

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



**July 23 – 27, 2007**

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

John O. Pastore Center – 41 Cherry Dale Court  
Cranston, RI 02920-3049  
e-mail [disabilities@gcd.ri.gov](mailto:disabilities@gcd.ri.gov)  
401-462-0100 tty via 711 or fax 401-462-0106

November 2007

Copies of this information are also available in Braille, large print, audio cassette, and electronic file on computer disk or downloaded from [www.disabilities.ri.gov](http://www.disabilities.ri.gov).  
Contact the Governor's Commission on Disabilities

# Table of Contents

Table of Contents.....	2
Topical Index:.....	2
Index by Organization:.....	2
Public Forum Sponsors.....	4
Purpose of the Public Forums.....	6
Procedure following the Public Forums.....	6
Community Concerns & Recommendations.....	6
Health Care.....	6
Housing.....	8
Support Agencies & Programs.....	8
Transportation.....	8
Testimony.....	10
Monday July 23, 2007- Independence Square II, URI Campus.....	10
Monday July 23, 2007- Middletown Library.....	29
Wednesday July 25, 2007- Woonsocket Senior Center.....	39
Wednesday July 25, 2007- Barrington Public Library.....	53
Thursday July 26, 2007- Warwick Public Library.....	60
Friday July 27, 2005- RI Department of Health.....	76
Written & Emailed Testimony.....	92

## **Topical Index:**

Accessibility pgs.....	<a href="#">33</a>	<a href="#">48</a>	<a href="#">75</a>	<a href="#">78</a>	<a href="#">79</a>
Blind and Visually Impaired pgs.....	<a href="#">30</a>	<a href="#">51</a>	<a href="#">59</a>	<a href="#">71</a>	
Deaf and Hearing Impaired pgs.....				<a href="#">64</a>	
Developmental Disabilities pgs.....				<a href="#">81</a>	<a href="#">82</a>
Education pgs.....	<a href="#">42</a>	<a href="#">69</a>	<a href="#">85</a>	<a href="#">86</a>	
Finances pgs.....				<a href="#">32</a>	<a href="#">56</a>
Health Care pgs.....	<a href="#">11</a>	<a href="#">14</a>	<a href="#">15</a>	<a href="#">31</a>	<a href="#">56</a>
Health Care Benefits pgs.....				<a href="#">43</a>	<a href="#">85</a>
Housing pgs.....	<a href="#">25</a>	<a href="#">28</a>	<a href="#">48</a>	<a href="#">65</a>	<a href="#">66</a>
Legislation pgs.....	<a href="#">78</a>	<a href="#">79</a>	<a href="#">81</a>	<a href="#">82</a>	<a href="#">88</a>
Local Government pgs.....				<a href="#">74</a>	<a href="#">77</a>
Mental Health Care pgs.....	<a href="#">11</a>	<a href="#">12</a>	<a href="#">41</a>	<a href="#">61</a>	
Public Notification pgs.....	<a href="#">21</a>	<a href="#">79</a>	<a href="#">90</a>		
Safety Programs pgs.....				<a href="#">67</a>	<a href="#">83</a>
Support Agencies and Programs pgs.....	<a href="#">16</a>	<a href="#">19</a>	<a href="#">22</a>	<a href="#">40</a>	<a href="#">46</a>
Transportation pgs.....	<a href="#">13</a>	<a href="#">26</a>	<a href="#">30</a>	<a href="#">32</a>	<a href="#">35</a>
Voting pgs.....	<a href="#">42</a>	<a href="#">43</a>	<a href="#">47</a>	<a href="#">53</a>	<a href="#">59</a>
Working and Health Benefits pgs.....	<a href="#">66</a>	<a href="#">73</a>	<a href="#">80</a>	<a href="#">86</a>	<a href="#">88</a>
	<a href="#">39</a>	<a href="#">60</a>	<a href="#">78</a>		
	<a href="#">12</a>	<a href="#">17</a>	<a href="#">24</a>	<a href="#">39</a>	<a href="#">47</a>
	<a href="#">68</a>	<a href="#">72</a>	<a href="#">84</a>		

## **Index by Organization:**

Brain Injury Association of RI, Inc. pgs.....	<a href="#">27</a>	<a href="#">51</a>
In-Sight pgs.....	<a href="#">37</a>	<a href="#">58</a>
Long Term Care Coordinating Council pgs.....	<a href="#">8</a>	<a href="#">37</a>
Looking Upwards, Inc. pgs.....		<a href="#">27</a>
Multiple Sclerosis Society pgs.....		<a href="#">51</a>
NAMI Rhode Island pgs.....	<a href="#">51</a>	<a href="#">58</a>
Neighborhood Health Plan of Rhode Island pgs.....		<a href="#">51</a>
Ocean State Center for Independent Living pgs.....	<a href="#">8</a>	<a href="#">37</a>
Office of Rehabilitation Services pgs.....	<a href="#">8</a>	<a href="#">27</a>
Opportunities Unlimited for People with Differing Abilities, Inc. pgs.....	<a href="#">37</a>	<a href="#">51</a>
	<a href="#">58</a>	<a href="#">74</a>
	<a href="#">27</a>	

PAL pgs.....	8	37	58	74
PARI Independent Living Center pgs.....				37
Rhodes to Independence @ University of Rhode Island/College of Pharmacy	8	37	51	58
RI Department of Elderly Affairs pgs.....				58
RI Department of Health pgs.....	8	27	37	51
RI Department of Human Services pgs.....			27	51
RI Department of Mental Health, Retardation & Hospitals pgs.....				8
RI Disability Law Center pgs.....	8	27	37	51
RI Disability Vote Project @ Community Provider Network of RI pgs...	8	27	37	51
RI Governor's Commission on Disabilities pgs.....	8	27	37	51
RI Public Transit Authority pgs.....	8	27	37	51

	<p><b>State of Rhode Island and Providence Plantations</b></p> <p><b>Public Forums</b></p> <p><b>To identify the concerns of people with disabilities and their families</b></p>
<p><b>Monday July 23, 2007 3:30 – 5:30 pm</b></p> <p>Independence Square II, Independence Way, Kingston, route 136 just west of the URI campus;</p>	
<p><b>Monday July 23, 2007 3 – 5 pm</b></p> <p>Middletown Library's Community Room, 700 West Main Road, Middletown</p>	
<p><b>Wednesday July 25, 2007 10 am – Noon</b></p> <p>Woonsocket Senior Center's Conference Room, 84 Social Street, Woonsocket</p>	
<p><b>Wednesday July 25, 2007 3:30 – 5:30 pm</b></p> <p>Barrington Public Library's Gallery, 281 County Road, Barrington</p>	
<p><b>Thursday July 26, 2007 3:30 – 5:30 pm</b></p> <p>Warwick Public Library's Community Room, 600 Sandy Lane, Warwick</p>	
<p><b>Friday July 27, 2007 3 – 5 pm</b></p> <p>RI Department of Health's Health Policy Forum basement, Three Capitol Hill, Providence</p>	
<p><b>Comments may be made in person during the hearing, or you can mail, fax or e-mail them by July 31st to:</b></p> <p style="text-align: center;"><b>Governor's Commission on Disabilities</b></p> <p style="text-align: center;"><b>John O. Pastore Center – 41 Cherry Dale Court, Cranston, RI 02920-3049</b></p> <p style="text-align: center;"><b>462-0106 (fax) or <a href="mailto:disabilities@gcd.ri.gov">disabilities@gcd.ri.gov</a> (e-mail).</b></p> <p>We ask that you use unscented personal care products. Please realize that what may seem to you to be a mild fragrance can constitute a toxic exposure for a person with an environmental illness. CART Recorders (real-time captioning) and assistive listening devices will be at all sites, courtesy of the Assistive Technology Access Partnership.</p> <p>"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 RIdc to get to and from the public hearing, tell the RIdc reservationist that this trip is for the Governor's Commission's Public Forums in order to guarantee your return trip, after normal RIdc hours of operation. The ADA fare is still applicable.</p> <p>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.</p> <p>Requests for language interpreting should be made to 462-2130 at least 3 business days in advance.</p>	
<p><b>Donald L. Carcieri, Governor</b></p>	

# Public Forum Sponsors

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, Inc.**  
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, Inc.**  
Carrie Miranda, Director

**NAMI Rhode Island**  
Chaz Gross, Executive Director

**Neighborhood Health Plan of Rhode Island**  
Mark E. Reynolds, Chief Executive Director

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

**Opportunities Unlimited for People with Differing Abilities, Inc.**  
Linda N. Ward, Executive Director

**PAL**  
Doreen McConaghy, Director

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

**Rhodes to Independence @ the University of Rhode Island, College of Pharmacy**  
Donald Letendre, Dean, Elaina Goldstein, Director of Public Policy

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

**RI Department of Elderly Affairs**  
Corinne Calise Russo, Director

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

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

**Center for Child and Family Health (Rite Care)**

Deborah Florio, Administrator

**Division of Health Care Quality Financing and Purchasing**

Dianne Kayala, Administrator Medical Services

**Office of Rehabilitation Services**

Raymond A. Carroll, Administrator

**RI Council on Assistive Technology / Assistive Technology Access Partnership**

Kathleen Burrell, Program Director

**Services for the Blind and Visually Impaired**

Ronald Racine, Deputy Administrator

**RI Disability Law Center**

Raymond Bandusky, Executive Director

**RI Disability Vote Project @ Community Provider Network of RI**

Stephanie Booth, Moderator

**RI Governor's Commission on Disabilities**

Paul Choquette, Chair

**RI Public Transit Authority**

Alfred J. Moscola, General Manager

**RI Statewide Independent Living Council**

Donald Phelps, Chairperson

**Spurwink/RI**

Raymond A. Arsenault, Executive Director

# Purpose of the Public Forums

The purpose of these public forums was to identify the concerns of people with disabilities and their families in order to assist the state in developing programs to improve the lives of people with disabilities.

## Procedure following the Public Forums

During September and October, representatives of the sponsoring organizations met to review the testimony and develop recommendations for action. Five working groups were formed to review the testimony: accessibility, community supports; health care; housing and transportation.

## Community Concerns & Recommendations

Concerns	Recommendation	Testimony on Pages
<b>Accessibility</b>		
Restaurant Accessibility (Newport)	<u>Committee Action:</u> Review with Accessibility Committee for possible next steps (e.g., enforcement) Alert Accessible RI (possible review for booklet)	34
Curb Cut Access	<u>Committee Action:</u> Review with Accessibility Committee (Harvey shared with participant at the forum the steps for filing a complaint)	48
Playground Access	<u>Policy/Education Action:</u> Review requirements for accessible playground access & develop policy and/or educate town recreation departments to legal requirements	75-79
Safe accessible pathways	<u>Committee Action:</u> Review with Accessibility Committee: Review next steps to ensure access (e.g., possible legislation or education needed) <u>Advocacy &amp; Education Issue:</u> Raise awareness to the need for safe accessible crosswalks (e.g., similar to raising awareness to fishing docks)	80
<b>Health Care</b>		
Lack of information by Consumers and their families regarding services that are available through different state agencies (i.e. Medicaid Buy In; Sherlock Plan; C-Map)	Information was provided on these possible resources Executive Office Health & Human Services should better advertise the existence of The Point. Also different agencies and programs need to be better informed regarding the services and programs of other agencies and organizations. Information about services, programs and benefits needs to be more comprehensive and better integrated and coordinated. Who takes the lead in facilitating a Consumer's navigation of the adult with disabilities health care system? The Care Managers in both Rhody Health Partners and Connect CARRE Choice will be able to facilitate this system navigation when DHS begins to enroll Persons with Disabilities on Medicaid into Managed Care.	14, 15,17, 69, 73

Concerns	Recommendation	Testimony on Pages
	Are there other ways the Commission can support the dissemination of information about resources?	
Applying for Social Security, lack of information on work incentives/benefits.	Brochures were provided at the forum on the Medicaid Buy in, information on the Work Incentives Planning and Assistance Program and Disability Law Center was provided. See Recommendation #1	12, 39, 69, 85
The cost of certain services such as renewing parking placards	Department of Human Services should consider a Consumers' income when charging fees; whether for parking placards or medication co pays.	32
Individuals who are eligible due to a disability for Social Security should be automatically eligible for the same health benefits as the elderly with out a waiting period. These individuals often end up uninsured or underinsured.	Is this a Federal or State issue? <u>Legislative Committee</u> should continue to advocate and support legislation in this area at both a local level and national level. Can States (or a group of States) impact Federal policy such as Social Security? Is there a State solution such as the State providing some funding assistance in the gap period between determinations and benefit eligibility to ensure some type of health insurance coverage?	32
Informational supports for persons on Social Security or Medicaid and may be working a few hours a week. To prevent loss of benefits.	See recommendation #1	39
Availability of mental health services.	See recommendation #1	41
Transportation not being on time for her appointments.	Consumer should complain to Medicaid. Transportation is an on-going concern for all Medicaid funded programs.	43
The impact of the budget cuts on DCYF services to children 18-21; and the impact of adolescents 17 and older being tried as adults.	Impacts of these budget decisions upon 17-21 year olds need to be monitored by Child and Family Advocates and organizations, and feedback provided to the Assembly and the Family Court. Current situation may require a legislative intervention.	62
Concern that the state's new commitment to Shared Living Initiative will decrease other options such as groups and other residential living arrangements for Persons with Developmental	Mental Health, Retardation & Hospitals should ensure a range of living choices are available to Consumers.	82

Concerns	Recommendation	Testimony on Pages
Disabilities.		
Decrease in mental health services for persons on Medicare (Medicaid??)	Consumers should be aware of National Alliance for the Mental Ill and the Mental Health Advocate’s Office as resources if they feel they are not able to access the services they need. See recommendation #1. The State offering Persons with Disabilities on Medicaid the option of enrolling in a comprehensive health plan will also increase the number of behavioral health providers and services available to Persons with Disabilities.	
The need to provide for criminal background checks for staff providing in-home services	Was this covered in last year’s legislation?	
<b>Housing</b>		
Lack of public transportation near affordable/accessible housing locations	State Planning, Developers, Legislature should consider linking transportation decisions with housing decisions in integrated fashion	48
Lack of affordable/accessible housing, especially for people with COPD	Legislature should, in housing-related rules and regulations, make highest standard of accessibility (“b-unit”) required, not merely recommended and consider issues of ventilation and non-toxic building materials in defining “accessible.”	25, 28, 48
Abuse in supported housing for people with Developmental Disabilities.	Mental Health, Retardation & Hospital should help create investigation unit to look into claims of abuse, similar to unit in Medical Assistance and one that exists for elder-abuse, for people with disabilities. Two time access rule should be amended; entry should be allowed more frequently in private establishments to investigate claims of abuse.	83-84
<b>Support Agencies &amp; Programs</b>		
Inaccessible kiosks at airport and netWORKri centers	Should legislation be introduced to require places to make these machines voice-activated? OR Should a complaint be filed with the GCD Accessibility Committee?	59
<b>Transportation</b>		
Limited parking available in heavy traffic areas and some handicapped parking laws are not evenly enforced in RI despite fines going to local	Modeling successful departments with creative and successful procedures like East Providence volunteer doing photo violations or to increase the fines to be more effective	

<b>Concerns</b>	<b>Recommendation</b>	<b>Testimony on Pages</b>
treasuries.		
Some disability parking applicants find the applications difficult to complete and some medical offices charge \$10 per page to complete.	If the application were simplified and there were rules of presumptive disability like for the RIdE ADA program on renewals this might alleviate some problems. Perhaps a call in number for doctor's offices to record the data might assist both Division of Motor Vehicle and the offices with the applications.	
Access signs are not properly placed for those needing assistance to parking, elevators or entrances.	Perhaps a one pagers for building managers may assist along with advisory committees consisting of people with disabilities and fire/disability/building officials	
Despite a RI law enabling RIPTA to place cameras in RIdE buses, no appropriations have been made to prevent recurring incidents for those drivers and riders.	\$\$\$ sought!	

# Testimony

## ***Monday July 23, 2007- Independence Square II, URI Campus***

>>>ELAINA GOLDSTEIN: Rhodes to Independence has been involved with a grant from the federal government and we've been involved, very actively for the last four years and I must tell you that it's from these forums that when we resubmit our grant to talk about the barriers for people with disabilities to become competitively employed, a lot of what issues come out of these forums that highlight what we will be doing and working on the following years. So a lot of the comments that you'll be making, not only my organization but many of the organizations that are represented up here, hear what you're saying and try to figure out how to improve the delivery of services, improve the systems so that your concerns can be addressed, you know, as soon as possible. And sometimes those concerns turn into actual legislation that the Commission is top-notch on getting legislative initiatives passed in the state house and then implemented. Sometimes it doesn't need that legislation, sometimes what we need is that an agency, let's say the Department of Health needs to hear that one of their programs is kind of not operating exactly as they want it to operate. Well, what do they need to do administratively to make their program operate better? So there's many thing that is can happen in response to the concerns that you bring up. Now, this is a little, well, I'm going to read what it says, don't laugh. To ensure that everyone here gets a chance to speak, there will be a time limit of five minutes each. When the timekeeper announces your time is up, please finish your sense. I don't think we'll be so strict. If there is time after everyone has spoken and someone wants to speak again, they may. Now, hopefully, anyone who did want to speak for sure, for sure for sure put their name down. I have that, we don't have a slough of people here but I'm hoping we can have a bit of a dialogue with everyone here in the audience today. When you do speak -- what I'm having everyone do here is everyone on the panel will introduce them selves to you and give you a little bit about what their organization does and so maybe when you ask questions you can fell us who you are and if you're representing just you or maybe representing an organization, let us know who that organization is. The panelists may ask questions to help understand your concerns better. And that's really a case where you're not quite getting what you're talking about, we can do that. But our job here today is not to solve your problem today, that's a tough thing to do. Our job here really is to listen and to hear. Concerns of everybody out there in the community. So now what I would like to do is to ask each of the panelists, we'll start down to my right over there, to introduce themselves and fell a little about your organization.

>>>HAROLD FAYERWEATHER: My name is Harold Fayerweather, Ocean State Center for Independent Living. OSCIL has been in business since 1988 to help people become more independent. And for a person to be involved with us, it's just a question if they want to be involved and to be involved -- and the service -- a question of housing, some are in the area of information referral, we have information referral specialists that handle all calls. Basically, we have a staff of eleven. And once again, as I mentioned, we've been in business since 1988. We're one of two independent living centers in the state, the other being PARI out in Pawtucket. Our executive director is Lorna Ricci. And the board of director Social Security made up of a staff, many people on the staff are people who have been disabled in one form or another so they're familiar with what the people need and request for services. Other than that, I'll just say once again, we're just people helping people become more independent.

>>>ELAINA GOLDSTEIN: Okay, thank you.

>>>STEVE BRUNERO: My name is Steve Brunero. I work at the Office of Rehabilitation Services. I would like to thank the attendees for attending the public forum today and also my future and current panelists before, some people I've seen here before. Any questions have you about the office rehabilitation services, I'd be happy to answer after wards. ORS is more commonly referred to as three separate divisions, the one most commonly known is the vocational program, assists people with

disabilities become successfully employed. Other programs are services for blind and visually impaired. A number of services run, some programs are children's services where they do children screening in schools for blindness and visual impairments also services for elderly with the and D. D. S. Determination of Disability Services, 100 percent federal which adjudicates. So if there are any specific questions, I'd be happy to answer after wards.

>>>DEB GOLDING: I am Deb Golding, I work for the Rhode Island Parent Information Network better known as RIPIN, and they have put me at the Department of Health, Disability and Health. And my focus is on adolescent health transition. Some of the things that the disability and health team that I work with at the Department of Health are working on for people with disabilities are health promotion, emergency preparedness, traumatic brain injury, adolescent transition and data surveillance. I know a little about what's going on with those things but adolescent health transition is sort of what I'm doing. I have three children, my youngest son has autism and that's how I got into the school.

>>>ELAINA GOLDSTEIN: Janet Spinelli is probably caught in traffic. She is hopefully going to get here and will be representing the Department Of Mental Health Retardation And Hospice.

>>>CHRISTINE MARINELLA: My name is Christine Marinella, staff attorney at the Rhode Island Disability Law Center, nonprofit law firm that provides legal services to people with disabilities we have a staff of approximately ten lawyers, and the executive director, and one paralegal. And Alexandra is here today if anybody wants to register to vote, we're getting involved with more and more so we certainly have forms here if anybody is interested in doing that. We provide services both on an individual level as well as systemically and we really appreciate this opportunity to hear from you about what you think are major issues impacting you bus that helps us to formulate every year, we have to kind of narrow down the cases and projects we can take on because of funding limits really and resource. So what we have with us today is, if you would like at the present end, we have a survey asking you to kind of check off the areas that you would like to see some focus on and we do use these, we set our priorities for the up coming fiscal year which begins in October. And we rely heavily on these forums to see which kind of cases we take for the up coming year. So you have a moment to look over this and fill it out. You can mail it in or hand it in to us, we really appreciate that. And we do systemic work on larger issues, not on individual, but larger issues and these forums are a great way to here what those issues are for a give year.

>>>ELAINA GOLDSTEIN: As I said Janet would be here and here she is. If you could just give a little bit about who we are and the organization we represent.

>>>JANET SPINELLI: Janet Spinelli, MHRH, division of behavioral health care, people with disabilities, mental health issues, substance abuse issues.

>>>ELAINA GOLDSTEIN: And I'm Elaina Goldstein, project director for Rhodes to Independence, which started as a grant to help people with disabilities become competitively employed and our job to look at all of the barriers that people with disabilities have and actually go into work. So, not only do we look at the issues of actual employment but the issues of health care and -- did you bring the Sherlock Center stuff.

>>>MATTHEW IRVING: Mr. Cooper said you had it.

>>>ELAINA GOLDSTEIN: Oh, no. It's unbelievable. Anyway, well at all the other ones get outreach materials on the Sherlock plan and also on the work incentive that is Social Security has, both 1619 A and B. What I did was I gave all of the copies for all of the forums to Bob Cooper at the Commission and I didn't think of just bringing extra ones for my own little thing here. In anyplace event, we operate out of the University of Rhode Island which is one of the reasons we're having the event here. And within of the things that I like to try to do is as I meet people at these different forums, anyone who is interested in participating in our advisory board, as a consumer, we're more than welcome to have you and our advisory board meets now every other month and actually our next meeting is going to be in September and we're going to be working with Raytheon. Raytheon came to our Social Security Summit and offered up, they have this rate six stigma which is a problem solving technique they use to actually save money in their company, many companies evidently foreign 500 all use something similar to this and they wanted to come and help see what they could do to help solve this problem that we have with the federal government's programs and

state government programs and how we could help facilitate more of an integration of getting these programs working together better to help people with disabilities back to work oh so that's going to be in September. I think this in this booklet here we have our contact information, how you get in touch with us, and we have a web site so we hope that people would like to continue [TO/] advocate on your own behalf or on behalf of whatever organization you have, we would love to have you participate what is the association with the pharmacy school, any with the Rhodes to Independence.

>>>ELAINA GOLDSTEIN: That's where we are, it's independence, like Independence Square. That's irrelevant, but the College of Pharmacy, because we do a lot with health care issues we are ear under the College of Pharmacy and Anne LeClerc with RIPTA, we administer the RId system and TIKs system and some of the drivers with the RId. As a planner work more with the RId program and fix service. Also a member of the state rehab council and a former member of the statewide independent living council.

>>>BARBARA MCCRAE: My name is Barbara McCrae and I work for PAL, an organization started by parents and friends who were looking for alternate living, and that's how we came up with the name PAL. All people on our Board of Directors are parents of children with disabilities, helping families navigate the system which can be challenging. I work in the Quality Of Life Initiative, we visit 400 people each year who receive support services from the division of developmental disabilities. And we get some feedback from our visit to the person, their agencies and their social workers and we do some follow up about issue that is might arise that a pothunters or needs and we do some follow up on those. Some of the data is also sent blind without any names attached to the human services research institute where they do a comparison on how Rhode Islanders are feeling about their support services compared to, I think about 25 other states are in the project. So, we also have another, a couple of initiatives that run out of our organization. One is the employment information network and part of that is a mentoring, kind of a support peer to peer, people call others who are looking for jobs and help them with ideas on how to find jobs. Weapon don't actually find people jobs, it's just more of a motivation to keep looking and some new ways to try and to keep talk being what you want because the more people that hear I speak up, the better chance that somebody will be there to listen. And we have a resource library, so, we just kind of, we're doing a lot of community belonging and kind of helping to promote relationship development and community friendships and relationships and really trying to look at the community so that people are not only out there doing things but also engaging and feeling that they belong in their own community.

>>>JEANNE BEHIE: I'm Jeanne Behie, representing the Governor's Commission on Disabilities today. I work for Washington County as a service coordinator working with children with behavioral and emotional issues helping them access information and resources and help advocate force their child, but more importantly, personally I'm here because I'm the mother of a son, a young adult son who was born with disabilities and I found it very important to find out the resources that were out in the community that would help him so over the years I've gotten involved in many of the offerings here, I've gotten on different boards just so I could find out what would be good for him and then later in life, both of my parents developed disability, they developed brain injuries and suffered vision impairment and my father was paralyzed so beside trying to get services for my son, I tried to find out what was available for my parents, too. So, if I'm not sitting on the panel for one of these public forums, I'm always in the audience then asking questions and talking about the concerns I have. So, if anybody has any questions about any of the things about Washington County CAS (phonetic) and many of the other organizations, I'd be happy to talk with anyone after wards.

>>>ELAINA GOLDSTEIN: Great, thank you. Is there anybody else who signed up that came in that wanted to speak? No, okay. Would you like to I'm going to have everybody speak, big surprise.

>>>GAIL LUSSIER: I can speak to problem with my daughter. So, I certainly am limited.

>>>ELAINA GOLDSTEIN: That's not limited, that's quite a lot of information, trust me. I just want to be sure that -- who here on the list would actually like to speak? I have a maybe and a question mark.

>>>BRIAN MONTEIRO: I didn't realize I was on the panel until I walked in here. The maybe was me.

>>>ELAINA GOLDSTEIN: Maybe was you. Okay, who is Laurie?

>>>LAURIE BOYERT: I'm the question mark.

>>>ELAINA GOLDSTEIN: Who is Ernestine? You know what we'll do, we'll make this pretty informal. All of you who came today are here hopefully because you wanted to, hopefully you wanted to voice a concern or you wanted, because that is the purpose of these forums. So, yes, sir.

>>>JEANNE BEHIE: Are we going to go around the audience and have them introduce them selves?

>>>ELAINA GOLDSTEIN: If they're comfortable, but first we'll here from Brian who I never met before, so, we're all meeting Brian for the first time.

>>>BRIAN MONTEIRO: Brian Monteiro from the Office of the Lieutenant Governor. I do some work on long-term care. I'm just getting my hands into all this stuff so I'm not as versed as some of you may be that's why I was shocked to see my name on this panel.

>>>ELAINA GOLDSTEIN: You were shocked, okay. Hopefully you will take back a lot of this to the Lieutenant Governor. For those of who do not know, the Lieutenant Governor runs the Long-Term Care Coordinating Council.

>>>BRIAN MONTEIRO: Once a month and I think resume meetings in September, if I'm not mistaken, I can get a definitive answer on that at the office, it's on my calendar but I know the legislature is not in session so we're kind of on a break right now.

>>>JEANNE BEHIE: What do you do about long-term care?

>>>BRIAN MONTEIRO: Basically discuss legislation, bills that come before the General Assembly. It's almost like a, this is, there's a committee and almost like we have here, people come and ask questions and things like that, different lobbyists come and we just basically monitor the long-term care in Rhode Island and monitor all of the bills that come through the General Assembly.

>>>JEANNE BEHIE: Is that private residences and group homes?

>>>BRIAN MONTEIRO: Yes.

>>>JEANNE BEHIE: Community based care only?

>>>BRIAN MONTEIRO: No, assisted living, nursing homes.

>>>GAIL LUSSIER: What about somebody in a private home by them selves who still live with their parents?

>>>BRIAN MONTEIRO: Are you guys getting visits from, say, a nursing placement, are you familiar with nursing placements?

>>>GAIL LUSSIER: On and off.

>>>BRIAN MONTEIRO: Then you're more than welcome to come. It basically covers the whole gamut.

>>>ELAINA GOLDSTEIN: Okay. How about, Laurie, why don't we start with you?

>>>LAURIE BOYERT: I just saw this in the newspaper, it said for people who have family members or who are disabled. I have a son who is 26 who was diagnosed at age 20 with bipolar disorder and that has changed him from what he was before because he was hospitalized. So, it's been like, I'll tell you it's been a nightmare. For me, not having this illness earlier in his life, not knowing where to go, having been hospitalized in another state and it's just been so frustrating and I applied for medical assistance from the state of Rhode Island thinking his meds cost him \$600 a month, he must be eligible for that. He has a menial job, \$7.50 an hour at Burger

### Health Care

King, used to work at Wal-Mart, but got fired for pushing a cart into a car. My concern is I'm 60 if I die first, who takes care of this kid who can't balance a checkbook, he did get a high school degree because he wasn't sick -- but he's definitely limit until then what he can do and chronologically is about a 14 year-old so I feel like, one of those agencies, North Kingston, it wasn't you -- we had a private doctor so we missed out on the services South Shore had to offer because I don't know that South Shore is where I

### Mental Health Care

should go, I wept once and was very unhappy with a doctor, but now I'm back there just to get the service that is are there and that's been really helpful. If only I knew that's where I should be going but when there's a doctor there you disagree with have you to leave, anyway I'm just really frustrated and I've applied for MHRH, your department, we have paperwork in there but we were denied medical assistance through

the North Kingstown, whatever, through the state of Rhode Island because he works. Well, I want my son to work.

>>>ELAINA GOLDSTEIN: That's a good thing. There is a -- when I said the Sherlock -- I can't believe we don't have the things here. The Sherlock Plan is a program that was created just for people who are working who can get into the medical assistance program, Sherlock plan is a kind of a medical assistance but it has different rules than the other medical assistance programs. One of the rule Social Security, you have to be working, the other rule is that you need to have a disability determination. Now, have you ever applied for Social Security?

>>>LAURIE BOYERT: No, and I'm college educated but I'm overwhelmed by this. I went to Social Security and they said, don't even bother, he has a job. This was like three years ago.

>>>ELAINA GOLDSTEIN: Would you bold that, please?

>>>LAURIE BOYERT: I'm just telling you what's happening to me. It's like people slam their head against a concrete wall and I have, you know, I don't know what to do.

>>>ELAINA GOLDSTEIN: All right. Well, you're here, and there are a lot people here at the table. You actually, there's a gentleman sitting behind you who actually works for the Department of medical assistance here, Brian, who knows a lot more than pretty much anybody in the department.

>>>LAURIE BOYERT: I'll be sure to talk to him.

>>>ELAINA GOLDSTEIN: But, there is a program in medical assistance called the March program, so even if you've been before or your son has never been on Social Security disability before they can go through and make the determination that he is disabled in accordance to be eligible for the Sherlock plan, that's the medical assistance department. But you need to .

>>>LAURIE BOYERT: I have that format home.

>>>ELAINA GOLDSTEIN: The department of ORS also has counselors.

>>>LAURIE BOYERT: He's had ORS services.

>>>ELAINA GOLDSTEIN: Roberta Green and Steve Brunero, but Roberta Green and staff do benefits counseling for people who want to work so that's for sure a place, that's two great people and I'm sorry to --

>>>LAURIE BOYERT: This is just what really truly happened to me and I became overwhelmed and I shut down. I was denied medical assistance, he was denied and when I saw he was denied, I started crying, threw out paper in a pile in my living room and didn't look at it for a month and when I did it said, you have 307 days to appeal it and it was too late and that was my fault because I as a parent couldn't deal with it because I'm going to work I have other people in the house and it was just overwhelming. So I'm glad you have this forum.

>>>ELAINA GOLDSTEIN: We're going to hook you up, we're hooking you up. Also, you go, give your name and address, I will send Sherlock in the mail, our brochures South Shore Mental Health --

>>>JEANNE BEHIE: I work in the children's department but I would be happy to meet with you after wards and talk to you about some of the adult services that perhaps you're not aware of yet.

>>>LAURIE BOYERT: I was really happy, we just started back there and the psychiatrist told me about a medical program that I've never heard of called Cmap or something like that, somebody with a mental impairment is eligible to get psychiatric drugs with no co-pay if going to South Shore Mental Health and have no

insurance.

>>>JEANNE BEHIE: You said he's been hospitalized because there's also case management services we don't have that.

>>>JEANNE BEHIE: I'll talk with you afterward about some of the programs.

>>>LAURIE BOYERT: Thank you. That's all, I'm just frustrated, that's it.

>>>DEB GOLDING: I would like to give my number, too, if you have the paperwork with your office. when I started working at the Department of Health, adolescent transition and figuring out what was had a and made the mistake of saying, isn't there an easy to read health brochure that tells you how to move around in the system and I said there should be one and they said, okay, there's your job, make one. So I've been working for about six months on this to actually put in, like this chronological order of date and age and then how you enter the health care system,

## Working and Health Benefits

## Mental Health Care

whether public or private insurance and what happens as you move along in your age, whether you're in a military family, whether you're on Social Security, whether you're in the mental health piece of it, DHS to get their pieces of it and I'm trying to get MHRH and I've gone to the military so we're trying to map out this whole thing and everybody is really excited about it, so hopefully it will be this tool where people can say, okay, I fit here so this is where I have to go that would be really helpful. So, anybody here who wants to get in on that with me, I would appreciate that. That's something that we're getting a lot of good feedback and I know trying to figure out the whole system myself, it's on a link from one thing to a next and you ask a question to somebody who picks up a phone and they may not even know the answer and put you right off and you think it's a dead end where it's really not a dead end.

>>>BARBARA MCCRAE: I would just like to you know that you're not alone, either. Because the amount of time it takes people to get to the right person to find out the information is too long for Rhode Island. So, I just want to you know that you're not alone. The frustrations that you have, I think many have, really. So, I don't know if that helps you.

>>>LAURIE BOYERT: Yeah, I guess so.

>>>BARBARA MCCRAE: But it's sad in some ways.

>>>ELAINA GOLDSTEIN: Ernestine, would you like to --

>>>ERNESTINE SWANLUND: No, I just really came to sit in on this.

>>>ELAINA GOLDSTEIN: Would you like to say something?

>>>SABOURIN LUSSIER: I'm her daughter, so, I find that transportation to work is

## Transportation

still a problem even with the -- they quit at four or five o'clock, and if you can find a job where somebody works two to six or something, you have no way or eleven to seven.

>>>ANNE LECLERC: What town are you in?

>>>SABOURIN LUSSIER: I'm in Wakefield and another person in North Kingstown works eleven to seven.

>>>ELAINA GOLDSTEIN: And the RIDE program won't do it after a certain time?

>>>SABOURIN LUSSIER: We've looked around it, there's no RIDE on Sundays when people go someplace, there's no RIDE after seven o'clock on Saturday nights. Also we've had trouble with medical appointments when I have work and she has -- Westerly seems to be off limits.

>>>ELAINA GOLDSTEIN: What is your name by the way Gail Johnston? But I think that's been fixed with the medical, RIDE is separate from the RIDE program?

>>>GAIL LUSSIER: No, you still can't get from South Kingstown --

>>>ANNE LECLERC: You're in Westerly?

>>>GAIL LUSSIER: We're in Wakefield, but sometimes she has to go to clinics at the Westerly Hospital.

>>>ANNE LECLERC: RIDE is an umbrella program, there are a number of different ones under it. The department of elderly affairs pays for a number of services for medical appointments for seniors. For certain people receiving medical assistance, we call them special medicals, dialysis, chemotherapy, those types of services. For people under 60, the only option really for anyone under 60, MHRH, the Arc pay for some trips.

>>>GAIL LUSSIER: We always pay for all our trips with the trip particulars like anybody.

>>>ANNE LECLERC: The only program for someone under 60, and not in the Arc is the American with disability programs they, the to provide the RIDE type service for people's whose disability provide -- a fixed routed system.

>>>ELAINA GOLDSTEIN: Do you know what that is the regular bus.

>>>ANNE LECLERC: Right. So it operates at the same time and the same location as the regular bus so if there is no public transit in general there's knock on the identify RIDE program. If the program closes at seven, the ADA closes -- a person's eligibility depends on their disability and how it affects use of the fixed routed system. But to get the trip there's now second level, when someone is deemed eligible needs to end within a quarter mile so, there are people eligible who don't live near a fixed route who don't live --

>>>GAIL LUSSIER: That's why we live where we live.

>>>GAIL LUSSIER JOHNSTON: And on the weekends, the bus route changes and it's more than three quarters of a mile because my son has the same problem on the weekends, bus does not go that close on the weekends.

>>>ANNE LECLERC: Sundays and Saturdays are different, weekdays are one, Saturdays less service and Sundays even less. So it is equivalent to the fixed route service. So if there is no fixed route service, there's no other service approximates.

>>>GAIL LUSSIER: Is that online?

>>>ANNE LECLERC: Yes.

>>>JEANNE BEHIE: If someone is receiving Medicaid, they're eligible through DHS like RITE care, but we're talking about adults on Medicaid, Frank do you have.

>>>FRANK SPINELLI: You're he will -- if you're eligible for medical assistance and have no other mines for transportation, there is a transportation hot line that will make arrangements to pick you up pick you up and take you back usually when 24 hour notice, same day is difficult.

>>>FRANK SPINELLI: I do not have that number but if you give me your number later, if you know somebody on medical assistance -- particularly from Wakefield to Westerly Pain Clinic.

>>>ANNE LECLERC: We have a general public service between Wakefield -- Westerly has flex service which is a combination between our fixed service and the RIDE program. Anyone can use it for any reason and it's the same fair as the bus. But because none of the services for Westerly are really in Westerly, there's no fixed route service down there. Westerly has a bus that stays in the area all day and then one bus that comes, Westerly to Wakefield three time a day. But people can go back in the Wakefield area, around nine a.m., to 11:15 and 2:15, so we call it bus stop at the end of your driveway, same type of vehicle as the RIDE vehicle but painted like RIPTA. But other than that, works just like the RIDE program buses. It's mainly by reservation and has some bus stop where is people can get on without reservation but goes into neighborhoods. So if you would like more information with that, I can give you that information.

>>>JEANNE BEHIE: One last thing, you mentioned the Wound Clinics and you probably know South County Hospital has a wound clinic and they provide transportation. I've been there a number of times in the last few weeks with someone and the services were excellent.

>>>GAIL LUSSIER: The other thing, which this lady might be interested in, what really services, like, I'm old, my husband lives in Texas, and I'm having trouble staying with her and having a husband in Texas without really feeling there's any support medically. Right now she's on IV antibiotics and pumps don't work and this kind of stuff. Is there a service for -- I'm sorry, talking about long-term care to have a nurse come in every week and check skin or check to be sure they've got food or check, that type of thing or a service to check their checkbook.

### Health Care

>>>ELAINA GOLDSTEIN: What health insurance TRICARE for Life Medicaid Medicare and TRICARE for Life military retiree. Three types, pending on the insurance that you have, are services available to you. Now Medicare for sure pays for -- they pay for home health care and so does Medicaid, I'm not sure about TRICARE same as Medicare. Most should have some sort of a skilled nurse, if you need a skilled nurse, most of them all pay for skilled nursing care does medical assistance pay for skilled nursing.

>>>STEVE BRUNERO: Not usually an ongoing private duty for instance just to check in to make sure someone does not have a burn, that they burned their hand cooking and couldn't --

>>>FRANK SPINELLI: The medical assistance skilled nursing is usually time limited, for example, someone may need ten units of nursing services that would be covered but having an R. N. would be every week is normally not a conferred service. But there may be other option that is we can talk about. Where will people in wheel chairs, wound care where they don't see.

>>>STEVE BRUNERO: I understand the need that's why I said there may be other options.

>>>ELAINA GOLDSTEIN: I think you have to look into it.

>>>FRANK SPINELLI: I welcome the conversation.

>>>ELAINA GOLDSTEIN: Also I would contact, she's military also, they also have benefits.

### Health Care Benefits

>>>FRANK SPINELLI: Most like Medicare and TRICARE like medical skilled nursing, intermittent crisis or acute episode, time specific, or, I fall and break my hip, we'll have someone come out that's what I find is available.

>>>STEVE BRUNERO: There are some shared coordination programs that are being developed that they fit nicely, too, so, I'll talk with you guys after.

>>>JEANNE BEHIE: And Gail, there's somebody who works at RIPIN who is very involved in TRICARE, Geri Elmer, and I'm sure she would be happy to talk with you about services.

>>>ELAINA GOLDSTEIN: Do you know what RIPIN is?

>>>GAIL LUSSIER: Yes.

>>>JEANNE BEHIE: Rhode Island Parent Information Network, 1-800-464 -- is it 3399, Deb?

>>>DEB GOLDING: I don't have my --

>>>JEANNE BEHIE: I think that's it but they're also online.

>>>GAIL LUSSIER: I was talking to Geri Elmer the other day because of a project I was working on and she was saying, between TRICARE and medical assistance, which is the first one and it seems to be always be -- Geri said Jerry sometimes doesn't think so there's often problems in that way. I'm not sure about that.

>>>ELAINA GOLDSTEIN: Isn't Medicaid always last? There may be a question who's primary between TRICARE and Medicare because Medicaid is always lost by TRICARE and Medicare would be I was told because I didn't realize TRICARE for Life was almost the same as Medicare and when we were going to Children's, we would give Medicare letters and started getting fliers saying TRICARE for Life was the primary instead of Medicare and secondary, or, would be Medicaid.

>>>STEVE BRUNERO: There's a citizen in the room with three coverages who still can't --

>>>ELAINA GOLDSTEIN: Right. And the other issue, is the service available to get, that's the other problem.

>>>GAIL LUSSIER: The kind of service I would like for checkup on regular basis isn't available from RITEcare or Medicare and I didn't think it was available from Medicaid.

>>>ELAINA GOLDSTEIN: That's the other problem.

## Health Care

>>>GAIL LUSSIER: Not somebody to pay for it, but we tried privately to find somebody who would come every week and I'm just not in those circles, every nurse, would you like an extra job just to come once a week and check -- everyone is busy. And another thing I have is what happens when kids, or young adults meet young adults and want to get married and live on their own -- is there support for two disabled that.

>>>JEANNE BEHIE: What kind of support are you looking for, kind of case management?

>>>GAIL LUSSIER: Case management. It's hard because they don't make a lot of money. Are we as parents always going to support them. Are they eligible for food stamp it is, fuel assistance, that type of thing.

>>>JEANNE BEHIE: Yeah, they are eligible if they have their own household. They don't need to be married for those kinds of things.

>>>GAIL LUSSIER: What if they're living in the house you own and you pay -- I mean --

>>>JEANNE BEHIE: If they're living in your house then your income would be a part of the consideration what if you're not living in that house with them or you're only living there because or you're there three weeks, or ten days out of a month.

>>>ELAINA GOLDSTEIN: You're actually on Medicaid.

>>>SABOURIN LUSSIER: Yes.

>>>ELAINA GOLDSTEIN: So she's already reached the criteria of income eligibility so there's, the different programs, food stamps and she needed housing all have their own specific income eligibility requirements but if you've made it to be on Medicaid, my guess is some of the other programs you would also be eligible for.

>>>JEANNE BEHIE: No, no, no.

>>>ELAINA GOLDSTEIN: You say you work also --

>>>JEANNE BEHIE: Just because you're on Medicaid doesn't mean you're eligible for food stamps.

>>>ELAINA GOLDSTEIN: I didn't say that but, but --

>>>JEANNE BEHIE: There's somebody at the Jonnie Cake Center twice a week to answer questions, could you call and see what hours they're going to be there and either call them or make an appointment to spike with them about it but I do believe they will real estate look at your income too unless it's a separate household, and

it could be a separate apartment with a different number. And also what supports do you receive from Waves?

>>>ELAINA GOLDSTEIN: What is Waves?

>>>JEANNE BEHIE: Adult service provider local evaluation services.

>>>JEANNE BEHIE: It's an adult service provider have I to say I'm disappointed there doesn't seem to be any urge to find everyone a job or get them working for a couple hours a day.

>>>ELAINA GOLDSTEIN: You need to be hooked up with rehab services, Steve Brunero, I love him, we have a known each other for many, many years. Why do you think I sat directly in front of him?

>>>JEANNE BEHIE: Gail, what you just said is a very valid point that there isn't much of a move to thing adults working when you look at adult service providers it's a lot less expensive for them to provide recreational services to people rather than do the job training, job exploration and job placement that people want and that's something I think that's not just indigenous to Rhode Island, it's a problem for every state that has adult service providers, it's more economically feasible for them.

>>>GAIL LUSSIER: Put them in a housing area.

>>>ELAINA GOLDSTEIN: I'm going to time out here because I have to say, I think that depending on the different type of disability group you're talking about is very, very different. And that is the, what we've been doing is working on this. There's agencies in this state that work on helping people with disabilities get employed. There's many people with disabilities getting employed so when talking about providers, one of the big problems is the provider in the community and what their own internal biases are for certain things. One of the things we hope to do next year is go out and train providers on the fact that there are, there is a huge, ticket to work act that passed in what was it 98 that it passed and congress, it's making a big thing, one of the big problems that came out of our Social Security summit, Social Security is kind of schizophrenic in this area. They have people once on disability and you go to a field office -- which one of you said this, we don't have anything to do with getting people back to work. Well, yes, they are supposed to have something to do with getting people back to work. That's one of the problems, if you go to Social Security Office and they don't tell you about going back to work, that's been part of the Social Security program believe it or not since the beginning of Social Security in 1965 and it really isn't something they do, they will say the people there will at ORS, you were at the summit, the people at ORS, voc. rehab. Like you said, this is overwhelming to find out about all of the information. But there is a big push, there has been a push. I think it's matter of getting the right information to people in the right time to be able to note about all this. I don't know how many people have heard of the Point, they're not represented up here but they're another entity in the state that has been developed.

>>>STEVE BRUNERO: Two one one, too.

>>>ELAINA GOLDSTEIN: Two one one, we're giving information out about the kinds of service that is are available for you. But if you didn't know about the Point, the Point has a telephone number and can call them and tell them about your specific situation and they will look up for you. There's another thing out there called ask Rhody, I think there was one big push for it. It was a program

that you key in where you live and you say the kinds of services you want and it was part of taking that, basically the crossroads database and putting it into online and adding in other additional information and services and organization that is provide services. So this issue really the issue is getting the information, people knowing that the information is there and where to get it. That continues to be a huge problem.

>>>JEANNE BEHIE: And Elaina, let me just say one thing, too, you work -- how many hours a week do you work?

>>>SABOURIN LUSSIER: The max, I think 20 hours.

>>>JEANNE BEHIE: Well that's pretty good.

>>>GAIL LUSSIER: And that's doing piecework, she's working. Two hours are doing customer at the office of Waves. So they're sort of employing her in house for two hours a week and the rest is, she used to come home and say, I did 874 pieces I'm so excited, okay, and she'll get 4.07 at the LaPlante Center.

**Support  
Agencies and  
Programs**

>>>JEANNE BEHIE: And my son works four hours a week. Steve, with ORS, he's considered gainfully employed. He's considered a success with ORS because he has worked four hours a week for a number of years at the same location. He would like to work a lot more than that. So we may say, it's not getting the information out there but ORS does look at her as successfully employed, and my son as successfully employed. But they probably don't make enough money to support themselves.

### Working and Health Benefits

>>>STEVE BRUNERO: ORS people are unemployed and under employed. Many people in the community are working a minimal number of hours but not enough to be independent. Many of those folks who I know very well, I feel are under employed if doing piecework. I don't want to get into specifics, but if someone is under employed and you feel they have the potential or capacity to work more hours, different job, I invite you to contact me individually so I can refer to you a counselor to work with Waves or planned center who get funding from ORS or MHRH but you need to call and let us know. It's true if you go out, it's competitive wages. And if it's ten or fifteen or twenty hours a week, it's successful. But if they don't come back and tell us, I'm looking for another job or more money, we don't know that. Sounds like she can use more vocational services. And when you talk to LaPlante or Waves, they keep promising you, we'll work on it, but a year will go by.

>>>BARBARA MCCRAE: Absolutely.

>>>STEVE BRUNERO: Sounds like she needs a rehabilitation counselor.

>>>BARBARA MCCRAE: I would like to know if you called, you know, some of these places, who would they, other than the LaPlante Center and Waves -- would Ask Rhody, or 211 -- what other places in this area might help her get a job.

>>>ELAINA GOLDSTEIN: First of all, there's Network Rhode Island.

>>>GAIL LUSSIER: I found Sabourin a job like at the new movie theater. She took on a job there, but Safes said we don't provide transportation. And sometimes it's support to get them to learn the job.

>>>BARBARA MCCRAE: Inflexibility sometimes of the agency to provide, I don't know, the nine to five kind of thing.

>>>GAIL LUSSIER: Not nine to five, like 8:30 to 4:30.

>>>BARBARA MCCRAE: You're right.

>>>ANNE LECLERC: We should talk about the flex program. South county commons you're talking about. They operate until 6:30 with weekends possible.

>>>GAIL LUSSIER: That was the other thing, the job was six or seven at night and getting out at eleven, so there was just no way anyone could.

>>>ELAINA GOLDSTEIN: There might be other kinds of work -- what Steve is talking about, ticket to work is all about that, getting additional training to be able to work. You seem like a very bright lady. You don't have to be working through Waves, right?

>>>GAIL LUSSIER: That's our service provider.

>>>ELAINA GOLDSTEIN: You don't have --

>>>GAIL LUSSIER: It would be a service provider. We don't have to have a service provider?

>>>ELAINA GOLDSTEIN: No.

>>>STEVE BRUNERO: Why don't we talk after so I can give you more information about providers out there, job coaching, training. There are a lot of services we can provide you with.

>>>GAIL LUSSIER: I thought LaPlante, and Waves, and Perspectives were supposed to --

>>>STEVE BRUNERO: They need funding to do that. So you need a state agency to do that. I see what they get every year and sometimes I'm tempted to say, I could do a lot better than that with the money.

>>>ELAINA GOLDSTEIN: One interesting thing I think you're bringing up, unless I'm, you know, what exactly are these agencies actually providing the types of services that the client needs for the money that they're getting. It's like day care, isn't that what you're asking. There's things called outcome measures that different providers don't get paid unless they are showing you guys -- unless you're showing outcomes. What is that called, it's all written up, looks wonderful, but never actually .

>>>GAIL LUSSIER: Whenever we have a meeting and we discuss the things we want, they put it in the.

>>>ELAINA GOLDSTEIN: In the plan.

>>>GAIL LUSSIER: And never follow through.

>>>BARBARA MCCRAE: Absolutely, I agree with that.

>>>GAIL LUSSIER: And the previous program I was in. --

>>>BARBARA MCCRAE: I think job development.

>>>JEANNE BEHIE: It's a problem.

>>>BARBARA MCCRAE: I think it's a big problem.

>>>STEVE BRUNERO: As a consumer, you have choices. Don't need to go to one particular vendor. In particular job coaching. We found in a survey a few years ago, there's a shortage of qualified job coaches in Rhode Island. So we started a grant for an agency to hire three or four job coaches educated and will stay on board because they're getting the proper salary. One problem with the vendors, job coaches and employment specialists are making ten or eleven dollars an hour and don't stay. So this grant is established to have people with a higher education and salary stay with folks. So there are choices out there, you just need to sit and talk with me after wards.

>>>CHRISTINE MARINELLA: We have a client assistance program at the Disability Law Center.

>>>GAIL LUSSIER: We've used the Rhode Island disability .

>>>GAIL LUSSIER: With the previous program because -- it was not a good outcome. I mean, the lawyer wouldn't even talk to me about anything that we wanted for Sabourin.

>>>CHRISTINE MARINELLA: Were you over or under 18?

>>>GAIL LUSSIER: Probably over, but she's not her own best advocate, and nothing was done.

>>>CHRISTINE MARINELLA: I'm sorry that you had a not great experience, but the law says, when a person reaches the age of 18, they are the person that makes the decision for their education. So as the lawyer, you would be the client, so I'm not able, putting myself in the position that the lawyer, and I know it's frustrating for parents, but we're not able to discuss it with you unless the client says, let's sit down --

>>>GAIL LUSSIER: She said it all the time.

>>>GAIL LUSSIER: I said it every single time, I want my mother here because she knows me very well, and there's some questions that I can't exactly get out there and she can. And the lawyer wouldn't even answer her. I was disappointed.

>>>CHRISTINE MARINELLA: I would be happy to talk to you.

>>>GAIL LUSSIER: Well it's over and done.

>>>CHRISTINE MARINELLA: that's okay. If there's something we could do to address what your concerns were, and use these forums to say, that's what happened in that situation because we see her as the client. But kind of starting off fresh, this is a different program, client assistance program, and again, you would be the client. But I just generally, if there's a family member, they would like to come in, we'll discuss that. But there are some issues of attorney-client privilege once you're in the room that doesn't always apply. So there are real reasons why.

>>>GAIL LUSSIER: I was up front with that person that I wanted my mother there the whole time. We didn't understand that.

>>>CHRISTINE MARINELLA: So we have this program that helps with not just educational issues but, as well as, vocational counseling program, and feels like you're not coming to an agreement of what the services are supposed to be. You tried to work that out and don't feel the agreement is being honored. We have a presence at ORS, Alex LaPlante is over there and has a good relationship with ORS and trying to make sure clients know their rights. And unfortunately, there are those instances where you can't negotiate, and we can advocate and become that, act as a lawyer for the person seeking services to try to get services.

>>>BARBARA MCCRAE: Do you have that social worker from DDD, the division of, I believe Peter --

>>>BARBARA MCCRAE: Do you know how much money is in your support plan?

>>>GAIL LUSSIER: About \$24,000.

>>>BARBARA MCCRAE: There's a program that runs out of, well out of East Providence, but throughout the state called Options and you can take your money, and you hire your own staff and you use the money.

>>>GAIL LUSSIER: I heard that DD would just fight that like crazy.

>>>JEANNE BEHIE: No, no. And we can meet with you afterwards and tell you about it.

**Support  
Agencies and  
Programs**

>>>GAIL LUSSIER: I spoke to another lady who tried that and they were trying to take her child away from her.

>>>BARBARA MCCRAE: If you need help advocating for that, you can contact PAL, and I'll give you information afterwards because the Options program is running, and it would be nice if there are more people using it because it is a way to use your individual support money. If you can find the support yourself, you don't

have an agency overseeing it, it's very difficult.

>>>JEANNE BEHIE: And supervise them.

>>>ELAINA GOLDSTEIN: Is she talking about Personal Choices, is this the Medicaid program?

>>>JEANNE BEHIE: No, this is DDD, funding for adults with --

>>>ELAINA GOLDSTEIN: Right, but that's not --

>>>JEANNE BEHIE: This is using this funding.

>>>ELAINA GOLDSTEIN: This is that --

>>>JEANNE BEHIE: It's hiring somebody to work.

>>>ELAINA GOLDSTEIN: Sort of like Personal Choices.

>>>FRANK SPINELLI: Through that program?

>>>GAIL LUSSIER: We're in the DD.

>>>ELAINA GOLDSTEIN: The DD waiver, that's probably it.

>>>FRANK SPINELLI: We'll talk later.

>>>ELAINA GOLDSTEIN: So we have it clear.

>>>FRANK SPINELLI: There's 154 slots within the DD waiver that people --

>>>ELAINA GOLDSTEIN: It's called consumer directed services.

>>>JEANNE BEHIE: That's a different program. You're talking about the one run out of PARI or something.

>>>FRANK SPINELLI: No, the DD waiver, 3800 people on the waiver. About 154 families were chosen to self direct services, to go through agencies like Options.

>>>JEANNE BEHIE: Okay.

>>>FRANK SPINELLI: Not the Personal Choice.

>>>JEANNE BEHIE: But the personal choice program?

>>>FRANK SPINELLI: If she's DD, she's already qualified. In all honesty, there isn't much, if you're having difficulty getting access to services through the DD waiver, you'll have difficulty with services.

>>>GAIL LUSSIER: So, you're saying that I probably would have a hard time doing the Personal Options if I with the DD waiver already?

>>>FRANK SPINELLI: No, I'm not sure who their network of providers are. They have a network of agencies that provide an array of services. You should probably talk to the case manager.

>>>ELAINA GOLDSTEIN: What Frank is explaining, if she's qualified to be on the Medicaid program through the DD waiver, there's like two components. The regular DD waiver, which is, you basically go through the agencies and sort of what you're doing it sounds like. Then there's another option that you have that if you want, you can sort of, as Frank -- it's called consumer directed care. So you're part of this DD waiver, but you can be directing your own care, or services. Hiring your own --

>>>GAIL LUSSIER: Like job coaches?

>>>ELAINA GOLDSTEIN: Yes. He said there's 154 people who are within the DD waiver who have chosen to do this but is there's a max, how many people can choose --

>>>FRANK SPINELLI: No, but there's limits on the services. There's a number of coaches, or --

>>>ELAINA GOLDSTEIN: That gives you another choice that is available to you now.

>>>CHRISTINE MARINELLA: Speaking of the division, you were raising earlier a question of home health care aid. I understand that in the past, they have done that if it's appropriate, that's the sort of service they can approve and provide if it's part of your plan.

>>>GAIL LUSSIER: The DD, you mean?

>>>ELAINA GOLDSTEIN: Yes. You have this chunk of money now, so I could hire a nurse to come every week to check her, from that money.

>>>CHRISTINE MARINELLA: We're talking about two separate programs. But under DD, if you're eligible for services and you have a caseworker, I'm not as familiar with

self directed care, but the other, someone to make a request for whatever particular service you're asking for. And if your funding level wouldn't be able to fund for that, that can be put into the plan and DD will actually arrange for a particular -- for example, nursing service to come in periodically. The situation I'm thinking about is very similar to the one you had posed so it has been done.

>>>BARBARA MCCRAE: You go through Peter and he puts in a request to services. You can get residential, you can get day, and then you can get family support if someone lives with their family.

>>>ELAINA GOLDSTEIN: Maybe even transportation could get added.

>>>GAIL LUSSIER: We have trouble with transportation for some reason.

>>>BARBARA MCCRAE: You're not alone on that one, not at all.

>>>GAIL LUSSIER: Especially if you need a wheelchair lift. We have a van that takes her around and actually, I should talk to you because it does say that she could drive the van herself. However she went to the hospital for about a year after she started driving and was going back to the hospital for month's time, so since then, we didn't know how to get her back to having driving lessons and get the van back.

>>>STEVE BRUNERO: South County Hospital is a new provider of drive evaluations. We can help with modifications with the van that's done.

>>>ELAINA GOLDSTEIN: Had your van been modified?

>>>GAIL LUSSIER: Yeah.

>>>ELAINA GOLDSTEIN: Well that will be a big help.

>>>GAIL LUSSIER: She needs to feel more comfortable driving. She thinks it's me, but --

>>>ELAINA GOLDSTEIN: Steve is going to be --

>>>GAIL LUSSIER: Steve has known me for how many years now, Steve, eight years?

>>>ELAINA GOLDSTEIN: See how the world works. There's one lady that has been sitting over here very nice in her peach shirt, we haven't heard from you at all.

>>>GAIL LUSSIER: I came just to listen and sit in. Thank you all for what you do. I just came to listen.

>>>ELAINA GOLDSTEIN: No questions for anybody?

>>>JEANNE BEHIE: No problems, everything is great.

>>>GAIL LUSSIER: I've been to a couple different states because my husband doesn't live in this state, and there are no places I've been that has the support that the state of Rhode Island has all the way around.

>>>ELAINA GOLDSTEIN: In spite of what you said, oh, my goodness.

>>>GAIL LUSSIER: If you find the right places to go --

>>>ELAINA GOLDSTEIN: one of the major issues you both brought up, not only knowing how to find out about everything, how do you find out and knowing how to find out about everything. That is really one major critical issues we have been working on and working on and have not solved.

>>>LAURIE BOYERT: First thing that surprised me, when I went to my son's medical director, he would say, this is where you go.

>>>ELAINA GOLDSTEIN: For my project perspectives, that is our focus next year, to do provider -- medical doctors. People talk about providers, they're talking about like job coaches, that's a different game. When talking about like physical therapists, occupational therapists, nursing, physicians, a lot of those people, all they know about when somebody has a disability, what they will do is encourage you to go on Social Security disability. They don't realize that all of these laws have been passed, that all of these other services are available. A lot of them do not know that, so that becomes one of those things that we are going to try to get throughout to the different societies, the medical associates to be able to start to educate those who are really your first line. I'm assuming you, too. And even the mental health employers to understand systems. There have been a lot of changes but if nobody knows about the changes to the system, nothing has changed.

>>>JEANNE BEHIE: When parents with kids with disabilities are asked who is the most helpful with sharing information, it's not the physicians, it's not the teachers, it's other parents. And I'll just give you an example of one of my experiences with a doctor. My son was born, and the next day, he was born with bilateral club foot, the next day, I noticed something wrong with his eye, and an ophthalmologist told me he was blind in that eye. Three months later, the ophthalmologist said to me, he's visually impaired in the other eye, too. And he

walked out of the room. And I stood there with tears coming down my face, and I walked out, and I said, I know that there's some sort of organization like services for the blind in the state, shouldn't I be given, can't you give me that phone number? And that's how I got a number. But I was told nothing. So it's very unfortunate and physicians and nurses do need to be educated. And there's many initiatives in the state to do that. There's parent coordinators and advocates being put in physician offices to work with families. But it is other families that really are sources of information. And some of those phone number that is Elaina just shared about 211 and -- what's the other place?

>>>JEANNE BEHIE: The Point and Ask Rhody.

>>>JEANNE BEHIE: So we are working at trying to change it.

>>>GAIL LUSSIER: And I'm a nurse and I can't tell you how many things I did wrong that hurt her. You have, you know, everyone has different fields but they stick to that field and don't venture out to find out what's around.

>>>BARBARA MCCRAE: That's why it's important that you came because so often parents feel so isolated at home and they are not getting the information they need to get help. When we visit, it's amazing how many parents don't know the services that are really available to their children, you know. And it's like, you can't believe that they don't know it. So you try to provide them with information and contacts, but, so, it's really great because and I think there's a tendency for parents to try and contact everyone. I think they're so overwhelmed most of the time that they just want to stay in their house.

>>>LAURIE BOYERT: I'm only here because I don't work in the summer. If this was the school year, I couldn't come

>>>ELAINA GOLDSTEIN: Even at five o'clock, you wouldn't have been able to come?

>>>LAURIE BOYERT: Maybe not, I'm tired, I'm pooped out. And have I to concentrate when I listen. I have a cadre of people here all saying different things. So you have to focus. I'm glad you're down here in South County because usually these meetings are in Warwick or Cranston. I didn't grow up here, I don't know how to get half the places. Butler Hospital has a lot of great programs but they're a long way away at night in the dark in the winter. I can't go up there. I won't go up there in the dark.

<p><b>Public Notification</b></p>
---------------------------------------

>>>ELAINA GOLDSTEIN: The Commission is really good about that. They try to have a forum in all different parts of the state, I must say, and they did a really good job this year.

>>>LAURIE BOYERT: Luckily I take the local paper so I saw it.

>>>ELAINA GOLDSTEIN: Too bad -- last year, I think we had maybe another four or five people. We're going to be here -- I don't know if there's anybody else that would like to share or ask any questions, we're here until 5:30 because there could be someone walking in at 5:25 because they did work.

>>>LAURIE BOYERT: That's what it sounded like, could you drop in any where in between?

>>>ELAINA GOLDSTEIN: We have to stay here until 5:30. So, you know --

>>>ANNE LECLERC: And if you think of anything later, you can send in written comments, as well.

>>>ELAINA GOLDSTEIN: If you would like to, I'd like to get your -- there's certain things as we're trying to find out, I find out mostly what is really going on through people like you. This issue about the DD, you know, the different, the providers, one of the things that I do, Gene over there works with me, we have, developing a Medicare/Medicaid link database. And we've been working on this report, it seems like forever, but this report from 1995 to 2001 looking at people that are on both the Medicare and the Medicaid program. And when we did this report, did these different reports, you find out that when you're looking at the cost of care from the Medicare program and the Medicaid program and you look at people with disabilities as oppose today people that are senior citizens as opposed to people that are really, really old senior citizens and the total bout of expenditures being spent. A lot of senior citizen would say people with disabilities get all this money and services that are provided to disability, senior citizens want the same thing if I take out the DD waiver population from people with disability and take out the costs affiliated with the DD waiver, people with disabilities actually get less money. I mean, less services respect spent on people with disabilities and are spent on senior citizens. So the -- now you could say, like Frank said, all of the service that are

available to someone who is in the DD waiver surpasses, I think, any other program that's in the Medicaid program, isn't it, pretty much any program as far as the actual services available?

>>>FRANK SPINELLI: In terms of community supports?

>>>ELAINA GOLDSTEIN: For the term of community supports, which is all of the waivers, the point of a waiver versus the traditional Medicaid program, you're waiving what, you have to be someone that would be eligible to be in a nursing home. But, instead of being in a nursing home, you're going to get your services through this waiver. And the services will be home and community based services, so they're home and community based waivers. So when the waivers are developed, they have to make sure that they're going to be cost effective and each of the waivers, and there's what --

>>>FRANK SPINELLI: Six.

>>>ELAINA GOLDSTEIN: Six waivers. Each has different services available to it.

And the DD waiver has been around probably, was probably one of the first waivers, right? And it does provide more services and -- so my first question was, interesting she would say this, my first question and I haven't met with Ellen Ellison (phonetic) yet to share with her this information to say, what are we doing -- because I've heard people in the past talk about frustration in being able to get people that want to be employed in higher paying jobs seem not to be able to get into the higher paying jobs because of the providers they're with under the DD waiver. And I could never really figure out what they're talking about. And over the last couple years, it's become really clear, I mean, job developers and all this terminology, I'm basically a health care person. So DD is very different than for me and the health population and very different for the physically disabled population. It's like, you know, different worlds. PARI and OSCIL predominantly deal with people that are physically disabled. And as far as the work environment goes, it's very different than these job developer people, isn't it?

>>>HAROLD FAYERWEATHER: Yes. You can refer them to the Office of Rehab Services, and in turn, ORS has also referred clients back to us based on what those needs are, whether for housing, you know, whatever it be. Basically an independent living center.

>>>STEVE BRUNERO: I and R is basically information and referral, so if we have a referral given from ORS. Basically, you would take, all that information may be able to be handled, everything from that call to making other referrals to other agencies. Like I say, we're all networking all the time. From the standpoint of direct services, we get involved with that depending on what those direct services are, what the needs are, and we advocate on behalf -- we want them to advocate on behalf of them selves. And then, basically, peer support. But you mentioned earlier about your daughter, I thought I was understanding like IEP plans, she's in school to 21. I'm saying even before 18, in the school system she was involved in, did they have IEPs for Special Ed. for certain equipment and everything else? You had to be involved with IEPs as a parent.

>>>GAIL LUSSIER: She was.

>>>STEVE BRUNERO: So, were there short comings then that turned you in the direction of Rhode Island Disability Law Center. So in some cases, what I hear about children in the hospital, well the physician may not give you the information you need, but even the social service department within South County Hospital, or social director there, I forget her name, but she's been very, very good over the years and made even direct referrals for peep toll OSCIL. Depending on the issues. And being involved with Steve for years. I'm pretty sure if Steve was involved with training, that also paid for your transportation to go to the training. That's part of ORS, too. So, it's a question of what do you want, what do you need and then being hooked up to the proper.

>>>ELAINA GOLDSTEIN: Did you know anything about the two independent living centers that are in Rhode Island?

>>>GAIL LUSSIER: We know PARI, OSCIL is --

>>>HAROLD FAYERWEATHER: And PARI in regards to the waivers, they've come up with the personal choice waiver. You or your daughter would run it yourself, you're the administrator. But PARI would have staff assisting you, so much money in the transportation, so much money is in to a nurse you want on a weekly basis to check

## Support Agencies and Programs

the burns or whatever. And this gentleman, like he said, will get together and talk to you about the six different waivers. But that's just one option. Depends on what your needs are.

>>>GAIL LUSSIER: As a parent, sometimes you're not sure.

>>>ELAINA GOLDSTEIN: Right.

>>>GAIL LUSSIER: And you get so much stuff coming in.

>>>HAROLD FAYERWEATHER: That's true.

>>>GAIL LUSSIER: Confusing because we're not used to the terminology and the different, all the agencies sound the same. But they're different.

>>>ELAINA GOLDSTEIN: I want to you give your name and address, too. One of the things, at least from our, again, I've been involved in this now for seven years, working and trying to, every time we seem to sit down in other places, I look at it like an onion, you keep on uncovering the onion skin and it's one thing after a next. There's loads of material out there. A lot of times the materials tend to be what I call governmentalize, it's probably all very accurate, but it's like, what we try to do is put ourselves, and it's easy for me because a lot of these programs I didn't know anything about. Listen, I have a law degree and when they start, I don't understand it. And how in the world does somebody going through a crisis going to be able to get through all of this. So what we're trying to do, and I think we have our first outreach, this, you know, back to work, how to get back to work and had people at ORS look at it and see if it's something that's easier to read than a typical kind of material -- doesn't look like a government thing. It's really hard for, I think, people that are so involved in the actual law and implementing the program to find of get out of their talk. Medicaid, my gosh, you want to talk about a language all to its own. Medicaid -- code, 1619 A and B, you're supposed to know what that is, 1619 A and B of what? And there's terminology that gets thrown out there. And when you're so involved in running the programs, you sometimes forget the people that are coming for help, you know, have no -- and I think that's a sensitivity that needs to be reinforced, especially with the field offices where you would go and talk to people from Medicaid and other social services. You go to a field office, are those people really more sensitive to know, how do you interpret this. People don't know the services they want. How do we provide people information without inundating them with information about all of the possible service that is available. So I think it's really important that when you have an opportunity to call somebody and the point is supposed to be very good at this that when you call, they have a sensitivity to be able to know to maybe ask you some questions that will help you describe some more information that then they could say from that, you know, there's other services available that you may not have known about that, might be useful. Very similar to what a lot of the people did up here, but that person that you call should be able to sort of ask you some leading questions that will provide them with some information that they can provide you back with additional information.

>>>GAIL LUSSIER: It would be hard on my end to take all of that. I know -- well we started with Perspectives, and because she was in the hospital for a year, they fired us, because I was working for them. And they also kicked me out of their .

>>>GAIL LUSSIER: And wouldn't let her back.

>>>GAIL LUSSIER: I supposedly didn't follow what they want, which I did.

>>>GAIL LUSSIER: Once you get someplace and you think you're fairly contractible and have a six-hour plan for the day that keeps a regimen and keeps your child busy, you really don't go any farther. You stay there because -- and the change is taking a chance of not having something as compatible for your child.

>>>ELAINA GOLDSTEIN: Do they have revaluations of any of these programs? You know how Social Security does their revaluation to find out if you're still eligible for Social Security.

>>>STEVE BRUNERO: As I said earlier, once someone is closed to ORS, they can come back at any time.

>>>ELAINA GOLDSTEIN: But it would be up to them?

>>>STEVE BRUNERO: They would come back to us because they lost their job or they're under employed, not working enough hours, maybe they've improved in their physical disability, whatever they have. People can come back. The question of transportation is a good one.

>>>GAIL LUSSIER: I called Cora .

>>>STEVE BRUNERO: Cora just came back last week, she's back as a rehab counselor.

>>>GAIL LUSSIER: I want you back.

>>>JANET SPINELLI: If you want to leave your number with me, I could have someone from MHRH --

>>>GAIL LUSSIER: Does that mean consumer choice.

>>>ELAINA GOLDSTEIN: Consumer directed plan, right.

>>>BARBARA MCCRAE: And how much money is in the plan, and then if you want additional residential support like you were talking about or if you wanted those to go into managing your own plan.

>>>ELAINA GOLDSTEIN: Any of the advocacy groups up here actually help a consumer through at no time consume I remember directed.

>>>BARBARA MCCRAE: We're learning more and more about options. We work with families to try to help them through it but I don't know how much success Dorian has had to have parents actually take the chance to move because it is scary to move and it's usually individuals who are just tired of trying to do it.

>>>GAIL LUSSIER: And also, your significant other there knows people around and doesn't want to leave because they have friends and they're afraid.

>>>JEANNE BEHIE: And that's a big deterrent from moving out because they have friends, they do recreational activities, and this will terminate that part of it.

>>>GAIL LUSSIER: And it's so hard to get any kind of friends when have you any kind of problem.

>>>BARBARA MCCRAE: You can call Dorian because she's really involved at looking at and sitting with families and going to agencies and really supporting families and people who are looking for changes in the services that they have. But we usually work with people from the DDD service, not usually people all the time in that kind of physical disabilities.

>>>ELAINA GOLDSTEIN: I think she is.

>>>GAIL LUSSIER: Is there an agency, we were talking about it being so hard to help, is there an agency that has, in the state that -- we were talking about, job coaches that were trained and they have a list of those people, or is that --

>>>JEANNE BEHIE: And are they in southern Rhode Island?

>>>STEVE BRUNERO: The expansion contract I was talking about earlier was with Goodwill Industries, they do not have -- they used to have a satellite here in this building at one time, but they opened up an office in East Bay, but job coaches can go statewide. So if you chose a waiver program or if you came back to ORS and Sabourin needed a job coach, we would pay for that. And that person would come down.

>>>GAIL LUSSIER: But you have a list of people.

>>>STEVE BRUNERO: There's three or four new job coaches through that grant. So, there are some other options.

>>>GAIL LUSSIER: This sounds like a personal one-on-one.

>>>ANNE LECLERC: Life Inc.

>>>STEVE BRUNERO: That's East Bay and they have -- Rhode Island people hate to come across the bridges, but there are a number of job coaches that are available for Sabourin. And when we meet we can talk about different options. I'm glad you and Laurie came here today. I'm hearing about programs and services and I've been in the system for over 30 years, that I'm unaware of. So I can imagine how difficult it is for you guys. But we're a small state and it shouldn't be as difficult to navigate as it is.

>>>GAIL LUSSIER: A lot better than other states. They wanted to put her in a nursing home.

>>>STEVE BRUNERO: What I wanted to say, I'm glad we came here today to talk about concerns and issues you have. And being a small state, you have a face and a name, and you can pick up the phone and talk to a Jeanne Behie or Steve Brunell .

>>>ELAINA GOLDSTEIN: We're running a job fair through Rhodes to Independence, and it will be publicized through local newspapers and on TV. We've have resources and training personnel on hand to help, that you might need to get another physician, and this will be some time in October. We haven't confirmed the date yet but more than likely it will be at the Sheraton on Post Road is where we're hoping to have it.

>>>GAIL LUSSIER: Just a short story, even with things in place -- my son had a job lined up to be a dishwasher at the Brighting Commons, and they were all, this looks great. But he had to take a drug test. He takes six medications so he got

## Working and Health Benefits

freaked out and couldn't pass the urine, so went back to the guy and said, I couldn't do it. And the man said, it's okay, take another one. Very nice. My son goes back, walking. Doesn't drive, so he has to go back to this agency in Wakefield, he has over diluted his urine sample now, and it's not valid. This is the second urine test, and then he goes back. And by then, he's completely not functional, can't do it, so he loses the job. And that's the story of his life. And so those are the kinds of things he goes through. We just put our hands up, and like, oh well, that job is done. And that's a job he could have done. He probably could have succeeded with that, but it's closed to him now because he couldn't urinate on command.

>>>ANNE LECLERC: They couldn't come up with an accommodation?

>>>GAIL LUSSIER: By then, no. They did, they accommodated him three times, but the second test he over diluted the sample, so that didn't -- the whole thing, it's just to show you the kind of things that happen that don't happen to anybody else it doesn't seem like. My son was walking to South Kingstown High School, I think you were in his class, because I was irate with him one morning, and an animal bit him in the leg, he didn't look, but as a result of that, he had to go through rabies treatments because he didn't even look. So it's just, it's like another world. And it makes us crazy.

>>>BARBARA MCCRAE: Something else you mentioned earlier, too, is as you get older, this comes up a lot on our visits. As parents get older and children are still living with them, finding housing and places where they get the support that people need is really tough. That's another issue, first I need medical.

>>>GAIL LUSSIER: I think there's a housing authority, my daughter was on a list for about three years, and she was eligible, and then she was sick and in the hospital for a long time. Then they put her back on the list and it's been eight years for her to get out and get her own apartment. But I think I've given, she's just going to stay in our house and I'll move out.

## Housing

>>>BARBARA MCCRAE: Housing is a big problem.

>>>JEANNE BEHIE: Just not enough low income housing, especially in South County.

>>>ELAINA GOLDSTEIN: Anybody know about -- can you talk about the housing bond?

>>>HAROLD FAYERWEATHER: I can't give too much about the bond.

>>>ELAINA GOLDSTEIN: Rhode Island housing works, the Rhode Island foundation, sort of the organization that ran this, it's called Rhode Island housing works. And they ran a campaign, you probably voted for it this last election about the housing bond that was available. One of the things we were very involved in I'm sure a number of the organizations here were very involved in getting that passed was, we wanted to be sure there was housing being developed for people with disabilities. What we did was when the regulation, it was time to write the regulations, we worked with the Commission and we worked with, actually the senior agenda to make sure there was going to be housing developed, and the ability to have the, the terminology is not accessible, it's -- I wanted universal designs, maybe it is accessible, but ways you build a facility in case she needs grab bars, things like that. The actual building itself would be able to hold on to them. And it doesn't cost as much money as if you have like a house that doesn't have sturdy enough walls. In any event, this was all put into the housing bond legislation so that anybody that will be building new apartments or homes has to meet these standards that are out there. So, I believe -- I'm not sure how soon the housing, you know, bond money is going to go out to the developers, but I'm sure they're in that process now. Do you use the computer at all? Housing -- RI Housing Works, a lot of information. They just put out another fact book. The other thing is that Rhode Island Housing, and I want to you contact Rhode Island Housing, they have, we were just working with them with different programs that are available to actually do home modifications.

>>>GAIL LUSSIER: I've already worked with them.

>>>ELAINA GOLDSTEIN: Because Rhode Island Housing is going to be very involved with the implementation of the bond program, so there might be somebody there that can talk to you. We're going to be working with them and helping fund something called the housing locator. Once this comes up, it should be unbelievable. Because right now, unfortunately, what someone has to do to get into affordable housing is go to each one of the specific housing authorities, which there's a whole bunch of them throughout the state. This housing locator is something that you would go onto and you would be able to find all of the different housing, apartments. And in, not only apartments, but also homes which doesn't seem to be your problem, but apartments

available through the state. It's a software program that has been developed and works in many other states. So that's what we're purchasing, and Rhode Island Housing would be the one that is the keeper of the locator. It's not here yet, but we're right in the process now of going through all of the governmental work that has to go through. I just want to give them money to buy it already. You would think I have the money, why can't I just give it to you now, buy it already. Talk about being frustrated. But we are very, very close now to coming up and providing something for people in housing, at least, that is going to be wonderful. So not here yet, but it's coming.

>>>ANNE LECLERC: I urge people if looking at housing and don't drive, pay attention to the new housing developments that come out with the bond issue. They're often located away from existing services including fixed route bus services, which means no transportation. This is an issue we keep pointing out,

## Transportation

affordable housing often has people included in it that happen don't drive and if it's located away from bus routes, we don't have money to expand, unless you're going to be giving us money to expand services. Not all housing authorities are on bus routes so that's something to pay attention to.

>>>GAIL LUSSIER: Rhode Island Housing helped me. I sold a raised ranch, a child with a wheelchair, and there were only two lots I could find, it was within three-quarters of a mile.

>>>ANNE LECLERC: So if anyone needs to check -- it's not driving distance, so, no one can check it for you. We had an unfortunate incident where someone told them they were not and she quit her job which was across the street from the Kent County Court house that has tons of service. Please check RIPTA or RIDE . We have people over the corridor, over the bay, you wouldn't think. Highways don't count. 95, any where a bus can't stop. You can't stop along the highway. But we'll check it for you if you have any questions, if you're looking for housing or someone is looking for housing and we'll rely on the ADA corridor. But please check and don't assume because we had an unfortunate circumstance where people were out who thought they were in.

>>>CHRISTINE MARINELLA: I would just like to go back to the surveys. And I'm going to ask, these will be out at the front. And even ask the panelists if they could go over it and --

>>>ELAINA GOLDSTEIN: We can do that now unless anybody else --

>>>CHRISTINE MARINELLA: Don't feel compelled. If you don't want to fill it out, you don't have to. And the back is optional if you want to identify yourself.

>>>ELAINA GOLDSTEIN: If anyone would like to speak individually up here, please feel free to do that. We'll be here until 5:30.

## **Monday July 23, 2007- Middletown Library**

>>>CARRIE MIRANDA: I would like to go ahead and welcome everybody. I am the executive director of Looking Upwards, a local nonprofit agency providing supports to adults and children with developmental disabilities; and the state government and the sponsoring organizations want to hear from people with disabilities and their families, their concerns and ideas for improving the lives of all Rhode Islanders with disabilities. That's why we are here today.

I am going to just explain the rules of the forum this afternoon to ensure that everyone who wants to speak has a chance to speak, there will be a time limit of five minutes each. When the timekeeper, Linda, announces your time is up, please finish that sentence. If there's time after everyone has spoken and someone wants to speak again, they may. We are going to ask if you state -- that you state your name and if you are affiliated with an organization that you state that as well. And the panelists may ask you questions to help understand your concerns better.

Okay.

Just -- okay. We are going to in one minute introduce our panelists here. And if you have not signed in, please sign in right over at this table over here. And we will -- you will be able to note whether you want to speak or not speak. And we are going to follow the list in the order of which people have signed in once we introduce the panelists.

>>>TIMOTHY FLYNN: I guess --

>>>CARRIE MIRANDA: We will let Linda start. We are just rearranging a little bit. Linda, you can begin.

>>>LINDA WARD: I am Linda Ward executive director of Opportunities Unlimited a small nonprofit agency with adults with developmental disabilities.

>>>TIMOTHY FLYNN: My name is Tim Flynn. I am a commissioner on the Governor's Commission on Disabilities, Chairman of the Legislative Committee. And what I sort of want to say is what we -- we derive our whole legislative agenda over what happens at these five public forums conducted by the commission. So really, what you say here is taken to heart and really -- we want to get your input. And we will take what we hear, create some sort -- create legislation that can address the various needs of whatever comes up at this meeting. So I thank you for coming and I welcome you.

>>>BRYAN HUDSON: Bryan Hudson attorney with the Rhode Island Disability Law Center. For those of you who don't know, we are the state's designated protector advocacy system for people with disabilities. We, due to Congressional mandate every year, set our priorities. So if you have any ideas that you would like to put down, forms are on the table and I will collect them afterwards.

>>>MARIKA TERLECKY: Good afternoon. My name is Marika Terlecky. I am representing the Brain Injury Association of Rhode Island. I'm also on the Governor's Advisory Commission for Brain Injury and I'm a brain injury survivor as well.

>>>DOUGLAS WOOD: I am Doug Wood, director of the RIDE program. We work closely with the Governor's Commission -- since the inception of the program, I am happy to be here and answer questions.

>>>MIKE MONTANARO: Mike Montanaro. I am supervisor of the East Bay Region.

>>>CARRIE MIRANDA: Okay. Also I want to make a note that there are a list of the legislative accomplishments on that table over there. And we also have someone over here who will be able to assist you to register to vote, if you are not a registered voter at the end of the meeting. Feel free to see Amy.

Okay. We are going to start with our first person listed and that would be John Pimentel.

>>>JOHN PIMENTEL: If I may, I am going to pass for now.

>>>CARRIE MIRANDA: And we also have Cheryl Grove. Cheryl.

>>>CHERYL GROVE: COPD is the second leading cause of disability and the fourth leading cause of death in the U.S. 11.4 million persons are diagnosed with COPD in the US with at least as many undiagnosed. COPD mortality rates are rising. Now claiming over 120,000 lives per year. 120,408 Rhode Island adults or 13 percent of the total population are diagnosed with COPD and asthma in the three Rhode Island counties with pollution monitors, compared to 2 percent or 19,278 children under 18 reported to have asthma. According to the world health organization's bold report, the global initiative obstructive lung disease quote tobacco smoking is not the only

cause of COPD. COPD is generally a progressive disease, especially if a patient's exposure to noxious agents continues. Stopping exposure to these agents, even when significant airflow limitation is present, may result in some improvement in lung function and slow or even halt progression of the disease. However, once developed COPD in its comorbidities cannot be cured. Causes of death in patients with COPD are mainly cardiovascular disease, lung cancer, and in those with advanced COPD respiratory failure end of quote. In the three pollution monitor counties in Rhode Island, 25 percent of the population or 232,942 persons have cardiovascular disease. Lung cancer is the leading cancer killer in the US causing more deaths than the next three most common cancers combined, colon, breast, and prostate. In 2007 estimated 167,000 persons will die of lung cancer and 213,000 will be newly diagnosed. The cure rate is under 15 percent. No one, Tammy Fay, Dana Reeves, Peter Jennings. Or my never smoker uncle is exempt. The national academy of sciences and the California air resources board quote having recent years conducted major studies of indoor air pollution and concluded that indoor air can have a major negative impact, not only on the lungs of those with asthma and allergies but on those people with healthy lungs who are not normally at risk for lung disease, end quote. On April 23, 2007, at the

## Housing

fair housing, it's not an option, it's the law. 39th anniversary of the fair housing act, the executive director of the commission for human rights confirmed the right to habitability protection from neighbor nuisance fumes including secondhand smoke and other consumer product VOCs through walls, floors, ceilings in HUD financially qualified apartment. It is a disability fair housing right. He confirmed this in front of Noreen Shokras and Richard Godfrey at the seminar that featured Kim Kendrick for fair housing and equal opportunity. The 2007 healthy housing Rhode Island investment vision report identified some practical ideas for general population improvement. But completely neglects the handful of Rhode Islanders critically in need of this disability fair housing protection today. As representatives of the two disability agencies involved with this report indicated, both a lack of interest and knowledge as recently as April of this year, this deficit is predictable. A year ago I offered my extensive knowledge at this forum on public record. My offer was not accepted. My offer is once again extended on public record with greater urgency and greater disappointment at this ongoing travesty of justice and humanity. Other communities have addressed this special needs disability health and safety issue, cost efficiently since the early 1990s. I can be reached at CG\_006@yahoo.com and don't need to find a funding source for my knowledge. That's CG\_006@yahoo.com. Thank you.

>>>CARRIE MIRANDA: Thank you.

Any questions from our panel?

>>>TIMOTHY FLYNN: I have a question. What are you looking for? What would you like -- I will look at your testimony and what I heard was you are seeking sort of federal protection in Rhode Island housing. What specifically --

>>>CHERYL GROVE: I'm looking for the type of accommodation that has been accomplished in other communities that provides protection from neighbor nuisance fumes through the floors, walls and ceilings. That typically --

>>>TIMOTHY FLYNN: --

>>>CHERYL GROVE: -- requires a weighing of segregated housing specifically for this special needs community. As the special needs community in the state that needs this kind of accommodation, it's probably less than 5, maybe 2. It's something that could very practically be accomplished.

>>>TIMOTHY FLYNN: Less than five -- I don't know --

>>>CHERYL GROVE: Quantity. Number of people.

>>>TIMOTHY FLYNN: Less than five people and there are two people. And so you are looking for sort of indoor air quality assurances in public housing?

>>>CHERYL GROVE: No. It doesn't need to be a general cover the entire population. It needs to be specific segregated housing where the people with the disabilities in that housing have a commitment to specific things like no smoking, no VOC disinfectants, very practical solutions. And I would be happy to meet with you, Tim, to discuss it in further detail.

>>>TIMOTHY FLYNN: I am just trying to get sort of a grasp on sort of similar legislation that you know about that's happened in other states where we could look at.

>>>CHERYL GROVE: I don't think it's required legislation. It's required a couple of people that are interested in meeting in on that need. I mean, you came to my house in Middletown two -- three years ago. That fellow that was a smoker and strong VOC user is now dead of cancer. And my diagnosis has been upgraded to COPD, which is irreversible because of that year of secondhand smoke and VOCs. That's unacceptable.

>>>TIMOTHY FLYNN: I am just trying to get an understanding as to -- you want sort of a community of individuals such as yourself --

>>>CHERYL GROVE: The special forum that was run in 2005 there were two people identified in the state as needing a protection from their neighbor nuisance through the walls and ceilings and floors. That could be a duplex in a low pollution area like Charlestown, Narragansett, or Newport.

>>>TIMOTHY FLYNN: So where do you see sort of enforcement coming from?

>>>CHERYL GROVE: It's not enforcement. It's simply somebody addressing it like you addressed special needs housing for developmentally disabled and other special needs communities. Is that legislation?

>>>TIMOTHY FLYNN: I think -- you know, there are certainly state funding that is incorporated in those kind of efforts. I just would like to sort of get an understanding as to what the road map to accomplishing this endeavor.

>>>CHERYL GROVE: Well, the first thing would be to meet with people that are knowledgeable and see what's happened in the two years since that special forum is. They set up a data base that has -- of course we know who the participants were and who identified that they were under HUD qualifies housing necessity. And we could find out who needs it. I mean, as I said, it could be as simple as a duplex where both people are bound by an agreement that they will lose their place in that property if they offend the rules agreed upon, like smoking.

>>>TIMOTHY FLYNN: Let's talk afterwards.

>>>CHERYL GROVE: Sure.

>>>TIMOTHY FLYNN: I am very interested in this. I don't want to hold up the whole forum.

>>>CHERYL GROVE: Thank you.

>>>LINDA WARD: I would be curious if you could share some states that have done something like this, you mentioned --

>>>CHERYL GROVE: I brought it to the home access seminar in -- I brought all the data to the home access seminar in Warwick in April and was told by the ADA coordinator that we are not going to replace all the vinyl siding in the state of Rhode Island. I don't know what vinyl siding has to do with secondhand smoke, but that was the response that I got.

>>>LINDA WARD: But what states do you know of have done something to accommodate this need? Again just because I would like to do a little research myself and if you put me in a direction of a state --

>>>CHERYL GROVE: Off the top of my head, there was a specific HUD funded project in the early 1990s in California. There's been private projects that were coordinated through independent living centers in Canada, you know. I can't -- I'm not -- you know, I brought reams of data to one of these -- and no one has been interested. So I didn't bring it with me.

>>>CARRIE MIRANDA: Any other questions from the panel?

>>>MARIKA TERLECKY: Just clarification. Can you say what COPD stands for?

>>>CHERYL GROVE: Chronic Obstructive Pulmonary Disease. It is -- well of course you are familiar with emphysema which smokers get but it is also from nonsmoking pollution types of things. And now there's a category which is chronic bronchitis. And oftentimes the asthma will lead into that with the triggers, the pollution, indoor and outdoor pollution triggers are not controlled and managed. You are welcome.

>>>CARRIE MIRANDA: Our next person requesting to speak is Pat Cole.

You pass?

>>>PAT COLE: I pass.

>>>CARRIE MIRANDA: Okay. Thank you. I don't have anyone else listed here to speak. But if there is anyone that is interested, if you could please raise your hand and share your name.

Okay.

Richard Costa.

>>>RICHARD COSTA: Yes.

>>>CARRIE MIRANDA: Go right ahead

>>>RICHARD COSTA: Okay.

Um --

>>>TIMOTHY FLYNN: Spell your name.

>>>RICHARD COSTA: Costa.

>>>TIMOTHY FLYNN: Thanks.

>>>RICHARD COSTA: There is a talking book program that every state in the country has but the state of Rhode Island does not have a descriptive video program in conjunction with that talking book program. And we are one of only four states in the United States that does not have that program. And I just wish that the state of Rhode Island could and would do something about that.

## Blind and Visually Impaired

>>>AUDIENCE MEMBER: Perhaps you can explain (inaudible)

>>>RICHARD COSTA: Would you like me to explain what the talking book program is?

>>>LINDA WARD: Sure.

>>>RICHARD COSTA: I'm sorry. The talking book program is a federally funded and state funded also program that -- where the blind and visually impaired and dyslexic can receive audio books, you know, for reading pleasure. Some school books can be obtained. The books that actually you can order through the talking book library and they are sent directly to your home. And then you can redeposit them once you finish reading them back into the mail and they are sent back. It's as easy as that. The descriptive videos are movies or documentaries that are just that. They're movies for -- again the blind, vision impaired where the movie is narrated. So that a blind person could watch a movie, per se, and know what's happening in the movie because the movie is again narrated.

>>>TIMOTHY FLYNN: Now, brief clarification. What -- so there is in Rhode Island access to talking books but there is no access to descriptive videos?

>>>RICHARD COSTA: Right. And most times the programs coincide with each other. So for a few more pennies -- because there is some funds involved to service these books -- but for a few more pennies -- and that's what it really basically comes down to -- the two programs could be coincided together.

>>>TIMOTHY FLYNN: Currently they don't coincide in Rhode Island.

>>>RICHARD COSTA: Currently they don't. And again we are just one of four states that does not have this program.

>>>TIMOTHY FLYNN: I would be interested in know -- have you sort of asked any -- have you gone to the -- who sort of runs this? Who sort of manages the --

>>>RICHARD COSTA: The talking book library of Rhode Island.

>>>TIMOTHY FLYNN: And so have you spoken to them and --

>>>RICHARD COSTA: Yes, I have.

>>>TIMOTHY FLYNN: And what kind of response did you get --

>>>RICHARD COSTA: That's why I am here today.

>>>TIMOTHY FLYNN: Do they say we just don't have the funding? Do they say what needs to be done?

>>>RICHARD COSTA: Yeah, part of the problem is that because of the funding in the state of Rhode Island as it is today is just a small part of the problem.

>>>TIMOTHY FLYNN: And so --

>>>RICHARD COSTA: A lot of the asking seems to fall upon deaf ears.

>>>TIMOTHY FLYNN: So -- who have you -- who have you approached that sort of has not responded?

>>>RICHARD COSTA: I called the governor's office.

>>>TIMOTHY FLYNN: Yeah.

>>>RICHARD COSTA: And I have gotten absolutely no response from them.

>>>TIMOTHY FLYNN: So, you are asking us to find the funds in order to fund this -- not talking book but what's the other --

>>>RICHARD COSTA: Descriptive video.

>>>TIMOTHY FLYNN: Descriptive video program.

>>>CARRIE MIRANDA: Any other questions from the panel? Okay.

Any other questions from anybody in the audience? ELIZABETH HACKETT.

>>>ELIZABETH HACKETT: My question is about the handicapped placards that we get for the automobiles. They are only good for two years. It costs somebody with a disability \$10 a page at a doctor's office to have those filled out. After the first one, why can't it be a

## Transportation

permanent, if it's a permanent disability?

>>>CHERYL GROVE: Can I add something to that?

>>>CARRIE MIRANDA: Yes. Can you state your name again?

>>>CHERYL GROVE: Cheryl Grove.

Additionally on top of that, I have a permanent dis -- adult onset permanent disability. I've gone through two renewals on my placard. Apparently the same doctor filled out the renewal application last year. And perhaps he was rushed on way to vacation or something, didn't fill it out the way it was wanted to be filled out. And my renewal on my permanent placard was denied. As a result, I went for six months and ended up having to go to a second doctor before -- without my placard, I ended up getting chronic bronchitis, very severe acute occurrences of it because I was not able to park in disability parking at Rhode Island Hospital for an appointment on an O zone day. I don't understand why that should be -- that kind -- it's a permanent disability. COPD is irreversible. Why did I have to go through that?

>>>TIMOTHY FLYNN: So, what I'm understanding here is you want people with what are classified as permanent disabilities --

>>>ELIZABETH HACKETT: Right.

>>>TIMOTHY FLYNN: -- to receive permanent parking placards without having to renew them?

>>>ELIZABETH HACKETT: Right. People with permanent disabilities are usually living on Social Security disability. So every time you go to have something filled out, that's taken money that you need to live on out of your pocket.

>>>TIMOTHY FLYNN: So you would like to see a -- again, what we are doing is we will create legislation here. We are not -- we can't talk to municipalities. We are creating legislation. So you would like to see legislation that states if someone has a chronic disability --

>>>ELIZABETH HACKETT: Yup.

>>>TIMOTHY FLYNN: Then he or she should receive a parking placard that does not have to be renewed?

>>>ELIZABETH HACKETT: Right.

>>>TIMOTHY FLYNN: That's what you would like to see?

>>>ELIZABETH HACKETT: Yes.

>>>TIMOTHY FLYNN: I want to be clear. Same thing with you, Cheryl?

>>>CHERYL GROVE: It was my understanding that the blue placard was a permanent placard. That was my understanding that the red one is a temporary. And the blue one is supposed to be a permanent. So why do we have to go through this exercise and deplete limited funds?

>>>TIMOTHY FLYNN: Well, you know, I can't answer necessarily for -- why the rules are the -- perhaps, perhaps maybe they anticipate maybe some people move out of state and so, you know, people have to renew every now and then. There could be any number of reasons, not really clear. But --

>>>CHERYL GROVE: When they lose their license in the state, wouldn't they automatically trigger --

>>>TIMOTHY FLYNN: Not necessarily. You know how bureaucracies work. Oftentimes left hand doesn't know what the right hand is doing.

>>>CHERYL GROVE: Even if you lose your license and you can't drive, you still need to go places. You still need to be closer than --

>>>TIMOTHY FLYNN: This is all true.

>>>MARIKA TERLECKY: So I understand, presently every two years you have to pay \$10?

>>>CHERYL GROVE: \$10 a page to a doctor to fill out the forms to renew the placard. And I was told that they are only good for two years. The most is three years on the placards.

>>>ANNETTE BOURBONNIERE: Can I suggest that maybe you want to talk to a doctor who's not going to charge you \$10. That's -- it just requires a signature that you still have the same disability. The renewal is a very simple thing and I think that you are probably getting

ripped off.

>>>CHERYL GROVE: They told me I had to fill out a whole new form.

>>>ANNETTE BOURBONNIERE: You shouldn't have to fill out a new one. And also I know that one of the reasons is people do move out of state. People die and other people use their placards. So it is a way to keep control over, you know, the

**Health Care**

legitimacy of the placards. Maybe legislation that says every five years or something like that might be worth considering. But I think that maybe you are really getting a bad job when somebody's charging you that amount of money, knowing that your income is limited.

>>>CARRIE MIRANDA: Can you just state your name for the record?

>>>ANNETTE BOURBONNIERE: Annette Bourbonniere.

>>>TIMOTHY FLYNN: Thank you, Annette. I appreciate your input there. Does that answer your questions?

>>>CHERYL GROVE: Yes but I still think --

>>>TIMOTHY FLYNN: But this will be -- we will certainly discuss it and we will take a hard look at this. I appreciate it.

>>>CARRIE MIRANDA: Do you have another question from the -- could you state your name?

>>>KRISTIN PRERINI: Kristin Prerini. I want to know why -- I had one of those

### Transportation

blue placards for a good 20 years, never needed it replaced. It got so brittle from being hung up all the time that it cracked. I called to get a replacement. Of course my local DMV they said, no you have to call the state. I called the state. The state told me I had to go to Cranston, thus take a day out of work, or I could mail them my broken one and be without for at least a week. And they would mail me one once they received my cracked -- and I just want to know if -- who do you -- how can you fight that? How can you get around that? How can somebody who's disabled and trying to make a living be without such a thing for a week or more?

>>>CARRIE MIRANDA: Comments from the panel?

>>>TIMOTHY FLYNN: I certainly hear what you are saying. I certainly understand the difficulty of missing that week and perhaps a better solution can be worked out. Can you think of one?

>>>KRISTIN PRERINI: I mean they should have -- the state should have records. If we applied -- we have been approved. Why can't they just mail us one? Then we can mail them the cracked one. If they are worried about fraud, that's fine. I understand that. But we can mail them -- and they can come after us if they don't have the broken one or what have you. At least we won't be without.

>>>ROBIN BURGESS: Temporary -- (inaudible) you would have to mail your other one in, in a certain time frame to -- the other one would be void like your --

>>>CARRIE MIRANDA: Can you repeat your suggestion and your name?

>>>ROBIN BURGESS: Robin Burgess, East Bay Mental Health. I suggested like the temporary license plates on cars. When you buy a new or used cars, these temporary plates that they could mail out or cards could have dates on them at which time they would expire and the permanent one would need to be in its place. That would give someone time to mail their old one and receive a replacement and not be without this desperately needed card.

>>>CARRIE MIRANDA: Thank you.

Another question? Just state your name again.

>>>CHERYL GROVE: Cheryl Grove. I'm wondering, being on a limited Social Security disability income, I don't get any of the discounts that seniors get.

And I'm wondering why because Social Security income is Social

Security income. It's as limited for me as it will be for me when I'm

65. So, it seems to me that's an oversight that could be addressed and hopefully starting at this state level is, you know, everything. You know the entrance into the beaches and the discounts and all of that, if -- right down to the prescription. Why are there varying rules between a Social Security recipient of 65 and a Social Security recipient of 55 or 50? If that's their -- if they are a low income -- it seems like it could be so much cleaner if we could just have a low income Social Security recipient across the board consistency of assistance. Do you understand what I'm saying?

>>>TIMOTHY FLYNN: I'm just trying to put it into sort of -- um -- so you would

want to see all senior -- sort of senior citizens discounts extended to persons who are recipients of any kind of disability --

>>>CHERYL GROVE: Low income Social Security disability recipients.

>>>TIMOTHY FLYNN: And you would want to see them receive any kind of discounts that are extended to persons who are 65 and over?

>>>CHERYL GROVE: Their green is the same as my green. Limited.

### Finances

>>>TIMOTHY FLYNN: Is that a yes?

>>>CHERYL GROVE: Yes.

>>>TIMOTHY FLYNN: I guess we can take a look at it.

>>>CARRIE MIRANDA: Any other questions from the panel?

>>>MARIKA TERLECKY: I just want to add to that, that the question -- the issue that was just raised right now, it varies state to state. And for example, just speaking on this issue, as a survivor now of, a brain injury survivor. When I was looking for supplemental health insurance and being that if you have a disability for a long time you have any number of preexisting conditions. So new -- getting proper insurance is difficult because they don't want to take you any more. So when I'm looking into supplemental health, whether it was with AARP or -- I looked all over on a variety of levels. If I had lived in Massachusetts, as I did for a number of years, I would have been able to qualify for services that people got at age 65. Because you are disabled. And that is your retirement plan. You are just getting it earlier, whatever you are getting for income.

>>>CHERYL GROVE: Exactly.

>>>MARIKA TERLECKY: Low or regular. But here in Rhode Island the law says you have to be 65 and it doesn't matter that you got disabled. You have to wait until the age limit. And in most other states, that is not true. And certainly it is not true in our neighboring states because I did my homework on that four, five years ago. And I know I raised it then and nothing has changed in that time. So whether it's trying to have a disabled person use their money more cost effectively, there does seem to be a discrimination on the age and the disability. And most of the states don't have that. Once you are disabled, you are basically getting your pension, whatever it is, how little or how much it is early. That's all it is because that's what you are living on. But when it came to health issues, I was really surprised because that's health insurance. That's not even saving \$2 at the movies or a parking thing. It's like if you are going to get health services to try to maintain some level of life for yourself after being disabled seriously, that's a lot of money we are talking about. So disability -- not trying to say it's any greater but I just wanted to raise it because I believe it falls in the same category because the insurance company sets it by age and in this state it's 65.

>>>TIMOTHY FLYNN: I would be interested in talking to you about that later on.

>>>MARIKA TERLECKY: All right. Thank you.

>>>CARRIE MIRANDA: Any other comments?

>>>AUDIENCE MEMBER: What splinters to me, what talked about, politician -- politics?

>>>CARRIE MIRANDA: This is the Governor's Commission on Disabilities. And this is a forum here for people in Newport County to share any concerns or --

>>>AUDIENCE MEMBER: People, like disabled people.

>>>CARRIE MIRANDA: Whether it's a physical disability or developmental disability.

>>>AUDIENCE MEMBER: People at the (inaudible) center.

>>>CARRIE MIRANDA: Yes, exactly. So we are here to share any comments or concerns or ideas.

A question in the back. Sir, if you could state your name for the record.

>>>PAT COLE: My name is Pat Cole. What about the -- getting into restaurants.

Some places like -- lifts and all that. Any possibility?

## Accessibility

>>>CARRIE MIRANDA: So your question is about the accessibility in the restaurants in Newport, that they are very hard to get into

some of the restaurants?

>>>PAT COLE: Yeah.

>>>CARRIE MIRANDA: Any questions or comments from the panel?

>>>TIMOTHY FLYNN: Well, you understand how accessibility works?

>>>PAT COLE: Pardon?

>>>TIMOTHY FLYNN: A lot of times, you know restaurants all -- if they are newly constructed, they have to be made accessible. Old restaurants, as we have a lot in Rhode Island and especially Newport, need to be made accessible only if making the place accessible does not place an undue financial burden on the owners of the said establishment. So a lot of times, you know, it costs a lot of money, as you can imagine, to make a restaurant accessible or build an elevator. Sometimes the cost of making a place accessible puts an undue burden on the owner of the establishment to

make themselves accessible and that is -- they are then exempt under the Americans with Disabilities -- that is the reason why you see it in a lot of places. Now it is also complaint driven. You can pipe up and sort of hire a lawyer and sue if you think that creating a -- making the place accessible would not in turn cause an undue financial burden on said establishment. But you have to prove that the cost of renovating a place does not put an undue burden on the owners of the establishment, which makes it very difficult. I'm not saying it's right or wrong. I'm saying that's the law.

>>>CARRIE MIRANDA: A question in the back, your name?

>>>JOY BENSEN: Joy Bensen. I am just curious who -- after something is made accessible, like streets or whatever, who actually comes around and checks to make sure they are? I don't know if that makes sense. But what department inspects those because so many times a parking spot will be accessible but the cut in the curb will be maybe right in front of the van. I just didn't know. Does somebody actually go around and approve those, what department?

>>>TIMOTHY FLYNN: I know that the governor's -- the commission itself has in the past advised businesses and schools, public entities as to whether a place is accessible or not, what it can cost to make the place accessible. So, you know, the Governor's Commission does that type of work. We hire state inspectors who go out and look at places, find out ways to make it accessible if a business comes to us --

>>>JOY BENSEN: I don't mean a business. I just meant on the street, like parking places, say. After --

>>>TIMOTHY FLYNN: I assume there is some sort of inspection process for any kind of work. Either it's municipal, de -- I imagine who does the work.

>>>CARRIE MIRANDA: I would say the best people to be able to give feedback about the practicality of any type of accessible modification would be people that are using them. I think what able bodied people find to be okay can be clearly not the case when somebody's independently trying to maneuver around, as we learned when we had the accessibility activities in Newport where people were touring about. People learned quite a bit about what actually wasn't so accessible that was touted as accessible. Any other questions or comments?

We have nobody else signed up to make comment at this point in time. The panel will remain here until 5:00 to receive any further comments for the commission. But we would like to thank you for joining us today and appreciate to have such a good size group, I think, for our Newport forum here.

>>>STEVEN PRATT: I have one comment.

>>>CARRIE MIRANDA: We have one more comment. Can you state your name for the record, please?

>>>STEVEN PRATT: Steven Pratt. The sidewalks in Newport and (inaudible) wheelchairs.

>>>CARRIE MIRANDA: The sidewalks in Newport? I'm sorry. I missed the second piece of it.

>>>STEVEN PRATT: Disabled for the wheelchairs. They go up --

>>>CARRIE MIRANDA: So they are not designed so the wheelchairs can go along the sidewalks?

>>>STEVEN PRATT: Yeah. I have a hard time going anywhere. You know --

>>>STEVEN PRATT: Not even --

>>>STEVEN PRATT: It's not designed for wheelchairs.

>>>CARRIE MIRANDA: Right.

>>>STEVEN PRATT: The only one -- you know, the only comment I have.

>>>CARRIE MIRANDA: Thank you. Any comments from the panel?

>>>MARIKA TERLECKY: Only to say that is quite an accurate statement here in Newport. And it must be terribly frustrating not only to not have the access but it limits your ability to live life.

>>>STEVEN PRATT: It is.

>>>MARIKA TERLECKY: If you don't have the access. Case in point, and this was raised just recently last week. I think it's worth mentioning here because I'm also a Newport resident. But we have the music festival here in Newport. People come from all over to it. One of the events was held on Goat Island, a brand new building, totally renovated, made beautiful, expensive. But it didn't have proper access for wheelchairs.

>>>STEVEN PRATT: Right.

>>>MARIKA TERLECKY: It didn't even have a ramp. A brand new building and it just opened up. It didn't have a ramp. And I, along with others, was volunteering that day. We had nine wheelchair people come to that concert. Had we not been able to ruffle up friends of friends that we knew to either bring the wheelchair in, assist the person, or carry the person in the wheelchair because over a half of them could not even stand. They wouldn't have been able to go to the concert that they already prepaid their tickets for.

>>>STEVEN PRATT: That's what I mean.

>>>MARIKA TERLECKY: And this is new and so --

>>>TIMOTHY FLYNN: Where was this?

>>>MARIKA TERLECKY: This is Bellmaire on Goat Island. I went to talk directly to the manager. I raised it with the city council member who I happen to know is on the city council here because it was a real concern that if I new buildings are doing this, as you already stated, we have many that are older and are protected. But when you add up all of them, there's very limited access here in this area for just what this gentleman is saying. And it greatly limits their ability to live life on this island.

>>>TIMOTHY FLYNN: What kind of feedback did you get when you approached the owners?

>>>MARIKA TERLECKY: That they are going to look into it. They are going to look into it. You know. Again I'm -- you know, sometimes when we wear many different hats and you have causes, it's hard not to. But it's like I didn't have the time to pursue it. But I wrote a letter to my own senator and congressman stating this is a clear-cut example because I didn't have to hear it hearsay. I was there to witness it, and was just so happy that I could get some friends to help people come in or they would have had to have been rejected. And in this day and time there should be no reason. That's a -- that is a federal violation versus I understand, Tim, what you raised earlier about the protection of the older ones and the cost -- I do understand that. I know that law. But here we have a new situation. The other thing that was raised --

>>>TIMOTHY FLYNN: Well, I also can say though, you can sue.

>>>MARIKA TERLECKY: Yes. Everybody can -- everyone can sue. But keep in mind --

>>>TIMOTHY FLYNN: I understand. I know what you are saying. A brand new thing --

>>>MARIKA TERLECKY: It takes money to sue for people who don't have the money to sue.

>>>TIMOTHY FLYNN: That's just the way the law is written.

>>>MARIKA TERLECKY: Right.

>>>TIMOTHY FLYNN: I understand that.

>>>MARIKA TERLECKY: But there should be enforcement in that. Just -- for example, **Transportation** it is the law to have handicapped parking for people. All right. We have all the signs. And I know this from being on another board. The State Wide Independent Living Council has nothing to do with Newport in this state. It's a statewide issue.

>>>TIMOTHY FLYNN: What did they --

>>>MARIKA TERLECKY: No one is enforcing when people who are totally capable to park elsewhere. It's rare to get a ticket or anything on that when people pull in a car. Meanwhile, if you are in a small town and you only have one or two handicapped spaces for people who really need it, they don't have anyplace else to go. I think we -- we need to pay attention to that, as we are looking to form -- it's one thing to form a law. The second part of that is to monitor and to enforce the -- if we are going to go through the money and hassle to create a law, let's protect the law and the rights that apply that originated.

>>>TIMOTHY FLYNN: Enforcement issue.

>>>STEVEN PRATT: And just another interesting aside on that, for a person like myself who had a permanent placard and went through a period where it wasn't renewed. I understand it would have been a \$500 fine if I had parked in a disability space with my invalid placard. Although I think that just a regular person coming in, parking, something like a \$25, \$50 fine. So I just found that to be a very interesting --

>>>TIMOTHY FLYNN: --

>>>AUDIENCE MEMBER: That's not true at all.

>>>TIMOTHY FLYNN: Say that again. If you have a placard, you park in a handicapped --

>>>STEVEN PRATT: If you have an expired placard but you use that and you park --

>>>TIMOTHY FLYNN: It's a \$500 --

>>>STEVEN PRATT: It's considerably -- the fine was considerably higher and I am happy to get my research and show it to you.

>>>AUDIENCE MEMBER: The way that works is if you were to loan your placard, valid or not, to another person who did not have the right to use it and allowed somebody else to use it, then you are fined \$500. If you have an expired one, that's the same as not having one, and the fine is \$100 across the state. It's no longer \$25 or \$50. It is \$100. But the \$500 fine is for fraudulent use when you are giving your placard to somebody who has no right to use it. That's the \$500 fine.

>>>STEVEN PRATT: Well, if that's the case, then it was misleading and thank you for clarifying that because that is much more comforting.

>>>CARRIE MIRANDA: Okay. If we have no more comments, I would like to thank everybody again for attending today. And as I said, the panel will be here until 5:00 to receive any further comments. And if you have not signed in, if you came in and didn't have a chance to sign in, if you could please sign over at the table. And just a reminder that Amy is also at this table to assist anybody in registering to vote that has not registered to vote at this time.

>>>TIMOTHY FLYNN: Yes, please sign in.

>>>CARRIE MIRANDA: Yes. Thank you very much.

>>>TIMOTHY FLYNN: Thank you, Annette. You want to switch places?

>>>ANNETTE BOURBONNIERE: No. It's okay. It's your turn.

>>>CARRIE MIRANDA: The panel is going to be able to take a ten-minute break right now until 4:00 and we will regroup here at 4:00.

>>>TIMOTHY FLYNN: Thank you, Carrie.

>>>CARRIE MIRANDA: You are welcome. Anything else I can do?

(Break)

>>>CARRIE MIRANDA: May I have your attention, please. I would like to call the meeting back to order. If anybody has any last questions, comments? Well, with all that said, I would like to thank you and adjourn the meeting. Thank you.

## **Wednesday July 25, 2007- Woonsocket Senior Center**

>>>LEO CANUEL: We're going to get started, not that we have to rush, we have two hours. The panel has to be here for two hours, you don't have to. My name is Leo Canuel, director of PARI Independent Living Center, hosting this panel today. We have a couple rules and things to go over before we get started and then I'll ask the panel to introduce them selves and explain their position and where they come from and what gets them here today. But the purpose behind this event today is this forum that is held on an annual basis and if you ever want to make a note, it's always during this week which falls July 26th and for people with disabilities, July 26th is a very important date because that's the date that the Americans with Disabilities Act was signed in 1990. So the Governor's Commission always picks this week to have these forums because it's very important for us to hear concerns and issues from the community for our next year's agenda. What you say today creates the agenda for what this group of people will do over the next year. And speaking for PARI our self, while we do have a satisfaction survey from the consumer, we also use the document that is developed from this forum, this is last year's document, and if -- this is my copy, but you're free to look at it today if you choose to, it has everyone's testimony of everything that everyone said at all of the forums that were held last year. And then what the Governor's Commission will do, their legislative committee will take these, this testimony and work out what the Governor's Commission is going to work out and organizations like PARI also use this document for our future planning. And what we as an independent living center are going to do over the next year and three years and five years to work on for people with disabilities. So I have to say, I've been doing this now for I think about five years and every year we learn something new and we take that information and develop our advocacy for the coming year so it's important for us to hear from you. So I hope if you came to listen today, that's great but while you're listening, something sparks your interest and there is something you want to say, please don't hesitate to say it. I run this forum very inn formally. Everything that you will be saying is going to be documented by the CART reporter. If you're not familiar with CART, CART stands for computer aided real-time reporting and what they do is verbatim writing exactly what we say. So if you're stupid like me and sometimes say something weird, it's up there and everybody knows it's up there. Couple formalities you should know of as we go along this morning. The bathrooms are out this back door and to your left straight ahead of you. The accessible bathrooms are out this way to my left, all the way to the end, you'll see that exit sign through the window over there, the bathrooms are just on the other side there. We have some basic rule that is we want to follow. Basically we try to give people about five-minutes to say what they need to say. While it is an opportunity for you to tell us, if you say something that interests the panel and the panel has a response to you because I've been to these forums where we've already had an answer to the problem the person is bringing but the person didn't know about the answer so sitting on this panel we've been able to give feedback right away and sometimes get your questions answers very, very quickly. So we try to have a little bit of a dialogue. And we do have interpreters in the room in the back of the room that I don't think we need, hi interpreters. Are you guys staying the full two hours?

>>>INTERPRETER: Yes.

>>>LEO CANUEL: So should someone need a sign language interpreter, we have them here. And we also have Harvey from the Governor's Commission who is our greeter and be sure to sign in even if you don't choose to speak, just sign in just so we have your name. On the back table, we do have a couple of handouts that if you'd like to take on your way out, we do have some information put out by the Sherlock Center regarding health insurance purchasing and buying health insurance for Medicaid. We have information on the public forum and all of the sponsors and participate abilities. We also have that's hot off the press, right here all of the bills from this year's legislative season that have been signed by the Governor. So these are all of the bill that is actually came a lot of them came from this, what we did last year what the Governor's Commission worked on and now they're law. So you can see the direct result of the two of them. But I haven't had a chance to reed this myself, I just printed it this morning but you might want to grab that, bedtime reading tonight when you can't get to sleep. We have information on voting, Rhode Island has a

disability vote movement going onto try to get people with disabilities to vote. So, this is some information on that. And then we have information on the Sherlock Center in Spanish so if you serve the Spanish community, you can access that. What I'll start doing with this fine woman right here is allow Lezlee to introduce them selves.

>>>LEZLEE SHAFFER: May name is Lezlee Shaffer, program director at the other independent living center based in Warwick, Ocean State Center for Independent Living, known as OSCIL. I've been to a number of these forums over the last ten years. And I'm here to really get some feedback from the community as an agency that works with people with disabilities to help them to stay independent in the community. We wanted to have some sense of what the concerns are for the average person. With money constraints being what they are, feedback from you folks will help us to start to look at some of the service provisions that we have and also help us to do some prioritizing in terms of where we should be putting more of our energies.

>>>ANNE MULREADY: Thank you. Hi I'm Anne Mulready, supervising attorney at the Rhode Island Disability Law Center, nonprofit law office in Rhode Island designated to be the protection and advocating agency for people with disabilities so we represent people with disabilities exclusively on disability related legal issues. As Lezlee and Leo have said, we use this process to help us identify what are the most important legal issues and barriers facing people with disabilities, so that will help us use our resources to focus on priority issues for people with disabilities. So this is a process that's very valuable to us and your input is valuable to us. We also have and I'll leave them on the table out back, a paper survey if you want to fill it out to give us some idea of what the priority legal needs are of people with disabilities. Thank you.

>>>CHRIS BUTLER: I'm Chris Butler, executive director of In-sight, statewide nonprofit people that are blind and visually impaired to help people with visual impairments to become fully independent in the community.

>>>SUSAN SILVA: Susan Silva, supervisor with the Office of Rehabilitation Services and here to get feedback on services you may have been happy with or things you think we might do better in the communities. We work with individuals with disabilities to help them become employed and maintain that employment. Thank you.

>>>ANNE LECLERC: I'm Anne LeClerc with the Rhode Island Public Transit Authority, work with the RIDE program and TIKs service, emergency preparedness and other things. Also a member of the state rehabilitation council.

>>>ARTHUR PLITT: I'm Arthur Plitt, Commissioner, Governor's Commission on Disabilities as well as a number of other disability-related organizations. I find the testimony very insightful and confirmation of some of the legislative issues that we're concerned with as well as getting an idea of what the real problems are for real people. Thank you.

>>>REGINA CONNOR: I'm Regina Connor, also a commissioner with the Rhode Island Commission on Disabilities and also the director of Vision Rehabilitation at In-sight working with Chris Butler. Interested of course in hearing what the issues are for people with disabilities in community. And in particular, if any of you are visually impaired or have family members or friends who are visually impaired and you're aware of particular issues you would like to bring forward, I'd certainly be interested in hearing.

>>>BRIAN MONTEIRO: Brian Monteiro, aid for the Lieutenant Governor and work on the long-term care coordinated council monitoring legislation that comes before the General Assembly, propose certain legislation. And that's pretty much it. We do a lot of work with community based care and nursing homes and things of that nature.

>>>LEO CANUEL: Okay, that's who we are. So let's start getting to the real reason we're here and that's to hear from you. Before you begin your testimony, please state your full name. And if you want to tell us what city or town you live in, that would be helpful, too. And also for the panel, as, if you begin speaking, state your name every time you speak so the CART reporter can put as a direct transcript who was speaking at all times. So the first person who has signed up to speak and you can just stay exactly where you are, you don't need to come forward. Right from your chair is fine, Michelle.

>>>MICHELLE ST. PIERRE: I'm Michelle, I live in Cumberland, for four-and-a-half years now.

>>>LEO CANUEL: Just don't look at it.

>>>MICHELLE ST. PIERRE: No?

>>>LEO CANUEL: Look at me.

>>>MICHELLE ST. PIERRE: I love living where I am. I go out, I go out and do activities at night, go with my father every weekend and when my father, my aunt, my cousin and my father and me, I take them out to eat every weekend.

>>>LEO CANUEL: Yep.

>>>FEMALE SPEAKER: You did a very nice job, Michelle. No questions? Maybe you'll have some questions later.

>>>LEO CANUEL: Is there something that would serve you better to help you go out with your family on nights and weekends? Maybe transportation or something else that would help you?

>>>MICHELLE ST. PIERRE: There is some activity trips that I could go to on the weekend but on the weekend I like to see my father.

>>>LEO CANUEL: Okay. That's fine. Is that it?

>>>MICHELLE ST. PIERRE: That's it.

>>>LEO CANUEL: Eileen.

>>>EILEEN PICCHIONE : From the Homestead Group in Woonsocket and I've never been

### Working and Health Benefits

to one of these forums and I didn't really know the procedure. But the only difficulties that we find with The Homestead Group is right now, we're getting individuals jobs in the community, we have several individuals who are working at the naval war college and as a result of the wages they're paying at the naval war college, several of our individuals are going to be losing their Social Security benefits so I was just wondering if there's a specific individual like in the Social Security administration or like in that area who could be of assistance to us, if anyone had the name of like a liaison.

>>>LEO CANUEL: Someone to help with benefit's planning.

>>>SUSAN SILVA: Susan Silva at the Office of Rehabilitation Services, we have some benefit specialists, two people right now, Jeanne Fay generally meets with individuals and I'm sure if you called her, she would be happy to meet with your groups and talk about benefits and what can continue even though you're working because you are entitled to certain things when working.

>>>EILEEN PICCHIONE: I know we've met as a group. She has met with the whole group but I think in these situations, it's a little more of a, like a smaller group within the group that were affected.

>>>SUSAN SILVA: That's fine, I think she would be willing to do that to, if you give her a call and I'll let her know also we spoke, you can arrange something because she'll meet individually.

>>>EILEEN PICCHIONE: Is she at the 421 number?

>>>SUSAN SILVA: Right.

>>>ARTHUR PLITT: I also serve on the Rhodes to Independence advisory committee and working on a retreat in September to address some of these problems. But I know that you may not be aware of the Medicaid buy in which may allow some people to keep their benefits by paying out a small type pen towards that.

>>>JEAN DIPIPPA: There's a brochure in the back.

>>>EILEEN PICCHIONE: Yes, I was looking at that, thank you so much.

>>>ANNE MULREADY: Anne Mulready from the Disability Law Center. We also have a project that represents people with disabilities when they're having difficulty with overpayments or managing work incentives so if you have individual clients who are beginning to have benefits problems, you should feel free to refer them to us and we actually go with Jeanne and do trainings. So, the wippa.

>>>JEAN DIPIPPA: Thank you.

>>>LEO CANUEL: So, as you can see, the reason why I like these panels is because we have all the experts and when you have a question we can usually come up with an answer rather quickly. There is no answer just yet. Moving on. Roger Harris.

>>>ROGER HARRIS: Well, you know my name. Hi Susan. Born and raised here in

### Voting

Woonsocket. I'm paralyzed veteran, here though, my capacity, I represent the Rhode Island Disability Vote Project, one of the founding managing directors, also on the steering committee and I'm here to hopefully register those of you who are not yet registered voters, I have registration forms with me and also have information about the project if you would like to have that as well.

>>>LEO CANUEL: Okay. Thank you.

>>>ARTHUR PLITT: Can I also make a comment? Many people don't realize that you can sign up as a poll worker to work on the day and always looking for poll workers for Election Day. It does pay a very small stipend so maybe that might be of some interest.

>>>LEO CANUEL: Small stipend that doesn't affect your benefits. Which is important because many times people -- go ahead.

>>>ROGER HARRIS: I just want to throw this out as well. There's a few cities and towns in Rhode Island doing elections this year. There's some specific elections, primaries, also general elections this year. So, I would behoove you if you would like to participate in the polls, definitely go out there.

>>>FEMALE SPEAKER: Who are the contacts?

>>>ROGER HARRIS: Local board of elections, board of canvasses.

>>>LEO CANUEL: Do you want to explain the disability vote project?

>>>ROGER HARRIS: Sure, I don't want to take too much time. The Rhode Island Disability Vote Project is made up of, we have about 26 member organizations. Our main focus is to elevate the disabled community in the realms of voting. We understand in Rhode Island there's upwards of 185,000 people with a disability. Of that number, there's about 20 percent of them who vote. That means 80 to 85 percent of people with disabilities don't vote and the reason they don't vote is huge. What we do is go out into the community and try to educate disabled community about the importance of voting, why is it important to vote and how to get them registered. Also we educate them on legislation issues that may come up that effect us with disabilities. One case, the closed captioning bill. We put a lot of energy into getting that bill passed this year. Closed captioning for people who are deaf or hard of hearing legislators who run for office who get public funding, now they have to spend some of that public funding on the commercials when they do ads for closed captioning for those of us who are deaf and hard of hearing. Another thing, I I'm going to hope to invite PARI, I'm not sure if you're members.

>>>LEO CANUEL: We are.

>>>ROGER HARRIS: And any other organizations who are not members, we're recruiting and I think there's strength in numbers. Like I said, 185,000 people with disabilities, imagine the power we could have in Rhode Island. Thank you.

>>>LEZLEE SHAFFER: Can I add a couple things, OSCIL has been involved with the group as well. Some of the other things that the organization has been doing is providing information about some of the new technology that's out there like the new voting machines for people who are visually impaired that are in place at the different polling places, accessibility and accommodations that you can request to get out to vote. And things like absentee ballots and such. And I think both centers do registrations for the registrations as part of our intake process when we go out into the community and we meet with someone in their home, we also have voter registration forms so that they can sign on at that point.

>>>LEO CANUEL: For us it's always a question asked when we work with a new consumer every year.

>>>ROGER HARRIS: One more thing. I was also appointed to the Secretary of State's Voter Initiative Task Force. Prior to my appointment, there was no one there representing the disabled community so I think someone from the disabled community got on that task. What they're doing is having public forums throughout the state, two coming up, one August 6th at the URI campus in Warwick and September 10th, I do believe in Newport. What they do at these forums, people come and ask questions regarding voting. The hope is, the hope for the Commission to make voting easier for people in Rhode Island, not just people with disabilities but for every Rhode Islander. Thank you.

>>>LEO CANUEL: Roger, do you vote?

>>>ROGER HARRIS: Of course; since I turned 18.

>>>LEO CANUEL: Next person on the list is Karen Racine.

>>>KAREN RACINE: I've never been to one of these, I'm Karen Racine from Cumberland. I'm basically here as a mom of a son who has a mental illness and I guess one of my sources of frustration is, he was sick when he was 8, he's presently 19, and kind of the different agencies that we've been referred to over the years, I just feel like people, a lot of times will say, we're going to do this, we're going to do that, and it never ends up happening. And it's

**Support  
Agencies and  
Programs**

kind of a source of frustration, you need Respite care, okay, you have two months, have you the application process and then you have, okay, you've been accepted but we're out of funds so then you wait so long and then you finally get someone in to help you and there's an anxiety issue and she invites him over and 22 other people and has a party and obviously that didn't work out, you know, referred to different like goodwill industries and, we're going to get him into this and that. It's a summertime program, it finishes, it's done. And that's it and then he has nothing to do so then he found a job, worked one week a month and then ORS signed off on him and, I don't know that there's really a question here, it's just a frustration of people from different services promising different things and I wish that they wouldn't say it if it's not going to happen. You know, he, up until present, he's going to be, he just started a week ago at Gibbs college, I have no idea if that will work out or not but basically sat in a chair for about a year because there wasn't anything to do, had anxiety issues, has no friends, there was no place to take him. You know, nothing really for him to do. You know, he got on SSI but that really didn't solve his problem at all. I don't know if there's, you know, it's the transition from teen to adult, there was no place for him to go. He also is, in addition to his mental illnesses, he's 6 foot 6 and 350 pounds and has issues with his feet so he has trouble walking long distances so that counts out a lot of different jobs he could possibly do. And I guess that's just.

>>>LEO CANUEL: Can I ask a question as to what type of a program -- I'm assuming he's transitioning into adult services, what type of a program are you looking for him, or is he looking for, sounds like you're looking for.

>>>KAREN RACINE: Like a social skills, not necessarily skills, there's nothing wrong with his skills, a place for him to go, to meet people, to get out of the house, someplace for him to go. I have been to a lot of different agencies. He is now hooked back up with ORS, they're involved again, but I just feel like I was disappointed by a lot of different agencies and there wasn't anything available and I tried Cedar, I mean, it's not like I haven't been trying.

>>>LEO CANUEL: Where does he live?

>>>KAREN RACINE: Cumberland.

>>>LEO CANUEL: Does the panel have any suggestions.

>>>FEMALE SPEAKER: I would ask if you've connected with the community mental health centers?

<p><b>Mental Health Care</b></p>
--------------------------------------

>>>KAREN RACINE: I tried here in Woonsocket and they have nothing available.

>>>FEMALE SPEAKER: Nothing available in what terms? They did not accept him into any of the programs.

>>>KAREN RACINE: Not as far as like a meeting group for kids his age, they didn't have anything. He has a psychiatrist, we have been seeing a counselor, I mean that wasn't really the issue, it was just a place to go.

>>>FEMALE SPEAKER: There's a place I think on North Main Street, the Oasis it's called, like a center for mental health -- whatever you want to call them -- they have all kinds of stuff going on there, it's on north Main Street in Providence.

>>>KAREN RACINE: Maybe some of the issue is his age, turning from.

>>>FEMALE SPEAKER: They might even have --

>>>KAREN RACINE: You know, high school kid into, he's now 19. He got his drivers license which was very nice through ORS, they tested him first because I couldn't have him try to drive my own car because he couldn't fit and I had to buy him his own and didn't want to if you couldn't drive, so, I mean, I have gotten some services. There's, there have been other ones that just.

>>>FEMALE SPEAKER: I know that group still exists.

>>>ANNE MULREADY: Anne Mulready. Is one of your concerns, is there a sense you have to find out what they were as opposed to somebody helping you coordinate the needs.

>>>KAREN RACINE: Probably.

>>>LEO CANUEL: When he was younger, let's say 16, how were services then?

>>>KAREN RACINE: I don't know, there really weren't any services for him. He was in school, they had said, you know, they had kind of hooked up with goodwill industries but that was just a summer one time job, they had him tested in the beginning and that just, it ended is what it did. They said, we'd look into training him for something, that happen never happened, kids were picking on him on the bus so

I had to drive him myself. I could go on and on and don't want to take a lot of the time but that's, you know, there wasn't any services for him.

>>>LEO CANUEL: Okay. Arthur.

>>>ARTHUR PLITT: Arthur from the Commission. Have you talked to NAMI (sounds like),. I know Oasis does have support groups.

>>>FEMALE SPEAKER: Rhode Island Parent Information Network.

>>>MALE SPEAKER: I was telling her about the Trudeau center, as well, they work with adults.

>>>FEMALE SPEAKER: Not adults with mental illness.

>>>MALE SPEAKER: They don't? I didn't know that.

>>>LEO CANUEL: Well, I would suggest that, I don't know Susan, if you want to help.

>>>SUSAN SILVA: I was going to say I would talk with you after the meeting if you like.

>>>KAREN RACINE: We're trying the college thing, have been recently hooked back up with ORS again, they had denied him because they thought, I don't know, he was working one week a month. You know, he's on SSI, well that happen didn't do a thing for him, really. So he did get the services but that didn't help him.

## Education

>>>SUSAN SILVA: Sometimes someone may ask if he's happy with his job and he said, just assume that he was. So we can talk afterwards in more detail.

>>>LEO CANUEL: I find one of the problems we have here in Rhode Island is first of all that transitioning from youth to adult hood because services for kids and services for adults are completely different. And the expectations are completely different. And many times, people tend to kind of just fall off when they transition so we need to make sure that services continue and that, we call it transitioning, that transitioning has been. And that's a difficult task sometimes to get that done. Okay, so you two can connect up afterwards. Linda Stone.

>>>LINDA STONE: I was born and raised in Woonsocket. And I have a lot of trouble getting places because I can't drive and I had an appointment, I have to go to Rhode Island hospital, no neurologist in Woonsocket that take Medicaid and Medicare so I have to go to Rhode Island and I had an appointment for an MRI Wednesday and they picked had he up two hours late, they're going to be there, they'll be there, from universal and Flex sometimes, they take you an hour ahead of time to bring you to your place and it's just too, it's too much. There's not enough rides for, you know, I go to a lot of doctor's appointments and most of them are in Providence because that's where the neurologists and neurosurgeons are and even though Friday they picked me up early from my other MRI but they picked me up two hours late and I went because I was going to wait a couple hours, I needed that MRI done, too. So I don't know what other transportations there are.

## Transportation

>>>LEO CANUEL: Mostly just to get from Woonsocket to Providence you're having an issue?

>>>LINDA STONE: Yes because that's the only place that takes my Medicaid for neurosurgeons.

>>>ANNE LECLERC: You're using the RIdE program now?

>>>LINDA STONE: I don't know the RIdE program.

>>>ANNE LECLERC: Flex is the Woonsocket local, how do you get to Providence.

>>>LINDA STONE: Universal, it's a van. I usually go in my wheelchair and they take me in that.

>>>LEO CANUEL: Medicaid funded.

>>>ANNE LECLERC: Yeah, it's different. There's another service called the American with Disabilities Act, it's under the RIdE program and I can give you the number and send you an application for that. Under ADA, transit companies have to provide this service for people whose disability prevents use of the fixed use system. So if you don't take a regular bus into Providence, you could take this one.

>>>LINDA STONE: I could but my MRI was at seven o'clock at night, I'm not taking a bus into Kennedy.

>>>ANNE LECLERC: The service is a van that will take you from your house to the MRI location, operates the same time as the fixed route so if you could get there on it's regular bus at seven but can't get to one, you can take this.

>>>LEO CANUEL: Is there a regular bus that goes close to your house?

>>>LINDA STONE: Yes, I moved to Main Street where the buses are right there, I purposely took that because of the buses. I can take a bus, but if it's at night, there's no way I'm getting in the middle of Kennedy plaza at night.

>>>LEO CANUEL: The RIDE service is kind of like a taxi service, van comes directly to your house, you have to get to the curb, the van picks you up, will drive you to, right to Rhode Island hospital and let you off at Rhode Island hospital and pick you up again at that same place at Rhode Island hospital and drive you right back to your house. So you're not getting off in Kennedy plaza, you're getting off at your appointment and, I don't know what the fee would be for that.

>>>ANNE LECLERC: It's \$3 each way.

>>>LINDA STONE: Sometimes that's kind of tough. I've already had two MRIs last week and then I had one of the week before that. And that's where my neurologists all are.

>>>FEMALE SPEAKER: Is Medicaid arranging your ambulance service?

## Health Care Benefits

>>>LINDA STONE: I don't know, I call universal, I don't know how I.

>>>FEMALE SPEAKER: You should call and complain about not getting to your appointments on time.

>>>LINDA STONE: They know that.

>>>FEMALE SPEAKER: Not Universal, call your Medicaid provider.

>>>LEO CANUEL: The number on the back of your Medicaid card, have you a number on the back of your Medicaid card, call that number and tell them what you just told us, you're trying to get there and universal is showing up two hours late.

>>>LINDA STONE: That was the latest, normally they're late and, you know, I even try to say my appointment is earlier than it really is and it doesn't do anything.

>>>LEO CANUEL: Because Medicaid is paying them to drive you to your appointment and pick you up and taking you home so it's their money and they should advocate for you to make sure that universal is getting you there at the time that you need to get there because I'm assume that go a seven o'clock at night transport, they're not really that busy at that time.

>>>LINDA STONE: No, it's the mornings, mostly in the mornings there.

>>>LEO CANUEL: Seven a.m.?

>>>LINDA STONE: Well, I guess.

>>>LEO CANUEL: They pick you up at seven so you can get there.

>>>LINDA STONE: Whatever time at no time morning, yeah. I have another question.

## Transportation

How come fibromyalgia, can't get a hand capped parking?

>>>LEO CANUEL: It doesn't depend on disability, it depends on function. It depends on how your doctor writes up the paperwork that states you're having an issue getting from your vehicle to the front door of the vocation. So it's function, not disability based.

>>>MALE SPEAKER: Can you look back on what she just said? I think that system is being abused. I know people that have just a bad toe and they get a handicapped parking tag and you're saying about how it's based on how the doctor writes up the script or whatever, I think it's not fair. For example I go to the state house quite a bit and all the handicapped spots at the present handicapped entrance is taken by legislators and I see them getting out of their cars. Physically they don't have a disability, visually I mean, they're able bodied, they walk in there and I question that each time I see one of them and they say, have I a sticker, I can park there, which is true. But I think that should be looked into. I think that system is abused.

>>>MALE SPEAKER: That's been a problem up there for a long time. Everybody complains about it. The best thing to do is before you go to the state house, call ahead so they can reserve.

>>>MALE SPEAKER: They'll reserve is spot for me?

>>>MALE SPEAKER: If you call ahead.

>>>LEO CANUEL: Call the Lieutenant Governor's office, say Brian.

>>>MALE SPEAKER: Okay, Brian.

>>>LEO CANUEL: And he'll be standing outside holding the spot for you.

>>>CELESTE BOURBONNIERE: Could you tell me more about the Flex?

>>>LEO CANUEL: Can you state your name.

>>>CELESTE BOURBONNIERE: Celeste. I lost my car so I have no way of getting around.

>>>LEO CANUEL: Hold on. I want to be sure Linda is done first. Do you have any more.

>>>LINDA STONE: No.

>>>ANNE MULREADY: This is Anne Mulready, I wanted to respond to Linda, sometimes, I know it's hard to believe but the DMV makes mistakes on their issuing. So it could be that your relatives did say the right things that would enable your relative to get a placard so that is something that our offices will help people with if they've been denied a parking placard, we'll look into it because sometimes the DMV, it's a paper shuffle and things get lost in the shuffle if area relative thinks that may have happened to them, you can call our office and we'll look at it.

>>>LINDA STONE: Your office is what?

>>>ANNE MULREADY: I can give you a card.

>>>LEO CANUEL: Always remember that any decision the state makes about anything, you can appeal. And I always encourage people to appeal. Just to have your case heard. And let me also add that there are some hidden disabilities that you would not see that people can get placards with, so, respiratory issues, card vascular issues, circumstance la toyer issues, you are you can get a placard so if you can't walk a long distance for those reasons. So it's difficult to say if you just see someone getting out of a vehicle and walking away that person does not have a disability. I'm not saying there's no abuses with the placard because I'm always questioning as to is the person the placard assigned to still living? You know. Dead people are still on voter roles and still using placards in the state of Rhode Island. So it's always an issue and I know that the Governor's Commission had looked into it and I was actually interviewed by channel 10 on this very issue because people are abusing placards which is illegal and if you're found, police can fine you.

>>>FEMALE SPEAKER: Couldn't you just take the placard from the person who is disabled, put it in your car and you go and park.

>>>LEO CANUEL: Yes. If you were to use my placard and didn't have a disability and my placard has my picture on it and the police officer says let me see that placard and your picture is not there, that's illegal and you can be fined and I can lose my placard forgiving it to you but if I'm already dead -- but, yeah, that happens many times where people's parent vs. a placard and they cover the picture so you can't see it and leave it there in the window. Let's go back to your, is it Celeste.

>>>ANNE LECLERC: I should have brought some brochures. Flex service is a general public service, anyone can use it for any reason. It's zone based and up here the city of Woonsocket is one zone. We have six others in the state, South County, Kent County and the ports mouth, Tiverton area. The service is mostly reservation based, you call and ask them to pick you up at your home. So any where in Woonsocket.

>>>CELESTE BOURBONNIERE: For doctor appointments and stuff?

>>>ANNE LECLERC: Any reason, anyone can use it for any reason, Monday through Friday six to 6:30.

>>>CELESTE BOURBONNIERE: I'm kind of way out.

>>>ANNE LECLERC: Any where in Woonsocket. It's \$1.50 each way, if have you a bus pass.

>>>CELESTE BOURBONNIERE: I'm in the process of applying, it's still pending.

>>>ANNE LECLERC: Bus passes works like on the fixed route passes. If you want to apply for the senior bus senior or disabled bus pass, you can use those as well. If you're transferring, it can take you to the regular because just like you would between two regular buses.

>>>CELESTE BOURBONNIERE: How soon do you have to call ahead?

>>>ANNE LECLERC: We ask 48 hours. They can sometimes do it less but Woonsocket is very busy so it can be hard to schedule it in less than that because right now it's one person doing the scheduling manually. The office isn't open on weekends. But the number, I can give it to you, it's -- I can write it down.

>>>LEO CANUEL: While she's taking out a pen. Let me clarify that the Flex service works within the Woonsocket area if you're going to Woonsocket but if you're going outside of Woonsocket does.

>>>ANNE LECLERC: It will bring you to a bus stop and if you can't use the regular bus, it can bring you to a RId e bus.

>>>LEO CANUEL: So in order to use RId e you need to be three quarters of a mile within.

>>>ANNE LECLERC: RIdE is an umbrella program, it's more than one thing, RIdE is just the vehicles and it's one phone number to call but there are multiple programs. One is the American with Disabilities Act I had talked about before which is equivalent service to the fixed route so it has to be in the same area if there's no fixed route service there, would be no ADA service. If the fixed route does run, it would operate at the same times. So if there's no Sunday service on fixed route, there's no service. If there's service until one a.m., there's ADA service, so equivalent times and locations. Programs on RIdE will limit the purpose, RIdE can't limit the purpose. On a RIPTA bus, driver can't ask where you're going and say get off. ADA is just like that. They might ask for statistical purposes but doesn't affect getting the trip. Other programs like the department of elderly affairs to senior meal sites, adult day care, some medical trips some under 60 for dialysis or chemotherapy, for trips on RIdE under certain, like the Trudeau center, they'll pay for though as well. Those are limited to time, usually more so than the ADA program. ADA now is the only one that charges a fair and it's \$3 each way, the rest of the programs are free. But if you want to go shopping or movies, you can use either Flex or if you're eligible for the ADA program, use that under RIdE.

>>>LEO CANUEL: You said ADA RIdE is the only one that charge a fee?

>>>ANNE LECLERC: In the RIdE program. Flex is a separate program. The Flex fairs are just like the fixed route fairs. Any passes work on Flex just like the other RIPTA buses.

>>>LEO CANUEL: Phone number.

>>>ANNE LECLERC: 877-906-3539. And it's instate, toll free.

>>>CELESTE BOURBONNIERE: If you called them up, you would tell them, like a pick up time and when you want to come back?

>>>ANNE LECLERC: Yes. If you want to go to the movies, you would tell them what time it starts and ends and they'll get you there. Or any other reason. If you are a he going shopping or something social, and someone else wants to go to work, they may ask to you move your time. In Flex we try to give work trips priority to be sure people get to work on time. But other than that we try to fit in all the trips we can. It is though first come, first serve. There are two-weeks in Woonsocket that operate 6:00 to 6:30 P.M., Monday through Friday but there are times it's packed full and they can't fit another person on. So if it's something like a shopping trip they may ask you to go another time.

>>>CELESTE BOURBONNIERE: So they would take someone to work on a regular basis.

>>>ANNE LECLERC: Yes we take people to work, if it's a parent with a child, we'll take the child to dare care, the parent can get off the bus and get back on and continue to work. The bus usually waits in that case. If someone is paying cash, they don't have to pay to get back on the bus if they're getting off to take the child to day care, it's considered the same trip for them. And it is the same size vehicle that RIdE uses, it's the exact same vehicle actually only it's painted with the RIPTA colors and has overhead sign like the regular buses. 281, it says 281 Woonsocket Flex, has a fare box inside. And our fare boxes will be changing July 30th, if anyone has question about that. If you show a pass, nothing will change right now but the cash products are changing, the rip particulars are changing, we're going to a different type of fare box.

>>>EILEEN PICCHIONE: Homestead Group in Woonsocket, I have an individual who uses RIdE, we've had several over the years use the RIdE program and we've had a lot of difficulty with dependability and if have you a person that's supposed to be picked up at three, it's four, we constantly get the busy signal, can't get through. Just a lot of problem with dependability and I've spoken with Bill Inlow before.

>>>ANNE LECLERC: He is the ADA coordinator, you should file an official complaint with the RIdE program. That number is 461-9760. They don't have an official complaint, it's hard to follow up on. The trip shouldn't be late. And on RIdE, they give a half hour window, if they say 3:00, they could arrive any where between 2:45 and 3:15 is considered on time because of the type of service. It's hard to keep that one to the minute. Flex does operate to the minute. Or tries to. But if they're showing up at four instead of three, that is a problem we want to know about. Because either they're miss scheduling or the driver -- if it's happening regularly, there's a system problem that needs to be fixed. If it's one time, something could have happened on the road or something.

>>>EILEEN PICCHIONE: What's happened is I can't get a hold of RIDE because it's busy.

>>>ANNE LECLERC: That will be changing, we're implementing a new phone system late fall, early winter, that happen should help that.

>>>EILEEN PICCHIONE: I've been calling the local cab company that provides the service because, you know, we have to make sure the person has a ride. Okay, thank you.

>>>ANNE LECLERC: Please let us know if this is a habit that they're not getting the trip on time.

>>>EILEEN PICCHIONE: It's been very consistently not consistent, I don't know how else to put it.

>>>ANNE LECLERC: Can I get the specific information after.

>>>EILEEN PICCHIONE: Yes.

>>>LEO CANUEL: There is a form that can be filled out and I believe it's online, or Bill can send it to you or fax it to you and you can send it back to document it. Also, I am part of a group of consumers with disabilities that sit as an advisory committee to RIPTA which we meet as a group quarterly with Al mess cola, down, so if there's an ongoing issue we should have it in this group and we can meet later for the particular to bring it up at the September or October meeting and address it that way.

>>>ANNE LECLERC: RIPTA administers the RIDE program, pay for the ADA trips but also the ones you get when you call the call center, they're with RIPTA. We meet once a week to discuss how the RIDE program is doing. We need the official complaints in order to follow up on them. So, let me get that from you.

>>>EILEEN PICCHIONE: Thank you.

>>>LEO CANUEL: Harvey, do we have anyone else back there on your list registered to speak?

>>>HARVEY SALVAS: No.

>>>LEO CANUEL: Roger.

>>>ROGER HARRIS: I have another question, all together different. Probably for Susan Silva I just re-signed in with ORS, I'll just say, I'm not comfortable with the caseworker, can I get another one?

>>>SUSAN SILVA: You should ask to speak to the supervisor.

>>>ROGER HARRIS: I know you're her supervisor.

>>>SUSAN SILVA: I'm not that person's most likely.

>>>ROGER HARRIS: She said you were.

>>>SUSAN SILVA: I'm a supervisor for the blind and visually impaired.

>>>ROGER HARRIS: I'll just call the office and ask.

>>>SUSAN SILVA: Right, ask for that supervisor and you can discuss your concerns with that supervisor.

>>>ROGER HARRIS: The reason I bring it up, this probably happened to other people, I went there in April and I didn't hear from her until two weeks ago. And she blamed me because I didn't sign the application so I said, why couldn't you call or send me a letter and I called her, Mr. Murphy, I think his name was and he said he couldn't find me in the system and then the next following day, she called, I went down there and she said the reason I wasn't in the system is I didn't sign the application back in April. That was kind of like dropping the ball I guess.

>>>SUSAN SILVA: Well, whether it's on it's application or not, you filled out the application so you intended to apply so it should have been considered. Definitely if you have any concerns, you can always talk to the supervisor, if you're not happy with that, you always have the right to appeal. I'm sure my partner over here will be willing to help you. Usually things can be resolved at the supervisory level, if you can't talk to that caseworker and resolve the issues to your satisfaction.

>>>ROGER HARRIS: Thank you.

>>>LEO CANUEL: Harvey.

>>>HARVEY SALVAS: In the beginning you mentioned testimonies from previous forums in the past years, those are all available at our web site at GCD at RI.GOV and it goes back to the beginning of 2002 or something, 2001 that we've been holding the forum.

>>>LEO CANUEL: Because we have the CART service, it is, you can do either way, you can do the direct transcript and read it for yourself or this, I believe this is

**Support  
Agencies and  
Programs**

an abbreviated version of it that we have. We've come to the end of those who said they wanted to testify and I would like to open the floor now to see if there are any other questions or issues that anyone in the room would like to bring up. And you just didn't check that wanted to talk. I hope it up for the panel also.

>>>JEAN DIPIPPA: My name is Jeanne representing Rhodes to Independence, and I

### Working and Health Benefits

would just like to announce we're having a job fair in October, the date is October 30th, it's scheduled right now, but will be the last week in October at the Sheraton Airport Plaza Hotel and it will be in the Convention Center Seine. There will be at least 30 representations of agencies throughout Rhode Island

that will help you to get positions. There will also be a resource room set up to help with resumes and cover letters, et cetera, things you may need to get a position and we will also have a training and development and resource center where they will help people to get into different programs or advise them as to where they need to go for those programs. All of this will be advertised either through PSAs or in the newspaper or local agency newsletters so that will start, probably being advertised within the next month or. So just keep a look out for that information and hopefully you can join us. If you need to make your bus ride reservations, you need to plan in advance for October.

>>>ARTHUR PLITT: Also mention, in case somebody has another question would you like answered or some testimony, you can write in your comments to the Commission and e-mail it disabilities at GCD at RI.GOV? Right.

>>>LEO CANUEL: And to let you know that on September 21st, PARI, OSCIL and ORS

### Support Agencies and Programs

and a whole variety of other organizations are sponsoring the 21st annual Independent Living Conference at the Marriott in Providence which is, we do have scholarships available for consumers to attend. If you're interested, you can check out PARI's web site at PARI.LIC.org and it's already up there. It's an opportunity for anyone to come and learn about disability related issues and we have a whole host of thing that is we're doing this year. It's a

day long forum from 8:30 in the morning until about 4:00 in the afternoon.

>>>ROGER HARRIS: For the Governor's Commission on Disabilities, in Rhode Island,

### Transportation

I'm a driver with a disability. And in Rhode Island there are handicapped parking, however they're not friendly to drivers who are disabled, especially drivers in wheelchairs. I find, especially downtown Providence and I know parking stinks for everybody in downtown Providence, I hear it all the time. But the handicapped parking can be addressed, I think. As a driver with a wheelchair, I'm getting out in the street and that's too dangerous. Also, there's other parking spaces where the curb is so friggin high, I can't get my chair out. I wonder if the Commission has any -- maybe somebody working on that? If not, I need a job.

>>>LEO CANUEL: Harvey.

>>>HARVEY SALVAS: The Accessibility Committee is responsible for disability parking in the state of Rhode Island now. The problem with on street parking in any community is that you cannot create what, you cannot create a parking spot that meets the standard for disability parking which we're requiring access isle for the chair to get out and sidewalks are minimal at best right now, about eight feet. And create on street disability parking that meets the standard that would reduce the additional sidewalks to three feet and we can't do that. There's a standard for new construction but in New England there's no new construction on city roads. They're all existing right now. So we're kind of stuck with what we have. There's no requirement by federal law for the communities to create on street parking that doesn't meet the standard. However, we promote that, we promote the cities to create on street parking even if they don't meet the standard, it's better to have a parking spot than not. To get an access aisle so you're not getting out into traffic as the driver is going to be almost impossible any where in the eastern see board. If you go out west to New Mexico and Colorado where they had streets that were city streets that were 4 and 6 lanes wide, it was easy for them to create those kind of disability parking spaces but here in, on the east, it's impossible.

>>>ROGER HARRIS: So I have to move to Mexico?

>>>HARVEY SALVAS: Just to maintain the lousy parking spaces we have and try to create more.

>>>ROGER HARRIS: On that, too, Harvey, curb cuts. The community I grew up in, there is not -- in the community that I grew up in, there is not one curb cut. I just had a meeting there yesterday in one of the community centers. I had to go away from the community center, use someone's driveway to get on the sidewalk and then roll back half a block to the community center. I've brought this attention up to our city council many years ago. I know they have done renovations there. They've actually taken the curbs off the road, put in the new road and put the same curb back without making any curb cuts. Maybe the Governor's Commission can look into that.

## Accessibility

>>>HARVEY SALVAS: If you file a complaint with our office.

>>>ROGER HARRIS: I've done that.

>>>HARVEY SALVAS: While a road is under construction, we would make sure the curb cuts are put in. The difficult part is after the road is completed and they didn't put it in, then you have to go through the federal government. But before, or while it's under construction, we can take on that initiative and get it completed.

>>>ROGER HARRIS: What if they don't ever do construction in the neighborhoods. The neighborhood I grew up in, they haven't touched it in 40 years, I know this, I live there.

>>>HARVEY SALVAS: The court decisions have been that the communities only have to put in the curb cuts when they upgrade the roads.

>>>LEO CANUEL: But the thing is, when they upgrade one side of the street and do put in a curb cut, then they have to do the other corners across the way because you don't want one here and no place to go. But if they put in a curb cut, they have to do all four. If they don't, then a complaint can be filed to do it. I have also -- you can petition the city or town to apply for grants that would do those upgrades and they can apply for grants to do just that, to do the upgrades for accessibility purposes.

>>>HARVEY SALVAS: And that's difficult in local communities because we're not aware much when they pave or when they do a sidewalk project. The state, we are. And we make sure that all of the state roads, that gets completed when the state roads -- but local communities have no vehicle to notify us that they're doing the streets. So we need the citizens to tell us that. Even if they're doing it right, and you don't know that, you can call our office and we'll go in and look at the plans for the upgrading of that street.

>>>MALE SPEAKER: Great.

>>>ANNE LECLERC: This is an issue with bus stops, as well.

>>>LEO CANUEL: One at a time, please, for the CART reporter. Anne.

>>>ANNE LECLERC: With bus stops as well because people park illegally with bus stops and usually not ticketed or towed. And where he can't put a lift because we need to be on a curb or even if it's deployed in the street, the person can't get off the sidewalk to get to the bus. I don't know if there's any recourse for complaints around that kind of issue.

>>>LEO CANUEL: RIPTA does not own the bus stops. The city or town the bus stops are in own it's bus stop so it's the city or town's responsibility to maintain the bus stop including maintaining the shelter if there's a shelter there and especially for snow removal, it is the city and town's responsibility to be sure snow is removed in and around bus stops for accessibility purposes. Does anyone else have any other comments, questions, concerns, a joke, good limerick?

>>>DOREEN MCCONAGHY: My name is Doreen and I'm hoping at each of the forums at

## Housing

least someone will be talking about accessible housing, universal design. I think when we're looking at folks with developmental disabilities cans folks with physical disabilities, there isn't a lot, there isn't enough housing and it's, for some of us it's reaching the critical stage. And I don't know -- talk being it in terms ever universal design and advocating for uniform designed homes in communities will help, but I think it's important to keep on the radar screen because the state is trying to get out of the business much creating living opportunities for folks which, you know, depending on how you look at it might not a bad thing if we're empowering individuals them selves to do this but we still need accessible housing.

>>>JEAN DIPIPPA: Can I speak to that?

>>>LEO CANUEL: Go ahead.

>>>JEAN DIPIPPA: We are actually looking into that, Rhodes, Elaina Goldstein can speak to that, she's out of town, she is on our web site, it's Elaina at URI.EDU and shell more than likely be at future forums. We are working on projects now, we have just hired someone who will be setting up a manual of sorts for moderations and living conditions. So it will be coming out, someone is doing something, it's just not complete yet.

>>>FEMALE SPEAKER: And the housing authority here in Woonsocket has been extremely responsive and the gentleman who is the director has been very helpful but we still have hundreds and hundreds of folks with disabilities that need good housing.

>>>HARVEY SALVAS: Elaina and the Commission have proposed an amendment to new low cost housing mortgage money that would require that all units be developed as B units which are adaptable units but that didn't pass the legislature. However, that money now is being distributed with the requirement that five percent of the units be B units and so there will be some more accessible housing. The requirement for universal design isn't standard, isn't quite as high as B unit, and B unit is what we're trying to achieve in Rhode Island.

>>>ANNE LECLERC: Anne from RIPTA again. I just would like people to keep in mind when talking about development of new housing, accessible housing, affordable housing to keep in mind that's often difficult to separate from transportation issues. A lot of people who live in either accessible and or affordable housing depend on the bus at least part-time if not all and there are some communities in our state who think the development of affordable housing should not be seen so it's up a hill, it's someplace the people can't get to a bus, we don't have the budget to keep expanding services, so the coordination if not located on a current line is important for people to consider. Because finding someone is house they can never leach doesn't meet all the problems.

>>>ROGER HARRIS: I just want to reiterate, I have brochures on the Rhode Island Disability Vote Project, information, and I also have registration forms if there is anyone in the room that is not registered, please feel free to take one, I'll be more than happy to bring it to the board of elections for them.

>>>FEMALE SPEAKER: They have it ease year, too, if you have a license and not registered, when you renew, you can register right there.

>>>LEO CANUEL: Any other issues, comments, that we need to discuss today?

>>>JUDY DREW, PH.D.: I just want to say one thing, Judy, I'm a commissioner, with the new change in state budget, many of the services that are targeted to help individuals with disabilities are under extreme scrutiny and I would use the word attack. And you folks are here because you're expressing concern about availability of services and the ride rights ever people you work with, if some of these programs are under funded in the way that's being discussed, access to services will further decline. So, we really need your support to be vocal because right now, folks are not being vocal, it's only those of us working these programs that are stepping up so we need grass root support from the community to let the Governor and the legislature know that these services need to continue in order to serve the needs of the people in Rhode Island.

>>>LEO CANUEL: If I could.

>>>JUDY DREW, PH.D.: I thought I'd put it out there because it's not well publicized.

>>>LEO CANUEL: And yesterday the Governor had a meeting with all of the heads of each department and talked about cutting 1,000 more state jobs. You need to understand, we talked a little bit today about how difficult it is to get services. I work quite closely with ORS and they're really under staffed at ORS and I'm sure the other organizations are, as well, cutting more state workers is just going to mean that the current state workers will be more stressed and less outcome is going to happen. So, you know, Roger, for your example, that sign thing, I'm not creating any excuses here but if we had talked about this maybe five years ago, that would not have been an issue and you would have gotten a phone call. Any technicality tends to put things off in any way and cutting more staff will not be an issue so definitely call to the governor's office if this is an issue for you, is something you would need to do. At this case, you do not call Brian at the lieu tenant governor's office. If you need to park, Brian is your man.

>>>ROGER HARRIS: All the more reason people with disabilities need to vote, they need to develop a voting block, someone with 185,000 votes has a lot of power.

>>>LEO CANUEL: We are, the panel, if they choose to stay, I personally am here until noontime. I know Harvey has to stay with me because I will call his boss and let him know that he left early. And I have his -- I have Bob's number on my cell phone. But, I thank you in advance of 12:00 for being here. For those of you that need to connect up with the panelist, please do. So I thank the panelists for coming this morning all the way up to Woonsocket and thank you for your fine testimony and your feedback. And I guess we'll see you next year.

(APPLAUSE)

>>>FEMALE SPEAKER: Have a nice one, everybody.

>>>LEO CANUEL: And thank you to the CART reporter for your busy hands.

## Wednesday July 25, 2007- Barrington Public Library

>>>SHARON BRINKWORTH: I would like to welcome you all here. Can you hear me? Okay. I will try to use my old schoolteacher voice (LAUGHING). The Brain Injury Association of Rhode Island is the host of today's forum and my name is Sharon Brinkworth. I am the executive director of the Brain Injury Association of Rhode Island. And we welcome you all here today. And one of the reasons that -- the reason that we are here is that the state government and the sponsoring organizations -- you may have seen on the paper that you picked up out front about the forums. All of the sponsoring organizations and the government agencies want to hear from people with disabilities and their families. We want to hear about their concerns and their ideas, if they are having problems with different services and so what. So that's why we are here today because it's all about improving the lives of all Rhode Islanders.

Okay. We have a couple of rules we have to follow. And to ensure that everyone has a chance to speak, there will be a time limit of five minutes. And when the timekeeper announces your time as -- if you can finish that sentence and then sit down. And if there's time, when everyone has spoken who wants to speak, then people can come back up and speak a second time, if there's time. And Brian Adae here is going to be the timekeeper. So he will keep his eye on you.

And also when you do speak, I need for you to state your name and also if you are connected or affiliated with an organization, to say where that is. And we need to have that so that the CART reporter can get your name and your affiliation.

Now we have a table of fine panelists up here. And the panelists are here basically to listen to your concerns. But they may ask questions from time to time, if they don't quite understand what it is you are saying. So, that might happen. Otherwise they are here to listen to your concerns and to take them back.

Each -- I would like at this time for each of the panel members to introduce themselves and their affiliation. And remember too that when you ask a question of somebody out there to say your name again and your affiliation for the CART reporter, okay.

>>>BRIAN ADAE: Good afternoon. I am Brian Adae from the Rhode Island Disability Law Center.

>>>KAREN LYONS: I am Karen Lyons with the Governor's Commission on Disabilities.

>>>KEN PARISEAU: Good afternoon. I am Ken Pariseau from the Neighborhood Health Plan of Rhode Island.

>>>GWENDOLYN REEVE: I am Gwen Reeve, Shepard program director of the Multiple Sclerosis Society.

>>>DIANNE KAYALA: I am Dianne Kayala, the administrator of the Adult Health Program and Medicaid for the Rhode Island Department of Human Services.

>>>PATRICIA RYHERD: I am Pat Ryherd, Office Of Rehab Services in the Department of Human Services.

>>>JANET SPINELLI: Hi. I am Janet Spinelli. I am with the Department of Mental Health, Retardation, and Hospitals. We work with people with developmental disabilities, mental health, and substance abuse issues.

>>>LAURA JONES: And I am Laura Jones from the Rhode Island Department of Health, Disability and Health.

>>>SHARON BRINKWORTH: Thank you.

The first person who signed up and wants to speak, Camille --

>>>CAMILLE PANSA: I didn't check to speak. I am here to observe.

>>>SHARON BRINKWORTH: Okay. You did not check to speak.

Joy Dennis.

>>>JOY DENNIS: Where would you like me to stand?

>>>SHARON BRINKWORTH: You want to just stand and maybe come forward or just stand at your chair is fine.

>>>JOY DENNIS: I will stand and come forward and hope I speak loudly enough.

Okay. What I am going to talk about is the talking book issue.

Talking book of Rhode Island is obviously a state organization and I have no complaints about talking book of Rhode Island. My -- the difficulty is with the material -- equipment, so on. However, many patrons of talking book Rhode Island also use recording for the blind, which is in Russel, New Jersey. Also talking book library often checks

**Blind and  
Visually  
Impaired**

with recording for the blind for material or its patrons. This prefacing remark is important because it isn't just that there are two entities and so on. The problem is with the new machines from both talking book and the blind. They are not compatible. And this is not the fault of talking book. However, it does complicate the use of reference materials from recording for the blind. Recording for the blind has made a proprietary claim, proprietary claim on its machine. In other words, you have to use their machines for their books. You can't use their books on talking book machines. Which means that only RFB at CD can -- CDs can be used on RFB players, CD players.

When I asked talking book plus librarians about this, I said that I would just wait until the talking book CD players were available. And that was when they told me that RFB's CDs were not compatible. So, more over I have discovered that from RFB, that one can pay -- excuse me -- one can play the CD only on their machine. Their CDs, their equipment, and so on. So that you cannot play any talking -- an RFB CD on the recording for the talking book.

I submit that this is a proprietary arrangement and discriminates those who cannot afford to buy an RFB player. I realize that the talking book plus provides the talking book player and that is a wonderful service. But there's a problem with doing the other.

RFB materials are often reference materials that users need for high school, college, university, and graduate school. I realize that talking book cannot of course recording for the blind to rescind its proprietary ownership. They can't because RFB is in New Jersey and it's not a state operated entity.

But could someone, someone urge them to do so. Perhaps someone could suggest the problem this poses for students especially. Thank you for your time and your patience.

>>>SHARON BRINKWORTH: Thank you.

>>>GWENDOLYN REEVE: I have -- Gwen Reeve, MS Society. I have a question. You purchase the machines and you only purchase one machine?

>>>JOY DENNIS: Okay. I have not purchased -- the machines, I think the RFB machines may be available now. I'm not sure. They cost -- I suppose you can get them for the lowest for \$250. But they cost around \$300, depending on the type of CD player you use. And you can play the recording for the blind materials only on their equipment. You cannot play them on the talking book plus. And I realize that the talking book plus machine has not been issued yet. I understand that and that's not a complaint. But what -- when they are issued, we will not be able to use the recording for the blind. And they are -- the recording for the blind textbooks, for those who are unaware, are textbooks that are paginated, so you can in Braille look, oh, page 32 and so on. You can go to different pages and so on. And they have reference charts. They read and so on. So it's quite useful for -- I would say any student from -- I would say even junior high on, in high school, college, and graduate school. So, this is a real problem.

Before this, if talking book plus did not have the material, they would check with recording for the blind. And they would send them -- RFB would send the material to talking book plus. They would send it to us. We could still play it on the talking book player. That will no longer be the case.

>>>PATRICIA RYHERD: For clarification, am I correct that the talking book recorder is free? There is no charge --

>>>JOY DENNIS: That's correct. Thank you for asking that.

>>>DIANNE KAYALA: I have one question. Is there -- what would be your suggestion? I mean --

>>>JOY DENNIS: Oh, the suggestion is somehow to make them compatible. If the machines -- I would think -- to make them compatible so that if someone wanted an RFB machine and wanted to purchase it, that's fine. But if they wanted to just use the talking book machine, the talking book CD player, the new one that will be issued, they should be able to play the recording for the blind. It's going to be a very awkward system. And yes, we will still be able to use the talking book plus machine. But we won't be able to use recording for the blind, unless you buy this machine that costs -- as you say you can get one as low as \$250 and they go up to \$320. And that is quite an expense for most disabled people.

>>>DIANNE KAYALA: Oh, sure. Thank you.

>>>GWENDOLYN REEVE: This is Gwen Reeve again. I have a question. You said that the machine for the talking book is free. The recorder is free?

>>>JOY DENNIS: Yes.

>>>GWENDOLYN REEVE: How did it -- how is it that that's free and the talking recording for the blind machine is not free?

>>>JOY DENNIS: It is not free because you join recording for the blind, become a quote member. And -- I don't have to pay this because I have been a member since before the flood. But there's a \$50 fee every year. And so you are a quote member. And other than those who have been grandfathered in, such as I, you have to pay this membership fee. So, it says that its members -- and they can -- but before, before these new RFB machines came out, they -- we could use the RFB, you know, cassettes and so on, on a talking book machine. You didn't have to buy a separate machine.

>>>LAURA JONES: I have a question. Laura Jones. My question is, is -- would -- what if the library was able to purchase several of these machines that people could check out? Is that something that would be a solution or would you -- do you read so much that you would really need it all the time?

>>>JOY DENNIS: That would be a partial solution. However, it would be necessary really to have -- for an individual to be able to have the machine. I say if we can work out some the compatibility issue, then there wouldn't be a problem. No. I do think though that is a good suggestion to have libraries across the state have -- purchase some of these machines. And then that way people -- some people could listen at least at the library and so on because I don't think you want them taking them out of the library. They may not be returned. But that is a very good stopgap situation. But I do think you are correct. Especially college students would be reading so much and -- I think that would be -- and also high school students in a fast track program, on the academic high first fast track would have excessive amount of reading as well.

>>>PATRICIA RYHERD: Pat Ryherd. I have another follow-up question. Pat Ryherd from Office of Rehab Services. As far as college students, if an individual is a client of services for the blind and visually impaired, the state agency and the economic need is met, the agency would purchase the RFB recorder for that college student. It would -- isn't it true that a high schools would be responsible for providing that provider for a blind high school student?

>>>LAURA JONES: -- Laura Jones. That could be provided under individual education plan as a resource that they would need in order to function in school.

>>>JOY DENNIS: Right. Then what about general readers, general -- I'm no longer in college or -- you can tell.

>>>PATRICIA RYHERD: I can't answer as far as general readers. But I could answer as far as students where Office of Rehab Services is helping the person become employed. So it would have to be part again of an individualized employment plan.

>>>SHARON BRINKWORTH: Thank you, Joy. Thank you for your questions and comments. I would like to introduce Bill Inlow who is also a panelist. We can squeeze you up here if you want to --

>>>BILL INLOW: I would be glad to. Sorry I'm late, folks.

>>>SHARON BRINKWORTH: Bill's from the Rhode Island Public Transit Authority.

>>>KEN PARISEAU: I assume you didn't take one of the buses.

>>>BILL INLOW: I didn't take one of the buses. They are always on time.

>>>SHARON BRINKWORTH: Are there any other panelists who snuck into the room while we were talking? No, okay.

All right. The next person who has asked to speak is Grace Grout. If you want to stand --

>>>GRACE GROUT: Or should I move forward?

>>>SHARON BRINKWORTH: Just address us, the panel, because we are in a straight line up here in front of you.

>>>GRACE GROUT: Okay. I am -- my name is Grace Grout. I am not affiliated with any agency per se. I am a consumer. I am an appreciative consumer of the RIDE program and have been since the early 1990s when I enjoyed full service living in Barrington center.

Upon moving to west Barrington in 1997, however, I found that I could no longer use RIDE weekday evenings or weekends. And -- I'm sorry -- I would like to know why my service has changed and what I can do to ensure that I may once again have full service. I have not officially been given an answer to my problem. And I am trusting that this will soon change.

## Support Agencies and Programs

## Transportation

I have few friends or family members that can help me out with transportation. I expect that one day soon I can take RIdE, for instance, to the Saturday meetings, monthly meetings of the national federation of the blind of Rhode Island and remain an active member.

It's a royal nuisance to say the very least to have to forego weekend and evening outings, as I'm a very active person. Everyone in the community will tell you I don't just sit around watching the grass grow.

I wish to have my situation addressed directly with patience and persistence. I will continue to seek a solution for my dilemma. Thank you very much.

>>>SHARON BRINKWORTH: Thank you.

>>>BILL INLOW: The --

>>>SHARON BRINKWORTH: Just give your name.

>>>BILL INLOW: The RIdE program has four parts, the department of elderly affairs, the department of mental health part, the Department of Human Services under the rite care part, and the part that I think this person is addressing is called the ADA or Americans with Disabilities --

>>>AUDIENCE MEMBER: Can you speak up, please.

>>>BILL INLOW: Part of the RIdE program, the ADA, Americans with Disabilities part of the program. That part of the program is called a paratransit program. Paratransit means comparable to trends geographically and time wise. What that means is the RIdE ADA program provides services where and when regular RIPTA buses operate.

For example, the 60 bus, regular RIPTA, large transit bus goes up and down County Road out in front of this building from about 7:00 in the morning until about midnight, 7 days a week. So a person in a RIdE ADA program living near this location would get service from about 7:00 a.m. in the morning until about midnight, seven days a week. This is all defined in the federal regulations, which is our attorney here today will tell you has the effect of federal law.

When you live in a different area, as you now do, Ma'am, evidently in west Barrington where there's only regular RIPTA bus service, perhaps during the weekdays and perhaps not on Saturdays or Sundays, as a consequence, the RIdE ADA program is restricted to those times near where those regular RIPTA buses are operating, again at the same time.

That's a procedure that RIPTA follows that's consistent with the letter of the federal regulation, which again has effect of federal law. And that's how we provide the program.

So, if you live near a bus line, if, when a regular bus is operating, you get good ADA service at that time. If you live in an area where there's not good RIPTA service or not as frequent, then the times that you get the service is defined by the times that those regular RIPTA buses operate.

Does that respond to your question? It's not the answer you want to hear but it is the fact.

>>>GRACE GROUT: Okay.

>>>SHARON BRINKWORTH: Thank you.

Thank you, Grace.

The next person to speak is maybe Paul Bohac. Did you want to speak?

>>>PAUL BOHAC: I want to speak. My name is Paul Bohac. I am a client of the Brain Injury Association and also -- what brings me the Brain Injury Association 21 years ago I was a student -- I graduated from Bryant College. I was working for Brothers construction and I drove my car erratically. The next time I woke up was three weeks later with two broken legs, mouth wired shut. I was in tough shape. Thank God that -- I had some really competent surgeons and I am here today. I suffered neurological damage. You can't see what happened to my brain. They call brain injury. It is -- I look pretty good. But if you looked at my brain, my brain is damaged. And because of that, I have made a lot of bad decisions because of my brain injury. But I can't say all it was probably but -- but long story short is I get services from Lake View now prior to getting united cerebral palsy, PARI. They give me aides to help me with my daily living situation because I am high function. I don't have to -- like I don't need people to help me get dressed in the morning, things like that. But I do have needs as far as going to see -- my father's in a nursing home. An aide took me to see my father in a nursing home. The other day and I see my parents in Cumberland. These are essential services that I -- my agency

**Support  
Agencies and  
Programs**

provides me only through the help of getting funding through these organizations. So, basically I am here to ask you to keep on funding these agencies so that they can provide services for me and other people who have suffered brain injuries because it is a hidden injury. I do have needs. And there are people similar to me who have needs. I would like to have that continue. I guess that's -- I took the RIDE -- I am an active person like this woman is. I do get around. I take the buses and I ride my bike. I get around.

Unfortunately for me driving is too high functioning of a task. I can only handle too much. Driving is way too much for me. Even my bicycle I get in accidents. So thank God I don't have a car.

But anyway, all I want to say is keep on supporting our brain injury and giving funding for our organization.

>>>DIANNE KAYALA: Sharon, can I say something? What I wanted to say is because of the testimony of last year -- I am Dianne Kayala with the Department of Human Services. Because of the testimony of you and other folks last year, the program that you are talking about was increased. It was more than doubled over the past year. So, I want you to know that speaking up is a good thing.

>>>PAUL BOHAC: Thank you.

>>>DIANNE KAYALA: It was heard.

>>>BRIAN ADAE: Brian Adae from the Disability Law Center. I wanted to respond to this fashion too, like my friend Dianne, as your part about speaking out and your voice being heard. I wanted to say without making any political commentary about the war in Iraq. But we are living in a time where we not only state but federal budget cuts and your voice being heard is very critical. Especially in context with budgets, federal budget being drawn into spending a tremendous amount in the war in Iraq. But a wonderful opportunity if you want to continue to have your voice heard is to make sure you vote, as well as contact your federal legislators. In particular that we are seeing a tremendous number of people returning from Iraq with traumatic brain injuries. And that is something that politically I think at this point in Washington, I'm sure that Sharon can speak to -- is very important.

In fact, if any of you are not registered to vote, I would encourage you to do so. And we do have somebody here in the atrium, the entry way who is prepared to help register folks to vote if you have not already done so.

>>>PAUL BOHAC: When I watch TV and I saw the specials on the people from Iraq and basically those people from Iraq 20 years ago, I suffered what those people suffered. So -- I went to brain injury hospital they gave me OT, PT, speech. I couldn't speak. I had to learn -- I was like baby. I had to learn how to walk, talk, everything all over again. They call it traumatic brain injury for a reason because it is -- it's a hell I would not wish on anyone, what I went through. But I don't look it. I'm a tough guy. Thank you.

>>>SHARON BRINKWORTH: Thank you, Paul.

I don't believe anyone else has signed up to -- oh, is there anybody in the audience who would like to speak?

Any of the panelists?

>>>GWENDOLYN REEVE: --

>>>JEANNE DIPIPPA: If I could make a quick statement. Just to notify all -- my name is Jeanne DiPippo and I represent Rhodes to independence and I am just doing a PSA actually. We will be having a job fair for those who are in need of jobs. It will be held October 30th in Warwick at the Sheraton post road, the airport -- the hotel there. And there will be no less than 30 representatives from employers who will be looking to hire people with disabilities as well as a resource center that will be helping with resumes and cover letters. In addition to that, there will be a resource center to help you with training and development if you need that type of service. There will be notices on TV, in your local newspapers, as well as in different agencies news letters.

Thank you.

>>>SHARON BRINKWORTH: Thank you.

>>>GWENDOLYN REEVE: All right. I am going to speak. My name is Gwen Reeve and I am with the Multiple Sclerosis Society of Rhode Island. And I thought that I would take some time to talk about some issues that I hear about a lot from people in the community that do have MS. And for those of you who are not familiar with Multiple Sclerosis, it's a chronic progressive disease of the central nervous system which

affects the brain and the spinal cord. And most people who are diagnosed with MS between the years of 20 and 50. Certainly there are people diagnosed earlier and people diagnosed later.

But one of the things that happens with people who are diagnosed in the prime of their life is that they've had the opportunity to work. And so many of them have significant work histories. Because they have significant work histories, when they need to go out on disability, and certainly not all of them need to go out on disability. But when they go out on disability and they can no longer work, and they have to apply for that permanent condition of disability.

## Finances

They ultimately get Social Security disability income. And that's the amount of money that they would have made had they retired at the typical 65, 66 years old. So for many of them, that's, you know, \$1200, \$1500. Certainly not at the poverty level but certainly not high. And what happens, since they are no longer able to work, if they are not collecting or getting medical benefits through a spouse or through somebody else, they frequently rely on Medicare for their health benefits.

And what happens there is once they're determined to be disabled, they don't automatically get Medicare coverage. They have to wait two years for medical care to kick in. And that means these people are uninsured for two years. Okay. And the cost of Multiple Sclerosis is phenomenal. The medications that folks use typically run at retail about \$2000 a month for one medication. So, we get a number of people in our office calling who can't afford their medication, can't afford to go see a doctor because they make too much to qualify for medical assistance and not enough to pay for their own medical care.

So, you know, what I would like to see at some point -- I don't know if it's going to be at the state or national level -- is some sort of stopgap or temporary medical coverage for people who are in that waiting period. They have been determined to be disabled. They can't work. They certainly can't pay Cobra payments which are pretty high because they are not making enough money. So they need some sort of medical coverage until the time that their Social Security disability with Medicare kicks in.

And again, I don't know if that's going to come from a national level since Medicare is national program. Or if it's going to come from the state, kind of stepping up to the plate which seems unlikely because of the cuts in budget. Anything that needs some sort of financial or fiscal note seems not get passed through the legislature.

I am kind of unhappy about that and I wish there was a solution because I can't tell you how many phone calls I get from people, again, who are in that I would say almost a limbo. They make too much to qualify for medical assistance which has pretty good benefits compared to Medicare and they don't make enough to purchase private health insurance. So that's a big issue for us.

Last year we were able to get the MS Society and the Governor's Commission on Disabilities were able to get MS injectable drugs put on to RIPAE's formulary, RI Pharmaceutical Assistance to the Elderly. That seems to be the state pharmaceutical assistance program. But for folks disabled, one, you have to be 55 in order to qualify for that program. So again, you have people who are 40. They can't qualify for it.

## Health Care

And the co pay for RIPAE is something like 85 percent. So RIPAE will only pay 15 percent for a person with disability who is not a senior.

And right there it makes it prohibitive because if you have to pay 85 percent of something that's \$2,000, you can see you are not going to get the drug that you need to slow the progression of the disease down. So there's all these Catch-22s. And even though we got the bill put through last year, not that many people are able to utilize it because the co pays are too high.

So those are two big issues for folks with MS. And then you have all the other issues that many people with any type of disability face. We have housing, affordable housing problems, problems with accessible housing. Problems with transportation, which I'm sure Bill hears, on and on and on. These are the things that people have to live with on a daily basis. And many of our people don't have relatives that can step in and help out. They are living by themselves. They want the independence. So what happens, we get people who prematurely end up in nursing facilities because they want the help -- they want to live on their own. They probably could with assistance. But there's not that many options for them. That's just what I wanted to say. Thank you.

>>>SHARON BRINKWORTH: Thank you.

>>>PATRICIA RYHERD: I have a question. Pat Ryherd. Have you found useful at all that some pharmaceutical companies will provide medications to individuals?

>>>GWENDOLYN REEVE: At one -- Gwen Reeve. At one point they did. And it's not that they don't any more. But with the advent of Medicare part D, they've curved that back incredibly. So, people -- so they're not as generous as they used to be. They are quite stingy nowadays with their supplying the drug. They've also funneled people towards a couple other agencies, one of them is NORD, National Organization for Rare Diseases, and Pen, which is Patient -- it's the Montel Williams thing. And at one point we would refer people to those organizations. But they have since been inundated with requests. So they are no longer taking applications.

So, unless somebody can be really creative and point me in the right direction, there's not that many resources anymore.

If you are not on Medicare but your salary is low, you are in the low income bracket, they may assist you. But they are very reticent to help anybody on Medicare part D. And with Medicare part D, most of the co pays are 20 percent. And so, with a 20 percent co pay, if you are on a drug called "Ticabry" or whatever, that's \$600 a month that you will need to pay. And again, that's prohibitive for most people on limited incomes.

>>>SHARON BRINKWORTH: Gwen, Sharon Brinkworth. I just was curious to know, do you have any statistics -- is MS, Multiple Sclerosis, on the increase? Is there more cases?

>>>GWENDOLYN REEVE: That's a very good question, Sharon. I think the reporting is better and the diagnosis is better. So, because of the use of MRI, people are being diagnosed quicker. And sometimes people go in for an MRI for migraine or other issues and they in fact have MS. Not only is it possibly on the rise, I can't say that definitively. But we know that more and more children are getting it. And so, we figure about 10 percent of the population that has MS are children under 18 years old, which is something we did not really know about ten years ago. So, it is increasing.

>>>SHARON BRINKWORTH: I guess, it's now time for me to say for those of you -- this is your first forum that you attended, it is -- the forum is held from 3:30 to 5:30. And so, we, as panelists, will stay here until 5:30 because we would not want somebody who just got off at 5:00 and rushed to get here and then have us all gone. So, that's why we are here to stay until 5:30. So, it's 4:15 now. You are welcome to stay, if you would like to stay. Or if somebody who didn't speak maybe wants to say something, that's fine too.

>>>LAURA JONES: Don't be shy.

>>>SHARON BRINKWORTH: If anyone has a question or anything like that they want to ask. But we will stay. So, feel free to get up and walk around and come back and sit down, I guess.

## **Thursday July 26, 2007- Warwick Public Library**

>>>LORNA RICCI: Before we start -- attention. I just took a peak at back and only one person has signed up to testify. I really encourage you to think about the issues or concerns or the populations you work with because this information today doesn't stay here. It goes on and representatives see this information. And it actually supports the kinds of issues later on. Let's say you want to call your legislator about a concern of yours. If you are not on record or the people who haven't already testified on record to that issue, your legislator may just say I haven't seen this issue anywhere. So please, I know there's a lot that wish just to listen today. But I encourage you really truly to think about an issue of concern, your own workplace, the people you serve, and really consider giving testimony. And, of course, if you wish to have written testimony submitted, I've got those numbers for you as well. Just giving a few more minutes to sign up if you wish to.

Should we start?

I guess we will get started. I welcome you to the Governor's Commission's Public Forum. I wish to start by thanking all our sponsors of today's event and the events happening all week. I hope everyone picked up a flyer. This gives the -- a little more information on our sponsors today. Please feel free to take it home. And most importantly, there's an address, an e-mail address and a fax number, kind of right in the middle. Should you hear something today you wish to submit public testimony, public testimony will be accepted in writing until July 31st. And the address is right on here. So I encourage you to submit written testimony should you choose to do that.

No glasses -- are glasses back there? I will wait --

>>>FEMALE SPEAKER: You want your glasses, Lorna?

>>>LORNA RICCI: Thank you.

The state government and the sponsoring organizations that have been written up in your flyer want to hear from people with disabilities and their families about their concerns and ideas for improving the lives of all Rhode Islanders with disability.

There's a few rules today. I would like to just say that I hope more people will sign up to testify. We are limiting testimony to five minutes. However, we may be able to give a little more time today since we don't have too many people signed up. But please change your mind, again.

We ask you to state your name clearly and spell it for our CART reporter. All of the testimony today is written down. It will be given to the Governor's Commission and be available in a written format for review, not only by you but by legislators. This goes to all of our legislators, all testimony that is presented these five days.

I wish to give a few minutes for our panelists to announce -- give their names and where they're from. And after that, we will start.

Just a couple of things. Should you wish to have coffee or something cold, we do have Felicia's right down the way. That's our panelists too, if you would like to get an iced coffee. Rest rooms, they are right to the right. I think that's it.

I would like to get started. I think we will -- I will give the mike. We can go right down if you give your names. Again I thank all our panelists today for coming out for today's public forum.

And then after that, we will hear from our first person who has signed up.

>>>BILL INLOW: Thank you. I am Bill Inlow, the Disability Services Coordinator at Rhode Island Public Transit Authority, RIPTA. I also work closely with the RIDE program. And I'm a member of the Governor's Commission on Disabilities Legislative Committee.

>>>KEN RENAUD: My name is Ken Renaud and I work for PAL and I wear a lot of different hats for PAL. Lately I have been doing a lot of family support for people who have been deemed eligible for services, as well as working on a federal grant to end violence against women with disabilities.

>>>ROBERTA GREENE: Hi, everybody. I am Roberta Greene from the Office Of Rehabilitation Services. I am the coordinator, ticket to work coordinator, planning assistance project coordinator, and special projects coordinator. So nice to have you here.

>>>CHRIS BUTLER: Chris Butler. I am the executive director of In-Sight.

>>>RORY CARMODY: I am Rory Carmody. I chair the Election Access Committee and part of the Rhode Island Disability Vote Project.

>>>KATE SHERLOCK: Hi. I am Kate Sherlock, an attorney from the Rhode Island Disability Law Center. And we have -- every year we are supposed to get our public input. In addition to hearing you here, we have some surveys available next to Alexandra in the back, if you want to take one and mail it to us and put it to writing to us what you are concerned about too. We would appreciate it.

>>>LISA ONORATO: I am Lisa Onorato from the Brain Injury Association.

>>>PAULA PARKER: Hi. I am Paula Parker from the Department of Elderly Affairs. I am the administrator of the Protective Services Unit and I am on the Governor's Commission for Disabilities Legislative Committee.

>>>ELAINA GOLDSTEIN: I am Elaina Goldstein, URI College of Pharmacy, and I would like to let everybody know there are brochures back there on the Sherlock Plan -- versus anything else Sherlock. This is the Medicaid Buy-In for people who work and are eligible for Medicaid. We have this brochure. And we also have -- we have a fact sheet in Spanish for those of you who need Spanish. Please pick them up. Thanks.

>>>COLLEEN ANN POLSELLI: I am Colleen Ann Polselli from the Disability Health Program --

>>>KATE SHERLOCK: I am Kate Sherlock. Again I forgot to mention Alexandra is in the back there with registration forms for anyone who wishes to use today as an opportunity to register to vote. Thanks.

>>>BILL INLOW: Introduce yourself.

>>>SANFORD LUPOVITZ: Good afternoon. Sandy Lupovitz, Governor's Commission on Disabilities.

>>>LORNA RICCI: I wish to thank our panelists. The way we proceed is I will be calling the first person to testify. This is not a debate. It is a public forum. So, when you provide your testimony to our panelists, they may ask for clarifying questions. But there won't be any more conversation really. If you are looking for more input, should you have a concern that one of the panelists could help you with, perhaps they will tell you they could meet with you later to give you some information.

But right now we would like to start by calling up Richard Gaffney. Richard.

>>>RICHARD GAFFNEY: You want me to sit down or stand?

### Blind and Visually Impaired

Good afternoon, everybody. My name is Richard Gaffney. I am president of the National Federation of the Blind of Rhode Island. And the thing I want to talk about today is also something that was brought up at our national convention and that was access to kiosk machines.

For example, if you go to the airport, if you wanted to print out a boarding pass, if you go to -- it's my understanding that RIPTA has them, where you get information. Any of these places that have these kiosk machines, we don't have access to it because it's all visual. And what we would like to see happen is some legislation introduced that would require places to make these machines be voice activated. There's a lot of blind people out there that use these services. And we think it will be of great help. Thank you.

>>>LORNA RICCI: Thank you, Richard.

Lee Strauss --

>>>LEE STRAUSS: Good afternoon. My name is Lee Strauss and I have problem. I am home bound and disabled from a major stroke and that's why I'm sitting in this mobile chair. Um, and alas, I am home bound because no one will pick me up and take me where I need to go. I have been refused by every entity that I have discovered. Such as -- certainly RIPTA, RIdE, Transwick, I am a resident of Warwick. And I have testified before the Senate Transportation Budget at the Senate Transportation Budget Hearing last year, which was sort of a last minute happening because I had no way to get there. I almost didn't get to testify. My granddaughter got some time off of work to take me to the State House. And once we went in where we were told to enter, we were immediately faced with about -- oh, I guess 10 to 12-foot long, very steep ramp which I certainly couldn't navigate and finally was able to snag two State House policemen who managed to push me up in my wheelchair so that I got to eventually to the hearing room and was able to speak there about this problem that I have just been to see you.

The people from RIPTA, the executive assistant director, and various other people who have come to testify on their budget requests for 2007 that day were in the room

### Transportation

and heard me tell the details of my problem and my attempts to solve it -- all unsuccessful -- came up to me at the end of the testimony and their heads had been nodding vertically the whole time I had given my testimony. And they were emphatic in their agreement with me. "Yes, Ms. Strauss, you put your finger on it. The trouble is access."

And I said, "and"?

And there was silence. And they said, "well, we've known about the problem for five years".

And I said, "and"?

And there was silence. And since then, they have told me that they have looked at my property. They've come on the property. Although I never knew they did. And they have decided that they can't give me any services because the home in which I am renting does not have properties -- does not have a paved driveway. I found this out in a roundabout way. I was not directly notified that was the problem. However, I have now been told officially that is a problem. It isn't my problem -- I rent. That is not a solution for me to pave it.

I do live in the three quarter guidelines for services; however, no service is forthcoming.

I've tried to contact everyone that are either executive directors of agencies or directors of agencies who provide services to the disabled have recommended that I try. I tried every single one that has ever been suggested to me. And I am no further ahead than when I started when I moved to Rhode Island three years ago.

So, there -- I am perfectly happy to work on the problem. I don't know the scope of the problem because it's never been studied. I am sure my problem is not unique. There have to be many, many Rhode Islanders who do not have access to the transportation systems that exist. No one knows whether we are 60, 600, or 6,000 people in that kind of situation because no one has never bothered to find out.

I think that the state and the ADA transportation system and RIPTA and RIDE and Transwick, and whatever other systems may be out there that I am not familiar with, although the law says that they are to provide access to transportation so that those of us who are disabled, have a disability that requires transportation, can live normal lives, full lives, active lives in our communities. Although it says so, in my understanding of the law, it's being honored in a breach.

That's why I am here today. I hope someone will have a recommendation for me or a suggestion. I am perfectly happy to work on the problem. I've done community volunteer work all my life. I know how to do it. I am willing to do it. But so far, as someone from an agency again -- not an agency but an organization by name responsible for this -- providing transportation or seeing that it's provided summed up the situation by saying for Rhode Island, no money, no projects, no prospects.

Not a happy thought to leave you with but that's where I'm being left.

>>>LORNA RICCI: Thank you.

Is there any one else who signed up?

Susan? Susan -- anybody else?

>>>SUSAN ELEOFF: Not at this time.

>>>LORNA RICCI: Does anyone wish to?

Oh, Jim, James DeBoer. James.

**Voting** >>>JAMES DEBOER: Hello. My name is James DeBoer. I am the lead organizer at the Rhode Island Disability Vote Project. And I just want to just give you all a quick update on what we are doing. I don't have a specific complaint or issue to bring to your attention but just to let you know a few of you are involved with the Rhode Island Disability Vote Project, and a few folks in the audience as well.

And the Rhode Island Disability Vote Project was started in really 2005, an initiative funded in part by Help America Vote Act funding to encourage people with disabilities to register to vote, to educate themselves about their candidates, to participate in the elections. It's a nonpartisan alliance. We do not support one particular party or another. We don't support any particular candidates. The thrust is to get out there and for people with disabilities to become even more involved.

Over the last year, we had our founding convention in this room in April. And we had about 100 or so people there. After that, we worked on a bill in the state legislature called Bill 5969 that was going to require publicly financed candidates for statewide office, Governor, Lieutenant Governor, Treasurer, Secretary of State,

Attorney General, to put closed captioning on their TV ads because right now many candidates do not even think to put closed captioning on their TV ads, which makes it more difficult for people who are deaf or hard of hearing to find out what's going on.

And the other thing that we -- was required of that bill was to require radio ad transcripts upon request, the radio ads. People could find out what was going on.

So we had a big effort around that and we got 1,082 signatures from the state, submitted the petition, and it passed the state legislature. The governor signed the bill into law on July 3.

So in 2010, encourage all the candidates to run with public financing. And that way they will all have to do closed captioning on their TV ads.

And coming up, we will be working on the presidential primary elections. This is the first time since 1952 when there has neither been a sitting president or a sitting vice president running for election for the presidency. So it's really an open primary on both sides. So it's a great chance to participate and make your voice heard.

Any questions or -- thank you very much.

>>>BILL INLOW: Yeah, Mr. DeBoer, did I understand you to say that the state law says if you accept public financing, then you are bound by that state law to have captioning?

>>>JAMES DEBOER: That's correct.

>>>BILL INLOW: It seems to me that we should urge candidates for public office to voluntarily comply with the --

>>>JAMES DEBOER: That's a great idea.

>>>BILL INLOW: -- the spirit of that law; and whether or not they're financially dependent on public support that we urge them to comply with the spirit of that law as a gesture of their respect for voters with disabilities.

>>>JAMES DEBOER: Yeah, I agree with that. Absolutely.

>>>BILL INLOW: Thank you.

>>>JAMES DEBOER: Thank you.

>>>LORNA RICCI: Any other questions? Any other testimony?

>>>LORNA RICCI: I think what we will do is we have some wonderful organizations represented here. If you have questions for folks, maybe what we could do is informally have -- if you would like to come up, talk to some of our organizations to find out a little more information about some of them. This might be a good time to use this waiting time while we wait for -- until 5:30 or wait -- hopefully other people will come to testify.

So, we have a little bit of a wait here. Please feel free to just talk among yourselves.

>>>BILL INLOW: Maybe we could reconvene in a half hour --

>>>LORNA RICCI: That's a great idea. What we could do is we could plan on reconvening in probably 15, 20 minutes. And by then if someone else in the room here wishes to sign up, we will hear more testimony then.

(Return from break)

>>>LORNA RICCI: Excuse me. We are going to reconvene in just three, four minutes. Three, four minute warning.

(BREAK)

>>>LORNA RICCI: Okay. Excuse me. We would like to reconvene. We would like to reconvene.

Lights.

Okay. We have two people who have signed up to testify. Janice Lebrun?

>>>JANICE LEBRUN: Yes. Thank you.

## Mental Health Care

I just want to say I really have -- me and my family had a lot of help from the Kent Center. We have a 12 and a 14 year old. One with Asperger's and one with PTNOS. We were going through a very difficult time. And we got children's intensive services, first for one child and then for the other. So we had a whole year of health with therapy in home and as an outpatient.

I just want to go on record saying they were very, very good. Thank you.

>>>LORNA RICCI: Thank you, Janice.

Does anybody have any questions for Janice?

Thank you, Janice.

Linda McCarthy.

Linda.

>>>LINDA MCCARTHY: Hi. My name is Linda McCarthy and I work for East Bay CASSP. And I just want to jump off what she was talking about with behavioral health as opposed to children with disabilities. One of the programs that are involved in our program under CASSP, we have the Children's East Bay Mental Health -- oh, my God -- sorry. I told him I wasn't going to be able to talk today because I have been in a workshop all day but I'm just kind of brain dead. Under the umbrella of our organization, right now we have CASSP which is Child and Adolescent Services Program. We have an enhanced CASSP which works with children who are going to -- on the verge of being in residential or have just come out of residential placement. We have the PEP which is the Positive Education Program. And we have the Project Hope Program.

And I'm just curious as to where in the system of care the process is that involves the children between the ages of 17 and 21. I haven't read anything in the paper in the past two days. And I was just kind of informed that there might have been somewhere as to where these kids are going to be placed. I know as of now if a child of the age of 17 is convicted, he will no longer -- or she will no longer be going into the Rhode Island Training School. She will be -- or he will be going into the ACI. Has that law passed? I guess that's a question that I'm wondering if anybody has -- can answer that for me. Do we know if that's been --

>>>SANFORD LUPOVITZ: How does that relate to disabilities?

>>>LINDA MCCARTHY: It does. Because right now children with disabilities, even though they are not children with physical disabilities, they are children with emotional and behavioral disabilities are now being placed out of their residential care, out of their foster care system. Children that were under the umbrella of being able to be supported until the age of 21 will no longer be cared for until that age. So, they may not have the physical disability but they have the emotional disability. Children with autism. Children that are being carried by elderly parents that because -- I mean, in my care we have children that -- parents have more than one child with disabilities. And I know they are not physical disabilities, but autism is still a disability.

And so I'm just concerned that we have children that are fallen by the wayside because of the new changes in the law. And I was just wondering if there was anybody here that knew of the changes that had come about for the children? Was there anybody that read anything on that recently? Can you address that?

>>>RORY CARMODY: Those were budgetary recommendations.

>>>LINDA MCCARTHY: Has it passed?

>>>RORY CARMODY: I don't know if it passed, but it is going in that direction. The intent is people who are convicted of a crime, 17 will be treated as adults.

>>>LINDA MCCARTHY: How about the children who have been in residential and foster care and being taken care of by the state until the age of 21? They are no longer going to be taken care of --

>>>RORY CARMODY: I believe some monies were restored to that program. There is also a threat again that that program, going away or losing funds.

>>>LINDA MCCARTHY: I know under the umbrella of this program, ours is being -- DCYF and DHS are the two systems. We are funded under DCYF and under our care. They're changing our program to include early intervention. So now what we are doing is we are looking at the local level ages of 0 to 3. But we are forgetting about the teens. So I just wanted to kind of bring that up.

And I had one more thing. Respite care. We have a lot of families. And respite is almost like a word that isn't even available any more for children and families. Respite to the families that are taking care of children with disabilities, and whether it be physical disabilities or emotional disabilities. So, thank you.

>>>LORNA RICCI: Thank you, Linda. Any questions for Linda?

>>>KEN RENAUD: I have a question for Linda.

>>>LORNA RICCI: Linda.

>>>LINDA MCCARTHY: Oh, I'm sorry. Yes? A question for me. Okay.

>>>KEN RENAUD: Ken Renaud from PAL. I want to clarify the respite question with you a little bit. So you are saying that people aren't able to access respite?

>>>LINDA MCCARTHY: No, they are not.

>>>KEN RENAUD: So they are going through social workers to try to access respite?

Or --

>>>LINDA MCCARTHY: The waiting list for home based therapeutic services or the respite is about a year and a half right now for anyone. And if you have -- in some cases, I have families that have two or three children with disabilities, and autism -- I mean now, you know the percentage rate is what? One in 160 something. And in Rhode Island I believe it's higher than that. So you are going to run into a lot of families that are so in need of respite. And if we can't find the support mechanism that surrounds them, if they don't have that natural support in place, and mentors are far and few between. We are just talking about whole group of families, whether they have disabilities with -- a physical disability or an emotional disability -- is very little respite for families.

>>>KEN RENAUD: I think a suggestion could be -- other than contacting legislators, obviously, so that they are aware of the issue, might be to make sure this Dr. Ella Nelson's office knows about that. She is posting stake holder meetings around the state for folks that are accessing services. So, that sounds like to me a suggestion that could be made to the Innovations Committee, which is really good information for that committee to have.

>>>AUDIENCE MEMBER: You were sitting here with no one to talk to.

>>>RORY CARMODY: It worked out well.

>>>AUDIENCE MEMBER: I got up --

>>>RORY CARMODY: Those committees are listed on MHRH's website. Those committees and work groups that Dr. Nelson is -- they are open to the public. And I think with HBTS we are a provider in Cranston. There's a lot -- our capacity and being able to find individuals within the program.

>>>LINDA MCCARTHY: Most definitely.

>>>RORY CARMODY: So perhaps things are not outreached to recruit young mentors even in the senior, high school -- college.

>>>LINDA MCCARTHY: That is one thing we are working on, getting children mentors. We are trying to address it through the senior high schools and children that have to -- the first year of college that have to meet certain curriculum and to try to get them involved in that.

>>>HEIDI SHOWSTEAD: Linda? My name is Heidi Showstead and I just thought of something that might be able to help kids on the cusp, so to speak. And I don't know if there's any programs involved. But I do know that if you can get children that either have had juvenile offenses or are kind of on that -- the fence, if you will -- involved in some sort of pet training or grooming or pet therapy. It really helps them to learn responsibility for others, to bond with the animals, and to have the guidance of a friend, so to speak. To have something that is dependent on them, even if it's a couple of times a week, will give them another focus and perhaps more career avenues.

>>>LINDA MCCARTHY: Thank you. That's something I will definitely -- when I go to family planning team meetings -- see if we can address that with families and see if we can get them moving in that direction because behavioral issues are involved around that. And if we can get them to work with animals.

>>>HEIDI SHOWSTEAD: I know -- I watch a lot of public access programs. And I know it works in women's prisons and it works with a lot of other mentoring programs. So why not have a positive push towards that to help the children in Rhode Island?

>>>LINDA MCCARTHY: There's definitely a positive push in Rhode Island now with the PBIS schools, the public based schools, positive based schools, and the positive approach to how teachers are working with children. Positive approach is definitely coming back. I mean it's not a new concept. It's something that we've known for how many years. But it is definitely coming back.

>>>HEIDI SHOWSTEAD: Because I do know that -- I've seen in motion animals especially the cats and dogs have the ability to really change people's lives and to put them on the right path. I would like to see some more of that happening for our youth.

>>>LINDA MCCARTHY: Most definitely, Heidi, especially with all these animals who have no homes right now. I don't think you expected your panel to go in this direction.

>>>AUDIENCE MEMBER: That's okay.

>>>COLLEEN ANN POLSELLI: I can address the respite issue and -- me -- hi, I am Colleen -- I don't think this is on -- Colleen from the Rhode Island Department of Health, Office of Special Healthcare Needs. And I'm also on the Cedar

Interdepartmental Team. So I am at DHS one day a week. So anyway, regarding the respite. There was up to date a limited respite program. And there were no slots available for children with special health care needs birth to 21. So that would be whether they had emotional, physical behavioral, okay. Now they did receive a waived DHS and they are taking applications for respite.

>>>LINDA MCCARTHY: Oh, thank you.

>>>COLLEEN ANN POLSELLI: So I don't know if that's on-line. You can get the applications from a Cedar Family Center.

>>>LINDA MCCARTHY: I am very -- we work hand in hand.

>>>COLLEEN ANN POLSELLI: They have the applications. Contact DHS, Paul Choquette. Regarding the HBTS list, they have just, you know, they have been working on the HBTS list, seeing if there's duplicates, going back to see if families still need the services or want them. So they are really working their way down. So it's much smaller. I think it may be down to about a year wait. There's also several new providers that have been approved. So it still will go in order. So there's some hope there. But definitely they are taking the applications now.

>>>LINDA MCCARTHY: Because it is being heard. I mean, there's a lot of families. If you don't take care of families that are taking care of children with needs, then the whole system ends up breaking down because you have one support mechanism, the mom or the aunt or the uncle or godmother or -- whoever. And they are the ones that need the respite. They are the ones that need to function on an --

>>>COLLEEN ANN POLSELLI: Slots are limited. I think about 300.

>>>LINDA MCCARTHY: I'm sure they are.

>>>COLLEEN ANN POLSELLI: Some are already committed. So now is the time.

>>>LINDA MCCARTHY: Well, I have two Cedar workers that I can contact on Monday. Thank you for that. Thank you very much.

>>>KATE SHERLOCK: I work with the 18 to 21 year old. If any of them have disabilities and are not getting the support services that they need, they can call us. We are still not sure how much we are going to be able to do depending on the demand. But we are willing to look at those -- we are willing to look at those cases. So any of those folks can call the --

>>>LINDA MCCARTHY: So this other than -- an access one --

>>>KATE SHERLOCK: It can be any disabilities. It can --

>>>LINDA MCCARTHY: That's a criteria for meeting the CASSP needs too is a disability. Thank you so much.

>>>KATE SHERLOCK: You are welcome. Thank you.

>>>LORNA RICCI: Well, next person is Paulette Brusso.

>>>PAULETTE BRUSSO: Good afternoon. My name is Paulette Brusso, member of the board of AG Bell -- can you hear me?

>>>LORNA RICCI: You need to talk right into it.

>>>AUDIENCE MEMBER: Paulette --

>>>LORNA RICCI: You have to get close.

>>>PAULETTE BRUSSO: Now, is that okay?

## Deaf and Hearing Impaired

My name is Paulette Brusso. I am a member of the board of AG Bell Rhode Island chapter and also I'm here as a grandparent for my five-year old grandchild who is hearing impaired. I would like to bring to the attention of all of you the need and concern of parents who are looking for an auditory oral option for education for their children who are hearing impaired. We are very happy that a program has been started at -- it's a state program that has been started. It's housed at Orchid Farm School. And it's a kindergarten -- a preschool kindergarten program. But now my grandchild is being mainstreamed into the regular kindergarten in Cranston. And I know several of the other parents are concerned that as their children grow -- so to speak -- grow out of this program, there isn't going to be any follow up. And this is something that we need to address as the children get older.

It was a very effective program while they are in their preschool years. But we are going to need to be addressing the concerns and needs that these kids are going to have as they go into the mainstream. We are going to need training. We are going to need faculty. We are going to need, you know, support all the way through until their high school years. I don't know if people are aware of that. I know some of the parents who are in the program haven't gotten a lot of support from their school systems.

Any questions?

>>>RORY CARMODY: Paulette, have you been involved with the Commission for the Deaf and Hard of Hearing or what their position is?

>>>PAULETTE BRUSSO: I have been to some of their meetings. But I don't know what their position is on this matter.

>>>RORY CARMODY: It would be something I would be interested in -- Steve Florio, his group. They may have more information, especially around advocacy issues. I know they work with the school department. Office of Rehab Services have folks who work with the deaf and hearing impaired too. But I think they get involved with kids more at 14 --

>>>PAULETTE BRUSSO: Right.

>>>RORY CARMODY: -- in transition. But it might be a place to start as well.

>>>PAULETTE BRUSSO: This program started as preschool.

>>>RORY CARMODY: Right. But you want to be able to carry those services throughout.

>>>PAULETTE BRUSSO: Right. Now who would be -- which one of you would be representative of addressing education issues? I don't know how -- where you are going -- you are just getting questions.

>>>RORY CARMODY: We are getting questions. And we will file the data, the information. And try to direct some of those questions to those people, the Commission on the Deaf and Hard of Hearing or --

>>>ELAINA GOLDSTEIN: Well, there is the Department of Education does have a special unit on -- what she is asking so there is actually an agency that has a special unit for taking issues. David Ciamco, if you want a name. He is a good person at the Department of Ed's contact.

>>>KATE SHERLOCK: And we represent children with special needs regarding their education as well. We have very limited priority. We actually have been looking at a related issue as a potential systemic issue. So please feel free to give us a call.

>>>PAULETTE BRUSSO: Okay. And what is --

>>>KATE SHERLOCK: From the Rhode Island Disability Law Center.

>>>PAULETTE BRUSSO: I work with -- she is on the Bell of -- AG Bell. She is the president. In fact, I am representing her right now because she is just traveling, just coming home from a trip.

But I think when this program was originated two years ago, when we met as a group of parents, we were all given the understanding that the program would follow the kids all the way through their education. And now I'm not sure exactly what the problem is.

There were two classes, two oral programs or classes at Orchid Farm. Now there is one. They took the teachers -- put them back at the School for the Deaf. I don't know why. That's neither here or there. But the question is really -- continuing services and also getting the information out to parents because we are finding from AG Bell and just people that we talk to in early intervention. I don't know if people are aware that oral auditory education for the deaf and hearing impaired is another option. They seem to be getting information from -- I don't know who is giving -- or family services or whoever they get the information from that the only option that they have is the School for the Deaf. And early intervention people don't seem to be aware that there is another option. I would like to ensure that that information's spread.

>>>LORNA RICCI: Thank you.

>>>PAULETTE BRUSSO: Thank you.

>>>LORNA RICCI: Next I would like to call Linda Bradley. Linda Bradley?

>>>LINDA BRADLEY: One minute.

>>>LORNA RICCI: If anyone has heard anything today that you agree with, you might want to sign up to testify that you agree with one of the issues that has been mentioned.

## Housing

>>>LINDA BRADLEY: Okay. Thank you. My name is Linda Bradley. And I am a Home Access Coordinator at OSCIL. And I just want to let folks know how tight it is out there. I know you heard that before. But the home modification program. I currently have a two-year waiting list for people for -- sometimes simple home modifications such as, you know, changing doors, changing steps, adding rails to allow them safe egress to and from their home. Our equipment money is less than it was when I started at OSCIL.

And I wanted to stress too that sometimes when I go out, I'm always looking -- I have a Scottish heritage, so I am always looking at the most economical way to do things and I do look at that very closely. If a person can use a piece of equipment or a less expensive modification, I certainly, you know, let them know that we are going to do the most cost effective solution.

So, we look at very, very closely. I think Lorna will agree. I'm kind of a master at that.

Also that -- a lot of the people own their own homes. A lot of the older folks. Their mortgages are paid off. They are living on SSI. They don't want to go to a nursing home. They want to stay home. And perhaps they're on such a tight budget because of the medications, because of just the way everything is more expensive, they cannot even afford to take out a second mortgage or a loan, even a low interest loan to do some of these modifications.

And again, we try to come up with some creative ways to help them with their problems.

## Transportation

The other thing was sort of related to the woman that had spoken about the problem with the bus access. I actually had spoken with Sue, who's our information and referral person at OSCIL about that case. And again, just trying to think outside the box, what else could we do there. And I had wondered if something could be done, such as like a board walk or a ramp or, you know, what is the policy? Is it that the driveway has to be paved? Or does it have to be not dirt? Does anybody know the answer?

>>>BILL INLOW: It has to be safe.

>>>LINDA BRADLEY: A-ha.

>>>BILL INLOW: For the customer as well as for the other passengers in the vehicle.

>>>LINDA BRADLEY: Okay. Is it the place where the person gets on to the bus that's in question or where the bus has to drive to?

>>>BILL INLOW: Where the bus has to drive to.

>>>LINDA BRADLEY: Okay.

>>>BILL INLOW: It has to be safe for all occupants of the vehicle.

>>>LINDA BRADLEY: So it doesn't have to be tar -- paved?

>>>BILL INLOW: It does not.

>>>LINDA BRADLEY: All right. Well, that's interesting.

## Housing

Sometimes with the rental situation, it's a difficult thing, even with our program. You know, working with the Governor's Commission on Disability, Harvey Salvias has been wonderful with helping us with some difficult situations recently. And you know, finding out and letting people know that if they are in a rental situation, their landlord cannot block their right to have that modification on the home.

However, they don't have to pay for it. They can -- they can make the tenant pay for it or say, well, I can't afford that so you have to pay for it. But they can't block it.

>>>KATE SHERLOCK: They may have the tenant return it to its original condition.

>>>LINDA BRADLEY: That's right. Yes. But usually with modifications that happen, usually the landlords are more than happy to have those modifications down because now they have an accessible apartment to rent. Or it has taken a set of old steps and it has changed those old steps into a nice smooth ramp for people to go up, or whatever.

So, you know, that's a tricky one. That's a tricky one because people renting cannot afford these modifications. So we do look at those extremely carefully.

So, I think that's pretty much all I wanted to say today.

>>>ELAINA GOLDSTEIN: Can I address? You know all the work we are trying to do with home modifications and understanding all of what's out there?

>>>LINDA BRADLEY: Right.

>>>ELAINA GOLDSTEIN: Rhode Island Housing took the lead on trying to get that home modification bond bill passed. And it's come to a point that they have two or three programs at Rhode Island Housing that they feel will help people do home modifications, aside from what you guys get from ORS to OSCIL. So she sent out a survey that she wants people to fill out. So I will -- give me your e-mail address. I will forward it to you.

>>>LINDA BRADLEY: Great.

>>>ELAINA GOLDSTEIN: Because you might want to fill out her -- you might have better information than I do on some of the questions that she's asking.

>>>LINDA BRADLEY: Okay.

>>>ELAINA GOLDSTEIN: Then find out what we want to do is put all of these home modifications places -- because MHRH is not here today but they also have a home modification loan program that Rhode Island Housing administers. So we still have to talk to them to see how that all works. But your programs work a little bit different than the other ORS programs, for people getting back to work, which I'm sure are different than the ones at MHRH, which also work different than the ones -- the other ones that Rhode Island Housing. But it needs to be clear that there's just not one place where people can go.

>>>LINDA BRADLEY: Right.

>>>ELAINA GOLDSTEIN: That's possibilities. Maybe some of these people on a one or two-year waiting list, one of these other programs might be suitable.

>>>LINDA BRADLEY: And I should say we do look at that. And again Sue is very, very up to date on a lot of that. She -- I go to her all the time to find alternatives. Sometimes even before they come to me, they've already been given information about -- well, try this. Try this. Try this. We do know some of them. But any other stuff is great.

>>>PAULA PARKER: I also wanted to mention that for elderly folks, the purpose of a reverse mortgage is to help them stay in their home. And if they are interested in that, it's nothing that has to be paid back until they either pass away or the house is sold. But the origin of reverse mortgages was just that, to either help elders pay their taxes so they could stay at home or to help them modify their home so they could stay there. And certainly there are a few banks that offer them. And it's one option for people who need that kind of assistance.

>>>LINDA BRADLEY: We had also had a small forum here -- when did we do that? In April. And we had some representatives from different agencies. And what we're telling folks as far as reverse mortgages is to be very, very careful. We recommend, you know, calling Rhode Island Housing to get information. Get information before you sign up with somebody because you could get -- you know, shistered by one of these, you know, will give you anything you want type of places. So they --

>>>PAULA PARKER: The department had introduced legislation this year to protect people who are getting reverse mortgages. We drafted a bill and it had a lot of safeguards in it for counseling and disclosure. The National Reverse Mortgage Lenders Association from Washington flew their lobbyists and lawyers up to Rhode Island. And although our bill passed in the House, it stopped in the Senate. So we are going back in the fall. And we have been promised that this year we will have a bill. But it's clearly the product as the baby boomers start aging where there are going to be a lot of private products developed and without regulation safeguards will be in the same predatory situation that we have -- so --

>>>LINDA BRADLEY: Very true.

>>>SANFORD LUPOVITZ: In your dealings with people who own their home and want to remain there.

>>>LINDA BRADLEY: Yes?

>>>SANFORD LUPOVITZ: Are you using the telephone dialer systems to automatically call police, ambulance, fire?

>>>LINDA BRADLEY: We often will recommend some sort of emergency response system, depending on the person's abilities. Some folks already have them in place. But we do let them know about the ATEL program, also where they can -- perhaps a person can't utilize a regular phone because of fine motor difficulties, whatever. So yeah, we do make sure that they have that sort of thing in place, if that's needed, definitely. Yeah.

That's a very important part of being home alone because you are not going to have somebody there all the time. It's a peace of mind for them and for their families and caretakers.

>>>BILL INLOW: I would like to pick up on the previous comment that is made about state legislation because these hearings do have an impact on -- I'm Bill Inlow from RIPTA -- have an impact on state legislation. I think it's good to be very concerned and cautious about reversing annuity mortgages and other instruments that take advantage of the equity that people, elders have in their homes. At the same time, I think it's very important not to lose sight of the fact that given the budget

## Safety Programs

constraints at the federal and state level, that we need to help this generation of elder people take advantage of that enormous amount of equity that is in their homes, to help them stay in those homes.

And again, especially given constraints on the federal and state budget. If we don't find a way to find some resources for home care and other kind supports for frail elders to remain in their homes, we will be in a great deal of trouble. It's good to be cautious about reverse annuity mortgages. But it's important that we take advantage of that incredibly enormous amount of equity that elders have in their homes. And I really think that's important.

>>>LINDA BRADLEY: I have to add to that -- sort of tongue in cheek, I guess. I live with my 86 year old mother and she has plenty of equity in her house. But she also lived through the depression. She's not going to touch that (LAUGHTER)

>>>BILL INLOW: She may have to leave her home, which is a real shame.

>>>LINDA BRADLEY: I think she would if she absolutely was backed against the wall. But you know, here I am living with her and I do this for a living and she doesn't want to change things.

You know --

>>>KEN RENAUD: Sometimes I wonder when people make comments that there's possibilities of taking some folks that have had some success with that, you know. They've done the reverse mortgage. They've had success. They are of that generation to tell, you know, their peers and people in their own generation that -- the story of how it helped them.

>>>LINDA BRADLEY: Yeah.

>>>KEN RENAUD: So the education component on top of it, I think, is important as well.

>>>LINDA BRADLEY: Well, I've done a few talks out in the community to, you know, church groups, senior groups. And those are always very informative to tell folks about, you know, the alternatives. And even just like I was saying earlier, some of the equipment that you can use in lieu of a major modification. So, I think education is a big part of it, definitely. I think we are planning to do another one of those home modification things next year. So, look for that. We will send it around to everybody. So --

>>>ROBERTA GREENE: Adding to that too, it's a quality of life issue that people ultimately have to make a decision about.

>>>LINDA BRADLEY: Yeah. It's really tough when you get there and you have to say, wow, I'm to the age now where I can't stay in my home or I have to think about that. It is -- and we may all get there.

>>>KATE SHERLOCK: We hope we do.

>>>LINDA BRADLEY: Yeah, really.

>>>LORNA RICCI: Thank you, Linda.

Any one else?

We have -- we don't have any one else officially signed up.

>>>HEIDI SHOWSTEAD: Lorna --

>>>LORNA RICCI: We do.

>>>HEIDI SHOWSTEAD: I just -- this is Heidi Showstead again. And I just want to

## Working and Health Benefits

say one quick thing. I notice with a lot of people what happens is when you are looking for getting jobs and employment and you are on a certain amount -- say you have a certain type of benefit or whatever. There's not a lot of collaboration between the agencies in the state. Like you go to one benefits specialist with the same qualifications. I get such and such benefit. Blah-blah blah. And they will tell you that one thing is okay and you are all set. And then you will go some place else and they will tell you a different story. And I think that happens with not only with work benefits and things like that, but also with the services that children receive in the schools. There's not a lot of collaboration between organizations. Rather you're just starting out in life or you are elderly. And I think it all starts with equal partnerships, collaborations for everybody involving all ages in life and all areas of independent living. That's what I think we need in the state is to work towards working more together as partners as opposed to separately.

>>>LORNA RICCI: All set? Does anyone have any questions for Heidi?

>>>ELAINA GOLDSTEIN: Who are you getting different information from?

>>>HEIDI SHOWSTEAD: Just in general, you get -- just in general, like if you go and you have a certain parameter and just a hypothetical situation because I know it happens to a lot of my friends. You know, you want to work part-time and you -- say you can make such and such amount. Then you try to do it and you have issues with benefits. Or there's a parent that wants to give their child the best education. And you know, one school department will work with the parents. Another school department will say it's not their responsibility. And it happens across the board, no matter what your age. And I just don't like to see that happening. I want equal access, equal collaboration, equal communication --

>>>ELAINA GOLDSTEIN: I think the problem is not collaboration. I think the problem is that there are people giving information that don't have the accurate information. That's the problem. Now, ORS have benefits counselors. They are the benefits counselors in the state. And they are the people you need to talk to about that. It's what they are trained for and they spend a lot of time, a lot of energy, and they are going out. Roberta Greene down there heads up the whole group and they go out and try to train as many people as they can who are giving information directly to people to make sure they are giving them the right information. And that is the problem. It's not that people aren't working collaboratively. It's that some people are giving information that don't have the accurate information. And they don't know where to go to get the best information or to suggest you go. Do you know what I'm saying?

>>>HEIDI SHOWSTEAD: Right. But my point is that it's not just one area of life. It extends anything from early childhood education all the way to the end of life and elderly and dependence and respite. And I think that everybody just needs to make sure that they are getting and giving the right amount of information and that they are all on the same page to benefit the lives of people that need assistance in the state.

>>>ELAINA GOLDSTEIN: Right. And what I'm saying to you is this issue is being addressed and it's addressed by creating the people who have the expertise. For example, do you know about the Point?

>>>HEIDI SHOWSTEAD: Yes.

>>>ELAINA GOLDSTEIN: Okay. The Point is an entity that has trained people on multiple areas. So you call them and if they don't know the answer, they know where to send you. So that's supposed to be helping people find the right information. I don't know how you control somebody giving out misinformation. I think what we can try to do is get better, better outreach materials so that people know where the right place to call is for the accurate information.

And that's sort of -- you know --

>>>HEIDI SHOWSTEAD: Thank you.

>>>LORNA RICCI: Any one else?

Would anyone else like to comment on anything that's been said, perhaps something that you agree with? Linda.

>>>LINDA: I agree with Heidi --

>>>LORNA RICCI: Hold on, Linda.

>>>LINDA: I don't need a microphone.

>>>LORNA RICCI: I know.

>>>LINDA: I agree with Heidi in one aspect that in the schools, it is not the same across the board. I work with two neighboring communities and what is a qualification for one school system is not a qualification for another school system. Same exact child has moved from one area to another area to get the services that they need. So, just a comment on what she says. With the educational piece that I know that the qualifications are not the same from school system to school system. So I don't know if that's where she had gone with that, for the educational piece.

>>>LORNA RICCI: Does anyone wish to comment?

Are there any other comments of anything that's been said today? Agreement, disagreement?

I would like to emphasize that everything that is being recorded is going to go to the Governor's Commission on Disability. Many of the people here, the panelists and other people who are interested organizations will be reviewing all the information. The Governor's Commission prioritizes the different testimony and begins to address ten to 12 -- we have someone who has been with the commission longer than I have --

## Education

they address -- try to look at the -- probably the most common kinds of concerns and begin to take those on and address them in the state.

I have to say that a couple years ago we heard testimony for the first time really on abuse against people with disabilities. You know, we have DCYF for children. We have DEA, elder abuse. We did not have any organization or any entity that would take cases between -- let's see. 22? 22 to 64 and a half (LAUGHTER)

>>>PAULA PARKER: 60. We take 60.

>>>LORNA RICCI: That group in there. And someone testified very eloquently that went -- as I just said. It became public -- it became written down. We looked at it. The Governor's Commission brought that forth as something they wished to put on their own priority list. Two years later, last year it became law. There now is a department that's looking into those cases. So testimony that happens here that you might be thinking what goes -- what happens with it after this. I have to tell you, it continues on.

Another wonderful point. Anything that's mentioned here today, again, becomes a record. The Governor's Commission on Disabilities sends it to all the legislators. They all have it.

Now three months down the road, one of you talks to your own legislator and says, you know, there really needs to be more -- better transportation. Your legislator will then say to you, is this an issue that really impacts a lot of people? You can now say, I heard it mentioned many times at the public forums. I know it's written down. You can see it for yourself.

It gives you credibility. It gives you a backup that this issue has been mentioned before. So, again, maybe a little sales pitch here. But I really encourage you, if you are here listening today, maybe representing an organization and you heard something that really -- you know will impact your own folks that you are serving, please take a second. Just to go on record that you agree with the need to look into this issue or that issue.

Public service announcement here.

With that, would anyone like to testify?

Do I see a hand? I see a hand. Yes.

Your name, please. Paulette Brusso.

>>>PAULETTE BRUSSO: I have a question about what you just said in terms of addressing the concerns that were brought to the panel. Are the items that are selected chosen by the number of people that they affect? Because in the example that I just gave, that's a very small population. Number one, the deaf population is a small population. And then the subgroup of people who want an auditory oral option for their children is even smaller subgroup of that group. So, is the decision being made to select the things that are addressed based on the number of people that it affects?

>>>RORY CARMODY: Sometimes it's looked at by themes. Like transportation applies to a lot of folks. Disabilities access. When you talk about voting not just encouraging people to register to vote and vote but voting equipment is accessible, polling places are accessible, that the campaign ads are accessible. So it really goes around themes. We look at that broad category. But under it, certainly issues that are relative to your grandson.

>>>ELAINA GOLDSTEIN: I can make a suggestion. I sit on the Legislative Committee for the Commission. That's where all of -- not all of it but many of the things that may be legislative action would go to the Legislative Committee. And what gets taken up is determined by the people on that Legislative Committee. Now that committee is -- I'm not -- I come -- anybody can come to that Legislative Committee. So if there is an issue that you really are very interested in seeing something, you can go to the Legislative Committee on the Commission and make the case before the Committee in addition to this, as a stronger case. And that way the commitment and the strength of people wanting to see something happen that really makes it happen. Not necessarily the numbers that are affected.

>>>PAULETTE BRUSSO: Would you be able to give me that information in terms of when --

>>>ELAINA GOLDSTEIN: Chris?

>>>CHRISTINE RANCOURT: They are posted on the Secretary of State's website. So you can find out -- about any meeting that the Commission holds by going into the Secretary of State website.

>>>PAULETTE BRUSSO: When you say 'commission' which commission?  
 >>>CHRISTINE RANCOURT: The Governor's Commission on Disabilities.  
 >>>ELAINA GOLDSTEIN: It meets once a month, usually Monday --  
 >>>RORY CARMODY: I can't remember which --  
 >>>ELAINA GOLDSTEIN: You will see it on there. Where the Commission's office is, which is in the Howard Pastore Center.  
 >>>RORY CARMODY: Near the new trial court.  
 >>>ELAINA GOLDSTEIN: Where the fires were. They were okay.  
 >>>PAULETTE BRUSSO: Or electricity.  
 >>>ELAINA GOLDSTEIN: I invite you to come.  
 >>>PAULETTE BRUSSO: The lady from the Sherlock Center for Disabilities, I can't see your name. Kate --  
 >>>KATE SHERLOCK: My name is Sherlock but I actually work at the Disability Law Center.

>>>PAULETTE BRUSSO: Oh, okay. I thought I saw someone here from the Sherlock Disability Center.

>>>LORNA RICCI: The information that you are looking for is right here. Did everyone take one of these at the registration table?

Right in the middle gives phone numbers, addresses, where to contact. I believe the website is on here for any information on the Governor's Commission on Disability. And the priorities -- and please correct me, those who have been on the Commission longer than I have. Once the priorities are put in writing, these are the priorities of the Governor's Commission. There is chance for public comment, correct?

So, the priorities I think are put right on the website for people to see. So you can see if -- but all the testimony I believe will be on the website. Do you have any idea Chris when it will be published?

>>>CHRISTINE RANCOURT: When it will be out?

>>>LORNA RICCI: It's a while.

>>>CHRISTINE RANCOURT: It takes a while because we wait for the CART reporter to get the information to us. As Rory indicated, we have to theme it out. So it does take a little bit of time. So I can't tell you three weeks from today. But --

>>>LORNA RICCI: You may want to check on it -- what's this month? This is -- the fall -- perhaps the fall?

>>>CHRISTINE RANCOURT: By the fall.

>>>LORNA RICCI: Ready by the fall. You can check the Governor's Commission's website and see the testimony as Chris has said. You will see everything right there.

Any one else like to testify?

Any comments?

Well, we are here until 5:30. Perhaps we can reconvene just about 5 or 5:25. Unless we see more people come in, we will announce that we are reconvening at that time. Give time for people to talk. Again there's wonderful expertise right here in the room.

(Return from break)

>>>LORNA RICCI: Excuse me. We have just a couple of other people that wish to go on record. I will ask some of the panelists who have anything they would like to (inaudible) Ken Renaud. We will be ending right at 5:30.

>>>KEN RENAUD: I would just like -- my name is Ken Renaud. I would like to go on record by supporting comments that Richard had had regarding the kiosk, the inaccessibility of kiosk for people that are blind. I think that as well as people that are blind, some kiosks are not universally designed for all people in general. And that it -- I really believe that it is the wave of the future with technology. You see kiosks popping up all over the place, in airports, NETWORK Rhode Island has kiosks now that are put there by Providence Journal. It's only classifieds from Projo. But I used it with some folks with developmental disabilities and it's very easy for them to navigate. But if somebody doesn't see, they would have to have somebody there with them. So I just kind of wanted to support Richard in his notion that there should be some attention being paid. Because when new technology comes out, it's a great thing. But if you have to retrofit things, you know, that's going to take three, four times longer to have things retrofitted so it's accessible for all people.

>>>SANFORD LUPOVITZ: Is the technology there? Is it available?

**Blind and  
Visually  
Impaired**

>>>KEN RENAUD: Is the technology there for kiosks to be voice activated? I believe so. Is Richard still here?  
Richard can speak to that.

>>>RICHARD GAFFNEY: Right. Most anything that comes out in the way of technology nowadays can be made to produce speech. So the technology is there. What they would have to do, if they need help, they could work with our national office and they would be able to help them out.

But as I said earlier, you know, as Ken says, this could be a real problem. In fact, it's getting to be a problem for a lot of us. And it's going to become a real serious situation if we don't do something soon. It will be a real crisis to try to do it once all the machines are installed. It's a lot easier to do it when you are building from the ground up than to have everything built and then go back and have to do it again. It can be done. But it's a lot more difficult.

Any other questions?

Thanks, Ken.

>>>LORNA RICCI: Thank you, Richard.

Was there someone else on the panel that wanted to speak?

Yes. You need to yell out.

>>>SANFORD LUPOVITZ: You already spoke.

>>>LORNA RICCI: What is your name --

>>>ELAINA GOLDSTEIN: I didn't talk about Rhodes to Independence. I will talk about Rhodes to Independence.

Yeah. I would like to talk to people about what Rhodes to Independence is. I don't

know how many of you have ever heard of who we are. We are basically, to be honest, a grant, a federal grant. But it's a systems change federal grant. And we attempt to work on a variety of different issues that our main purpose is to help people become -- with disabilities -- become competitively employed, which means to be able to get actual jobs that make a living wage and help get

out of poverty, get off of SSI, get off of Social Security disability, and be able to work and not lose your healthcare or other benefits that you need. So, when I was talking about the Sherlock Plan, the Medicaid Buy-In, that's one of the first projects that we were involved with in getting that legislation passed. We have been doing a lot of work on housing issues. And we have been working on the issue of home modifications. And we have been working on another issue about housing registry. This is for people to know where they can get -- whether it's a rental unit or a house that is accessible. And accessible defined in a very broad way. Rhode Island Housing, we are very, very close now to contracting with a wonderful organization that has an amazing web based system that will help what happens here in Rhode Island. Because in Rhode Island right now you have to go to individual counties to sign up for their housing. This would be one integrated place where all the information is for all the different -- any city in Rhode Island. And the information about the types of accessibility, not just let's say mobile accessibility but any other types of accessibility. It's really a fabulous product. And they are in the cogs of state government now with the RFP process. But really hopefully the beginning of next year that should be hopefully up and running, which would be really helpful for people to be able to know of other rental units where they could go if their current rental unit is not accessible.

## Working and Health Benefits

The home modification loan program, which we had legislation out there, because of the budget crisis in the state, it's just really seems to be incredibly difficult to get even another bond passed. As I said a little bit before, Rhode Island Housing is taking the lead. And what we are doing -- we are doing a systems study to find out all the different programs that are out there, home modification programs. Who's eligible. How somebody needs -- what they need to go through to get that home modification. Because it's very different depending on where you are going. So we are going to try to make that much more of a system. So that people know that there's a hierarchy depending on your income, on where you can go, to actually get some help to get financing or -- and who actually will do the home modification for you.

## Housing

Because there's a lot of issues out there from what we understand, from ORS, there's not that many builders or construction people that are bidding to do a lot of these jobs. And that seems to be a problem that has been surfacing here. So if -- you might

have money. You might have -- but if you don't have somebody to actually do the home modification, it's not going to get done. So we are kind of looking at it from a systemic standpoint to see what the problems are and do something about it.

## Transportation

On the transportation issue, it's probably the most frustrating issue that we have worked with at Rhodes to Independence. We got a grant from one of the transportation associations in Washington. And those people were supposed to do a lot of technical assistance for us. But it was very clear when I went to a five day -- it was intense where I didn't know a lot about how public transportation is developed in other states. And to understand how the structure, the infrastructure for public transportation in other states is very, very different than the infrastructure here.

Regarding strategic planning. RIPTA is a provider of public transportation. And so much has been put on to RIPTA's shoulders as far as strategic planning, and everything else under the sun has been sort of delegated over to RIPTA without the funding to really be able to do everything that they have been asked to do.

Other states have a Department of Transportation that's either involved with the strategic planning or they have a department in the administration that is in charge of strategic planning. So that's one of the areas that we really felt was in need to sort of get more -- somebody within state government to be more actively involved in the general strategic planning for public transportation across the board.

And there's a coalition that -- one of the environmental groups put together and there's study after study. There was another study that was done this year on transportation issues. So, figuring out what we need to do to get it out of the studying phase and into changing the way the system works is sort of the big, big issue that needs to be addressed, especially for people with disabilities and senior citizens, and to be honest with you, anybody who really doesn't have a car in this state. So many people who are on the welfare system need public transportation. And then there's the environmental groups who want to use public transportation. So that becomes the broader issue, not just for people with disabilities who need to use public transportation but for the rest of the state.

So, anybody out there who has ideas on how to address this issue, wants to address the issue, we are going to take another stab at this next year and see what we can do with -- it continues to be an issue that's brought up. I think we've identified what the problem is. So now it's a matter of really trying to get some people around the table who can really make the difference and making something happen.

>>>LORNA RICCI: Ding! (LAUGHTER)

>>>ELAINA GOLDSTEIN: I am going to have my friend Paula talk the Point.

>>>LORNA RICCI: Actually we are done. (LAUGHTER)

We are done.

I encourage you to go to the website. Governor's Commission on Disabilities website around the fall -- or maybe soon you can check it for testimony that you've heard today. And I thank you all for coming. And probably same time, same place next year. And that's it. Good night. (APPLAUSE)

## Friday July 27, 2005- RI Department of Health

>>>KATE MCCARTHY-BARNETT: I'd like to welcome everyone here this afternoon. My name is Kate McCarthy-Barnett, at the Department of Health we'd like to welcome you here today. We are happy to have you here today. The purpose of the forums, really the state government and sponsoring organizations really want to here from people with disabilities. Their families regarding your concerns and ideas for improving the lives of all Rhode Islanders with disabilities. We do have a few rules to review although we're a small group, we would like to start out ensuring everyone has time to speak that each speaker take about five minutes and after hearing from everyone, we'll go back and have time to include additional questions. The panelists are here this afternoon to answer questions and help to understand your concern a little better so at this point I'd like to ask each panelist to state your name and your affiliation, ors or agency you're here to represent.

>>>BILL INLOW: I'm Bill Inlow, Disability Services Coordinator at Rhode Island Public Transit Authority, RIPTA, I also work closely with the RIDE program.

>>>DEB GARNEAU: Deb Garneau, Health Department.

>>>KATE BOWDEN: Kate Bowden staff attorney with the Disability Law Center.

>>>JOHN DUPREE: John Dupree, National Alliance of Mental Illness of Rhode Island.

>>>JOAN WOOD: Joan Wood, Neighborhood Health Plan of Rhode Island.

>>>ELAINA GOLDSTEIN: Elaina Goldstein, Project director of Rhodes to Independence the project trying to help people with disabilities become competitively employed.

>>>KATE MCCARTHY-BARNETT: Thank you and thank you for taking time this afternoon. Housekeeping. Rest rooms are on the first floor you can take the elevator. After we call your name we'd appreciate it if you could state your name again and if you're representing an organization or agency because the CART reporter will need to document that. So to become I would like to invite Eileen Morrisette to share any concerns or questions she has for our panel members this afternoon.

>>>EILEEN MORRISSETTE: That's me. I'm here to observe, I'm a student getting involved with Special Ed. indication for visually impaired children and I'm here to observe.

>>>KATE MCCARTHY-BARNETT: Okay, thank you for coming. At this point then Barbara Torres.

>>>BARBARA TORRES: Hi, I'm with Family Voices of the Rhode Island Parent Information Network.

>>>KATE MCCARTHY-BARNETT: Any questions or concerns you would like to share?

>>>BARBARA TORRES: At this moment, I don't.

>>>KATE MCCARTHY-BARNETT: Thank you so much for coming. Okay. I think at this point then we also have Marilyn McCullough who signed up. Marilyn, did you have any questions or concerns you would like to share? And if you could state your name again for the CART reporter.

>>>MARILYN MCCULLOUGH: Would you like me to stand? Marilyn McCullough. I'd like to put my phone number on record, 401-419-7787. I'm actually here today for two reasons, and it will take nine minutes.

>>>KATE MCCARTHY-BARNETT: That's fine. Take your time.

>>>ELAINA GOLDSTEIN: You have two hours.

>>>MARILYN MCCULLOUGH: I'm here because of current difficulties I'm having with the recreation department, and I'm here for self. Recreation commission, excuse me.

>>>ELAINA GOLDSTEIN: Did you say for yourself?

>>>MARILYN MCCULLOUGH: Representing myself. I'm having difficulty with the

### Local Government

recreation commission in the town of Hopkinton trying to put in a handicapped playground. Just a brief history of what has occurred and brought me to this point. My daughter Sarah Jane McCullough was severely handicapped and confined to a wheelchair. Not only was she non verbal and ambulatory, but vision and hearing impaired. We often go for walks in Crandall Field in Ash away, and one day at the playground, a comment was made, isn't it a beautiful playground? Yes, but we can't go over there. At the time I didn't think twice about it, it was just something we do not do. And you have to understand, to get to this playground, I'd have to push her wheelchair through the grass which is very difficult, lift her one foot off the ground to put her on the board walk and wood chips to push her through to get to the equipment. Once in the playground area,

the only thing that we could have done to watch the kids play because there is no equipment for Sarah to play on and to accommodate her wheelchair and to me that would have been very cruel so we didn't do that. Well, Sarah died in March of 2003. And at that moment, I had vowed that no wheelchair bound child should ever be denied the ability to play at playgrounds. I had received permission from the town of Hopkinton to build a handicapped playground in Sarah's memory at Crandall field. My goal is accessible as well as usable playground for children and adults of all abilities, thus allowing perhaps for the first time a true sense of inclusion for a child of special needs can play together with their siblings, it will be added to the existing playground connecting the two together as one with a board walk surrounding the

### Accessibility

existing playground starting with the parking lot. This playground design is specifically tailored for adults and children in wheelchair while accommodating children with special needs but are ambulatory. Within the first year of Sarah's death, my family and I with help of dedicated volunteers raised over \$109,000. Three years since the funds have been raised and the playground is still not built. I'm here today because I have more barrier from the recreation commission from specific equipment needs, colors to accepting the solutions and recommendations from our expert engineers when addressing these concerns. I'm consistently providing them with research on every piece of equipment showing the documented benefits a child with special needs would receive as well as the benefits of colors and contrast. Over the past four years, the recreation department has asked me to change the site locations numerous times, changes, reflecting every location change, they have consistently claimed that 100 percent of this community donated funds belong to the town and claim it as their town money. Yes, the town is holding the funds in my daughter's memory for this playground but it is not the town's money. Had I known in lieu of flowers send money to the town of Hopkinton to build a handicapped playground in Sarah's memory would have added so many delays, I would not have. I believe the recreation department sees this as a burden, not as a gift and they have never embraced this project. The latest concern as of July 24th, '07 is that they do not really want to put concrete in the playground area and that was their quote. Please understand that this equipment must have a concrete base or the playground cannot be built. They have stated concerns about the concrete base cracking and lifting the equipment. With respect to the commission, they have justifiable concerns as their basketball court poles were lifted up. However I brought in an expert engineer who knows this location and has actually build buildings at this site and with proper installation and special concrete fabric he assures us this will not happen. Thus meeting the manufacturer's warranty requirements for installation. The response to this was, they have no maintenance money to fix it should the equipment up root. The recreation department received an approval last year for an open space matching grant of 125 thousand dollar from DEM to build a handicapped playground for total playground cost of \$250,000. The grant request was written against the funds I had raised that the town is holding in my daughter's memory. I do not know the details of this grant but I do know the funds were awarded to the recreation department. In 2003, I had inn kind donations for concrete and excavating. It is now 2007, those offerings may no longer be available to me to fall back on due to the great delay of the Commission on this project. However based on the grant that was awarded the to the recreation department, there should be money for maintenance should that be necessary. I feel the recreation commission has danced and skirted around moving forward with any significant progress for too long. I've been asked the last two years from the community and investors what is the status of the playground all I can tell them is we're working on it. The truth is we have had all of the money needed for three years. I can't understand what the true delay is myself. Do they just not want it? I don't know. I have raised 100 percent of the money. We have the town council's permission and we have a location, I just want to put it in. The children have been waiting too long, why? Where is accountability to these children? The community and investors are now losing patience. Not only do I owe them an explanation but they require an explanation for documentation of their donation. I requested the commission toe assist me in providing an explanation to the community and investors as to see why the delay and what we intend to do to move forward. The response July 24th was they do not owe the community any answers, but just tell them we are working on it and you can go to the paper. Enough is enough. I need help, I need

accountability from these people, any legal advice to assist me in moving this forward to help create a time line and a start date or to help me to remove the funds to allow me to put the playground in at another location. I believe this needs to be looked into. That's my first reason why I'm here.

The second reason for being here is I believe there is a natural element that is missing in the family dynamics which is family recreation when it comes to people in wheelchairs. I believe all playgrounds must be integrated to stop the discrimination. Changes must be made and it must be mandated. People affected are the children. The parents who are in wheelchairs who cannot take their typically developing children to the playground as they need accessibility to monitor and keep them receive and additionally the families who cannot bring their grandparents who are wheelchair bound to see their grandchildren play on a Sundays afternoon. How much longer must we stay home because they cannot get to the playground? So, how can we make change and the answer is in three steps'. First, we need to support the grass root sites such as mine by doing so there must be funds set aside for legal advice and support, assisting in gathering local and political support and assistance in navigating administrative process. Second, we need to address the brown field sites. By doing so we need to influence the design of the existing playground when they come due for refurbishing. Or legal reasons or insurance concerns or just general maintenance. We need to identify and influence the decision makers. As examples, who is paying for the playground, the funding sources. We need to identify the local town councils, planning boards, building inspectors, and playground equipment manufacturers because they provide a lot of the design advice and need to meet the commercial needs. We also need the playground equipment manufacturers to promote equipment for all abilities. And finally the third is we need to address the green field sites. On the playground should be mandated to have integrated playgrounds. By doing this in this order, this will allow us to use what resources we have to most benefit now and build on the future. The grass roots efforts can be done without much cost. The brown field sites are where most of the changes are and opportunity also happen but it will require the convincing of other people. green field sites may have less opportunity for immediate change but they will be more focused on government regulations. And I would just like to say that we all know our children learn through play, my life goal to plan date a law to require at our playgrounds. Would you join me in investing in our children's future?

>>>KATE MCCARTHY-BARNETT: Thank you, Marilyn. I'd like to open it up now to the panel for any feedback .

>>>BILL INLOW: First of all, I appreciate very much your testimony and energy. You don't have a playground yet in your daughter's honor but her mother's actions and advocacy on her behalf and on behalf of other children with disabilities would make her very proud. I'm not -- can you explain the difference between a brown field and a green field?

>>>MARILYN MCCULLOUGH: Brown fields are the existing playgrounds that currently exist. Green fields are potential new sites.

>>>BILL INLOW: Okay. I wonder about the applicable, you know, the laws either local ordinances within the town of Hopkinton versus state rules or procedures versus some kind of federal. I'm not a lawyer so I just wonder what -- have you had some advice at least from some attorneys?

>>>MARILYN MCCULLOUGH: No, I haven't. Unofficial advice, more opinions. Again, our town council has been expecting this to move forward. It is the smaller component, the Recreation Commission, who has created the obstacles. I actually will have a letter to address to the town council and the town that I haven't mailed yet, I was hoping that perhaps it could be reviewed and you could advice me if, to wording that I need to change to address the importance of this. To be accountable to their people Patricia Ryherd, work for the office of service but also a member of the Commission on Disabilities. I believe at the National level, there is information about that. And I think that we can provide you with some information. So, if you don't mind, just calling the Governor's Commission on Disabilities and gives about a week, we'll see, you know, like what there is at the federal level and at the state level, examples of designs and what relevant laws there are. I appreciate your advocacy.

>>>PATRICIA RYHERD: Off the top of my head, it's 462-0100. And that will get you into the general mailbox and then someone will call you back. There are like five

different phone lines but that gets you into the general mailbox of the Governor's Commission. If you want to, at the end of the forum if you want to leave me your name and address and telephone number so I'll be sure that it goes both ways.

>>>MARILYN MCCULLOUGH: Would that help me with my current situation or for my future desire to make changes?

>>>PATRICIA RYHERD: Hopefully both.

>>>ELAINA GOLDSTEIN: I was, just to give a suggestion had on what to, when you get into the federal, I don't know the federal. But if you've gone to the city council and the city council has given you the go ahead, I don't know what the hierarchy is there in the town but there has to be a hierarchy that this recreation commission has to report to somebody. So, I would -- I would be happy to work with you on sort of just getting through the bureaucracy of it to see who to go to. But you start there and then you have, you've got your city council and council people so -- have you gone to them?

>>>MARILYN MCCULLOUGH: I have. And since 2003 --

>>>ELAINA GOLDSTEIN: And they don't seem to be able to do anything.

>>>MARILYN MCCULLOUGH: Well I haven't recently and I have a letter addressed to them, perhaps you could review.

>>>ELAINA GOLDSTEIN: I'd be happy to talk this out with you because then what you want to do, you have your city council and you also have your state legislators, I don't know who your representative is in the state government here and who your senator is but those are the next two people that you would want to get involved in this. And hopefully, one of them is actually very, you know, interested in helping people with disabilities. And kind of just stick it, stay there. And then, I don't know if the commission, the recreation area, I mean, I don't know what laws of the federal government, I mean, the ADA doesn't cover recreation, does it?

>>>PATRICIA RYHERD: Yes, it does if there are federal funds involved. If there are federal funds involved then it would provide for federal access for the Governor's Commission on Disability has a mediation program where they will help an individual and a town or whatever, you know, entity to try and resolve an issue in order to find it so again, when you give me, you know, your name, I'll make sure that you connect with the Governor's Commission.

>>>>JOHN DUPREE: I want to be sure, this is my first time here in this capacity, but I want you to know one thing, you might also find helpful if you haven't already have a thick file of all of the paperwork that you're doing so you can say, I did this, I did this, when you go to the proper authorities say this is what I've been through, I'm sure you already have this and know this but make sure you get a paper trail going. I have this mailed on this date, this is who I called on this date, keep a record of phone calls, the e-mail, whatever. Have a very precise record keeping and that will serve you down the road.

>>>MARILYN MCCULLOUGH: Thank you.

>>>KATE MCCARTHY-BARNETT: Thank you, John. Bill.

>>>BILL INLOW: I think I heard you make a reference to the member or the chairperson of the recreation person telling you to go to the newspaper if you wanted to.

>>>MARILYN MCCULLOUGH: Yes, he was, one of the members on the commission, he was not the chairperson. That person did not show up, so.

>>>BILL INLOW: Sometimes media exposure does move even petty little politicians at the Recreation Commission level at the town of Hopkinton, most people in those groups, most politicians or public officials I know always want to go up higher, you know, and you can't go higher if you don't get elected. They're probably appointed, the Recreation Commission, are you appointed by the town council?

>>>MARILYN MCCULLOUGH: I believe five-year term volunteers.

>>>BILL INLOW: Sounds to me like they're calling your bluff. What newspaper covers the town of Hopkinton?

>>>MARILYN MCCULLOUGH: Westerly. Thank you. In addition to this, Congressman Langevin has attended events I've had and I've e-mailed him and have not heard back yet from his office. I'm not one to be out there pointing fingers. So I was wondering if that is the proper channel I should take at this point of just open this up to the community and let them put the phone calls in.

**Local  
Government**

>>>BILL INLOW: I agree. I mean, I think you've made an incredibly appealing presentation here and I would think that, you know, most newspapers like controversial things, and this is controversial -- shouldn't be. It's emotional. And if the town council won't exercise their authority over the Recreation Commission, it seems to me you might want to expose it to some public scrutiny through the newspaper. I think, I don't know.

>>>MARILYN MCCULLOUGH: I think I was.

>>>BILL INLOW: After four or five years, time for being nice is over, I'd be madder than hell with all that money you raised and the other money you found out about.

>>>MARILYN MCCULLOUGH: I am. I'm not one to voice my anger, but I wanted to make sure this is just, properly so to make those channels.

>>>BILL INLOW: Enough is enough, I admire your patience. I wouldn't be that patience but I admire your determination. But they weren't very nice to you, so, sometimes the system doesn't work you have to jerk the system around a little bit, I think. Good luck to you.

>>>KATE MCCARTHY-BARNETT: Excellent points. Anyone else on the panel have any feedback or comments? Okay, thank you so much Marilyn, we appreciate your coming to share this afternoon. The next person listed here is James Deboer.

>>>JAMES DEBOER: I don't want to speak, but I do want to mention vote are registration cards if anyone wants to register to vote and information about the Rhode Island Disability Vote Project.

## Voting

>>>KATE MCCARTHY-BARNETT: Thank you James. At this point I would like to open it up to anyone else who did not actually sign up to speak this afternoon to share any feedback or comments that you've had on what's been shared today. This is -- I'm just -- share if you have anything to share? Okay. Any other feedback or comment from the panel members?

>>>BILL INLOW: I think it's important to note something I've heard at several other of these hearings. And some were attended much better, not that numbers are critical because quality of the comments made were great. But the point was made that some current pieces of state legislation, some good positive administrative change that is have occurred over the years frequently come from these hearings. I understand in Newport there was a big turnout and quite a bit of input. I was at the hearing in Barrington yesterday in Warwick and there were some fine comments made highlighting some issues that in fact are important to people with disabilities. And the record here is provided to the Governor and to all of the members of the General Assembly. Take an issue like accessibility of playgrounds for all people, including grandparents and parents as well as children, that's an important issue. And that could be highlighted in these hearings to make a difference.

## Legislation

>>>KATE MCCARTHY-BARNETT: Absolutely they make a tremendous difference. A few new people stepped in. We've opened the floor if there's any questions or comments you had regarding issues for people with disabilities or their families if have you any concerns or ideas of issues you would like to see improved upon?

>>>ALEXANDRA: One of the people who joined us is a student in character in universal design, and Marilyn you were talk being your hopes for the future in at the presenters of playgrounds, can you talk about that a little bit?

>>>KATE MCCARTHY-BARNETT: That's Alexandra.

>>>MARILYN MCCULLOUGH: As far as my hopes for the future, I'd like to partake in some type of policy making to create change so that all playgrounds require complete integration for accessibility and usability for people in wheelchairs and -- which, almost kind of falls into other children, piece of equipment meets needs as well as of other children than special needs children. Existing playgrounds and I had some ideas about what we could do to make those applications as well as new playgrounds and I expressed some concerns I have about an existing playground we're trying to modify currently and that was mainly where -- I need legal advice and support and advocacy through my local charges and higher up.

## Accessibility

>>>KATE MCCARTHY-BARNETT: Alexandra, maybe from your perspective, you could share what you know about playgrounds and what's incorporated.

>>>ALEXANDRA: Well, it's kind of hard to say because there are no really guidelines for playgrounds or anything like that. There are suggested things that

need to be done but it's very difficult to accommodate every single existing playground to an inclusive playground so it's just the whole bit. I would love to see that happen, too because I definitely, I'm into the whole idea of inclusiveness and getting the kids playing together and that would be like a dream come true but in terms of right now, I do have a lot of ADA guidelines and suggest material that I could probably share.

>>>KATE MCCARTHY-BARNETT: That would be great.

>>>ALEXANDRA: I would love to do that.

>>>KATE MCCARTHY-BARNETT: I just want to piggy back, you mentioned legal a few times and I didn't know if you had any thoughts on the legal?

>>>KATE BOWDEN: Well, it sounds like there's the potential for this to be a legal problem so you may want to talk to lawyers but it's not a situation where I could provide legal advice to you because it's not my area of expertise and I wouldn't give legal advice in a public forum because it would lose privilege. But if you feel, you should, I could get you numbers to the legal referral service in Rhode Island, I can't think off the top of my head of lawyers who would be well equipped to handle the problem but I'm sure there's someone out there that could do that.

>>>KATE MCCARTHY-BARNETT: That would be great. That's a good connection. We have another participant interested in sharing.

>>>DEB GARNEAU: Deb Golding. I would just like to add that it's becoming more and more difficult for kids to just get around in neighborhoods and towns and I think there should be safe pathways leading to all playgrounds, schools, there aren't any and now there's so many construction projection, kids are isolated and even trying to teach a kid how to ride a bike on a road, there are few sidewalks, I just find it's becoming more and more difficult to thing around unless you're in a car. Thank you.

>>>KATE MCCARTHY-BARNETT: Thank you. For people that recently joined. Thank you.

>>>PATRICIA RYHERD: Have you seen the brochure called Accessible Rhode Island that lists what is accessible and the Governor's Commission has advocated for things like fishing dock SOS that people can get down in wheelchairs and go fishing, beach buggies so that people can get safely on a beach and a variety of other areas. So, one thing is that unfortunately we don't always know even what is available, not to say that there isn't necessary for more, I'm not saying that but again we need to know what is available.

## Accessibility

>>>DEB GARNEAU: Crosswalks, my son has autism and trying to teach him to be safe and there's no, you know, crosswalks any where canners how do you teach him to cross the street, or where he can cross the street safely on his own when he gets older.

>>>PATRICIA RYHERD: I need to advocate for crosswalks, and that's an ongoing process and you probably need to deal with your town or city to see about getting one crosswalk in one specific area. It has to be unfortunately, you know, place by place because it just doesn't happen. And in the past, unfortunately, sometimes crosswalks have been put in places where it's not safe type of thing. So, it is an individual advocacy issue.

>>>DEB GARNEAU: There are construction projects in the town I live that are lasting for year, so a child could actually live in their neighborhoods, grow up and never be able to cross the street for their entire childhood. It doesn't make sense to me, if you're having a construction project examining on for eight or ten years there needs to be some type of accommodation.

>>>KATE MCCARTHY-BARNETT: Any feedback from the panelists to those points? Again, I think in terms of the Governor's Commission on Disability there's an accessibility committee and as this is reviewed bit legislative committee, all of the members who serve organizations and sponsoring agencies, you know, will be reviewing it and looking for those key areas and how the commission can move forward either with legislative priorities or suggested policy areas or further education. So, please note that your testimony will definitely be reviewed and will be, you know, looking at that also for next steps on behalf of the Commission and those agencies and organizations that are here today.

>>>ELAINA GOLDSTEIN: I heard this at another meeting. There is a legislative committee and that is really the commission that decides on which issues they want to move forward legislatively and anybody can come and participate in the legislative committee and people that do come and participate and make their arguments really do get things done. So,

## Legislation

if you would like to carry this further, not that -- it will be in the testimony, could you participate in that legislative committee. The legislative committee, I believe, it's on the web site, it meets every month. I guess that there's a hiatus in the summertime, but usually the second or third Monday of the month but on the Secretary of State's web site, is that where all of the Commission meetings are -- and I would definitely recommend that you come. Because I've seen people that had specific issue that is they wanted to get addressed and they were -- this would be a key place to do it.

>>>PATRICIA RYHERD: And to follow up on that, when the Governor's Commission advocates for something and for example there's testimony required at the state legislature, there is a need for individual citizens to come and testify. Or again if ten people write to their local legislator about a particular issue, preferably at a time it's being discussed, that make a difference in the state of Rhode Island, ten letters can make an impact.

>>>KATE MCCARTHY-BARNETT: Thank you. I would like to open it up again to anyone joining us this afternoon, any additional questions, concerns or issues you would like to bring up to the panel? And the panel will actually be here for a little bit longer but feel free if you have had the opportunity to testify or listen, you can.

>>>MARILYN MCCULLOUGH: I actually do have one more thought. I had experienced **Transportation** about two weeks ago parking lots at Hasbro in the Providence area where I had to park on the second floor which is fine but I had a crate of resources that I was bringing and I had to carry them all down this flight of stairs, there was no elevator. And although I do not have a handicapped -- I don't need a handicapped spot, I really felt that that whole bottom floor, one, should have, the main floor should have been all handicapped accessible for all those families'. Because if those few handicapped parking spaces are already in use, those families that still need to use handicapped parking end up parking up the second and third levels, how do they get down? There's no elevators? And I just found that --

>>>PATRICIA RYHERD: That's Hasbro Hospital you're talking about, not Hasbro Company?

>>>MARILYN MCCULLOUGH: Well, I'm sure it's an independent parking garage. But the first floor was combination of handicapped and regular parking but there was no elevator so if those spots were filled for the families, they would -- or parking in general, they would have to move up stairs but there's no elevators on the second and third floors.

>>>PATRICIA RYHERD: Well the Governor's Commission has the Accessibility Committee and if you want to put in a complaint, they could explore it there is a standard for the percentage of places that you have to have for handicapped parking you know versus the general public but that shouldn't discourage you from exploring the issue and if you wanted to write a brief note to the Governor's Commission about the accessibility issue and see if there's a solution to it, absolutely.

>>>MARILYN MCCULLOUGH: I just, at one time I needed those parking spaces but I found it ironic because I was going to the children's hospital and that there was no elevators.

>>>KATE MCCARTHY-BARNETT: That's another reason these forums are so important because you're raising issues in locations that maybe the commission is not aware of and in reading the testimony it can go back to the accessibility committee or whoever might be checking it out in terms of the Commission, actually go out and evaluate and look and see if the codes are not -- another question?

>>>DEB GARNEAU: Deb Golding, I have another location I went to, actually went to with the whole accessibility thing in my head, had to go there, it's the new Kent County Courthouse. It's a beautiful building but there are very few signs. The only direction thing I see top point new any direction is this television screen that's note a huge one and if you're trying to read, I couldn't even read it as it was flashing on what was on what floor, there were no signs to the elevators. The elevators were silent so if you were standing, by the time you get to the door opening, it would be closed on you already. There were no signs any where and there was nobody to answer any questions as to where anything was. So, I just thought that was --

>>>PATRICIA RYHERD: Thank you.

>>>KATE MCCARTHY-BARNETT: Another good observation, if you. Any other comments from the panel? Again, if anyone else has any questions or concerns that you would like to share and if you have shared your concerns and -- feel free to, you don't need to stay, you can certainly leave, the panel will be here though to listen to any questions, you know, for the next hour or so. So if you have any other thoughts, we welcome your ideas and sharing.

>>>PATRICIA RYHERD: Why don't we take a five-minute break?

>>>KATE MCCARTHY-BARNETT: Why don't we take a five-minute break and we'll reconvene in five minutes. Thank you.

(FIVE-MINUTE BREAK)

>>>KATE MCCARTHY-BARNETT: I think we're going to get set to reconvene. Okay, we're going to reconvene now. At this point, I'd like to welcome Mary Wambach who is here, too, from the Corliss Institute and has testimony to share. Welcome, Mary.

>>>MARY WAMBACH: Thank you very much. I am deaf for those who don't know me. If

## Legislation

you can't hear me, please speak up. What I'm here about today is the initiative. This was part of the Division of the Developmental

Disabilities. About six or seven months ago. First I want to say that my comment today is with all respect for the Governor, administration, and legislature. I'd also like to say that I'm speaking not only as the Corliss administrator but recognized group to criminal justice, law enforcement, program workers in the area, and abuse of people with disabilities and senior citizens. There are a lot of concerns about the Shared Limit Initiative. I also want to say there's a lot of hope about this initiative. I've spoken with many other disability leaders,

## Developmental Disabilities

individuals with and without developmental disabilities and there's an agreement that this initiative will provide an option for people with developmental disabilities who are ready to live in a more independent setting and who are able to self report when there's abuse, molestation, exploitation or neglect. The

concerns for many of us though is that in the state's cost cutting endeavor that the shared living option may supplant or replace residential services that now exist in Rhode Island. I think there may be a misconception that Rhode Island has fully implemented what we call the empowerment model. And you may be familiar with that but in fact you're not, I'm going to back up. Residential programs, up until very recently were based on the medical care taking model which is one in which the professional whether a doctor, nurse, therapist, social worker, a CNA or direct support staff, it's the one that helps and the one that makes decisions. Over the past ten years, not just Rhode Island but the nation has been trying to make a shift to the empowerment model which is one in which the consumer or client makes their own decision or at any level getting more involved in the decision making. We haven't implemented that yet for many reasons. First it's still new. Second many people in the, or people that have been there for years are still not willing to accept the philosophy of the empowerment model. Third and I can speak with experience for residential programs with three shifts it's almost impossible to get all of your staff together for training because you can't cover all of the shifts when they're training people. I can tell you from my experience as a trainer and model that collecting groups at state level and at National level, it's not fully implemented. Because the dilemma between the states and between the nation, only works if every single municipality works and they don't. There are many, many municipalities in our country that are not even online yet. You're still writing notes on hand, they don't have the money, don't have the staff. I can also tell you from my law enforcement work that many first time offenders are still dealt with a felony charged and it's reduced to a misdemeanor with the understanding they will take anger management or therapy or community service but they did commit a first time felony and many of you know that the people with disabilities is, we can't always come up with enough information to stand up for a court case. They're not trained investigators to appropriately gather the information either. So many cases of appeals of exploitation and negative do not make it to court simply for those reasons. I want to urge you with all possible strength to ask that we have public hearings on the 207ic of shared living, that we go into this very, very slowly and third that we look at what the current standards are. I know for example that there are only two annual periods during which the new provider which will be an individual as oppose today an agency has to give access to their home at the residence or property owned by the consumer.

I don't think this is in most cases. If anyone would like to contact me for more information, you can contact me at the Corliss group.

>>>KATE MCCARTHY-BARNETT: I'd like to open it up for any feedback from the panelists.

>>>BILL INLOW: Could you elaborate a little bit on the twice a year access to information, expand a little bit on that, Mary, please.

>>>MARY WAMBACH: Sure. Right now in the residential programs, there's access into the unit or apartment by appropriate manager, direct support staff, by quality -- if any report is made, under the new shared living arrangement, there are only two times annually when the agency which for example could be Corliss would be able to enter the residence of the provider who is the individual. It's a huge risk for people. For example, at Corliss groups are predominantly deaf. For a deaf person, in order to report, you have to have a land line because TTYs are not like cell phones, you can't pick them up and run with them. You need both hands to sit and type. You need to know that nobody is going to disconnect that line and you need to know that you can make a call without somebody looking over your shoulder. How can we assure that in this shared living arrangement? For people with other developmental disabilities who are not deaf, there is the same concern. How do we know that they have access to a telephone? How do we know that they can use their phone without somebody sitting there telling them what they can't say or just looking at them to make sure -- again, there are people with developmental disabilities who may welcome this initiative and who may be able to self support and figure out other ways to report if telephone doesn't work but for many people with developmental disabilities, there's a huge risk.

>>>ELAINA GOLDSTEIN: I was involved with the new personal choice waiver that used to be the old PARI waiver which was modeled after, I believe the DD waiver that allows for the personal choice. And I remember sitting there going through a lot of these issues which were how, I think it was like criminal back checking on the person that the individual with disability wants to hire, how do you know who this person is? Is this person going to be someone that's not going to abuse them or something like that. I haven't really followed up on all of what has happened regarding the person choice program or the DD waiver program. Do you have any information on how successful people have been at hiring the right kind of people so that there are no abusive problems because maybe that could be a model that they could use in this arrangement, or --

>>>MARY WAMBACH: I know Leo and Lorna from way back when. I lived in Boston and I believe that there is more -- not people with developmental disabilities but wanting to hire their personal attendants and the problem there is that Rhode Island doesn't have a unit that investigates abuse.

>>>ELAINA GOLDSTEIN: For those waivers either?

>>>MARY WAMBACH: No. We want to do it and the law passed but there's no funding.

Right now in reality people with developmental disability under the umbrella of quality assurance have a better chance of having an investigation and having the police be brought in than people whose disabilities are not developmental.

>>>ELAINA GOLDSTEIN: They do? But you're still concerned with this even though?

>>>MARY WAMBACH: Absolutely. Massachusetts's system, their system is not person but they have -- I'm trying to remember the name of it, the commission for persons with disabilities, their unit investigates personal care attendant abuse, exploitation and, I believe they have protective services for people with developmental disabilities so they have people trained to work with people with disabilities. The average patrol person, police officers, the average investigator with all respect don't know that people with disabilities can speak for ourselves. So they might go to an interpreter and say, what happened to her, or, if I was with a respected he want where I was abused, they might think, oh, she's deaf, so go to this person, they're the abuser. So there's a huge problem. We don't have a trained unit and we don't have an identifying unit to do the investigations for people with disabilities in wheel chairs, who are deaf, who are blind. That's a good issue and thank you for bringing it up.

>>>ELAINA GOLDSTEIN: But it could all be one group. I think your point, the empowerment model, you're calling it the empowerment model, people want

## Housing

## Legislation

## Developmental Disabilities

## Housing

to get out of nursing homes, live in their community, do their own thing. This issue really doesn't get discussed enough because, you know, you're too paternalistic, you're too this but there needs to be a place for protection in the development of all these things in case something happens. And you can't develop -- but I think that if you bring into the mix these other two programs that are Rhode Island's way of moving to the empowerment model, I think that everybody would say, they all need the same thing so, it's not just one issue out there. So it's now become a critical mass so to speak of people that need this unit or protective services.

>>>MARY WAMBACH: I would agree with you. I think that we already have a unit with training for people with development the disabilities and other disabilities, why not expand that. But I want to be clear, some people with other disabilities or people that are deaf might disagree with me. They might feel that those of us who don't have developmental disabilities need a separate unit. And I respect that. But I agree that we're all in this together. And there can be more cost to set up new training instead of expanding.

>>>ELAINA GOLDSTEIN: Well they spent a long time at DEA for the elderly and then finally got somebody and then they wanted to -- I know, it was the commission, didn't the commission try to make that unit for people with disabilities as well as senior citizens but then they cut the disability portion out because it was going to be too costly. Does anybody?

>>>PATRICIA RYHERD: I know that the Governor's Commission did advocate for it, I apologize, I don't know what the outcome was.

>>>ELAINA GOLDSTEIN: But we could backtrack. It was only a couple years ago, really that this happened because this issue of abuse for people with disabilities in general, there's no. And I remember, who was going to handle it, was it going to be MHRH, where was this going to be handled. There's layers, there's layers of this. Thank you for bringing this up.

>>>MARY WAMBACH: I believe the biggest problem is that society still doesn't want to believe that there are people who will purposely target and find and harm people with disabilities or children for that matter. People are still shocked when there's a newspaper expose on this they say oh my God, how does it happen. And I'm one of the National specialists not because I want to be but because nobody else was doing it. There are peep that will make it their life work to find weaknesses in the system and that's why I talk about -- I don't want to say -- we haven't really yet implemented. People can move to Rhode Island from other states and we do not have a system that can find what they did in that state because it's not in the system. And people are out there who want to move from state to state and you read about them in the newspaper, say, this couple welcomes disabled children and they've adopted 18 and three foster children and I'm not saying there aren't any good people but when I see one of those stories, say, oh, no.

>>>BILL INLOW: Under the residential programs in the past, you talked about how there was very good access to the place where the people were being served. And under the shared living initiative, only twice a year. Is that a regulation or some rule that the department of mental health retardation and hospitals or whatever department is responsibility for this shared living initiative came up with?

>>>MARY WAMBACH: The shared living, it's very interesting. It shifts titles, it shifts ultimately liability because right now, for example, under Corliss and other programs, we become the provider. And we not only have to go with DD, MHRH, regulations but we have our own internal policies to back it up. In shared living, Corliss and other agencies become the agency instead of the provider and we find an individual who wants, who welcomes a consumer into their home and they become the provider. So directs are much fewer and we have standards for many of the areas. That governs this arrangement, that makes me very nervous. I'm not a big fan of paperwork but protect people that cannot protect them selves.

>>>BILL INLOW: But there are standards like guidelines rather than regulations that are binding. But who said and where is it written down that it would only be twice a year that there would be access to the home where the person lived.

>>>MARY WAMBACH: It's in the application and I don't want to sound like -- there's an obligation to provide training. There's supposed to be an inability for

## Public Understanding

## Housing

the consumer to contact the agency, the program staff. But in the worse case scenario.

>>>BILL INLOW: Exactly.

>>>MARY WAMBACH: That's my concern, that if you had some suspicion that there was abuse, exploitation or negative going on, could you have the authority to go into the home and deal directly with the consumer.

>>>MARY WAMBACH: So what I did, we did complete the application but I said until something changes and maybe you won't accept this, we'll only do it on our property. Why? Because if it's our property, there's a gas leak or water pipe spray, you think there might be burning in the apartment and you could go in. And, yes, we would utilize it if we felt that a person with a disability was -- but under the current arrangement, it's someone else's property.

>>>KATE MCCARTHY-BARNETT: Any other feedback or thoughts from the panel? Well, thank you, Mary.

>>>MARY WAMBACH: Thank you. I just want to add a final comment. I am absolutely not saying get rid of the shared living program. I think it has value and for many people will offer an empowerment option. But please, please do half you can to make sure that in its -- that it doesn't replace residential living services in Rhode Island. Thank you very much.

>>>KATE MCCARTHY-BARNETT: Thank you, Mary. I'd like to open it up again to other people who are joining us this afternoon if you had any additional thoughts or feedback. Or concerns or issues to share on the topics we've talked about here today or any additional topics? Okay. I'd like to bring it back then to the panel members to see if there's anything else you feel is important to share based on some of the topics we've heard today and maybe other initiatives you've Elaina.

>>>ELAINA GOLDSTEIN: I'm actually going to go get the -- well have you a copy let

## Working and Health Benefits

me just use that. Take this opportunity to share with people here about a program, again what our job at Rhodes to Independence, one of our jobs to remove barriers for people with disabilities to get good paying jobs and become self sufficient. And many of the barriers kind of begin with health care. And we in 2006, a

program was implemented within the Medicaid program called the Sherlock plan. And it allows a person to make up to 50,000 a year and buy into the Medicaid program because many times a person is concerned that had they won't be able to get health insurance or their employer won't provide health insurance. And this brochure, what we've done is looked at another work incentive program called 1619 A and B and that's if you're on SOS. So many kids are on SOS and as they move from graduating out of high school into either going to college or going into work, they can actually and then they're on SOS, they can actually move onto a paying job and parents and everybody doesn't have to worry about them losing their health care which is the Medicaid program because they would continue on in the Medicaid program paying in a certain kind of premium which isn't as high as paying into Blue Cross and you would still keep the benefits. So this little brochure explains the little road you take as you move and you don't have to worry about not having health care coverage because you want to get a good paying job and you're going to lose your Medicaid or potentially lose your Medicare. We have a person in our office who just counsels on the Sherlock plan, but the department of ORS has a wonderful unit there led up by Roberta Green and she has two benefits counselor who is are important people to talk to and for your different agencies to know about them because they have the accurate information. There's a lot of program that is somebody with a disability could be on, all with very different income eligibility requirement SOS when you're thinking about going to work you want to be sure you're looking at your full package of benefit answer what you would potentially lose, what you couldn't lose but on the health care front just to know that we really have addressed the health care issue and not to worry about that and not stifle people that really want to move ahead and get jobs and work more hours because they're afraid. And we're really trying to change that attitude with health care providers a lot of peep who will are in the disability advocacy world know this but sometimes you wind up with some paternalistic health care employer that is look at somebody with a disability and say, oh, got to be on Social Security disability because otherwise you won't get everything you need. There really is a -- not just an empowerment model but the disabilities for people because of technology and they also have really -- I feel like I'm the little rah-rah cheer leader for ORS these days but

they really have accessibility and devices -- there's amazing things that people can do with amazing disabilities because of the technology that has come about in our lifetime. So I just wanted to focus people's attention on that and anything that you can be doing as a, you know as a parent and a lot of the great stuff you're doing with trying to get playgrounds and stuff, same people that need to understand that kids can play inclusively in playgrounds need to understand these kids are not limited in being able to get jobs and make good livings and become architects, right?

>>>ALEXANDRA: Right.

>>>>JOHN DUPREE: I just wanted to share something that happened at the Providence Center, my name is John Dupree. Something at the Providence Center, the past two years there have been cutbacks, the department of MHRH, cutbacks affecting the meant am health consumers Medicare only at the Providence -- Medicare only and that is that they are not being allowed at this point, it's my understanding, they're not allowed a nurse or case manager, only a contact person. I don't know even know what that is. I want to tell you something, I've been in the mental health system for, going on 19 years and overall, basically I've had a nurse and case manager and doctor. And without those people, their bedrock support and foundation for recovery. We do need these things and other centers around this state except for the Providence center to my knowledge have made the cutbacks accordingly. But at the Providence center try top fund it and work it out so people can be kept on longer and could have more services. You know, find a way to make it work. And this is going to have a grave impact because plane people, I see more and more, my friends who are hurt, who will having their lives impacted negatively and it is a grave situation and I know the final situation, federally, locally, statewide, it's tough but I just had to make it known here that some things are hang that can hopefully be turned around at some point soon because I'm just -- I don't know what to do. I just found this out Tuesday and I'm just kind of shocked.

>>>KATE MCCARTHY-BARNETT: Thank you John, anyone on the panel have any thoughts for John?

>>>PATRICIA RYHERD: That's a very serious issue. It's going to be very complicated and I don't know, you know, what planning is involved in that. I just wanted to follow up very briefly to Elaine's, thank you Elaina. The work incentive counselors which is what they're called rather than benefit counselors now, they also provide informational sessions periodically about going to work when you're on SOS or SSDI. And in August, there's going to be such a presentation in Spanish because one of the issues that we need to deal with in Rhode Island is accessibility for individuals who are disabled who don't speak English. So I have a flier about that and that also has the phone number, how to contact the two peep who will are the work incentive counselors if you would like to get furthered information or call them. I should also mention our fact sheets on the Sherlock are also in Spanish. That's one language, there are others.

>>>KATE MCCARTHY-BARNETT: I think we had a comment.

>>>DEB GARNEAU: I want to back up further to what Elaina was saying. My son is only in elementary school but having a child with a disability and having them included in a classroom, so if we're talking about inclusion and jobs and all that is corrects I wonder why the Department Of Education isn't, wasn't on the panel that I was on. Were they invited? And I don't likes to Special Ed. indication because I believe it should be education for all kids. Because that's part of the process to get a job to know that these things are available to you when you're a kid.

>>>PATRICIA RYHERD: Good point.

>>>ELAINA GOLDSTEIN: Just to -- actually, this was brought up.

>>>KATE MCCARTHY-BARNETT: Is this feedback for Deb?

>>>ELAINA GOLDSTEIN: Yes, this was brought up, was it yesterday? All of these are going together but yesterday in Warwick, there was a student bringing it up. They have transition, is it called Transition Council, Transition Coordinators. I'm not sure why the Department of Ed, maybe -- I don't know why, but there are a lot people within the Department Of Education that deal with all of this. And the person yesterday was really talk being how in each of the different school systems, the same child could exist in each school system and get very different services and that is really a huge problem. It was something, you know, I wasn't aware of until actually

## Health Care Benefits

## Education

last year because I thought, well, you have the idea and that's going to filter down and it really does not.

>>>DEB GARNEAU: It's town to town, school to school.

>>>ELAINA GOLDSTEIN: I don't know under what rubric it belongs secretary second if you can get children with all their -- you can have a whole generation that think people with disabilities are no different.

>>>BILL INLOW: Your point, I guess Miss Golding, is the Department Of Education

## Education

should be represented here since so many issues are he will vent to children and ultimately to adults with disability. I think that's a really good point and we ought to have that in the record that certainly the department of education ought to be fully engaged with these public hearings and with the Governor's Commission on Disabilities and listening to citizens from throughout the state about concerns for children and other people with disabilities, you're right. Thank you. We'll follow up on that for sure.

>>>DEB GARNEAU: And the Department of Health and Retardation, MHRH but just around the Department of Health, we have a few initiatives happening. It seems like this is more turning into networking time so this is a good time to get this out. One of the things we're trying to do is look at children that are in Special Ed. or that have disabilities that are in schools and encouraging them around health promotion, wellness and really getting them empowered to handle their health care on a go forward -- helping with that transition so we have a few initiatives we're working with the academy of pediatrics and looking at, with the department of education and looking at some of the resource that is can happen around parent education and youth education through RIPIN and transition centers and that kind of thing. So it seemed important to put that out there. And the other thing that we are looking at as well is, an accessibility study/survey, we're starting that with a first hand, for a self assessment for the YMCAs to look at their facilities and their parking and their equipment and accessibility and friendliness of the site itself and we're looking to partner with the commission as well and looking at some of the physical facilities for medical services. So that's a plan to really enforce that because there's a lot out there around homes and buildings and different public places but not much of it is enforced and the A technical assistance that some of the providers may be getting is smaller. So we are hoping to make an impact in that area.

>>>KATE MCCARTHY-BARNETT: Great. Thank you. I just want to open it up again there's any other comments. I think we'll take another five-minute recess at this point.

>>>MARY WAMBACH: I just want to ask, did all of you bring brochures?

>>>KATE MCCARTHY-BARNETT: They're on the outside table.

(FIVE MINUTE BREAK)

>>>KATE MCCARTHY-BARNETT: I'd like to invite our panelists back to the table. At this point, I would like to invite Barbara Torres, who is interested in speaking this afternoon. Barbara is from Family Voices at RIPIN, welcome Barbara.

>>>BARBARA TORRES: Hi everybody, I'm Barbara and there was a concern, I myself have severe asthma and so does my child. He's five years old, he's getting ready to go to school and I have other kids, I let them take the school bus and I've noticed that the school busses, the drivers are smoking before they pick up the kids so that's a big concern because if I'm to let my son go on the bus he may have an asthma attack before he gets to the school so that's thing I wanted to share, there are a few parents willing to talk about it if up want them to come and talk about that issue.

>>>KATE MCCARTHY-BARNETT: Thank you, Barbara. I'll toss it over to Bill, I think.

>>>BILL INLOW: I work for Rhode Island Public Transit Authority, RIPTA. Obviously we have a rule that says no smoking on the bus. By passengers or drivers. And I am fully aware that some drivers, before they get people on the bus, smoke cigarettes on the bus. We try our best to enforce that rule, discipline the driver. It's, you know, again, it's a rule and we do try and enforce it. It's hard when -- are you talking about RIPTA buses or school busses or both?

>>>BARBARA TORRES: To be honest, it's both because when I was younger, I had an asthma attack because of it and I was in a hospital for two weeks.

>>>BILL INLOW: A regular --

>>>BARBARA TORRES: Yes, a RIPTA bus and now it's the school busses and it's hard to have a child that has severe asthma. I'd rather walk him toe school if I have to.

## Transportation

>>>BILL INLOW: I wish I could tell you that there was an easy answer for that, obviously. Again, we have the rule if you catch people smoking on the bus, they get disciplined. What we would really like to do is teach the drivers that they're -- they can hurt other people in addition to their own health by smoking on the bus and we would hopefully have people working for us who care about your child and other people with respiratory issues and people in general. And you wouldn't smoke on the bus because it's the wrong thing to do. Unfortunately, people who smoke cigarettes, many of them are addicted to smoking and it is very difficult to get them to stop. Ideally, if they would at least step off the damn bus and smoke and smoke the cigarette off the bus because we try to recognize that our drivers who do smoke are addicted to nicotine and so we try to schedule a time that they can step off the bus and at least smoke out in the air and not on the bus. Some of the drivers -- we have 400 drivers at RIPTA and most are good and decent people and some are absolute jerks and they just smoke on the bus because they want to. They smoke on the bus and I regret it but what you can do, I can give you a number to call, 781-9400, and ask for customer service and I would urge you or anybody else to report any driver they see smoking on a regular RIPTA bus or school bus any time and we will try our best to work where that driver to try to prevent that from happening. Thanks for speaking up.

>>>KATE BOWDEN: Do you have jurisdiction over school busses?

>>>BILL INLOW: No I'm just talking about RIPTA, you -- I would call the school, I guess, and complain about any school bus driver you see smoking on the bus any time whether or not there are kids on there because you're right, the smoke hangs in the air and can trigger an asthma attack which can be very serious, right, not just an inconvenience, not just a child with a serious asthma problem doesn't like the smell of the smoke, it's a dangerous situation for that person.

>>>BARBARA TORRES: I'm pretty sure, well not pretty sure but some school bus drivers own their own buses and if you own your own bus and then work for the school, I don't know whether it's the school's -- do the schools have their own buses.

>>>BILL INLOW: A lot of schools subcontract.

>>>BARBARA TORRES: Especially the short buses, Special Education buses.

>>>PATRICIA RYHERD: It may be that you need to talk about to your Special Ed. indication director in the School Department because really you're asking for a special need because of the disability. And leave it up to the Special Ed director. Again, I don't know, I'm suggesting you should explore that. I'm not saying for sure.

>>>SUSAN SHEPHERDSON: My name is Susan Shepherdson. I wanted to ask if that phone number, that phone call would be confidential, to customer service if someone made the phone call in you do not have to give your name if you give a complaint to at RIPTA. We would hope you might and give us your phone number too so that we can follow up, tell you whether we did something or not but you do not have to identify yourself same I think one thing about parent Social Security they know when their children leave the house they're vulnerable to the world and we always hope as marry said that people care for our children and there wouldn't be retribution but I think it's scary for parents to see their kids going out anyway, so that they wouldn't be in the position of their child receiving less than kind care. What made me think it was, I live across the street from an elementary school and I'm in the city so there's police out there making sure the police are safe and my city has a strict rule against smoking and the police officer who sits out there, he smokes cigarette after cigarette and throws the butts on the ground and one day I thought, I should say something to him and then I thought, what am I nuts, let him smoke, that's what made me think of it has anything to do with anything, just a side bar. I know we do feel our children are very vulnerable when they leave our care.

>>>JAMES DEBOER: You said smoking is not allowed by any driver or passenger on -- is that only RIPTA.

>>>BILL INLOW: There is a rule at RIPTA.

>>>JAMES DEBOER: On a school bus in I don't know about school busses, at RIPTA, no one is supposed to smoke on the bus any time, any where, customer or driver, it's a rule frequently broken by drivers especially when there are no passengers on the bus to report on them. But we're working hard to try to discipline the drivers that need to be disciplined and inspire the drivers by telling them things, when you smoke on a bus and the smoke hangs around can be harmful to somebody with asthma or another disability. But in terms of school busses, I don't know that there's a rule but I would imagine that most school systems would certainly not allow drivers to smoke

while passengers are on the school bus and I would imagine also that they probably shouldn't, I would assume they have rule that is they are not supposed to smoke on a bus even when there aren't any gold there are also bus monitors, too so potentially two people smoke willing.

>>>KATE MCCARTHY-BARNETT: I know they're looking into putting cameras on the RIDE buses, is something similar being thought about with the other busses.

>>>BILL INLOW: Recent state law and we've been working on it for a while even before the law mandated it but a recent state law that probably came out of one of these hearing a couple years ago, incidentally, that talked about vulnerable people being on the RIDE vans and sometimes being alone with one driver and that's a very vulnerable situation. In fact we have had I think so dens where there have been arrests and prosecutions for a sexual exploitation as well as other inappropriate, illegal behavior by a driver on the body much a person with a disability. So, we are installing in the next couple years videotape cameras, five, on each RIDE van that will at least tape, it's not live into some center with cameras but it will at least tape the activities in and around each RIDE van and then those, all, the videotape cameras will be installed in the next couple years on all RIDE vans and we're going to try to get the money to put cameras on all big regular RIPTA buses, as well. To document when something really happens that's wrong so we can prosecute people but more importantly to inhibit that kind of inappropriate behavior in the first place.

## Legislation

>>>MARY WAMBACH: First I want to say that sounds wonderful. Second I want to ask if you can make sure that the department doesn't have that on others because often they record and rerecord and nobody looks at them everyday and when you try to look at what happened last week, Wednesday, it's already been rerecorded and you can't go back.

## Transportation

>>>BILL INLOW: The equipment we're installing on the RIDE vans, when a RIDE van comes in at the end of a day, it down loads automatically, wirelessly into a data bank. We keep it -- you can setup the system to keep it 30 days, 45/60, so many days. Again, no one is going to look at it unless there's an incident reported and then we'll go back and look at it to document it I'm not saying somebody is going to sit there and monitor the safety of every passenger on a RIDE van all the time but it will rerecord, it doesn't rerecord because it dumps the information out every time when a RIDE van comes out at the end of the day into a big central storage area. Everyday, it stores into a massive storage system, wirelessly in RIDE central.

>>>PATRICIA RYHERD: In response to the issue of confidentiality, and, I think the best thing to do is try and prevent the problem from happening rather than after it happens as far as the asthma situation and the school bus. So again, you can contact, for example, Special Ed. indication department in August if your child is going to start using a bus in September. So it's always better if you can prevent it so that they know that on this specific bus, there is a child with asthma. Doesn't always eliminate it but it's more likely to prevent it.

>>>KATE MCCARTHY-BARNETT: Thank you Pat.

>>>MARY WAMBACH: I don't know about Rhode Island, in terms of retaliation to anyone. I don't know if Rhode Island has -- it's a funny thing about English because it sounds like it means better but it means worse, in some states they have they have something called enhanced sentencing for any crimes involving children, people with disabilities or seniors and that might be a -- to retaliation because it can be kept up to a higher class with worst punishment and that can be added and it is in some states, for crimes of retaliation related to initial crimes involving a child or person with disability or senior citizen.

>>>KATE MCCARTHY-BARNETT: Thank you, Mary. At this point are there any other comments or question from those of you who are joining us today? Any initial feedback from our panel members? Okay then I would just like to thank those of you who are joined us today, thank you for area testimony and thoughts and questions you have shared. Please know that the Governor's Commission on Disabilities and those sponsoring agencies and organizations will be reviewing your testimony and looking at it for potential legislative or policy changes. And if you're interested in following that process, we welcome your feedback and you can check out the Governor's Commission on Disabilities web site as well as the number path had given earlier the 462-0100 to keep in touch of when the legislative committee meetings are meeting and

we just want to thank you for coming today and also thank the panel members for sharing your time and expertise for those of us here this afternoon. So, thank you.

## Written & Emailed Testimony

7/28/07

To Whom It May Concern:

I just wanted to thank you for sponsoring the Public Forums which were held last week. I attended the one on 7/23 at Independence Square. I found it to be very informative and helpful. The panel members were encouraging and I left with a positive feeling.

My son was diagnosed with Bi Polar Disorder in 2001 and I am still trying to get help for him. While some of my searches for help have been frustrating, a few have put us on the right track.

NAVIGATING THE SYSTEM IS NOT EASY, but your forum at least gave me hope AND made my endeavor more personal. Now I will picture a face behind each address/ agency I work with.

<p><b>Public Notification</b></p>
---------------------------------------

My one complaint is that the event was not well publicized. I just happened to see it in the local paper. Had I not read the paper that day I would have missed out on a great opportunity. I'm not sure what the solution is to informing everyone of any further forums- but I'm sure many others would have benefited from attending.

Thank you again,

Laurie K. Boyett

34 Whitford Street  
Wakefield, RI 02879