefully we can get RId to be more efficient and helpful.

KATE: Thank you. Bill, did you have any feedback?

BILL INLOW: As you said, Doug Wood is the director, he's not here. I'll convey those comments. Both the positive ones, and I thank you for those, as well as the critical ones, and I thank you for those as well. We serve 3000people a day with the RId program. That's up from 750 a day eight years ago. And the numbers of

people who qualify for the RIDE ADA program, major qualification of which is that their disability has to prevent you from using regular RIPTA transit. In accordance with the federal law, the RIDE services, people can't use a regular RIPTA bus. Paratransit is comparable to transit, only operates where and when regular RIPTA buses operate. That's our minimal requirement and quite candidly due to the budget, and the cost of fuel, I don't see any hope we'll be expanding the volume of our services. We are working hard to increase the quality, to decrease the inconveniences and outright mistakes and error that is we make in providing services to our customers with disabilities. We do have an advisory council that meets every month. I'd be glad to give you my card a venue wards and have you join that. It's made up primarily of our customers with disabilities who use regular RIPTA buses as well as people who use RIDE vans and I am pleased to say that our general manager, meets every three months personally with those customers with disabilities and not only speaks to them but listens to them and so we have heard these concerns. Right now the RIDE program is going through a transition program --reservation computer system that has caused a lot of inconveniences to our customers and we regret those. It is our best hope that we will rapidly improve those. But I want to be really clear. We serve 3000 people a day with the RIDE program. Many multiples of that number are served everyday who are regular fixed route buses including a lot of people with disabilities who ride fixed route buses and we regret the mistakes we make but we're proud of the things we do well we do a lot trying to minimize the mistakes and increase the quality of service we provide. Thank you very much for your input.

MALE SPEAKER: Thank you Bill.

KATE: Thank you Bill, thank you Karlton. Next person who requested to speak, Rosanna Doughtey.

ROSANNA DOUGHTHEY: Thank you. I thought I might have to wait. I am here because I have a daughter, 30 years ago she has been in the state system since she was 13 and she has a couple of concerns, especially with all the changes that are going to be coming about financially with the Medicaid co-pays. And with the RIPTA, with the cutback in service and the possible having to pay for their bus passes. Right now she uses, she has a free bus pass and she uses it everyday that it's available to her. She lives down in west Warwick, she's serviced by Kent County mental health. She does live on her own. She's been living on her own for, not quite two years now. She uses the bus because they've cut down on transportation over at Hillsgrove House so under the program that she is using I'm sorry (phone ringing), let me turn this phone off. I'm sorry. She uses the bus to get to Hillsgrove House. She uses the bus to get to some doctor's appointments and some she has staff that take her to the doctor's appointment. I live up in Burrillville so she uses the bus number 9 which RIPTA has looked at to try and maybe cut or make sure she uses that to come up to my house so that I don't have to travel down from Burrillville to west Warwick and back again to bring her from my house down to west Warwick and back again to bring her home so that I just have a one way commute. And with the financial end of it, with Medicaid, she is concerned because it says she price it had out with her pharmacy that it would cost her about 47 dollars a month for her medicines because she take a total of 16 different types of medicines. Now if you put that in with having to pay for a bus pass or having to pay for bus service, you're squeezing people that have a very fixed income and it's not just her. It's like a good portion of the people on SSI because she's on SSI, and the Medicaid. And those were the major concerns that we had and I thought, well, they want to hear what the families and members have to say (phone ringing).

Transportation:  
Affordable

Medicaid: Co payments

KATE: Well, thank you for sharing. I would like to open it up to the panel members if you have any thoughts or feedback.

TIM FLYNN: She lives at Hillsgrove House?

ROSANNA DOUGHTHEY: She doesn't live at Hillsgrove House.

TIM FLYNN: I'm unfamiliar.

ROSANNA DOUGHTHEY: It's a club house for the mentally ill down in Kent County. It's provides a place for the people to go, some type of staffing services, counseling, not really counseling services but it tries to get people in transitional employment, they have different tasks to do at hills grove house so that it gives them some

type of in-house, not really employment but volunteer work. It also helps them to get their GED or get into college, to get scholarships. It tries to make them active productive members of society.

TIM FLYNN: She lives on her own.

ROSANNA DOUGHTY: She does live on her own but she is serviced by Kent County. She is on a program called RIACT (sounds like), she gets a limited, I don't think any transportation except for a caseworker. She gets to see a psychologist and a psychiatrist under limited terms. At this point because she's been in a downward spiral, they're going to be moving her down to a mobile treatment team where she'll get more services.

TIM FLYNN: Okay.

KATE: Frank.

FRANK SPINELLI: Frank Spinelli. Medicaid program. I assume your daughter is on Medicare because Medicaid does not have co-pays.

ROSANNA DOUGHTY: She's not paying anything right now. She is on Medicaid and she is concerned about the possibility of having co-pays with her drugs, with her taking so many of them. It puts a big crunch on a limited budget.

MALE SPEAKER: I understand which is why a year and a half ago that doesn't necessarily mean in the future we may, and the concerns would be real, but at this point in time there is no Medicaid co-payment or plans to do so. Just want to make sure.

FEMALE SPEAKER: They don't have the plans right now, okay, then I will bring that back to her.

FRANK SPINELLI: I don't know what the future will bring with the state of the economy, but right now

FEMALE SPEAKER: Your name again.

FRANK SPINELLI: Frank Spinelli.

KARLTON BONTAGGER: Mr. Spinelli, I'm on the rehabilitation waiver, I'm wondering would this be something, through Medicaid that would be something that would help her.

FRANK SPINELLI: You mean going onto directed?

KARLTON BONTAGGER: With my waiver, I have somebody from Lake View Ocean State come up and help me with, organizational things, to get my apartment properly equipped so that I can live I live on my own and the things that might not be organized properly on my own can be addressed. I'm wondering if this would be a program that would serve her.

FRANK SPINELLI: I would have to look at it: The PATH (phonetic) waiver has unique requirements you have to meet across the disability community so you would have.

KARLTON BONTAGGER: Okay, thank you.

ROSANNA DOUGHTY: Right now her services from Kent County mental health are good.

MALE SPEAKER: They did evaluate her and move her up to another level because as you said she's spiraling in the wrong direction --which is a good thing that they're doing that.

TIM FLYNN: At the beginning, I didn't get your last name is?

FEMALE SPEAKER: Last name, D-O-U-G-H-T-Y.

TIM FLYNN: Thank you very much.

KATE: Thank you. At this point in time we'd like to open it up to anyone else who is here today who did not necessarily identify that you wanted to speak but if you have something to share, we'd like to open it up to everyone else who is here, if anyone else has anything else to share.

DIANE CUCEIA: Diane Cuceia. I'm on disability and my son was diagnosed with a brain disorder, I've owned my own home for 18 years, I've called every state agency in the world to see, Jack Reed finally sent me to Rhode Island housing to fix things around my house because when you only get the little amount you get, it's enough to pay the gas bill, maybe, because you're on a budget with everybody. And they said the only which they could help me is if I had a mortgage and I was losing my house. I said well, I was fortunate enough

when my husband was alive, he did pay my house off and like, what's the problem? We don't understand. I still have to pay house insurance, gas bill, my electric is astronomical. I don't know who else to turn to. I haven't applied for anything other than my son gets death benefit from my house so I don't know where else to go. People who own their own home on disability and paying 150 a month toward the gas company, 125 a month toward the electric company and you need a phone if anything happens, they found my son one day in the park facedown with blood all over him and rushed him to Hasbro, they can't do surgery yet because the tumor on his brain isn't big enough. It's been one thing after another, I've had issues with my town and I had flooding and my insurance company wouldn't pay, I've had mold where I had to take my tax money and have removed. I don't know who else every state agency I turn torques they always tell me to call another one and nobody seems to know, like, what's going to happen to people like me with their homes, they'll lose them for 3000 people cans tax sales because they have other things that they have to pay? I don't know if there's any help for anybody like us

KATE: Thank you for sharing. Open it up to the panel.

ELAINA GOLDSTEIN: Are you on Social Security Disability now?

DIANE CUCEIA: Yes.

ELAINA GOLDSTEIN: you get benefit from your husband.

DIANE CUCEIA: Because he's deceased.

ELAINA GOLDSTEIN: you have a certain income. Are you on Medicaid also or not?

DIANE CUCEIA: I get the red, white, and blue card.

ELAINA GOLDSTEIN: so you're not on Medicaid.

DIANE CUCEIA: They kicked me off because I get that.

ELAINA GOLDSTEIN: because of your social security income.

DIANE CUCEIA: They said I have United Health with it, Blue Cross, they said I wasn't eligible any more so I pay for my prescriptions. It's \$3 but sometimes I go with pennies to CVS for prescriptions. So I don't know what else I'm going to do. I mean I've had to let my house insurance at times laps to pay for a gas bill or electric bill. It costs me a hundred dollars because I didn't know there was a program that would take me to Boston to the surgeon for my son so I had to borrow money and a car because my car would never make it there. Now I found out there's place that is would have given me a ride there but nobody ever tells you until like you're in a situation, like, okay, I didn't pay my gas bill.

ELAINA GOLDSTEIN: there's a called the point. Are you familiar?

DIANE CUCEIA: No.

ELAINA GOLDSTEIN: it's informational and referral agency. Does anybody know the number of the point? It's P-O-I-N-T, the Point. If you call there and you tell they have a broad range of services that are available across so you wouldn't have to call every agency. Also if you call 211.

DIANE CUCEIA: I tried that.

ELAINA GOLDSTEIN: that wasn't helpful?

DIANE CUCEIA: They couldn't find any programs for me. And they cut down heating assistance last year and supposedly cut it right off this year and it's going to hurt a lot more people. Even people that work and make really good money, it's going to hurt so many people. I'm on the board of directors at Tri-town so when I see a lot of people come in now, more than ever because they can't afford food.

ELAINA GOLDSTEIN: can you work.

DIANE CUCEIA: I tried to get apart-time job for ten hours a week because I have bad anxiety.

ELAINA GOLDSTEIN: I'm serious because you don't have to work that much, I'm saying, but, to start out, but if you there's a program called the Sherlock act plan that, you can be making actually a lot of money and still be on Medicaid, and potentially, if you increase your income a little bit, I think you just need more money is really what you need so you won't lose your health care though if you were able to do that and there's people at the office of rehab services who could be incredibly helpful with that and help you get trained.

DIANE CUCEIA: I am.

ELAINA GOLDSTEIN: I mean, you could apply for services to ORS and you can work if you're getting SSDI, you know, your benefits are not going to be effective unless you're working at a certain level of income, probably ten hours a week if that's what your goal is not going to effect your income. So you would be making your money, say, even \$8 an hour.

DIANE CUCEIA: I would work 40 hours a week if there was a job where I didn't have to use my hands all the time and I could be available to my son.

FEMALE SPEAKER: Ever applied for voc. services or office of rehab?

DIANE CUCEIA: Nobody has told me.

FEMALE SPEAKER: I'll give you my card and you can apply for services and a counselor will meet with you and help you and evaluate your skills. You obviously worked in the past. We provide all kinds of training and work opportunities. You know, assistance, on the job training to give the incentive to help you become employed. We can purchase whatever service that is could help you become employed. So it might be a good idea to at least check it out. I'll give you my card after.

DIANE CUCEIA: I do miss working a lot.

FEMALE SPEAKER: It's a great way to feel better sometimes too.

ELAINA GOLDSTEIN: You're very articulate.

FEMALE SPEAKER: You could also connect with Family Voices at Rhode Island Parent Information Network around your son's condition and some service that is might be available, their number is 727-4144.

DIANE CUCEIA: I did sign up with brain injuries in Warwick but that's.

ELAINA GOLDSTEIN: Introduce yourself, Sharon.

DIANE CUCEIA: Far for me to go from North Providence, especially with gas being 4dollars a gallon. Taking a bus I would probably have a panic attack but I d read the fliers whenever they send them and they're always from to answer questions so I appreciate that.

ANNE MULREADY: I just want today respond that some cities and towns have tax abatement programs for people with disabilities so if you're getting yourself in a position where you feel like you're getting behind on that you might want to check with your city and town and it's not consistent throughout the city and state but that might be something worth looking into as times get tougher, making that more a statewide thing because some cities and towns it has helped peep am keep their homes.

DIANE CUCEIA: Every time I go to the doctor, they always transfer just when they start to get to know me and all the things that are wrong with me, transfer to women and infants so I never get a doctor long enough to fill out the forms.

ANNE MULREADY: Maybe with your son's disability, too, your city or town might include that as a household member.

FEMALE SPEAKER: Thank you.

FEMALE SPEAKER: I wanted to ask, id you say you have a Blue Cross plan through Medicare and you're paying co-pays.

FEMALE SPEAKER: I do.

FEMALE SPEAKER: We could look into, they have different levels. I believe they have a level that doesn't have a co-pay associated with it. They have different plans within their Medicare. So, if you want I could give you my card and we can make a contact and we could look into that for you.

DIANE CUCEIA: Thank you very much. I appreciate it.

KATE: Next person requested to share is Tony DuPonte.

TONY DUPONTE: Hi. I really appreciate this opportunity, I saw it in the paper. Disability and I'm talking about is intellectual disabilities, low developmental students and in Bristol County Rhode Island in Bristol and Warren and Barrington, we've had adults

Education: Intellectual disabilities

attend a GED program, the night school, for 23 years and all of a sudden this year, our budget, the budget was cut and we were disconnected. We don't have any funds, which really don't amount to too much because it's only about three salaries, comes to approximately six thousand dollar from October until May, we meet once a month, once a week, excuse me, once a week. And it really is, when you think about the fact that these people have intellectual disabilities, when you think of the fact that they get such good attention for the Special Olympics and that's very important for their social and physical and many other things, it's so important that they continue their intellectual development. The state and the federal government has been very good in allowing them to be in school until they're 21 years old and it's a shame if we have to stop at that age, and that's what I'm advocating for, for the department of education, the state department of education, to recognize these people as adult who have special needs but they're adults and should come under the umbrella of the adult education budget, shouldn't be discriminated against. We've had it for 23 years. It's a combination I think of the town or city who submits and gets a percentage of their budget from the state, I think that's how it works out. And I'm sure they're not discriminating intentionally but this is what happened this year. So that's what I wanted to say. Thank you very much.

KATE: Maybe, does anyone on the panel have anything to share?

ELAINA GOLDSTEIN: is this a specialized. money, do you know?

TONY DUPONTE: Well, each town gets the state provides adult education moneys to each town. So Bristol, Warren, Barrington is regional setup. So they get a budget to handle things like most commonly is GED. Okay? And other things. It could be computer. It's multiple things. I think most of the budget comes from the state. We have a director of adult ed. but sometimes, I mean, it's kind of unique that Bristol, Warren and Barrington does this, I think every community should do it because these people are in all communities. And they really, I mean, after --imagine after 23 years, they're still coming to class. They've come for 23 years and some of them have continued to come for 23 years. I mean that in itself shows that it's something that helps them, socially, and now the big key thing was the computer. I mean,-- one of the problems with the low developmental is their writing, their handwriting is such that it's not too clear. When they do the computer and see their sheet come up, they just jump for joy because it looks so good and it's not anything, you know --it's level 3 or 4. I'm not talking about advanced but it's just so, the money, your question was, the moneys come from the state. I'm a little confused because I think the state received extra money this year in adult so, I don't know why this happened. We have 20 students in those three towns and we're going to try and continue it in other ways but I'm just advocating it for Bristol county as well as any other community in the state. Okay, thank you very much.

KATE: Thank you, Mr. DuPont. At this point in time if you could just state your name.

MARGARET WINTLE: Margaret Wintle. My question is regarding health care. I have a daughter, disabled daughter in her 40s and she was always covered on a family plan either by my husband or myself but this year we both required and no longer have a medical, family medical plan, and we were refused services for my daughter because she only had Medicaid, and I just want to know if this is legal, and if so, how can you determine which doctors or hospitals or walk in facilities will not accept Medicaid, because this was very embarrassing to us, and also, stressful to my daughter because we could not get medical help for her in an emergency situation.

FRANK SPINELLI: Every hospital in Rhode Island accepts Medicaid. So if you were at a hospital and they refused you as a matter of fact each hospital in Rhode Island, public hospital, they're not-for-profit are required to treat emergencies. Anyone in this room has a situation where they're total they can't, they should be put into the department of health. Doctors, there's no law in Rhode Island or any state that requires any doctor or provider to accept Medicaid. They can choose not to. We have maybe about ten percent of the provider communities in the state has decided, as a matter of fact, in certain specialties, particularly unfortunately in the area of psychiatry, a lot won't accept any third party coverage, whether Blue Cross or whatever. If your daughter is on disabilities, we have a new program, we have two programs, care management program, one is called partners she can enroll into one of our managed care programs, like Blue Chip, United or Neighborhood and they will help your daughter access medical providers. The other policeman is called connect care choice.

ConnectCare choice, if primary care doctor is a member, will get a nurse manager to help make arrangements for the specialties. So there are options available to help you get the doctors. But particularly in specialties, there's some specialties in this state that, and my colleague sin third parties will tell you, they can't even get them to enroll in their own plans. They just decided they want private picks, there's nothing we can force them to do. So I would recommend that you might want to contact our offices, or the Point, to direct you, to get information about the health plans or ConnectCare Choice. Most of the primary care doctors in the state accept Medicaid. Do you want to add to that anybody.

FEMALE SPEAKER: Thank you very much.

FEMALE SPEAKER: I guess I would just as somebody from Neighborhood Health Plan which is one of the plans that Frank referenced participating in Rhody Health Partners,-- we both have extensive networks of primary and specialty care doctors and we know when we started the program what we heard from consumers like yourself and your daughter was the importance of access particularly to specialists and behavioral health providers, as well as support in getting those services if you're having difficulty, finding the doctor.

FEMALE SPEAKER: Less doctors --

FEMALE SPEAKER: Yes, you would be enrolled in a program that's just Medicaid, so you would be pointed to providers in the Medicaid network that take Medicaid. So that's definitely an option for your daughter to find providers.

FEMALE SPEAKER: Thank you.

KATE: Any other okay. Thank you very much. The next person who has indicated that they have something to share this afternoon is Susan Heard thank you. Susan.

SUSAN HURD: My name is Susan Hurd. I guess everyone can hear me, I just want to make sure. I'm disabled with a medical condition that's includes neurological Lyme disease and weekend my immune and nervous system so I deal with severe allergies and multiple chemical sensitivities. Over two percent of the population is disabled with multiple chemical sensitivities known as MCS creates overwhelming obstacles and disability challenges. There needs to be a tremendous amount of education awareness to provide accommodations. So, what I did today is managed to get some information photocopied so that you folks can have a better understanding of how accommodations can be provided. That's how change starts to happen. I could go on about my own tough story and I know that there's only a limited amount of time. I will tell you that I am a success story and I have overcome overwhelming obstacles with the help of the occupational rehab services, I have been able to get my masters degree and become a holistic counselor in training. My goal is to become licensed in the next year, work in an integral clinic, still low income, not getting paid doing my internship training. So, hopefully in time, my economic status will change. In the meantime, I am threatened with homelessness repeatedly. And I also have a lot of trouble finding places to work and to attend many events. On top of chemical sensitivities which creates adverse neurological reactions Ideal with severe life threatening reactions to peanuts and nuts so many place that is have food, people will have peanut snacks and that's enough to give me a reaction which also makes housing tough, I can't be in apartment buildings. I need I've been trying to do what I can with the HUD in getting rental accommodations. There is no housing available for chemical sensitive people in this state N this country, the only HUD complex to accommodate those with chemical sensitivities is in Marin California. Just like people who need wheelchair accommodations, people with sensitivities need activities that require more green materials being used. We're talking about zero to low VOC paints in carpets and building materials. That makes all the difference between me being able to live and work in a place. So often I've been hunting for housing, so many landlords tell me, I just put brand new carpeting and painted and immediately I say thank you very much, I can't be there. Trying to find a place that will work for me is a needle in a haystack. I've been very fortunate with at least with my internship that I work at the rehab hospital in a clinic where they make these accommodations. Simple things, air pure fires, honoring fragrance free, skipping the purr fumes and strongly scented deodorants. It causes harm and a lot of peep don't understand that. in Nova Scotia, a leading university providing accommodations partly because over 600 employees came down with MCS at their city hospital. The result is it has an impact on everyone so they started making changes back this is a

Multiple Chemical  
Sensitivity: Awareness

10,000 population international university and they're doing it. Dalhousie, their health and safety office a whole excellent pact which I photocopied to help you understand what goes on. For example, one of the questions hearsays what happens if I don't adapt sent free practices and the response is you are taking the risk of possibly causing harm or severe pain or discomfort to someone around you, that could easily be avoided. When employees or students miss time from work or school because of MCS there is a cost. Illness means lost productivity, lost opportunities for learning. Finally you undermine. Dalhousie provides an environment which supports all members of the university community. I think that's an excellent response and this is something we all could be doing. Another question here. I would resent being told or feel uncomfortable telling others what kind of personal care products to use. Isn't it the request to adopt sent free practice intrusive on individual's right to where whatever he or she wants? Their response. It may at first seem that asking people to use sent free personal care products touches on a personal and private matter but when the scents from these products affect the health and well being of other people, it then goes beyond just a matter of private concern. The goal of this awareness campaign is not to target peep am personally or to criticize people's preferences, rather it's to prevent real harm to real people. I say bravo to that. I wish more people just understood this, that it is real harm and when people show up wearing overwhelming fragrances when you go into buildings with new carpeting down, it automatically prep vents me and others who are disabled with MCS from being there. I have a good head on my shoulders and have a lot to offer and so often I'm not able to contribute or be included because accommodations just are ignored or not understood. So the more education, awareness that we do, the more that sensitivity with accommodations will take place, just with like happens for any other disability accommodation.

TIM FLYNN: Question. Are you involved have you heard of toxicology project in Rhode Island.

SUSAN HURD: Yes, with Liberty Goodwin, yes, thank you so I would like to pass out to you folks on the committee information dealing with Dalhousie, to show maybe you folks in RI how to better help us. They also have an article dealing with employees and supervisors, how to make accommodations and handle it because it can get awkward and people can get out of shame. So they have excellent suggestions in how to go about this.

KATE: Thank you Susan.

SUSAN HURD: I also copied my own handouts that include suggests for housing accommodations as well as web sites. To help you better understand, housing and medical accommodations. And just some facts on MCS.

TIM FLYNN: If I can interrupt for one second. I think it's great. What we can do is attach all of this to the record of this meeting and in a report we send out, we can file that as an attachment. Maybe you and I could talk after this meeting and figure out the best way to get that done, to send it to our legislators and the Governor.

KATE: I can take copies on behalf.

TIM FLYNN: You can take copies on behalf of the panel here. I've been on the legislation committee for probably seven-years now and, you know, in the past, say, four years, with liberty's help, we have become aware that this is a real issue and really causes problems for people to access services, hospitals, schools, and the like. We really have sort of, we're making a push in that direction so I would encourage you to join our legislation committee and help us formulate a way that we can either institute rule making or legislation to make this happen.

SUSAN HURD: I would be happy to do that.

TIM FLYNN: I thank you for coming.

SUSAN HURD: Chemical sensitivities is on the rise because of the amount of toxicity in the environment and it is something that is apart of our life but as of right now over 30percent of the population is chemically sensitive to some degree. People get headaches, asthma attacks, migraines, vertigo and it's increasing to 60 percent of the population which means more people than two percent will become severely disabled as I did. A lot of people with Lyme disease also develop sensitivities for reasons that are understood.

TIM FLYNN: Thank you very much.

KATE: Thank you for your testimony. I can take those and then we can pass them out. At this point in time we'd like to open it up again to the floor if anyone else joining us this afternoon would like to share anything or have any questions for the panel members.

KATE: Any other thoughts or suggestions for the panel members? Welcome.

FRANK MARTIN: My name is Frank Martin. I've only been in a wheelchair for nine years. You know, government grants that peep people don't know are there. I had an idea about I was trying to think, why couldn't the disabled community get a grant to stop (inaudible) these old mills have elevators and so you get to start from scratch and not do a lot of rehab. But I got too sick again. The past nine years I spent more time in the hospital than I've actually spent out and I here in Providence and I think it was because I was going to sue them because they put me in the developmentally disabled ward for nine and a half months at the say so of a nursing home that I was sent to. Months later then found out the owner of the nursing home had been embezzling all the time, and one week later they said, get your stuff ready, we found you an apartment and dumped me in this hole. They had a \$1,500 grant but gave it to some ambulatory guy who lasted one night so when he didn't make it they gave me his broken furniture. My house looks kind of like a junkyard. I thought it was a half decent idea to buy one big complex where, especially for younger people.

TIM FLYNN: Frank, could you speak up a little.

FRANK MARTIN: There's not a lot of accessible stuff to do after dark in Providence. In my neighborhood you hear gun shots quite a bit. Like right now I have a nursing service that if they put me, because I changed to an 88waiver because I had to go to the nursing home and I could teach the nurses in circles on how to run back pumps. About killed me after six months. They told Zambarano that I was smoking pot and drinking and some baldheaded director guy said they had a place for me I told them I said you think you're accepting me you're crazy. Then this social worker said they won't send you there, I promise, do you want me to call them? It was my friend's daughter that I grew up with. Then wound up sending me up there and locking me up for nine and a half months until they found out that, you know, they lied. They never even took a test. I said didn't you like ask for tests for anything. Why would I escape from a nursing home, I had an apartment, I could take a taxi home. Just giving you the raw edge of the sword, you know, when you took the 1500bucks and gave it to the other guy who is still back up there. They need to make like, more accessibility for people who still have, you know, the wherewithal to do, or want to do things, and be able to get to do them, you know. It's still a lot of things I've never done in my life even though I have I had done many by the time I got hurt but there are still many I want to do. But it's, you know, the cash thing, you know, but I'm never well enough to go to work. At rehab, they twisted my neck around, the halo was stuck in the guardrails of the bed and the lady perforated my urethra so I was stuck with kidney --they wouldn't let me go, you know, even though I signed the DNR or whatever it is.

TIM FLYNN: Can I interrupt you for a second, Frank? Where are you now what are you looking for? Are you getting any you're living in a house.

FRANK MARTIN: In an apartment.

TIM FLYNN: And are you receiving home care services?

FRANK MARTIN: I have an agency, a girl I went to high school with happened to --because they were trying to stick me, you know how they back door some people the first time I was at Zambarano, the legal aid said Frank whoever you're talking to up there, stop it because we're never going to hear from you one day.

TIM FLYNN: I can't hear you, Frank, I'm sorry.

FRANK MARTIN: There were allegations ever patient abuse and I was giving information to a nurse and I said, don't use my name, well she went ahead and used my name.

TIM FLYNN: I'm just trying to keep it current as to where we are now.

FRANK MARTIN: Well, where we're at now, I don't know, I'd like to oversee a project of that size, even, that's what I did all my life with buildings, you know.

TIM FLYNN: So, you're living you have a roof over your head and you have services at home so you can get up in the morning and do all that.

FRANK MARTIN: I still have the same wounds I went into the hospital with. I know what works at healing me and what doesn't.

TIM FLYNN: Are you healing now?

FRANK MARTIN: They send in a nurse every other day and whatever progress I make when they're not showing up, they rip it off before they bother to wet the bandages so two weeks worth of skin growing will come off in two seconds. Doesn't make any sense to me.

Housing: Accessibility

ANNE MULREADY: Frank, I think I heard you say two things that you think there should be more accessible housing options for people with disabilities and then maybe more options for recreation and night life that are accessible those are the concerns for you.

FRANK MARTIN: Yeah, but right now he's kitting everything, so until they either turn it over to somebody else and they let more money go, none of it will happen.

TIM FLYNN: You say you want to work, right?

FRANK MARTIN: Yeah.

TIM FLYNN: But your health is getting in the way.

FRANK MARTIN: Well these stupid tubes are supposed to be reversible, have the operation and have it reversed and they told me that whatever that woman did to me, it was beyond the scope of work for him to fix it.

ELAINA GOLDSTEIN: Are you on Medicaid right now?

FRANK MARTIN: Medicaid, Medicare, Blue Chip Optima.

ELAINA GOLDSTEIN: Sued like some of your problems.

FRANK MARTIN: I've never sued anybody.

ELAINA GOLDSTEIN: I wasn't going to tell you to sue exactly.

FRANK MARTIN: I was hit by a car in a --

>ELAINA GOLDSTEIN: I think you need to get your health care stabilized.

FRANK MARTIN: I'm trying but how do you stabilize your health care when they don't listen to what works and doesn't. How can the state come into my house and then say you have to go to a nursing home.

ELAINA GOLDSTEIN: I'm not sure who is saying that. I was going to suggest, Frank talked about, the new programs that are out there now when you're on Medicaid, you can join up with Rhody Health Partners and join up with connect care, those are two programs where they actually will, there's a team of people what are going to be working with your whole condition to kind of help stabilize all of this rather than maybe being in the fee for service system that I think you may be in.

FEMALE SPEAKER: Did you say you're in Optima? I think we can talk about being sure have you a care plan that works for you.

ELAINA GOLDSTEIN: once you get that done, you need to get to ORS because it sounds like you really want to work.

FRANK MARTIN: The vocational thing, my social worker talked to me about that before they sent me for IV --

ELAINA GOLDSTEIN: we're going to think on what Tim was saying. I know it's hard to forget the past, not keep it current but try to get you a future. Sounds like you want a future, right?

FRANK MARTIN: Yeah.

ELAINA GOLDSTEIN: this lady is going to help you get your health care stabilize, it's a very good program. I glad you made it here today and this lady over here is going to get you involved with a plan to help figure out what you said you had good skills or things you've done before you were injured that there there's a lot of things with assistive technology, things you don't even know that is corrects you could work maybe not in

the best of health but you could still do. They could help with all of that, I think you just need good people helping you get coordinated here.

FRANK MARTIN: I called a friend of mine, to change my waiver because I had to get on that because the wound center had some kind of contract with this nursing home for extended pump care. Stupidest thing I ever did in my life was let people with licenses take care of me.

ELAINA GOLDSTEIN: I hear you had some bad problems herewith some people but I think that Beth is going to try and get you a good care coordinator person that's going to be able to, you know I'm glad you made it here today because.

FRANK MARTIN: This is where I got my EMT license in this building.

ELAINA GOLDSTEIN: You have an EMT license?

FRANK MARTIN: I did until they told me I was too old when I was 31. Interviewed me I went to high school with and the other guy was like 67 years old, told me I was too old. Go figure, you know.

TIM FLYNN: Thank you Frank.

KATE: Yes, another --

DIANE CUCEIA: Diane. I was wondering if it was possible, they have there versed mortgages for the elderly, I called up and said would I be eligible, I'm only 46. They said no, if they could start a program like that for people on disabilities like myself that eventually, my son has two more years of high school, say, when he's hopefully goes to college if everything works well and we do go to sell the house with the economy how it is, people like me can't afford even a one percent mortgage, if that would be a possibly. Because I've called numerous places about it, to start another program. Because it seems top work well for the elderly, they get to live in their house until the situation arises, either they pass or decide to sell their house.

ELAINA GOLDSTEIN: were you involved with that, the disability law center, the reverse mortgage bill.

DIANE CUCEIA: I think something, like people on disabilities would be a great.

ELAINA GOLDSTEIN: MHRH

MALE SPEAKER: No, we saw the bill but were not involved.

ELAINA GOLDSTEIN: a bill just passed I think last session, the Department of Elderly Affairs was involved. Some people were getting ripped off so a piece of legislation I'm assuming for the elderly but when there is a piece of legislation like that, it's possible what the Commission could do and the Legislative Committee, take that legislation and have it affect people with disabilities at age

Housing: Reverse mortgages

DIANE CUCEIA: Basically carry it over to our taxes, our water bill was astronomical, just our basic necessities, not go overboard because we should be able to manage some of our money but with prices going up it would help people like myself pay their bills, even if there was an allotment.

TIM FLYNN: I never even thought of it but sounds like a terrific idea.

ELAINA GOLDSTEIN: Ask you to join the Legislative Committee, too.

DIANE CUCEIA: Sign me up.

KATE: Does anyone else have any questions or suggestions, concerns they'd like to share this evening? Okay, I think at this point in time then, just want to thank everyone for coming this afternoon, for sharing. As we mentioned, it's your thought and feedback, suggestions and concerns that help the Commission on Disabilities and the sponsoring agencies really look at these issues in detail. The legislative committee will be reviewing all of the testimony that's been shared this afternoon and this evening and policy recommendations, legislative recommendations were made from that so the paneling members will be staying for about another 15 minutes so if you have any direct questions for them, they'll be here for a few more minutes but we wanted to say thank you so much for taking the time to come this afternoon sharing your thoughts. Thank you.

## 7. **Written & Emailed Testimony**

Public Forum Written Comments

From: Susan Eleoff  
Ocean State Center for Independent Living  
1944 Warwick Ave  
Warwick, RI 02889  
July 8, 2008

As an Information and Referral Specialist at the Ocean State Center for Independent Living (OSCIL), an organization advocating for persons with disabilities, I receive many phone calls from people with disabilities and their family members and caregivers. The majority of callers are looking for financial assistance to maintain independence - thus allowing them to remain in their homes and communities. Often callers are seeking funding for ramps, widening doorways, and making bathrooms accessible. Other common requests are for rails, grab bars, bathroom equipment, stair lifts, and assistive devices for activities of daily living. With so many funding and program cuts, I have to tell callers that OSCIL has at least a two year waiting list for home modifications.

It is my understanding that our state government wants to keep Rhode Islanders at home whenever possible, thus avoiding costly nursing home expenditures. In order to remain at home, however, many people need financial assistance for home modifications and assistive technology. Most of OSCIL's callers are living on Social Security and are low income. They can barely afford utilities and food and do not have resources to pay for or take loans for home modifications and assistive devices.

On a related note, cutting back hours for home health aides and homemakers is also detrimental to keeping people with disabilities in their apartments and homes. Several callers have told me they are on waiting lists for DHS to assess their eligibility for long-term care waiver programs and do not know how they can remain at home without help. Some have said the lack of home community support services will force them or their family members into nursing homes.

Obtaining affordable and accessible apartments is another key concern of people with disabilities calling OSCIL. The waiting lists in most cities and towns are years long.

OSCIL has recently worked with some individuals who were "stuck" in nursing homes due to the lack of accessible and affordable apartments.

As well as seeking affordable housing, many people with disabilities need affordable transportation because they do not drive. Bus service needs to be increased and fares must remain affordable. Currently, a round-trip fare on ADA Paratransit is \$7.00. This fare is already difficult for some to afford.

Keeping people out of nursing homes and helping others relocate from nursing homes back into the community should be a high priority. With resources so limited, our legislators need to conduct an in-depth review of the cost savings by providing community support services, transportation, home modifications, and assistive technology instead of using Medicaid dollars to pay for nursing homes.

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I am disabled and am unable to pay the cost of fuels. I had to rely solely on agencies to supply my heat last winter. My rent was \$1000. a month and I had to pay all utilities. I only get \$1100. so my son shares the cost, but he too is disabled and gets \$881. the oil averaged \$250. a month and we are very conservative on it. We also have propane and the electric. I do not get food stamps and have to pay part of my medical. Our total monthly bills come to over the combined amount we both make. So I got a part time job to make ends meet. Now, this will not work because of the rising cost of everything. I will be in the same boat as if I hadn't had a job at all.

Housing: Affordable

My part time job only affords me minimum wage at 20 hours a week and this is just a temp job. So, where does my family go from here? I also have to leave here because my landlord was foreclosed on. Rents are so out of reach we may end up in the streets. I am too old (62) for this, and disability doesn't allow for the cost rising until the end of the year.

We are given a cost of living allowance, but the amount given doesn't even match the actual cost.

I was once a working class person, I didn't ask to be disabled, I would rather work, I could certainly make more and live better.

I am so disgusted with the system. Is there any fix for us? ?

More and more people are forced into the streets. I remember when the homeless numbers were only a few hundred. Now they are in the thousands.

M Petrangelo, Coventry, RI

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Unfortunately i will be unable to attend any of the forums being conducted this week.

My major comment is the inability to help a great majority of disabled people find jobs. Many people like

Employment: Job  
placement

myself are quite able to work o an extent and make a positive contribution to the company that hires us. I have thirty five years of accounting experience and still can not find a job! The state needs to make a better effort at telling

employers about the tax benefits of hiring disabled people.

Thank you

Matt Ferrucci

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I cant attend your forum. I do have a disability. My biggest problem is that I have Medicaid. Thanks be to God. But then there is another problem. Is not easy to find specialist that will accept Medicaid. I have

Medicaid: Inpatient  
services

arthritis. Every once awhile one of my legs act up. I get the worse pains. I was sent to have an E-M-G. The ones that could see me right away was the APC Building in Providence. I get there and I get an intern. the intern then

tells me that for that test to really work that I would have to wait another week and go back to them for the test. I wanted to have the test done right away. I have been suffering with this pain for over 2 weeks. I take pain pills. They only work for a little while and then the pain is back. I also feel that i get the run around because i only have Medicaid. You realize that gasoline has gone up too high. I am on a fixed income. Then to top it off they are telling me I need to go back to Providence for another test. In the past I have gone for the injections for the pain. Its my understanding that these injections only last for awhile. I heard that the operation may be better for me. I just can't find the right Doctor for this problem. I do my best with what I have. I have had this problem for many years. I am not complaining about my regular Doctor for he has great, and he has done the best that he can for me. I just wish that I could find the proper care for my leg or legs. Even in the Memorial Hospital they are so booked that I would need to wait to be seen. I really need a specialist that knows what he is doing about my legs. Osteoarthritis, and this pain. Because of this I also have to go for counseling. For I get so depressed with the pain and i cry. I am trying to keep active. But is hard to now do my house work. I don't know if this is the right place to write to. But please! At least let me know where i need to go. Also a place where a real Doctor will see me. I don't want any intern practicing on me. If they do. I want a real Doctor in the room with the intern. I also don't want the intern looking down to me. Meaning the intern is no better than I am. I am human. I can tell by their stares and also by their actions. I don't like the idea of the Doctor being in the other room and sending the intern in the room by herself. Thank you. May God bless. I can be reached at

Date: Wed, 16 Jul 2008 12: 48: 25 -0400>

Judith Jorge

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Dear Sir/Madam:

I am on disability because I have muscular dystrophy. I have an adult onset type that is slow moving. My problem is the housing issue. I would like to see the process for finding an appropriate apartment made easier. I am on the waiting list in Cranston and Warwick. I am told that it will be a couple of years before an apartment can be found for me. I would like to be able to download one application and fill it out and e-mail it to all the appropriate apartment buildings in the state. It would hopefully cut down on paperwork for everyone. One of

the biggest problems is that most of the apartments in the state do not have elevators. In California there are a lot of apartments with elevators. Make a requirement that all apartments now being built in the private sector and public sector should have elevators and have ground floor apartments that wouldn't require climbing stairs.

I would like the state to have a database of people who are looking for housing and are disabled that would be accessed by private and public housing authorities so that they could contact the people.

I can't think of anything more that would help me right now.

Thank you for your concerns and hope that this is helpful to your agency.

Sincerely,

Sharon Ellery

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Dear Commission

I am e-mailing my testimony in hope it will be a contribution to this Public Forum.

Housing: Home  
modifications

This program has  
impossible to relay my good  
of independence once again  
away, you would better understand the grief it gives you not to have independence.

While I realize many programs are being cut and funding is becoming hard to acquire, I sincerely feel Home Modifications and Adaptive Equipment should not be one of these programs.

Adaptive equipment

benefited me so much, that it would be  
fortune to you, and have you grasp the feeling  
given to me. If you have ever had it taken

I was sad, and didn't talk about my feelings. A devastating surgery left me unable to move my leg never mind drive. I had to find a way to get to my Doctors appointments, grocery shop, pay bills and just get out of the house. This is a chore when you cannot drive, for even public transportation does not take you to places dear to your heart .

So I stayed home, became tired and fat. Became sad and felt helpless. Then I spoke with Linda Bradley from the Ocean State Center For Independent Living. She gave me a spark of hope. A way to regain what I had before my illness, a reason for being.

With her help and OSCIL, I had a hand brake put into my car and now you cannot keep me from the things I need to do and Church and friends and well who knows what else I will be doing now.

I thank Linda, OSCIL and the Commission for making it all possible, and I urge you to not take away these services to others as I know how they are feeling even though they may keep it inside.

Please, please consider not cutting this program or its funds. I thank you and many more thank you.

As is said, God works in many mysterious ways. I will be praying that the mystery of why ill health is given to some will be, as he wishes, somewhat heeled by you.

Thank you so very much

Mae Anthony

Woonsocket, R. I.

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To whom it may concern:

Transportation: Disability  
parking placards

I am considered permanently disabled because of a lung problem and have been granted handicapped parking privileges by the state of Rhode Island, Division of Motor Vehicles. In January of 2009 my privilege expires and under our present state law it must be renewed which will require the same process it took to get the privilege in the first place, i.e. a form completed by my Doctor and resubmitted for review by an independent panel to see if it has merit. The registry has told me that this panel only meets monthly and has so many requests that it does not finish reviewing them every time they meet so the review is pushed up to the next meeting date. I have talked to other people who are in my situation who have told me it takes months for

this renewal process. One unfortunate person applied in January and did not receive the red sticker with the new date until late May. In the interim the handicapped person can't park in designated parking spots without subjecting themselves to being ticketed and paying a fine.

My question is if a person is permanently classified as handicapped why do they have to reapply every two years? This seems like a waste of time for the panel whereas if they only had to review those who are deemed temporarily handicapped it could take less time and speed up the process for all concerned.

Thank you for considering my request.

Gail C. Durfee

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Received July 15, 2008

Veteran's Benefits:  
Spouse support

Please help elderly widows 81 and up. We are devastated enough when our husbands die but to lose \$2600.00 a month in income from the V. A. too is too much. The V. A. needs to let us keep our husbands compensation checks until we die. I'm 81.

(For) Jenny Lupino

Warwick

P. S. I'm bankrupt and if I go to a nursing home it will cost Medicaid \$6000.00 a month. My V.A. Champas Medical stopped too and I am a sick Diabetic widow of RI. Judges keep their husbands checks! This happens to lots of RI widows like Carmella Perry (Cranston) and Florence Scotti (Pawtucket). V. A. checks gone.

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FAX TO: 462-0106

RI GOVERNOR'S COMMISSION ON DISABILITIES

FROM: JAY PADROFF

I am adding to my remarks made at Providences' Public Forum last Friday (7/25/08).

Please let me see a copy of the dictation taken and let me know how these various matters are being addressed by your office.

Please let me know how I can be of further assistance and keep me informed of all your meetings that are open to public participation or witness.

Providence Public Libraries

Discrimination

Complaints against Providence Public Libraries specifically management: Dale Thompson, Dan Austen, Donna Whiting; also circulations Beverly Kleiberd; fox Point's Sandy Oliveira; Rochambeau branch reference librarians; PPL's board of trustees; security agency staff.

Refusing my request to acknowledge electronically on my card "HANDICAPPED ACCOMMODATION REQUIRED" although Kleiberd and Whiting conspired against me and notated surreptitiously on my electronic card record for staff not to accommodate me. They also phone or emailed various librarians who were accommodating me in order to threaten and berate them. Donna Whiting told me mysteriously on the phone, "We're watching you."

I have received shabby treatment at PPL since my letter to the editor appeared in ProJo a few years ago citing the lack of handicap accessibility and unfriendliness to the disabled.

I had been assaulted at Fox Point Branch while making my way down the indoor stairwell when elevator was often out of order. The past few years, this elevator has been totally shut down, yet PPL management fraudulently lists this as one of the handicap accessible branches. PPL should close and relocate all branches not handicap-accessible.

PPL's enmity toward me has escalated since last fall, and I have experienced overt and subtle anti-handicapism and anti-Semitism there.

At Central/Empire, I have complained of the following: refusal to keep any seating near reference desk (2<sup>nd</sup> floor); continually filthy and rusty and disrepaired handicapped restroom (2<sup>nd</sup> floor); moving free periodicals away from entrance and up to 2<sup>nd</sup> floor; unplowed and dangerous Empire Street after snows so that I could walk to cut curbs at corners.

Last fall, I reported difficulties and discrimination to Serena Conley at Providence City Hall who said she couldn't do anything although the RI Attorney General's office told me that Providence City Hall is in fact responsible for PPL and their bad behavior.

PPL's management has used their security and surveillance mechanisms and personnel to intimidate and humiliate me in an attempt to take away my First Amendment rights.

Case Study: One incident at PPL's Central/Empire branch (the cornerstone of PPL's "empire")

A frail elderly Jewish woman I know went to the downtown library on Monday 3/24/08 at 7PM to read that day's Pro-Jo. She walks real slow with her walker. She was accompanied by a differently-abled male neighbor (witness).

She would normally have entered on Empire, then made a left, found the newspaper on the shelf in the periodical room, sat herself down, and read the paper till closing. She infrequently came to the library these days and had helpers take out books for her, on her card.

But the periodical room had just been disassembled (with handicapped adults being ordered out of the room by security). She was directed to the unattended reference desk on 2<sup>nd</sup> floor (no seats) to get the newspaper. Then they demanded her library card which she had not brought, and they sent her back to 1<sup>st</sup> floor circulation to replace it before she could look at the newspaper. From there, back up the elevator to 2 to get the paper, and there was hardly time to read it before the library's closing at 8.

#### RIPTA

Transportation: RIPTA

- 1) Trolleys: Replace with mini-buses that have no steps like in Key West, FL
- 2) Kennedy Plaza horrendous misery for handicapped.

Last Halloween, at about 5PM, I was changing buses at K. P. and fell down with my quad cane while trying to avoid a pile of horse shit. It took two police officers to lift me off the ground and get me over to the proper kiosk. Isn't it obvious that K. P. was more than okay fifteen years ago, and that it's been destroyed and made an awful hazard a disgrace by a variety of unwholesome factions (including RIPTA < the State House, and Providence City Hall). Give us back the wonderful K. P the way it used to be. Now it's worse than the San Antonio Greyhound station. Put it back the way it was.

#### DHS Adult Services Division

Medicaid: Homemaker service

I have not received consistent, reliable homemaker services (title 20) in all my time in RI. In California, I have been able to hire my own people and have them reimbursed monthly, which works better than having to go through these peculiar RI health-care agencies whose personnel don't seem capable of meeting my needs. DHS won't pay Homemaker Agencies, which would meet my needs –this smacks of "restraint of trade. "

There appear to be under-the-table dealings between the privileged agencies and the DHS. This needs to be investigated. The culprits I have dealt with in this mess are Frank Spinelli (personally referred to me by Jane Hayward), Frank McAleer, Michael Gorman, and through his secretary Gary Alexander.

I have found DHS Adult Services to be devious and duplicitous. When I finally arranged to have a hearing, I was "in-house" and I did not receive a fair shake (nor could I expect one given the characters involved).

Furthermore, I am very dissatisfied about having my Medicaid switched over to this neighborhood Health Plan Rhody bureaucratic megaplex. I have not received adequate, satisfactory dental services in all my years spent in Rhode Island.

## MY DISABILITY TESTIMONY

To Governor's Commission on Disabilities From: Gail A Patterson

Name: John O Pastore Center Date Sent: July 29, 2008

CC: Forum Comments on Disabilities

Message: My comments for Disabilities Forum (unable to attend because of illness)

My name is Gail Patterson, born and raised in Rhode Island since 1961 and a U.S. citizen all my life. I am now 47 years old with 3 adult children from a previous abusive marriage. I was a stay at home mother who sacrificed her career and future to raise my children myself at home when they were young.

After sixteen years of marriage, I finally could no longer bear the abuse and divorced their father. Finally, able to enter the work force to help support myself and children I began a career with working with the elderly.

Social Security: SSDI benefits

Unfortunately, during the time of building up my credits with social security, I had become physically unable to work any longer with having to have several surgeries on my cervical discs and also degenerative disc disease and other ailments that deemed me by the judge in a court, as "disabled".

After that ruling, I was then denied assistance from disability because I was lacking about 4 credits toward social security. Unable to continue working, I applied for S.S.I. which by that time I had met and married my

Social Security: SSI benefits

present husband today. Social Security denied me any assistance based on his income in the household which was slightly over the accepted amount for me to receive any help. I then appealed that decision with legal assistance to help me

with my case. During the time of appeal I was allowed to have Medicaid assistance as a second insurance to help me while appeal was in progress.

Again, social security insurance and Medicaid was denied to me and I was taken off the Medicaid. Now, unable to prove my disability to gain any help anywhere in the state of R.I. I receive no help whatsoever.

It is a struggle to gain any beneficial help for my disabilities now. With my health becoming even worse off now, I cannot even dream of earning the extra credits I need for permanent disability. At least the Medicaid insurance was helpful with paying my co-pays and for oxygen and other needs for all of my health problems. I feel I am a victim who has fallen through the cracks of the red tape that exists in the disability program in R.I. We are honest people, and my husband works very hard (physically) as a sheet metal foreman who cannot make ends meet with all the additional costs of my medical bills. I need insulin for diabetes, oxygen for sleep disorder, pain medication for my bodily chronic pain for degenerative disc disease, pain therapy etc...the co-pays are killing us quickly and I feel I am entitled to some type of assistance because of my disabilities. What good is it to be deemed disabled in a court of law, and then left on your own to try to live a productive life? I cannot even keep up with my own housework on my own, I need help....but, can't afford it.

There has got to be an answer to this predicament somewhere. The lawyers have given up on my case and now I am left to just suffer physically and mentally, being told there is nothing I can do to help my husband with our financial problems....please help me find an answer. Is there anyway to get any type of help in my situation, or do I continue to be victim of the system?

Gail Patterson

THANK YOU FOR HEARING MY TESTIMONY

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To whom it may concern:

Because of the new \$2.00 CHARGE TO AND FROM MY PULMONARY THERAPY AT NEWPORT HOSPITAL, I will not be able to continue. I live at Anthony House in Portsmouth, am on oxygen 24/7, and have a genetic lung disease that is helped by monitored physical therapy sessions three times a week. Ongoing Pulmonary Therapy was ordered by my Pulmonary Doctor, Dr. Sidney Braman at RI Hospital.

I am 66, disabled and on social security, pay almost half of my income on medical insurance, oxygen, prescriptions, and doctors appointments. I pay \$50 a month for the ongoing rehab at the Newport Hospital as well. I will now have to stop going to Pulmonary Therapy because I can't

Medicaid: Transportation

afford an extra \$50.00 a month in transportation. And that \$50 a month for transportation is not deductible for HUD as a medical expense. If it were I might be able to tolerate it.

I am now doomed to go downhill physically and have my breathing ability compromised. Pulmonary rehab keeps me in better breathing shape. I am so very disheartened to be caught in such an insensitive new rule from the DEA that effects my future health, and the health on many who will be forced to stop going to physical therapy.

I am also saddened that the poor seniors, who were going to and from meal sites for their \$3.00 lunches, will not be able to afford the cost of a \$7.00 lunch. Many of them are on very low fixed incomes, and find it difficult to get to a grocery store.

There must be more humane ways of cutting real fat out of the RI budget.

Sincerely,

Pat Hegnauer