



Report on the Concerns of People with Disabilities and their Families:



Identified during Five Public Forums July 21 – 25, 2003

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

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Copies of this information are also available in Braille, large print, audiocassette and electronic file on computer disk. This document is also available on the Commission's website <http://www.disabilities.ri.gov> in Adobe pdf format.

Contact the Governor's Commission on Disabilities to arrange for a copy.

This report is dedicated to the memory of

Justin Dart

Former Chairperson of the President's Committee on the
Employment of People with Disabilities,

United State's Rehabilitation Services Commissioner,

Founder of Justice of All,

and the

"Father" of the Americans with Disabilities Act

Who taught us the power of listening to

People With Disabilities And Their Families

Before making Policy

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Chapter A Introduction

I. **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.

II. **Procedure following the public forums**

During August, 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: coordination and information; education and employment; family and financial supports; health care; housing and transportation.

III. **The top three concerns expressed at the forums**

Concern 1. **Access to Comprehensive Health Care for people with disabilities:**

Recommendations:

- (1) Establishment of a [Medicaid Buy-In](#) Program for Persons who are eligible for both Medicare and Medicaid and return to work;
- (2) Lowering the age for the [Pharmaceutical Assistance](#) discount (without state co-payment) for people on SSDI who are younger than 55;
- (3) Expand [Home Care Services](#), so people can remain living in their community;
- (4) Adjust state's [income eligibility level for Medicaid](#) for persons with disabilities to match the Family Independence Program level and then adjust annually by the cost of living;
- (5) Increase the number of [Personal Care Attendants slots to 150](#) and add rehabilitation services;
- (6) Adjust the state procedures for coverage of mental health care to remove gap:
 - (a.) [Expand the Medicaid formulary](#) to include the American Hospital Formulary Service pharmacologic-therapeutic classifications categories that have not been determined by the federal "Drug Efficacy and Safety Implementation (DESI) Commission" to lack substantial evidence of effectiveness;
 - (b.) Establish "real" [mental health parity](#) with "medical health"; and
 - (c.) Reduce the [waiting list](#) at Community Mental Health Centers
- (7) Provide state funded health insurance coverage during the 2-year wait from SSDI recipients to be covered by Medicare.

Concern 2. **Expand Employment Opportunities for adults with disabilities:**

Recommendations:

Better preparation for employment ([transition from school to career](#), [vocational training](#));

Elimination of the disincentives to employment:

- (a.) The loss of [health care benefits](#) (see # 1, 4, & 5 above) and social services if working); and
- (b.) Creation of Work-Related Infrastructure: [transportation](#), [personal care services](#), job coaches, and other support services available for people with disabilities who are working (see # 1, 4, & 5 above);

Concern 3. **Affordable and Accessible Housing for families that include individuals with disabilities:**

Recommendations:

- (8) Funding for [modifications to homes/apartments](#) owned or rented by families with disabled members;
- (9) Fund the [Neighborhood Opportunities Program](#) to expand the public and private market of affordable/adaptable housing; and
- (10) Establish of Congregate housing program for people with [traumatic brain injury](#), probably via the TBI Trust Fund legislation.

The Public Forums Advertisement and List of Sponsors



Public Hearings State of Rhode Island



To identify the concerns of people with disabilities and their families

Monday 7/21/03 6 - 8 PM

Cumberland Library, 4097 Diamond Hill Road

Tuesday 7/22/03 6 - 8 PM

Independence Square, Independence Square II Independence Way, Kingston
(on Route 138, just west of the URI Campus)

Wednesday 7/23/03 5:30 - 7:30 PM

Newport Public Library, Lower Level Program Room, 300 Spring Str.

Thursday July 24, 2003 3:00 – 5:00

Warwick Public Library, 600 Sandy Lane, Warwick

Friday 7/25/03 5 - 7 PM

Department of Administration, Conference Room B (2nd Floor)
One Capitol Hill, Providence

Comments may be made in person during the hearing, or you can mail, fax or e-mail them by July 30th to:

Governor's Commission on Disabilities

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

462-0106 (fax) or disabilities@gcd.state.ri.us (e-mail).

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.

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

The RI Commission on the Deaf and Hard of Hearing will provide sign language interpreters. Sign language interpreters have not been confirmed at Newport; call tty 222-1204 to confirm interpreter.

When making the ADA reservation with Ride to get to and from the public hearing, tell the Ride reservationist that this is for the Governor's Commission's Public Forums in order to guarantee your return trip. The ADA fare is still applicable.

For more information or to request accommodation needed, please call: 462-0100 or 462-0101(tty) at least 3 business days in advance; arrangements will be provided at no cost.

A sign language interpreter will be at the Warwick Forum. Other requests for language interpreting should be made to 462-2130 at least 3 business days in advance.

Donald L. Carcieri, Governor

These hearings are co-sponsored by the commissions, departments, and organizations listed below that provide services and/or advocate on behalf of people with disabilities:

Office for Better Long Term Care, Roberta Hawkins, Executive Director; **Brain Injury Association of RI, Inc. & Brain Injury Resource Center**, Sharon Brinkworth, Executive Director; **CranstonArc**, Thomas Kane, Executive Director; **Commission on Assistive Technology**, Marie Younkin-Waldman, Chairperson; **Assistive Technology Access Partnership (ATAP)**, Regina Connor, Project Director; **Department of Health**, Dr. Patricia Nolan, Director; **Department of Human Resources**, Jane A. Hayward, Director; **Department of Transportation**, James R. Capaldi, P.E., Director; **Governor's Commission on Disabilities**, Doreen McConaghy, Chairperson; **J. Arthur Trudeau Center**, Mary Madden, President/CEO; **Long Term Care Coordinating Council**, Lt. Governor Charles J. Fogarty, Chairperson; **Mental Health Consumer Advocates of RI**, Neil Sharpe, Executive Director; **Newport County Community Mental Health Center**, J. Clementine, MS, President/CEO; **Ocean State Association of Residential Resources**, Donna Martin, Associate Director; **State Center for Independent Living**, Lorna Ricci, Executive Director; **PAL**, Doreen McConaghy, Executive Director; **PARI Independent Living Center**, Leo Canuel, Executive Director **RI Breast Cancer Coalition**, Marlene C. Arthy, H.L.D., Chair; **RI Commission on the Deaf and Hard of Hearing**, Steven A. Florio, Executive Director; **RI Disability Law Center**, Raymond Bandusky, Executive Director; **RI Office of the Child Advocate**, Lauren D'Ambra, Child Advocate; **RI Public Transit Authority**, Alfred J. Moscola, General Manager; **State Rehabilitation Council**, Annette Bonniere, Chairperson **Statewide Independent Living Council**, Steven J. Carr, Chairperson

Chapter B Community Concerns and Recommendations

Below are the community concerns, as raised by people with disabilities, their families, and others at the 5 public forums, and recommendations developed by the forum sponsors in response to those concerns. After each “concern” are citations of the page(2):line(s) in the transcripts related to this concern.

Even if each of these “concerns” does not match reality, the misperception indicates a need for better outreach / awareness of services and coordination among providers to ensure families in crisis are able to quickly and effectively access the appropriate services.

I. *Coordinating and Information*

Concern 1. Conflicting information provided by state and federal authorities about the “PARI waivers”.

Testimony starts at page:line 2:40 [PARI Waiver](#)

Concern 2. Not clear where families find information and resources concerning disabilities.

Testimony starts at page:line 8:23 [Information 1](#), 47:37 [Information 2](#), 49:23 [Information 3](#)

Recommendations: Assist in the development of the Aging and Disability Resource Center.

User-friendly information should be posted on Web sites with links to other agencies.

Feedback from the communities they serve should guide these efforts.

Concern 3. Need access to newspapers—e.g., via NewsLine—so people who cannot read print or hold newspapers can get information that helps them find jobs, do their jobs, and be informed citizens.

Testimony starts at page:line 42:33 [NewsLine 1](#), 43:33 [NewsLine 2](#)

Recommendations: Determine whether Internet newspaper sites provide similar or greater access. Seek input from National Federation of the Blind to clarify exact costs of bringing NEWSLINE to RI.

Identify a funding mechanism; advocate for bringing the service to RI and getting The Providence Journal to participate.

Concern 4. No closed captioning of government TV.

Testimony starts at page:line 47:2 [Captioning TV](#), 51:1

Recommendation: Establish a caption center for state government video productions.

Concern 5. Agency that provides interpreters does not understand American Sign Language or deaf culture.

Testimony starts at page:line 58:19 [Deaf Culture](#)

Recommendation: CDHH should do more training and advocacy with hospitals to address problems with securing qualified interpreters.

Concern 6. Need to provide education to correct misconceptions about mental illness and to help affected families understand mental illness.

Testimony starts at page:line 64:6 [Mental Health 3](#), 67:1

Recommendation: The National Alliance for the Mentally Ill, the Mental Health Association Resource Center, and Butler Hospital should continue their efforts in this regard.

Concern 7. Discontinuity of care when people leave the ACI, need for post-incarceration transition services—e.g., housing, health care, etc., to prevent recidivism, hospitalizations, and other problems.

Delay before those with mental illness (and other disabilities) are picked up by public mental health (or other service) system means they go without medications, reversing progress made in prison, and costing state money when bad consequences ensue.

Testimony starts at page:line 63:6 [Mental Health 1](#), 64:17 [Mental Health 2](#), 73:5 [Mental Health 4](#)

Recommendation: Incarcerated persons with disabilities should be provided transition services, through the Aging and Disability Resource Center, prior to release.

Concern 8. Agencies unresponsive and dismissive toward clients, fail to provide requested information.

Testimony starts at page:line 84:36 [Client Assistance](#)

Recommendation: Increase awareness of the Client Assistance Program.

Concern 9. Not clear where to direct complaints about violations of disability parking laws, lack of curb cuts.

Testimony starts at page:line 49:31 [Parking Violations](#), 50:24 [Curb Cuts 1](#)

Recommendations: Governor's Commission on Disabilities should conduct a publicity campaign to inform the public concerning where and how to complaints.

Governor's Commission on Disabilities should post this information on its Web site as well.

Concern 10. Need for easy to open doors in public buildings, such as banks.

Testimony starts at page:line 84:11 [Open Doors](#)

Recommendation: Governor's Commission on Disabilities should increase awareness of ADA obligations.

Also see: [Education & Employment: netWORKri](#), [Education & Employment: Blind Vendors](#), [Employment and Training: Office of Rehabilitation Services](#), [Family & Financial Supports: Early Intervention](#), [Family & Financial Supports: CEDARR](#), [Health Care: Sign Language Interpreters](#), [Transportation: RIPTA and Web-based Travel Planner](#), [Transportation: RIPTA and Travel Training](#)

II. *Education and Employment*

Concern 1. Need a curriculum or training materials for parents to teach offspring with developmental or other disabilities how to stay safe in the community.

Testimony starts at page:line 38:27 [Safety Training 1](#), 52:13 [Safety Training 2](#)

Recommendation: Refer to the Interagency Transition Council with a recommendation that “independent living” and “activities of daily living” skill training be provided through high school special education programs, for students prior to them exiting the school system.

Concern 2. It is very difficult to find jobs, in rural communities. Exhausting and time-consuming to find job opportunities for people with disabilities; need a list of disability-friendly workplaces.

{ While the issue was raised at the forum in Kingston and only concerning individuals who is hard of hearing

and individuals who is developmentally delayed, this is an issue in all areas that do not have transportation and community supports.}

Testimony starts at page:line 16:13 [Rural Employment 1](#), 17:29 [Rural Employment 2](#)

Recommendations: netWORKri should explore ways to promote awareness of its services among people with disabilities.

The Ticket to Work program should be publicized when it arrives.

Expanded flexible statewide work related transportation system and increase coordination of state agencies (i.e. Office of Rehabilitation Services (ORS), Network RI etc.).

Concern 3. RI Department of Labor & Training is not involved enough in federal work initiatives for people with disabilities.

Testimony starts at page:line 16:28 [netWORKri 1](#), 34:25 [netWORKri 2](#)

Concern 4. There is not an effective outreach to link up people with mental illness to employment services.

Testimony starts at page:line 39:5, 73:42 [netWORKri 3](#)

Recommendation: Consolidate job preparation programs (such as the Office of Rehabilitation Services) in the Department of Labor and Training to provide a more integrated serve and expand outreach activities.

Concern 5. Individuals on Medicaid who want to work are severely limited in how often they work or how much they earn, for fear of losing services.

The income cut off is only \$169 / month above their Supplemental Security Income (SSI) benefit. Any earnings above that are taken by the state for health care services. The RI standard is one of the lowest in the US for the total cap being \$769 and it becomes counterproductive as people stop working losing dollars to live on for the benefits received.

Testimony starts at page:line 4:1 [Medicaid Buy-In 1](#), 30:32 [SSI Limits Work](#)

Recommendations: Adjust the income eligibility criteria for Supplemental Security Income (SSI) & Medicaid to encourage work, not discourages work.

Enact Medicaid Buy-In.

Concern 6. Blind Vendors program is mismanaged.

Testimony starts at page:line 67:21 [Blind Vendors 1](#)

Concern 7. Information and advice needed to help business owners in blind vendors program grow their businesses.

Testimony starts at page:line 70:21 [Blind Vendors 2](#)

Concern 8. There is a lack of awareness amongst the public about the businesses in the Blind Vendors program.

Testimony starts at page:line 69:24 [Blind Vendors 3](#)

Recommendation: Program should explore linkages with agencies such as the Small Business Administration, Senior Core of Retired Executives, and Bryant College to obtain low-cost or free guidance for vendors on how to run and market a business.

Concern 9. There is a lack of communication from the Office of Rehabilitation Services (ORS) to clients.

Testimony starts at page:line 84:31 [Office of Rehabilitation Services](#)

Recommendation: Refer these issues to the Advisory Council on the Blind and Visually Impaired and the State Rehabilitation Council.

III. *Family & Financial Supports*

Concern 1. The level of Social Security Disability Income (SSDI) payments for individuals just over the limit for SSI isn't enough to pay rent, utilities, food and out-of-pocket medical expenses.

Testimony starts at page:line 2:24 , 63:18 [SSI Limit 2](#)

Recommendation: Adjust state's income eligibility level for Supplemental Security Income (SSI) for persons with disabilities to match the Family Independence Program level and then annually by the cost of living.

Concern 2. Too much government red tape in applying for early intervention services.

Testimony starts at page:line 44:10 [Early Intervention](#)

Recommendation: The Early Intervention program should appoint an Ombudsman.

Concern 3. Appeal process for CEDARR, very parent unfriendly; little information provided for CEDARR appeals, making it difficult for parents to get due process.

Testimony starts at page:line 33:3 [CEDARR 1](#), 33:16 [CEDARR 2](#)

Recommendations: Agencies should provide clear information concerning their decision-making and appeals procedures during initial eligibility intake.

On enrollment, client should receive an explanation of grievance procedure; denials must specify reason.

The Rhode Island Disability Law Center should look into this if not already doing so.

Concern 4. There is a lack of consistent information and coordination between MHRH and DHS concerning respite services. No explanation as to why respite services are reduced.

Testimony starts at page:line 32:9 [Respite Care 4](#)

Recommendations: Create one stop / no wrong door entries into the human service system, through the Aging and Disability Resource Center.

MHRH should appoint an Ombudsman.

Concern 5. There is not any respite care, for caregivers of younger adults with disabilities (between 22 and 55).

Testimony starts at page:line 8:29 [Respite Care 1](#), 36:7 [Respite Care 2](#)

Concern 6. Need for assistance to families with aging caregivers, and for transitioning younger family members with disabilities.

Testimony starts at page:line 86:19 [Respite Care 3](#)

Recommendation: Create a respite service for caregivers of adults with disabilities (between 22 and 65).

Concern 7. Misconceptions of DCYF about parents who are deaf lead to children being taken away from parents.

Testimony starts at page:line 60:17 [Parents who are Deaf](#)

Concern 8. The Department for Children, Youth, and Families (DCYF) takes children away from parents with disabilities.

There is a need for support system.

Testimony starts at page:line 63:22 [Parents who are Disabled](#), 86:26

Recommendations: The Commission on the Deaf and Hard of Hearing (CDHH) should provide training to

DCYF to teach about deaf culture and correct misconceptions.

Create family support services within DCYF that is knowledgeable of the needs and abilities of people with disabilities that can link families to community support networks.

Concern 9. Need peer support programs for people with mental illness and other disabilities, throughout the state.

Testimony starts at page:line 64:1 [Peer Groups](#)

Recommendation: Expand peer support programs statewide and improve information dissemination about peer support groups.

Concern 10. Trusts established by individuals with disabilities for their own long term / chronic medical care taxed.

Testimony starts at page:line 38:2 [Trusts](#)

Recommendation: Exempt trusts set up by persons with disabilities to cover future long term / chronic care expenses from taxation.

IV. Health Care

Concern 1. Many people with disabilities who are under 55 and on Medicaid do not have prescription coverage.

Testimony starts at page:line 5:2 [Prescriptions 1](#)

Recommendations: Provide RI Pharmaceutical Assistance for the Elderly (RIPAE) coverage for persons with disabilities who are on Social Security Disability Income (SSDI)/ Medicare (only not Medicaid) who meet the RIPAE income level, regardless of age.

Concern 2. The Medicaid “spend down”, for people who are just over the limit for Supplemental Security Income (SSI) creates an enormous financial burden, when there isn’t any assistance with medical costs until after the person spends \$8,000.

Testimony starts at page:line 3:10 [Medicaid 1](#)

Recommendations: Adjust state’s income eligibility level for Medicaid for persons with disabilities to match the Family Independence Program level and then annually by the cost of living.

Concern 3. Low pay for Personal Care Attendants (\$8.50) isn’t enough for a “qualified” Personal Care Attendant (PCA).

Testimony starts at page:line 6:9 [Personal Care Attendants 1](#), 20:17, 81:13

Concern 4. Personal Care Attendants don’t have health insurance, temporary disability insurance and are not covered by workers’ compensation as independent contractors; the consumer might be responsible for purchasing workers’ compensation insurance.

Testimony starts at page:line 6:26 [Personal Care Attendants 2](#), 7:9 [Personal Care Attendants 3](#), 15:7 [Personal Care Attendants 4](#),

Concern 5. Not enough Personal Care Attendants, only 80 slots for the state, families have to wait until one of the current “slot holders” dies or moves out of state.

Testimony starts at page:line 8:9 [Personal Care Attendants 5](#), 14:15 [Personal Care Attendants 6](#), 45:9 [Personal Care Attendants 7](#), 66:29 [Personal Care Attendants 8](#), 80:23 [Personal Care Attendants 9](#)

Recommendations: Provide incentives for Personal Care Attendants, such as health insurance coverage.

Establish a Personal Care Attendant Service to employ PCA, and manage withholding tax, health, workers' compensation and temporary disability insurance, etc.

Increase the number of Personal Care Attendants slots to 150 and add rehabilitation services.

Concern 6. No transportation to medical specialist out of state (Boston).

Testimony starts at page:line 15:33 [Out of State Health Care](#), 21:3

Recommendation: Under unique circumstances when specialized care is not available within the state – the health insurance carrier should provide coverage for transportation.

Concern 7. 2 year wait for Medicare once qualified for SSDI.

Testimony starts at page:line 39:9 [Medicaid 2](#)

Recommendations: State should provide health insurance coverage during the 2-year wait from Medicare Coverage.

Concern 8. Most employer-based health insurance does not include hearing aid coverage, but does cover other adaptive equipment.

Testimony starts at page:line 45:30 [Hearing Aids](#), 58:22

Recommendation: Create parity for health insurance aids (wheelchairs, walkers, hearing aids, eyeglasses, etc.)

Concern 9. Hospitals fail to provide qualified sign language interpreters for deaf parents of hearing child-patients.

Testimony starts at page:line 55:21 [Interpreters 1](#), 59:1, 60:1, 61:9

Recommendation: Commission on the Deaf and Hard of Hearing (CDHH) should provide education and training of health-care providers regarding their legal responsibilities for informed consent.

Increase the pool for interpreters by establishing an interpreter-training program in RI.

Concern 10. Medicaid restricts the use of newer psychotropic medications.

Testimony starts at page:line 63:31 [Prescriptions 2](#)

Recommendation: Expand the Medicaid formulary to include the American Hospital Formulary Service pharmacologic-therapeutic classifications categories that have not been determined by the federal "Drug Efficacy and Safety Implementation (DESI) Commission" to lack substantial evidence of effectiveness.

Concern 11. Low pay for mental health workers causes high turnover.

Testimony starts at page:line 64:12 [Mental Health 5](#), 74:12 [Mental Health 6](#)

Recommendation: Conduct a review of competency requirements and certification for mental health workers, which could lead to increases in salary.

Concern 12. There is not parity between physical health care and mental health care.

Concern 13. Large backlog – long waits for mental health service at the community centers.

This is a critical issue that is relevant to access to care for all Rhode Islanders.

Testimony starts at page:line 73:25 [Mental Health 7](#)

Recommendation: Adjust the state procedures for coverage of mental health care to remove gaps.

Concern 14. Medicaid has restrictions on accessories to walkers and lack of knowledge concerning newer assistive technology that can provide greater independence.

Testimony starts at page:line 84:21 [Medicaid 3](#), 55:4 [Auxiliary Aids](#)

Recommendations: Compare coverage with other states to make recommendation for accessory coverage. Aging and Disability Resource Center should link up service provider system with TechACCESS.

Concern 15. Medicaid supplemental policies place limits on hospital aftercare services for individuals with chronic impairments.

Testimony starts at page:line 87:41 [Medicare 4](#)

Recommendation: Expand Medicaid supplemental policies to ensure proper aftercare services, rather than placing individuals in lower level of care until their condition worsens to the point that Medicare will cover greater level of care.

Concern 16. People with mental illness are often incarcerated instead of receiving appropriate treatment.

Testimony starts at page:line 63:6 [Mental Health 7](#), 64:17 [Mental Health 8](#), 73:5 [Mental Health 9](#)

Recommendations: Refer this issue to the Special Legislative Commission To Study Services To Persons With Mental Illness In The Criminal Justice System and monitor their progress.

Seek model state law on mental health diversion programs.

Also see: [Coordinating and Information: PARI Waivers](#), [Coordinating and Information: Information & Resources](#), [Coordination and Information: Deaf Culture](#), [Coordination & Information: Mental Health Misconceptions](#), [Education & Employment: Medicaid Disincentives](#), [Family & Financial Supports: SSDI/SSI](#), [Family & Financial Supports: Early Intervention](#), [Family & Financial Supports: CEDARR](#), [Family & Financial Supports: Respite Care](#), [Family & Financial Support: Peer Support Groups](#), [Family & Financial Supports: Trusts](#), [Housing: Traumatic Brain Injury](#), [Transportation: Ride Scheduling](#)

V. **Housing**

Concern 1. There is a lack of accessible and affordable housing statewide.

Testimony starts at page:line 20:14 [Housing 1](#), 36:1 [Housing 2](#), 39:13 [Housing 3](#), 84:5 [Housing 4](#), 86:13 [Housing 5](#), 90:15 [Housing 6](#)

Recommendation: Increase Funding for Housing, Incentives to construct housing.

Concern 2. There isn't any congregate housing for traumatic brain injury (TBI) survivors.

Testimony starts at page:line 21:37 [Traumatic Brain Injury 1](#), 53:12 [Traumatic Brain Injury 2](#)

Recommendation: Establish of Congregate housing program for people with traumatic brain injury, probably via the TBI Trust Fund legislation.

Concern 3. There is long waiting list, for modifications/additions, due to a lack of funding.

Testimony starts at page:line 15:20 [Home Modification 1](#), 20:7 [Home Modification 2](#)

Recommendation: Increase funding for home modifications.

Concern 4. There is not a central location for information on housing and methods to adapt housing for accessibility.

Testimony starts at page:line 48:1 [Home Modification 3](#), 49:17 [Home Modification 4](#)

Recommendation: Increase awareness of Independent Living Centers (ILCs) and One Stop info centers.

Concern 5. People with Mental Illness who have been in prison are not eligible for public housing.

Testimony starts at page:line 73:35 [Mental Health 10](#)

Recommendation: The Departments of Corrections and Mental Health, Retardation and Hospitals and the Housing Resource Commission should jointly develop a solution to housing of ex-felons.

Concern 6. Poor maintenance of existing Federally subsidized housing.

Testimony starts at page:line 78:7 [Housing 7](#)

Recommendation: Establish/streamline complaint methods for HUD funded housing.

VI. *Transportation*

Concern 1. The Americans with Disabilities Act (ADA) Paratransit trip fare (\$2.50) too high.

Testimony starts at page:line 6:20, [RIde 1](#)

Recommendation: Investigate funding to increase subsidy available to RI Public Transit Authority (RIPTA).

Concern 2. Need to schedule RIde trips too far in advance.

Testimony starts at page:line 5:3 [RIde 2](#)

Concern 3. RIde is unable to provide on-demand service, same day registration & trip.

Testimony starts at page:line14:5 [RIde 3](#)

Recommendation: Expand the fleet of vans and increase funding to meet the demand.

Concern 4. There is a lack of RIde transportation on weekends throughout the suburban/rural parts of the state.

Testimony starts at page:line 14:9 [RIde 4](#)

Recommendation: Increase system capacity to address need.

Expand fixed route system to meet demand on weekends.

Concern 5. Poor quality of RIde vans; shake up passengers.

Testimony starts at page:line 76:32 [RIde 5](#)

Recommendation: Review standards of vans and van maintenance.

Concern 6. RIde's ADA eligibility requirements exclude many individuals who are unable to use RIPTA's fixed route buses.

Testimony starts at page:line 30:12 [RIde 6](#), 87:4 [RIde 7](#)

Recommendation: Expand RIde service statewide for general service.

Concern 7. Need information to help people with developmental and other cognitive impairments use RIPTA; including address-to-address directions on Web site and travel training or curriculum so parents can teach their children.

It is cost-effective to empower people to use fixed-route buses rather than RIde service.

Testimony starts at page:line 27:11 [RIPTA 1](#), 29:17 [RIPTA 2](#), 29:31 [RIPTA 3](#)

Recommendations: RIPTA should meet with representatives from the disability community to get feedback on its Web site and explore ways to empower more people with disabilities to use fixed-route buses rather than

Ride service.

RIPTA should develop a system to allow route planning to happen through RIPTA website.

Concern 8. Need for more bus shelters and better signage at bus stops.

Testimony starts at page:line 28:1 [RIPTA 4](#), 40:22

Recommendation: Refer to RIPTA's Accessible Transportation Advisory Committee.

Concern 9. Need for more travel training so consumers can better utilize existing transportation network.

Testimony starts at page:line 29:3 [RIPTA 5](#), 35:34 [RIPTA 6](#)

Recommendation: Develop funding to expand existing capacity for travel training.

Concern 10. Fixed route bus drivers are too interested in staying on schedule, so they are not willing to use wheelchair lifts and/or tie-downs.

Testimony starts at page:line 75:25 [RIPTA 7](#), 80:11 [RIPTA 8](#)

Recommendation: RIPTA policy and/or training for bus drivers.

Concern 11. There is a lack of evening/weekend bus service.

Testimony starts at page:line 81:15 [RIPTA 9](#), 78:26 [RIPTA 10](#)

Recommendation: RIPTA needs additional government funding to restore evening weekend service to suburban areas.

Concern 12. During winter, many bus stops outside of Kennedy plaza impassable due to snow.

Testimony starts at page:line 76:8 [Snow Removal 1](#)

Concern 13. There is a lack of snow removal on sidewalks, bus stops and curb cuts.

Testimony starts at page:line 79:11 [Snow Removal 2](#)

Recommendations: Inform municipalities of their ADA obligations.

Enforce existing snow removal ordinances or have municipalities clean the sidewalks and curb cuts.

Concern 14. There are very few cross walks that have audible traffic signals.

Testimony starts at page:line 39:22 [Audible Traffic Signals](#)

Recommendation: Install audible traffic signals as required by TEA 21, where ambient traffic noise doesn't provide enough clues for pedestrians with vision impairments.

Concern 15. There are not enough van accessible parking spaces; no information on what is required.

Testimony starts at page:line 49:31 [Van Parking](#)

Recommendation: Conduct awareness program for stores and parking lot managers.

Concern 16. There is a lack of curb cuts at pedestrian crosswalks.

Testimony starts at page:line 50:24 [Curb Cuts 2](#), 51:7 [Curb Cuts 3](#), 82:10 [Curb Cuts 4](#)

Recommendation: Inform municipalities of their ADA obligation and work with the Department of Transportation (RIDOT) to speed up installation of curb cuts on state roads.

Also See: [Coordinating & Information: Disability Parking](#), [Health Care: Transportation to Out of State Providers](#)

Chapter C The Testimony

I. Public Forum, Monday, July 21, 2003, Cumberland Public Library

Leo Canuel: Good afternoon, my name is Leo Canuel from PARI. We don't have a lot of people here, but it says on my paper we have to start on time so I guess I have to do that. Uhm, what I would like to do is start by having the panel introduce themselves, and then because there are so few of you, maybe we can go back to you and introduce yourselves.

Victoria Wilcox: I am Victoria Wilcox; I am on the Governor's Commission on Disabilities and serve on the Legislation Committee.

Mr. Engstrand: My name is Jim Engstrand, and I am a staff attorney for the Disability Law Center, which is publicly funded by legal assistance and other kind of advocacy groups.

Michael Spoerri: My name is Michael Spoerri with the disability and health program with the Department of Health, and I have been here for a week, and I am here to hear from you guys what's going on with the disability community in Rhode Island and how I, and the disability program, can serve you guys.

Sharon Brinkworth: My name is Sharon Brinkworth. I am the executive director of the Brain Injury Center of Rhode Island and serve on the Governor's Commission for Grievances.

Liz Graves: I am Liz Graves and I am on the Independent Living Council and I am on the state Rehab and Governor's committee, so I actually represent more than one council.

Mr. Therrien: I am mark Therrien, and I work for the transit authority. Anything you have concerning issues on RIPTA and transportation services.

Leo Canuel: So because we are so few, let's go around the room and tell us your names and which city or town you're from.

John: John and I'm from Cumberland.

Karen: Karen, from Pawtucket, Rhode Island.

Beth Cooper: Beth Cooper from Cumberland.

Male speaker: Ron McMinn, Vice Chair of accessibility and parking, and I am also a commissioner on the Governor's Commission.

Leo Canuel: Mr. Pitassi just came in.

Mr. Pitassi: yes.

Leo Canuel: What hat are you wearing tonight?

Mr. Pitassi: I am just going to listen.

Leo Canuel: We're just introducing ourselves.

Jim Pitassi: I am Jim Pitassi on the Governor's Commission for Disabilities.

Vicky: I am Vicky, and we're doing research in the Rhode Island area.

Leo Canuel: Thank you. And we have our CART reporter. Just a couple of housekeeping notes at this point. We need to make sure that everyone who arrives tonight signs in. So if you have not signed in, there are sign-up sheets on the back table. Make sure you sign in. And we do have listening devices, and we have an interpreter for the deaf, if need be. We want to let you know some other housekeeping rules. If you need to use the restrooms, the ladies room is to the left, and men's room to the right. The purpose of these public forums is to identify the concerns of people with disabilities in order to assist the state to develop programs to improve the quality of lives for people with disabilities. The basic format of the forums are, they're very casual. Basically, the panel is here to hear your concerns and uhm, we might respond with some suggestions, but if we don't have all the answers tonight, we'll take the information back to the commission and put your information with all the other people that testify throughout this week, and come up with a report and from that, they create the legislative agenda for next year which doesn't -- it seems far away, but really isn't that far. So that would be for 2004, and the work that they want to do then. If you're interested on looking at the transcript, it will be on the Governor's Commission website which is www.gcd.state.ri.us. Anyone is open to speak this evening. Sign the sign-up sheet. You'll have approximately five minutes or so and, you know, we'll just go from there. This is supposed to close at 8 o'clock, so we'll keep right on going until people have nothing else to say. Okay? So, let's get right into it. The first speaker we have is Harry. Right there is fine.

[SSI Limits 2](#)
And
[Medicaid 1](#)

Harry Dunbar: I can't see how \$692 for a family of two a month is allowed. No one can live on that. The most is \$700 without any electricity included. And I worked hard all of my life, and I have got middle-class person and now I am going into a spend-down of 8,000 dollars. So I want to know, if you know --right now I have to pay Health to Health,

Coast to Coast and that's costing me \$310 a month plus 23% of that plus a \$2,000 deductible. I need some help somewhere. I have to depend on my wife or the RIPTA bus or the other bus there, ride. If they get there on time and you know, I always have to depend on somebody to give me a ride. And for 25 years I am used to jumping in a car and going. I am tired of waiting for people to give me a ride. I get, SSDI. And at the end of the year on my own Coast-to-Coast they have a Medicare and Medicaid. How come I can't get them now, and have three different kinds of coverage? Right now I have to pay everything out of my own pocket. You guys have Ricare for people with children or single parents with children. How come you can't come up with something for people like myself? I wouldn't mind paying some of it. Come out with something like the Ricare program, because I can't get any food stamps or heating assistance. I can't get section 8 because I make too much money. All of that stuff is out of reach for me.

[PARI Waiver](#)

Female speaker: Could I ask a question that kind of rides on what he's saying? How do you determine, to the end the PARI Waiver, John's only allowed to make \$757 a month, and his social security check is \$1200. And the rest goes back to the state. Where do you come up with that amount? How do you determine that's the right amount of money that someone can make in order to qualify for these programs? Because really, like I said, that doesn't cover someone's rent never mind any utilities or anything extra, personal care attendants.

Jim Engstrand: I will express an opinion here. The figures you're mentioning on the cutoffs for what you're allowed to keep come from some old fashioned ideas as to what some indigent person should have to live on.

Female speaker: Maybe an elderly person, but when you have someone who's disabled, and the supplies that are needed for john's care, all of the things just for his care alone, I don't think they're factored into the costs that we incur continually. What are they doing to reevaluate it? Do they do new surveys or new assessments of these things, or maybe it should be based on the type of disability that they have.

James Pitassi: Are those federal or state numbers?

Female speaker: State.

Male speaker: The ones they're talking about are the state.

Female speaker: So the Medicaid program is funded by federal and state. But the law has not changed since 1965.

Harry Dunbar: That's how I have \$692 that law dates back to 1962.

Leo Canuel: The levels, while they're determined by the state formula, is determined by the federal government per SSDI and Medicare.

Male speaker: Which one? Medicaid is covered by whom?

Jim Engstrand: States will set levels like the \$700 figure you're looking at. There's a joint state and federal funding. They had to make it complicated.

Female speaker: Who do you talk to change that?

Male speaker: The state for that level.

Harry Dunbar: The state tells me to go to federal; federal tells me to go to the state.

[Medicaid Buy-In 1](#)
And
[Social Security](#)
[Disability Income](#)

Male speaker: Some things come from one, some come from the other.

Harry Dunbar: I start with my centers up here in the State House. Called the governors and now I am here talking to you.

Leo Canuel: There was legislation proposed this year called the Medicaid buy-in bill.

Male speaker: I have been talking to Mr. Balfucco, and he hasn't gotten back to me yet.

Leo Canuel: It's basically died at this point. Nothing new was funded this year. Because for the passage of the Medicaid buy-in which may not have helped you this year.

Harry Dunbar: It hasn't helped me for the last year and-a-half.

Leo Canuel: But it's a phase in process that we're trying to work on. Other states have this, it's a Medicaid buy-in where, if you are unable to purchase Medicaid, like you would purchase Blue Cross Blue Shield coverage, and your premium would be based on your income, but what would happen is, in this case, with this particular legislation you had to be employed or working towards employment-- but future legislation would include people that are just in your situation that need the medical coverage. We all know that what Medicare covers. Unless you're going to the hospital, Medicare doesn't cover it.

Female speaker: He doesn't have that.

Leo Canuel: Well -

Male speaker: I get no Medicaid, Medicare. All I have is the Coast to Coast, for a family of two, \$692. With her check and my check we're way over the markers. We've got like four months in one month.

Victoria Wilcox: The whole issue you're talking about, prescription drug coverage, it's something we've been working on the legislation committee and trying to do. Because if you're older, you know your prescriptions are covered, but if you're, you know, not elderly and disabled -

Harry Dunbar: All I am saying is I am in the Catch 22, like you're saying.

Female speaker: So you said you're working on it, but what steps are being taken for them? When you say you're working on it, what does that mean?

Victoria Wilcox: It means we've supported legislation to improve prescription drugs for people with disabilities and trying to lower the age at which people become eligible for Medicaid assistance.

Male speaker: Is there a time frame on that?

Victoria Wilcox: Every year we go after that and get shot down, but we'll keep doing it.

[Ride 1](#)

Harry Dunbar: And now the Ride program I still have to pay \$2.50 each way.

[Prescription 1](#)

Every corner where I try to save some money, I can't pay for my medications.

Female speaker: He takes 25 medications in a day.

[Ride 2](#)

Female speaker: Question about the Ride program, we have our own van that broke down and then you know, unexpectedly and said what can we do as far as getting John to therapy or a doctor's appointment, and we went in and asked ride, and they said, you need to give us more notice and reserve a ride further in advance. What happens when we're in a situation like that, where something unexpectedly breaks down and we need a ride?

Mark Therrien: You can make reservations in advance. 3500 people a day call in at the last minute that's the problem. I know the van could just go with a lift or something, but if you know something for scheduled appointments you would be on time. You can call in and if they can do it, they'll try to do it. But on some days, the trips are just full already.

Leo Canuel: RIPTA, their budget is sort of tight at this point.

Mark Therrien: 50% short fall.

Male speaker: Buses, too, right? RIPTA buses?

Leo Canuel: The new buses -

Mark Therrien: The money for the buses mostly comes from federal government 80%. You can't use the money for anything else. So keeping a new fleet like your own personal car means it's cheaper to maintain. So the ride vans get replaced every 5 years. And the buses get replaced 15 years. When you pay \$2.50, on average that ride costs about 15 dollars. I know that's a lot to you, but it's very subsidized through RIPTA to give you that transportation. If you're going to a hospital or a specialist in Newport it's still \$2.50. Ten years ago there, wasn't that option. So the ADA law has made a big change.

Harry Dunbar: My license has been suspended -

Leo Canuel: But the ADA law that gives you that access is something that came along after a long time. Groups like this in the country are now pushing for it. Governor's Commission and the groups in our state are lobbyists who try to make a change. It can take up to 18 months from the time that RIPTA orders a bus until the time it actually gets it into Rhode Island. So RIPTA is always trying to project ahead as to what the need is going to be 18 months from now. And sometimes that can be difficult.

Victoria Wilcox: I think it's good that you did contact your representatives.

Harry Dunbar: I contacted the senator.

Female speaker: We wrote a letter to senator Thompson in Washington, DC.

Victoria Wilcox: It's important to do that. We can do our lobbying, but the more people that lobby, the better chance that something will happen.

Leo Canuel: We thank you for bringing this to our attention tonight, and it's documented as part of your testimony.

Harry Dunbar: The only reason is Senator McBurney told me and Bob Cooper told me that you were here tonight.

Leo Canuel: Thank you. John, did you have any other issues that you wanted to bring up tonight?

[Personal Care Attendants 1](#)

John: Just kind of new in this, I have been injured for 2 and-a half years and still learning a lot of what's going on. The big thing is it always comes down to money with the aides that we have, and as far as trying to survive on the income that we have. We supplement more to it. How does that budget work? How do you determine the amount?

Female speaker: How much you pay and-

Male speaker: Where does the money come from with PCA's?

Leo Canuel: How's the money hourly rate determined for PCA's? That hourly rate is regulated by the state through Medicaid program. So Medicaid tells us at PARI to pay the PCA's so much and that's what we do. And depending on your financial need, there's a formula that we use if you need to make a co-payment towards the PCA.

John: They determined that \$8.50 was enough for a qualified person -

Female speaker: How often do they evaluate that?

Leo Canuel: One at a time, please, for the cart reporter.

Leo Canuel: It just went up, not this year, but it went up last year. So there was like, I believe, a 3% increase last year. We again, always lobby for improvements in the PCA program, and I can talk about that a little bit.

[Personal Care Attendants 2](#)

Female speaker: Is there any talk of getting any benefits, medical benefits for PCA incentives to keep them in the program and keep them working for us?

Leo Canuel: Tell me what you would like to see.

Female speaker: Even if they could buy into a program where they pay just like at my job, I have to contribute to my own health care benefits, where they could maybe buy in and pay a percentage of their health care. We have several single mothers working for us. You know that they don't have another spouse that gets medical benefits with their job, and that's a big thing for them. So even if it's something where they could pay a percentage or get a better rate maybe, we've had aides who have to leave us because they need to get a job that pays medical coverage.

Female speaker: I think that's probably our two issues.

Leo Canuel: Any other comments from the panel?

Jim Engstrand: You asked how was that level determined? There's no real scientific thing behind it. It comes from some very old-fashioned settings, perhaps decades ago, and not all of them have been made automatic adjustments. If you look at AFDC levels, they're almost absolutely flat with no inflation adjustment at all. Some of the figures for Medicaid have gone up here and there but not realistic at all. Accounting for the increase and housing. 20 years ago you could probably pay \$90 in rent and have an apartment. But you know, that's not real anymore.

Female speaker: Right.

Sharon Brinkworth: Do you have problems in keeping a PCA once you get one, or is it just that there's very few PCA's?

John: We've been fortunate. We've been able to get PCA's. We lost one because of health benefits. Health benefits is probably one of the number one reasons why they can't stay especially a single mother. They have too. If someone gets hurt on the job, with the lifting and everything else people have to do.

Female speaker: We also supplement an additional \$3 an hour to make it comparable to what they would make in another place. It's hard work in the morning, but when you have to get john up for the day it's a lot of physical work and it's a hard job. So, you know, I think I probably would take the job for that other thing. So we have to supplement out of our own pocket in order to keep good PCA's with us. It's fortunate that I have a good job, but if someone didn't have the means to supplement, I would think they would have a very hard time keeping a good PCA.

Liz Graves: One of the functions of the State Independent Living Council is to inform legislators about the needs. We're preparing papers to be sent to the legislature. The committee is working very hard on getting these issues together and making sure that all the politicians and people in position are informed so they know as the issues come up, they are very informed. And this is not just a Rhode Island problem. It's a national problem. The national independent living council meeting last year, it was brought up on all the states that they have the same problem. And the only thing that works is advocacy and getting informed as to where they stand and how you can be involved in pushing the issue.

Female speaker: We would never have known of this type of forum or even what's out there. There's been times when they've called us and asked us to call the treasurer. And that's great. Still being new into the situation, the first two years we were learning how to survive, now we need to know what to do to make it better and people need to know about these meetings and speak up for themselves. People have to back whoever is pushing the legislature and scream louder than someone else. So I think PARI is very good at that.

Liz Graves: There are some surveys that we are conducting right now and this is for the purpose of the next year's plan. The State Independent Living Council they're responsible for putting together a plan for three years with funds coming in and advocacy and training and information to the public. So if you are willing to fill out the survey and having someone hear your voice and anyone who would like to come to any of the councils, your voice will be heard.

[Personal Care Attendants 5](#)

Beth: I just wanted to add to the PCA comments, not only may certain people have difficulty getting a PCA, but even getting into the PCA program is a problem. There are 85 spots throughout the state for the program. And basically, it's a situation where someone else on the program either unfortunately passes away or moves into another setting before someone else is added to the program. One of the things that needs to happen is that needs to be increased to 150 spots, so people waiting and needing the service can go ahead and take advantage of it. So that's another thought to throw out there.

Female speaker: It's probably cheaper for the state to contribute to PCA's rather than having someone be in a nursing home or -- I think Maine has a publication, that it still costs a lot more to take care of a person at a facility than at home.

Harry Dunbar: My wife and I have been talking for the last two days, - like sometimes throw my laundry in the sink there, or out in the toilet bowl or out in the kitchen sink wherever it lands. I put the clothes in there but sometimes I don't even do that.

[Information 1](#)

Female speaker: He has a lot of brain function dysfunctions. And he's getting worse over time. He got sick and it's been problem after problem, so I don't know where to go to help me help him.

Leo Canuel: Sharon and Beth could talk to you when we're done.

Sharon Brinkworth: Something else, which is probably needed, is respite care.

Leo Canuel: Could you explain that a little bit more?

[Respite Care 1](#)

Sharon Brinkworth: I will try. Respite care is for caregivers. Basically as I understand it, and jump in if I am giving the wrong impression, when you are the primary caregiver for someone, you need a break from it. You need to be away from it, and I think also the person that you're caring for needs some kind of break from their caregiver, and it's just that respite is to have someone else come in or have the person go somewhere for a few hours a day.

Leo Canuel: We're also having some conversations about a day program. I hate the analogy, but the analogy of a senior center, this is a similar thing to what a day rehab program would be. You would go, you would get some services, activities, a variety of other things would happen, like a senior center, but not for seniors specifically. There are a lot of people with disabilities that don't want to go to a senior center with seniors. I agree with that.

Harry Dunbar: You can tell by my medications and what I am taking so -

[Personal Care Attendants 3](#)

Leo Canuel: One other thing I think to add to Beth's comments that would enhance like your PCA program, is to insure that the PCA's have an increased rate so that taxes can be withheld from their pays. Right now, PCA's are considered independent contractors and if you look at the regulations, they're written under the IRS rules, PCA's don't fit into that hole of independent

contractor. So we've been advocating for an increase in the rate so that increase would be basically the employer's contribution for taxes and worker's compensation so that the PCA if we're at \$8.50 an hour for PCA's, and you start taking taxes out of that, they should go work at McDonald's, they would make more money. So we have to keep working on that issue. And right now, if a PCA gets injured on the job, there are no worker's compensation benefits.

James Pitassi: Is there a way for the PCA program to actually have it set up under a company so that then they would be employees of that company and I am sure, you know, you have independent contractors and then special employer/employee relationships, that might give the PCA ability to get into medical plans and those kinds of things, but you would have to have an umbrella agency company running it. Has anyone ever looked at that?

Leo Canuel: There are several models out there we can look at. One model is the model that we run under here and that is PCA's work directly for the consumer. And what other states have done they've put into place fiscal intermediaries, that's like a pay roll entity, but the PCA still works for the consumer. So that consumer still has control. Another model is that vendor that provides PCA services, i.e. PARI, the PCA would work for PARI.

James Pitassi: Exactly.

Leo Canuel: The problem with that as an executive director of PARI, that would mean I would have about 200 PCA's working for me in homes completely out of my control. My liability insurance would go through the roof because we would have no control over the PCA's. And also the consumer would not have any control over the PCA's because they wouldn't be working for the consumer, they would be working for me. And that's not a philosophy in theory in a PCA program. Other models the home health aide program, where you actually work for a home health aide entity and the home health aide goes into your home. The PCA works as home certified home health aide and goes into the consumer's home. We have always advocated for a PCA program in a way that it is now whereby the consumer is the boss. Running the business, running the show. And that's what I continue to advocate, I think that's the best model. It gives people a different option from home health aides. If the PCA starts working for a home health aide agency that's the same thing as having home health aides it doesn't give you another option. The fiscal intermediary program I am very familiar with it because it works in Massachusetts very well, function have had very little problem with it and the consumer is still in control of his or her services.

Male speaker: Do they get benefits, does a PCA benefit because of this new arrangement is what I am wondering?

Leo Canuel: They can't. There are possible opportunities for PCA's to be able to get health benefits and other types of benefits. In Rhode Island, there's been some talk about allowing PCA's the ability to buy into rite share rite care. There's been legislation put forth for those issues. It would be a very expensive thing. But it has never gone anywhere. I think that's the best way to deal with it here in Rhode Island seeing as how we have the program is already in place. Just sign them up and get them in. Especially with PCA single parent PCA's with children, we know a lot of good PCA's that can't stay as PCA's because they don't have health coverage for the kids. It's an issue. He lost a good PCA.

Female speaker: Or what happens is they end up kind of working under the table, but still then collecting some sort of government subsidy or benefit and that's not benefiting government either. They don't want to be honest and say they have a job because they'll lose whatever benefits they're getting from the state like medical coverage. What's holding that back? You said you brought it up and it's never gone anywhere. Where is it stalling?

Leo Canuel: The legislation? It died in committee and was never voted

Out. Again, forums like this can bring these issues forward and the Governor's Commission can work on that along with other people that are representatives at this table, and other entities across the state.

Sharon Brinkworth: I have to say again, echo what someone else said talking to your own legislator and your own state rep it's so important because they don't really represent that many people. They've down sized and they're representing a few more but it is rather small and when a piece of legislation like this comes before them, if you have talked to them about the problems you've had, they're going to sit there and think twice I think, and about whether they want to consider it when they know there's someone living in their district having this particular problem. Because they know that if they vote against something like that, that you have ways of finding that out.

Harry Dunbar: A representative told me there was a senator that's going to be doing the same thing I said, and I still haven't heard nothing on that. Senator McBurney hasn't said anything else. I have been having conversations with these people I can give you a list that goes on and on.

Leo Canuel: The best thing you can do when you talk to a legislator, state or federal, is tell them your story. I can go before the legislature and we meet in a room like this and they sit up there and listen to me as I give testimony but in the back of their head they're thinking this guy is doing this and getting paid. And it means something a lot of legislators value our opinion.

Harry Dunbar: Up at the state house, I have been there so many times.

Leo Canuel: So have I.

Harry Dunbar: I even asked them if they wanted me to go and talk to the Congress or Senate House or whatever to be a speaker and tell them what my problems are.

Leo Canuel: I think that's where the most effective advocacy is, is when people tell their stories and they hear at the state house how it effects your life personally. I have gone to hearings and gone to a variety of political official political activities and have heard senators and representatives stand up, I have been getting flooded with all kinds of phone calls and e-mails and faxes we have to pass this thing, we have to pass this thing. And at one point I went up to one of the guys I knew and I staid how many e-mails did you get. And he said 6. And that's because they assume there's 300 that didn't call.

Harry Dunbar: I offered to go up and speak at the State House and they hadn't given me a call back.

Leo Canuel: Any other issues that we would like to talk about? Why don't we take a short break and give our cart reporter a chance to rest her fingers, and we'll come back in about ten minutes or so and see if there's anything else that you would like to discuss.

(recess)

Leo Canuel: We're going to get started again. Are there any additional comments or questions or testimony from those that spoke before the break? No? Anything new that we need to bring up? Are you going to give testimony?

Female speaker: Me? No, I am sorry, I am late. I just thought I would sit in for a little bit.

Leo Canuel: Your name,

Female speaker: Alyssa Forleo, from Ocean State Association of Residential Resources. I believe we're going to have someone sitting on the panel later in the week.

Leo Canuel: I think unfortunately, we sort of have wound down from all the testimony that's why we took a little break. Everyone sort of testified in the first hour. So we can hang around for another hour if you really would like, but how many want to go home?

(laughter).

Leo Canuel: How many want to stay?

Victoria Wilcox: one year, we left. We thought we were done and people showed up. So now we try to stay until the end. So we can hear the testimony of someone if they come in late. Sorry.

Leo Canuel: We'll hang around until 7:30. If you have any more information, we can take that. If not, have a good evening. Sure Jim, run right out.

James Pitassi: that's the good part of wearing all the hats that I wear. Take care and have a good evening.

II. Public Forum, Tuesday, July 22, 2003, Independence Square II (Kingston)

Casey Gartland: Hi good evening we are going to get started. As we talk, get this forum going more people will come hopefully. I am Casey Gartland. I am here representing the hosting agency, which is the ocean state association of residential resources. OSAR, is a conglomeration of private providers in the state of Rhode Island providing support to developmental disability, both children and adults. I am actually Vice President of governmental affairs. I also work for Prospectus Corporation, which is one of the participating agencies. My role tonight will be to start the process by having the panel introduce themselves. And then also keep track of the time for the participants wishing to say something. Now we are in an interesting position here. We have some people who signed in to the forum, but no one has checked off saying they have anything to address the panel with, I hope that will change once people realize we have nobody who has set aside time to talk. Those in the audience at this point if you want to address something this would be a good time once we get started. Okay. I am going to pause here for a minute because I think somebody else is coming in who might be on the panel. Hi. Come on down. Have a seat. So I guess what we will do next is to have -- start by having the panel introduce themselves from left to right. Are you all set?

Chuck Messina: Attorney with the Rhode Island Disability Law Center.

Pam: Hello everyone I am Pam Zellner I am a coordinator at the Rhode Island Commission for the Deaf and Hard of Hearing.

Jeanne Behie: I am Jeanne Behie. I work for Rhode Island Parent Information Network as transition coordinator helping students plan and -- plan for their adult life and to access information and resources. I am also on the state Rehab Council and the state Transition Council.

Paula O'Connor: Hi I am Paula O'Connor President of the Brain Injury Association of Rhode Island.

Brooks Almonte: I am Brooks Almonte, here to represent RIPTA, transportation planner.

Casey: Now I know from my experience with the forum last year, a lot of the people here represent different aspects of parts of the field that we all counter either on a daily basis or monthly basis, whatever. So, sometimes if you are going to address the panel, one person might have more information than another, not so much to answer questions. That's not the role of tonight's panel. The role of tonight's panel is to collect the concerns and issues from the audience. What they might ask though is elaborating questions to elaborate or clarify information you are giving them. As long as the audience understands they are here to collect information that would be helpful. I also want to make mention that we do have assistive listening devices here available to people if we need them. We also are transcribing everything that's being said here tonight on the computer in a perfect world it would be up on the screen but we will hopefully see about correcting that later on maybe not tonight but when transcript comes out.

Jeanne Behie: Unfortunately I have to leave at 7:00.

Casey: Thank you for letting us know. Okay. As I said at the start, we have a few people who signed in, yet nobody has actually checked off saying they have any kind of issues or concerns they want to address the panel. However I am going to re-open that if --

Gail Johnston: I wasn't exactly aware what this was for. PARI had called and told us about the meeting and asked if we would come and speak about the personal care attendant program and the needs for more slots, I believe. That they have very limited number of people that can get into the program. And to

Casey: Okay. So you already started addressing -- could you hold on for a second. What we are going to do in the form then I am glad I have participants, that's great. If you could do me a favor when you get up to speak, say your name and address where you are from and the area such as you did that you have a concern. I also want to point out that once transcribed the information of this will be posted on the governors commission disabilities website which is www.gcd.state.ri.us in about a week. Later in the summer, the sponsoring agencies will review the testimony, prepare recommendations, which will also be posted on the website. You ideally by the end of the summer. The recommendation of transcripts will be printed and sent to the state congressional officials and members of the general assembly. And lastly the recommendations will be used to develop policy and legislative initiatives for the next year or until they are accomplished. Okay. With that thank you very much for holding. If you go ahead.

Gail Johnston: I am Gail Johnston I am a mother of a young woman with a disability since birth. And we got into the PARI program approximately three years ago. And it's made a world of difference between my daughter and I, and to my daughter. It got her out in the community a little bit more. And I can't imagine continuing on the way we went. And anybody else that was in the same situation, it's a difficult situation because there isn't a whole lot of support in the community and it's -- it made a great deal of difference in our lives. And I think it's worthy of anyone's life to get them on the program. I don't see any reason that somebody should have to live any other way. I am also kind of surprised. It seems like there is not a lot of interest, do most people not know about these meetings? Or can't people get here, is transportation a problem? I know transportation sometimes is a problem, depending on time.

Casey: Understanding enough Brooks is from RIPTA a lot of issues last year were transportation issues in terms of public transportation, that kind of thing. I honestly don't know why there aren't a lot of people here. I know what I intend last year, this is probably about average what we found last year too. However this is one of five that are happening throughout the state and they are happening in different regions, okay. So for example, tomorrow night I believe is new port and the one's up north may be largely attended. As to why this one is not is may be the time, that was announced I am not quite sure. Did you wish to say anything else, ma'am?

Gail Johnston: I wasn't prepared.

Casey: They are fairly informal. Please.

[RIde 3](#)

Gail Johnston: Transportation is a big issue for a lot of the people that Sabourin and I have met a lot has to do with RIPTA they seem somewhat limited as to last minute -- to get people to a doctor appointment. Sometimes you can't get RIPTA because it's the day of -- they are fairly inflexible.

[RIde 4](#)

There probably is a need for that but it's hard for transportation. Sabourin uses it but again she can't go different places - I think on Sunday we can't get any place. I am not sure. I think I have given up on Sundays. But even when she goes to go out, we can't get her home. So we have to make other arrangements for that. I would think that would be a lot of people have the same problem.

Casey: Okay. Does the panel have any questions to ask?

[Personal Care Attendants 6](#)

Jeanne Behie: I have a question about the PARI program and the personal care attendant. You were saying that you think there's a need for more people to get on the program. And that would be to get a personal care attendant.

Gail Johnston: Yes.

Jeanne Behie: What's the issue that you see it as preventing people from getting personal care attendants.

Gail Johnston: I think it's funding. I think they only fund for so many clients. And we were lucky enough to get it about three years ago. I think there's a long waiting list. And the thought -- if I was gone, as many parents I am sure worry, that some day they are going to be gone, the thought that PARI is there and she has somebody that will come in and help her is just very reassuring. You know, there's so many things parents probably worry about and that's one of them. But I am not even sure this funding is going to stay forever. And I think everyone talks like it's an emergency and maybe it is a growing program, but it really -- I can't see any reason why anyone should be shut in their home.

Jeanne Behie: Thank you.

Casey: any other questions? Thank you. At this point I am going to interrupt. Michael if could you give an introduction.

Michael Spoerri: I am Michael Spoerri with the Disabilities and Health program at the Department of Health and I am one week old. Kind of hoping just to hear from you guys, just to learn more about the disability community in Rhode Island and how I and we at Disabilities Health program can better serve you.

Casey: Thank you very much, Michael. Is there anyone else in the audience who would like to address the panel? Again I would like to remind you do not have to be a professional public speaker if there's anything on your mind really this would be the opportunity. The Governor's Commission is extremely influential in the work they do in Rhode Island and so, and information that they receive can be definitely acted upon. If there is something you are thinking of this would be the ideal time to mention it.

[Personal Care Attendants 4](#)

Gail Johnston: Actually. I have another issue. It's along with PARI and the fact that a lot of these people that do come and help disabled people get a very fairly low wage and no benefits and I think their push is to be able if get them to buy in to some insurance plan possibly or for them to pay social security and some other benefits that goes along with working a job. And they were hoping that -- I think the state might help these people that help others.

Jeanne Behie: So, I would think then that they are considered private contractors then. Okay. And that's an issue I think with -- was an issue with the EPSDT program, what used to be called the home based therapy program. Also those workers were considered independent contractors, with no benefits.

Gail Johnston: Because they also -- they have no TDI or anything if they got hurt on the job. Which sometimes entails lifting and helping -- so they would have no insurance.

Casey: Sure.

[Home
Modification 1](#)

Gail Johnston: I am assuming as a homeowner the homeowner would probably be sued for some kind of financial help if somebody did get hurt. And also I think Mrs. Behie knows there's a program for helping to accessorize a home so people can get in and out of their home easily or in and out of the bathtub or in and out on a toilet that type of help seems like it's my private opinion.

Casey: That's okay.

Jeanne Behie: We appreciate you sharing.

Casey: If you weren't here -- sure. Okay.

Gail Johnston: Maybe you can say something.

Sabourin Lussier: I don't know, you said everything. Like you always do. You never let me speak.

Jeanne Behie: Sabourin, what do you see some of the needs in the disability community. I am sure you have come across certain issues.

[Out of State
Health Care](#)

Sabourin Lussier: the RId program. They -- if -- I don't know how to say this. But for me, I have doctors in Boston and it's hard for my mom to sometimes get the day off, whatever. So I kind of wish that the ride program can expand their routes from like Massachusetts-- like over the border kind of, or to Connecticut so the people who can't get availability from other people, they can use the ride program and get to the doctor's appointments.

Gail Johnston: Actually we should add the RId program is wonderful to start with.

Sabourin Lussier: It -- that's part of my life. And I love it because it gives me -- gets me places.

Gail Johnston: And also their drivers are very pleasant, friendly nice. I can't say enough nice about the RId program to start with.

Sabourin Lussier: That's just the one thing I wish is that they can expand their routes so they can adapt to the person that's riding it, so they can help to get -- be helped going to the doctor's, you know.

Casey: Thank you, Sabourin. Once again I will ask anybody else have --

[Rural Employment 1](#)

Cheryl Resmini: I am not sure what I wanted to say. I am Cheryl Resmini. I have a daughter who is hearing impaired and has another disability she's 22. The problem that we have mostly is in jobs, finding jobs. We live down in Carolina so it's kind of secluded but she works with Nap Tree in Westerly. But I found that I had to do a lot of research on my own, which is like a part-

time job for me. You know, kind of exhausting. To find jobs that are suited to her ability. So I am kind of -- we get kind of frustrated -- we find a job that might be right and then it end up being more than she can handle then back to square one. Whereas it took maybe five or six months to find the job, and that has to end. Which might be in the case right now. So she's back to putting out, taking applications, you know. Her goal is to get her own place, you know. But if she's-- if she has a job for maybe six to eight months and then she's laid off because the slow retail season, then she's back to getting depressed and no job and then the goal of, you know, her own place is further away. So, I just find it really hard to get a job for a lot of these, you know, kids, and adults with disabilities. I don't know how they can be helped but I know -- because we are in this area, it's a little difficult.

[netWORKri 1](#)

Really need more -- I don't know, more offices or more contact down here too. To work with instead of just the agency that she's working with, you know because I know they do their best but I have to do a lot on my own which shouldn't be - I don't mind doing it. You know, I have become a good researcher but there's only so many jobs that she's suited for. So it's kinds of tough, the job really needs to be worked on. I don't know how but --

Pam: I am curious. Why are so many jobs limited for her, is it due to communication access? Is that the issue?

Speaker: Not really.

Pam: Let me go ahead and rephrase that. Does your daughter receive access, full access to communication when she is working on the job?

Cheryl Resmini: Yes, yes.

Pam: Does she receive reasonable accommodations when she's working?

Cheryl Resmini: Yes, of course you still get -- she's still -- what's the word? Not discriminated but, you know she's had to start wearing her button that says "face me, I am hard of hearing" at work because of some comments that were made. It doesn't make it easy.

Pam: Some people are in fact ignorant and they don't know about some of those things about your daughter. And they do use those buttons. And those have become very popular in the workplace. So, yes. What area would you like to see her improve in, in terms of job employment? Apparently she has commute access that doesn't seem to be a problem. What else would you like to see improved, more job training?

Cheryl Resmini: I am hard of hearing too so -- so I am reading this too. She is taking classes at CCRI she is taking ASL. And she would like to become an interpreter. I just do not know what level of licensing she could, you know, obtain. Attain, whatever. I think if she worked with the deaf, she would be more comfortable. It's really hard for her to work with all hearing people, thank you. That is what I found. I think she is more comfortable with people she went to school with, or with other people with disabilities. And sometimes I think we push them to, you know, you start mainstreaming in high school. It's not always the answer because there's still different; I think she's more comfortable to be with other people with disabilities. So, that's the kinds of in between, you know, the training - I don't know. I think the sign language would be good but I am not sure that's the answer either.

Pam: One of the resources that we offer in our office is a list of organizations and agencies in Rhode Island for people like your daughter, and myself as well. Perhaps we could find some of those of beneficial resources and see if we can work on that. And if that doesn't work, perhaps we can try another organization and just experiment and see what we can come up with. I would be happy to give you my business card at the end of

this forum and you can contact the office.

Cheryl Resmini: okay that's why I am here to get more resources. Thank you. Thanks.

Pam: Great. I will talk to you afterwards.

[Rural Employment 2](#)

Gail Johnston: Gail Johnston again. I sometimes think that there is a lot more opportunity if you live closer to the city. I find it easy for Sabourin to find volunteer jobs. However, we are not having a lot of luck with a good paying job. Prospectus is a service that helps her with her jobs and she does work at prospectus and a job that she's not really happy with. So that's why she likes the volunteer jobs, it gets her out to different things. But it does seem sort of limited in this area for jobs for these kids. And I don't know --

Sabourin Lussier: Or training also.

Gail Johnston: Training. You have to go quite a-ways for training. And we have a transportation problem. And I have -- we have the problem that we do a couple of volunteer jobs. Actually, we have done about ten volunteer jobs in our life but it never works into any kind of paying position.

Casey: Thank you.

Gail Johnston: Not that it's absolutely necessary to be paid but it would be nice.

Casey: Sure. Any questions from the panel about what Ms. Johnston just said? Okay. Is there anybody else in the audience who would like to address the panel?

Ray Carroll: A moment of quiet so I come really to listen. I am Ray Carroll. I am the Administrator of the Office of Rehabilitation Services and I have been attending meetings like this for years and thank god that we have a number of high quality individuals who come out to express needs and barriers which really reflect the barriers of many, many people. The needs are great and the resources very limited and each year when we have these meetings, we basically hear the same commentary or concerns. Poor coordination of services, lack of resources, or need for more resources, transportation issues are always reflected. So, generally we don't hear many new barriers. The PCA issue is one that we had worked on for many, many years because as a values based organization that believes in partnerships, providing customer centric programming, we have heard this many, many times. But we need to unite with the public to educate the general assembly and other policymakers to indicate that the services that we provide are very cost benefit and save untold taxes when you make an individual move into economic independence and to live independently. And sometimes I get a little depressed or disappointed when I see a small turnout, but after all this is July and usually in the middle of vacations and the like and we do appreciate, you know, mostly mothers, I might add over the year. Jeanne Behie is on the state Rehab Council and that's a group of citizens, volunteers who are trying to work with us to really generate more resources. I was sitting here and what was I doing? I was looking first at the number of personnel vacancies we have currently in our office and some of it may be normal attrition. But we have kind of a hiring freeze in the state going on right now. So we have a number of vacancies, I think I see about 20 to 25 vacancies in our office. We run a lot of programs, the disability determination services provide staff to adjudicate medical eligibility for SSI and SSDI and they are overwhelmed with applications. We are getting about 15,000 a year. Particularly, as the aging of America in Rhode Island, the baby booming demographic people are acquiring diseases and disabilities and they are applying for disability services under SSI or SSDI. The vocational rehabilitation program, where your daughter probably should be an applicant if she isn't already, also has restraints. We have a waiting list. We call it an order of selection. And that provides a problem to serve all of the individuals. We are very interested in transition services as Jeanne is in the panel and there's

probably 11,000 students in the public schools receiving special education services and we are probably only serving maybe one-tenth of that. So I guess I am just saying while we have a moment of quiet, that the needs continue to be very, very great. But the resources continue to be limited. And what we hope to do is develop, you know, these working partnerships so that when it comes time to express these to places like the house finance committee, maybe you take the time to come out and personally tell your story. Now some individuals don't like to do that. There are issues of privacy and confidentiality and why should you have to go out to the state house and wait for hours and bare your soul telling your personal story, which can be e-effective. We as bureaucrats have to work within the system. So I am just taking a moment while we have quiet to talk about some of these dynamics. Everyone talks about transportation, RIPTA, you know, the ride program, the paratransit they try to address a lot of these issues. They have a passionate group of consumers that neat our office with bill and low and others at RIPTA to try to address the need. But as you read the newspaper, you see the budget shortfalls, the deficits and the like that we have to cope with. So pleased a couple of mothers and others have come to reinforce pretty much what we know is that we have programs that work, they are under financed, they are under-resourced. And the staff that we have is doing a good job. The PCA program, I am particularly sensitive to because I know what you are talking about. It's a Medicaid waiver program that is capped at so many slots. And I think the number is 80. And it probably should double because there is a wait list and many others could use this very invaluable service. But there's another macro or larger issue of no new programs and roll backs or cut backs that we are all coping with. And even if the public arena, you have the nonprofit community, which are kind of like pseudo-public entities which are affected also. We have the Disability Law Center we work hand in glove with the Disability Law Center to assure that everybody is entitled to their rights and responsibilities under these many programs. So I know I am coming on a little long. I came here really to listen but with a little bit of quiet, I just appreciate you speaking out to reinforce and reeducate all of us of the needs of these particular programs. I don't think you have to live in the greater providence area either. Demographics are more and more people are moving to South County and other areas and we are trying have our staff out stationed to provide the services, not at hope high school but hat westerly high school and all the other schools as well so they are not disenfranchised at all. So that was just a couple of comments. I appreciate the moment to express this.

Gail Johnston: Gail Johnston again. I just realized that I haven't gone to these meetings except for the last three years and that's only because we have the PCA program. I am not exhausted, I am not dragging myself or in bed at 7:00 at night. Up at 5:00 in the morning. Hey, I can do more stuff. So, that's what helped me be here.

Jeanne Behie: I wanted to just emphasize something that Ray mentioned about students in high school with special needs and --only a small percentage of them being hooked up with the Office of Rehabilitative Service. And I think that under lines the need for publicizing the programs that are out there and getting the word out about certain resources that are available for the disability community. And I think the Governor's Commission really should focus on how we can let people know that there are certain programs. I know we are limited by resources but there are things people are eligible for that they are not aware of. I know Ray and the Office of Rehabilitative Services. There's a move to let people with physical disabilities understand they could be eligible for ors services and you know they are not aware of that.

Gail Johnston: Gail Johnston, sometimes when you look at the amount of money that has taken for Sabourin. It's staggering sometimes you don't think you get any benefits from it, like in school and it just seems like some of this money is wasted an things aren't done that are said to be done, or it costs -- you would think ten times the amount that it would cost you to do it. And it's sometimes -- it's just not -- I don't know what the word is.

Jeanne Behie: Pay back.

Gail Johnston: Cost effective. That is the word. You know, I get these notices every year about how much is allotted to Sabourin for training. I don't feel she gets that much training. And we say, maybe we should try to do it and take half that money and do a better job. But I don't know. Doesn't seem like the money is used

effectively sometimes. Anyone else look at the money that's spent?

[Housing
Modification 2](#)

Ray: We look at it carefully. You talk about home modifications how important that is.

Gail Johnston: Oh that happens.

Ray: How expensive that is becoming and so forth. But we are very judicious in our fees and the spending that we do.

Audience member: I am not saying you are judicious but I am just saying there aren't a lot of people watching over how that money is actually -- actually used. You know. Casey. You have. I was going to say we have somebody else join us if you would like to say.

[Housing 1](#)

Gail Tarzwell: Gail Tarzwell. I am a parent with a disability and I am very concerned about affordable housing my child is 17 right now. We live here in South County she's born here and I really don't know how she's going to afford to live here when she's an adult. Is there anyone out there that's working on being able to keep people with disabilities in their home communities, where they grew up, where she's got a job now at Shaw's and she's at the high school, included as much as possible. We are just -- I just don't want her to, you know, have to leave town. I think it's a concern for many of our non-disabled kids how they are going to afford to live here. But I am especially concerned when I think about how services are best provided for folks with disabilities if they can live in town. I don't envision Allison will be driving a vehicle that will allow her to live out of the immediate village areas of our town in South Kingstown so I didn't know if there was any group in the government that's looking at that, to try to preserve some land for congregate living in our local areas.

Casey: Again you weren't here. We talked about some people may not have answers for your concerns but they are being document and will be shared with the general assembly. That being said I can make a response I don't know if anyone else wanted to make a response.

Jeanne Behie: After you.

Casey: It is an issue that the governmental affairs committee does share every time we meet, most of the time we meet with the general assembly member here in Rhode Island we also go to Washington every year for a conference and share with our four congressman and-- two senators and congressman they know it's an issue. And it's always on the agenda for this conversation in Washington. It's a step-by-step process. I know just recently there was more money set aside for support of housing but I don't know if that's what you are really looking for per se but that is the route a lot of providers are going for, specialized housing, you know section 8, via the housing authority. Still I wonder if you are also asking though a little bit more about not having to go that route so much as - not so much assistive living but just available housing that's shared with anybody even people without disabilities is that kind of what -

Gail Tarzwell: The whole gamut I am concerned about the option, there be a continuum out there that while we work so hard to make Allison independent, that the only option is going to be group homes and the only ticket in there is I go into a nursing home.

Jeanne Behie: Right.

Gail Tarzwell: That's what I am hearing that there are many parents who are in their 50s and 60s and looking down the line and being told by the state, basically, you have to keep your child at home because there isn't any available housing out there. There isn't the funding to get the kids in independent in their living environment.

Jeanne Behie: I know of parents who have been told very similar things that they were interested in looking at a group home for their son and they met with DDD and they -- which is the Division of Developmental Disabilities -- and they were told that the best option would be for them to purchase some housing, a condominium, rents an apartment, and then they would get support through DDD. And through an adult service provider but it would be the parent that would have to purchase the housing.

Casey: I would say that's very much to what I am hearing too. For the record if we kind of summarize what you did say because what you said is something that I hear from a lot of parents, which is that, it's those who are supported. Those with disabilities who don't seem to have many issues and that they are not presenting a threat to the community or a threat to themselves or a threat to the family members who tend to be the last on the list to do stay home with older parents. Unfortunately I know that's a way the peripheral system. I want to get that on the transcript as well.

Jeanne Behie: So there really needs to be more housing. Not just at the federal government level, but in towns and at the state level there need to be more housing available. Options for people to stay in the home, with perhaps an accessible apartment, with some funding to do -- to put an addition on. I know there are funds for modifications, it's limited. So there really needs to be more attention paid to that. And I think one of the ways that we, as parents, because I am also a parents of an adult child with disabilities, is to encourage our children to become voting members of society, and also to join different advocacy groups so that they can let their needs be known.

Casey: Very much so. I would also encourage you -- I would say to contact your housing authority because they also should be aware of programs and specialize money, bond money for example, for building or for access for people. They should be aware of that and let you know about that.

[Traumatic
Brain Injury 1](#)

Paula O'Connor: Yes, I did. I have a son who is a survivor of brain injury and unfortunately, because Rhode Island has no group homes for survivors of brain injury, he's been living in Vermont for six or 7 years now. I am currently looking into getting him back in state and some housing. There are several different avenues to go down. And one is as Casey said there are different funding sources out there for mortgages and so forth. But there are other ways of looking at it too. We are finding other families in your same situation and going in together, which is what we are looking at now. It takes -- it takes a lot of work.

Audience member: Is there any source of information and exchange in this or is it all word of mouth?

Casey: What information particularly?

Gail Tarzwell: About the private -- the families getting together and --

Casey: Situations I have heard have been very grass roots. It's not because someone came up and said this is what you should do. It's because the parents looked at the future and decided to work together. Which is interesting how this thing got started. It's been very grass roots.

Gail Tarzwell: Plus I hard parents say I really don't want to be landlords for the long-term here. And especially with premise liability, being -- you have that case that came down about the mom who had the mentally disabled son and now her insurance company is I guess on the hook because he murdered the next-door neighbor. I don't know if anyone heard about that. But that is making a lot of parents with disabilities, especially mentally ill very concerned about having adult children live at home because this mom was basically held responsible because she knew he had a disability and she knew the guns were in the house. The court said, well you have those two pieces of information. Put the two together. You are responsible for what your adult

disabled child did. So that's another whole layer of worry that I have as a parents. I also happen to be an attorney. So I know about these things. And to have to not only worry about what your disabled child could possibly do on the premise or to the neighbor, but to have to worry as a landlord of what the other disabled children who may be living in that premise might do. That's very scary to me as a lawyer and as a parent. And as an investor in real estate that might house people with disabilities. So, --

Casey: Do you mind if I ask the story that you are talking about is that local, Rhode Island?

Gail Tarzwell: yes. That was North Providence. It was just decided by the Rhode Island Supreme Court.

Casey: Do you know if the person involved, if they were support bid the Division of Disabilities or DHS.

Gail Tarzwell: I don't know.

Casey: Thank you. Did you want to say something?

Gail Johnston: I am all set.

Jeanne Behie: Gail, I can put you in touch with a parent who's actually purchasing a home for their adult child and he will be living with some other adults with disabilities. If you want to just see how they are doing it.

Speaker: I think we do need some forum for exchange of what people are doing, how they are doing it, how's it working, what are the risks, what are the pluses and minuses.

Jeanne Behie: Actually Family Voices, which is a national organization with a state chapter in each state, it's for families of children with special healthcare needs. They have just started a family to family kind of center, where they are connecting families with similar interests or needs or desires to each other and they can communicate about these things, about the disability or about housing, about medical issues or things that are important. And I can get you some information on that. Or they also, I believe have a website www.familytofamily.com, I believe.

Gail Johnston: Thank you.

Casey: Okay. Once again I will open it up to floor. Anyone else who would like to address the panel with an issue or a concern or just a comment? Please, Jeanne.

Jeanne Behie: With all this talk about housing what I would like to say and I am only speak being myself as a parents with a child with a disability, but I heard just the effort it takes for these mothers that are here, for me, to really get the services our kids need. And it starts from birth, with dealing with the medical profession and then we go through school. And, you know it never ends. And as a parent, I am tired. I am tired. My son is 20 years old and I am tired. And I don't relish the thought of having him live at home in an accessible apartment. I want him on his own. So, you know, let that be heard too that there are parents out there, and I am sure I am not the only one, and we are tired. And we want more things for our adult children, but we really don't want to be so much a part of it.

Casey: Sure. I would -- as somebody who personally starts -- is starting to work with our support staff and people who -- I am becoming more involved in the voting process that if you are involved with a company thaw find out who their governmental liaison is and keep in contact with them because often we need to do movements, have rallies, and talk to people, to post card drives to pull families in on this type of work. So that's what I want to say. Encourage to see if they are currently involved in some fundamental group because it's

strength of numbers that make any kind of changes.

Ray Carroll: That's a good point actually. One of the concerns is the indifference. We are talking about public policy here and how can we move up the food chain, if you will, to get our fair share of the resources and there is unfortunately a fair amount of indifference and apathy of people not voting. Whether it's in local elections or national elections and so forth, which is of some concern basically. And we are moving through a period where we see, you know, 5 billion dollars a month going overseas to support the war effort, which is resulting of course in insufficient resources to fund the issues and interests that we have. So these are some of the pressure points and you know, we have jewels of information. I am thinking again we refer many people to the parent information network. Which is a small group that has vast knowledge and so forth. So you have to have this connectivity, even though we are in a high tech kind of environment and so forth, there is such incredible information overload that really you don't know where to go to get these questions answered. We also have a program that deals in assistive technology and we tried to put in place a hot line or a resource so if anybody out there has any issue or question pursuant or relevant to assistive technology, they can call and get some entree into where to get the information and so forth. But even though that initiative is going on ten years, it still is little known and I think kind of under utilized as well. So as we get inquiries that come into our office, we try to farm them out to other disability specific or issue specific hot lines so as you continue to dig and dig, you come up with a resource that can meet your particular special needs and as you said, it's great that we have some individuals express their views and it could be multiplied hundredfold by many that elected not to attend this evening. And last year, and the years prior, many of the same stories have been told and the fatigue factor, both from the parent view and from the provider view does, I have to say get one down because we have written white paper and done cost benefit analysis and you name it, with these particular issues. And then our chagrined as we move through the budget process, which just concluded here our recently that didn't provide the kind of resources that we would like to enhance home modification programs, enhance PCA program, programs that work that are tested, and yet don't have the kind of resources that are needed. So in any event, that's my own fatigue factor setting in and so forth. We get so irritated with our inability to tell our story and effective way we use economic development, personal stories, which I -- which we do use human interest stories. But it puts the spotlight on individuals and we are so sensitive to privacy and confidentiality, you know, we don't want to put people at risk in that particular arena. So part of it has to do with public policy. Part of it has to do with voting and making sure you continue to educate at every level the policymakers to assure that we get our fair share, affordable housing. All the issues that come up. We have a list like this. We heard a view from them this evening and we will throw them into the hopper again in hopes that we can once again be effective in getting legislation passed. The Medicaid infrastructure grant that was one that was very, very important. So people would not have to lose their benefits to take the risks of going to look for a job and so forth. Any way, that's just a thought. I get a little pooped myself and, I am glad Jeanne brought that out because that is a major issue that is not expressed all that often. Where people are really exhausted in trying to get through the bureaucracy, even though we have tried to streamline it. All we are doing are administering the law and the regulations that have been passed by our representatives in the congress and the general assembly. And it was interesting that, that issue you brought up with the parent, with the individual who had mental illness of some sort. That would -- that frightened me when that ruling was made and so forth. And I don't know what the impact of that will be. You know, down the line. But it really inhibits us, you know, from assertively moving some of these areas.

Gail Johnston: Gail Johnston. Talking about housing I saw some housing units at Crutchton Mountain if anyone is interested in that. They look like homes but they look like small homes but they were four handicapped accessible, total apartments with two bedrooms each and about six years ago I got the plans and I tried to build one in this area and I tried to go to the state and several agencies told them I would build it. I would pay for it but I wanted them to take it when I died. And they wouldn't. I ended up building a house just for Sabourin and I, big enough to have other people come and live with her when I die and have somebody stay with them, if they needed it. And what it cost me to build a totally handicapped accessible house was almost minimal added to the house. If there's some program we could talk to builders and just tell them the few things

they would have to do to start more houses in the area would be easily moved into without any extra money.

Jeanne Behie: And actually there's an article in today's paper about how people are not planning ahead for --

Audience member: Baby boomers.

Jeanne Behie: For becoming disabled as they become older and the chances are, most people will.

Gail Johnston: Many people have told me oh; you won't have to move out when you get older. No, but you would think most people would know they would want to try to stay in their houses if they can pay their taxes on social security. But it seems like it would be a smart way to build a house for resale, and everything else.

Jeanne Behie: You are absolutely right.

Gail Johnston: If that word could get out somehow.

Casey: I don't know if you are familiar with Access One, the company that's in South Kingstown that gentleman, he does try to work with various builders in the area but not sure -- Access One won. I forgot the gentleman's name he started the company a few years ago and serves a consultant to go to homes and tell them how to make the home accessible.

Audience member: He's handicapped himself.

Casey: He takes you to his own home, which is entirely accessible. Gives people tours. Audience member: a van with wheels, barrier free lift in the bathtub.

Casey: Anybody else would like to address the panel? Would the panel like to ask any more questions?

Jeanne Behie: Sabourin.

Sabourin Lussier: I think as a person with a disability, myself, I would want to stay in the home that is made handicapped accessible for me. And if the people don't have the resources for that, they should look longer and harder because I know some people who do not want to leave their home. But their homes are not handicapped accessible.

Casey: Sure. Okay. Okay. Well if there's no more comments I would like to thank everybody who did take time to come out and make comments and I would like to thank our panel members for taking time out of their day to come down and listen to everyone's concerns and issues. Again just to remind you within a month, you can go to the website I talked about earlier and find a transcript of this hearing and it will be shared with the general assembly. Okay. Great. Thank you very much everyone. Have a nice evening.

III. Public Forum, Wednesday, July 23, 2003, Newport Public Library

Sharon Kimbriel: Good evening, welcome to the Governor's Commission on Disabilities forum in Newport. My name is Sharon Kimbriel and I am moderator tonight and a member of the statewide Council on Independent Living. And as we start our meeting, there are a couple of things that I would like to remind you of. And one is that each speaker and that includes any of you who are going to be speaking and any panelists to please state your name and your organization, city and town. When you begin speaking. If you stop speaking and then start again, you at least need to say your name and that is so that the cart person there can have your name on there and when it's transcribed the transcribers know who's speaking as opposed to just not knowing

who said what. Now the purpose for tonight's meeting for those of you that don't know is to identify the concerns of people with disabilities and their families in order to assist the state to develop programs which improve the quality of life of people with disabilities. So that's the purpose for what we're here for. This is not a session of complaints and then feedback or panelists sticking up for their agency, or whatever. We're here to gather information, to discover what needs more to be done for the governor's commission on disabilities to improve consumer's life style and ability to get along in the state of Rhode Island. Oh, yes, we need to have a sign-up sheet. And we will all is from the commission, the governor's commission on disabilities and he's going to be passing around a sign-up sheet. If you wish to speak, then please put your name on the sign-up sheet and I will call you if we, we'll see how much time we have, I may need to kind of break in and say, we're running short on time, we want to give everyone an opportunity to speak. So, uhm, now, I will ask since I have introduced myself, I will ask the panel to introduce themselves and what agency they're from and we'll start here to my left.

Harriet Holbrook : I am Harriet Holbrook I am with RIPTA.

Sharon Kimbriel: Does everyone hear okay? All yes

Michael Spoerri: I am Michael Spoerri I am with the Department of Health and the Division of Special Healthcare Needs.

Marika Terlecky: Marika Terlecky Brain Injury Association of Rhode Island.

Annette Bourbonniere: Annette Bourbonniere the state rehab council.

Camille Pansa: Camille Pansa statewide Council on Independent Living.

Chris Reidy: Chris Reidy from Newport Mental Health Center.

Sharon Kimbriel: Any clarification on anyone in the panel is. Also, does anyone have a hearing problem? We do have the modifier here or adapter if anyone needs that. Okay. It would be very nice if people wouldn't mind in the back to kind of move up front so we fill things up. From up here, I feel like I have to speak very loud to make sure those in the back can hear. So if you don't mind, are there any questions that the group has as to how the procedure is while all is getting the people on the sign-up sheet of who wishes to speak today? Any questions on the purpose of what you're going to speak about? Our interpreter is Christopher Hoss and our court reporter is Sherri Viera. So we welcome them for coming and helping. May I have a raise of hands of how many people do wish to speak tonight so we can look at the time. 1, 2, 3, 4, 5, five people wish to speak? And the rest of you are here to observe? And listen I assume. If you decide you want to speak at any point, which I know I did last year at a meeting myself, then you can do that. But at his point, five people speaking and we have a little over an hour, so you're going to have plenty of time. The while the list is still going around, I would like to just call on the first person's hand I saw here, which is the lady right there in the black shirt, yes would you give your name organization, if you're from an organization and you can start.

RIPTA 1

Renee Doring: Okay, my name is Renee Doring and I am the parent of Megan Reynolds here who is 14 and-a-half years-old and she has downs syndrome. She recently started learning how to use the public transit system to take the bus to school and to her volunteer job and that's been going extremely well. And in doing that I was thinking of life for Megan when she's an adult and realizing that driving isn't an option for her knowing she'll be using RIPTA. I started thinking about how I am going to teach her about RIPTA. Basically, which buses to take where and looking at the RIPTA website I had a difficult time ascertaining what bus to take to get where she needed to go and exactly what bus stop to take. And so, I came up with an idea for a website that would supplement the RIPTA site. And what we would do is basically map

quest with RIPTA and we would provide address-to- address directions with RIPTA in the middle. And as a profession, I am a software developer for CVS pharmacy and I mentioned my idea to colleagues and they were interested in the idea and willing to help. And so we started to explore this project and, uhm, through exploration, we learn that had this type of thing actually exists for other public transit authorities. They have a website that they use. I really need to help Megan two things: I need the ability to find exactly what bus routes if there are multiple routes that will take her to an address within a reasonable walking distance. And I need to be able to identify all of the stops on the routes, not just the ones where you have a schedule listing, so that I can tell her exactly where to get off. And so, I don't want to go through the whole presentation but that's basically what my idea is and my friends at work are willing to help me work on it. And I have been in contact with Mark Sousa who will be presenting after and he likes the idea as well. He thinks it will be beneficial to people. Some of the challenges that we see I have already mentioned that the bus routes are difficult to read for me to even for me to find it let alone for my daughter to find places to go. I am a little nervous so I have kind of skipped around quite a bit. What we would like to see happen is for this functionality to be available in Rhode Island. And I am hoping that money is not going to be an issue to make it a reality and so, my team is willing to work on developing whatever solution it is, but we need to work with RIPTA and there might need to be other issues involved as well. We're willing to work at seeking grants to fund the project. And we would like to reach out to current RIPTA users to get ideas on what they think might be useful, because I have only touched on the tip of the iceberg in anticipation of my daughter using RIPTA and people now using RIPTA will have more ideas. So -- do you have any questions?

Audience member: I have something to say for that.

Sharon Kimbriel: What is your name?

RIPTA 4

Tim Rawley: Tim Rawley, I also take buses from Newport from the group home and back to Phoenix One and if you set up a spot where there's a spot that has a sign on the pole. If you have a good designation to be dropped up put a bus stop there in case of bad weather or whatnot. They'll drop them off, they'll have shelter if it rains or snow or whatnot. Have her friends or things write them a letter, stating where the bus stop is and maybe they can set one up. I've been in mental, I am 43, I have been in mental illness since I was 16 since the war, so there are a couple of good ideas. Bus stops and the little signs the bus drivers will see it. He drives right buy and he smiles when it goes by.

(laughter)

Sharon Kimbriel: Excuse me, the gentleman in the back, what is your name?

Donald Goyer: Donald Goyer I am from Middletown, there's a bus stop at the station but there's no cover. You stand in the heat and we start sweating and we are doing utility works and car traffic goes by, I think it would be really nice to put something like that up. It would save a lot of money taking the bus 4 dollars a trip. People pay 4 or 5 and it's all the traffic and all in Middletown packed up with traffic the snarl ups. I do a lot of work on the buses. I think it would be nice for the bus drivers to see the people standing here and say hi, how are you doing? That's all.

Sharon Kimbriel: Thank you; there was another hand back there.

Ray Petrucci: Ray Petrucci, I have been taking the buses and the only thing I can tell you is that if I had to stop this system and start a new system I would have the same problem she has. Because I don't even know how I started to do this. You ask somebody and it happens. And you're down there at a certain time and the bus comes by and it picks you up.

Sharon Kimbriel: Your name, sir.

Male speaker: Me?

Sharon Kimbriel: Yes.

Male speaker: From doing that, the patients although mental health, if they want a book tending or a place to put their fish aquarium or cabinets we build sheds for them. We charge them for the wood. That's a little hobby, we build furniture. We bring home about 800 dollars every three months between the three of us.

Sharon Kimbriel: Thank you.

Male speaker: Thank you.

Sharon Kimbriel: Any other comments concerning the transportation and the proposal that she has come up with and ideas.

Mark John Sousa: Hi, my name is Mark John Susa.

Sharon Kimbriel: Hi Mark.

RIPTA 5

RIPTA 2

Mark John Susa: I live at 51 Puritan Drive in Warwick Rhode Island. And I am the President and CEO of Accessive Community Transportation. And I teach people with disabilities how to take the Rhode Island public transit authority and I started with at the end of uhm, 1999, and into the fall time. So this is fairly a new program. I teach people with disabilities how to take the Rhode Island public transit authority and I am going to keep doing this for many more years. I also got contracted with the Office of Rehabilitation Services, which stands for ORS, and a lot of people with disabilities would like to get around for personal use. And no one is funded or trained to use. RIPTA fixed routes for personal use. And I have four problems: most people want more curb-to-curb transportation because, they don't know how to use fixed route buses. There are not enough ride buses and it's starting to slow down and run into that problem. And it also costs a lot of more money to use them than fixed route buses, which are canned cheaper. And after I train people, they can use regular buses, but sometimes they want to go to new places and they can't figure out which buses to take and the final one, they have learned how to use a fixed route bus, it would be good if they could go to the RIPTA web page and use a program that helps them make the travel plans independently and I also would like to add that this is the 21st century, and it would make more sense if maybe some of the RIPTA bus drivers for passengers like my friend, Megan, to have map quest, which makes most sense, in most cases. Now, the idea of mapquest we're talking about is getting from point a to point b, like for example we would like to know the following things: if we could get a bus closest to our house and go from there up to providence, and you can do many different things. Like one idea is site seeing. Also in conjunction of meeting with other buses, we would like to go to -- from Kennedy Plaza and get the nearest job address of where we would like to work. Like for example I used to work at the Trudeau Center, which was on the Post Road in Warwick. It's right near Apponaug Four Corners and now I am working from my house. Thank you for listening to me.

(applause).

Sharon Kimbriel: Thank you. And yes, your name?

RIPTA 3

Renee: Renee. I would like to add one of the things although I said the two thing that I need, is to be able to find the appropriate bus routes and appropriate stops, that would require my

assistance to help Megan where she needs to go. Additionally what would be nice to have is some type of time component because I anticipate Megan will have difficulties planning with time. Time is still an issue for her. So, the scheduling to leave your house at 7:40 to catch this bus at such and such a time which we get at Kennedy Plaza at this time and board the next bus at such and such a time, that would be important as well for her to be able to use it independently.

Sharon Kimbriel: Okay. Thank you Renee. Yes, sir your name?

John Susa: My name is John Susa I am Mark's father. I am here though, speaking on behalf of the Paul V Sherlock Center on Disabilities at Rhode Island College. I would like to address two topics. One is related to transportation, the other one is related to some Medicaid rules that we believe are barriers to employment. Both of these things that I want to talk about are employment related. The first is annually, the division of developmental disabilities does a survey kind of assessing quality of life of people with developmental disabilities and the most current result of that survey indicates that virtually two thirds of the people who were surveyed felt that they are not getting adequate support. And are looking for more support in all-different aspects of their life. There is a limit to the funding that's available to provide that kind of support understandably and when the survey queries about some aspects of the lives of some of these individuals they ask the question, do you get around to where you want to go most of the time? And 84% of those individuals said yes. When asked how they get around, the statistics indicate 68% are driven door to door by staff of either residential vocational programs. Another 14 and a half % are driven door-to-door by their families. 7 and-a-half% use any kind of public transportation, and virtually all of that is RIde door-to-door service. The reality of [RIde 6](#) these statistics indicates that when people use their service dollars for transportation, being driven around door to door at about 25 to 30 dollars an hour, that's a very expensive use of those funds and those funds then are no longer available to provide training for employment, for more independent living skills, all kinds of things. So we see that the problem of the inability of individuals with disabilities to access and utilize public transportation as a barrier to more independence because the resources that are dedicated to them are being consumed in providing transportation which is actually available through a much less expensive way through RIPTA, particularly people who use the ride program, not the ride program but fixed route program. So we would like to urge the Governor's Commission to look at this data and consider what from a policy prospective to encourage more travel training, like mark provides, right now he's provided travel training for employment purposes. Most people responding to this program are using transportation for recreation, leisure and personal use. If they used fixed routes for that purpose, these numbers would change and they would have more money to provide support. I know an individual who live in South County who uses door to door transportation by staff of a vocational program just to get back and for the to work here in Newport. And he has no help in shopping, no help in cleaning his house. No help in taking care of himself and he's in pretty significant distress. That's one issue.

[SSI Limits Work](#) A related issue, even when people are successful in gaining employment, particularly individuals with developmental disabilities, who are on the home and community based waiver, more individuals or the PARI waiver, when they work, they are limited in the amount of income they can earn by some Medicaid rules which say that for individuals who live in group homes, that are funded by the developmental disability, or through PARI, they are only allowed to earn \$169 a month above what they would have earned with the SSI. Any income earned above that has to be returned to the state to pay for medical care. We consider this a significant barrier. Who would want to work 40 hours a week, four weeks a month, and end up having to return almost all of what they earned except for \$169 back to the state. That's why a lot of people don't work. There's no incentive. There are some ways around these regulations. There's a way around these regulations for individuals with developmental disabilities. They can have their work deemed as a therapeutic experience, in which case, that \$169 limit can be waived. Virtually no one knows of that fact, and not everyone would agree that work is a therapeutic experience.

(laughter).

But that's the way the regulations are written. However, an individual who does not have a cognitive disability who's on the PARI waiver cannot even get that exclusion. So individuals who are on the PARI Waiver, I see are living in even greater degree of poverty, and they are often potentially much more capable of getting full-time employment. But this particular regulation is a significant barrier. So, we are encouraging the governor's commission on disabilities and all other appropriate government agencies, to review those regulations and maybe I will offer an opportunity to work with us to look at how we can change the regulations to remove barriers to employment and instead, put in incentives. The irony of all this is that the federal level, the barriers have been removed. These are state specific barriers. In federal employment policies now, encourage people with disability to say work, they can earn up to several thousand dollars a month without losing Medicaid. Once your income has exceeded 169 dollars in Rhode Island you have to give it back anyway. If the commission could look at that we would really encourage it. Thank you.

Sharon Kimbriel: Thank you.

Female speaker: I don't know if you are aware there's a movement to get Medicaid legislation passed in the state of Rhode Island.

John Susa: I am aware of that but that has nothing to do with this particular regulation. The regulation is a regulation that has even if you're lucky to buy in, you then become subject to the regulation and you can not make over 769 dollars so it's a catch 22 situation for those people on these particular waivers, the PARI Waiver and the home and community based waiver of DDD. If you're not on the waiver if you have a disability of maybe an emotional behavioral mental illness then the Medicaid buy in would work very well and that would not apply. But people on the two particular waivers, no matter what, would end up, you know, are really not being encouraged to work.

Sharon Kimbriel: Thank you, are there any clarifying questions?

Marika Terlecky: Is this supplemental information.

Sharon Kimbriel: Yeah would you give your name?

Marika Terlecky: Do you know what year the federal regulation barriers were removed?

John Susa: Last year. Starting last year, they've started all of those Ticket-to-Work and the relaxing of the Medicaid not the Medicaid but the SSI rules. It's possible to continue to keep Medicaid if you've been on SSI. Several years after you start earning significant money, but if you're receiving medical assistance in Rhode Island even though the federal government lets you keep it the state government will take it from you.

Marika Terlecky: Is there any state that has made some success since this has happened that we can use for a model for to see.

John Susa: Some states in the west, Washington State, Oregon, that 769 dollar income limit is a state determined number and some states have a much higher number than that into you know, 1,000 or several thousand dollars. That's going to be a decision I believe could be made at the state level. It involves DHS, it involves probably ORS and would definitely involve the general assembly and the Medicaid, federal Medicaid people because they're all kinds of usually formulas developed many years ago to figure out what that cap is.

Marika Terlecky: Thank you.

Sharon Kimbriel: Thank you. Okay. Kelly Reed, excuse me, sir, you had a-

Respite Care 4

Kelly Reed I am a parent of a special needs child who has an involved medical problem and I have run into a snafu of respite services. It took me a long time to get approved for it and it's confusing to find out who's eligible what you're eligible for, and from most parents I know, and my daughter is on title 19 and I recently received a letter from the Department of MHRH telling me this particular program has been transferred over to Department of Human Services, there will be no change in your program, we want you to know it's changed from MHRH to Department of Human Services and then there was another sheet behind it by the way your respite services are now significantly reduced. And I can't get anyone to explain why or tell me what's going to happen. The person who signs the letter didn't know the letter went out. It just seems to be a lot of confusion within those two departments of what at least from what I am aware of, children services of what's really out there and who's eligible and it's very hard to get an answer from anybody. When a change like that happens and it does effect you, I can't get any reason behind it, I can't -- it's very frustrating to deal with the state on these kinds of things and get straight answers from people.

Sharon Kimbriel: Thank you any panel members want clarification?

Michael Spoerri: What was your name?

Female speaker: Kelly.

Michael Spoerri: I don't know directly, I can find out for you.

Kelly: It is a big issue of parents trying to get the services and then getting this letter within the letter it's odd. But that's typical of how services while dealing with the state on getting services for your child, how to get therapy, who does what, try to you can talk to Medicaid and find out what Medicaid covers for additional supports and things, I get educated through parents and my pharmacists, I do not get educated by the state. They say everything is supposed to be easy access, the social worker told me she didn't know what the Katie Waiver was .I think it would be great for people to find out, I have an almost 15 year-old listen to what you're talking about and where do we fall under and what does this mean for me. I am sitting here thinking there's a lot more to learn and it's only by meeting other people not by professionals educating us and there is no handbook within the state to walk you through these things. It's difficult.

Chris Reidy: Chris Reidy Newport Mental Health, have you connected with one of the CEDARR Family Centers?

CEDARR 1

Female speaker: Yeah, but you know, they haven't exactly impressed me to be honest with you. I find it just another way of dealing with the state again; do you know what I mean? They talked about having a great center and each center would have all of these professionals help you access the system.

Chris Reidy: But have you gone in and actually gone through a case review process?

Female speaker: I didn't need to because I had already been established with a home program and I had everything up and running that I did by myself.

Chris Reidy: And you were approved for respite services?

Female speaker: I was approved for 180 hours.

Chris Reidy: But there's no provider?

Female speaker: I found my own provider and I had a letter saying by the way you now have 38 and it was just like by the way.

[CEDARR 2](#)

Sharon Kimbriel: The lady right behind you do you have a question?

Chris Sumar: Chris Sumar and I have an 11 year-old autistic son and we have been working through Katie Becket and the EPS federal grant moneys to have a wrap around home service for our boy. The past couple of years I have noticed much more stringent dividing of the hours and in the last year, every time we put together a new prescription which is a treatment plan with the agency, that's working with my son, it takes months for us to hear back, which we get two line blurb on what's not been accepted where the agency gets the full written blow by blow and then we have to go through an appeal process. The appeal process we go before the Department of Human Services and currently, you're addressing not the people who made the decisions other people with the attorneys for the state, with the lowly parents who have to present why they feel that their child's situation justifies the hours. And frankly, you don't even have the accurate information to counteract what they said in the denial because you didn't get the full denial, you got the short two-line version, that instead of getting this amount of hours you're going to get with my sons it was a weaning thing, instead of a 40 hour program, he was going to have 32 over the next month 28 and by this September he would end up with like 10 hours. My son is severely autistic who does very well with this program. It really enhances his life, brings out his potential, it's educational, it's community oriented, it's safety, it's language, his word production is so much more when we have the therapist in the home, and not that the family doesn't try because our life is focused around this boy, and we have our life and another son, but I feel that the state is making it so hard for parents and in fact, we couldn't get a case to be appealed until September which before our last appeal was within four months. Everyone's been getting cut back and frankly, I feel very annoyed. I feel like it just comes down to the dollar that uhm that it's taxing the family, to the point where it would be potentially that my son would not be able to live at home and that is not what we want. But I can see as he gets bigger, my son is a big kid and stronger that it could come to something like that and I think that would be as a result of this weaning process. So I am just here to voice for my son and these other parents who I know and have talked to who have done the hearing thing, that I think this is a real mistake on behalf of the state. They're paying for the lawyers to be there. They're paying for the people to sit before the hearing and they're holding back on the kid that needs it. It doesn't make good financial sense to me. Not to mention that if we get denied we have to go to court and at that point we'll have to hire an attorney at our expense and it's not that easy you know? It only makes our life even harder to manage my son you know? He's a great kid but you can't be in the next room with him like not in the same room with you. So that's why I am here. I think it is a big mistake. What we don't pay in the short run, we'll pay in the long run.

Sharon Kimbriel: Thank you.

Female speaker: You're welcome.

Sharon Kimbriel: Catherine Max?

[netWORKri 2](#)

Catherine Max: My name is Catherine Max I am a community planner and educator. I am here to help find solutions. My business is to help find funding particularly federal funding for programs, state agencies as we all know are being asked to do far more, with far less these days. Some of the most exciting new programs and opportunities are related to what Mr. Sousa has been talking about and I am sorry, Megan's mom as well, with regard to removing barriers to employment for disabled people, transportation, as we know is one significant barrier. There are others. I am not a client of Department of Health or RIPTA I am an interested person. I am not here with all the answers, but I know that there are solutions; there are solutions at the federal level, which Mr. Susa referred to. They are offered primarily through the United States Department of Labor, the disability employment initiatives program. There has been funding this is the second year of funding for pilot programs that seek on that allows states to seek innovative

solutions and develop programs that remove institutional barriers, physical barriers to full employment opportunity, for people with disabilities. I only have one suggestion, I have listened and learned quite a bit tonight I am interested in providing solutions particularly through obtaining federal funding which is my specialty, I would urge only this, that as advocates for people with disabilities, that community members at large and agency representatives to urge the state department of labor to become actively involved with disability issues and particularly with removing barriers to employment for disabled people through as you mentioned the ticket to work program, school to work transition programs for high school students with disabilities; many states there are 8 states so far, who successfully competed for funding and establishing programs for state clients right now focused on removing barriers to full employment for people with disabilities. There is a U.S. Department of Labor program offered through of course through state programs, but to take full advantage of some new initiatives at the federal level, to remove barriers, to fulfill employment, the state Department of Labor particularly through the one stop centers really need to become involved. Also the department of education, the federal department of education has established because I think new programs, the state may take advantage of but forgive me if I am not an experienced or knowledgeable speaker on the subject, but it appears that perhaps state agencies might become more competitive on behalf of persons with disabilities that certainly would take some organization and some push on the part of those interested and the organizations that support people with disabilities. The programs are out there. They do exist. Mr. Susa seems to be well aware of them. The Department of Labor state Department of Labor and Training would benefit the disabilities community in efforts to transition from school to higher education; from higher education or from school to work; and from work to utilizing the benefits that and the advantages of living in a larger society has to offer disabled people. But it takes partnering I believe with the Department of Labor and Training as well as RIPTA and the DOH and Department of Education and other state agencies who traditionally in the past have served the needs of the disabled community. The Department of Labor is potentially a new partner. I suggest strongly that the council look at including the Department of Labor and being active with the department of labor to help realize a new future for people with disabilities. Some of the current barriers, the shock to my way of thinking, income barriers that have been erased at the federal level. It's shocking to me to find out, tonight, that there's another layer of state legislation that there is a disincentive for people with disabilities. Thank you.

Sharon Kimbriel: Thank you. Excuse me, yes, what is your name? Would you like to make a comment?

Wanda Mainelli: Wanda Mainelli. I am interested in finding out about physical disabilities because I have two baby brothers born prematurely and they're tiny and one of them has a dissipating collarbone from a fall down the steps that he made as a child. He had legwork. They're both very bright and both attended college and they're capable of doing heavy mental work and one works for Raytheon as an engineer and the other worked for Bausch and Lomb and attended Mitchell College. One worked as a mechanic but I am afraid, he because he was only 2 pounds when he was born.

Sharon Kimbriel: Thank you. Excuse me, the gentleman in the yellow jacket in the back has had his hand up several times and I passed over him. Give us your name please.

[Ride 6](#)
and
[RIPTA 6](#)

Bud Cicilline: Bud Cicilline and I am from the Newport County Mental Health Center. First I want to say thank you to the commission for coming out and listening to the concerns about what folks are saying. I also want to support the statements and comments that were made by people so far particularly Chris who makes a very good case. I also want to say thanks to the consumer that I know who are here like Ray and Paula and Tim, Don and Joe. The issues that are being discussed tonight are pretty familiar, transportation has been mentioned I think we started with that and that's been a perennial issue, it's statewide particularly for people with disabilities. We've worked with RIPTA ourselves but as many have often reflected in meetings I attend it's not as good as it can or should be and we would like to see an improvement in that area. As I was sitting here I was making a list, one of the things we would certainly want to see happen more often is employment. And we would like to see the development of employer friendly list of people who would be willing to hire an employee a person with disabilities. There are

some but not nearly, as many as there ought to be.

Housing 2

There's also another issue that does effect the population that we're working with and concerned about is affordable housing lots of times people want to have some options and be more independent, and the options aren't there. We think that's holding things back. Still another issue that I hear when I go to my monthly meetings from some of the folks is an opportunity for more leisure time activities. That's something that is mentioned repeatedly and if there were some volunteers in the community

Respite Care 2

who would be willing to organize some activities, there would be a number of people who would attend. Respite for families is also an issue. That's an ongoing issue particularly for the families that take time out and take care of folks. The state doesn't realize how much this means not only to the individual on a personal level but also in a financial way. If all the people who are caring for children and other family members with a disability, and say it's not our responsibility and you're eligible for this program and that program, the state would cave under I think. These people are doing a tremendous job. We should give them some support and certainly respite isn't anywhere near where it ought to be. There are other concerns nationally that I think we have to be mindful of. We've seen some initiative to privatize Medicare and Medicaid might be around the corner and I think we have to be ever vigilant not to let that happen because I think it can and might have the way these programs get dealt with at the state level. The eligibility may change state by state. Another thing that we watched from a distance is the United States Supreme Court changing the rules with respect to the Americans with Disabilities Act. They modified it and modified it to the point where some people may not be as protected. Fortunately in Rhode Island we passed a law saying that the original ADA is what holds for Rhode Island residents. Whether or not that will stand federal challenges later on I am not sure. Back to something, I am not sure that we have this, but there are plenty of cities all over the country that are disability friendly with respect to mobility, getting around and there are curb cuts and things of this sort that make things easier for people. I don't know if we've done enough in our own state with respect to that but look at new project especially in the projects that the State of Rhode Island undertakes to have this requirement of things being disability friendly. We passed the legislation to construct bike paths along roads. Correspondingly we should be doing something like that. Lastly I would like to raise a question about the status of the job core program. It's supposed to be happening in Exeter and where that might be and if the commission would look into that. Particularly to see if there's an opportunity for us to see the job core slots that will be there in the future that some are specifically marked for people with disabilities. Thank you again.

Sharon Kimbriel: Thank you, okay. Don Goyer.

Don Goyer: Are there any people that people put money aside in insurance that get. I ended up putting away life insurance and buying a house with it. I had to close my business down because. But I think one of the most things in pay is to put some money aside for like vacations and things like that or use part of your SSI check. Mine was by the hour at work. I worked in machine shops and foundries. I had enough money for like cards for my friends and hot chocolate and I think it's worthwhile. If I had to do it over again, I probably would do the same thing. Annuities, like put a certain amount. You don't have to die like in insurance. That's about it.

Sharon Kimbriel: Thank you. Mr. Turner?

Mr. Turner: yes, that's me. I just came really to listen to try to understand what's going on. I was in a group home at one time. I had schizophrenia and I still have that illness and I have been over in Slaterville and they've got me on the right medication. So my life has just been getting better and better all the time. Maybe it's my faith in god and faith in the system. I just have been pretty lucky I guess you could say. Bike paths that would be great for Middletown I think. Because I do work. Before I got my job at Wendy's I was working over at the uhm, at a church ten years doing bathrooms for an hour, scrubbing toilets and graduated up. The lady there said that the manager that hired me said you scrubbed toilets for ten years and I said yeah, I did. She said we will take you. Thanks

(laughter).

Mr. Turner: I got my own house now, I got my own house with two other people Ray, the guy that lives with me and that other guy named George. He lives with us. We just we have bad times and good times like usual, but the thing is we have subsidized housing too, so it's low income. So my story has been a success story but like I said, I came to listen and maybe someday be able to help others.

Male speaker: I have something to say on that.

Sharon Kimbriel: thank you.

Male speaker: Me and Joe go back two or three years, Timothy, me and Jim go back we got a job at Wendy's and that was Monday he said Joe it's pizza day, he said when the moon hits you he said what is your name is in Italian. What is Joe, gusep. So we're really good friends like that. We're a big happy chran there. So-

Sharon Kimbriel: Thank you.

Male speaker: You're welcome.

Sharon Kimbriel: Everyone that signed up that wished to testify has done so, are there other people that have something maybe that's come up in your mind since you've sat here and that you would like to speak to? Yes, sir, what is your name?

Ray: Ray, I just listened to all the problems that I hear over here and I just wonder if there's enough money in this country to help people any more than they have

Sharon Kimbriel: Thank you. Any other comments or questions to the panel?

Donald: I am Donald even 150 would be helpful. I am only getting like 200 dollars a week, and I am running a house t. Leaves me with 30 dollars a week that's all I have got. But we have a great staff. I bought a great brand new guitar. I have a 65-dollar -- (inaudible).

Sharon Kimbriel: Thank you Don Yes.

John Susa: I am wondering,

Sharon Kimbriel: Your name again?

[Trusts](#)

John Susa: John Susa I would like to respond to this gentleman and comments he made also. In the state of Washington, they have recently enacted a program that allows individuals with disabilities to shelter their earnings. Just like CEO's of major corporations. They have created specialized trusts that allow people with disabilities to take their income, shelter it for future use, like retirement or some other use and then have taxes and all of those other you know, provisions applied at that time so they don't lose eligibility for Medicaid or SSI or whatever, or for the rest of their families. In fact, in Washington they're actually being proactive about this because for every 4 dollars an individual earns and shelters, the state government will add in an additional dollar. It would be a wonderful thing to have here in Rhode Island. I don't believe it would cost a lot of money, even if the state wanted to be more citizen stingy they wouldn't have to put in that dollar. Let this gentleman work as many hours as he can and because they don't want to bounce him off various programs, they can pay him his legitimate value as a worker, he can take the money shelter it and use it in the future including into his retirement. I would like to talk to anyone about that. I know a little bit

about it.

Male speaker: I have something to say.

Sharon Kimbriel: Excuse me give your name.

Male speaker: My brother-in law went over to Italy and I told him if you get Italian dollars and bring 1200 back you get twice as much here in American. He got like 2400 in American money. From 1982 to 1991, he owned the brick marketplace. The storage manager, the place setter, I did everything for him and all I had to do was go in. Every Saturday night there was a 40-foot tractor trailer truck, bring it down 40 stairs, stock it and mark it, put it on envelope, store it in packages, wash the windows, doors, vacuum, clean, stock the shelves, when he came in everything was ready for him. It was like 3 dollars an hour all the rest of my friends were on welfare. Thank god for Newport Community Health.

[Safety Training 1](#)

Renee: This is Renee again. And I am not sure if this group of people can help me with this, but one of the concerns I have with my daughter is as she becomes more active in the community, she is going to be out in public and I am trying to find a curriculum or some training materials. I don't want a trainer, per se, I might want that eventually, but I want to know what things should I teach my daughter to keep her safe? Similarly, I have looked on the Internet and I have seen lists of things that universities teach their students or students can read to be safe. And I think I mentioned this to Claudia Lowe from the Down Syndrome Society and she brought it to the Developmental Disabilities Council and one of the things I thought we might be able to do is develop a program where we could have a small group of people together and maybe train them on some things and one of the things I was thinking might be fun would be to train them on observation skills, such as being able to identify characteristics of somebody that they would need to tell the police officer, should something have happened to them. I don't know what other things I should teach my daughter but that was one thing I was thinking that a group might be able to teach her, that I might not be able to teach her myself. I live in providence and have approached the school department my administrator and she was not aware of any curriculum that Providence has to teach this. And I have approached the TASH program on the web and they're not aware of anything on public safety. I want my daughter to be aware of society and she's been that way throughout her life and I want that to continue but I want to make sure I've prepared her for that experience and so I really, if anybody has any information that would help me with that goal of mine, I would appreciate it.

Male speaker: I have a couple of things.

Sharon Kimbriel: could we hold off on that until the woman behind you who hasn't had an opportunity to speak? What is your name?

[Housing 3](#)

[Medicare 2](#)

Karen Bell: Karen Bell I am physically disabled and on SSDI. I am sorry to be here late. My two major issues are housing and medical. Luckily, I was fortunate enough to get my SSDI on the first try, which a lot of people don't. Now I have to wait two years for medical. I have a chronic incurable disease so medical is kind of important. Housing, once I am on SSDI the housing shortage is phenomenal with a two to ten year wait. I don't know what people are supposed to do during the two to ten years. To me those are major, important things. If you get on SSDI you need to wait two years to get on medical. Someone who is disabled needs medical and the other is housing. I don't know if those have been discussed but those of my two major issues.

[Audible Traffic Signals](#)

Sharon Kimbriel: All right. Thank you Karen. Are there any questions the panel would like to ask for clarification? Are there any other comments that we need to have to the governor's commission disabilities concerning what the needs of the disabled and their

families are? What is your name?

Liz: My name is Liz. What I think we need more of I know providence has it, with the stop signs and lights and the bells that go off, so whether somebody could either see or hear it for the crossing, we don't have it down here on the island and I think we need it here. So I felt that was very strongly for that to be addressed.

Sharon Kimbriel: Thank you. Points of clarification? Yes, Donald one more comment here.

Donald: When I was in school at Bryant College I was on the dean's list, we chose different way to see break our money. In the school like this there's must be a school around here, like that does mopping or cleaning dishes and eating all kinds of goodies, they give the people here enough money to go home and buy like either food or soaps or laundry stuff like that and it's taxed legal. They have the book it's called cost accounting and tax media accounting. I did four semesters and majored in Accounting. People say it's brilliant but Bryant College is like the name of the game. If you don't have a business to deal with where is everyone? Bryant College is way out there. I used to drive my truck in get 50 dollars an hour to drive a truck there and back and donate my money back. I was working 70 hours a week and give 40 hours a week to like boy scouts or elderly people who need money. I would like to sign up to do a day shift treatment here at this library if I could get a ride in and explain to people or maybe like a board of canvases or jury or whatever.

Sharon Kimbriel: Thank you very much for your offer. I would, excuse me I would suggest there's another half an hour of time until this meeting is over. If there are no further comments for the commission of needs that you have and I will check with you in just a moment, that I would suggest that we formally close the meeting but people who want to get together and discuss things possibly to do that, some of the information we're having is personal information, it seems like the commission might not be involved in, but some networking among people could happen here. So I would ask you to tell your name again.

Wanda O'Mally: Wanda O'Mally actually I have three brothers with disabilities. I am the healthy one. I was the firstborn.

Sharon Kimbriel: Okay, any other comments for the Governor's Commission on Disabilities or questions for the panel members themselves?

Male speaker: Yeah, when's the cookout?

(laughter).

Female speaker: They need funding.

Sharon Kimbriel: Yes. Okay. Al is there any comment you would like to make from the Governor's Commission on Disabilities?

Al Tardie: No I don't have any comments. We'll put this together and work on it.

Sharon Kimbriel: In case you don't know, I don't know if you know what happens here, but this is all written up and all the meetings around the state, there are five meetings this week, the recommendations are taken from the transcripts and they're printed and sent to the state and congressional officials, members of the general assembly, they're posted on websites and the governor's commission on disabilities hopefully will have some posting on their website in about a week after this is all over. We ought to give them a little more time than a week maybe, and hopefully, some of your suggestions and I think there were some very proactive comments that came in that can be very helpful to the commission and I want to thank everyone for coming and stick

around and talk among yourselves and if there are panel members here that don't have to leave right away, maybe you can speak with them.

Male speaker: I wanted to know if you can give him a camper trailer for his backyard.

(laughter).

Sharon Kimbriel: Thank you all for coming. Folks, we will be staying here until 7:30, so if you want to continue.

Sharon Kimbriel: Excuse me ladies and gentlemen, it is now 7:30 and the meeting is officially over, thank you so much for coming and giving your input, suggestions and comments. See you next year.

IV. Public Forum, Thursday, July 24, 2003, Warwick Public Library

Lorna: Hello welcome to this afternoon's public forum. This is a public forum put on by the Governors Commission on Disabilities working with many sponsoring agencies around Rhode Island to make it happen and I thank you for being here today. I am Lorna Ricci. With us here today are our panelists. I am going to through some, maybe joining us a little later but right now with us, Sue Eleoff from the Ocean State Center for Independent Living. Susan Stenhouse from the governor's office, Deputy director office of the governor community relations. Also, Dennis Costa and I can't see further down. I am visually impaired so bear with me. We have with us -- I will be reading your name Michael Spoerri from the division of health. Kristin Connors from the office of James Langevin, the caseworker there and last -- next to last is Kathy Herin and Steve Florio from the Commission on the Deaf and Hard of Hearing. Also joining us and I am going to be jumping around just to be able to tell you who might be coming hopefully will be Paul Choquette from the -- representing the Governor's Commission on Disability and also he works for PARI independent living center, also we are expecting Nicole Rossi from the Statewide Independent Living Council and Lisa Labitt from East Bay Collaborative. Anybody else that joins us, I will make sure they are introduced. The important thing today is to make sure that if you are going to be testifying, that you have signed up. Also we need to have you sign up if you are just present here. We are trying to make sure we have a count. Has there -- is there anyone in the room that has not signed up at all, either just for coming for attendance or wanting to testify? Could you raise your hand? Great. We have assistive technology to assist those who may be hearing impaired. We have a listening device, should you have a hearing aid, and wish to hear better -- yes?

Donna lee: I am showing the device.

Lorna: Donna Lee is showing -- you need to see Donna Lee and we can make sure you are all set up to hear every word that is said today. We also have with us two sign language interpreters, Rosa Norberg and Jen Maloney who will be interpreting for the deaf today also just a little housekeeping, should you need the phone, the phone was to the left as you came in the main door in the back. Rest rooms go out this door to the right. We are very relaxed atmosphere in here. We have wonderful coffee shop up as you came into the right, if you did not see it. As you came in there was a coffee shop there. You are free to get ice coffee and bring it back to this room. That's perfectly okay the purpose of this forum today is to identify the concerns of people with disabilities and their families. In order to assist the state to develop programs and services to improve the quality of life of persons with disabilities all the transcripts of the day, basically every word that you see on the screen here is going to be put into a publication, something like this. This was last years. Every single word, verbatim. This transcript is then made available to legislators, or all of you. You could actually see this maybe a week from now on the governors commission website, that's gcd.state.ri.us you can actually see that in about a week it should be ready. Sponsoring agencies going back one step, what will happen with everything that's said today and on the other forums happening all week, the sponsoring agencies are going to be looking over all of

this testimony and grouping the testimony according to issues and subjects. This testimony will then be provided to legislators. This is how policy is changed in our state. You, members of the audience today who will be testifying, could actually be making some major public changes and think of that as you are speaking today because, this is a very powerful time, a very powerful chance for you to present your issues. The meeting process first of all, we want to give everyone here a chance to speak. I would encourage people to keep your discussion to about five minutes. Try to be brief, to the point. Please, at the very beginning, always state your name. The organization you represent, if you do. And the city and town of which you live. Please, the audience and panelists do this. The reason is, the stenographer, the court reporter will be taking down your name as it goes into the public testimony, in the past, we just had "panelist said, we are actually trying to have the testimony start with the person who actually made the statement. Panelists are here just to really listen to what you have to say. They are here to listen and gain an understanding of some of the concerns of people with disability. They may ask clarifying questions, if something is not clear, you can ask a question. You will have that chance at the end of the public testimony. However, this is not a debate, as I said we will ask you to speak in order as you signed up. If you are not sure of the order you can go right back and ask Leslie, she has everybody's name she will be giving to me to be able to read who will be next. Again, you will have about five minutes to speak. Leslie also is our timekeeper. Leslie, give a raise. There she goes. Check it out. She's the one who will keep you to task. If someone begins to run over, she may be actually asking you to wrap up your testimony. We are trying to end this session on time at 3:00. 5:00, sorry, 3 to 5. Oh, it's over. You all missed it (laughing) written testimony is also acceptable. Should you be in the audience today and hear a concern that really affects your life that you wish to add but maybe you are a little shy to testify, I do ask that you testify today. This is your opportunity. However, I understand people sometimes are nervous about speaking in public. You can write down your testimony and submit it to the governor's commission on disabilities by July 30. And the address is available on their website. It's cherry lane in Cranston. Are there any questions? Excuse me?

Audience Member: 41 Cherry Dale Court.

Lorna: If you can't remember that you can call the Governor's Commission on Disability or our office and we will make sure you get the address. You can also e-mail your concerns to them. Are there any questions on today's procedure? Great. Then we can move forward. Our first testimony of today is Richard Gaffney. Richard.

[NewLine 1](#)

Richard Gaffney: Good afternoon and thank you for allowing me to testify here today. My name is Richard Gaffney. I am the President of the National Federation of the Blind of Rhode Island and I reside in East Providence, Rhode Island. We are here to talk a little bit about a program that our national office sponsors, and that's news line. Now, NewsLine, we had legislation in last year. Unfortunately, it died in the house committee. But what news line does is it provides access to over 85 newspapers across the country, to those that are print handicapped. Not just the blind. At one time it was called news line for the blind. Now it's news line for the print handicapped. And what -- the way it works is you would call in to a toll free number, it's a centralized number out of the office of the National Federation of the Blind in Baltimore, Maryland. And what they do, you would have a 6- digit code you would dial plus a four-digit security code. Once you dial into this number, you can access any newspapers. The journal up unfortunately is not on there yet. But any of the newspapers that are there, you are given a menu and prompts to go where you want to go within those menus. For example, if you want to say the Washington Post. Number three was the Washington Post. You would hit 3. This is all done by telephone. Once you hit 3, then you want the editorial section, they say number 5 is editorial. You press five. And go on from there. There's a way to go forwards, backward. There's a way to spell a word. And why do we think this program is important? This program is important because it provides access to newspapers for people that are no longer able to read print. Either those that are blind or those that, seniors and are losing some of their vision and have a hard time reading the regular newspaper, and also those people that have severe disabilities. They can't hold a newspaper. For example, someone with Arthritis, let's say, can't hold a newspaper. This would be beneficial to all of them.

Another reason is it would allow -- especially the visually impaired. Those of us that have been vision ally impaired all our life haven't had access only to what we hear on the radio and on TV very much to the newspaper. This will provide access. It will make the blind and those that haven't had print access more informed voters. Also it would allow some of us to look at want ads in the paper and perhaps become employed and reduce that 74 percent unemployment rate that's currently among disabled groups. So we feel the program is a valuable program. My vice president Barrie Humphries is going to talk about using the program. He's used it quite a bit. I used it a time or two and enjoy it very much. And it's really amazing you can get on and read all these newspapers all across the country. That's all I have to say unless anyone has any questions.

Susan Stenhouse: What's the cost?

Richard Gaffney: The cost to our national office we would have to pay like \$50,000 a year. That would be that cost. Now the way we wanted to do this last year, and the way we want to go with it again this year is we were going to ask that penny surtax be charged to telephone lines in the state. That money would be paid to the state agency for the blind and visually impaired and they in turn would pay the bills to national, and also there would be an additional administrative cost for them. And also have enough money with adding that penny tax to do marketing. We are going to market the program and get more and more people interested. We currently have on our active list in Rhode Island right now 65 people that are participating in news line.

Lorna: Thank you before we move on to our next person, I would just like to recognize Kathy Herin who is from the Alliance For Long-term Care. I didn't give her title. I think that's very important for everyone to know. Also I would like to recognize Andrea Castañeda, she's a staff person from the Governor's Commission on Disability. Have a peak at Andrea. If you have any questions after the testimony, you can call the Governors Commission and talk to her. She's in charge of all the forums. Next we will hear from Barry Humphries

[NewsLine 2](#)

Barry Humphries: Good afternoon everyone. My name is Barry Humphries, Vice President of the National Federation of the Blind in Rhode Island and I reside in East Providence. I have used this service off and on for a year. It has brought a new understanding of the world around me and especially was helpful during our recent war in Iraq. Interviews, exactly what was going around Iraq and the terrain and damage and it gave me an excellent picture that you would not get on TV or public radio of what was going on there. And is still going on. On the lighter side, it also gives -- I also get entertainment reviews and just general entertainment news from a variety of sources, from the New York Times. That's my favorite and U.S.A. Today and a variety of other sources that's something I never enjoyed when I was growing up. And once in a while I check financial news. This would be especially important to wanting professionals who are in that field to get up to date information they need to do their jobs each and every day and help them become better informed citizens. I would hope that more and more people would be able to use this service in the future and it would also have -- we are able to have locally funded. I was one of those who testified this year on legislation, it was unsuccessful. But I hope in the future -- I have faith that we will prevail and with your assistance, I think this will happen. Thank you.

Lorna: Thank you, Barry. I will also like to inform you that Nicole Rossi has joined us. She's from the Statewide Independent Living Council. Next we would like to hear from Thomas Daniels and after Thomas will be Kathy Podgurski. Thomas

[Early Intervention](#)

Tom Daniels: Good afternoon. I am Tom Daniels from Warwick, Rhode Island. I am here on behalf of my son Ian, who is 34 months old. I believe it was January, he was sent to early intervention at Trudeau. Since then I have had a very rude awakening to governmental red tape. I am sorry Kathy you said you were from long-term care.

Kathy: Yes.

Tom Daniels: thank you. So-called misinformation regarding papers that are needed for a diagnosis for my son to find out whether or not they have Autism? I guess -- I really don't know where to turn. That's why I am here to speak to you. My wife and I have been trying very hard to deal with whatever problem he is having trying to get a diagnosis. It seems to me that the people that are supposed to be there with these programs are actually -- actually not helping him. So we are feeling that we are getting -- we are dealing with his problem and he becomes very physical with us. And when we turn to the people that are supposed to be there to help us, we are getting mentally just devastated, both ways with everything that's going on. Recently, I have actually had to contact long-term care where I ended up being told that after repeated misinformation -- that misinformation happens. To me this is unacceptable for anybody, not only the state. It doesn't matter who it is it's unacceptable. Misinformation does not happen at all. There are reasons for it. And those reasons I don't know. I don't know. I mean I have just -- I am at my wits end. Thank you for your time.

Lorna: Does anyone have anything they would like to say to Mr. Daniels?

Michael Spoerri: I am here representing students with special opportunities so I would like to talk to you afterwards, okay.

Lorna: Steve, did you have anything you would to say.

Steve: Not the issue of autism.

Lorna: You put your hand up, I call you.

Sue Eleoff: Sir, you can also call the OSCIL office and maybe we can find some advocates or resources for you, to help you -- because you shouldn't have to do it all alone.

Tom Daniels: Thank you.

Lorna: Mr. Daniels, that information can be obtained at the back, along any one at the back can give you that number.

Tom Daniels: Thank you very much.

Lorna: Kathy Podgurski

[Personal Care Attendants 7](#)

Kathy Podgurski: My name is Kathy Podgurski. That's p- -- as in Paul -- o-d- -- as in David -- g- as in George -- u-r- -- as in Richard -- s- -- as in Scott -- k-i- -- as in Isaac I live in West Warwick. I am here today. I would like to thank you for the opportunity to speak with you today. I lived in section 8 since 1979, January. And I am able to deal with that through the Medicaid waiver that PARI offers. Right now they only have limited slots around. We would like to see that increased to 50. There -- 80 slots excuse me in one city, in Cranston -- without the - sorry I would like one of the slots -- there are a lot of people who could live better, more independent lives if they had somebody to take care of them. My family has paid their dues. They have always been there for me. They took care of me for the first 27 years and it's time for them to take a rest. With the PCA, 60, five hours a day. They don't have to worry about issues sleeping, other things that families worry about my biggest fear is that without the increase of the PCA program and a lot of people, including myself, could end up in a nursing home, which is not a viable option for me. I wouldn't get the care that I am getting with the PCA right now. Vca -- I have their number. I can call her and say, I need help, come get me. My parents and family do that. But it's good to know -- it's

assuring for me to know that I don't have to depend on them. Even though they are always there. That I have somebody else to take care of me. If I had to move out of my apartment, into a nursing home, I don't know what that would do to me but, live a healthier life with the PCA. And this is my greatest fear is having that taken away from me. Thank you.

Lorna: Thank you, Kathy. Does anyone on the panelist have a question for Kathy? No. Thank you, Kathy we have another panelist who has joined us today bob smith from the department of transportation. And I think bob is going to move up closer, so he will be handy to -- if he has any questions of people giving testimony next we would like to hear from Wayne Cook, Jr. Wayne.

[Hearing Aids](#)

Wayne Cook: Good afternoon, ladies and gentlemen. My name is Wayne Cook, Jr. I guess I am here wearing two hats today. I represent self-help for the hard of hearing. I am the Statewide Coordinator for our group. We represent people who have hearing loss. We have 250 chapters nationwide. And we deal with issues, like I said that deal with hearing loss. I am also a member of the Governor's Commission on the Deaf and Hard of Hearing. I am also the chairperson. I am here today to talk about the hearing aid insurance. There was a bill introduced this past session that dealt with hearing aid insurance for children, up to the age of 18. But after that, there was no hearing aid insurance bills for people over 18. The cost of hearing aids is very, very expensive. They can range from \$900 to well over \$3,000 or \$4,000 each, if you need two, you can see the cost of hearing aids are very, very expensive. In my case I am hearing impaired, I wear two. My wife is also hearing impaired and she wears two. So we are always trying to scramble for -- to come up with money to pay for the cost of a new hearing aid. The life expectancy of hearing aids is roughly five or six years. If you take really good care of them. The present hearing aid insurance bill that is on law in the state of the Rhode Island has a big loophole. It's optional, that the health insurance providers can carry, offer riders. But the loophole is if you go to your personnel department or wherever, this is the only way you can get it. If your company will go that distance for you. That leaves out a vast member of people who do not work for a living or cannot work for a living, who are retired. I would like to see mandated hearing aid insurance, where it would have to be offered whether you work, whether you do not work, as a rider to anybody's health insurance policy. I think the need is there. Roughly there are 28 million people who are hearing impaired nationwide. It's estimated by our organization that in the state of Rhode Island there is over 100,000 people with some form of hearing loss. Even some members of the deaf communities wear hearing aids to help them deal with emergency situations and so forth. So there's a need out there in the community to have a bill presented next year, hopefully, that will help in some manner to cover some cost of the hearing aids to people of the state of Rhode Island. Thank you.

Sue Stenhouse: Sue Stenhouse with the Governor's Office. Can you tell me just for clarification, there currently is mandated hearing aid coverage?

Wayne: Optional.

Sue Stenhouse: For children?

Wayne: There's an optional law in the state of Rhode Island, like United Healthcare, Blue Cross. They have to offer a rider for your policy. If you go to your business -- if you go to your personnel office, and you ask your employer to check into this for you, it's up to the employer to -- it's in the employer's hands to see if he will go that extra mile to get that rider because it is the cost of their insurance. It's optional that the company or the health insurance has to provide it. It's optional in that it is not mandated by law. It's only optional that the company provide this policy. We would like to see it mandated that it be covered just like they just passed a bill for the language need that mandated there would be coverage. We took six years to get this bill passed. It wasn't what we wanted. We wanted mandated but we figured it's better as something than nothing. But we didn't realize there was a big loophole in the law that only people can only get it through their employer. I have called united health. I have called blue cross. And asked to try to buy a rider personally. I am a retired person.

And they said the only way you can get a rider for your hearing aid insurance is through an employer. So I think there's a big loophole that needs to be covered. Thank you

Lorna: Anyone else have a question for Wayne Cook? Thank you, Wayne. John Tolento is next and after john will be Charles Pollock. John Tolento

[Captioning TV](#)

John Tolento: Good afternoon. My name is John Tolento and I am a Commissioner on the Deaf and Hard of Hearing. And I am here for a couple of reasons. First of all, I really want to emphasize to you all that we have a great Executive Director who has been expanding our resources. So to one and all, we want you to make sure you take advantage of that resource. Also, I didn't know that Steve or Wayne were going to be here. But the main reason I am here is that I read your book, I read this here. And I say, thank god these proceedings are not televised if they were televised I would not know what the definitely was going on because the State of Rhode Island does not have closed caption on its Public TV. Now, it is so difficult for me to comprehend that. That if I wanted to watch the proceedings of what's going on at the state house, at the legislative committees and so on and so forth, I am lost. I can't hear it. I don't read sign language. So I can't take advantage of the sign person. So, what I am saying is that the state is depriving thousands of people from being able to know what's going on in the state. I can watch r. Rated movies. I can watch reality. I can watch soap operas. They all have closed captioning. But if I want to know what's going on in the state house, I am lost. I have to read the papers. And you know what happens when you read something in the paper, right? It sort of gets misplaced, if you -- so I am basically here to push this. I know that the state has the facilities to do closed captioning and they are just supposedly looking for -- off the top of my head, Maybe 25 or 30, 000. And after they got through getting rid of all those cell phones I think they can afford to put closed captioning. So I want to thank you very much for having the patience with me and maybe next year, I will be able to say, hey. I saw something on closed caption from the state. Thank you.

Lorna: Thanks John. Does anyone have a question for John? Steve

Steve: I actually have a comment. A follow-up to what John was saying. I just want to let everyone know that I have spoken about captioned TV with the state office. They have all the equipment -- not only the resources, they have the equipment. They have enough -- the funding as well. I spoke with a couple of people who are involved in that, that discussion is going on. They are trying to figure out what technology is available and how to work it out. So it would be nice if it happens soon. They have everything in place. And we are hoping by January 2004, it will begin having captioning. Especially during the legislative session. As far as the hearings and all that, we don't really know what's going to happen because there are so many hearings going on at the same time. So to choose which one is going to be captioned we don't really know about what's going on about that. But just for the general assembly, discussion will be captioned hopefully it will be happening very soon. But they do have the funding for that. Thank you, john

Lorna: Thank you, Steve. Does anyone else have a comment? Next wee like too hear from Charles Pollock. Charles

Charles Pollock: okay. Can you hear me now? It's a joke.

(laughing)

[Information 2](#)

I am a member of RICAT, OSCIL and the Brain Injury Association of Rhode Island. And I have been involved with this since -- I was hit by a car and I found -- my family found that there really was not any specific telephone number or people that we contact in the state of Rhode Island to help me out. I have gone through considerable amount of heartache to reach and to the people that would help me, because my house had -- I was in the hospital for six months. And after I left the hospital, my house

needed ramps because I was in a wheelchair.

[Home
Modification 3](#)

And for me to get ramps built before I came home was a very difficult problem. Because there was no one available for the State of Rhode Island that would recommend a person to do that specific job. There was no one specific that I could call to or my family could call to, to say could you please build a ramp for this person. I had to build it with friends of mine, my brothers, et cetera. Each and every place in the house needed a ramp. The doors had to be widened so I could get through a wheelchair. The bathroom had to be rebuilt because all I could do was live on the first floor. So there was considerable amount of things that were needed before I came home from the hospital that I could not have done by calling a specific number or a specific person that the state provided. Independent living is very important on a lot of people who are in my position, who are totally disabled and can't get around or can't get into a house or into a building or into a plant or into a store. And it's very, very frustrating for the person with the injuries who can't do this type of thing. And I have found that there's no specific number or person that I can call to say, why isn't this door the way it is? Where can I go to find somebody that can fix that door so I can go in that building. Okay. The whole thing that I am trying to stress is that my family, my wife, my children had to go out and we searched this whole project to find people to build and do everything. The bathroom, the house, the doors, the ramp to get out of the car into the house, et cetera, et cetera. Was not available or -- no person was available to supply this type of information for me and for my family. And hopefully down the road that the state will provide this type of service for a person like myself that requires. And one question is it or is there someone or is there a number that I can call or anyone else can call that will give that information? I don't want to question you. But hopefully in the future there will be.

Michael Spoerri: Brain Injury has the resources. I think it's a little outdated. But they are working.

Charles: Right.

Michael Spoerri: Have you been in contact with PARI?

Charles: No. The thing is when I initially came out of the hospital, there was no one available that would, you know, take the ball and run with it, other than my family and they had to find the people that could supply this type of work or people that could do this type of work that I could utilize to do it or supply, so I could use the house independently. And hopefully -- I am at a point now that I can. But before when I first came home I was in a wheelchair. Then I am walking and crutches. Now I am in a cane so -- it's been a long hard road and really there's no one that can supply information that anyone, like myself, would require. So -- I don't know if anyone has an answer for that or if they don't. Hopefully you will. Thank you.

Sue Eleoff: Are you talking about getting information on contract, just general information, or information on funding?

Charles: Not basically funding. Information on where and whom I should call to get someone to build a ramp so I can get in the house, or a ramp for the inside of the house, or a door to be widened so I can get my wheelchair in there or bathroom that can be rebuilt so that I can utilize the bathroom. There's a lot of things to consider when you come home in the condition I came home in and there was no really person out there or a number that I could call, or my family could call, that would give me this type of information. Thank you.

Lorna: Thank you, Charles. If I could add, this is just another example of miscommunication in our state or lack of connection because of many such similar stories that we heard at the center for independent living, both OSCIL and PARI have tried to do a marketing campaign to get the word out for folks who are newly disabled to find us and I thank you, Charlie, for your example of how someone, newly disabled is usually lost in the system. And finally finds their way to agencies they need. But thank you for your testimony. Next I would like -- did someone raise your hand? I don't want to miss any questions Everett Maxwell is next and then after

Everett will be Shelly Green.

Everett Maxwell: They call me Max thank you for allowing me. I am a private citizen. I have been the father of a quadriplegic son for the last 18 years. Eight of those were in New York. I would like to add a little minute to my five minutes and tell this gentleman, I went through the situation he's in ten years ago when I moved here to Rhode Island. There just wasn't -- and I don't think there still is a central --=

Lorna: Everett could you motion that you motioned to Charlie.

[Home
Modification 4](#)

[Information 3](#)

[Van Parking
and
Parking
Violations](#)

Everett: I digress from my time. I might make an analogy of the homelands security that we just established nationally there. Were all sorts of departments doing a lot of things but none of them were addressing this one issue. People such as this gentleman and when I needed it ten years ago it wasn't there. I had to navigate my own problems how to get buildings, funding, bathrooms. This gentleman was the first speaker. There ought to be a lifeguard department or something. The best liaison probably is through the hospitals. When I lived in New York, the New York State Department of Rehabilitation location vocation rehabilitation they deposited it there because many people wanted to go back to work or get some kind of training. They were the source that fan the out to all the agencies. They may have been a bucket to put it into. But at least there was a bucket when I lived in New York. There wasn't a bucket in Rhode Island and ten years ago there still wasn't. I am going to briefly address -- I am the father of a son who wanted to be here today but couldn't. I am going to address three observations because I have been an observer of the handicapped disability scene here for ten years. Van accessible parking spaces and handicapped parking spaces. I spoke to someone on the Governor's Commission a few years ago and he told me there's a percentage of spaces and public parking lots such as parking centers and restaurants allocated to handicapped. If you find out that number, I imagine the woman in the back could give me that, I observed all sorts of places and that rule is not being followed. I can mention none of the largest volume restaurants in the state, the most well known restaurant in the state with probably the most number of parking spaces in the state but I won't name it but everybody ought to know what I am talking about and they have four handicapped spots. None of which -- I am very friendly with the people who own it I go there quite regularly I am not knocking them. But I am not naming. But none of those are van accessible. None of them have that extra little line. Now vans, when my son first was injured he was able it drive. He no longer is. Our first van that he could drive that had swing out that came out only this far and could drop down and go off. All the vans that are being built now have drop out vans from the back. A few people go in from the rear and Chrysler came out with that cute little car and they have a rear entry for a person to sit in the back. But most of the vans if you go to the disability expo have this ramp that comes up very few, if any places have a space next to a ramp handicap spot large enough to do that. So you end up with my son and with other people, more elderly people you end up dropping them off some place, going and parking the car and coming back. If it's raining and so forth. So someone should be looking into these van accessible and really measuring off these vans to make sure there's enough space. That would probably require legislation. But at the end, I will go over what my questions are the second thing. I am an observer. I hang around downtown a lot. I am retired but I like to go out to lunch and dinner. If a person is staying at the Westin Hotel or is at the Convention Center, and wishes to go to city side of Water Place Park which is to go from that hotel or Convention Center to the Capital Grill or that Irish Pub or the Brew House there. If the person is in a wheelchair, unless it's changed within the last 60 days, the person in the wheelchair must go all the way out past the built more. Okay. So, the first one was the van accessible spaces and just the number of handicapped spots in public accommodation such as shopping center the village of East Greenwich. At one time had three handicapped spots along the entire street. Back to the Westin Hotel you cannot get to the Westin people are walking people in front of the old train station. People in wheelchairs must go all the way up. That is since the Courtyard Marriott was built. Before that there was direct access third, Newport Rhode Island, Washington Square, if you go to the Thames Street end of Washington Square and look at the old

statehouse two theaters are on the right. I believe there are four handicapped spots on the left side. We go there quite often. My son, my wife, and I. If you get out of the handicapped spots, there are no curb cuts in Washington Square. If someone wishes to go across the street, back down toward Thames Street or go to a restaurant or the bank he must go down a long alley, up a driveway and come back now, these are just my observations. My question is what agency, what person, just as this lifeguard -- what agency, what person is out there observing this and looking at it and what agency or agencies are responsible for enforcing this? Now, that's not a question I expect to get an answer to today. It's a question I hope you people from the Governor's office and Congressman's office and these agencies will address years ago, I don't know if he's still there. In the Department of Transportation a friend of mine 20 years ago had a great job. He was called a sign man. His job was to drive all over the state Westerly, to Woonsocket with a list of signs to see if the signs were still there. If they were still appropriate, right turn at the -- no longer a right turn there. That's all he did. It was a great job. I don't know if there's still such a job in the state. If there is, I would like to apply for it. But where is the agency, people, person that goes out and says there aren't enough parking lots in that -- spaces in that lot. There's -- not wide enough to accommodate a van. Thank you very much. Or contact the city of Newport. Thank you very much.

[Curb Cuts 1](#)

And

[Curb Cuts 2](#)

Lorna: One minute, Max.

Sue Eleoff: You can start with the Governor's Commission on Disability they recently had a reorganization there where people from the Building Code Commission are now under their umbrella. And I know in the past they have had committees about handicapped parking. I am not sure exactly what they are doing now or what their priorities are. But I think if you contacted that agency --

Max: I don't think I should contact. I am asking this group to look into it as a group and put in a report and contact everybody.

Sue: There have been complaints almost every year about curb cuts in Newport so that's nothing new.

Charles: You can't get a wheelchair on the curbs.

Max: It appeals to so many people.

[Curb Cuts 3](#)

Charles: I called the Mayor. The people that run Newport and told them that there are only two handicapped parking spaces down in the city and they said, no there's four. I said show me. He called me back and said yes, there's only two. So there are only two handicapped parking spaces in Newport right now. And all the sidewalks don't have anything to roll a wheelchair on.

Lorna: Thank you Charlie Pollack for your additional comments. I would like to recognize Shelly Green. Shelly green. And next will be Shirley --

Steve: There was a comment.

Lorna: Max you have --

Bob Smith: Hi. Bob Smith from DOT, trying to keep up with the comments but just a couple of things, the dot works very closely with the Governors Commission on the Handicapped for establishing priorities around the state of where there are places where there are curb cuts that are currently problems. All over the state, there are places where there are not curb cuts. Unfortunately when most of the roads were built back in the 30s and 40s, these types of things weren't thought of. So we are trying to prioritize roads, prioritize areas, critical areas

that are of importance to people with disabilities that we are working with the governors commission to try to establish hot spots and roads that are of primary concern. There are a lot of them. We don't have the resources to do all of them at once. I will say a couple of the places you mentioned, Newport for one is a project that just got started to do some signal work on America's Cup Boulevard. I think they are addressing those between Thames and America's Cup. If you show me exactly where you are talking about afterwards I will make sure that's on the plans. We also have a project at the big intersection downtown near the Westin. A small project we are having problems with people crossing in fronts of those highway ramps that extend into that intersection. We are trying to route everybody around there. So if you can show me where the route is that's lacking, we can see if we can get that into that project.

Max: I mention -- these are three examples of ten years of observation. I have probably 35. My question is what agency or agencies are responsible for seeing these problems, being aware of them and then enforcing -- for example the city of Newport should fix the problem not the Rhode Island state Department of Transportation.

Bob: If it's under a city or town jurisdiction road. They are responsible. If it's a state highway we are responsible. The problem again is that there are so many roads, which ones do we do first? And that's where we are have been working with the governors commission to identify which roads are more important from an accessible standpoint. They have been helping us to prioritize the roads. They are getting information from you. So, I would contact the Governor's Commission and they have been pretty good about passing that along to us and working our priorities.

Lorna: Thank you. That's panelist Bob Smith from the Department of Transportation. Are there new other comments for max? I would add, too, max, that you had said it's really the panel and the testimony that needs to be -- make some changes. But you as a private consumer, your testimony is so powerful. And if you wouldn't mind giving your name and phone number to some of the folks in the back, I think Bob Cooper and Bob Smith's office would love speaking with you directly on some of your concerns if you wouldn't mind doing that. Next we will hear from Shelly Green.

Safety Training 2

Shelly Green: I hope you say the same thing to me when I finish. I am the mother -- the sibling and ex-wife of a brain injury survivor. I also sit on the board of the brain injury association of Rhode Island. And I wanted to just have the opportunity to tell you some of what I am dealing with, both as a parent, caretaker, and also as a person trying to legislate. I first want to say in every year in the United States 2 million people sustain a brain - traumatic brain injury. I would like the opportunity to share my story. It's every parent's nightmare. The police knock on your door at 5:00 in the morning and tell you to get to the hospital right away. The fear begins and the horror starts. My only son, today, fell asleep driving. He was not wearing a seat belt when he hit a telephone pole on Smith Street. He suffered a traumatic brain injury. At that moment I could not believe how -- I could not believe it was real. This could not be true. He had just come home from serving during the gulf war. He was healthy and strong. I saw him a few hours ago. He was fine. But as I kept saying no, I knew how horribly real it was. And I could not stop it. I was not going to awake from this nightmare. It had only just begun. When the doctors walked around the corner with a priest to tell me my son had a traumatic brain injury and would not live the night, and if he would be brain dead, she turned and walked away. At that moment -- that was just the beginning of the doors that would shut in my face every time I tried to get help. There wasn't a question that she was available for with any answers. She left me with the priest and he did the best that he could as I did. Let's see. I ask god so many times why. My 21-year-old smart, hands some healthy baby boy had been taken. Why, as I ask god, I am sorry I am nervous and not reading my own words. Why as I thank you god every second he lied in his broken body in a coma alive. Praying that one-day he would come back to life to me for him. As I mention, I am the sister of a brother who died in St. Rono Hospital. I am 47. He had his injury and was institutionalized two years after he was born with a brain injury and two years after he was institutionalized where we were not allowed to see him. Nor -- my family chose not to talk about him. For me this has been a horror right from childhood. The institution

wouldn't allow us to come in. Which is unbelievable because I know that's really all that they have at that time, especially. I mentioned that I was an ex-wife. I was remarried. My husband when my son had the accident I was only married three months left because he couldn't deal with the trauma, the lack of support and what this was going to mean to our new marriage. He had a motorcycle accident in 2000 and now he's brain injured. I will lobby to my death if that's what it takes to educate and prevent traumatic brain injuries to work for programs in Rhode Island to get support for victims and the families that are faced with this crisis. I thank god every day for the miracle I have been given. My son, after many years can live independently. The process has been an unbearable journey. I should say semi-independently. He needs an awful lot of supports. I do want to add I had my son as a teenager, which makes a greater impact to the story. I finished junior high school, high school. Put myself through college. I have a degree in social work and to have this happen after all of that, we have come through just as another emotional component to the story. Not necessarily any more to what you are here for. But for my story the process has as I said have been an unbearable journey from hospital to hospital for rehabilitation center to rehabilitation center from mental health facility to mental health facility. From organization to organization. From state to state. Because he was over 21 at the time of his accidents and was not an organic injury he fell through almost every crack. He was -- excuse me, it was the help and store of the VA hospital that we found a program in Connecticut working with traumatically injured adults. In efforts to -- gain a greater quality of life I had to take this child, who at the age of 26 was at most like a young teenager with lots of dysfunction and move him from the only lifeline, which was me. In need to support him I would drive two hours each way as often as I could, each week. That continued for more than a year. He continued to make improvements with the program. We moved him --excuse me -- we moved him because the program shut down due to lack of funding. So for two years he remained in Connecticut while I tried very hard to get him back in Rhode Island. Again I am a single mother with not a lot of income. I couldn't afford to set him up in his own apartment. We found housing back in Rhode Island. Today he now lives in elderly and handicapped housing although I am grateful to have found affordable low-income housing back in Rhode Island for today, where he belongs, is far from the situation that he deserves. Today's dream was to become a police officer. Instead he spends most of his days when he is not with me or my mother sitting in front of a television without much service and without much to do. Fewer than one in 20 individuals with traumatic brain injuries will receive the rehabilitation they need. This fact greatly reduces the ability of a survivor to achieve a productive and fulfilling life. For every dollar spent on rehabilitation, \$35 is saved. Why is a nation are we so willing to waste money but unwilling to use that much needed money to support our citizens in need. Traumatic brain injury impacts every area of your life, your world, and your spirit. As you fight endlessly for the life and needs of your unable child, you watch your own as you know it quickly disappear, families, friends, support, jobs, monies, pleasure, freedoms, peace and dreams fade away. As a parent, you will want nothing greater than the life of your child. As you read my story or hear my story, you may imagine what this is like to experience, as I would have before my son's crash. But believe me, you cannot even get next to how this impacts and feels -- excuse me, how this feels and impacts your world. The pain and lack of support, devastates your life at a time when you need all the strength and hope just to face another day. I am almost finished. In your effort, you are often dismissed. The scope of this problem is far beyond what most people are aware of. The statistics I will cite from the national brain injury association. It is the leading cause of death and disability among children and young adults until the age of 45. It is the fourth leading cause of death over all annually. It -- traumatic brain injury claims more than 5,000 lives annually. An estimated 6 million Americans, more than two percent have disability due in resulting from a brain injury. 2 million people sustain a brain injury every year. And as technologies increase, that number is growing. My son had the accident 11 years ago. If it had been just a few years before he would not have survived. Technology wouldn't have allowed that. Each day, 5,500 individuals sustain a brain injury every 15 seconds an infant, child, teenager adults sustains a traumatic brain injury. Males are 14 -- the ages of 14 to 24 are at the highest risk and are twice as lucky as females to sustain a traumatic brain injury due to lifestyle and risk exposure followed by infants and the elderly. Approximately one in ten are touched by brain injury in this country. Please do not close your hearts and minds to the needs of those suffering from traumatic brain injury. We must educate and fund programs to help prevent or care for those traumatically brain injured, if saving lives is not enough of a reason for increased --saving taxes should be. The cost of traumatic brain injury is estimated

[Traumatic
Brain Injury 2](#)

to be 48.3 billion dollars annually. Hospitalization accounts for 31.7 billion dollars of that. As fatal injuries will cost this nation 16.6 billion dollars. And in case you are not hearing that clearly that's billion, with a b. The cost to save my son was over 1 million dollars and the account is still tallying. Please let's put our healthy brains together and prevent and advocate for the rights of those who are unable to advocate for themselves or for the families who are too overwhelmed to face one more battle. If you have any questions or contacts -- questions please contact me and I left my phone number. I left a copy of my testimony with my business card. If there's anything I can do to help support you, help support us. I am there, yes?

Kath Herin: I am Kathy Herin with the Alliance of Long-term Care. And one of the things that we have been working on in the past year is discharging patients from the Eleanor Slater Hospital into the community. And when we sat down with the people at the hospital and tried to think of different types of programs, one of the things that I have recognized as a nurse and working in different areas is that we need a stronger unit in one of the hospitals for rehab and getting people ready with traumatic brain injuries to go back into the community. Your son is very fortunate he has you. But for the people who cannot take care of these people, the frustrating part is trying put somebody like this 41 years old a long-term care facility that they don't really belong in. So one of the things we stressed with the people at the hospital is we need to develop some type of a unit that's going to concentrate-- that was just one of our ideas -- to concentrate on traumatic brain injury get these people not ready to go into nursing homes but get them ready into the community again with services. So somebody is working in that. My director, Roberta Hopkins is working on that. We recognize --

Shelly Green: And I believe and am grateful for that but this is 11 years later - I just want to add, I believe that and I think that is great that is happening. Recently, we had a Director of the Department of Human Services saying the same thing we know this is existing we know what the problems are, we know what the needs are but every year goes by and there aren't any changes and again, it actually it would be saving this country money if that's the only reason that they would care to take action, then let that be the reason. Why is this happening? 11 years later there was a gentleman in the back with his son ten years later. This day and age with the reality, with the communication, with everything happening, it's unforgivable because -- you are right. I am absolutely one of the lucky ones. I am only 47 and my son is 32. I know people that are 67 and their son is 42 that are half my height, trying to take people from their wheelchair to the bathroom or whatever. And can't even go to the grocery store unless they have somebody to take care of them. Families get burnt out. It ends up being the mother most often and very often nobody else.

Lorna: Thank you very much for your testimony.

Shelly Green: Do you want copies? Anyone want copies?

Lorna: Next we would like to hear from Shirley Heathcove. Oh, sorry another question.

Kathy Herin: I want to assure you after hearing what you testified to today I will go back to my agency with a little bit stronger motivation to push for what you said.

Lorna: Do you have another copy of your testimony for Kathy?

[Auxiliary Aids](#)

Shirley Heathcove: I am going to be brief I wrote this down because obviously I can't speak -- I am looking at my writing, I can't write and I probably won't be able to read. Really. On here I am concerned about any budget cuts that would affect OSCIL, Ocean State Center for Independent Living. Thanks to OSCIL and the professional services and adaptive equipment, I am living independently and have been spared an early nursing home stay. OSCIL is the foundation of our community. Providing adaptive equipment and counseling to many disabled consumers, allowing them to achieve and accomplish and perform the ideals in life. It provides the visually impaired with special new vision. And the

hearing impaired, meaningful equipment and support to open up the silent world. OSCIL services are vital. Even a small cut could be devastating and have a devastating effect on the consumers who dependent on services from OSCIL. So I hope when you go back and the powers that be start-making budget cuts you recognize OSCIL and the very vital services that they perform. Thank you. See just in time.

Lorna: Thank you Shirley this was an unsolicited comment and thank you very much. Next we would like to hear from Barbara Cofrieda and John Cofrieda that would like to testify as a team.

Interpreters 1

Barbara Cofrieda and John Cofrieda: Maybe we can get another chair. Hello everyone. My name is Barbara and this is my husband John. We are deaf parents of two daughters that can hear. I have a long story and I will start with my daughters. When they were born, we had troubles with interpreting situations. We needed an interpreter for our daughter's doctor's appointments. We had to do a lot of education to the doctors in the hospitals to provide sign language interpreters. In May 2002 is where the story conditions. My daughter was sick, she wasn't feeling well (continues) I thought maybe she had bronchitis or pneumonia at that time my husband was laid off and I was working so my husband brought my daughter to the doctor. At that night, my daughter could not sleep. And she told us she could not breathe and looked awful. We took her to the hospital immediately. We brought her to Hasbro. And I had to go to work that night because I was the soul supporter of the family so my husband brought my daughter. And they told me that our daughter was in ICU and had a heart problem and I was shocked. The first thing that ran through my mind was, was there an interpreter there? And how would we get one? We could not communicate with the doctors and the hospital staff. So I drove immediately to the hospital. And my daughter was in ICU, hooked up to monitors. And my husband John was there. And he will pick up the story.

John: It was early in the morning, around 5:00. And the nurse had done an exam on my daughter and told us it was a very serious problem with her heart. And that she would be admitted to the ICU due to her fast heartbeat. And I told the nurse that I needed a sign language interpreter. And an interpreter came. But it was not a professional qualified interpreter that could communicate in American Sign Language. And that communication of that interpreter, when she came or he came there was a lot of misunderstandings. But my daughter at the same time who was ill had to correct the interpreter for me. While she was ill in the hospital at this time. So one hour later, the interpreter left. They were only there for one hour. And then they provided another interpreter. Still was not a qualified sign language interpreter, due to this extreme serious problem and I knew that we could sue the hospital but I knew that we needed to have one, a qualified American Sign Language interpreter. So to pick up the story,

Barbara: Due to the misunderstandings about what was happening, I contacted at that time OSCIL was running the referral service. And they had a list of interpreters that were certified and licensed. And I had known -- I knew some of the interpreters but I did not know the interpreter of the two that had shown up that night with our daughter. So it was very confusing. So I requested specific names of interpreters certified and they were able to come, but not for a long time. So we had some other gaps of time at the hospital where we were waiting for an interpreter and my daughter's name is Michelle. So we were waiting all day and she was there for four days. And then during her stay, we had some emergency. They would have an interpreter come. Then she was brought up to the bedroom but we did not have an interpreter during the time she was waiting and the nurse would come and the doctors would check on her. And she's a minor and I am her mother and I don't want to just be sitting there with people communicating and I don't know what's going on. I did not want them to ask her the questions because she is a minor, who was not feeling well. And she needed to be directing the questions to me. I was tired of asking for an interpreter and not getting one. So they told us that they might send her home the next day I said what time. And they said they did not know. We would have to wait to hear from the doctor. So I arrived in the afternoon -- the both of us arrived in the afternoon and my daughter said I am ready to go. I am going home right now and I didn't know -- there was no interpreter and no doctor. So we felt very uncomfortable. There was very -- there was a lot of medical issues that were concerning us. We did not know if there was anything we needed to know before she was discharged. They told us it was time to go

home and we signed the forms but we felt so overwhelmed and we didn't have the correct information. Soy called the doctor flew the Rhode Island relay to get the information. And then she had a follow-up appointment with the doctor and they did have an interpreter, a certified interpreter who I requested. And I was able to gather a lot of information. And at that time, what I asked about the interpreter in the hospital, they say call this number -- no call the hospital. No call this number and I didn't even know specifically who to be in contact with, who would let me know which interpreter is available, who could I let know which interpreter I felt more comfortable with so I didn't even know if the interpreter was confirmed or not confirmed. So I was used to OSCIL letting me know when an interpreter was being confirmed for other assignments. In the hospital I felt very lost and confused. We found that Horton Interpreting Agency, who has a contract with the hospital to provide interpreters, was not providing adequate services. I have a list here -- they have three interpreters on their list of interpreters they use for the hospital and they are not certified. And two of them I will not use because they do not know American Sign Language and I do not feel comfortable with their services. I requested certified interpreters now through the commission's referral service. I have done that many times much so they told me I would have an interpreter. I will go to an appointment. Mind you this is a very stressful situation. I have been going through hell for one year, from May 2002 until now with my daughter's health and this issue. So, I expected an interpreter that I requested and an interpreter would come that was not the person I was expecting. And I just -- I was very upset and go ahead with the appointment and the person was not qualified. They could not read me very well, to be able to communicate with the doctor what I was trying to express and my daughter was so aggravated because after every appointment she would go home and tell me everything that was missed or the communication that did not happen. So this was uncalled for. The interpreter is there -- is a communication facilitator so this has happened, many, many times. And what happened recently was this past June; the doctor told us that my daughter needed to go to adult doctor now because she's almost 16. She was with a pediatric doctor until then. So we went to -- I requested an interpreter for this new doctor. And I had the same interpreter that I was not comfortable with. We went ahead with the appointment. The two of us here, my husband and I. And we were having the appointment with the doctor, explained what happened, her history. What the procedures was. She was planning to have a heart cauterization ventricular. So she was going to have a test six months -- we are talking six months before this. So we went to Boston for -- the referral of our doctor to go to Boston. And when we were in Boston, everything worked out great. We requested interpreter. They had one that works in that department through the mass commission of the deaf and hard of hearing. We showed up. There was an interpreter. She was -- or he was with us all day. And that's what I want here in Rhode Island. That kind of service. So, our recent experience was my daughter had another test and it was in Rhode Island, with a new doctor. And so we were holding our breath and we were in the office. And the interpreter said, my daughter and I were talking about the date for the next test and the interpreter would not voice what we were saying because - my daughter and I were talking and the interpreter needed to let the doctor know what we were talking about and she said or he said no. That's a private conversation. I said do you know what the code of ethics is for interpreters? And the interpreter said, yes. And I said, we are in the same room together. We are allowed to -- you are allowed to voice about what I am saying and the interpreter brought up another experience that was not relevant to this situation. So we ended up arguing about something that had nothing to do with what was going on with my daughter. So I said, that's it. I am writing a letter. I have to let someone know about this. So again, we went home my daughter Michelle told me everything that had happened, what communication problems there were, what the interpreter did not voice for me during that appointment. So it was very frustrating. So my daughter, as a child of deaf adults wrote a letter and I wrote a letter as well and we sent it to the department of health. Horton interpreting agency, commission for the deaf and hard of hearing, the hospital, and which I do have a copy here that I can give all of you here today. I would be happy to give those to you, complaining about the services. My daughter, you know, was worrying about -- my daughters were worrying about her father and me. If they had moved and who would take care of us if we needed to go to the hospital if they weren't around. As well as other members with the deaf community. That we always need to scream and try to get help for interpreters in medical emergencies. So I am here to do something. I have already been in touch with agencies in the hospital but it seems like Horton will say oh, no it's blue cross. Blue cross-says its Horton. They said blue cross pays for the interpreters, which is something I just found out. So it's very confusing. This road that we traveled. They have not told me how many

interpreters they have on their list. I had to go through the commission to find out Horton only has three sign language interpreters on their list, which will not produce adequate services for all hospitals. What if there was a trauma with many deaf people? There's only three interpreters that would be able to service all these people? So that was the situation and that's where we need help. I am screaming and crying for help. For the services for the deaf and hard of hearing, relating to interpreters.

Lorna: Question from Kathy.

Kathy Herin: About a month ago, I received a phone call from a relative, from the Alliance, complaining that his mother had her advance directives written incorrectly because there were no interpreters at Rhode Island hospital that could do that for her. Instead of making herself a full code they made her a no code. When I called this into the department of health, somebody did go out to investigate and it's funny this is coming out now because when the department of health surveyor called me back, she said --

Barbara: That same thing happened to my husband.

Kathy: She said everything was charted. There was an interpreter. Until you enlightened me today on what type of interpreters are being supplied to families, because I said, please call her son, find out because as far as he was concerned, the people they were sending down to interpret were people that had a very minimal amount of sign language. And because of the frustration of her not having an interpreter, her dementia got worse and she really had more breathing problems. So now I will take your letter and fax it to the person I was working with in the department of health as a validation that maybe they are supplying interpreters but they are not supplying the type of interpreters they need. So I wish to thank you today.

Deaf Culture

Barbara: Horton does not have any information about interpreting issues for the deaf and deaf culture. They are an agency that works with foreign language interpreters they do not understand American Sign Language and deaf culture. That's exactly what happened to my husband, John and myself. They were not professional interpreters.

Interpreter: Earlier while Kathy was speaking Mrs. Cofrieda was talking to her husband and I wasn't able to voice it, do you want me to repeat that?

Barbara: My daughter was worrying about her father during that time when there was no interpret. My daughter was -- in her hospital stay, having heart problems, having to interpret for her father. Can you imagine? That's what I was talking about before.

Steve: First of all, I would like to thank you for your time to come here and testify. My name again is Steve Florio from the Commission for the Deaf and Hard of Hearing. I want to thank you for coming. I know you and I have met about a month ago about this issue and we are working very hard to fight on their behalf on this issue. And what had the hospital not providing qualified interpret, and also other -- from another agency, not the commission on the deaf and hard of hearing -- we need to say the law says if a licensed or certified interpreter -- there's a waiver in emergencies. That's why the other interpreting agencies which I will not name, that are running for profit as a business feel they can put anyone there regardless if they are qualified or not. They feel as long as there's a body there, they have fulfilled their service. So this is what why the deaf community will not stand for it and will want to change legislation in that part of the law about the emergency situation. And the other problem is some interpreting agencies are not too committed to providing improving the quality of interpreters they have. They are for profit business. Like I said I am not going to name any agencies, but that has been common practice. And some of the doctors and hospitals do have contracts with other interpreting agencies that provide foreign language, Spanish, Portuguese, other foreign language interpreters, spoken language interpreters. But sign language interpreters are not something that they are familiar with. So they just

have them on their list. So blue cross is willing to pay for interpreters for doctor's visits and appointments pre and post surgery during the hospital stay. The hospital is required for the interpreter. So that's another issue. So it's very complicated. And there's many different layers to this. I met with the blue cross administrator to make sure that they have some flexibility that they are not just only committed to working with one agency if a patient requests a specific interpreter, for example a male who's going in for an appointment would like a male interpreter, and say that agency does not have any male interpreters on their list, they have the right to contact a male interpreter from another agency. So they should not just be limited to working with one referral agency. So it would be okay if they had a primary contract with one agency but then also have contracts with other issues -- with other agencies to meet the needs of all deaf and hard of hearing people. And it's also not just related to blue cross. Yesterday I met with Bill Kirkpatrick he works for Life-Span. He represents four hospitals, Hasbro, Rhode Island hospital, Miriam and there's one more. And he represents the four hospitals and he's working on improving interpreting services there. The commission had a town hall forum in the winter and we met with many deaf and hard of hearing people. And the top number one priority was increasing the service of emergency interpreter service is not just medical, but legal. In Massachusetts, there are five divisions. And there's one office that is the main office for interpreting. That's in Boston the metro office for the Boston area. And then there's the northeast, the southeast, different groups there. And one is only for medical and legal emergencies. And it took Massachusetts a long time. But now -- and they finally achieved that goal and that is the same goal we would like to achieve here. To have a medical and legal emergency service for interpreters in Rhode Island. I do not guarantee that will be overnight but we are committed to improving the services in Rhode Island. In a coordinated system with partnerships working with everybody here. I hope everyone can work with us to make sure that would happen. And it's not an extremely complicated issue, really it's funding. And once there's funding -- I would say between 200,000, depending what kind of model we would need to meet Rhode Island. Connecticut has -- and Massachusetts have different models, different services. So that's just to give you some background on the issue.

Barbara: Just to add to that during our hospital stay Blue Cross said that we would have an interpreter in the mornings only and you said I need an interpreter all day because, as you know you do not know when the doctors will come to visit you in the room. So if we had an interpreter there in the morning and the doctor came in the afternoon, we were stuck. So we would like to have the interpreter there all day. Regardless of exactly what is happening on. So we would have complete access to communication for anyone that was entering the room, either a nurse or a doctor, just like any parent who can hear has that access when their children are in the hospital. It was very terrifying.

Lorna: Are there any other questions from the panelists? I would also like to add that I am so glad that this has been brought up today because I think many times people in the hearing community, many people who work at the hospital, doctor's offices, lawyer offices, many people are not familiar with the term qualified interpreter. They think qualified -- that word is just a good interpreter. And qualified is a technical term under ADA, a person who has the proper screening, has been a school, who has the right certification. A qualified interpreter, I do agree with Steve, there are a number of for profit agencies who I don't think are aware of this. And Ocean State Center, or OSCIL who had the service was -- funded by the commission. Now the commission is running it. Very much aware that qualified means screened interpreters or certified, nationally certified. And I am so glad that your testimony has brought this forward for everyone's understanding here on the panel. Thank you very much. I would like now to bring our next person forward, who would like to speak. Bonnie Abols.

Parents who
are Deaf

Bonnie Abols: Thank you so much for allowing me this time. I forgot to identify who I am. I am Bonnie Abols and I -- hold on a second, the communication issues here. The interpreter's voicing but someone needs to sign at the same time. Okay and I am from the Ocean State Center for Independent Living in Warwick. I want to tell you about a problem that I have been dealing with for many years. Since I have been working for OSCIL, I work specifically with children and their families with DCYF. Often times DCYF takes children away from their parents and sometimes the reason they do that, I am not quite sure about, is it the culture they misunderstand. Children who are non-deaf that are

parents of deaf children they called them children of deaf adults otherwise known as CODA. There's a particular culture that comes from being deaf. And the children are accustomed to a particular culture. And the culture may not be the mainstream American culture. And it's been my concern in my observation that recently there was one child that was taken away from their home at the age of 11. And they told the parent that the parent can't have that child until the child was 18. And they are saying whatever their reason was, they -- so from the ages of 11 to 18 is 7 years they won't be able to see the parent. How will they communicate with the parent until the child becomes 18. Then perhaps they forget the sign language that they were accustomed to since birth. And being a deaf mom myself, I had that experience. My daughter was taken away from me. They said I couldn't afford to feed her. But my daughter was very adequate communicated with me and they said excuse me -- the interpreter miss understood. They said I couldn't communicate. My daughter and teach my daughter but we had a wonderful relationship that I could educate her in the daily things that parents do. There are so many training programs that are available to parents to be able to provide education and training to become good parents. Even though there's a communication barrier. It seems DCYF has the wrong information. They continually take children away from parents who are deaf, based on the communication between the parents and children, thinking they can't communicate with their parents, with their children and that's not adequate. So I need something for you, something to be done perhaps by the panelists. We have wonderful programs for children of deaf adults. And we have children who are now adults who have deaf parents who are now mentoring younger children who have deaf parents so they can learn how to experience this in a successful way to have a successful family life. There are other states that have programs and they are terrific programs. I know specifically Massachusetts has a wonderful program. And I am hoping to be able to set up a program very -- in the near future. There is no current program set up in Rhode Island about older children of deaf adults, who have -- can mentor younger children. We are just doing this as we go by, day. There's a lot of information you may want to look over. I don't know, you could get it through the library, the internet, just to give you some ideas of what a wonderful program would look like, where children of deaf adults can mentor or children of deaf adults and they can have a successful happy life. If you would like a copy of that, I would be happy to share that with you. Are there any questions? Okay.

Lorna: I think that ends our testimony for today. Is there anyone that would like to testify who has not signed up? Maybe something said today has sparked a concern in your own life. Sounds familiar? Yes? No? Well, I think I would like to -- at this time close the testimony and thank everyone for attending. I would particularly like to recognize our panelists, thank you so much for coming out this afternoon. I would like to thank everyone who graciously testified. I know it's very emotional and we really appreciate you coming forward. We with like to thank allied court reporting for the court reporting service today. And our interpreters Rosa and Jen and I would like to personally thank the OSCIL staff, basically OSCIL closed down this afternoon to have everyone come out and make this --the public forum turn out smooth today. And I think they did a great job. And last but not least, I really would like to go on record, thanking bob cooper; bob cooper is the secretary of the governors commission on disability. Bob really brings us all together. He's the one who makes lots of phone calls, has lots of committee meetings to make these public forums happen. These public forums happen across the state. Maybe you saw the ad. There were five that were held every day this week. And this is just a wonderful opportunity for people to come forward and express their concerns and I wish to publicly thank him and I think we would all like to thank him on record. Thank you Bob, for your initiation and your perseverance for making this happen. Thank you all for coming today. And I think we are closing 15 minutes early. Thank you.

V. Public Forum, Friday July 25, 2003, RI Department of Administration (Providence)

Doreen McConaghy: Four minutes late. Hang me for 4 minutes I've been on 95 since 20 past 4. The Governor's Commission on Disabilities and all of its partners who have been sponsoring these forums all week long are very Happy to see people. We want people to certainly bring issues that are critical and important to

them and this is the great forum to do it in.

Interpreter: Can you speak up a little?

Doreen McConaghy: Sure. I would like to go around the room once so that everyone knows who the heck is here.

Charlie Feldman: I am Charlie Feldman I am representing Consumer Advocates as well as the national alliance.

I am Mitch Henderson at MSCA.

Wayne Cook: I am Wayne Cook representing the CDHH I am the chairperson.

Anne LeClerc: Anne LeClerc from RIPTA.

Judith Kapuscinski: I am Judith Kapuscinski I am chair of the Advocacy Committee and there's some information outside if anyone wants it.

Casey Crothers: I am Casey Crothers from the Brain Injury Association.

Scott Greco: I am Scott Greco representing GCD.

Regina Connor: I am Regina Connor from the ORS.

Rory Carmody: I am Rory Carmody with the Governor's Commission on Disabilities.

Paul Choquette: I am Paul Choquette I am with PARI.

Interpreter: I am Sharon Lane and I am with the Governor's Commission on Disabilities as well.

Don Deignan: I am Don Deignan I did not sign in so I will spell my last name, Deignan. I am a member of the PARI board and also a member of the Governor's Commission on Disabilities.

Doreen McConaghy: We also have around the room at least one member from the commission that I can see. Who might that be?

John McDonald: John McDonald the Vice-Chairman of the Governor's Commission on Disabilities.

Doreen McConaghy: Thank you. My name is Doreen McConaghy. Okay. Ground rules. The ground rules are when somebody is speaking, it would be nice for everybody to be listening because we want this record to be accurate. And I believe that any issue regarding individuals with disabilities is appropriate to bring before this commission hearing. So,

Paul Choquette: I don't mean to interrupt.

Doreen McConaghy: By all means.

Paul Choquette: I am on the Legislative Committee; we've done them for about three years now in this format with other sponsoring agencies here along to listen to the concerns of people. We are taking we have an individual who's doing real-time captioning for us as well as taking a record of everything that's said here

because of that we ask that when somebody does speak they identify themselves so that the stenographer can get their name so that it will be part of the record. We ask that people do try to limit their comments to about five minutes for right now so we can make sure we can get everybody that's testifying and later on if there's more time left, and you have something else to say we would definitely like to hear from you. Some of the panelists here may ask some questions to clarify what it is you're mentioning. So again we want to be very informal. We're here to listen and what we do with this information that we get is go through it and use the information we get from these hearings to solve the problems either legislatively or through policy or by informing individuals who are maybe not following the rules exactly how they should be so that people get what they need. We have a sign-in sheet for people who wish to testify. We want them to sign in and Scott is the keeper of that sheet and what we can do is go off that sheet with the sign-in and go in order and have everyone have an opportunity and see what happens. We have assistive listening devices if anyone needs them. They're up at the front of the room and Scott can assist you in getting one. Ladies and Men's rooms, they're out that door to the right and they are accessible, they have automatic door openers and that's it.

Doreen McConaghy: Mr. Feldman,

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and
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Charles Feldman: This is the first time I've been to one of these so I wrote up some issue on a piece of paper that I feel are important. I represent none who represent mental health consumers in Rhode Island people with mental illness. So I'll go through the issues. The first issue is mental health courts we have a couple of them in Rhode Island but we need them everywhere in the state. People with mental illness were being warehoused in jails and prisons and in hospitals and they're no longer warehoused in hospitals but they are warehoused in jails and prisons and there are more people with mental illness in jails and prisons than in hospitals. And Rhode Island is pretty good about having treatment in the community, and I want to point out that when people get treatment for their mental illness or substance abuse issues that often accompany them, they're no more likely to end up in the criminal justice system than anyone else. It's the untreated mental illnesses that lead people to end up in jails and prisons. So we need programs throughout the State of Rhode Island. The and I forgot to announce my name, Charles Feldman.

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The second issue is an SSI cost of living allowance. The state has abandoned its duty to

help out the underdog by not providing the cost of living increase for people on supplemental security income this year. It was one issue taken up by the one Rhode Island platform, which was endorsed by over 100 organizations. So there is a lot of support for this, but it just didn't happen this year and we need to make it happen next year along with a retroactive raise. We need affordable housing. At the Providence Center, more people are being seen who are homeless than ever before and it's been found out that for people on SSI, they can't afford to rent an apartment at market rate anywhere in the country, so we need more subsidized housing. We need no restrictive for laries for medications. The state has a policy that you have to fail on two of the older medications first before you can get a newer better medication. I know I couldn't be working at the job I am at now unless I was on a newer more effective medication. I know this isn't a state issue but it's ironic that the government is one of the organizations that discriminate against people with mental illness by not having insurance parity that's equal coverage for mental health treatment along with other medical issues. We need access to treatment. At the national alliance for the mentally ill where I work, we found out that people are not being accepted into treatment and then the problems get worse and they end up in a crisis being suicidal or in an emergency room or whatever, so we need access to treatment for everyone who needs it. We need supports for people to go back to school and get jobs because people with mental illness can recover and there is a lot being done on this but we need more people going back to recover as fully as we can. We need to educate the public and we need to educate everyone about the fact that people with mental illness are not people that people should be afraid of. That when people's mental illness are treated, they can go on to live full lives and people need to be accepted for who they are. But we need to get rid of the stigma. We need client center treatment including peer support. There are 3 peer support centers for people with mental illness and we need possibly more because evidence has shown that people with mental illness recover better when they get not only psychiatric

support, but peer support. We need education and support for families.

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Families need to be included in people's treatment when the mental health consumer wants them to be and uhm, they need to be kept abreast of what's going on. Because it's very hard for the families when someone is going through a crisis and the family is left out. Children need to be treated at home or in the community. As a matter of fact one thing I am thinking, and Anne is here from the Disability Home Center, and Sherlock Center was interested in the Olmstead Act, which is people need at least a receptive environment. That's what we need to do in Rhode Island.

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We need more money for mental health workers because there's a high turnover rate because of the low pay. People who have a traumatic history have to start all over again with a new provider once they've gotten to know someone and it's very traumatic for the person to start over again and over again and over again with new providers. We need to make it so that mental health workers are not entry-level workers but that they'll stay for the long haul. So these are some of the issues I thought of that I wanted to bring up today. Thank you.

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Rory Carmody: Would you explain a little bit more about the mental health courts. What is the process of that? How does that work?

Charles Feldman: They have a social worker assigned to the court and the court meets when necessary. It doesn't meet 40 hours a week or anything. It meets when there's a need for it to meet and the social worker will meet with the person and the judge will divert someone from the criminal justice system on the condition that they get treatment and it prevents them from having a criminal record and from spending time in jail. And there have been, I wish I had the figures with me, but I believe from the Kent County court I believe in the past year there were about 60 people diverted. And as I said, when people get treatment, they're no more likely to end up in the criminal justice system than anyone else. It's the untreated mental illnesses that cause people, usually minor crimes, although occasionally something serious will happen and it's important for people to get treatment ahead of time not only when they come in contact with the criminal justice system, but to get treatment all along to prevent them from coming in contact with the criminal justice system and when they do come in contact with it, it's important for them to be diverted into treatment so they don't end up in a cycle. The way it used to be, people were being in jail and prison and then they might get treatment while they were in there, but then they're let go and there's no follow-up and they go back to being I will again and get caught up in the whole situation again.

Rory Carmody: If a person gets into trouble with the law do they have to identify that they're a person with mental illness or can the court refer them to the mental health court?

Charles Feldman: I believe what happens is that the judge in the regular court notices that a person may have mental health issues and that's when they are referred to the mental health court. I guess they could come out and say it but they're not likely to do that if they're there in the first place.

Don Deignan: I would like to follow-up my name is Don Deignan and I am a member of the commission. You had said there are mental health courts in a couple of our counties, you said Kent.

Charles Feldman: Kent County and one in Providence.

Donald Deignan: So there would not be one in Newport, Washington or providence county. So would it be your feeling that if we had one of each of these entities in each of the counties of the state.

Charles Feldman: There are 8 areas for people with mental illness for people in the state. It's simply to have availability for everyone in the state. I don't care where they're located as long as everyone in the state has access to one.

Donald Deignan: but there's one of the in two of the state's five counties. So theological thing to do would be to create an analogous body in each of the three remaining counties in the state. I wanted to follow-up and have you clarify that, thank you very much.

Charlie Feldman: Thank you.

Mitch Henderson: I have one more comment to add to what Charlie said. The cost of housing someone in the ACI for typical 2 and-a-half years which is this in for a year out, come back in again, that cycle cost 100,000 dollars so Charlie mentioned 60 people, 60 times 100,000 dollars and you can immediately see this concept, it would save the taxpayers a lot of money as well as helping the consumers involved.

Male speaker: Right. It's something new to Rhode Island.

Scott Greco: I want to clarify what Don was leading up to, right now if you have a mental illness and go into a jurisdiction of say Bristol or Washington county, there is at this point, no deferment program that's possible.

Charles Feldman: That's correct. It was experimental in Kent County and then it was introduced I believe into a providence court.

Scott Greco: So basically what you're asking for right now and I don't know if it's doable, you're asking to have the program expanded into all five counties.

Charles Feldman: right.

Scott Greco: Sounds logical.

Female speaker: Can I ask a follow-up question, I know you mentioned about the cost savings that is available if you could divert people from the ACI, is that something that you would look at in terms of expanding capacity, because I know Charlie said that was a problem as well. Getting to the people who need it and getting effective treatment. I don't know if that was part of your recommendation or not.

Charles Feldman: When John F Kennedy started it, the money was supposed to go from the state hospitals and follow them out into the community so they could get treatment in the community. I am not sure I exactly understand your question. You're saying the savings from not having people in jails could be used for the mental health system. Certainly. The problem is there are different jurisdictions and different departments and they're all fighting for their own budgets so what's practical and what is happening may be two different things.

Scott Greco: Is it a jurisdiction of the superior court?

Charles Feldman: Superior Court I am being told.

Scott Greco: If I could make a quick recommendation and you can follow-up with the commission, if you could or another agency that would if you would write a letter to both the chief of the Superior Court and also the Attorney General's Office, and just spell out and ask them what their response would be to expanding the jurisdiction into the other counties and if you could follow that up with correspondence to the commission we would be interested in seeing what they have to say.

Charles Feldman: Okay.

Scott Greco: It would be easier for the commission to if this doesn't make the legislative package for the

following year, if we could go in with the support of both the court system and the attorney general's office, it would help our fight at the legislature. It would make it a lot easier for us.

Charles Feldman: So a letter to the Attorney General and the Superior Court judge?

Scott Greco: Whoever the Chief justice is on the Superior Court. You might want to forward one to the District Court as well, that would be Judge DiRobbio.

Doreen McConaghy: If there are no other questions.

Charles Feldman: May I mention that you're interested in this.

Scott Greco: Absolutely.

Doreen McConaghy: The next person is Miss Meradian.

Miss Meradian: That's me.

Doreen McConaghy: You're next.

[Personal Care Attendants 8](#)

Miss Meradian: There are people on the panel that could represent PARI far better than I am a consumer and they know more of what's going on. The only thing I know is that I received a call from Beth and she requested I come here tonight because PARI is in dire need of hearing from disabled people like my husband and myself. I believe she said they found they could use 160 people and this helps people at nursing homes and places like that and I think it's a very good program. I've been on it since the 80s and if it wasn't for that I don't know where I would be right now. This is my PCA I should say our PCA that we called on to speak. Without her help, I would be up the creek more or less. So that's all I have to say. If you want to know anything about the services of PARI, you can ask my husband or me.

Judith Kapuscinski: I am Judith Kapuscinski from the Statewide Council on Independent Living, and you may have said it and I just didn't hear it you're asking for more PCA slots?

Miss Meradian: Yes, for PARI and Independent Living. The state council when I was on it, at one time, they knew I am sure you know too, because you must know Beth, she goes to your meetings.

Doreen McConaghy: Other questions? I am afraid I am going to ruin this next name. Is it Betina? Last name begins with a "C"? Okay. And you just signed in a minute ago and I am sorry I can't read it.

Victoria Hay: Victoria, Victoria.

Doreen McConaghy: Okay.

[Blind Vendors 1](#)

Victoria Hay: I am Victoria Hay I am a vendor with the State Services for the Blind and I've come to say give you an insight on the program itself and I am very concerned that it's not being managed well, and that we're losing vendors and facilities and uhm, I am going to go by my notes now, ran Randolph I don't know if anyone knows about it.

Male speaker: I know all about it. Good evening ma'am.

Victoria Hay: Well.

Male speaker: I know about it, my cousin Eddy Beck was involved many years ago.

Victoria Hay: Okay. It was to give economic stability to people who are legally blind or totally blind and I've been in the program maybe 12 years. And we own our own businesses. We may not own the building they're in, or the equipment, but we do own the receipts. And it gives us an ability to work and to make our own way and have a sense of pride. It's a very good program, but unfortunately, there's a lot of things that need to be improved. And uhm -- sometimes the way things are communicated we don't feel that we're on at least I don't feel that we're on the same level as the managers. We we're told that we are not business people we do not own the business. That, in itself, makes a person feel devalued in a sense, because this program was made to give us some pride and to be able to earn a living. Sometimes we're not allowed to make decisions on things and I think we need to be given more autonomy. Such as equipment that we may need, and there are many there's federal funds and state funds that come into this program, not to mention that equipment equals money. I mean if you don't have equipment you can't make much or sell much. A lot of facilities have been closing down, a lot of vendors have been leaving the program. And they need to be updated; they need to have mentors from the business community to come into the program. The people that manage the program have very little business experience. Most of us in the program have been on the job every day. It's always been said that you give a disabled person a job and they'll be there every day and that's exactly how it is. There are some people I probably can't say 100% of us, but most people they want to earn a living. our--

Scott Greco: Can I interrupt you for a second. The management team that you're complaining about right now, what's the name of the organization?

Victoria Hay: State Services for the Blind.

Scott Greco: They're the ones that run the Coffee Plus.

Victoria Hay: They run the business enterprise program.

Scott Greco: Exactly so, and this is to clarify for my own good, you answered directly to the people at the State Services for the Blind or is there an interim person?

Victoria Hay: There's someone who heads our program directly.

Scott Greco: But are they employed by the State Services for the Blind?

Victoria Hay: Yes.

Scott Greco: And it's a state funded agency?

Victoria Hay: Yes

Scott Greco: Continue.

Paul Choquette: the positions that manage the program are funded through federal money through the department of education. They're similar except they are an offshoot of the program.

Scott Greco: Is there some kind of a board that all of the vendors that belong to?

Victoria Hay: It's a committee that hardly ever meets.

John McDonald: it's meeting on Wednesday.

Victoria Hay: Right but how many people are going to show?

Scott Greco: Is this a general feeling among the vendors?

Doreen McConaghy: One at a time, please.

Victoria Hay: A lot of what I say that they feel there are a lot of people that don't want to voice their opinion. Some people I've got to say, have been so dependent most of their lives that they feel that they just want a living and so they don't speak up. And I can't say it's 50% or a quarter of a%, I don't know, but I know that the feeling is there. I've been in the program long enough to do that.

Scott Greco: Which location do you have?

Blind Vendors 3

Victoria Hay: The Federal Building. One thing I have to say is that we need better locations. A lot of locations like I started out in the health lab that was the morgue and there were like 50 employees there most of them brought their own lunch. It was a lesson in what? How not to earn money? And at the same time we were told maybe we didn't price right. Maybe we weren't good to our customers. But the real reason was, there was nobody there. They finally had to close it down. There are a couple of facilities still like that now where no one is earning a good living. I mean one facility became available was up for bid and it said, something to the effect of, earning \$200 a week. What is that? I don't think most people can live, I mean you know, it's not a living. And sometimes they'll get a wage -- they match the wages because it's so low, I don't know how to put it and some of the low earning facilities. But instead of having that facility go to a facility that has more population. Some facilities either there's too much competition, too many restaurants around or else it's not updated, you know, somebody is sitting in the corner making sandwiches that's it or else they're buying someone else's and they're not even making their own. But I really do feel that if we had some kind of business people from the business community to come in and give advice and ideas, like on pricing, on different products, this would open let's say a very moldy closet door and let some fresh air in. We really do need that. A lot of times we have facility that is you don't even know exists in a building. My particular facility is in the back of the federal building. I had to wrangle with management to get a sign to put in the hall, which I feel that I have a right to advertise my business and people should know that I am there. But this is not uncommon. Even in Boston they have facilities that nobody knows are around. Another facility that I know of is like on the third floor and has a competition of another restaurant with it. It's very poorly planned sometimes and it needs to be done over or something, I don't know. But, the only way that you do earn some money is probably getting a court, because like the story goes, crime pays.

(laughter).

Victoria Hay: And that's it, but otherwise, you rely on a very small population. Some buildings only have 150 people. You know half of them are going to go somewhere else so you live on minimal wages. But one of the biggest problems that I find is that we're not on equal terms and sometimes we're treated like we're not even given our opinions, or for instance, if I have something wrong with the refrigerator, I am to call up them and whatever happens, however long it takes, I can't call up the repair person. That's not allowed. And sometimes, you feel very childish in some instances. Here you are supposed to be someone who's making decisions all throughout the day and there's a no, no, on some of the things you're supposed to do. In the real world that's not how it is. Obviously the repairman would not go there just to "waste money". We should be able to get at least repairs done. But that's only a small piece of the pie. What I was talking about in signage, there's a lot of

problems in state services saying the building doesn't want signs, but you walk down the hall and you see blood drive here, they put signs here and there or whatever. If the building signs, how do you earn a living if you don't let the public know you're there. And there's another undercurrent, there was an incident, not naming who or what, but there was a demonstration on a certain piece of equipment, and this person was demonstrating say you can make this amount of a profit and someone interrupted from the program and said they get free lease where they have their facilities. They don't need that much profit. And there's an underlying idea that you're supposed to have cheap prices, why? Because I guess you get a cheap rent. I don't know. But it's a sense of pride. You just feel like you're not like the next person. So, I think what I am trying to say is that the program needs to be done over or something, I don't know. Refurbished, and I think a lot of behaviors and the way we're looked upon should change, and I say this, if you want to help the disabled you take the DIS out of it and you enable them to have a sense of pride to be able to do something; to have the right to earn like everybody else does. I guess I've done my complaining thank you.

Doreen McConaghy: Thank you.

Rory Carmody: Does the Randolph Shepherd Act only have this program?

Victoria Hay: You can have it in City Hall

[Blind Vendors 2](#)

Rory Carmody: The idea of a business mentoring, what about Johnson and Wales?

Victoria Hay: I've thought of them but also I am in the Federal Building and I thought that would be a good hookup, they have lots of programs within them. And I think it should be even if it's Joe Schmoe who owns a small restaurant he's learned a lot and can pass that on to others. If it's like a monthly meeting where we all get together and listen to a lecture of someone who's been through the mill it's something.

Scott Greco: Have you addressed the concerns with the Services for the Blind?

Victoria Hay: Yeah.

Scott Greco: Have you like gone through the formal process with them where you documented where I've requested a, b and c and they've answered us in this respect?

Victoria Hay: No I haven't.

Scott Greco: I definitely understand your frustration. My concern is that what jurisdiction the commission has over another state agency? What I would recommend is that you possibly you know, either set up some kind of a written correspondence with them or if you would like to set up a meeting with them and maybe have some representatives from the commission sort of mediate I think that's where we may be able to do that but I don't know if we have the authority, I may be wrong.

Donald Deignan: If I may, when I introduced myself I did not list all of the things that I do because it would have taken an inordinate amount of time. But one of the capacities in which I serve is as Chairperson of the Governor's Advisory Council for Services of the Blind which is the advisory group that oversees all of the operations of that agency and one of the members of the Governor's Advisory Council has for many years been Bob Connor a member of the Association of Blind Vendors he has not been a regular attendee at our most recent meetings, but I would invite Victoria to write directly to us and come and speak at one of our upcoming advisory meetings because your concerns are certainly of importance to me and my colleagues. I think we can do all we can to address them with you and to address them to the agency. I would certainly welcome the participation of my colleagues on the Governor's Commission on that endeavor if they wanted to take on

additional responsibilities but there is, for the benefit of my fellow commissioners and everyone else here but there is already in place an Ad Hoc advisory committee. So you would be welcome to come to a subsequent meeting of ours and/or write to us and we would hear your concerns take them seriously and do whatever we can to serve as an intermediary and advocate to address them.

Victoria Hay: That would be nice.

Male speaker: When's the next Governor's Advisory meeting going to be held.

Donald Deignan: September 15th.

Male speaker: What time and where?

Donald Deignan: 4 o'clock probably in the third floor conference room at 40 Fountain Street.

Male speaker: Thank you.

Doreen McConaghy: Thank you Victoria.

Anne LeClerc: Since this was brought up on the flip side, RIPTA has space. We opened some transfers center and when we opened Kennedy Plaza we had offers to the business program and right now we have space in Woonsocket and we're trying to work with them to get a vendor.

John McDonald: That's being worked on.

Anne LeClerc: It's a difficult process when you're trying to offer space. I don't know if more information could be offered.

John McDonald: Right now what's happening in Woonsocket space, the space is very small that they're offering and we're looking at tying it together with another Woonsocket location to make it financially viable for an operator who's running it. One of RIPTA's requirements is to have a live person there all the time. Income potential has to be enough to support something like that.

Anne LeClerc: Kennedy Plaza had much more potential and we never got a response on that one either.

John McDonald: They backed away from it because the management of the program was influx at the time. That was before Randy was actually hired.

Victoria Hay: When he became head of State Services.

John McDonald: And nobody was actually in Andy Maher's position.

Victoria Hay: But I asked the question many times why is Café LeFrance there and not us.

John McDonald: They turned the space down because they didn't think anyone wanted to work on Sundays.

Doreen McConaghy: If they're sharing information that's beneficial can that happen at the end of this evening and we can continue on with people if there are no more questions?

Male speaker: I have a question. You were all mentioning there's supposed to be a meeting next Wednesday.

John McDonald: That's a closed meeting.

Male speaker: What's it in reference to?

John McDonald: The Rhode Island Community of Blind Vendors. It's not a public body.

Male speaker: It's not a public body? Do you want to put that in writing sir? It's not a public meeting.

John McDonald: It's a private organization.

Male speaker: It's a private nonprofit.

John McDonald: Yes.

Male speaker: Nonprofit. Does it have a C15 status?

John McDonald: No.

Male speaker: Good.

[Mental Health 4](#)
and
[Mental Health 9](#)

Mitch Henderson: I am Mitch Henderson I am on Mental Health Consumer Advocates of Rhode Island and I am also disabled with a mental illness. Charlie Feldman has covered a number of issues tonight and I'll just address two or three more and the main one I want to talk about is discontinuity of medications and health care for those who are mentally ill. And the analogy here is basically is if you had a wheelchair for 9 months of the year and someone took it away for 3 months how would you feel? How would you continue in your job or your life? What we're seeing down at Oasis and other places in the state, often time somebody for example leaves prison where they've been on medication and been helped, and then they get out of prison, and they aren't picked up by the public mental health system so that they again get their medications. Well, what happens when you have this discontinuity, you can go right back where you started before you had medications. Your illness can take over and we certainly don't want somebody who has somehow gotten into prison in the first place to go back there again. So what's happening when we have discontinuity in services is we're being inefficient as a government. We're saying we'll help you some of the time and then, if you go back if we don't help you sometime, you may end up in a hospital that costs 20,000 dollars a week or so for someone who's mentally ill, the state pays that or you may have to go back into prison and spend \$37,000 a year. That doesn't make sense. It's a waste of money. I may refer now to the new Freedom Commission on Mental Health, President Bush's Commission statement that just came out. One of the statements was the commission finds that the current system they're talking about the mental health system is unintentionally focused on managing the disabilities associated with mental health rather than promoting recovery and this limited approach is due to fragmentation gaps in care and inequality. And the thing I am concentrating on here is the gaps in care that's something we have to work on in the state and take the money that's saved and apply it to help consumers who need help.

Scott Greco: Is there a problem with them qualifying for state subsidy programs or income verification, or are they not meeting certain criteria.

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Mitch Henderson: Some of that happens because of the issues of criteria for acceptance but other ones occur because of large backlogs at the community mental health centers. If you have to wait for 3 or 4 months for example between the time you get out of prison let's say or the time you get out of a hospital. You get out of the hospital and then you're going to be hooked up with community services. If it doesn't happen in a reasonable amount of time then there's a gap. But you're right about some of

the problems are created by the stringent criteria that's used by the mental health system to weed out people who supposedly are not eligible.

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The next thing I would like to talk about because we see it in our organization, we see a lot of people coming out of the ACI who don't have housing. And they are not qualified for housing usually for one thing. That just goes with the system. So they're homeless. And you know, if we don't have temporary housing, this is going to make it more likely, it's almost going to motivate situations where these people are going to get extreme and possibly end up in prison again. I came from Maryland two years ago they had a fine program of housing and services to help bring people out of prison to get them temporary housing, get them a temporary job and get them started again. If we don't get people kick started, and they get out into these situations, we can create problems. Two more things to talk about.

[netWORKri 3](#)

One is the issue of jobs for those who are mentally I will and my sole comment is that the state has to be more proactive for people who are mentally ill. People mentally ill are not going to necessarily walk into an employment office and ask for help. The state has to recognize that many of these people are in drop in-centers, they're out on the street, they're at places like traveler's aid, that's where we need help in getting one-on-one interaction so that people can be linked up to jobs, even temporary jobs. So I wanted to stress that when we talk about recovery, we talk about making someone feel good about themselves, we talk about getting around stigma, having a job is important. It makes you feel good about yourself. And we want them to have a job they feel good in.

Scott Greco: What would you do to recommend outreach though?

Mitch Henderson: I would recommend that state employees actually get out into the community and find people who are homeless or mentally I will to try to get them jobs. You can't wait back in the office for these folks. There's got to be more proactive. That's all I am saying. Be more proactive.

[Mental Health 6](#)

The final thing has to do with pay for mental health workers and I happen to know a little bit about this because my wife is a social worker. If you're working fee for service in this state and you're getting 50% 60% of the fees if you're working in a psychiatrists office and you're paying for your own insurance benefits and all that stuff you don't end up with all that much. And the insurance companies are the ones who are controlling the pay of our social workers and other mental health workers and as Charlie said, if these workers don't feel that they can continue on down the road and have a good professional development, they're not going to stay in the profession, they're going to do something else. To drive the point home, I will tell you that my wife, goes out of state to Maryland and flies down there and gets paid twice as much per hour than she does here in this state. So she spends some of her time out of state. Why not? It shows you the disparity that we have here. That's all I have.

Donald Deignan: Can you tell us which agency in Maryland state government is responsible for the management of these post-incarceration transition services that you mentioned. I am curious about that. Who is responsible, do you recall?

Mitch Henderson: I believe it's the Department of Corrections.

Donald Deignan: Department of Corrections. Thank you.

Mitch Hendrson: But there's an overlap here of responsibilities between MHRH.

Donald Deignan: Certainly but I was curious to know what the model was so we could look at analogous arrangement in the State of Rhode Island. It seems like a successful program on the basis that you told us and I wondered who administered it for our informational purposes.

Scott Greco: If you do have information on that particular program you can forward it to us and that would be

appreciated also.

Male speaker: I would like to emphasize what Mitch said, it helps if someone has housing, has a job, has access to education, if they don't have it, and they're live not guilty a shelter on the streets they're not as likely to recover as if they have all of these things.

Scott Greco: I worked for the Department of Labor and Training and unfortunately, due to budget and state budget FTE requirements we don't have the capacity to do that, but as information only, our network Rhode Island offices which are our the old unemployment offices which have a conglomeration of different state agencies, we have people from occupation rehabilitation, department of labor, department of elderly affairs, in those offices now, we just received funding a couple of years ago, we had actual people that handle people only with disabilities now. So if your organization want to say do referrals we have our Providence and Pawtucket office.

Male speaker: We're starting to up lines of communication to do what you're saying. But again energetically in the state --

Scott Greco: Right but if we could take one step at a time. I would recommend contacting the office managers and get in touch with the disability experts there right now and doing good work with people with disabilities. Not just people with mental disabilities but all people with disabilities.

Doreen McConaghy: Other questions? That concludes the number of people that have signs up.

Sharon Lane: Should we ask for a break for the interpreter now are we done.

Doreen McConaghy: No, just let me make this comment and we'll give you a break. For those people sitting here listening, if you have decide you would like to speak, come and check next to your name and we get back from break, it will be your opportunity. Thanks.

Doreen McConaghy: can we be seated, please? (tapping on the table) okay, we've had another person decide to speak and their name is checked. Adrienne.

Adrienne Aldridge: I would like to.

Scott Greco: Can we have everyone's attention please.

[RIPTA 7](#)

Adrienne Aldridge: Yes, my name is Adrienne Aldridge. I am going to start off with Rhode Island public transportation. This is an issue that had been addressed going back at least about a year and-a-half now, and this was also worked out with Dr. Beverly Scott, who by the way, is an extremely fine lady, very intelligent and she's very nice to work with. And I am sorry that she left. Now we have a new bus terminal, we have new buses and they did something about the drivers which were being complained about and tried to replace them with new ones and there are severe issues because the number one thing RIPTA is interested in is recovering of funds, whether it be from the people who take the buses, or their trolleys or whether it be collecting it from whatever source they can from disability, the ADA's are collecting it from the state or the federal government, whatever. But we have something very essential here and that is the fine human beings who take the bus. They're not getting what they should and they're not being treated the way they should. RIPTA has the paddle where they keep their buses intact. That's their time schedule and that time schedule every single driver is afraid of they want to be at point A and up to point B and back to point a by such and such a time. They don't care if the person has the foot or their leg in the bus how much of the person gets in the bus. They don't care if they slam the door shut on them. The main concern is to get as that paddle has told

them and I've told the supervisors down city, I told them, your paddle system may be one thing but you can't run the system without the people who take the bus, and if they can't enter and exit the bus in the orderly fashion you're not going to have a bus system. It's going to be a tragic thing but it's coming. You can't run a bus system like this.

Snow Removal 1

And what concerns me even more is we're going to be heading into cold weather. No one seems to care to keep their curbs clean, and now the new bus terminal has heated pipes underneath so you don't have to shovel snow but I am talking about where the bus supplies service to. There is no way for people to hardly climb over say snow hills, hills of snow, nobody goes around and makes access with shovels or what have you or other means, nor do the owners come out and shovel there driveway. Nine out of ten, also do you know how many buses you have going by, the lifts do not work. Even the new buses. Now, what happens is the new demand from the boss is that everybody gets on the front and off the back. Okay. Number one, you always have problems with the lifts as it is. You need them for the people who have wheelchairs and need to access the service and also to get off the buses, and now you've added the pedestrians going to the back be it with their strollers also that they're carrying, be it with children on their arm, be it with whatever it is that is going with them out that door, now, after you empty the whole bus the bus driver comes up to get the wheelchair last. Now, I would like to know, with all of this going off the back door don't you think you're putting considerable poundage on that wheelchair lift? I mean, the design of it is for a wheelchair, not to have people stampede through at every stop or at the end of every stop or the start of it, you know, the main points. It's not right. You're taking the use of the wheelchair ramps off. They don't even run right anymore. They don't run correctly. And you have the new wheelchair buses, which are designed with a person and gets on the front and is in back of where the driver is and from there on in you have the seating around it. Where did you put all those buses, down in Newport. There's one in Providence, Rhode Island.

One. These buses are all directed out to the exclusive area. Myself and another gentleman took the how can I

Ride 5

say, we took up the thing of, the job of getting the message through to the bus service about putting a door forward also on the RIDE buses because if you have to sit in back and you're on the way to a medical appointment, you don't need the medical appointment anymore, you need trauma. That's how bad you get shaken back. This is not right. And they still haven't corrected it. They have one or two buses where they do now have that new system and they send it to everybody but somebody who is in a wheelchair. I have yet to be on that bus or the ride bus that excuse me strike that, I was on the regular bus down in Newport one day that went down to the beach and then he dropped me off on the way back, you would not believe it. It was going down a hill where the bus went back down the main street there, you know where all the traffic goes up to the, oh, I can't think of the name of the street I am sorry, it's one of the main streets, where you go up from America's Cup Avenue to.

Rory Carmody: Thames.

Adrienne Aldridge: Is it Thames, it goes up to where the estates are.

Male speaker: Bell View Avenue.

Adrienne Aldridge: Yeah, the one that goes up there. Well, and if it goes to the beach, it goes further straight. Well, all the way down there's like a wall, a stonewall, and the street is not wide enough for a wheelchair, only certain areas, it may be wide enough if you go parallel to it you may be able to sit on it. I had to sit there and yell across the street to a few men that I saw if they could please lift my chair down or somehow get me down, you know maybe get a few other guys with them, two more guys and they could lift my chair down, which they did. And they said, my god that is not an appropriate place for a bus driver to leave you off. I said, believe it or not, he did. I have no other way of getting up there, there's no ramp or anything. And that was the new bus. And I tried to tell him when he was getting me off. I said I can't get off that, I don't think it's big enough. He said good buy, have a nice day and the bus shot off. This is what I am talking about the so-called paddle. Follow the time or else and I am not only speaking on behalf of consumers. Do you know that the majority of the drivers based on where they're at, if they hadn't put up some sort of a petition in the beginning they didn't

even have a place to stop every so often if they needed to use the bathroom. And I spoke to them and said how can you do that. If these people and the drivers are expected to go a whole day and not use a bathroom, you can expect to have problems, they're going to get kidney problems. They can't do that or otherwise. So finally they let them use the bathroom down at the bus terminal. But there are a lot of problems. And I shutter to think if these problems the major problems don't corrected now, if they don't get a handle on it, we're going to be right back with the bus service in the winter time is going to leave us sitting, by that I mean people in wheelchairs, or the people standing but they can get out of it quicker, we can't. I remember getting soaked head to foot. Sorry, my lift isn't working, they never even tried it, and they just went by. But that's unacceptable. I mean, you have a lot of people who testify on behalf of them getting the funds federally, if and when, even if you're not working or not, you pay into the tax system one way or the other, if you're on disability or something like that, you get your money on how can I say, the disability, you still pay every time you go to the store, you pay various taxes, either state or federal. So I am just saying, you have a lot of taxes that go into it, you have a lot of petitions. I know every time I vote there's an issue on the bus service and of course, you vote for it to see to it that they can better whatever the problem is they're having but guess what?

Doreen McConaghy: So to summarize --

Adrienne Aldridge: To summarize it, it needs to be addressed over all. They can't turn or close their eyes to the fact, winter and cold weather comes it will work itself out. I am sorry.

Doreen McConaghy: So it's better respect from the drivers, working lifts, it's.

Adrienne Aldridge: Working buses too.

Doreen McConaghy: And the scheduling.

Adrienne Aldridge: Right and they have to have the schedule approached and they have to treat people like human beings. You know, we're not these little I don't know whatever they think, whoever hops on the bus very quickly and they can get them on the bus very quickly and shove them off at the bus terminal. You're lucky if everyone gets on. And they're told hurry up, hurry up gee they have to get their feet on the steps. There's someone else in front of them. What are they supposed to do? Push them down and go over them. I just can't believe what's been done a year and-a-half ago. I said at that time, please do not close it because as the saying goes, when the fox takes a break, the rest go out to play and they're at it again. So don't close it. That was my motto. And there's another issue I have.

[Housing 7](#)

And that is concerning the quarters that get federal funds and where you get subsidized housing. Meaning apartment complexes, you know, companies that built apartments, like the one that has been designed strictly for those who are disabled and they made beautiful designs and they really did. They might have put the shelves way up somewhere but that's because someone who was disabled wasn't in the designing group. But you have some people who damage the property consistently, they get immediate corrections and then you get one person who's living there for 10, 11 years since the property existed, has yet to have the floors done, has yet to have their apartment painted, you know what I am saying? And I spoke to them and it made no difference. I was told they would do my floor and they promised they would do the floor but not until a year from now because they needed to get out of debt. All right, they needed to get out of debt. You've got somebody in there who has burned a car out front, crashed his car, is in and out of the building drunk as can be and on drugs, wrecks everything, is turning everybody's life upside down every single day we have no peace in our apartments anymore. He goes around banging on everyone's door at night. Everybody filed complaints and then one night, he went in with somebody into the office, --

Doreen McConaghy: So this issue is with management companies of HUD subsidized housing.

Adrienne Aldridge: Excuse me?

Doreen McConaghy: This issue has to do with management companies of management-subsidized housing.

Adrienne Aldridge: Right and not all of the buildings are taken care of like this.

Doreen McConaghy: That would be the management company.

Male speaker: It has to do with something called a landlord too. They're not willing to get the lawyer to have the guy evicted, which is right within the lease. Some of these landlords hire management company to see run these buildings and they won't move until someone goes and says this is what is in the lease and they go to the representative and say look, this man is doing something that's not in the lease, let's get him out of here.

Doreen McConaghy: Okay thank you.

[RIPTA 10](#)

Male speaker: To summarize RIPTA, this bus company I don't understand why if they've got buses down in Newport, why half of them aren't up here. I lived in San Diego for five years and took the buses, they had the lifts in the front and a lot of times I would be up at the state university and one day I was up there, and it was someone in a wheelchair. It was a woman bus driver, having a problem getting on. I helped them get him on for the bus driver. This is 2003; this is not 1980 or 81.

Anne LeClerc: Can I address it.

Male speaker: Address it because I am getting ready to --

Adrienne Aldridge: He interrupted what I was a saying and have him address his name.

Doreen McConaghy: What's your name?

Male speaker: Allen Temkin.

Rory Carmody: Temkin.

[Snow Removal 2](#)

Anne LeClerc: We would like to have them in Providence. The reason they're all in Newport honestly is that's the only city that enforces no parking at bus stops. And the only way the lift can be deployed is on a sidewalk. That's why we don't have them in Providence.

Adrienne Aldridge: I am sorry, could you say that again.

Anne LeClerc: The ramps at the front of the bus need a curb to go out to.

Adrienne Aldridge: We have plenty of curbs.

Anne LeClerc: Right but the city doesn't enforce no parking at bus stops so a bus can't always get to a curb we couldn't deploy you into the street.

Scott Greco: We're not here right now all we're here for I am talking right now, let me talk right now.

Male speaker: Excuse me citizens bank is -- Connecticut you're out of order right now.

Scott Greco: Right now we are not here to have a debate between the public and the RIPTA. This is a forum for people to address concerns and then the commission will take all of the concerns that are addressed and bring them to the appropriate whatever, RIPTA or whatever agency that we feel that is necessary to bring up suggestions to or whatever we have to do. We're running at 6:30 right now. We have the room until 7 o'clock. There are other people on the list.

Doreen McConaghy: This is the fifth hearing we've had. This is the last hearing for this particular year what has happened in previous years is all of this information gets put together in a very big document. The commission then puts together a committee and the committee goes through and pulls out the common threads and that becomes part of what is the legislative package for the coming year.

Male speaker: Right.

Doreen McConaghy: I don't know if Paul, the Chairperson for the Legislative Committee wants to speak further on that.

Paul Choquette: One of the things that we try to do from these hearings is to get an idea of what the issues are. And many times, the issues somewhat of what is being raised right now can be solved in a manner that doesn't need legislation. But we need to hear about them and again, the more times we hear about them, that tends to make it a priority for us to try to attempt to change them and we do work with the agencies that are involved to try to change the policies, if necessary, or the procedures, if necessary, so that these concerns can be addressed. So we need to hear them, and again, I want to echo what Scott said we're not here to debate, just to listen. And we want to be able to have everyone heard here tonight, we do have the room for another half an hour so that everyone has an opportunity to let us know what their issues are and we will again, use the information to make the changes that we need to take place in order to have the issues resolved. Thank you.

Doreen McConaghy: Other comments, questions?

[Personal Care Attendants 9](#)

Chamana Maaordan: I wanted to speak. My name Chamana Maaordan I work for Hope and Richard and I had no idea why I was coming here tonight when I came, believe me and it's very interesting, but I don't think that people realize how much it takes for someone that's disabled or in a wheelchair or maybe blind, to just live their life and get on with their day. And they're worried about losing their PCA's and they would literally be up a creek without someone to help them. It consists of getting dressed, eating, my 9 year-old daughter was deathly sick last week and my husband said why don't you stay home. I said if I stay home they wouldn't be able to eat. It's bad enough to be disabled and finding people to work for or with them that won't treat them badly or leave them anywhere or just be a jerk. But then they have to be worried about is this person always going to be able to come in. Will I have them enough to have them do my laundry, my personal needs, my shopping and if I want to go out, will I be able to do that? So it's hard. It's very difficult for them and I am glad I came tonight. But I mean, if they didn't have the help that they had, I really don't, I think they would have to go to a nursing home which would be the next thing. But there's no place for them there. That would be like killing them. Do you know what I mean? They do their best and it's hard, I really feel for people who are disabled. You're talking about getting off a bus in a wheelchair and I've seen that. I take the bus every day. It's very difficult. People don't realize how scary it is. I have food, but am I going to be able to have someone cook it for me. It's very scary. Thank you.

Doreen McConaghy: Thank you.

Hope: I would like to say something, we do cook.

(laughter).

Hope: We would not starve to death, not in our house. My husband does a lot of Italian cooking and I do American.

Female speaker: He cooks better than I cook.

Hope: So we tell her what to cook and how to prepare it, she does cook. She stands in front of the stove and we tell her, but if she didn't come, I know a lady on this board that has had some of my husband's Italian stuff. And our defense, the program we belong to is independent living and you make it sound like we're not independent and believe me, let anybody try to make me do something I don't want to do.

Donald Deignan: I have a question I want to commend you for the testimony you've just given us. My question would be you do the job every day, how do you think from your point of view, from the point of view from people who do what you do, how can we improve the program. If you had your way how can we improve your working environment for you? What kind of things could make you do your job better and more attractive for people like you?

RIPTA 9

Chamana Maaordan: Honestly, well, the transportation, I don't have a car right now, and I have two kids and I have to I take the bus to her job, but she lives right on Atwood Avenue, but after five o'clock there are no buses leaving from there. And when I leave her house I have to walk home or ride a bike home. Sometimes there's no transportation and I have to get there and get home. But for the PCA I would think if something did come up and like my daughter is 9 months old and they want their mom. If I was to stay home, someone else would be able to get there and I wouldn't feel guilty. Do you know what I mean? I took her to work with me one time, thank god they let me. And yes, they are very independent, they do great cooking, but, I would think having someone else able to cover more hours also, I don't have many hours, and it becomes like, do I get another job and will it conflict and day care,

Scott Greco: How many hours do you work now.

Chamana Maaordan: It varies. We have another one there's two of them. During the week I work two hours at night during the week and then on the weekend whichever day I am working 9 or 10 hours.

Scott Greco: You're paid through the agency.

Chamana Maaordan: Yeah.

Scott Greco: When you go in for two hours are you only paid for two hours.

Chamana Maaordan: Yes.

Doreen McConaghy: Thank you.

Charlie Feldman: Can I say one more thing. Charlie Feldman Bob Cooper of the Governor's Commission on Disabilities gave a presentation at MHCA's annual conference and he pointed out people with disabilities need to unite and have cross advocacy and support each other, especially with one Rhode Island having started up, if we could unite and get more disability issues in the Rhode Island platform next year would be great. We should keep this in mind and we will be stronger if we unite. Thank you.

Scott Greco: We invite everybody to a Commission meeting.

(laughter).

Doreen McConaghy: Yes.

Curb Cuts 4

Adrienne Aldridge: I would like to make sure it's brought out and brought for the record that all the sidewalks and access ramps or lack of need to be all gone over. You have some ramps, which are so pitched that if you went down and I know, it happened to me, you go over in your chair. And a classic one would be right across from Providence Place on the corner. That's one that pitches down so badly. And you have them where they want to put in a fast ramp where one is needed and so what they do is they cut out a piece of the sidewalk and then put it in but it's not leveled down enough at a pitch for a wheelchair and then you have sidewalks which are on an angle. If you're in a wheelchair how are you supposed to go through that, you've got telephone poles going in the middle of it, you've got signs and all of these things are just not looked at. You've got some streets, no access ramps have ever been done and this goes back before I think the ADA law went in effect just when the former mayor went in, Cianci and I know having been on the phone to Maine where their office was, asking them please, to do something about getting the access ramps on all the corners here in Rhode Island and the streets done so that you have proper access. I mean, I explained it out in detail. And what was lacking and I know that they did follow-up on it, but nothing ever was done. Now they started putting in some of the access ramps, but you have like a hodgepodge doing of it. It's really not being handled correctly and you need to have somebody oversee that project who will keep tabs of the whole area of Rhode Island and make sure that it is done right so nobody gets hurt anymore. Thank you.

Male speaker: I have a suggestion in that regard, perhaps someone who is disabled ought to be on the ought to be helping RIPTA and the city of providence in the inspection of sidewalks and other places, since someone who is disabled would have a real passion for making things right.

Paul Choquette: I can address that from the Commission stand point one of the subcommittees is called the Access Committee which is responsible for looking into issues regarding accessibility in public places. What I could suggest to you, is even for yourself or other people if you see areas that you feel need to be looked at, you could put them down on paper and get them into the commissioner's office and then the Accessibility Committee can look at that and there are people who use wheelchairs on the committee, the staff of the Governor's Commission could go out and review the sites and we do have a way of working within the Commission with the dot to prioritize changes or modifications that can be done. So that is a very good way to try to get those things that are priorities done quicker than they should be. I would suggest if you have certain places that you know of on certain streets if you could put them down on paper and get them to the commission and then the commission can address them.

Scott Greco: Going one step further with that we recently passed legislation that's actually setting up a hearing board or a disability court, and we're in the process of forming that right now to be a five member hearing panel, and we have pretty fast jurisdiction with the new legislation to any of these complaints now, can be actually heard in front of a board, the board of jurisdiction is very fast we have spoken power and the ability to cite and fine and that doesn't go for just private industry but through municipal and state government as well.

Female speaker: I wanted to ask about the buses. I was under the impression that they're not supposed to leave the garage if the lifts don't work. They're supposed to be checked.

RIPTA 8

Anne LeClerc: The lifts aren't working from everything we're being told in the company, the lifts are working, the lifts that don't go out-- the buses don't go out if the lifts don't work properly.

Female speaker: I was present on one bus that said I don't want to be late on his schedule, so they'll go right by me.

Anne LeClerc: I'll bring that up to the director. They shouldn't be letting people off where they're not safe.

Female speaker: When she spoke of the paddle, sometimes those paddles aren't up to date. One bus driver had a paddle for my route, which had changed two years ago, and he was going the wrong way and I told him you're not supposed to turn here. He said that's what my paddle says. I said your paddle is old. If the paddle is the bible, what does the schedule mean, what does the route on the schedule mean.

Anne LeClerc: They should match. We change service three times a year. He could be doing an old paddle schedule.

Doreen McConaghy: we haven't had anybody new come in. I think we've given everybody an opportunity. If people feel there's nothing else to say, do we get arrested if we adjourn 15 minutes early? I would like to thank the individuals that came to testify, and I would like to thank the panel for giving up some time and sits here and listening and asking questions. Thank you very much.

(applause).

Male speaker: I put the whole panel under citizen's arrest.

(laughter)

VI. Written and Emailed Testimony

Tracy Miyake

Warren, RI

To the Commission:

[Housing 4](#)

I would like to express my concern at finding handicapped accessible housing in Rhode Island, East bay in general. We are trying to find rental housing that will accommodate our wheelchair bound daughter, and we are not finding success. I know we are not alone in finding difficulty rather than finding affordable, accessible rentals... Thank you.

To whom it may concern:

[Open Doors](#)

I am a 53-year-old woman with M.S. I use a cane, and I have trouble going to public places with doors. Most doors have heavy handles, which are hard to push. Maybe special handicapped lanes could be available at banks and stores so that the disabled do not stand and wait in lines for a long time. Would a few chairs be nice to have in department stores? The disabled could sit and rest for a little while. Well thank you so very much for reading my comments. God Bless you and have a good week.

Sincerely,

Deidre Groce

To whom it may concern:

[Medicaid 3](#)

On behalf of our son, Roger P. Masse Jr. who is disabled, I would like to bring to your attention that Roger had a prescription from his doctor for a walker. Upon going to PVC with the prescription Roger was denied by Medicare-Medicaid being that the walker had extras such as a brake, seat, and basket. Roger needs to rest intermittently while walking. The price came to \$149.00, which was paid, but he could not afford. How could this happen? If Roger fell and got hurt it would cost the state many more dollars besides \$149.00. I would appreciate your looking into this matter. Even a partial payment would help.

Sincerely Yours,

Sandra Masse

West Warwick RI

Luther Giordano
 Woonsocket, RI
 July 30,2003
 Sirs/madam's:

[Client Assistance](#)
 And
[Office of Rehabilitation Services](#)

I am disabled with delayed onset, chronic post-traumatic stress disorder receiving Social Security Disability insurance as my family's sole income. For over ten years, I have been interfacing with the organizations in Rhode Island allegedly existing to help the disabled I have found them to be organizationally designed to discourage and dismiss "clients" after their initial enrollment (They cannot collect funds for non-enrolled people.) I have found the people who work for them superficially polite especially in face-to-face meetings, even enthusiastic as plans are discussed. And then, the pattern continues: letters ignored, email ignored, voice mail ignored Information about available services promised at interviews is never sent,

By way of illustration, this is my latest experience with Vocational Rehabilitation. After a period of several years of non-action, I was notified that XXXX was being promoted and would no longer be my counselor If I wanted another one, I was to contact them, I happily did so, hoping that perhaps this one would do his/her Job. "I received no further communication from Vocational Rehabilitation. Phone calls and letters requesting an appointment were ignored. Finally, Social Security sent a letter informing me that they were considering recertifying my case and inquiring into the various services I was receiving. I replied that, other then regular medical care, I was receiving none because (a) no one in Rhode Island takes Medicare or Medical Assistance to treat PTSD with my underlying causes and (b) Vocational Rehabilitation had ignored all my attempts to set up an appointment (as usual) About a month later, I received a phone call from my new counselor who set up an appointment. I met with her over a month ago (I cannot supply her name, as I was not given her card. Phone calls are good for not leaving any permanent record.) I outlined my proposal as I had previously to XX. XXX. Information and assistance were promised (as had XXXXX.) I have not heard from her since nor do I expect to without further complaints to the federal government.

Non-profit organizations (so-called advocacy groups) also follow this pattern. Clients are enrolled so that their service population is as large as possible to secure their funding. Face-to-face meetings generally take the understanding tone that of course government agencies don't understand the special needs of the disabled, but we do because we are or our best friends are some of their best friends are also those government bureaucrats they work with them "closely" we are told and they understand the process." Obviously, those of us who are disabled cannot possibly understand. They will help us then the pattern begins again: letters ignored, voice mail ignored, emails ignored, state services for the disabled are virtually non-existent unless perhaps you have "connections." State services for the workers who "service" the disabled are by all accounts superb. Early on in the process of dealing with these people, I requested information about numbers of applicants, numbers of successes, all the usual information that a program would be judged by I have never received even a polite acknowledgment of the request Perhaps the Governor can receive one, but I doubt it My experience has been to be lied to, patronized, and abused by state employed and state funded workers the disabled are easily dismissed They just don't remember appointments or names they were never given. Wait long enough and the disability will almost certainly worsen thereby proving that no assistance should have been rendered. It would have been a waste of time.

Dear Governors Commission on Disabilities Representative,

[Parents who are Disabled](#)

My name is Ann-Marie Angrisani. I am a 26-year-old female with mild cerebral palsy and spastic quadriplegia. On April 10,2003 I gave birth to a baby boy. His name is James, and he needs me. The Department of Children, Youth, and Families has taken him away from me because I am unable to care for him alone. The agency I am presently with does not support children of individuals with disabilities. James currently stays with my foster mother Jean Doire. The state has given me until November to get a support plan in place so that I can get my son back. I have called agency after agency,

and have gotten nowhere, and my time is running out. I would appreciate any help or leads that you could give me. I would like to find a home and agency in Northern Rhode Island that could care for my son and I.

Thank you in advance for your help

Ann-Marie Angrisani

Middletown

Subj: Governor's Commission on Disabilities

Date: 7/18/2003

8:09:40 AM Eastern Standard Time

From: Diane Osagie, Johnston

To: disabilities@gcd.state.ri.us

Dear Sir/Madam:

[Housing 5](#)

I am writing in response to an advertisement in the Providence Journal regarding the concerns of persons with disabilities and the people who care for them. My concerns are as follows; My mother, who will be 80 in two months, i.e. now taking care of my 54 year old sister who was diagnosed with MS approximately two years ago. My mother recently applied for housing for the elderly/disabled on behalf of my sister in four different, facilities within the Town of Johnston and the Town of Smithfield (we have lived in Johnston most of our lives) and was told that there was a two to three year waiting period. In the meantime what does my mother do?

[Respite Care 3](#)

In 1977 my father was diagnosed with MS (multiple sclerosis) and my mother was his only caretaker from 1977 to 1996 when my dad passed away. Approximately six months ago my mother was hospitalized with a pulmonary embolism for which she is still under doctor's care for today. I find it very disheartening that my mother is once again burdened with the task of caring for my sister who has the same disease as my dad had. Of course, my mom does not look at this as a burden, it is her daughter and she will do whatever she has to in order to help her. So does this mean that she now has to jeopardize her own health and well being to care for another? Just to give you an example approximately three weeks ago my sister fell in the hallway of their home and my mother, as hard as she tried, was unable to pick my sister up and had to resort to calling 911.

My concern is my mother and her health and well being and being able to enjoy her last years caring for herself. I find it most unfair that we have lived and supported the State of Rhode Island all our lives, and now in a time of need we are told we have to wait two to three years to receive any help from the State. Does my mom have that many years left?

Try and put yourself in my shoes (or my mom's shoes) and tell me what would you do? Where does one go from here? Any suggestions and/or help that you may be able to render will be most welcomed and appreciated. Thank you for your time in this matter.

Mr. Bill Enlow

Americans With Disabilities Act Coordinator

Rhode Island Public Transit Authority

Paratransit Division

265 Melrose Street

Providence, RI 02907

Dear Mr. Enlow:

I am writing on behalf on one of my constituents, Mr. David Cataldi, regarding his wife Judith's denial for access to the Rhode Island Public Transit Authority's (RIPTA) Paratransit RIdE program.

[RIdE 7](#)

For two years, Judith Cataldi has sought access to RIPTA's RIdE program, but has been met with nothing but hostility and resistance. With only 10 other vision left, Judith Cataldi suffers from R.P an incurable eye disorder that will soon rob her of what little sight she has left. Forced to quit her job, give up her automobile and relinquish any shred of independence she desperately clung to, Mrs. Cataldi sought some relief in the form of the RIdE program. Unfortunately, however, Mrs. Cataldi was told she did not qualify. Despite the RIPTA-published article informing that they provide "door-to-door transportation services" to among others, "individuals with disabilities," Judith Cataldi was told she did not qualify Despite the eligibility

requirement as indicated on RIPTA's website of "anyone whose disability or specific impairment prevents travel to or from bus stops," Judith Cataldi was told she did not qualify. Despite the fact that blindness is a recognized disability impairing her ability to travel the half-mile to the designated pick-up point, Judith Cataldi was told she did not qualify. In RIPTA's own words, "public transportation should be available to everyone," but is not to Mrs. Cataldi. With her ability to see gone, and with it her independence Judith Cataldi has lost something else: the hope of freedom, coming in the form of one small bus trip to and from her house; not exactly taxing, when the RIde bus travels by the Cataldi house to begin with.

It will not be long before the percentage of vision dwindles, from 10 to none, and what the Rhode Island Public Transit Authority does not recognize as a disability is more than that to her and her husband- it is heartache, and it is forever. Therefore, in accordance with all applicable rules and regulations I would appreciate your reconsideration of Mrs. Cataldi's request for entrance into the RIde program. Thank you in advance for your attention to this request.

Sincerely,

James R. Langevin

Member of Congress

JL/dol

CC: Mr. Al Mescola, Acting General Manager, Rhode Island Public Transit Authority

Ms. Doreen McConaghy, Chairperson, Governor's Commission on Disabilities

West Warwick

July 28, 2003

Governor's Office

RI State Capital

82 Smith Street

Providence, RI 02903

Dear Governor Don Carcieri,

[Medicaid 4](#)

Excuse me for not using the correct heading; it is not meant to be disrespectful. I am praying that this letter is actually read by you because my 77-year-old disabled husband, George, really does need your help. In fact, this situation is very stressful to me, as his caregiver, advocate, and mother of our 20-year-old son, Andrew. I truly have no other person to turn to. After several weeks of rehab, George came home from a nursing home on July 17th unable to sit up in bed, stand, pivot into his wheelchair, and go into the bathroom to wash his hands, etc. The agency, Assisted Daily Living, 2809 Post Road, Warwick, RI 02886, sent over a physical therapist once, on July 21st, who noticed raised sores on his ankle where he had had an operation at RI Hospital (1989) for a multi-ankle fracture at Brenton Point State Park. A nurse did not see it. The agency is claiming that I am neglecting George because I am demanding physical therapy?

United Health Medicare Complete approved this last week, for three visits a week for two weeks. George was standing and sitting in his wheelchair at the rehab hospital in North Smithfield so I do not understand why he was transferred to Wildflower, Greenville when I requested that he needed to be closer to where we live, and asked for him to be transferred to Kent Rehab in Warwick. He went into RI Hospital on May 27th, and was transferred to North Smithfield on May 30th, and was doing so good until he was transferred again on June 20th to Wildflowers Nursing Home.

They ignored my wishes, even though I have Power of Attorney for finances and my husband's health. I even thought Wildflower was holding him on purpose for financial reasons because they are in receivership. So I decided to send an application to his doctor at the VA Medical Clinic to place him on a waiting list for the VA Nursing Home in Bristol. Wildflowers told me that the physical therapy was over on July 7th, and that they could not find an ambulance service to carry him into the house because of the eight steps. The VA always sends Universal Ambulance with two people to carry him out. We never had a ramp since he's been in a wheelchair for about seven years now. I had to sell the old bungalow we lived in for 17 years, hoping to find a

ranch house with a big bathroom that I could fit with long grab bars, etc. The real estate agent, David Sullivan from Globe Realty, 900 Reservoir Ave., Cranston lied over and over, telling me to trust him, and talking me into signing a 60-day rental agreement with the new owner. Closing (4-12-02), and I rented my house (\$990.40 p/m) until I moved on 1-7-03, after the stress of going to court for an eviction notice against us.

We are currently renting a 2-story house for \$1200.00, and we are on a waiting list for rental assistance for one to three years at the Cranston Housing Authority. I do not know when I will get this Voucher eight. In the meantime, my husband's income is only \$2027.00 per month. Why is the Dept. of Human Services sending me papers to sign? They want to know about any savings, and what kind of car I am driving. We didn't get a lot of money for the house (30-year VA Mortgage at 9 and 1/2 %, and a second mortgage at 10 and 1/2%. Yes, we were house-poor, with the house needing a new roof, repairs, etc. Now we are rent-poor. Habitat for Humanity is considering this family at the present time. Andrew, our son, completed one year of college at CCRI, and is starting at RIC full-time

Soon. He will have to go on the work/study program, probably on campus.

My husband has had a Medicaid card for quite some time. Also, Andrew was receiving state medical assistance off and on during high school, graduating from Cranston East on June 12, 2001. His father was not at the performing arts center. We have never had a wheelchair-accessible van. The 1995 Ford Contour I am presently driving, along with my son, was bought before my husband was in a wheelchair, and on an electrical oxygen unit. I have not been able to find an affordable used van as yet. Along with a ranch style house to either purchase or rent with an option to buy. Other families have what they need in this state. I really feel uncomfortable with the present situation. The only help I have ever received was from the diocese of Providence 's respite program. For the last three years I have had certified nursing assistants twice weekly to help bathe and shave my husband. This was still difficult because I had to call various agencies to ask for male certified nursing assistants. My husband weighs 240 pounds (I weight 120). I paid \$6.50 per hour. I was only given one visit a week per year so my hours wouldn't last for the year, July to July. I applied to the Dept. of Elderly five months ago (West Bay Community Action), and was told by the Director, Paula Dunn that my husband qualified for homecare, and this would cost \$5.00 per hour, and I could use the same agency that the respite program used. I have not received the letter informing me of how many hours I will be given. What do these agencies want from me? The Dept. of Human Services never gave me state medical, always turning me down because of the Social Security check we received for Andrew. That check stopped in June 2001. Andrew has been working part-time at Brooks for 1 ½ years at minimum wage; he cannot do work/study and work at Brooks, and keep his grades up so he is taking a leave of absence from Brooks soon. I have always wanted employment; especially in the last seven years because of financial hardships only I have never been able to help my husband have a better quality of life, thereby having him independent, and able to get out of a house in an emergency. My son, Andrew, has witnessed the lack of support I have received, and thinks I should be independent, that is, employed. I need several more work credits to be eligible for Medicare, and I will be 62 years young September 16th. I am very frightened of losing my health, or even getting high blood pressure. How would I be able to afford a prescription? My son, Andrew, sees that his father is no longer attempting to sit up in bed, much less stand and pivot into his wheelchair, and I do not have any help. I worry about my son's health. I constantly think. Why us? Does the state really think I have the money to pay for a daily nurse, certified nursing assistant, and physical therapist? Well, I do not! George lost his life insurance, and family medical coverage after retiring in 1991. He worked for supermarkets all his life as a meat department manager. His nearest relatives are in Chester, Pennsylvania. I am from Massachusetts, and have an older son living in Woonsocket (former marriage). My husband has an older son living in Santa Barbara, California (former marriage). I have RI relatives, and I am related to an assistant attorney general in the Justice Department, Providence, by marriage (my aunt from Bristol - may her soul rest in peace).

I certainly want you to take this letter seriously. Governor Carcieri, and I have a positive suggestion, which I am sure you will find very interesting. Legislation passed in the state of RI giving full state medical coverage to caregivers could be a first in our country. I would like to know how to begin the process of doing this, because I don't want others to go through what we, as a family, went through, and it is not getting any better.

A reply would be greatly appreciated, and as soon as possible because George has multiple medical problems, namely, Myasthenia Gravis, Chronic Obstructive Pulmonary Disease, Congestive Heart Failure, Diabetes (non-insulin), Atrial Fibrillation, Hypertension, Osteoarthritis, Eyesight is poor (blurring in both eyes), and there is a steel rod (or rods) in his left ankle. His physician at the VA Medical Center is Dr. Khaja Ahmed. George had to receive daily radiation treatments for prostate cancer 3 years ago at Roger Williams Clinic.

Respectfully,

Anna M, Nicolaidis

CC: Doreen McConaghy, Chairperson; Governor's Commission on Disabilities United Health Medicare Complete Dr. Khaja Ahmed; VA Medical Center; Alliance for Better Long Term Care

Hi.

E-mailing you about public forums planned in near future. Why is there never a forum for the people in Barrington, Warren, Bristol and East Providence? Most of your children with disabling problems are affiliated in the Bristol-Warren area. Look at the number of Special Education Services. 833 ? give or take These problems also affect their school education. Between the District, and the School Comm. there is a lack of accountability. It seems as though a few selected groups locally have a lot of good ideas to offer.

The timing of these meetings is another issue that lacking. If your priority is a disabled member of your family or yourself you are not going to trek out at that time of night. Maybe a survey should be done prior to setting the locations and times. Just thought you would value the most information from the appropriate sources.

This would enable your records reflect more factual information. In any event, we will all attend the Governor's forum in September or October.

Sincerely,

Julie McRoberts

[Housing 6](#)

Hi, I am writing my concern because I cannot make the meeting. My Mom and I share a vehicle, and she'll be using at that particular time. My concern is, I have been inquiring to get a Disability/Elderly/Family apartment for a long time. My concern with this is, most of them have a rule about the Pounds and height of animals. Most of them only take Pets up to only 20 Pounds. I have a Cocker Spaniel, and her maturity weight is 24~27 Pounds. Her height will only go as high as 19". In most apartments the required height is 19", which, she is okay. I can not understand why a few pounds would be such a Huge Concern to them. My pet is my companion!! She serves a great deal of company to me!! I wouldn't give her up for anything. I sent her to obedient school. So, I have alot of training devices, and ways of making her obey. I also have Doctor's letters and, allot of apartments still say, "No it doesn't make a difference". I must say, she is a very Good Pet. She is a Joy to have, not a Nuisance like some pets who Bark Continuously. I must say, I take very good care of my pet!! And she is not a Barker nor does she bite!! She loves people.... Anyway, that is my Concern. I feel they should be a little more lenient with there rules.

Thank You

Mary Angelosanto