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

July 26 – 30, 2004

Prepared by the

Governor’s Commission on Disabilities

John O. Pastore Center – 41 Cherry Dale Court

Cranston, RI 02920-3049

e-mail disabilities@gcd.ri.gov or

fax 401-462-0106

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The Public Forums Advertisement: List of Sponsoring Organizations

Public Hearings
State of Rhode Island

To identify the concerns of people with disabilities and their families

Monday 7/26/04 5:00 PM- 7:00 PM
OSARR,1130 Ten Rod Road C-104,North Kingstown

Tuesday 7/27/04 4:00 PM - 6:00 PM
Independence Square, 500 Prospect Street, Pawtucket

Wednesday 7/28/04, 3:00 PM- 5:00 PM
Warwick Public Library Community Room, 600 Sandy Lane, Warwick

Thursday 7/29/04, 3:00 PM – 5:00 PM
George Washington Management Area Forestry Headquarters, Glocester
(on Rte. 44, 4.5 miles beyond Chepachet, turn right into driveway at sign reading
DEM Division of Forestry Headquarters)

Thursday 7/29/04, 3:00 PM – 5:00 PM
Westerly Senior Center
39 State Street, Westerly

Friday 7/30/04 3:00 PM - 6:00 PM
Salve Regina University, Rodgers Recreation Building, 2nd fl**.** Conference Rm
(on the corner of Webster Street and Lawrence Avenue, Newport)

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).
We ask that you use unscented personal care products. Please realize that what may seem to you to be a mild fragrance can constitute a toxic exposure for a person with an environmental illness.
CART Recorders (real-time captioning) and assistive listening devices will be at all sites, courtesy of the Assistive Technology Access Partnership.
The RI Commission on the Deaf and Hard of Hearing will provide sign language interpreters, except at Thursdays Hearings.
When making the ADA reservation with RIde to get to and from the public hearing, tell the RIde reservationist that this trip 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.
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:

Brain Injury Association of RI, Inc. & Brain Injury Resource Center, Sharon Brinkworth, Executive Director; **College of Pharmacy/URI**, Donald Letentre, Dean; **CranstonArc**, Thomas Kane, Executive Director; **Council on Assistive Technology,** Jill Waller, Chairperson; **Assistive Technology Access Partnership (ATAP),** Regina Connor, Project Director; **Department of Elderly Affairs**, Corinne Calise Russo, Director; **Department of Environmental Management**, Frederick Vincent, Director**; Department of Health,** Dr. Patricia Nolan, Director; **Department of Human Services**, Jane A.Hayward, Director; **Governor's Commission on Disabilities,** Paul Choquette, Chairperson; **Housing Network**, Brenda Clement, Director **J. Arthur Trudeau Center,** Mary Madden, President/CEO; **Long Term Care Coordinating Council,** Lt. Governor Charles J. Fogarty, Chairperson; **Ocean State Association of Residential Resources,** Ray Ross, Director**; Ocean State Center for Independent Living**, Lorna Ricci, Executive Director; **PAL,** Doreen McConaghy, Executive Director; **PARI Independent Living Center,** Leo Canuel, Executive Director**, Paul V. Sherlock Center on Disabilities/RI College**, A. Anthony Antosh, Director; **RI Breast Cancer Coalition,** Marlene C. McCarthy, H.L.D.,Chair; **RI Commission on the Deaf and Hard of Hearing,** Steven A. Florio, Executive Director; **RI Association of the Deaf**, Earnest Okwara, President; **RI Coalition for Affirmative Action**, Donna Fishman, Chairperson; **RI Disability Law Center,** Raymond Bandusky, Executive Director; **RI Coalition for the Homeless**, Noreen Shawcross, Executive Director; **RI Higher Education Assistance Authority,** Robert J. McKenna, Chairman; **RI Public Transit Authority,** Alfred J. Moscola, General Manager; **State Rehabilitation Council,** Willam Anderson, Chair**; Statewide Independent Living Council,** Sharon Kimbriel, Chairperson

Introduction

Purpose of the Public Forums

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

Procedure following the Public Forums

During 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.

Community Concerns and Recommendations

Below are the community concerns, as raised by people with disabilities, their families, and others at the 6 public forums and recommendations developed by the forum sponsors in response to those concerns. After each "concern" are citations of the pages 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.

Accessibility Concerns

Pages in the Testimony relating to:

Assistive Animals, 29, 41
Chemical Sensitivity, 96
Disability Parking, 60, 62
Government Services, 62, 101
Recreation, 70
Rest Rooms, 50, 59, 61, 70, 71
Sidewalks, 51
Snow Removal, 53, 56, 59
Stores, 50, 56, 59, 61
Voting, 38

Concern # 1. Poor accessibility of state and public buildings (external and internal barriers e.g.: stairs, poor in/egress for entrance doors, poor bathroom access, and limited aisle access)

Recommendations: Enact legislation to enhance the power of the Governor's Commission on Disabilities or other appropriate entity to enforce compliance with state regulations regarding building accessibility
Governor's Commission on Disabilities and partners develop instructional/education packet with guidelines/sample letter and possibly a fill in the blanks and sign complaint form for consumer dissemination

Concern # 2. Fraudulent use of Disability Parking Placards

Recommendation: Add a photo picture of the individual to whom it was issued on the placard. Amend existing legislation to provide for stricter enforcement of violations

Concern # 3. Illegal use of designated disability parking spaces

Recommendation: Increase fines for illegal parking; Add fine info on signage for designated parking spots

Concern # 4. Use of materials such as bricks for sidewalk construction, which are not properly maintained and buckle resulting in uneven/hazardous surfaces

Recommendation: Enact legislation to mandate maintenance of sidewalks etc., or amendments to existing legislation to enforce compliance

Concern # 5. Lack of snow removal resulting in poor accessibility (curb cuts, walkways, parking spaces)

Recommendations: Enact legislation to provide specific provisions for snow removal from access sites (ramps, w/c curb cuts, building walkways and entrances, parking areas)
Consumer education packet (as described above)

Communication Concerns

Pages in the Testimony relating to:

- Assistive Technology, 55
- Education, 100
- Internet, 34
- Oral, 24, 27, 35, 93
- Visual, 26

Concern # 1. Due to a lack of visual captioning, individuals who are deaf or hard of hearing are missing their turns at the Division of Motor Vehicles' offices.

Recommendation: The Governor's Commission on Disabilities' ADA compliance specialist and the Commission on the Deaf and Hard of Hearing should work as partners to meet with the Division of Motor Vehicles (and other processors of licenses, i.e. AAA) to develop effective visual communication at all consumer-oriented locations.

Concern # 2. Individuals who are deaf cannot get up-to-the-minute information about flights at the airport due to a lack of visible signaling devices, large screens or signs to announce incoming flights, gate changes, and delays.

Recommendation: Representatives of the Governor's Commission on Disabilities and the Commission on the Deaf and Hard of Hearing should meet with the Director of the Airport Corporation to develop effective visual communication at their terminals. Since visible signaling would be critical in emergencies, it may be possible to use Homeland Security funds for this purpose.

Concern # 3. It is unclear whether shopping malls have visible fire alarms to notify people who are deaf of emergencies.

Recommendation: The Governor's Commission on Disabilities and Commission on the Deaf and Hard of Hearing should work with shopping mall management/local fire prevention departments to determine whether the malls have visual fire alarms. If not, they should follow up to ensure correction of the problem.

Concern # 4. Agencies and businesses often do not know how to arrange for an interpreter.

Recommendation: Commission on the Deaf and Hard of Hearing should continue to provide outreach and training regarding interpreters.

Concern # 5. It's difficult to get an interpreter at night and on weekends. This can threaten individuals' lives, leaving them unable to communicate with health-care professionals during emergencies.

Recommendation: Addressing this problem is Commission on the Deaf and Hard of Hearing's top priority. It hopes to launch a new Emergency Interpreter Referral Service soon.

Concern # 6. Most state Web sites are not fully accessible; they fail to provide a text-only option for people who cannot see Web sites.

Recommendation: Governor's Commission on Disabilities' Web master should contact the Sherlock Center to learn more about the concerns. If its site is not fully accessible, the Governor's Commission on Disabilities should correct any problems. The Governor's Commission on Disabilities should follow up with representatives of the blind and low-vision communities, and the Office of Library and Information Services, to ensure the accessibility of state Web sites.

Concern # 7. Police officers fail to communicate effectively with individuals who are deaf. People are being arrested and imprisoned without interpreters to tell them their rights and explain what is happening.

Recommendation: The Commission on the Deaf and Hard of Hearing should provide training for current police officers and new recruits on the rights of people who are deaf, how to communicate with them, and how to get an interpreter. This is one of the Commission on the Deaf and Hard of Hearing's top priorities.

Concern # 8. There's a long wait for speech therapy in Rhode Island. For children with developmental delays, this wait further slows their development.

Recommendation: If the problem reflects a shortage of speech therapists in early intervention and education fields, the RI Speech/Language/Hearing Association should work with advocates such as parent groups, the University of RI's Speech & Language Department and other colleges and universities, to identify incentives to attract more students to the field of pediatric speech therapy. Grants, scholarships, or no-interest loans could be granted in exchange for service of a specified number of years in Rhode Island.

Concern # 9. Many people who are hard of hearing who need hearing aids cannot afford them. Group health insurance policies do not cover hearing aids, while often covering other prosthetic devices.

Recommendation: New legislation, passed in the 2004 session, mandates insurance coverage up to $1,000 every three years per hearing aid per ear for children under age 18. Commission on the Deaf and Hard of Hearing should work with the Governor's Commission on Disabilities to advocate for improved hearing aid coverage.

Concern # 10. RI offers too few services for those who are deaf. This can result in individuals being unable to complete their high school education after interruptions due to illness.

Recommendation: The state needs comprehensive case management services for people who are deaf. Students have the right to obtain accommodations to meet his educational needs. Both the Office of Rehabilitation Services and the Commission on the Deaf and Hard of Hearing provide services that can help. Further efforts may be needed to increase consumer awareness of their rights and services.

Concern # 11. Many problems stem from a shortage of interpreters. RI has no college-level interpreter training program.

Recommendation: Commission on the Deaf and Hard of Hearing should work with the Office for Higher Education to address RI's lack of an in-state program to train qualified interpreters.

Employment Concerns

Pages in the Testimony relating to:

Concern # 1. Employers do not know what's available or where to find out about what's available e.g. tax credits for providing accommodations for employees & customers with disabilities, job training and work opportunity tax credits.

Recommendations: The Division of Taxation, Department of Labor and Training, and other agencies should disseminate information on tax credits to employers. In addition information on tax credits regarding people with disabilities should be disseminated through the Able Too...cable TV program; expand the RI.gov website; and provide training - hands-on, website.

Concern # 2. There is a need for educating employers on abilities of the individuals with disabilities

Recommendations: Provide training to employers; create partnerships to employers; and publish success stories in local newspapers

Concern # 3. There is a need for service provider skills/knowledge in job/person matching & a need for improved listening skills in service providers.

Recommendations: Individual skill inventory compared to available labor market; identify agency resources, needs, and funding requirement; and utilize the Department of Labor and Training's Labor Market Training

Concern # 4. There is a need for a case management system to assist the Traumatic Brain Injured become employed and to maintain employment.

Recommendation: Establish the Brain Injury Trust Fund (also see Family Support Concern # 4; Health Care

Concern # 5. Communication barriers exist for people with disabilities securing interviews and successfully completing interviews.

Recommendations: Provide speech to speech relay technology and educate employers on abilities

Concern # 6. There is a need for equal access for people with disabilities to training, including accommodations while in training and on the job.

Recommendations: Spread knowledge of JAN (Job Accommodation Network); Develop/provide education effort to move from reliance on others to reliance on self – self-advocacy. Involve the Division of Developmental Disabilities sooner in the transition process, use technology; and focus on independent living to foster self-sufficiency

Concern # 7. There is a need for more Employers on the Governor's Commission on Disabilities

Recommendation: Increase employer representation on Governor's Commission on Disabilities

Family Support Concerns

Pages in the Testimony relating to:

Case Management, 70, 97
Domestic Violence, 19
Financial, 31, 32, 36, 39, 98
Recreation, 44, 46
Resource Directory, 36, 44, 54, 63, 75, 80, 97
Respite Care, 8, 33, 34

Concern # 1. There is not a comprehensive central information and referral center that families can turn to for assistance in finding the appropriate service providers (of counseling, education, health care, employment, financial, peer supports and other services)

Recommendations: Establish a statewide information and referral phone number (211, currently used in several states, including Connecticut). State funding is needed to continue the ability of Crossroads to update information, a centralized, easily accessed number, and the existing Real Choices project developing a web-based resource directory and benefits screener would be a good combination to address resource issues. Create a centralized disability coordinator to provide the continuum of health resources available throughout the state. Host forums/workshops to discuss and update the public to the services available (especially for adults with disabilities.

Concern # 2. There is a lack of coordination of treatment and rehabilitation

(See Health Care Concern # 1)

Concern # 3. Social Security Disability Income benefits are insufficient to live on and current rules discourage people with disabilities from creating Individual Retirement Accounts, etc. since those "resources" will be counted against income eligibility rules.

Recommendation: Provide a state supplemental benefit and revise Federal rules on SSI allowed assets

Concern # 4. There is a lack of funding for families to modify home or yard to accommodate a family member with a disability.

Recommendation: Create flexible funding plan such as cash and counseling for families (already in development for Medicaid eligibles). Expand the independent living home modification program to provide modifications for Medicare only recipients and to assist family caregivers, so the individual with a disability remains in the community rather than be institutionalized.

Concern # 5. Supports not available in RI for people who acquired a traumatic brain injury after age 21.

Recommendation: Establish the Brain Injury Trust Fund

Concern # 6. Families often feel isolated, especially the primary care giver, due to a lack of respite care. There is no system in place to provide substitute care giver in cases of domestic violence.

Recommendation: Create protection status for adults w/ disabilities that can be accessed through a 211 statewide information and referral phone number.

Concern # 7. General educators are afraid of mainstreaming children with disabilities.

Recommendation: To create a disability awareness program, as part of the RI Department of Education's Comprehensive System of Personnel Development

Health Care Concerns

Pages in the Testimony relating to:

Case Management, 95

Concern # 1. There is a need for case management for adults with disabilities.

Recommendations: Develop a managed care Health Plan option for adults with disabilities on Medicaid and Medicaid & Medicare. This would enable:

- Service and resource development
- Care Coordination and Case Management Services
- Improved access to a network of providers
- Provider resource development
- Increased advocacy
- Additional benefits
- Improved Family and Consumer service

Amend existing legislation relative to insurance to require case management services for adults with disabilities within a specified delivery timeframe and Explore existing case management programs for children with disabilities provided by DHS to use as a potential model for a similar program for adults with disabilities.

Concern # 2. There is a need for increased rehabilitation services.

Recommendations: Amend the State Medicaid Plan to include physical therapy, occupational therapy, speech/language therapy and psychological therapy as part of the rehabilitation process. Amend to legislation under an existing Act relating to insurance to mandate carriers to provide coverage for physical therapy, occupational therapy, speech/language therapy and psychological therapy as recommended by medical providers.

Concern # 3. There is a need for increased pharmaceutical assistance

Recommendation: Lower the age of Medicare recipients in order to qualify for pharmaceutical assistance. Participation of adults with disabilities in the State's discount drug program.

Concern # 4. There are barriers to Medicaid services.

Recommendations: Establish a Medicaid Buy-In option for low income adults with disabilities who may not qualify for Medicaid. Continue to develop the next steps in the Medicaid Buy-In for workers with disabilities and create supplemental funding resources for adults with disabilities who do not qualify for Medicaid. The Department of Elderly Affairs health care co-payment program should be expanded to include personnel care assistance for Medicare only recipients.

Concern # 5. There is a need for assistance in locating resources & availability of resources in one location

(see Family Support Concern # 1)

Concern # 6. There is a need for medical provider professional development. There is a shortage of speech & language therapists

Recommendations: The Department of Health's Disability and Health program should collaborate with Brown University Patient Advocacy program and seek opportunities to include discussions on issues of disability and health as part of the project. Conduct forums/workshops for medical professionals to raise awareness and education of disability and health care and collaborate with other organizations or agencies conducting similar programs. Establish an interest free school loan program targeted at health care fields with staff shortages.

Housing Concerns

Pages in the Testimony relating to:
- Assistive Living, 5, 7, 17, 55, 63, 68, 77, 78, 81, 83
- Independent Living, 16, 35, 39, 99
- Safe and Affordable, 30, 31, 34, 37, 79, 85, 87, 94

Concern # 1. Affordable Housing is more difficult for people with disabilities to locate especially that is also accessible.

Recommendation: Promote funding efforts for incentives for affordable housing to be built in areas that are also accessible for transportation.

Concern # 2. Independent Living is not sufficient because of long waiting lists or supporting providers canceling programs, thus causing traumatic effects due to funding and qualified people to staff.

Recommendation: The programs need to be funded and staffed with case managers helping to assure medications/transportation and other things are available.

Concern # 3. It is difficult to find Information on available housing and organizations use differing accessibility standards that creates confusion

Recommendation: Better pooling of information with the Realtors and Multiple Listing Services and use of the Federal Fair Housing Accessibility standard in listings.

Concern # 4. Supportive Housing is not sufficient in the areas people want to live and work.

Recommendation: Increase funding to create housing with supportive & independent living services. The Housing Resources Commission should conduct a survey to determine the areas people with disabilities want to live and work.

Transportation Concerns

Pages in the Testimony relating to:
- Curbcuts, 49, 94
- Disability Parking, 56, 58, 68, 94
- Private Vehicles, 101
- RIde, 20, 21, 30, 31, 56, 65, 72, 86, 91
- RIPTA, 30, 31, 50, 85

Concern # 1. There aren’t enough curb cuts and cars are parked blocking the curb cuts

Recommendation: RIPTA sending letters to cities and towns recommending enforcement of curb cut laws and no parking laws. When contractors interfere with accessibility, they should provide alternative access. RIPTA should be aware of curb cuts when they create stops.

Concern # 2. There are not enough disability parking spaces: spaces that are wide enough; van accessibility for parking, for vans only; and “standing” parking in an accessible handicap parking space.

Recommendations: Towns and cities need to enforce the disability parking laws. ADA requires parking space size and the amount of handicap parking spaces made available depending on the overall total parking spaces. The Governor’s Commission on Disabilities should complete an assessment and enforce correction. A public awareness campaign should be undertaken on disability parking requirements.

Concern # 3. Lack of funding for vehicle modifications

Recommendation: Increase public awareness of current services and revise the State Medicaid Plan to include vehicle modifications for adults with disabilities.

Concern # 4. There isn’t an emergency response paratransit service and there are not enough services within the RIde Program: drivers are having difficulty finding destinations; some customers can not afford to pay for RIde; and persons outside the ¾ mile corridor of a fixed bus route do not receive ADA paratransit service

Recommendations: Increased funding for RIde. Better training for drivers on routes and destinations. Expend RIPTA’s Flex program. Provide literature to educate customers with information on the RIde program and rider education should include budget counseling.

Concern # 5. Lack of services in South County, need to schedule more trips from Providence to Westerly

Recommendation: With more people moving to South County, RIPTA should complete a new travel assessment to provide needed services in this area.

Concern # 6. Public and paratransit service reductions due to RIPTA fund cutbacks
Recommendations: Rhode Island should fully fund RIPTA (Rhode Island Public Expenditure Council recommends additional funding of RIPTA). Create more public awareness of RIPTA services.

The Testimony

July 26, 2004 - OSAAR, North Kingstown

Rosemary Carmody: Good evening we are going to begin tonight. I want to thank everyone for coming. I do have a list of other -- if other people want to testify, we will go through the list of the people who indicated they do want to speak tonight. My name is Rosemary (Rory) Carmody. I'm employed by CranstonArc providing services and supports to folks with developmental disabilities and their families. What we are doing tonight is really collecting information from you about issues that are important to the people that you may support; issues that are important to people with disabilities and to their families; issues that need to be collected, categorized and presented to the Governor, to the Governor's staff as well as to all state and Congressional legislators who collect this information over the course of the next week when we have I think five more public forums coming up throughout the state. We appreciate your input, your advice, your criticism, anything that's important to the people that we provide support to in the state of Rhode Island. The late disability advocate Justin Dart said, "We must vote as if our lives depend upon it because in fact it does." so I also urge you as professionals, as individuals, as family members to encourage you're family, your friends, and your co-workers to vote. It doesn't really matter to me who you vote for. It matters to me that we exercise one of the greatest freedoms we have in this country and that's the right to vote. I provided some voter registration forms over there. In the event you are not registered to vote, we would be happy to help you after the meeting to register for that. It is a great freedom and one we should embrace in these times, in the uncertainty of our budgets.

We are not here to answer questions tonight. We wish we could. We wish we had the answers. But we are here to get your information, your input, your thoughts and we promise to do something with it, that your words won't go unnoticed or unheated. I'm going to begin by introducing the panel -- having the panel introduce themselves and go quickly around the room.

Victoria Ferrara: Vickie Ferrara and I'm with the Sherlock Center on Disabilities. That's where I work and I'm also a Commissioner with the Governor's Commission on Disabilities.

Richard Temple: Richard Temple, I'm a neurophysiologist at Brown University, Rhode Island Hospital. And I'm here representing the Brain Injury Association tonight.

Paula O'Connor: Paula O'Connor, I'm president of the Brain Injury Association.

Ed Scott: Ed Scott and I'm the director of specialized transportation for the Rhode Island Public Transit Authority (RIPTA).

Francine Knowles: Francine Knowles and I'm the manager of the Family Outreach Program, raising children with special healthcare needs in the Health Department.

Marie Strauss: Marie, I'm an administrator at the Department of Elderly Affairs in the community services division.

Coffee Bell: Coffee Bell, I'm the vice chair person of the statewide independent living center.

Bill Anderson: I'm the chairperson of the State Rehabilitation Council.

Ed Rawlings: Ed Rawlings, Vice chairman on the Commission on Deaf and Hard of Hearing, CDHH.

Linda Ward: Linda Ward, President of the board of directors' post -- and also Executive Director of Opportunities Unlimited.

Rosemary: We thank you allowing the space this evening. OSARR was gracious to give us this space.

Mary Madden: Mary, From the Trudeau Center.

Tracy: Tracy, from Perspectives and also on the Governor's Committee.

Marshal: My name is Marshal. I'm a rehabilitation psychologist and I am in private practice at Angel Street Psychiatry.

Kathy: Kathy, I'm going to school for special education and I have a parent that's disabled.

Christine Hennessey: Christine Hennessey from Narragansett and I'm here to speak on behalf of services needed.

Speaker: I have to -- I'm a consumer.

Jeanne Behie: Jeanne Behie from Washington County CASSP {Child and Adolescent Service System Program} and I also am the daughter of two parents who became disabled later in life, one with a traumatic brain injury, and one with a stroke that left him severely paralyzed. And I'm also going to be his mother. Disability on all sides.

Andriane Resmini: I'm Adrienne and I'm a student at CCRI and I'm hearing impaired and I can also sign.

Debra Saul: Debra Saul. I am the recipient of a fellowship from the Governor's Commission on Disabilities.

Steve Brunero: Steve Brunero, Office of Rehabilitation Services.

Rosemary: All right. We are going to begin and we will go through the list of those who want to testify. The first on the list is Christine Hennessey.

Health Care Resources

Christine Hennessey: Okay. I'm here today because of much needed brain injury services and support, such as assessments, information, follow up, case management and education throughout the state to people with Traumatic Brain Injury and their families as well. Myself being one of these people. Like many of you can relate to, I got up one morning and went to work and ran some errands. But that was the last day of my life as I knew it. On my way home that evening, I past by the school I substituted at that day and I could see my apartment building in front of me. And out of nowhere I was struck in the head through my car, my driver side window, not by a baseball from the park to my left, but by a deer who ran into my car, leaving behind some teeth, an antler, hair and glass, and left me dazed and surging and working for the life that I loved before this impact and a mild traumatic brain injury. I was brought home from the scene and I was told for a year to give it time, that I would be fine, and that everything would snap back the way that it was. But almost four years later, me, my husband, my family and friends are still waiting, and that day hasn't happened yet. Every aspect of my life has changed. My skills, my relationships, my work, my vision, but especially my stamina. I can't tolerate busy or noisy environments or lots of movement, and processing new information is a challenge. And in daily life everything is challenging, requiring lots of structure, a lot of transition time, cues and checklists. Reading and using a computer is still limited to 15 or 20 minutes. But it doesn't feel like anything is leisure anymore since so much focus and attention is required for everything. It's just exhausting. The services and support that I have received and am receiving now have helped me greatly get to where I am today and much closer to my dreams and goals of returning to work and raising a family. But I went a whole year without services or any direction other than receiving physical therapy. Recovery could have started much sooner and maybe I would be farther along today; maybe some problems would have even been lessened. But especially understanding what I was experiencing and why would have been much more helpful. Regarding insurance, the providers were limited and not local. And at that time I was only given the name of two neuro-psychologists in the whole state. I currently just completed vision therapy going once a week to Massachusetts for a year. And only a small percentage of the initial appointment was covered. Neuropsychological and psychological services have been helpful beyond words to help me focus and identify my strengths, to put things in perspective, and to move forward. And cognitive therapy is helpful. But even with my primary care's letter to extend benefits, the insurance didn't pay the provider over the allotted benefit. People like me may not know or have difficulty knowing what to do next, where to start, how to get there, or even know what goal is appropriate which is why daily living, work professional and personal goals is so challenging and sometimes even forgotten once learned. This is why I'm here today. Funds and services are needed to help people be as well as possible. Need a lot of direction, follow up, support, and many different services that doesn't fit into the number of session's insurance may provide. I have been embarrassed of and hid my deficits from family and friends for a long time. And even just a few months ago I would rather have stayed anonymous and continued toward working, getting back to work in silence. But I realized that silence is part of the problem. And a song -- a verse from a song kind of sums up that particular feeling. "And I don't want the world to see me because I don't think that they'd understand. But when everything is made to be broken, I just want you to know who I am." I thank you for your time and attention.

Rosemary: Thank you. Christine, Are you up for a few questions; is that okay?

Christine: Yes.

Rosemary: During your recovery, what was the most frustrating aspect of it? Was it the insurance, paperwork, lack of resources? What? If there was one thing you could target as being --

Health Care Counseling

Christine: Probably lack of direction, not knowing what to focus on, not knowing to do things differently or how to do them. Just even in daily living.

Rosemary: The coordination of services or resources you needed?

Christine: Yes.

Rosemary: Would you be willing to give your testimony to a House Finance Committee or to a Senate Committee as well? Part of the issue around traumatic brain injury has come up in creating a regional center in Rhode Island or at least a hospital that specializes in Rhode Island would be helpful to get people who have such poignant testimony in front of those folks.

Christine: Absolutely.

Rosemary: Thank you.

Paula: Excuse me. Christine, haven't you been giving testimony?

Christine: Yes. I have given testimony. I don't remember the names of the committees right off the top of my head, but over the last couple of months.

Rosemary: Good.

Victoria: Christine, when you said that you had lack of kind of direction, was that due to -- be the service provider or doctor who was kind of giving you some initial direction. Were they off base with what they were suggesting to you or prescribing for you?

Christine: Time was the prescription.

Victoria: Time.

Christine: Deficits were identified but giving it time was the suggestion.

Victoria: Okay. So, in your case was it the lack -- like the medical staff, lack of understanding of what your injury was that prevented them from -- I'm trying to -- hooking you up with existing resources or they just didn't know?

Christine: Could you say that again?

Victoria: I can't remember -- (Laughing).

Christine: I understand. (Laughing).

Health Care Resources

Victoria: Was it that the medical providers did they not know where the resources were to hook you up to them or did they just think that your injury wasn't that severe so that time was going to take care of it? What do you think the gap was in that way?

Christine: Probably a combination of not knowing, not having specific information to offer of where to get help, how to get help other than gives it time. And also I don't think when I look back, I was probably able to communicate as well as I am now because I really didn't understand what was going on? I just knew everything I went to do wasn't quite working for me. And I didn't understand why it would take me all day just to pick my husband up from the bus station. But I wasn't able to get anything together.

Health Care Counseling

Francine: Did I understand you to say that you thought that perhaps with supportive counseling to help you understand that would have been beneficial at that time? Like to deal with what was going on, like emotional support?

Christine: Yeah. At the beginning other than frustration I probably didn't experience anything other than that. I think as my awareness has changed, emotional support is more helpful and needed now actually. I'm not sure how helpful it would have been earlier on.

Paula: I think the other part of the problem too is there aren't an awful lot of trained professionals in the state in brain injury. And that's one of the things the Brain Injury Association (BIA) is working on now is a training video, which you may have been involved in somewhat.

Christine: I heard about it, but I was not involved. That's off the ground?

Paula: It's very close.

Christine: Excellent.

Rosemary: One more question. Were a lot -- did a lot of your services require you to leave the state and to go to another state for service?

Christine: Just the vision. Yeah.

Rosemary: Thank you.

Christine: Thank you.

Rosemary: Next is Jeanne Behie.

Health Care Resources

Jeanne: Actually I will add a few things to what Christine said. Having experienced -- having to access services for my mother after her brain injury. It's not just medical providers of brain injury that have trouble directing people, but rather medical providers of any specialty are not really trained to share information and help families and people access resources. I think what families of children with special healthcare needs find the most information they get are from other families, other people that have experienced similar things. But there's a sad lacking of information with medical professionals and I will give you an example. My son is 21. His first year of life was spent in seeing specialists, orthopedic specialists. Before we left the hospital we found out he was visually impaired. And so we went to a lot of vision specialists, have been to Massachusetts for some assessments there too. And when he was about two and a half months old, he was having a vision exam and the optomologist said well, you know he's totally blind in one eye but I think he's also visually impaired in the other eye. And he said that to me and that was the end of our visit and he stepped out of the room. He was done. And as a parent, I can tell you it is absolutely shocking to hear something like that. And if it wasn't for the work that I had done prior to this as a social worker for home healthcare years ago, I wouldn't have known to say to the receptionist through my tears; shouldn’t we get a referral to services for the blind?

Health Care Insurance Now, no parent should have to go ask for the help themselves because as you say, you don't know what help is there. I can tell you that since my son was born, I work part-time. And one of the reasons I work part-time is so I can access information and resources with him, fight the insurance companies over the services that he needs and is entitled to. And now I actually do it for my mom too. This is not unusual. This is very, very common. We are lucky to have cedars in the state. At least the way it was designed it was designed to help families coordinate services. The reality may be quite different than that.

Health Care CASSP I mention if work for Washington County CASSP. And that's a program for families of children with emotional behavioral problems that put them at risk for being placed outside the house. We help families coordinate services. If you want to see a successful program, take a look at how the mental health services are provided to families in this state where we really do provide services; in-home therapy, in-home counseling, psychiatrists outside of the house, you know. It really kind of wraps around the family and gives them the support that they need. So there's many areas that are lacking, many areas that Rhode Island excels in. I can also tell you that the United Way was looking at how to better provide services in the state. And one of the things that came up through those meetings was a coordinated -- a coordinated call center where people could call in to one number in the state and at least get referred to the information or the agency that they needed some help with. That's a great idea. We need something like that because unless you've navigated the system, it’s a very lonely place to be. One of the things that struck me with my mom and the help she needed was how expensive everything was. And in order to get the services the extent that she needed, the maximum number of days in a rehab center was each of the children. There are five of us, calling the doctor and putting pressure on the doctor to recommend the maximum number of days in a rehab center. And we got it. But not everyone gets it. And I’m happy to say that because of the rehab my mom got, and because of all of us kind of working together and looking into the best rehab centers, my mother made a miraculous recovery. But she needs live-in help now, as my father did for five and a half years after his stroke. There’s no insurance that pays for live-in care. I write a check every -- I transfer money every week, $650 so my mom can pay for live-in help. My mom had her accident two years ago. My dad had live-in help for five and a half years. How do people afford that? I can tell you that every bit of money they earned is going to the live-in help, and it went to my dad's live-in help. It’s very tough. It's very tough to know how to get the services and brain injuries. Insurances don't cover the amount of care that's needed. I think the only -- I went to the brain injury conference that has been held. In fact we actually had lunch together. How do families do this? My thought is that it's through a lawsuit. That's about the only way that you can pay for the services that are required. From what I hear, two percent of the population has brain injuries. It's one of the highest percentages of disabilities. And we can talk about what services are needed, but I can tell you if you are not affected right now by a family member with a disability, the chances are you will sometime in your life because as the population ages, people are going to become disabled and they are going to need more care.

Health Care Resources There’s also some other areas that we need help in. For families that are low income, there should be a buy-in for Medicaid. Families with private insurance quite often do not get the services that rite care provides. Rite care provides wonderful services, quite inclusive. But most private insurances don't provide that much help. We also in South County need therapists, psychiatrists, psychologists. It's very difficult to find who provides private therapists who accept insurance, private therapists who accept Medicaid.

Housing: Assistive Living Very difficult. I'm sure you have all been hearing about the housing issues in South County. I work with families that are homeless. I didn't know there were homeless people in South County. These are people who are scrambling to find food from food pantries, live in hotels year-round because there's no place in supportive housing for them. There is such a need for this.

And I thank you for listening to some of these concerns. I probably could take the whole meeting talking about all the concerns. But I will let other people talk. But I will say that there are wonderful services that Rhode Island provides. And we are very lucky that it's such a small state. And we are lucky that you have these hearings.

Rosemary: Thank you. Anyone have any questions for Jean? I think you echo a lot of people's sentiments. Thank you for your testimony. Brendan is up Brendan -- would you like to speak?

Employment Job Training Brendan: My name is Brendan Rominy. I'm an adult with disabilities. I have dreams just like you. I have an apartment, get married, go on vacations, and eat out occasionally. To do this I need a better paying job, more hours to work. I work -- job training programs for adults who are going on to college.

Speaker: So more programs for adults who aren't going on to college. They need -- not just for adults with disabilities.

Rosemary: Thank you, Brendan. We have Adrienne Resmeni.

Adriane: I work at TJ MAXX. I have to - hearing -sometimes puts the strain on my back, behavioral too.

Victoria: We are having trouble hearing.

Adriane: I have --

Victoria: Adrienne, could you talk a little louder?

Speaker: You were just saying -- do you want me to just repeat what she said?

Victoria: We couldn't hear.

Speaker: She works at TJ MAXX and she finds that the work strains her back. She has been working there for what? About a year and a half.

Adriane: Yes.

Victoria: But you have many talents.

Adriane: Yes.

Victoria: And things that you are good at, but TJ MAXX doesn't really utilize those talents.

Adriane: No.

Employment Job Placement Victoria: So, better connecting people with disabilities with jobs that they're better suited for.

Rosemary: Thank you, Adrienne.

Bill: Adrienne, what would you like to do?

Rosemary: Bill is asking what you would like to do.

Bill: What would you like to do? If you had a chance to get a job, what would you really like to do?

Employment Job Training Adriane: I would like to go out and be an interpreter just like you. I can hear. I have been taking ASL classes. I know the teacher. I can hear and sign at the same time. So I found that out at school we always use sign language. And I want to be able to --

Speaker: You went to School for the Deaf?

Adriane: Providence.

Speaker: What did you find when you went on school trips?

Adriane: School trips?

Speaker: Who did they use to sign to the other students?

Adriane: Yes

Speaker: They used you, right?

Adriane: Yes

Speaker: So when they would go on school trips and somebody would be giving a tour, she would interpret it to the other students. And where are you taken American Sign Language courses?

Adriane: CCRI in Warwick. At the center that I go in and all hearing people are there, mentally disabled. But there's one only one deaf girl that I know nobody knows sign language. So I helped them out. And I helped her out, help her mother out.
Coffee: Adrienne, the courses that you are taking, do they have a placement program? Would they place you?
Speaker: She works at the center where all disabilities, mentally, physically. We work at the center. I work out of there.
Speaker: She was asking if CCRI has a placement center to help you find a job.
Adriane: No. I don't think so.
RIC, URI, CCRI: Office of Student Services
Speaker: I have a question and also -- I'm just learning about something now that I know is available at RIC and I understand is also at CCRI and URI and you probably know more about this than I do that there is -- is it called -- it's an office of student services. I don't know the acronym but there are mentors. They appoint people that are there whose sole job is to help you kind of get through the system and to maximize it. My question is what has gotten in the way? What do you see as an obstacle to your becoming a full time interpreter?
Speaker: How many courses do you have to take to become a full-time interpreter?
Adriane: I have to be a licensed -- I would need, you know, between jobs, school. And trying to, you know --
Speaker: Is it --
Adriane: Mom's helping me also. She is helping me out too.
Speaker: So you are in school now?
Adriane: Yes.
Speaker: Okay I wasn't sure if you were still in school or you were out of school.
Adriane: Still in school.
Speaker: Okay. Thank you.

Employment Discrimination

Speaker: I can tell you what a big barrier is to job placement though when you have a disability is just first of all getting an interview. If you have a speech problem, a lot of times you won't even get that interview. There's an awful lot of discrimination out there when it comes to jobs. And so getting a foot in the door, to even get to you can have the correct qualifications but there are a lot of barriers. It takes a lot more than just the qualifications.
Ed Rawlings: I'm with the Commission of the Deaf and Hard of Hearing. And if you have not been in contact with them, they may be able to give you some assistance, direction. And I have a pamphlet here that I can give to you so that you can make contact with them.
Rosemary: Adrienne, maybe after the meeting you can talk to our interpreters and talk to them a little bit about their work as well.
Adriane: Okay.
Rosemary: Thank you. Oh, Katherine.
Speaker: I will speak --
Speaker: Sorry. I didn't know I was supposed to write down.
Rosemary: You are Marcia --
Speaker: No.
Speaker: I'm Kenneth. I would like to --
Rosemary: Okay.

Housing: Assistive Living

Kenneth: These ladies over here help me just get my footing. My mom has been in a nursing home for over 20 years. She had brain damage, has lived in a nursing home for 25 years, and just moved from one that closed down to another one. As a youngster, I didn't know what was available. I don't even think her siblings knew what's available to what her other options were. She's good. She used to get around with a walker. She went from a wheelchair to a walker to a cane. And she was stuck in this nursing home for 25 years. And she has a good amount of capacities. When she was younger she had a lot more than what she has now. She's getting up there in age. She was like 39 when she -- so it would have been nice if somebody knew there was assisted living. If there were other services, employment, some volunteer people that were out there, some mentors. Still that's an issue with me. I can visit her. It's not necessarily a family member. Somebody that's a peer. Somebody that she can talk to that's from the outside world. She's not feeling with people -- in their 70s and 80s and has declining health.

Rosemary: Thank you.

Bill: We have several questions from the panel here.

Coffee: Go ahead.

Marie: I want to say I'm from the Department of Elderly Affairs. Perhaps after the meeting we can meet and I can give you some information about the issues that you identified.

Kenneth: That would be great. Thank you.

Coffee: I just wanted to know if anywhere along the way you heard about OSCIL or PARI.

Kenneth: I had not heard about either one of those. And I had called up the Department of Elderly Affairs probably about four or five years ago and asked for what kind of services could they give me. The gentleman I talked to told me that I could get one of those little packets. It was --

Coffee: That helped?

Speaker: Exactly.

Coffee: Have you contacted OSCIL or PARI?

Kenneth: No. I don't even have any --

Coffee: If you give me your name and address, I will give you that information.

Rosemary: Thank you.

Health Care Rehabilitation

Speaker: Excuse me. I come with notes. I'm a rehab psychologist in private practice. I told you that already. And very simply, I have always believed that when something happens to somebody's body, it just doesn't happen to a spine or a brain. It happens to a whole person. And as an aside, I remember being a college student and thinking this and then a graduate student and I never really thought that this was rocket science. No offense to myself. I really didn't. But the majority of my peers were stunned by this revelation I have been involved in medical rehab in disability for 20 years, both in hospitals and in community settings, in freestanding rehab hospitals as well as general. And this evening I want to speak about my perceptions of the needs and concerns of individuals with brain injury and the families. Some of the stuff I'm going to say I know you already know and please excuse my lack of better editing. Brain -- traumatic brain injury is often associated with long standing cognitive and behavioral disabilities which can be great obstacles to social, vocational, and self-reintegration. There can be great changes in the family system, such as changes in the marital and parental relationships, the loss of a breadwinner or a child care provider.

An old grad school professor said to us -- he said, "I want you to picture a mobile. You know like one of those things hung over babies cribs. Each person in that mobile is a member of the family. And now when you pull on just one, the whole mobile shakes and moves." And I just thought that was a perfect way of describing something. The process of rehab involves continuous measured experimentation or risk taking by both the individual and the family in order to relearn these skills and gain independence. And the time may be measured in years. And it's often difficult to accurately predict how long it's going to take a person to reach -- and I can't stand saying this word -- optimal -- because I never believe this -- the final thing -- but their optimal level of functioning. I will frequently get clients who come in and say, “it's been a year and a half and everybody says it should be over. Why do I feel like mud?”

Employment Job Placement

Throughout my political experiences I have seen a wide range of responses and outcomes. I have seen individuals who were initially written off in terms of their future potential achieve quite significant and noteworthy vocational and social goals. I was just talking about this with my husband this morning that I wondered how many people thought that Jim Langevin would be speaking at the Democratic National Convention next to Ronald Reagan after he had his spinal cord injury. I had witnessed the effects of under or unemployment and the devastating implications it can have on a person's sense of self-worth and their feeling of not being a contributing member of their family and society.

Family Support Respite Care

I have seen families feeling isolated and in pain because of the behavioral stressors and because of their difficulties in obtaining some respite. I have seen marriages fall apart because they weren't able to adapt to the change. And I also watched as relationships have grown much stronger and far more resilient.

Let me talk a little bit about the individual. One of the single most important predictors in rehab is the personality of the individual, their desire, their passion to get well, if you will. And please forgive the little bit of vernacular here but I always talk to my clients about the piss and vinegar that runs in their veins. As I think it's our responsibility as members of the community to do everything we can to support that hope. We can do this by taking the time and the effort to understand the person as they are and as they were prior to the injury. We need to know. We need to ask. We need to include it in our evaluations that they were what were their hopes, dreams, life goals and prior to the injury. And in terms of policy, we need to make that almost part and parcel of when our providers do the evaluation. I don't care if it's a physical therapist, a speech therapist. It doesn't matter. It shouldn't just come from somebody in mental health. This -- I'm not saying that we deny the existence of the injury but rather we have to look for opportunities in addition to the limitations. That's so -- in terms of the family. They are -- how do I say this without making an understatement? Families

Families are of crucial importance. They provide a stable and familiar environment. They provide a perspective that I know I can't have in the privacy of my consulting room. And they provide a benchmark regarding the individual's mood and progress. We need to educate them. We need to educate them regarding the range of support services available to them and their family member both locally and within the greater New England area. It's just not that far to go to New Hampshire if we need to. These include -- and I'm not saying we should have to go to New Hampshire. Don't take my head off. But that people need to understand what's available to them. These include but are not limited to case management, outpatient rehab programs, structured day programs, assistive technology, support groups, and counseling. And also I think they need to become advocates.

Health Care Resources

I tell -- when I used to work in the hospital, I would tell my patients and their families, "Look, you are one patient. The nurse has six of you. She's a very nice person. But she's tired. And if you want to get something done, you need to be a little bit of a pain in the neck, not a rude pain in the neck, but a pain in the neck." Finally, the third component is in addressing the needs of concerns is the collaboration of the external support system, all of us, as well as others that are out there. Particularly in times of tight budgetary constraints, we need to focus our energies on centers of rehab, private service providers, our voluntary civic and support organizations, our religious centers, our families. And our clients need to know what's out there. What are the programs? What do they offer? Where are they? Are the buildings accessible? And how might these services change as they go along in the rehab process because what they're going to need at day 20 can be vastly different than what they are going to need at day 320.

I learned in school you don't need to know all the answers. You just need to know how to go about finding the answers, which is a good thing. Our method of information dissemination also needs to be multifaceted, where the information is available from several different resources, from the acute care hospital, rehab program, from local agencies and organizations, from educational assistance. And we need to assist in access both in the availability of health insurance, obviously, and transportation, to make sure they can get to where they need to be.

Finally, as a person works to go toward school or vocational reintegration, we need to work with these institutions and work sites. So when a person with a disability goes to college, they need to know who that point person is that's going to help them navigate around that system and help them get everything that they can and are entitled to. Likewise when they go back to work, there should be a meeting between them and their supervisor to help reintegrate them, to help knowing what's a reasonable schedule and what are we going to do when -- when a problem occurs. Thank you for your time.

Rosemary: Thank you, Marcia. Questions? -- I'm sorry, Jeanne, go ahead

Speaker: It was good to hear you say when they reenter and go back to work. Because one thing that struck me when I went to the brain injury conferences and sat at the table to speak -- to speak with other people that were there, every single person I met there or I should say not one of the people I met there was able to go back into the same work. So do you find that -- what percentage --

Speaker: I don't have --

Speaker: I know not one.

Speaker: I don't have any statistical numbers on what percent return to the exact same form of work. But I do know of people. I can give you anecdotal evidence of people who have gone back. But when I look at what made them able. I'm speaking of a grad student I know who had his brain injury when he was completing his dissertation.

Speaker: Is that the law student?

Employment Job Training

Speaker: No, that's not the law student. This is a different person in a totally different state. Initially, he was told by one provider that for a job that he could -- you know those little silver paper around the gum. That's what he could do. That really didn't sit well with him. But another provider said wait a minute. Our state will give you money for books. And let's get a professor in there that can give a little bit of an understanding that you are going through so that we can make your comprehensive exam still valid but -- within a reasonable accommodation. He got his PhD. It took him longer. He lost a couple of years, but he got it. So I can give you anecdotes like that. I can't give you numbers.

Rosemary: Marcia, when you talk about educating people and the whole range of services and supports and resources, who's the most likely candidate or group that would have all of that information? Or is there such an animal?

Health Care Resources

Speaker: Right now when I have a client referred to me, my first call is -- if it's a brain injury related referral, my first call is to the Brain Injury Association. I can tell you I'm still learning about the services in Rhode Island. I have only been practicing here for three years. But if I had to target the point people, I would say some good social workers in the acute care hospital, obviously people in the rehab hospital. And again, even if -- and they're going to --the client is going to get their first input from the physician because that's who they are going to see even if the physician can say, listen please go see social worker or point person x. So I would have to say those two people right off the top of my head.

Rosemary: So is it safe to assume that everyone who gets a brain injury is referred to the Brain Injury Association?

Paula: We only hope.

Rosemary: Are there ways of coordinating that connection? --

Paula: There are cases we have been in touch with hospitals and there are still people that go through and it just doesn't happen and I don't understand why. We – it’s better. It's a lot better than what it was.

As a matter of fact, we are just gathering -- updating a resource guide which lists all the different associations and councils and so forth. That should be available within the year. It does get better and our telephone calls have -- since we opened the resource center, I’ve got to say they tripled. Tripled. Unfortunately, there's just too many out there.

Rosemary: Marcia, in regards to traumatic brain injury and rehabilitation, are there services you see sorely lacking in Rhode Island that you didn't see in other states or in your practice now you see are really absent?

Marcia: That's a really good question. I don't know if this is lacking in Rhode Island. Please excuse my ignorance but I have only been here three years. But I think if we could really find a person or persons in the school, in the voc end to really be able to work with people on a long-term basis. That could be really helpful.

Victoria: When you say schools, do you mean public education, kind of elementary, high school, or do you mean college?

Education Transition from School to Career

Speaker: My first free association is to college. But it goes across the board. I know in k through 12 they -- the student can have an IEP. And so I’m going to hope that people they are being referred to would have some understanding of brain injury. I don’t think that's the case. But I can't swear. I didn't think so. But I never like to accuse of us, I’m sure. But I was thinking more along the college line. But some training for the k through 12.

Speaker: If I could speak to the pre-eminent facility in Rhode Island would have been the Sargent Center. They were the first facility in south eastern New England area for the 23 years that I was a Special Ed Director. And we would have referred students to that facility. It had been known throughout the northeast. In the years I was in Warwick and Lincoln, we referred students there. But they've -- over the years as many facilities have done, they have expanded their base mainly because the number of students that were being referred, which is I think a positive thing. The school districts were doing more to integrate students within the school districts and providing services within the school districts because the federal law and many parents were saying we really want the students to be integrated into the public school systems. So instead of having them removed from the school systems and placed in facilities where they were really targeting the type of disability, which depending on your philosophy and the need for the services, the school systems were kind of providing these things from within. Whether they were as well-designed, shall we say, and with the folk with the knowledge base has the quote that Sargent had that's a whole different story. That's part of the problem with integration.

Education Resource Directory Speaker: Yeah. I want to say that talking about where people could get information about education and brain injury. Right now I guess the Brain Injury Association in Rhode Island. But for educational rights and this would include k through 12 and then college, Rhode Island parent information network has people on staffs that are knowledgeable about transition issues and would have the information about what somebody's rights are, what the resources are out there in the community. So that would be -- I would think a natural place for Families and individuals to go for assistance. And one of the things that I found most helpful was the Brain Injury Association of Rhode Island, was getting material that explained some of what to look for in rehab -- in a rehabilitation center and also for different stages what a person can go through when they experience a brain injury. So it helped me. It helped my family kind of know that what we were experiencing, what we were looking at was very typical. For instance, feeding tubes are very typical for people with brain injuries.

Employment Discrimination Speaker: And you know one of the points you made before, which I have also seen and I -- I don't even know if this is public policy issue -- is the stereotyping that goes along when you have a disability. And as the person reenters, they kind of feel kind of squarely. If I tell them I have a disability, they can feel good about meeting their quota. But they're also going to discriminate me discriminate against me. They might. They might not. I don't know how to do -- how to educate in terms of public policy and how to tell people -- I mean, I can do it one-on-one or if I had a group therapy going on. But in terms of public policy, how do you get people to understand just because you speak differently doesn't mean that you belong in a crib. And I continue to question that and work on that and if there was a public policy way to help with that, which would be great. I just don't know what it is.

Speaker: That sounds like work for the rehabilitative services, doesn't it? Public education on hiring people with disabilities.

Rosemary: Actually the governor's commission has a committee that works on that, human resource professionals talking about (hiring) you and not about hiring a disability. You are hiring a person first. And they might -- might need some accommodation, might need some assistance. But you are hiring a person that is qualified for the job. It's certainly something to work on together.

Employment Job Training Speaker: I think most of our agencies look at education. I think that's a critical issue in breaking down barriers that exist. I know roads of independence grants, educating not only people in the community but also educate professionals about disabilities. Get some employment opportunities. Education is something we are always looking at improving.

Rosemary: Even the NetworkRI system. The one-stop centers. The focus is less on underemployed or people with poor employment histories and people with disabilities, but finding better jobs for people when you are employed or not. You could go in as an employed person looking for something better. Those one-stops have changed the nature of employment for folks as well. They look of that too. We went away from the stereotyping. Thank you.

Education IEP Speaker: Thank you. I don't know where to really begin because there have been a lot of areas that's been discussed thus far. I have a child who has Down syndrome. And just recently you were talking about discrimination. On the side of, you know, how they speak or how they don't speak, whatever. I have a child who's six years old, Down syndrome. And he doesn't speak at all. Dr. Frachelle had suggested that my wife and I learn sign language. Because we were having problems with communication. He was starting to bang his head on the floor and because he wasn't communicating. So we thought that was a good idea. So, in the IEP we always stressed sign language. Recently in this past school year, we actually had teachers tell us that Sean cannot learn sign language because of his disability and his fingers. These are directly from teachers. And I know that he signs with us. Dr. Frachelle and Dr. Armarc have all seen this where he signed. He's not signing as a professional would. But at least he gets his point across.

That's where I want to start. It's that type of discrimination that we experienced. I just am appalled as to that type of thinking going on. Our IEP that we've recently gone through in May, we still have not signed. This is a child who is 6 years old, does not speak. And they want to give him a half an hour group therapy. A total of one hour per week. That's not sufficient for a child who is not speaking. I heard an administrator that actually said more time with speech therapy would actually hurt him. I talked to other people in the profession and totally disagree. This is a professional, an administrator that is saying these things. I have done an awful lot of research. This is just one binder. I have gotten a lot of this stuff off the internet. And I found that he was recently diagnosed with Oromotoraproxia. By the suggestion of Dr. Frachelle and Dr. Armor, he requested that we at least find out if there is something medically wrong. Maybe that's the reason why he's not speaking. And then of course we found out that he has Oromotoraproxia. I have done a lot of research on that and basically when I tell the administrators about the situation, they say, well, He's still going to get half an hour. That's it. We had an actual doctor's note stating that he needs more time from Dr. Frachelle. And from what I understand, he's a leading doctor in Down syndrome. And this other administrator actually said, this note means nothing. It's a piece of paper. We're not even going to look at this when we make our decision. Well, I have a lot more. We've gone through -- my wife and I have gone through hell and high water for this child. We've gone through several IEP's. And it's amazing that everywhere you turn within the school system -- I will say this it's the Cranston school system. Everywhere we've turned, we've hit a roadblock. We actually had an administrator as witnessed by an advocate that we had with us change a block on an IEP stating we were agreeing with the IEP. To go to that, that length is appalling. And from everything that I have been reading in here and on the internet. It's incredible that this is something that is not just indicative to Rhode Island but also is nationwide. And that's one of the reasons why the idea was started. I actually could go on and on and on. I can hit upon many different facets. We're not going to look at suing because that is the game that's being played. We have a number of people that we know that to get a one-on-one whose child is autistic. They had to get an attorney. As soon as they had an attorney, they capitulated. Why is that? From what I understand, Cranston legal defense fund is out of this world. It's a joke. The legislature, they even know about it. I don't know why nothing is being done. I mean, this is something that is -- has been known I guess since 1997 when they last revised it. The idea program is right now in the senate in congress where they are going through ABCD. They are comPARIng them.

Rosemary: And the no child left behind act is also coming up for hearings again. And we need to advocate for full funding for that to get as many federal dollars back to us. It's an important year for IDEA and for children's acts.

Speaker: They are talking about fully funding, all right. Where it was supposed to be 44 percent and actually we are getting 18 percent.

Rosemary: 13 in some communities.

Health Care Therapy

Speaker: 13 in some communities. So as far as that's concerned, if that's the situation -- why did Rhode Island send back $38,000? That's what I want to know? Why did other communities, other states send back 6 million, 3 million? Why? I just don't understand. I mean, my whole idea of course is my son Sean. That is my prime situation, to get him the services that he deserves by law, not an hour per week in group therapy. And they really don't care. That's the indication that I'm getting. We've -- they've done nothing but lie to us. I mean, I can give out names right now but --

Rosemary: Let's not.

Jack Reed and Jim Langevin.

Speaker: I can -- well, this is something that's got to be brought out. I've e-mailed Jack Reed. I've e-mailed Jim Langevin and we are actually thinking about e-mailing the entire congress and the President of the United States because -- this has got to stop -- to put parents through what I consider hell on earth. This is a child who is 6 years old, virtually defenseless. And I can tell you when you hear of a story from another parent seeing your child being pulled by his coat backwards. And, of course, he is a child with Down syndrome that can't speak. We can't get it from him. The mother called us up and was in tears. Her child goes there too. So my wife went there unannounced and saw my son Sean, a 6 year old child leaving the IEP building alone. The IEP to them means absolutely nothing. He is supposed to have a one-on-one per the IEP. There was an administrator that said verbatim, Sean will not have an IEP -- I mean a one-on-one. Only found out that they were not signing to our child. It was September -- it was before September 26 when it was just one of those -- let's go meet the teacher. And our first question was, how's signing? How's Sean taking the signing? She had no clue as to what we were talking about. We later found out that she didn't read it because it was in another location. She had my son in summer school.

Rosemary: Does Sean have an educational advocate now?

Speaker: I tell you; going down that road we have had two, two advocates that attended both meetings. We got a letter on both of them that one was appalled as to the way we were treated, bullying tactics. I have seen it right in the internet. So, they tried everything in their way to aggravate, to insight, and of course we were just sitting there and taking every shot that they gave us. We got a letter from one of the advocates. We got a letter on the second one. We had an administrator that said, well, it's your right. You can sue us but that's all right. We are going to win anyway. Our pockets are deeper.

Rosemary: Maybe not. Have you utilized RIArc as a resource?

Speaker: They are the ones that meet on Tuesday, correct?

Rosemary: I don't know. It would be Jim Healy or Mary O'Caffrey,

Speaker: There was a program that we have not been able to because been able too attend only for the certain reason Mary has been taking sign language classes. So, I wanted to go. But my job is, you know, very inflexible in that way.

Rosemary: Just another advocacy group, another avenue to pursue to get some respect.

Speaker: You know, another person here has, you know, talked about well, you know, it's very difficult to find exactly out exactly what you are supposed to do. I utilized the internet. Thank God my job allows me to do that anyway. But it's just amazing that you can't -- or I haven't been able to pinpoint a step by step instructional manual stating do this, do this, and do this. Call here, call here, and call here.

Health Care Resources

Rosemary: Unfortunately the woman sitting next to you, who left, Jeanne Behie from RIPIN has a manual and would be a good person to connect with. I we'll make sure you have her name and number.

Speaker: I've got an awful lot of other things. Another administrator in Cranston -- I can't understand why there're so many administrators. Maybe that's why Cranston is such a state --

Rosemary: Let me just state. I work for CranstonArc which is not in any way associated with the Cranston school departments. You don't have to type -- you probably typed that in.

Speaker: Can I ask you a question?

Speaker: Sure.

Education Inclusion

Speaker: Do you think that the -- difficulty is light but I will use the word -- difficulties that you are experiencing are in due partly to the fact that general educators don't have enough education in special ed, in that they are scared -- pardon the expression -- mainstream children with different disabilities into the classroom as well as in terms of a budget crunch. If you don't have to give the money to somebody when your pie is very tiny and you can get them to shut up, then you don't have to come up with the more for that. Do you understand what I'm saying? I wonder if it's kind of like a mix-up of all of those. Do you think there are other things involved? I'm amazed that you have a good sense not to take a swing at a couple of these people.

Speaker: I think you are absolutely right. It is a mixture of things. Of course, the one thing that they are going to tell you is it's not a budgetary issue. It's not a money issue, absolutely not. And you know it is.

Rosemary: Which then begs the question to be answered? Why are we returning money?

Speaker: Right.

Speaker: That was a shock to me. You know, you would think that -- there's only one state that had a zero balance. It escapes me which one. It's in the book somewhere. But there was only one state that had a zero balance. And it's just amazing. But I think that inexperience, possibly fear, possibly. I don't think that they know what they're doing.

Speaker: I don't think they know what they're doing either.

Education IEP

Speaker: They feel that -- all right. Well, this is a child -- especially when somebody is saying to me, he can't learn. Your son can't learn sign language because of his disability and his fingers. Now, we all know Down syndrome children have I guess shorter fingers or whatever. So it makes it difficult for them to sign properly. Okay. So when he does milk, when it's supposed to be done this way, so he does it this way. Are you going to be able to go to McDonald's and say milk, more milk? You know, probably not. How many organizations have people that are able to translate sign language in their businesses?

Speaker: Are you aware that the West Warwick school department is suing if think its BMW because of the woman that hit -- is it BMW?

Rosemary: The driver -- the car who struck that young woman.

Speaker: They are suing for the special ed services that she may now need. I think she was in middle school, correct?

Speaker: Yeah. That was an article -- I printed that article up.

Speaker: I would be interested to see what happens.

Rosemary: Lifelong.

Speaker: The other thing too is why is it -- is everybody afraid of the school department? I mean, you talk to --I for one have talked to a reporter because I refuse to go to the way of getting an attorney. I'm not going to play that game because all they are going to do is just get the best attorneys, and Edwards and Angels or whomever. And then they are going to go ahead and wait until you run out of money. And I talked to a reporter. It doesn't matter. I will blast e-mails to NBC, CBS, whatever. Whatever it takes. I just think this is ridiculous. That's why I'm here. I'm here because I think that there is something that can be done. I mean, first on a state level. But also I’m looking at a federal level now. I want to change the way it's -- this is done, this is operated. I want to change the way this is actually administered because when you have -- oh, I don't know five administrators that are talking to you, you know. You have to have all of those administrators? Now out for jobs? No. I'm out for -- at least let's get something reasonable. If we're having a budget crunch, you know, I don't know. I have no idea. Let's resolve the issue. Let's get the politicians involved in this issue as well.

Bill: So, can I just kind of bring this to a bit of a focus here? Have you dealt with the superintendent? Have you asked the superintendent? Have you gone to the superintendent?

Speaker: We have.

Bill: You have gone to the assistant superintendent, the special ed director of the school district, the assistant superintendent, all three of those people?

Speaker: Basically yes.

Bill: Have you gone to all the members of the school committee?

Speaker: They had a meeting and they said they were going to get back to us. Bea Lansy is the one who orchestrated that. They called us. They were to call us right back. They still have not called us back.

Bill: The town council, the mayor of the town? I'm not trying to I’m not making -- being argumentative. I want to make sure you go to the local people first before you work your way up because your next level is your understanding under your rights is if you prevail, if you do get an attorney and you do prevail in one issue your attorney is paid for. You recognize that?

Speaker: I do.

Bill: All you need to do is prevail on one issue.

Speaker: But from what I understand, there is a couple in Cranston that is up to $100,000 right now. They mortgaged the house to the hilt. They still haven't been -- and won all the way through and they still haven't been paid.

Bill: I'm not saying it doesn't --

Speaker: That's enough to tell me that I don't have $100,000.

Bill: Right. And that unfortunately is the drawback in the way that’s done, particularly in that scenario. I'm not saying that particular school district. If it makes it any less onerous for you not all school districts in the state of Rhode Island or the country act like you are dealing with right now. I just want you to understand that. Not all school districts are like that.

Speaker: Well, that would be refreshing.

Bill: Because -- number one, they wouldn't be able to survive. And number two, not everything works like that.

Speaker: Well, the Cumberland school district, they’re pretty good. I believe its East Greenwich is another one. They're fairly good. Smithfield they were at one time from what I understand was excellent. You know, I don't know them all. But I just know the ones that are horrible. And that's the unfortunate thing that we are running into. And -- so I know that it's not universal, every school system is horrible. Unfortunately we can’t move -- we don't have the income to move into East Greenwich. It’s very expensive --

Bill: Right.

Speaker: -- To live there as far as housing is concerned. But -- I think I said enough. I hope that this will, you know --

Rosemary: It becomes a part of the public record so you can take this written document and certainly present it anywhere you want to.

Speaker: Great. How do I get a copy?

Rosemary: After the public forum, all of the public forms are held, we go through the information and we do a written or a print copy that will be available.

Victoria: It will be on the Governor's Commission website also.

Rosemary: As well as available --

Bill: Because we will get this on the public record, let's go through a couple other things. Have you filed a complaint with the department of education office of special education services?

Speaker: I believe my wife has.

Bill: You need to do that to make sure you have that on the record.

Speaker: Okay.

Bill: File it with Jennifer Wood, who is the chief legal counsel for the department of education. And you need to file a complaint with the office of civil rights. It's an OCR complaint.

Speaker: Now from what I understand, once you have done these, that does -- the next step would be hearings and -- that's not where we want to go.

Bill: Well, if you file an OCR complaint, okay, which is a section 1983 complaint, it brings the folks down from Boston. And the special education director will deal directly with the complaint from OCR. And in the complaint, when you lodge the complaint in Boston, you specifically state in the complaint exactly what's happened, okay. And by doing so, OCR will then go back to Cranston and say to Cranston, we received this complaint. Please respond to this complaint. And they generally have I think its 15 days. Haven't done one in a while but I think its 15 days to respond initially to the complaint. It is a painful experience.

Speaker: You say it's section 19 --

Bill: Section 1983 complaint because in essence what you are doing is you are saying somebody's violating your son's civil rights. Because if you -- when you actually file, if you filed in federal court, that's what you are filing under.

Speaker: Where? -- How would I get my hands on something like this?

Bill: Go direct -- I don't practice in the state of Rhode Island so, you would need to deal directly with the office of special education services here in Rhode Island who also has an OCR officer at the department of education. Say you want to file a complaint under section 504 in Rhode Island.

Victoria: I think the phone number for the office of special ed is 222-4600.

Speaker: Are you able to do this complaint on-line?

Bill: I don't know. I've never done it. I only had to respond to these things as a special ed director, not as a parent. And as a parent I never had to do it because they never treated me like that as a parent.

Speaker: In what little that I have given you -- and I will direct it to you because you are talking to me at this point -- I mean, do you see something as very odd why they would do something like this?

Bill: I know all the people involved that you are talking about.

Speaker: That's -- (laughing)

Ed Rawlings: I would like to say one thing. Again, the commission might be able to offer some assistance and advice, particularly on the signing because they work with the deaf people, the deaf school, and the school for the deaf.

Speaker: Excellent.

Ed Rawlings: If you can contact them, they may be able to assist.

Speaker: Okay.

Ed Rawlings: At least with the signing.

Speaker: Thank you. Thank you very much.

Rosemary: Thank you. Are there other folks who did not sign up to testify who would which to make either comments or comments to add?

Housing: Independent Living

Speaker: I just in the scheme of everything else, it's a minor thing. But the young man sitting over there was talking about his dreams and his hopes for the future and wanting his own apartment and a job. One of the things that we encounter on an every day basis is housing for people who want to live in their own place, who no longer want to live in a group home, no longer need a group home, who don't want to live at home with mom and dad anymore. People just can't afford a place to live. And so there are some initiatives being worked out with housing in general in Rhode Island. But I believe that it's something that needs to be paid more attention to, most -- many of the Section 8 buildings that typically are elderly and disabled have now become elderly only. So you are even shut out of those. Getting Section 8 certificates, we've actually had people who had to turn them back because we can't get landlords who will take the low rent that they will allow. So it's again in the scheme of many other things that we talked about today, it's not probably as important. But it's definitely for people who want to move on and have a more independent life. It's definitely an issue.

Rosemary: I think the last statistic I saw was a two bedroom apartment in Rhode Island runs about $1,000 a month

Speaker: Yet the city of Cranston (laughing) section 8 offices will allow you for a two bed $650 and you try to find something for that. There’s absolutely nothing.

Housing: Assistive Living

Paula: Housing is a real issue in my scheme of things. I have --brain injury survivor. Hit my son he was 12, he's 29 now. Because there are no group homes for traumatic brain injury survivors which are the appropriate thing, not a group home retarded. He has been living in Vermont in a group home setting for traumatic brain injury to the tune of $4,000 a month. I would very much like to see some housing for traumatic brain survivors. That's one of my goals.

Speaker: I have to echo that because in my practice I have already come -- I have already worked with two families who have significant housing needs where the person really either doesn't want to be at home or really can't be at home. But where are they going to go? Somebody who needed to institutionalize her husband because there was no other place to put him. And that's why she had to come see me because of her -- that's ridiculous.

Paula: It's the same with this girl's mother being in a nursing home.

Speaker: She could have been somewhere else.

Paula: That's right.

Speaker: And I don't think -- and correct me if I’m wrong. I don't think that it would take; you know we are not talking about a large institution. I mean, a couple of houses, you know, a couple of four-bedroom houses that would house eight people and be staffed would really do a whole lot. So, that's -- I have to agree with you.

Rosemary: Are there any other comments?

Ed Rawlings: I would like to make one more comment on the Commission for the Deaf and Hard of Hearing. In the last three months we've -- I created our website and we are attempting to make that a one-stop center for information on the deaf and hard of hearing. And that website would be www.cdhh.state.ri.us and there's a lot of information already on there. And we will continue to accumulate and make it a one-stop shopping.

Rosemary: Great. Thank you. Well, I want to thank everyone for coming and for your input. It was very -- it is very helpful, very poignant, and very timely. And all of this will be put together in a format and shared with other people. I think some of the major areas we talked about tonight that really stuck out was certainly coordination of care across all disability groups, health insurance, the Medicaid buy-in, the resources, how to find them and access them, housing again across all disability groups is a huge issue, employment, respite for care providers, discrimination, and certainly education. And those are some of the categories that all of this information will be categorized against, including from the other forums that we have throughout the state as well. Vicky said it will be available on the Governor’s Commission website as well as you can request print copies, large print as well as the typical print but again thank you very much for coming.

July 27, 2004 Independence Square, Pawtucket

Tim Flynn: Excuse me, ladies and gentlemen; I think we'll call this meeting to order. I just want to thank everybody for coming here. Welcome to the general public and members of the panel. Basically, what I think we're going to do is the purpose of this meeting is to identify the concerns of people with disabilities and their families in order to assist the state to develop programs to improve the quality of life of people with disabilities. That's our mission today. We rely on you, the general public, to come to these meetings and state what your issues are and to spell them out in a way that we can then address them, create programs, create legislation in order to solve any of the problems you might have. I think what I would like to do is start off the meeting by having the panel members introduce themselves and I would appreciate it if you would state your name and the agency your with.

Ralph Rodriguez: My name is Ralph Rodriguez the associate director of the Rhode Island department of elderly affairs. I'm looking forward to hearing what people have to say. In the back of the room I've put some of these little booklets which are the Department of the Elderly Affairs pocket manual and even if you are not here -- I think you'll find the booklet helpful. It talks about Medicaid, Medicare and has a list of many, many organizations for disabled folks and related things. It's a very handy book. In addition, I want to mention briefly, if any of you are aware that the Department of Elderly Affairs in cooperation with the Department of Human Services and several agencies are working to put together something called a one-stop program.

Health Care Resources

Fundamentally, what the idea is that there will be a location probably at the Pastore Complex in which an individual who is elderly or disabled, can come to that place and sort of find out about the full gamete of services available to them and apply for the full gamete of services in one location. In addition the goal will be to have at least two other satellite sites, probably one in northern Rhode Island and probably one in southern Rhode Island, where similarly an individual can come in and avail themselves of the true range of services. So with that, I look forward to hearing what people have to say.

Yahaira Martinez: I'm Yahaira Martinez from the State Rehabilitation Council; I'm on the Public Outreach Education Committee. We are always looking for volunteers to come and join us. Basically, what we do is try to make life easier for people with disabilities.

Tim Flynn: Thank you.

Arthur Plitt: I'm Arthur Plitt, Governor's Commission on Disabilities and I'm involved with a whole bunch of other organizations in Rhode Island, from mentoring to other things. I just wanted to mention last year a number of the people testified in a variety of areas and RIPAE (Rhode Island Pharmaceutical Assistance Program for the Elderly) got expanded because of it. The Medicaid buying is law now which we'll see, giving people the opportunity to apply their Medicare Medicaid program and at the same time work and put money in their pocket, and also the disability business enterprise committee got suspended and should help as I say more people who want to be in business, do business as a businessperson.

Tim Flynn: It's very important because what is said here really does lead to positive impacts on people's lives. So I encourage everyone to speak out, speak thoroughly and speak their minds.

Jeanne Fay: I'm Jeanne Fay and work for OSCIL which is one of two independent living centers in Rhode Island. I'm a benefit specialist there and I'm only going to tell you about my program. I work helping people understand how employment SSI or SSDI payments, Medicaid and Medicare. Please feel free to call if you have any questions about these services.

Tim Flynn: I'm an independent living counselor. I also serve on the legislation committee on the Governor's Commission on Disabilities. That's my role and I'm here to help you in any way.

Neil Young: I'm Neil Young from the offices of families raising children with special health care needs through the Department of health. I'm from an early intervention program, which is for toddlers from birth to 3. I try to help kids with delays.

Catherine Sansonetti: I'm Catherine Sansonetti a staff attorney at the Disability Law Center which is a federally funded nonprofit organization that provides information and referrals to persons with disabilities and also provides representation for variation of issues.

Casey Crothers: I'm Casey Crothers and I work for the Brain Injury Association of Rhode Island. I'm a TBI grant coordinator for the 3-year federal grant.

Mark Therrien: I'm Mark Therrien from the Rhode Island Public Transit Authority. We are also the RIde program.

Tim Flynn: Thank you Mark. That is the length of our panelists. I think I just sort of have a checklist I have to mention here. I want to make sure everyone understands. There's a public phone outside. There are restrooms down the hallway. We can utilize those. What's going to happen here is we're going to make a transcript of everything that's said at this meeting. The transcripts will be posted on the Governor's Commission on Disabilities website. The website is www.gcd.state.ri.us each transcript will be posted in about a week's time and later this summer, we'll all get together and we'll review the testimony and prepare recommendations will also be posted on the website by the end of this summer. So recommendations and the transcript will be sent to state officials and to members of the general assembly and they will be used to develop policy for the next year or until they are accomplished. We want to give everyone who wants to speak a chance to speak. They might ask to clarify questions so we can be sure we understand what your specific issue is. As I said, you'll be asked to speak in the order on the sign up sheet. Looks like we have three people who want to speak this afternoon. So I mean, we have plenty of time, you can take your time when you speak. We're here until 6 o'clock. So with that, I would like to invite Fredericka Jay. Please stand up and state your name and what organization you're with and the town you're from.

Family Support Domestic Violence

Fredericka Jay: National Federation of the Blind. I would like to address my letter to Mr. Cooper and members of the panel. As a legally blind woman, my husband of 30 years I was shocked and horrified at the fact that the three-page complaint was not bad enough to have my spouse remove me from the marital domicile with a restraining order. The reason I write to you is two-fold. I would like to work with you to write an amendment to the guidelines in the law regarding domestic violence to open the eyes of the judges making these decisions. I can not see, I live in terror and never know where my mentally abusive spouse is. I'm hoping this amendment will be titled "Helen Keller amendment." I am hopeful this amendment once in place would protect future women and/or men from the abuse I have suffered for two years. Secondly, please have someone read this three-page complaint aloud working with you before the next legislative session begins. Thank you in advance, Fredericka.

Tim Flynn: Thank you very much for having the courage to speak out about a very personal issue. I know from experience that an issue that affects people with disabilities not just blind, but everybody that is abused. I have a question for you. You said you wanted to amend the domestic violence law and call it the Helen Keller law. Are you familiar with the law you're talk being and perhaps you can spell it out.

Fredericka Jay: Not yet, I haven't done a whole lot of research. I've been in touch with the Rhode Island Coalition Against Domestic Violence against women I've sent a copy of this letter to Will Andrade, the director and a copy to Representative Peter Kilmartin he's my representative in Pawtucket and he's on the board to work on changing the law.

Tim Flynn: Really? That's very effective. Anyone here that has anything they want to add.

Fredericka Jay: When I ran the letter by my older sister, it might be a copyright issue with the Helen Keller amendment. But I would like it to take care of all disabilities, blind, deaf, wheelchair bound, mentally challenged whatever, because it's just

Tim Flynn: Would it be called people with disabilities amendment?

Tim Flynn: Next on the list to speak is forgive me, Harry Dunbar. Hi, Harry, how are you?

Harry Dunbar: I have five questions do you want to go through all five now.

Harry Dunbar: Tim, how come Leo doesn't return his phone calls.

Tim Flynn: That's not an issue we address right here.

Harry Dunbar: That's one of my problems because I called him 7 months ago and he called me back ten days ago.

Transportation RIde

Harry Dunbar: What happened in an emergency if my car doesn't start I can't call RIde because RIde needs 24 hours ahead of time.

Mark Therrien: Flex has been put in South County. If you're in the Pawtucket area there are a lot of other transit services. We don't have the resources to put flex there.

Harry Dunbar: I would like to see one in there. Because if my car doesn't start who can I call to take me to the doctors?

Mark Therrien: We have it in the plan for service but there's no money in the budget.

Harry Dunbar: How come there's no money in the budget? You guys send 22 or 24 buses of RIPTA down to Sacono. I think it was, new transmissions, new motors new seats.

Tim Flynn: Harry, I think what your issue is you want to have the flex service expanded in Pawtucket because if you need to get to a doctor's appointment.

Harry Dunbar: What of people with disabilities the car won't start and to get them to a doctor's appointment, what do they do?

Tim Flynn: You reschedule. I would imagine.

Harry Dunbar: How come we can't get the RIde program in case of an emergency?

Tim Flynn: If it was an emergency, then your request would be called in.

Tim Flynn: I don't want to minimize your issue.

Health Care Medicaid

Harry Dunbar: You said something about the Medicare Buy In Arthur.

Arthur Plitt: Yes.

Harry Dunbar: That's been passed to have a new Medicaid law why isn't only to 2006.

Arthur Plitt: Because it's going to take some time to set up the procedures to make sure everything works smoothly. Buracracy but at least its coming.

Harry Dunbar: But what about the last two years?

Arthur Plitt: Sometimes you don't pass something the first time around.

Harry Dunbar: I figured all that should be done and ready to go. Now I have to wait until 2006. My medications are $300 and change apiece. What do I do?

Tim Flynn: What have you been doing so far?

Harry Dunbar: I have to use my spin down its like 85.00 dollars every six months.

Tim Flynn: I think you understand this has been an issue over 7 years and we've been try to go lobby the legislature to get it passed and think year we were fortunate enough that the legislature was open to a passage and we worked hard, and I think you understand how legislation works.

Harry Dunbar: Right. But what I'm saying for the last three years you guys couldn't get it passed. So I'm saying, what we are going to do if we didn't get it passed. I have to wait two more years before I can do something.

Tim Flynn: I mean, I think as Arthur stated, you know, the law is passed as it was written up this year.

Harry Dunbar: I'm saying, someone is passing the buck to the other person.

Tim Flynn: I think the commission has done a good job in getting it passed.

Harry Dunbar: I met with Bob Cooper and my state representatives and we've been working on it. I even sent letters on it.

Tim Flynn: And you're probably one of the big reasons why it got passed because you've been there.

Harry Dunbar: I'm wondering why it's taking so long to get it into effect.

Tim Flynn: I don't have a magic lantern for you.

Harry Dunbar: I know but I'm just saying --

Tim Flynn: Any other issues you want to discuss?

Harry Dunbar: No.

Tim Flynn: I appreciate you taking the time to make those points they're very valuable. There's one more speaker, Anna Martin.

Anna Martin: The other day I went to the grocery store to go and look at stuff. I was right near side bar where food is and there was a space between me and the side bar thing. And there was a lady who was very manually could walk and she went through. Instead of going around me she said, why people always have to go in front of me. You guys should talk to grocery store people and the attitudes people have about people in wheelchairs, they think we're crazy. I might be crazy but that happened along time ago but not because I'm in a wheelchair. So I really think the attitudes about people in wheelchairs are still terrible.

Transportation RIde

Anyway, may I please say something to the RIde person, please? Every time I call up for the RIde, they come and the guys have no idea where they're going or they blame the people that work there and the people that work there blame the guys. So that's what I hear all the time.

Mark Therrien: What community do you live in

Anna Martin: North Providence. And today I had to ask the guy, are you going to Prospect Street because the last time someone picked me up he took me to the wrong place. I told him I had to make sure we were going to the right place.

Tim Flynn: Are you finished?

Anna Martin: Yes.

Tim Flynn: I appreciate you coming here today. So if you had to say you're upset that, I guess addressing your first concern we are a legislative body and we would have legislation that would be entered into law. We can't legislate attitudes. As much as I would like to we can't do that. We can talk about public awareness campaigns and that sort of issue. That's important. But it's most important that we get ourselves out there and advocate for ourselves. I appreciate your point on that.

Male Speaker: How do you expect us to advocate?

Tim Flynn: It's called getting up and going outside and talking and meeting people.

Male Speaker: I do that all the time.

Tim Flynn: Okay.

Male Speaker: Go a little bit further with that.

Tim Flynn: I don't understand what you're asking me to do.

Male Speaker: Advocate to whom? The people outside. We've all done it. Who else do we have to go to? We all talk to our representatives. Who else do you want us to write letters to?

Tim Flynn: I don't have an answer for that I think you've done it.

Male Speaker: Take it a step further.

Tim Flynn: Harry, this is a discussion we can have outside of this meeting. I will be happy to talk to you later on. I would be fine with that.

Male Speaker: All right.

Employment Discrimination

Gladys Franco: Good afternoon my name is Gladys Franco I’m Columbian. I’ve had arthritis chronic arthritis from the age of 3 years. I don't have any kind of assistance at all here. I only get medical help and I receive medication. I've been in this country for four years. I have been trying to act as a normal person. And I believe I’m a normal person as far as I’m concerned. As far as other people are concerned I am not, I am invalid or disabled. I know how to work. I've worked in different firms. And they noticed my disability and they lay me off. I would like to be able to get employment and I want to be able to work. I don't want to receive anything. I want to be independent and have my own apartment. Despite the fact that I have to pay bills. Despite the fact that I have to pay bills and rent I’m not completely independent because I have to live with my family. I heard about this program through the newspaper. If you are able to help me, I want to be useful. I want to be able to earn my own living. I want to be able to get up and be able to buy my own things and go places and do things for myself and be able to live as other people do. I would like to see an office for people that are disabled and are willing to work.

Tim Flynn: Thank you very much.

Gladys Franco: Thank you.

Yahaira Martinez: There is an office in Providence helping people with disabilities.

Gladys Franco: I have already been there, but they only allow you four hours of work a day and 100 dollars a week and I can't do anything with 100 dollars.

Yahaira Martinez: If the employment you had and where you were working they laid you off because of your disability, if you are disabled and they lay you off and let you go because of your disability that's discrimination. Unless you're not able to do the work.

Gladys Franco: I am able to do it.

Yahaira Martinez: They laid you off because of that reason.

Gladys Franco: They don't tell you exactly for that particular reason. They won't tell you that. That it's for that particular reason. They tell you just by looking at you; they will tell you what they think of you. They know that if they tell you it's because of your disability, you will take action and they won't do that. Something else I would like to say, people that are willing to work, why don't they put them to the test, let them do the work and see the results. I'm willing to work, but they won't let me work.

Yahaira Martinez: If they laid you off, they are supposed to give you a reason. Do you understand? And if they don't give YOU the reason it's against the law.

Gladys Franco: I don't want to look for a lawyer. I just want to work. I don't want to sue anybody and get money from a lawyer.

Yahaira Martinez: It's something that you're entitled to.

Gladys Franco: I need proof and I don't have the proof.

Yahaira Martinez: Well, you just tell the lawyer you were doing your work and they laid you off.

Gladys Franco: They tell me do this work, and they tell me do it this way, I try to do it the way the boss tells me. If I do it the way I can and the way I do it and I do it fast, they don't like it. They don't like it.

Yahaira Martinez: I’m going to give you my name and my number and we can talk.

Tim Flynn: Thank you, I think that’s it. Unless you have another concern.

Catherine Sansonetti: Yes, one of the comments.

Disability Law Center

Tim Flynn: Could you explain to Gladys what the Disability Law Center is? Cathy works for the Disability Law Center.

Catherine Sansonetti: One of the things that you mentioned was that sometimes they won't give you that disability as a reason for layoff, and I wanted to let you know that doesn't matter. We can still evaluate whether or not you have grounds for any possible legal claim and sometimes suing is more about trying to get the person back into their job than it is about suing for money. So there are other remedies than what people traditionally think of when they think of lawyers. Many times we can help the person go back to work and intervene on the person's behalf and talk to the employer about what's legally required. So if that comes up again, you can call the Disability Law Center and one of the attorneys will look into the matter for you and let you know frankly, whether they think you have a claim or if there's anything we can do on your behalf.

Female Speaker: And how can I prove that?

Catherine Sansonetti: That's our job. (Laughter).

Female Speaker: Okay.

Catherine Sansonetti: Sometimes it doesn't have to be so obvious, we can pick up on sneaky little clues and do our magic with that. We can interpret what we see to lead to certain conclusions that may not always be what would be very stated.

Tim Flynn: Are you available to have someone speaking Spanish for her?

Catherine Sansonetti: We do have an attorney that speaks Spanish.

Tim Flynn: Gladys aren't you glad you came here tonight?

Female Speaker: I have to do that some day. It could start something big for people who are disabled and willing to work.

Tim Flynn: There are means and agencies in place to address these kinds of issues. I mean discrimination didn't begin with you, it began a long time ago and we all face it every now and then. So it's very good you came out and spoke out and you should call the Disability Law Center.

Catherine Sansonetti: Especially for I don't know, if there are any agencies that may be able to help you to go back to work or to help you do that, to give you certain things you may need on the job because of your disability. I really encourage you to call our office and ask to speak with our Spanish speaking lawyer, who maybe can provide you with names of referrals and agencies who might benefit you in your search or to just generally advise you.

Tim Flynn: Your name, Gladys Franco from Central Falls. Anyone else want to speak?

Female Speaker: I was just going to ask.

Tim Flynn: Wait one second while we close the door.

Female Speaker: Certainly. Tim, last week was the first time I’d ever attended a lecture at the internal institute for some reason what Gladys has raised, while I was there I familiarized myself with the institute because they hold computer classes and ESL classes and I’m not hearing from her that she's looking to sue, but I think she's look for assistance a little more expansion and can't a facility like that maybe be of some benefit to her.

Tim Flynn: It sounds good to me.

Female Speaker: This is at 645 Elmwood Avenue.

Employment Job Training

Gladys Franco: I have gone there and I also have gone to one on Broad Street. I have gone there to seek employment and also the one on Broad Street. I am looking for a job in a factory where I can do packing or jewelry, sewing. I have to look for a steady job so I can go back to school. Because the bills -- I have to look for the job first and then later on I can go to a place where the lady referred to.

Tim Flynn: I'll try to wrap this up here. I thank you for your suggestion. And Gladys, are you working now?

Gladys Franco: No.

Tim Flynn: So how long have you been looking for work?

Gladys Franco: Two months.

Tim Flynn: Do you feel like you're going to get close to

Gladys Franco: No.

Tim Flynn: How many jobs have you had in the past?

Tim Flynn: About?

Gladys Franco: Around 50.

Tim Flynn: You're not afraid to work then. I think, you know, we don't have a direct answer for you right away, I can't -- does anyone else on the panel have job training or job assistance programs. But I think if there is any kind of discriminatory behavior, you want to talk to the Disability Law Center.

Arthur Plitt: Network Rhode Island, have you been there?

Gladys Franco: Yes. I'm telling where I've gone. (Laughter).

Gladys Franco: This is a last resort and I decided to come here.

Tim Flynn: Thank you, we're glad you came. And you now know that you have some recourse if and when you get a job that you can't be fired on the basis of your disability. And so, you know, you've gotten jobs before, I have a feeling you'll get another one.

Gladys Franco: Thank you.

Tim Flynn: Thank you. Anybody else? We have Paul Bohal. State your name and where you're from PARI

Paul Bohac: I'm Paul Bohal from the Brain Injury Association of Rhode Island and I just want to say that you were saying been grants and things like that. Before there was I became brain injured 17 years ago and there wasn't anything for me. The PARI group took over my case where there wasn't a Brain Injury Association and they gave me some counseling and all the support that the government can give for the Brain Injury Association and PARI independent living it's very worth while because unfortunately, brain injury is a hidden injury you can't tell anything is wrong with me. I sustained a brain injury and have lost cognitive and I'm not the same person I was. The government is able to give you a normal life. I encourage you to do that for the Brain Injury Association. Thank you.

Tim Flynn: Terrific. Thank you Paul. Anybody else.

Nancy Fuller: I have a question.

Tim Flynn: One second. Right here. This lady.

Communication Access Oral

Nancy Fuller: My name is Nancy Fuller I'm the president of the Rhode Island Association of the Deaf and we have some concerns regarding the deaf community that's been ongoing for sometime including the DMV. When one goes in there, there are speakers but no visual captioning available. This happened last week to some people. They went to renew their license. They're not sure what window to go to and when numbers are brought up they're brought up very quickly. There's a brief display of the number and they're missing their turn. And also when they're doing the eye test looking into the device for the eye test, often what happens is the DMV will call the person by name and the deaf person or hard-of-hearing person misses that information. Just a month ago, I went to the airport here in Rhode Island, and again, there was no visible signaling device or signage with display to announce when flights were coming in, a change in gaits or if there's a delay. There's a lack of access. Just some ideas the DMV there are some gaps and there's not equal access for deaf people in this regard. That's the concern I wanted to bring to the panel.

Tim Flynn: I thank you very much. Naturally, I am not familiar with the hurdles you have to overcome. But as I said at the beginning of the meeting, the legislation committee will review it and come up with recommendations because you certainly should have equal access to services that the rest of society shares. So thank you very much for going on the record.

Nancy Fuller: Could I add one thing. The shopping malls, the Providence Place Mall for example it might be a good idea to have visible fire alarms. I don't see where they put those in public places such as that. You need that for deaf people who won't know in the event of an emergency there was an evacuation going on unless there are people running in their direction and they're relying solely on visual information.

Tim Flynn: All sound like very good suggestions to say me. Thank you very much. Over here.

Angelina Texiera: Angelina Texiera. The airport should have terminals with large screens that state the flight and gates. The airport has screens with the gate numbers on them, that because it changes they should have large screens with the gate information. It's hard for the people to know where to go. Just in schools they use screens the gates should be used. My question is, Mark Therrien, are the proposed cut that you mentioned in today's paper are they going to be permanent or what's the situation on that?

Tim Flynn: The purpose of this meeting is not to answer a question like that. If you want to talk to Mark on your own you can certainly do that. but we're here to talk about legislative issues for the future. I don't want to step on what you said, I'm glad you mentioned it but we can't be commenting on newspaper articles.

Mark Therrien: I'll definitely speak to you on that.

Female Speaker: Thank you.

Tim Flynn: Your name please.

Anne Martin: Anne Martin. I would like more services. I would like to do some volunteer work. For me to do work it would take all of my medical stuff away. So I don't want to do that. I would like to do more volunteer work. I'm a normal person. I might be disabled and stuff, but I think there should be definitely more services for people like me to do volunteer work. Nobody knows what's going on. I really wish and hope there would be more services for people that are very nice and would really like to do more services, volunteer services. Something for me to go out and explore the nice people in the state.

Tim Flynn: Anne, I am certain you have a lot to offer. And I think there are volunteers in action in Rhode Island.

Yahaira Martinez: I stated that the state independent living council is always looking for volunteers.

Tim Flynn: As are a lot of nonprofit organizations. They would be happy to have people come in and volunteer. So just pick up the phone and find an organization that you know something about, call them up and volunteer your time.

Casey Crothers: My name is Casey Crothers, Brain Injury Association of Rhode Island, have you found that in the past doing volunteer work, that you need additional help to have the volunteer situation be able to work with you along with your disabilities.

Female Speaker: I think so. Because people are like nah -- people I talk to, it's like I'm speaking from another planet or something. They should really have respect and realize there are people that are disabled that really want to do volunteer work.

Casey Crothers: Do you think it would be beneficial if there was a program that could help tie you up and help you work out any problems with the volunteer opportunities?

Female Speaker: Yes.

Casey Crothers: Thank you.

Tim Flynn: Would anybody else like to speak?

Volunteer work

Rosemarie Coffee: My name is Rose Marie Coffee and I'm with the PARI Independent Living Center and I worked with people to transition people getting into the community from an institutional setting and what I find a significant need for is more supports for people traumatic brain injuries, you can contact me and I give have opportunities to offer them for support. What I find is that people in these situations are surviving accidents and are left with permanent disabilities, do not meet the criteria for going to an intense rehabilitation service, they might having halfway completed the services, but they're not ready to live independently. So I hope that if there's an opportunity in the future to support the kind of day treatment, clubhouse program for people to come to and have constructive things to do as Anne said, opportunity to say help as a volunteer to work with their peers, whereas she could have an opportunity to work with other people who are going through the trauma of a brain injury and adapting to a new life whereas people could really benefit from coming together under one roof. That's had a I would like to see. That's what I will concentrate on today. Thank you.

Tim Flynn: Any questions? I have one. In a perfect world, I mean how many people of a program you need to serve.

Rosemarie Coffee: People maybe wouldn't need it all the time or indefinitely, but we use as a pass-through to get on their feet. I'm probably not in a position to project numbers but hum, Casey help me out here maybe a couple of dozen at a time.

Casey Crothers: I would say there are approximately 7 to 8 hundred recorded brain injuries in the state per year. Many of them are not accounted for after the fact because they don't qualify for any services, so they're not hooked in anywhere so they're not actively on the service roll, so they just go through the cracks but there are 800 people admitted to a hospital with somewhere between a mild and severe brain injury. That 7 to 800 do not capture people who never went to the ER and were released. Only the ones admitted to the hospital.

Tim Flynn: What happens when they're released?

Casey Crothers: Some family members pick up the slack, in some cases, people that have some cognitive problems and behavioral problems are being housed you know, fall into troubles with the laws they previously did not have. They're doing a tracking system on people with potential TBI's at the ACI and getting the results they expected from it. Some people are going to travelers, different things are happening. Some of them are more unfortunate than what we'd like and sometimes families do what they have to do even though it's quite a burden to assist the person.

Female Speaker: That's a good point because a lot of people are ending up in nursing homes which are very inappropriate placements but it's the only thing that's out there. That's really an inappropriate placement there should be more opportunities for people. There are people homeless without any services. So there are several people falling through the cracks.

Tim Flynn: Thank you very much for your comments. Does anybody else want a chance to speak? Well, I mean I would like to -- I think we advertise that we're going to be here from 4 to6. So I think we all have to stick around until 6 o'clock in case anyone comes in. I would like to thank you all for coming and voicing your opinions.

Communication Access Visual

Female Speaker: Can I ask a question? There were a number of issues that were taken up last year and news line is one that federation members followed.

Tim Flynn: I beg your pardon. I forgot to have you state your name.

Female Speaker: This is quite fascinating. Blind and deaf we're having a great time. (Laughter).

Legisilation

Almas Kalafian: My name is Almas Kalafian. I am a retired school teacher I love community work. I recently joined the Federation of the Blind a few months ago and they were very committed to helping Mr. Cooper with the news line legislation. Are there other kinds of legislation that did get passed this year? Since we have a little time, what were they and what were the steps taken after legislative committee evaluates or goes through the different areas around the state and finding what may be valuable to pursue what happened next? And how hard was it? News line did go through its struggles and we were very surprised because it seemed like it was a no brainer piece of cake we weren't asking for any money, but it was still very difficult for Mr. Cooper to get this passed in the 11th hour. So I’m listening around this room and I’m glad I came to hear all of these sorts of problems like if news line is a problem, what be done with brain injury situations and other situations we hear about in this room. After legislation and the committee looks at things what happens next?

Arthur Plitt: The process is that the committee meets generally once a month, sometimes a couple of times a month, depending on the legislation. There are people that go up to the State House to lobby. There are requests for people to write or call their legislators in regard to particular bills. You are always welcome to come to any of the legislative committee meetings to find out about them, or to talk about a particular agenda.

Tim Flynn: If you can log on to the Governor’s Commission on Disabilities website it's very good about tracking where recent legislation is. And there are hearings held. People testify at hearings. There's nothing better than having someone in the front of the room who is enduring the problem. It's very powerful in convincing legislatures for support. Then I think it's about lobbying and finding out who the committee members are that the legislature is working with. Find out who the committee members are, where they're located and then you try to encourage people in those areas to contact their legislators. And knock on their doors. The squeaky wheel gets the oil in legislation. Nothing happens if no one sort of squawks about it.

Almas Kalafian: Are other agencies, organizations around the state, do they network, do they you know, attach themselves?

Tim Flynn: There are representatives, probably 10 different agencies that are represented so they provide their resources, we're appropriate on appropriate bills and I'm not going totalk about someone who's blind because I don't understand the various issues. But you know where it's appropriate. But there is a lot of lobbying that happens of course. Does that answer your question?

Almas Kalafian: Yes.

Tim Flynn: Anybody else?

Communication Access Oral

Nancy Fuller: Nancy Fuller Again. I'm curious how many of the panelists have experienced getting interpreters before? Have you had the experience of getting an interpreter? A show of hands if possible. Very good. A lot of times many agencies aren't even aware of how to go about getting an interpreter. It is about having the opportunity to educate people maybe having a one-stop. I have Joanne from the commission for the deaf and hard-of-hearing. She's taking down information. Any state agency really, not just state agencies, we're trying to expand our work in outreach and get the word out. CDHH has allowed many times to get the word out to all organizations, agencies business entities in Rhode Island. That's the place, the Commission for the Deaf and Hard of Hearing that's the one stop for interpreters.

Arthur Plitt: Just a comment. Can you hear me? I'm Arthur Plitt from the Governor's Commission on Disabilities. I just wanted to mention in regard to some of the comments that were made, with all the talk about security, home land security, terror, whatever, there has been a great effort on the part of the Commission to make sure that the announcements from the Governor's Office to emergency preparedness, do have that interpreter status and that it's not let's say hidden so that somebody who is looking at the television, they can see the interpreter on the screen. There have been instances in the past where you know there's a problem, but if you're deaf, you don't know. Again, it's because of people who speak out. Not a legislative issue, but sometimes that's a need to talk to the agency to keep pushing.

Nancy Fuller: Another concern again we have on a daily basis, business hours 8:30 to 4. What about overnights and weekends. Someone would go into the hospital, and imagine at 3 a.m. the office is closed for business hours. Where is the access to your doctor? It could be a life and death situation. It's a very life threatening situation. When there's emergency times non business hours overnight make sure the Governor's office is aware of that maybe the Governor's Commission on Disabilities I know has worked with CDHH to try to bring information forth, but it's good actually to legal liability and law schools.

Tim Flynn: I am not familiar right now with the process that happens. I think that you've made an excellent suggestion and for those people who need it if there's someone on call, I don't know how it works. You're on the record. The committee will then take your statements and make a recommendation. I think we're sort of trying to say things. Why don't we break for 15 minutes and see if anybody else comes and then you know, if anybody does come in we'll reconvene. But I wanted to thank everyone for coming and follow-up on the website.

Tim Flynn: Ladies and gentlemen I want to thank everybody for coming. I think that we can all adjourn. I want to thank everybody for coming and thanks for joining us.

July 28, 2004. Warwick Public Library

Lorna: I would like to get started. If people would like to have a seat. I would like to welcome you all today to the public forum. This is provided by the Governor's Commission on Disability with assistance from many sponsoring agencies. The generosity of a lot of organizations and human service agencies have helped to make this possible. Some of them are right in the room. Give them a hand, in particularly the governor's commission for making this possible (applause).I would like to introduce myself. Notice it's on my card a lot of times I do forget.

Lorna Ricci from the ocean state center for independent living and I'm the hostess. I will be keeping things moving along before we go any further there's a couple of things, I just want to make sure happen so when we get to the point of testimony we are ready to go. Has everyone in the room signed up as just being here, just attendance sheet? If you haven't, could you raise your hand? We have someone in red, lady in red. If someone could maybe bring -- great, a sign-in sheet to her has anybody who wishes to testify, have you signed up to testify? If you haven't, raise your hand. If you changed your mind and now you want to, raise your hand. That's okay too. And I should add if -- for those who are here to observe, if you hear something that really strikes something in your heart, you are passionate about as well, it's never too late to sign up to testify and just go to the back and you will go to the bottom of the list and you can then at the end basically say you agree with an earlier testimony and maybe add a few words as to why you agree. So that's perfectly fine also I just want you to know that coffee and refreshments, should you begin to get a little sleepy eyed, is available around the corner to the left. You passed a coffee shop for purchase and you are able to bring your coffee back to the room, just be careful. You are able to bring it back to your seat .rest rooms as you go out to the -- out the doors that you came in, you take a right and they're right there I would like to go over the purpose of today's meeting. The purpose of these forums is to identify the concerns of people with disabilities and their families in order to assist the state to develop programs to improve the quality of life of persons with disabilities. All testimony today is being recorded by a court reporter. This testimony will be up on-line for your review in about a week. If you go to the Governor’s Commission on Disabilities website and that is in the printed material that you had in front of you so you don't have to scribble it down quick, but it is gcd@state-- gcd.state.ri.us. It's in the printed material should you forget what I said members of the people that have been the sponsoring agencies as well as other interested citizens are welcome to review the testimony. The testimony recommendations based from that testimony3 as well as the testimony itself that is in print will go to all the legislators after today's meeting. They get that in a couple of months. So basically just so you will know, anything that is said today as well as testimony from about five other forums that are taking place this week will be on the desks of legislators to review it could be this time next year something that was brought up at one of our meetings has now become a new policy in the state. You never know what's going to leave from your testimony today. It's very, very important the meeting process. First of all you did need to sign up as you came in. We are going to try to have time for everyone to speak the panel is here to listen. We have some very important people here that are listening to your testimony. But they really are truly hereto listen and only clarify should you -- ask for clarification if there's some testimony, some wording that you used that's unclear such as maybe you used initials or acronyms. The panel may ask you to please, what does that stand for. That kind of thing. Or if something is a little confusing, they may ask you to restate what ever you had said so it's a little clearer we will be speaking in order as you signed up. There's quite a few here to testify. About how many are testifying?

Speaker: We have eight now.

Lorna: Eight. That's not too many. We probably have about ten minutes, no more than ten minutes. And I’m going to be kind of the keeper of time. So if you do begin to go longer than ten minutes, I may rudely interrupt you. Please laugh, I didn't mean to say that I will have to say that we need to wrap up to move on to give someone else a chance the last thing I ask you to do is before anything you say -- I’m going to ask you to come up to the table. We do have this roaming mic should you wish to stay at your seat if it's more convenient. We will definitely be able to accommodate you. I ask you state your full name and the city and town in which you live. Remember this testimony is going to be in writing and your legislators are always looking for the constituents that live in their towns and cities, so it's very important that you do name where you are from I would like to introduce now the very distinguished panel. At the far right we have Kathy Mckeon. Give a wave, Kathy. Just incase I get people wrong, make sure I’m listing them right here Margaret Hoye is from the State

Rehab Advisory Council. Domenic Diorio is also from the State Rehab Advisory Council. Ann Leclerc is representing the Rhode Island Public Transit Authority here today Ray Bandusky from the Rhode Island Disability Law Center. Nicole Rossi is from the State Wide Independent Living Council. Michael Spoerri is from the Rhode Island Department of Health. Kristen Connors is here representing Langevin's office. I hope you all saw him last night on TV. And Suzanne Eleoff is from the Ocean State Center for Independent Living or OSCIL. She is here as our I nr specialist I would like to take a minute to thank our interpreters, Chris West and Jon Henry for their service this evening, and Jen Moore from Allied Court Reporting also there's a few distinguished people I would like to recognize if you could stand. Curtis James from the Commission on the Deaf and Hard of Hearing, and Steve Florio the Executive Director for the Commission on the Deaf and Hard of Hearing. Dianne Kayala is from the Department of Human Services -- gave you a new title, sorry. Gwen Reeve is from the Multiple Sclerosis Society, Gwen, and finally a person I really love and adore, Eileen Naughton, Representative Eileen Naughton is here with her grandson. Thank you for coming. Is there anyone else?

Speaker: Suzanne Shapiro.

Lorna: I jumped right over Sue Shapiro. She is here from the Office of Rehab Services and also from Youth Leadership Forum if you want to grab her later from information on that I think it's time we get right to our testimony. If I could have the list. There she is the first person to testify will be Darlene Hartmayer.

Darlene Hartmayer: We like to be visible. My name is Darlene Hartmayer. I live in Providence. As you can tell I use a service animal as well as a wheelchair now. I had a couple of issues that I wanted to –

Lorna: You need to talk more into the mic. A little louder

Health Care: Medicaid

Darlene Hartmayer: Okay. Being nervous doesn't help. I wanted to talk about three issues. One is I'm a Medicaid recipient and I will say it out loud. I needed a machine that cost $100 and they're renting it for$56.51 a month. That is five times the price of the machine. My tax dollars are going to that too. And then they told me that since my doctor didn't fill out a, form, I can't have the machine. I think my dollars deserve a better chance than that my daughter wound up in a manual wheelchair. It's costing the state $123 a month for a wheelchair that costs $350 to buy. And she's going to be in it for about six months, so we will have paid for the wheelchair twice over now I'm not saying that we should buy everything, but somehow or other we need to look at our rental and our actual price versus this is a waste of money, a big waste of money. If I can rent a machine, buy a machine for $100 which is going to stretch my limits but I'm going to buy it and the state will rent it for $56.51 a month for ten months, before they will give it to me. Five other people could have used the machine. That was one issue

Accessibility Assistive Animals

I have a service animal. There is no provision for anyone to help me with my service animal. If I am living just on SSI, I can't afford its vet bills unless I want to give up food or lights or gas or rent. I'm not asking for a big supplement. But a little help with her vet bills would be nice. Not all of us get our animals from agencies. My dog is self-trained. And she does a very good job she's been my best friend for a long time but my legs for three years. I knew I was going to be in a wheelchair 11 years ago. I tried to prepare myself for that. It's a little hard when you are going to go get a ramp and you are told because you don't need nursing home level care you can't have one. That was what Medicaid told me when I asked for a medical waiver. I don't need nursing home level care so I don't need any of the things to help me be independent what is the point of having -- saying we want people to be independent if we are not going to provide them with the tools so that they can be independent.

Housing: Safe and Affordable

OSCIL provided the ramp. I sort of resent the fact that OSCIL had to pay for it, but I'm so grateful that they did I was told I couldn't have a lift chair because I can still actually get out of a chair and walk. The point is I would like to stay as mobile as possible. And I would like to stay in my own home my landlord has been very gracious. He's allowed me to make some adaptations in the home and allowed me to have a handicapped ramp on the apartment building we need to make sure that people are not being locked up in their houses because they don't need nursing home level care because eventually they will need nursing home level care if for nothing else but depression. It is depressing to sit in a room all day long. I don't want to go to a nursing home. So I'm doing everything in my power to keep myself agile, mobile, my mind awake and alert. I do volunteer work but I need to -- I need to know that if I want to be independent, somebody's going to help me be independent and shouldn't have to beg for that. I don't think anyone should have to beg for that those are just the issues that bother me. I mean, affordable housing is another issue. But hey, that's an issue every where. It should be an issue in our state as well but I can't talk to that. I actually live in an affordable housing unit but my dog; she means a lot of to me.

Transportation RIPTA I have to give RIPTA credit because now that I'm in a wheelchair and I have to use the dog, they actually did bring a bus near my home and help me figure out a way to get myself on and off the bus with the dog. I thought that was really a very special thing to do for me because it's -- she's never had to get on the back of a bus before. For that matter, it was a new thing for me too I haven't tried it yet. I'm a little bit of a coward. But I am going to do it.

Transportation RIde Because I can't afford the RIde van all the time either. There's just, you know, it just doesn't come into my budget I guess that's what I wanted to say today. I'm still nervous, but I think I got it all out thank you.

Lorna: Thank you. You did a great job.

Darlene Hartmayer: Up Angel.

Lorna: Next --audience member: excuse me. I have a wheelchair. I can give you if you want one.

Speaker: Actually we are in the process of finalizing getting this one. Of course, there is one thing you should know. They are requiring my doctor four times to rewrite the prescription for the wheelchair that I'm in. Because and they keep denying it because he doesn't write it right.

Lorna: Maybe you need to talk to each other after the forum. You two connect next we would like to hear from Rhonda O'Donnell – Rhonda O'Donnell.

Rhonda O'Donnell: Hi. My name is Rhonda O'Donnell from Warwick, Rhode Island. I actually live right over here past citizens off Strawberryfield Road. And I have three different issues. I will hog the microphone a little bit the first one and I don't really know who to address this to hopefully somebody here can address this issue. It's about clustering. If there can -- any studies because just on a personal note, in the area that I live in, the year that my son graduated sixth grade, so you are talking 50 kids. We have since had five parents of those children diagnosed with multiple sclerosis. I have Multiple Sclerosis by the way, I forgot to say that. And five of us out of 50. Now that's 10 percent. That's to me off the charts. Is something in the neighborhoods, something being near the airport, something being where the dump used to be, something being near the area where they had to rope it off and do -- I believe a superfund behind Leesona used to be. That's the area I live in. Don't know any or all of the above questions. I just find that unbelievable that five out of 50 kids would have parents who come down with multiple sclerosis. Also a teacher in that elementary school they went to and another parent of the child who was a couple years ahead of them. All of -- all I know of there's seven. There's probably more that I don't know of. That's an issue that I just kind of want to put out there. Hopefully maybe somebody can take that ball and run with it. To me, there's an issue there. Some kind of clustering.

Transportation RIde Second thing I want to address is the bus route and there's a RIPTA person here. I don't happen to need it. I'm still able to drive. But I have a friend who -- her leg is very affected and can't drive. She lives in Coventry. And I guess the rule for the RIde program is you have to live within three quarters of a mile of a bus stop, which she does not. I don't know exactly how far she would have to get in her car, drive to the bus stop to get the bus, which is dangerous because her right leg is affected. So for her to drive from her home to the bus stop, she would be taking her and other people's lives at hand to get to where the bus could pick her up so she could be mobile and get to events, doctors appointments, stores, whatever that RIde gives rides to again that doesn't individually affect me, but I do know people through the m s. Community that it does affect also I am an MS self-help group leader, so I do know a lot of individual personal stories.

Housing: Safe and Affordable And in my group alone, some of the people I know have housing issues. So I'm just -- I just want to speak to the fact that we do need more. I know we do have some. But we do need accessible and affordable housing I have several people just this week going through, okay, I'm trying to tell them the steps you have to get the applications in Warwick housing. Then there's the federally funded ones at Sparrow's. I don't really know all the ins and outs. But I tell them as best I can what they need to do to get the ball rolling and one gentleman that's in my self-help group, he is a young man. He's in his 30s. He he's the father of two young children, lives on the third floor apartment. And if any of you have seen people walk, I walk with my walker. My legs are pretty affected and he is maybe a little bit behind. He's not as severe as me but has a lot of problems. I can't even imagine walking up three flights of stairs every time you need to go in and out of your apartment, with little kids, getting them to the bus or to school. He has been having a problem finding housing so I just kind of want to hammer home the point that we do definitely need more accessible and affordable housing for people with disabilities. And those are my issues. Thank you.

Lorna: Thank you very much for your testimony. Tyra Mongasarian. I killed your last name. Tyra.

Family Support Financial

Tyra Mongasarian: Hi. I just have my name is Tyra Mongasarian. I'm from Warwick, Rhode Island. And my concern basically, I'm newly diagnosed as of March, March 23rd, with MS. My concern is this just happened all of a sudden. And I guess I'm just concerned. I just my parents are involved. Not just you anymore, it's that your family is involved just as much as you are when you have a disability. It's not just you. It's a concern. It's everyone around you, your friends or loved ones my concern is they're helping me not only financially but with a lot of other things. And I get depressed and angry and mad and whatever have you. I have an IRA and I cannot get on SSI or I can't have welfare because I have money that I put away that I am just concerned because I saved money that I want for social security one day when maybe I won't have any. I have to take it out, I believe, to help myself, which if I can't get a job later on or my limitations are, that I can't see as well because I have problems seeing and I have a walker and certain things. Sometimes it gets better my concern is what happens if I can't to my best ability have a job to be able to afford to do things. And whatever I have put away to save I have to go into. Then what can I do?

Transportation RIPTA

What -- I applied for the RIPTA bus services. I'm not driving at this moment. I can't get to and from some of my appointments. I have to call and cancel them. And I'm embarrassed to say I don't have a RIde there. Family members, obviously, they work. They have a job. And again, RIPTA is great but I sometimes I can't get there because I need transportation to get there also. I guess there's medication that's very costly for MS.

Health Care Insurance

Patients, insurance. I have COBRA right now. It will probably last me for I don't know how much longer. But with that I can't have a disability there's different things I'm concerned with. I don't have answers for. This is just brand new to me. I'm just -- I don't know what --I just need some answers and help on what I can and could do. I guess that's basically all I thank you.

Lorna: Thank you so much. I would like to announce that we have another panelist who has joined us. Sharon Brinkworth from the Brain Injury Association of Rhode Island. Sharon is here and also there's assistive living listening devices. The Governor's Commission on Disability has just brought them. They're available for people if you would like to try one out even or use it to help you hear better assistive listening, yes next is Lori Gardner. Before I asked for Lori's testimony, I didn't want to mention or perhaps after this meeting, Ann Leclerc from RIPTA may want to speak with this young lady on some of the services and talk further about the RIPTA buses and the flex service perhaps. Please, if there's anyone from the panel that wishes clarification, you don't have a mike. We are down to two here. But please give a hi sign as we have testimony. If you do have things to say, please -- I may be controlling the mike but not all the words, how's that? Lori.

Health Care CEDARR

Lori Gardiner: Hi. I am Lori Gardiner. I have a five-year old son that has Down syndrome. I'm having safety concerns with my child. He is very strong and very active. I've gone through the CEDARR {**C**omprehensive **E**valuation, **D**iagnosis, **R**eferral and **R**e-evaluation and supports and services} program trying to find somebody to give me some kind of help to safety proof my house; try to teach him about the dangers of running out into the road. He's a fence climber. He's five years old. I have a foot five chain-link fence that he can get over. And he has fallen into my neighbor's pool. Luckily she had the cover on the pool. And he went to his chest, not over his head, got himself to the side and somebody pulled him out he needs constant supervision and it's very, very tiring to have to be watching him 24 hours a day. But what happened to me was when I called CEDARR looking for help, I got started with Easter Seals CEDARR and I was with him for several months and unexpectedly they just went out of business. No reason given. They just closed up and my case was transferred to Solutions CEDARR, who took over and came out to go back a little bit, what happened when I signed up with solution CEDARR, I'm a working mom. I made an appointment for them to come out after I got out of work when I got out of work, there was two messages on my machine from the lady from cedar saying that two hours before my appointment and one hour before my appointment that it was required an hour's notice -- I know to confirm the appointment so that they weren't showing up uselessly to my house when I made the appointment, I specified that I get home at 2:20and I could have an appointment at 2:30. I was never told of that policy. So she didn't come out to my house. She said she was sorry but she couldn't get a hold of me to confirm the appointment. I could call if I had any questions but she was going to be going out of town for a few days so, when I got home it was very upsetting to me not having been told that policy, I felt like she was going on vacation and she just didn't want to keep my appointment. So, she made up this story about there having to be an hour's confirmation before your appointment so I let it go and it really made me angry. And then it got to the point where after the pool incident, I felt I really needed to get help from somebody because I'm so concerned for my son. So, I called back and complained about the issue that happened. And they said we don't have that policy. That's not true. So, here I am looking for help for my child and I felt like I was lied to.

Health Care CASSP

They sent two other people out that have been out three or four times. And I had heard of a program called CASSP through another parent. And she had gone to a seminar they gave at a local school district and it was led to believe that they may help with funding for the cost of a fence around your property. She lives on a lake me, I have the concern with my son falling in the neighbor's pool so I tried to go through them. And the one that she had given me, the name didn't service my district.

Family Support Financial

She gave me a sister service and they told me that they're not a financial lending institution, that they're not just here to hand out money. She didn't know of anyone that could help me so I feel like there's supposed to be all these programs out there to help you but I'm -- I feel like I'm not getting any help from anybody. My son is covered under the Katie Becket waiver by the way but CEDARR has been coming out to the house. And several weeks ago after maybe four visits, they came to my house and said they recommended I put a stockade fence with the bad side facing the neighbor's property so that the smooth side was facing in my yard and my son would not be able to climb over the fence so that -- he could not fall into the pool again. I told them I felt at this time we had -- we were having financial it's a little tight right now. And we felt like we couldn't afford to put the fence up. And I felt like I was made to feel guilty that -- how would I feel, he said to me if your son fell into the neighbor's pool and drowned. Why didn't you why can't you put it on a credit card, the price of a fence. And I feel guilt enough without, you know, getting that type of comment made to me. He also said that he would like me to know that because sometimes when people are depressed they feel like they can't make a decision. And it could look to somebody on the outside as if I'm neglecting my child. And that was very upsetting to me. I have gotten shoe tags for my child that says Down syndrome and our phone number because he has been lost several times because he's a wanderer. I have an id bracelet for him. I got slide locks on all my doors. But my concern is that he's getting taller and pretty soon he will be able to open them so, I feel like I need help and I haven't been able to get any and when I hear the lady that speaks about all the rental fees and all that wasted money, I feel like there's got to be a better way to get money to some of these other services so that we can get help for our children. That's why I wanted to tell my story today and I thank you for your time

.Lorna: Thank you, Lori. Any questions for Lori? Next is Pam Doucehe. Pam, do you want me to bring the mic to you?

Health Care Rehabilitation

Pam Doucehe: I want this -- I brought this pad so I wouldn't forget what I was talking about. I had a brain aneurysm at work and my life was completely -- went completely downhill. Good job, benefit pay, and friends gone. I am so grateful the brain association is here to show support and help me and so many other survivors. The BIA of Rhode Island is a nonprofit and I want so much to help feel useful, not useless. I do volunteer work from time to time. I because talking about a bill a bill serves for the survivors of traumatic brain injury who as of now have a hard getting what is needed. We feel empty, useless, and depressed. Lack of anything to do or go where we can't be of some use to mingle with others and feel a sense of purpose. I am looking forward in my lifetime for a center that the elderly have, a place we can go, relearn and be with people who can help us help ourselves. There are many states that have approved money from speeding fines for the BIA. The scope of our problem is for beyond what most are aware of allow me to share some statistics about brain injury. One is a leading cause of death and disability among children and young adults until the age of 45. Number two, TBI claims more than 56,000 lives annually. Three, estimated 6 million Americans more than 2 percent have disability resulting from brain injury. Four, each day 5500 individuals abstain a brain injury and saving lives is not enough of a reason for increase funding saving the tax payer's money should be. Thank you.

Lorna: Thank you. Thank you very much for your testimony. Sharon Terzian.

Sharon Terzian: My name is Sharon Terzian. I'm from Warwick. I'm the I’m also web mistress at the Sherlock Center of Disabilities and I run a number of websites, some other things Sherlock Center is involved. I also have a child with disabilities and I have two very different things to speak about.

Health Care CEDARR

The first thing is the CEDARR's Program. I actually helped write the CEDARR’s policy a long time ago. And I agreed to be a guinea pig about a year ago and happen to come out even though my apple cart was all mine and I didn't need anything from what I have seen, I’m dealing with I think its family solutions on Thurbers Avenue. I feel that it's a huge waste of my tax payer dollars. And I’m really sorry to say that because as a parent and being involved with the policy on that, we really had high hopes for the program. They came out several times and spent a lot of hours at my house picking my brain about everything known to mankind about my child, and I do understand the need for that.

Family Support Respite Care

But, you know, a whole hour spent on doing my family tree at one point they came out once and they wanted to speak to my husband because he was such a high incidence of divorce among disability families. It was just way too intrusive considering all I wanted was two hours of respite a week now I’m on what's called maintenance. They come out every six months. And to be honest with you, they ask me what's going on in the state because I know more than they do. It's just been very, very disappointing experience for me. I know what they charge only because of where I work. And I just consider a huge waste of my tax payer dollars. They really need to actually be able to offer you some help not just write a book about you.

Communication Access Internet

The other thing I wanted to speak about is being a web mistress and running a number of websites. I'm really kind of dissuade at the lack of ADA compatibility in the websites that run within the state the last time I checked, I do believe that the governor's disability council website wasn't even fully ADA compliant and that concerns me as a web mistress at the Sherlock Center, I’m very sure ours passes and the graphic site. Since the rules just changed again, I have been in the middle of changing the site again at least have a text only option for people who can't see websites. And most of the websites for the state, if not all of them, do not have text only and are not ADA compatible people with disabilities really do need that kind of stuff. It may be a really small minority, like I rip my hair out how many people go to the trouble for this. But it's just got to be done it's actually the law. That's all I have to say yes, ma'am?

Lorna: I'm sorry. Your name again? Sharon. I know this is your opportunity to present -- Thank you.

Kathy: Thank you, Sharon. I'm Kathy McKeon from Elderly Affairs. I know this is your opportunity to present to us. But if I could get your name and phone number before you leave, we are working on a website development right now for an Aging and Disability Resource Center. And you could provide some great information. Thank you.

Sharon Terzian: Just call me at the Sherlock Center.

Lorna: Thank you. Next is Ed Glevay. Ed would you like me to come to you?

Housing: Safe and Affordable

Ed Glevay: Yes, please. My name is Ed Glevay. I won't take up a whole lot of your time. I have two gripes and one -- I would like to say OSCIL does one hell of a good job but my gripes are with the city of Warwick. When I applied to them to put a ramp in, handicapped ramp in, they shot me down by about 6 feet, I guess. I would lose my front door so I could get out of my house. I barely fit through it. OSCIL is the ones who put it in for me another gripe I got is with the Governor's Handicapped Commission. I spoke to two different people with them and I got lip service. All kind of promises, but nothing ever happened. And it really aggravated me the biggest complaint is with the city. You got to get these people on the ball when somebody applies to get a ramp put in. Make sure it's big enough to go in. They said well, the house is too close to the street. And I wanted to tell the mayor my house was there long before the street was. When that street went in, it was cull path. And then they widened the street and of course, it got closer to the house. So that cut down on the size of my ramp, supposedly. I only hope our honorable mayor who never has to use one of these scooters or any thing to get out of his house in a ramp because I hope it's about 14 inches narrower than what his scooter is. And let him see how much fun it's going to be for him to get out.

Lorna: thank you, Ed. Gwen Reeve.

Housing: Safe and Affordable

Gwen Reeve: Hi. I'm Gwen Reeve. I live in Bristol, Rhode Island and I am the program director for National MS Society here in Warwick. And I just want to share with you a few things that continually come to my attention from members who call us at the MS society. We have about 1700 registered members, people that have MS. There are several more people in the state that have MS. that aren't registered with us and typically the problems that they call in for have to do with affordable and available housing, which you heard about already.

Family Support Respite Care

We also get lots of calls about respite care, the lack of respite care, the lack of affordable home care, not having enough money to pay for that, for their families another big issue that we frequently hear is the problem medical coverage during that waiting period when they're applying for side and even when they are perhaps granted a disability, it takes two years before Medicare kicks in. And it's very, very difficult for them to pay for medical coverage.

Health Care Prescriptions

I don't know how many of you are aware that most of the disease modifying drugs for m s. Cost $15,000 a year, and that's one medication. The average numbers of medications people are on are about 12 if they have MS. So it's very, very expensive. The last thing I wanted to mention is this year we proposed a bill that was sponsored by Sue Stormily to have MS. injectable drugs as well as drugs that treat MS included in our pharmaceutical assistance plan, RIPAE. And it never got out of the state. We are discouraged by that we are the only state in the United States where MS. Drugs are not covered on the pharmaceutical assistance plan. And I think it's time that people start looking at that instead of maybe lumping the drugs that are available based on diseases, drugs that treat certain diseases to open it up a little bit more. I would really like to see that pass this year where people who have MS And need assistance can get that through the pharmaceutical assistance plan. Those are the big concerns I have and many of our people have Thank you.

Lorna: Thank you Gwen. Bonnie Abols. Bonnie.

Communication Access Oral

Bonnie Abols: Good afternoon. My name is Bonnie Abols. I'm from West Warwick. I work for OSCIL, Ocean State Center for Independent Living. Thank you for having this forum today. Why did I come up here? I'm just going to make it really brief here. One of the topics I'm concerned about are police incidences and related with the deafness that is going on. Often I worked with some deaf consumers who have come to me and with many different issues concerning the police officers. For example, one person was arrested and they did not provide an interpreter when he was put into the prison there. They he was forced to sign a contract. He wasn't sure about his they didn't even concern about his reading level or whether he understood his rights or anything like that. He did not know what was going on and was not aware about the situation, and I worked with him on many occasions. I really hope we are available to provide some training for the police so they could learn how to communicate properly with the deaf and hard of hearing and really learn about the deaf person's rights and getting an interpreter and really the priority in communication with them. And that's really all I wanted to say. So thank you for listening to me today.

Lorna: Thank you, Bonnie. The last one I have signed up to testify is Jeanne Fay. If there's anyone else who wishes to testify, something that has been said today that you agree with or has spurred other ideas, if you would like to sign up, it's not too late. Jeanne Fay.

Housing: Independent Living

Jeanne Fay: Good afternoon. I'm the mother of a very lovely young woman who has developmental disability. About five years ago, I began working in the field of human services. And I was surprised and delighted to learn about the endless possibilities that existed for her future. Thanks to the supports provided by agencies which are funded by the MHRH, specifically division of developmental disabilities. It seemed possible that she might live, work, and socialize in the community with the appropriate support services that are needed to keep her safe a couple of years ago, however, representatives from the division began to tell parents that their sons and daughters may need to live at home rather than in apartments or group homes. I suppose that this was due to the high cost of services, and I could certainly understand this. I altered my expectations, began to think about purchasing a duplex or a home with an in-law apartment so that she and a roommate or possibly a husband could live with me and still have some degree of independence. I expected, however, that the division would provide a day program as well as some additional hours of staff times that my daughter could work and participate in community activities. Lately, however, I heard that there's a waiting list for these services. I have spoken to one mother whose daughter graduated from high school and then had nowhere to go. She was a single mother with no family support. And she faced the choice of quitting her job or leaving her daughter at home alone while she worked. I do not want on find myself in this position a year from now. Although I'm not a single parent, I am the primary breadwinner because my husband works part-time in order to be there when my daughter arrives home from school at 2:30.unlike many families, we have never had two full-time incomes due to my daughter's needs. We certainly love our daughter.

Family Support Financial

And we don’t want to wish and we don't wish to burn the state of Rhode Island with our parental responsibilities, but we are going to need some support. We will need to know that our daughter will have somewhere to go during the day, that she will be safe, and that we can continue to work and support ourselves and our family we hope that the legislature will understand that cuts in the MHRH budget are hurting and will continue to hurt families and young adults with disabilities.

Lorna: Thank you, Jeanne, Elsie Lane. Elsie.

Health Care Prescriptions

Elsie Lane: I just want to make -- I agree with Rhonda with the clustering of MS Patients in our area. And also with Gwen with prescription for. You first get MS. And your prescription plan doesn’t cover it. You have to call around to call pharmaceutical companies yourself. And if every other state has this -- I don’t know why the state of Rhode Island -- because it's very -- that medication is very expensive. Thank you.

Lorna: Thank you, Elsie. Is there anyone else that wishes to testify? Susan:

Susan: I have a question. Could you state what neighborhood this is with the MS Clustering?

Elsie Lane: Strawberry Hill Road.

Rhonda O’Donnell: Right off Strawberry Field Road, Lippitt School area.

Lorna: Lippitt school area. Strawberry Field Road and Lippitt School. And that question was directed at the testimony via the lady talking about clustering.

Rhonda O’Donnell: My name is Rhonda O’Donnell. 10 percent of kids' parents developed -- sorry. I said it in my testimony. I wanted to reiterate there was 10 percent of that one particular class. And to me that seems off the charts. 50 kids and five of us went on to develop MS. Also a teacher in the school who doesn’t have a child there. That makes six. And then there's a parent of a daughter a girl who was a few years ahead of them, so that makes seven that I know of. It's just amazing. Again that is the area where there's a superfund site. They are cleaning behind Leesona. There used to be a dump back there. Who knows. And we are very close to the airport. I don't know. We don’t have the answers, but I’m just curious. I think it's off the charts. I just wanted to –

Lorna: What district is that?

Rhonda O’Donnell: You got me? I know ward three.

Lorna: Ward three.

Rhonda O’Donnell: I don't know about district.

Lorna: You need to say who you are.

Gwen Reeve: I am Gwen Reeve. To put some perspective on that number, the national prevalence is 1 in 1,000. So clearly what Rhonda is saying is accurate. 10 percent is a lot higher than what we would expect to see. Thank you.

Lorna: Thank you. Any questions from our panel? A comment.

Family Support Resource Directory

Charles Pollock: I have a comment. My name is Charles Pollock. I'm a member of RICAT. And I have observed the questions that have been asked. And looking at all the questions, is there one number in the state that can be called that can direct the people in certain directions to go into, to get answers for these questions they are asking this was my problem when I got hit by a car. I came out of it and my wife, my children had to go out and investigate and find out where they could send me, where I could go, where I can get this, where I can get that, where they can put a ramp -- get into the house, a ramp for inside the house. There was no one that we could call that would give us the answers or the direction of to where to find specific people that will give us the answers all I want to know is there anyone in the state or is there any group in the state that you can call that will give you the answers to any of the questions that were asked tonight. Thank you.

Lorna: Thank you. I have another person that's asked to testify. Linda Chicoine, Linda.

Housing: Safe and Affordable

Linda Chicoine: My name is Linda Bradley Chicoine. I'm an occupational therapy assistant and I work for OSCIL as the home access coordinator. I just would like to take a few minutes to speak about the importance of home modifications. I work with consumers who want to remain living as independently as possible. And they want to stay in their current dwelling. I provide assessments of their abilities and their needs. And I seek solutions to solve the problems that are barriers to their independence. These might be simple things such as adaptive equipment, grab bars, railings, or we might do bathroom modifications, kitchen modification .these people do not have the resources to pay for these modifications. We need to keep the funding for our home modification program so we can keep these people in the dwelling that they choose to live in. The options for moving into affordable, accessible housing is very limited. And we want to be able to let people choose where they are going to live and how they are going to live any of us could experience a disability through an illness, an injury, or just normal aging. This disability becomes a handicap when we encounter a barrier in our environment. So I want everybody when you go home tonight to notice the steps that you may have to go up into your house and say to yourself, boy, if I was in a wheelchair, could I get into my house? Measure your doorways in your home. If they are less than 32 inches wide and if you were in a standard wheelchair, you couldn't get through. Can you imagine not being able to take a shower or have to use a commode because you couldn't get into your bathroom now do you want to move? You need a home modification. Don't cut our funding.

Lorna: Thank you, Linda. Is there anyone else that wishes to testify? Back again.

Charles Pollock: I have another fact that the disability people can take unhand because there are 24.6 percent of you people in the state of Rhode Island. And if everybody votes for the people that do work for them, the politicians, then it will have an effect. So believe me, there are 24.6 percent of us out there to make a difference. So if we want, vote. It will work. Believe me. Somebody will look for us if we have that much percentage. Thank you.

Lorna: Charlie, that was a nice segue. I just so happen to have a voter registration form. If you are not registered to vote, you can fill out this form, mail it to the address right on here, or give it to the person in the back. OSCIL is a voter registration agency. Leslie, give a hi sign. You can give it to Leslie. And if you have any problem filling this out today, it's very simple. Name, address, basically four or five questions. It's just the bottom part of this. You can fill this out. If you need any assistance, Leslie can help you. She will put a stamp on it. She will mail it out to the registration address on the back, and you become a registered voter you can actually vote and in this November's election and this is a biggy. If you are not a registered voter, Charlie said it beautifully. If we want anything to change in the state, in Rhode Island, in America, this is where it starts. We need to be voters. People with disability have got to get out and vote. So anyway, just so happen to have this. If you would like to complete it today, if this is completed before -- where's our legislator? I believe it's August 15th?

Speaker: It's earlier than that.

Lorna: It has to be soon

Speaker: For the primary.

Lorna: For the election in November, before August 15, I believe.

Speaker: September 2.

Lorna: September 2. In any case, you have time, but not a lot of time. And please if you are a little timid and want to really read the small print, I encourage that. Take one of these before you leave and right on the back is the address. Stick a stamp on it and you can mail it in yourself. And you will probably get a call from your local representative. I would bet or someone welcome you to --that you are a new voter and welcome you to a wonderful, wonderful activity that you will be able to do in November.

Domenic DiOrio: Lorna, Margaret has a comment

Accessibility Voting

Margaret Hoye: Lorna, would you explain to the audience the new procedure in the voting booth with the new accessibilities for handicapped.

Lorna: Yeah. For those who haven't voted in a while and are used to the machines that you turn, they are no longer there. You are going to be going to a stand, kind of a plastic table. And you have-- actually you have a ballot which is about the shape of this that I'm holding. And you fill in the lines to complete a form one section to another section. I believe it looks like an arrow. You complete it and that's how you are going to vote for the person of your choice I think what Margaret is mentioning is that folks who are visually impaired or blind, you actually can vote independently now you just need to make sure though that you call down to the statehouse -- if you are interested, please let me know. I don't have the number right on the top of my head. You do need to let someone know ahead of time that you are interested in doing it this way. And you can vote independently if you are blind or visually impaired.

Speaker: I also wanted to say the Brain Injury Association; you can register to vote there also. People can register to vote at the Brain Injury Association too. And that's 934 Park Avenue in Cranston.

Lorna: Thank you for saying that if anyone needs assistance you can assist them in that. It's really so simple. It's a shame not to if you are interested in the form, if you need it read to you, please just ask anyone at the back table, could I have a look at the voter registration form and you will see for yourself how simple it will be to be able to register to vote does anyone else -- anyone else a registrar? The Brain Injury Foundation is, OSCIL is, PARI is. If you go home and think about it and you decide you would like to, maybe bring your husband and adult children. That's what I did. I brought all my adult children with me. Make sure they are all registered. Did you have a question? Kathy: thank you,

Lorna: I just wanted to add that I did bring some pocket manuals from the Rhode Island Department of Elderly Affairs with me today. They're here at this table and I will move some in the back. If you know of someone, if you have a neighbor, a parent, an aunt, an uncle, someone who doesn't have a copy, I would appreciate people taking them and passing them around and then lastly, just to mention very quickly that one of the reasons that DEA is so pleased to be cosponsoring these hearings this year is that we are working on a project that the federal government calls an aging and disability resource center project. And in the next couple of years we hope to have a phone number, a website, and a building that does just what this gentleman in the front talked about, gives people a place to get started with their inquiries thank you for your good input today.

Lorna: Thank you, Kathy I have another person who wishes to testify. Shelly Green. Shelly want me to come to you? You can come up to the panel that would probably be easier.

Shelly Green: Good afternoon hello my name is Shelly Green.

Lorna: You have to talk very close.

Shelly Green: Put it in my mouth. My name is Shelly Green and I am a mother, sister, and ex-wife of a brain injured victim. My son and ex-husband are both injured due to automobile accidents. My brother had been born with a brain injury and died at the age of 7. So brain injury has impacted me for over 43 years of my life the last ten years or so I have been it doesn't seem like its working. For the last ten years or so I have been advocating for rights and services of brain injured people. And I do have a written prepared testimony. I'm not going to read the whole thing to you for your sake. But I will leave a copy with each one of you, and do want to point out some things that have really impacted my life and my world my son Todd fell asleep driving home in 1993. He had a car crash and hit a telephone pole. His head and face went through the windshield. The good news was he broke his face and cut it in half the bad news was he was suffering a traumatic brain injury as you know; it's every parent's nightmare you get the knock at 5:00 in the morning on your door to tell you to get to the hospital right away. My son was just home from serving during the gulf war, only home for five weeks in school to be a police officer at the time of his accident. He's now 33 years old. He was 21 at the time of the accident that's part of the problem. Because he was 21, there were little to no services beyond rehabilitation to get him back and living a life that would have some quality for him and as my world as well the pain and lawsuit in my son's traumatic injury was always followed by the fear and the loss of services excuse me. The loss due to the lack of support in services available that I have to tell you is almost as equally as traumatic for me as his injury. It was appalling to me that we could be in a situation and have almost no services if it weren't for the fact that my son was a veteran and was able to get some services from the VA hospital. We had no resources and nowhere to go often when there's a brain injury involved, as many of you may know, there's lots of other dysfunctions beyond the physical impairments that he had. He suffered a lot of depression, frustration, the loss of his ability in life. With a brain injury, there are impairments. You are still very aware of what's happening and it was more than he could deal with at that time, having been so strong and in school to be a police officer. So he would have a lot of psychological setbacks, talked about suicide. And if it wasn't for the fact that he was thinking about suicide, we wouldn't have even been able to get the VA hospital to help us through that experience at the VA hospital, they found a program in Connecticut that worked with people with disabilities.

Housing: Independent Living

It was independent choices for living. And in that we moved him from Rhode Island. Todd lived at home with me for about two years. I took him home at 22 in a wheelchair and diapers. I'm a single mother. I was a teenage mother. And my choices were to put him in a nursing home or bring him home and find a way to take care of him. Having been a sister of a person that was institutionalized and died in an institution, that was far beyond anything I could even comprehend I took him home. Quit my job. No child support. No savings. two children to feed and my son extremely disabled. Thank god I have been blessed. I started a business through that and is doing well and I have been able to support myself the program in Connecticut that I mentioned a little bit ago closed down after Todd had been in the program for only about two years due to lack of funding. That program was two hours away and efforts this was very traumatic for the family. I had to move Todd from his only lifeline at the time that was me. Move him to a program two hours away. Although he was 24 at the time, he was about 13 years old in his abilities and his reasoning. So that was extremely traumatic. I would drive, two, three times a week what ever I could do to see him to provide support because of lack of funding that program no longer exists. Moved Todd back home to Rhode Island. Lived with me again. That wasn't working out for him. He wanted independence. So we were able to find housing, thank God, and handicap and elderly housing, which we are very grateful for but forgive me for saying this, I really feel it's just a warehouse for the lost. There are no programs for him. He's now getting some support through east bay mental health center so he’s involved with the population. Although he's a blank because he has to take medication, he has to have somebody involved with that to make sure he's getting the doses that he's remembering, et cetera. The biggest thing and I’m really going off my preparation here -- the biggest thing that I want to express to you is how devastating this is to your world. You not only lose your child and you never want anything greater than that back, the life of your child back. You lose your friends, you lose your families. You lose your job. You lose your supports. You lose your freedom. You lose hope and the efforts to gain supports for him, I can't tell you the number of doctors and providers that were unaware of what happens to a brain injured victim so we were trying to explain to these professionals. And I was always grateful for anything that we could get.

Family Support Financial

But I was devastated by the lack of support that our state had for anyone in this situation and having said that, I want to just talk about some statistics. I just have to find them, if you will bear with me for one second. I’m sure a lot of you know this is the leading cause of death and disability among children and young adults under the age of 45.although there's little to no exposure about those facts, it is the fourth leading cause of death over all annually. Traumatic brain injury claims over 56,000 lives annually. It’s an estimated 6 million people, Americans; more than 2 percent have disabilities resulting from brain injury. 2 million people sustain a brain injury every year. Each day 5,500 individuals sustain a brain injury. Every 15 seconds, someone receives an injury. It's every three minutes that a woman receives breast cancer. Look at the difference in the awareness, in the supports out there and again I won't continue to read the statistics. But I do want you to please open your hearts and minds to those suffering from traumatic brain injuries. We must educate and fund programs to help care for and prevent traumatic brain injuries if saving tax payer's lives is not enough of a reason for increased funding, saving if saving lives is not enough of a reason for increased funding, saving the taxpayer's dollars should be. It costs over 1 million dollars to save my son. And the account is still tallying with the proper education and supports, he could contribute something back. He is able enough to do something if somebody would provide him an opportunity.

Employment Job Training

And if I could have him work for the business I have, I would. But we do hospitality staffing. And he could not handle the trays although I do have him come clean the office let's see. I just again, just want to say the same that I already said. Just review some more statistics. And just asking to please support those with traumatic brain injury. It is an overwhelming process. I do want to say one other thing. I am a strong woman. I don’t mean just physically but that's certainly one, emotionally and mentally. I'm also a young mother, which was my son is about 6feet tall and thank god I’m a strong and able woman. I know people suffering with this injury that are half my height, probably 15 or 20 years on me trying to take care of people that aren't able to take care of themselves.

Health Care Insurance

One of the conferences that I went to through the Brain Injury Association, which has been a lifeline for me, had a doctor there who was being questioned by an insurance company. And in that testimony, he was asked, well, because my son can walk and talk now, although he falls a lot, has a lot of disability still. He was able to be more mobile because people see him that way. And they say oh, he looks great. It's not about how he looks. It's about what's happening in his world and what isn't happening in his world anyway, the testimony given by this doctor was the question by the attorney for the insurance company. He can walk, can't he? He can dress himself and feed himself. He can do this, can't he? And the doctor kept saying yes, yes, yes. I'm sitting in the audience feeling angry because there's so much more to the story. The doctor said, so can my 7 year old son, but I wouldn't leave him alone to provide for himself. so that just encapsulates all the issues that I want to communicate. And thank you so much for listening and please help us.

Lorna: Thank you, Shelly. Is there anyone else who would like to testify? Anyone else? We will be here until 5:00 in case anyone else decides to join us. What we can probably do now is maybe take a break. And if people would like to get coffee, I hope it's still open there or just kind of stretch your legs a little. We will take a break until perhaps 20 of, in case other people join us.

Lorna: Excuse me. Hello. For anyone else who would like to testify, who has maybe had a chance to think about some of the testimony and maybe agrees, would like to add something to it, perhaps a personal story that maybe illustrates even more so something that was said today? No? I would like to just give the mike for a minute to Domenic. He has kind of an interesting announcement to make, since we have sometime.

Employment Job Training

Domenic DiOrio: Thank you so much. I'm going to come out of the closet. I have 7 disabilities. I had to retire from the West Warwick school department because I suffer from severe cluster headaches. A man in my life, was out of money, he sent me to Chicago migrate, sent me to a foster hospital. I live on oxygen. I'm trying to avoid a wheelchair because I am severely arthritic. And I'm now taking steroid injections. But that's my little story. The other story is as a vocational educator, I am a fellow at Ohio State and working with Goodwill and Traveler's Aid and Crossroads, I became more involved with those with disabilities and welfare recipients. I just had been awarded a Rhode Island Foundation scholarship, modest generating some money from industry business. I will be going to Switzerland. I will be going to Copenhagen. And I will be going to Stockholm to study their vocational programs along the lines of apprenticeships and hopefully I can come back with a seamless progression of competencies so I can advocate to business and industry in partnership to help all of us who are disabled to have entry level position, meaningful ones, with career paths when I am told in Germany people who are 15 and 16 years of again wheelchairs working on hydraulics and becoming self-sufficient. I'm also aware that people with disability, those who are locked out of work are starting their vocational education when they're years old .my statistics agree. There are 70 percent of Rhode Islanders living below the poverty income. There those just slightly above it than the average will go up to 73, 74 percent. This is a rich pool of people who are not being tapped. Now, going into a global economy, there are new employment needs. There are 72 or 73 percent of our population in Rhode Island locked out. They include those with disabilities, 23 percent, the rest are those on welfare. I just had a student, a welfare friend of mine who I service with Jim Langevin, the mother of Congressman Langevin. She just got her Ph.D. And she was a battered woman. She got it from UConn. I'm glad it was part of her life. I'm also addressing the issue of sex offenders. The homeless that I have been very closely working with. I am a professor of history at Rhode Island College part-time. Children between the age well, young adults between the ages of 18 and 24 are not working, are not going to school. You look at the societal problem that we face every day, which are also costing us a lot of money. There are wealth of people who do not wish to be on welfare. There are those with disabilities who don't wish to be obtaining SSI or would like to complement their income to work extra amount of hours and I'm on the adult literacy Rhode Island. I just developed a program on literacy for the department of human services and goodwill. And the literacy levels in Rhode Island are anywhere between 5th grade an 8th grade. Also military base evaluator out of Ohio State. And most of the people who go awl are young adults who have literacy levels below 9th grade. And they are incarcerated because they cannot understand computer driven weaponry so my hope is to and I'm very stimulated today and energized to leave Rhode Island College. I made my decision today to make my commitment to all of us who are with disabilities. I want you to pray for me that I will be successful. Certainly we can all enjoy quality of life. So thank you.(applause)

Lorna: Thank you, Domenic. Well, we are -- winding down the last ten minutes has there been a huge rush back there of people who want to testify? I don't think so. We are going to stay here until 5. And people wishing to leave, they are free to leave. The panel will be here. What I might do is just let some of you talk. I know there was great conversation going. You are welcome to stay. And we will just have a little time for people to network and talk about services and maybe get some assistance right here in the room for the next few minutes. And then we will end at 5:00 if I don't hear of anyone else who wishes to testify. Does anyone wish to testify before us -- no? Question or testify?

Accessibility Assistive Animals Speaker: Comment as we know I have a dog. As we know I run into problems all the time because I have a dog. One of my problems is we don't educate our police. I literally had to wait for a policeman to be called so I could be served in a restaurant. And he had absolutely no idea what the rules were. I feel I should be carrying around the rules. I have given them out enough times. We need to educate our police to the ADA rules. They really would like to know. I know because the ones on my beat, they know our neighborhood we have dogs. If my dog is out, there's something wrong. My dog doesn't go outside without me. If that dog is running around, I want somebody to know. Something's happened to me. We need to educate the police. All the police, state police, city police, whatever. They need to know. Darlene Hartmyer.

Lorna: Anyone else? Anyone else want to sing? (laughing). I think we are done. Again, please feel free to network. And I won't come back at 5:00. It will just be over at 5:00. And I thank you all for coming. You have been wonderful, wonderful testimony today. And I thank you all for sharing. And I will see you, same time next year. Please pass the word to others who wish to testify. Oh, one other thing. If today really meant something to you as far as you seeing some wonderful panelists hearing what you have to say, that this is a wonderful opportunity to share things that are on your mind. I ask you to do a couple of things. Go home and talk to your neighbors and friends who also have issues that you know would love to have a chance to tell their stories. And make sure that you take the notice. I think it's in the back to the public hearings that are happening tomorrow. There's two tomorrow and one Friday. So those of you who have friends and neighbors, relatives who probably -- really should be testifying. You have three other opportunities in which to do so. So please let them know that they may go to those other sites around the state and testify. Do just what you did today. and thank you again for coming today. Thank you for all the testimony. Thank you for our wonderful sponsors, our panelists, and thank you very much.

July 29, 2004 George Washington Management Area, Gloucester

Steven Wright: I'll introduce myself; I'm Steven Wright with the Department of Environmental Management Division of Parks and Recreation. This is a forest environment building. The folks up here have been nice enough to let us use their building.

Corinne Russo: I was interested to know what came out of the meeting yesterday.

Female Speaker: Would that be you?

Steven Wright: That's not me.

Corinne Russo: Lucky you.

Steven Wright: Just for your benefit, I would like to have everyone on the panel introduce themselves.

Judith Kapuscinski: I'm Judith Kapuscinski and I'm representing the Rhode Island Statewide Independent Living Council based in Warren.

Kate Sherlock: I'm Kate Sherlock from the Rhode Island Disability Law Center providing free legal services to people with disabilities.

Victoria Wilcox: I'm Victoria Wilcox on the Governor's Commission on Disabilities (GCD) and we use the testimony from the public forums to help guide our legislative priorities.

Female Speaker: Do you all guys form like an ad hoc committee?

Victoria Wilcox: What generally happens is after the hearings, people get together in sort of ad hoc committees and review the testimony and come up with recommendations based on that testimony.

Leslie Shaffer: I'm Leslie Shaffer and I have two hats tonight. I'm with the Ocean State Center for Independent Living Center, one of two in Rhode Island, and I'm also representing the ATAP program, Assistive Technology Program.

Female Speaker: That's different than TechACCESS or kind of the same thing?

Leslie Shaffer: Are you talking about TechACCESS?

Female Speaker: Yes.

Leslie Shaffer: Where as TechACCESS would help a person identify types of adaptive equipment we have a grant through the state for people that meet certain income guidelines to be able to obtain the assistive technology.

Female Speaker: So you work together?

Leslie Shaffer: Yes.

Suzanne Goldenberg: I'm Suzanne Goldenberg representing the State Commission on the Deaf and Hard of Hearing and the Commission works to provide information to the public and to serve deaf and hard-of-hearing peoples' concerns to promote understanding and legislation and to help actually solve individual questions if you would have any.

Corinne Russo: I'm Corinne Russo from the Department of Elderly Affairs and we work to advocate for older people and the needs they have regarding their own disabilities.

Pam Corcoran: I'm Pam Corcoran from the Department of Health.

Frank Harris: Frank Harris, with the Rhode Island Public Transit Authority (RIPTA).

Victoria Wilcox: We might have to speak up a little bit.

Harvey Salvas: I'm Harvey Salvas with the GCD. I'm the State ADA Coordinator.

Steven Wright: The purposes of these forums is to identify the problems with disabilities are having and to improve the quality of life of people with disabilities and the transcripts from the testimony today will be on the Governor's Commission on Disabilities website and that will be www.gcd.state.ri.us and that takes place in about a week. Later on this summer agencies will review the recommendations and they will be posted on the website.

Female Speaker: Is this the first year?

Victoria Wilcox: It's been going on a number of years.

Steven Wright: I think this is our fourth year.

Female Speaker: I haven't caught them.

Steven Wright: The recommendations will be printed and sent to state congressional officials and members of the general assembly and used to develop legislative initiatives for next year. Having said that you're our only

participant, we usually limit the number of minutes but… (Laughter).
Steven Wright: We're all ready to hear you.
Victoria Wilcox: Can you state your name?

Family Support Resource Directory

Joanne Hallberg: I'm a resident of Gloucester, Rhode Island but also the chairperson of the local advisory committee (LAC) which is the parent group of -- it's a parent group like a PTO (Parent Teacher Organization) whose parents have children with special needs. So our special ed region is the North West region which is Foster, Gloucester, and Scituate and it usually lacks and is very low in membership. So I'm trying to beef that organization up. That's what I'm trying to do. So I don't know. Some of my concerns are generally being a very rural area in the northern part of the state is we don't have a lot of local access to some of the services we need and I find it very hard, I'm also a working parent, driving home from Cranston in my instance and coming home in the evening to be able to attend anything to drive back, you know, south, so that's one reason why, you know I don't go to many things and I think that's the concern of my parents.
Victoria Wilcox: What kinds of services are available elsewhere but not here?
Joanne Hallberg: General knowledge. Jason is 6 years old and just recently a number of us, because of the fact we were trying to start up the, discovered knowledge of agencies like CASSP didn't even know it existed. Now, everyone has an intake evaluation but we didn't even know things like that and it's because people don't get together to discuss what's available kind of thing. I had a personal instance where I hate to tell you I called the Rhode Island Disabilities Law Center and never got a return call.
Victoria Wilcox: Oh, no.
Joanne Hallberg: That was another concern of mine, although it would probably pertain to DCYF. Jason has Down syndrome but also has a disorder where his esophagus was attached to his intestines, so he eats mainly soft foods, such as peanut butter. We don't have a lot of choices up here for daycare providers, and they got a child in who has an allergy and just having peanut butter in the whole center. There's no parameters involving that so the day care provider, even though I called other centers and they accommodate, she decided because of her liability reason, to ban peanut butter altogether, and I was trying to get a hold of someone there to discuss my rights as far as suing for medical negligence, but I don't know if you know Dr. Prushel at Rhode Island Hospital and he's world renowned in the area of Down Syndrome, he had been on a seminar and when he returned he wrote a doctor's note for my son and they had to concur with the note. Otherwise I was going to sue them for medical negligence. But I never got a call back.

Family Support Recreation

And there's other thing like I wouldn't know about the assisted TechACCESS stuff.
We decided to start this other mom and me, a sports group for special needs kids under the age of because we have someone trying to get Special Olympics started up here, but we felt children under the age of 8 want to play sports too. So under the BQUSA we started TOP Soccer which is soccer for special needs kids we've done a challenge league for baseball, and although not lately although we do have a blind child, we would like to know if there's any information involving special sports equipment that we might get some time. It's general knowledge up here of getting access to things.
Judith Kapuscinski: Are you familiar with the Rhode Island Parent Information Network (RIPIN)?
Female Speaker: I'm a recent SILC chairperson and they're getting together all the lacks to start a coordinated effort and I got the website and I didn't go to the last meeting because I had a LAC meeting, but I went to the other meeting they had at Chelo's in Warwick and I have them coming in September, October for bullying and November for stress relievers and then for my lack meeting I have them coming in for basic rights. But I feel like I'm one person trying to bring everything up here.
Judith Kapuscinski: I'm exhausted just listening to you, with your children and everything else you're doing.
Joanne Hallberg: It's because of that reason, and I find the parents up here are at a loss and have a lot of questions and are like thirsty for general knowledge of something. I can't answer to elderly affairs, although personally at one point in time I was doing the sandwich thing.
Corinne Russo: Do you feel as though if more information were provided at the local level within you physician's offices and --
Joanne Hallberg: I don't know how many people go to physicians up here I go to Johnston.

Female Speaker: Do you feel more information should be available in the schools and school systems? Is that a source of people gathering and getting information?

Joanne Hallberg: That could be possible. But I find now that I'm getting more information like these RIPIN seminars I went to the PTO and said listen, "I've set these up you're going to co-sponsor this with me and that's how we're setting it up." PTO's do the fun social kind of stuff. These things are going to serve well into our sit survey.

Victoria Wilcox: I'm going to be the new person who's a pain and just ask everyone to please restate at least your first name when you speak because it's a lot for one person to keep track of. If we could do that every time we speak it would be greatly appreciated.

Judith Kapuscinski: Miss Hallberg the lack of information, where in your mind would be the best place for it to be and in conjunction with that, what is the availability of internet access out this way, through the libraries or the schools or --

Joanne Hallberg: I personally feel the best way to disseminate information is through the schools. I'm not exactly sure how available internet access is up here as far as whether or not families' incomes can provide that. I don't know how many families have computers. Based on the population of my small sports group about only 50% have internet access where if we have to cancel the game, I have to call. I don't know about internet access and what was the third part of the question.

Judith Kapuscinski: I was wondering if the internet access through the libraries.

Joanne Hallberg: I don't know if the libraries are active enough. We have Harmony and Manton. I bring the kids there in the summer I'm not seeing a lot of kids there especially kids with disabilities. I went there and spoke to the librarian, and she had Ronald McDonald storyteller, last year I brought my other son and brought to her attention, do you realize that children with disabilities go to an extended school year and can't go to some of these things. This year she changed it to 3 o'clock just because I mentioned something. But he and another child, they are only two. There's a large population of children up here with developmental disabilities. I have 17 kids under the age of 8 in our sports program. It's mostly down's and autism, and a couple of special kind of things but, yeah, seizure disorders and that type of thing.

Steven Wright: Anyone else want to add anything? Panel members.

Joanne Hallberg: I'm just trying to get more knowledge to try to be able as the LAC chairperson pretty much to try to help people up here. I mean they have enough trouble trying just to go through their IEP's every year.

Female Speaker: Tell me again what the name of your organization is?

Joanne Hallberg: Which one is LAC? It's a Local Advisory Committee and in education circles when they hear that they know it's the parent group for parents of special needs kids. I would love to change the name.

Female Speaker: Sounds like you have a lack of something. Well, RIPIN is trying to address that. We're so consumed with other things like doctors' appointments and so forth.

Joanne Hallberg: I can let you guys go home early if you want.

Female Speaker: We have to stay anyway.

Steven Wright: We're here.

Joanne Hallberg: I can sit and chat, its okay with me.

Female Speaker: RIPIN also disseminates a great deal of information out of their office and a lot of people don't know about that. Besides the workshops, they have a huge library and that kind of stuff. They will take questions over the phone.

Family Support Recreation

Joanne Hallberg: Prior to me being told that I was taking the chairmanship, it seemed like previous chairman just had meetings because they're required two to three people just staff people showed up and I'm to the point of rewriting the by-laws. Because of the TOPSoccer program and the challenger program, I don't know how you guys know they're set up. We have high school kids serve as buddies for these guys and they're the ones that spend the time with them. They're knowledgeable about their ailments, we have one kid who constantly has seizures and his buddy works him through that. So the parent does not go on the field at all. It got to be a greater program than I ever imagined. All I wanted was for him to be able to play soccer or baseball or something and the buddy and the children formed these bonds that were intense and incredible of the because of that the assistant director at the special ed department had some positions open during easy end of the school year and asked if some of the kids wanted to work there. Some of them were under 16 so they weren't employed but they were helpers and because I felt bad for that, the last minute, at the end of the school year, we had two bake sales and were able to give them the stipend giving them a very small token of our appreciation. But it gave the high school kids so, of them at Ponagansett High School have to do a legacy project, and that's why some of the seniors came to do a TOPSoccer program but they haven't left. And some of them have decided they want to go into education and become special ed teachers. So we want to afford them the classroom type of experience.

Education IEP

Another thing coming out of our lack group, I have a mom who has a special needs student but also a regular student in college, and they're going into speech therapy. When Jason was in early intervention at the age of 2 when I was told he was ready for speech therapy they said he had to be on a waiting list because of the lack of speech therapist. I got on the phone with the department of I think it was the department of health, but then I called Charlie Fogarty's office because he's the Lieutenant Governor from Gloucester and I thought I couldn't have a speech therapist because we were up in the Gloucester. But we got this idea the student majoring in speech therapy, he's written a letter to Governor Carcieri of including speech therapy in the legislation where it's 0% interest on student loans if you go into certain areas, like pharmacy, teaching and we would like to add speech therapy because there's a shortage of speech therapists in Rhode Island and it's unfortunate when you have a child who's ready for speech therapy and has to be on a waiting list that already has developmental delays to begin with. We've started with that, and I think he's gotten one phone call. But if it's going to be in the notes and it will get to the elected officials, this might help in that way. It's a vested interest thing.

Judith Kapuscinski: Could you just, the soccer program, is called TOPSoccer, it's the outstanding program in soccer. If you go online and look it up it's supported by under oil but any soccer association can get a charter from them and they send them information on how to run it and all that. Soccer the regular soccer program is another field it has to be so much and what this charter does is allow you to make the field whatever way you want and do whatever you need to help these guys play soccer. The first year was fun but we had problems one kid liked to sit in the net all the time, Jason liked to sit in the woods. We did better with indoor soccer. The kids had a great time and we had a banquet. We went to the Situate Arts Festival and he had come home and bought a soccer scarf for Griffin who is in a wheelchair. The mother thought that was great and went back to the festival and bought all the kids scarves. Because of the legacy project, they did a power point presentation. If I thought of it I would have brought my laptop and shown you guys. You would all cry. (Laughter).

Joanne Hallberg: I'm glad I just thought of that. Speech therapy would really need to be put in there.

Leslie Shaffer: Leslie Shaffer, I don't know whether you've seen a program called real sports on HBO. I was watch it go over the weekend and they had a whole segment on a sports program for special needs children that started with the work of two parents that had children that used wheelchairs and couldn't participate in the regular league and that program in about 6 years has grown to I think they said about 70 or 80 different locations all over the united states.

Special Ed needs in Foster, Gloucester, and Scituate

Joanne Hallberg: It's a matter of getting the word out, because we have a lot of parents who don't know about us. Is it Cheryl at RIPIN she does the seminars and she hadn't heard of us. When you talk about the needs region, Foster, Gloucester and Scituate it's almost unmanageable. Especially when you're talk being people complaining to have things around here. We're working on it, we're working on it.

Steven Wright: Thank you for your testimony and as I indicated earlier the sponsoring agencies will review the testimony and post recommendations later on at the end of the summer.

Joanne Hallberg: Thanks.

Corinne Russo: Thank you very much.

Female Speaker: Good luck.

July 29, 2004 - Westerly Senior Center

Donna Cone: its 3:00. I will start precisely on time. I am Donna come from the department of elderly affairs. We are very happy to be here today. This is the first year that we have partnered with the disabilities community and we are formally in terms of these hearings. The purpose of these forums is to identify the concerns of people with disabilities and their families in order to assist the state to develop programs to improve the quality of life for people with disabilities. And one of my tasks was to determine the order of speakers and then divide the two hours up to be sure everybody could speak. But only sky here indicated that she wanted to speak and I don't know if you do too.

Speaker: I guess I could.

Donna: You have an hour apiece.

Speaker: no, no, no, no.

Speaker: if you don't speak your mind, nothing's going to get done.

Speaker: I don't know that. That's the concern here.

Donna: okay.

Speaker: Hi neighbor.

Donna: What we will do then we will just begin. Just a couple of housekeeping tasks. The bathrooms are right out this door and to the left. Come on in. You want to sign in and there's water back here. We just had the water fountain refilled. Now after this forum, there will be a posting of the transcripts, the information that's being recorded here, of all the testimony on the Governor's Commission on Disabilities website in about a week. And that website is www.gcd.state.ri.us. And it’s given on this handout that's available here if you didn't get one. The sponsoring agencies, and there are a number of sponsoring agencies, will be reviewing the testimony and preparing recommendations which will also be posted on the website by the end of September. The recommendations and the transcripts will be printed and sent to state and congressional officials and to members of the general assembly. And these recommendations will be used to develop policy and legislative initiatives for the next year, or until they are accomplished. Now I’m planning for us to be through no later than 5:00. So we have to finish by then. We can make room for you. We are just starting.

Donna: does anybody here need sign language? This woman here.

Speaker: I don't even know sign language. I tried to learn it.

Donna: All right. Would members of the panel like to say any words in the beginning before we start taking testimony?

Speaker: Excuse me, could you face me when you talk.

Donna: I’m asking if members of the panel would like to say a few words before we begin taking testimony from the audience.

Speaker: you may think this is weird but when you talk sideways, I don't hear you.

Donna: Okay.

Charles: I will start. My name is Chuck Messina. I'm an attorney with the Rhode Island Disability Law Center. We are located in Providence, but we provide service statewide. Our services are for persons with disabilities. We provide free legal advocacy for persons with disabilities and their legal and civil rights claims. We don't handle every legal problem that a person with a disability has. We determine annually which problems we are able to assist people with. We have currently about seven or eight different federally funded grants that provide different levels of legal service to people with disabilities, so it doesn't matter if you are a person with what we call a developmental disability or mental illness, traumatic brain injury, if you are a person whose disability developed after the age of 22, if you are a social security or SSI recipient, if you are a person with a disability who's having a problem with voting, that's our newest grant. Those are the sort of problems -- you are in our population and we are happy to talk to you about our -- sorry -- your legal problems. We do have an intake system and I have cards that I can present so you can call. We have an 800 number, we have a TTY. We also provide interpreter services for our clients who are deaf or hard of hearing free of charge. We are very happy to talk to you and see how we can help you out.

Speaker: You need a microphone.

Charles: I usually project a lot louder than this but I’m often afraid to.

Speaker: I’m going to stay until everybody has their turn.

Patti: My name is Patti Thompson and I'm a recent appointment by the Governor on the Commission of the Deaf and Hard of Hearing. I am hard of hearing myself. And also have other handicapping conditions. Right now I'm representing the Commission for Deaf and Hard of Hearing. So if you have any questions relating to that, I would be -- if you have questions later or come see me individually and I will try to help you to the best of my ability. I live locally.
Speaker: In Westerly?
Patti: I live in Westerly and I'm a retired schoolteacher.
Speaker: How old are you?
Patti: How old do you think I am?
Speaker: you look about 55.
Patti: I'm signing you up. I'm 62. I will tell my husband that. He will be happy.
Speaker: You are as young as you feel.
Patti: You got it.
Speaker: Sometimes I feel like 120.
Patti: You are doing well.
Speaker: On energy pills, yeah.
Anne: I'm Anne Leclerc. I'm a planner with RIPTA. And RIPTA also has the responsibility of administering the RIde program. Questions on RIPTA or RIde, I can answer them.
Speaker: I didn't get your name.
Anne: Anne.
Bill: I'm Bill Nieranowsk. I'm a commissioner on the Governor's Commission on Disabilities and I'm here to provide answers and support of any questions you have about services we offer.
Casey: I'm Casey Crothers. I'm from the Brain Injury Association of Rhode Island, Brain Injury Association of Rhode Island.
Donna: Okay. Let me say just a word or two about the Department of Elderly Affairs. This is as I said earlier the first year in which we have joined the Governor's Commission on Disabilities at these hearings. And we are privileged to do this. I brought along copies of -- this is the regular copy of what we call a pocket manual, which is information about all our programs. Then I brought the large typed-face version for people who need it to make things bigger. And then finally, finally the Spanish version and one thing I did want to mention, you will be hearing much more about this in the coming months, the department of elderly affairs and the department of human services have received federal support to develop an aging and disability resource center and this center will have its physical location on the John O. Pasture Complex in Cranston. It will also have its virtual existence on the web. We're in the process of developing the center so that we will have people physically present. And there will be information on the web about all the services that are available to elders and to adults with disabilities. So this is a new initiative for Rhode Island and I just wanted to give you people heads up that that is coming. So now why don't we call on people to testify? We have sky cane who has indicated that she wants to talk to us today. So, the floor's yours.
Speaker: Okay. Where do you want me to sit?
Donna: Just where she can hear you. We're all set.

Transportation Curbcuts

Susan Cane: My name is Susan Cane. I prefer to be called sky. And when I go into Providence, no matter what season it is, I'm always going off of the curve, going up on the curve because people in Providence are parking in front of the ramps and just about every store in Providence has stairs, no ramps.

Accessibility Stores

There are a lot of stores I would like to go into, but I don't do stairs very well. I mean, you know, it's not right. I mean, I can walk as long as I hold on to something, but lugging this thing and my backpack, that's something else but I'm in this contraption because I can't trust my legs. Left right, left right. Sometimes my left will be in front but my right will stay behind. I'm tired of falling down but it's not right. It's not just in Providence; it's in a lot of places. There are not enough ramps. I mean one time I got off of the bus, coming from timber 2 here, I call it that because there's no transportation. I mean there's only a 7:00 bus to Providence and you get your business taken care of. And then you have to hang around until 5:00 to come home. That's just too long for me. And then I sleep for three days afterwards. I mean anybody that doesn't have much energy, it's too much. In the wintertime, I have to shoot the idiots who do the plowing. The sidewalks are covered with snow. You can't find the curve. You can't even find the ramp. What are you supposed to do? Put a board there and fly up like Evil Knevil in the street.

Donna: I have the sign-in sheet.

Speaker: I'm sorry. Sorry I'm late.

Transportation RIPTA

Speaker: You know, I have been -- it frustrates the hell out of me and this thing is ready to fall apart on me. It used to never make any noise. I would like to get a scooter but I'm not eligible for one according to social security, I'm no longer disabled and I can go back to work. Yeah. If I can stand without holding on to -- I thought I tripped her for a minute -- as long as I'm holding on to something, I can walk. But I have no warning when this stays behind. I'm very stubborn. It took me three months through my thick skull that I wasn't walking right but anyway, can anything be done in Providence? Can there be more rides from Providence to Westerly?

Anne: I can talk to you after that. There are other options besides the park and ride bus.

Speaker: a lot of times by the time I get to Providence, I don't have much time to take care of my business. You know, and then -- I can't rush around like I used to. I don't have the energy. It took four energy pills to get here. So, you know, I don't know -- I know nothing's going to happen in my lifetime. In the future for other people --

Anne: There are other buses you can take to get to westerly.

Speaker: From Providence?

Anne: I can tell you about them.

Speaker: before 5:00?

Anne: They don't come directly here. You have to transfer in Wakefield.

Speaker: I tell you on that one. Even here in Westerly, nobody believes in anything level. This place is like a roller coaster.

Speaker: this is very true.

Speaker: it's a breeze going down the hill, but it's a pain in the ass going up. I find it easier going up backwards. I may not trust my legs. If they stop, I'm still sitting. I won't fall. But they do get caught underneath. But, still, I mean, this is the 21st century. Where the hell is the improvement in things, you know?

Speaker: it's out there, but you have to find it. Nobody can hand it to you. You have to find it.

Speaker: say that again. This is my ear.

Speaker: I said nobody's going to hand it to you. You have to find it. In other words, you have to find them. They want –

Speaker: I didn't even know this was going on until I found out.

Speaker: they want to be found. I keep telling my doctors.

Speaker: My doctor sure told me about them.

Speaker: they don't know. I'm the one telling my doctors about it.

Accessibility Rest Rooms

Speaker: let's hope something is done, huh? But still, there's -- there are a lot of places that need to have something done about it. I mean, like I said before, one time I got off the bus and mother nature was knocking on the door so damn loud. I had to find a place that had a lift, you know, in back of city hall.

Speaker: Is there?

Speaker: I try to use other words for the bathroom. But I had to leave my chair outside. There was no room for it to go in. And that was the most disgusting bathroom I had ever been in. It smelled awful. It stunk.

Anne: In Providence?

Speaker: In Providence City Hall. I mean, I had to hold the door closed with my foot without slipping off of the toilet, which is not a good -- I'm not that tall. (laughing) I've got short legs. It was not easy holding the door closed and staying on the throne at the same time, without missing. You men, you are easy. You can stand on one leg.

Anne: Sky, Kennedy plaza does have accessible public restrooms.

Speaker: Kennedy Plaza does. But mother nature wasn't going to hang around for a trolley to come by.

Anne: It's across from city hall in Providence.

Speaker: No, it's not.

Anne: Kennedy plaza.
Speaker: it's right across the way from Kennedy plaza. And they don't open their bathrooms until 8. Anne: it was earlier?
Speaker: No, wait a minute.
Anne: they are open at 6:00 a.m.
Speaker: They closed the bathrooms at 4. But back then they didn't have that there. It was in the process.
Anne: under construction, okay.
Speaker: but I must have put on hold for an hour and a half trying to find a bathroom that I could get into. I mean, there were stores, but I couldn't get into them. And I just made it by the skin of my teeth.

Accessibility Sidewalks

I mean, also the sidewalks, the streets that are brick. I lost count how many times I took a fling out of this thing. Some bricks are missing in the sidewalk. My wheels catch it. I wouldn't see it until it's too late. Come on, this is the 21st century. Where the hell is the pavement? Get rid of the bricks for one thing, they're a menace and kids can pick -- dig them up and use them for a weapon. That's probably what they are doing with them anyway. But it's crazy. Just because a town of Providence was built like that doesn't mean it has to stay like that in the 21st century people in wheelchairs, it's very hard when you have to keep fighting bricks and rugs. Especially when the road has a crater inside of it too. I mean, you think anything could be done -- how hard is it to bring up the bricks and put down pavement, you know, like you would a street, you know. It doesn't take that long. Is anybody here from Providence? Anybody ever go to Providence?
Speaker: I work in Providence and I agree with you. I know –
Speaker: about the bricks?
Speaker: some of the sidewalks have been replaced with bricks.
Speaker: yeah.
Speaker: and some of the bricks are in disrepair. It's difficult if you are in a chair to get around. I think that's probably something that should be brought to the city of Providence’s attention. I don't think there's anyone here --
Speaker: this has to do with people in wheelchairs because it's a menace.
Speaker: right.
Speaker: I lost count how many times I flew out of this thing because my wheels were caught in a crater or a brick missing and I couldn’t see it.
Speaker: I agree with you. I think that probably the best thing to do is to bring that to the attention of some of the city officials in Providence.
Speaker: in other words, city hall?
Speaker: have you talked to anybody at city hall about that?
Speaker: not yet. I didn't know who to talk too exactly.
Speaker: that's probably a good place to start.
Speaker: oh, believe me, I will. But I have to be able to get inside the building first.
Speaker: you should be able to call them and talk to the appropriate individual. Do you have access to a telephone?
Speaker: I have a speaker phone at home. But I need to be able to get into the building. See, people have a tendency of hanging up on you if they don't like what they are hearing. And they don't want to see my temper. I have a nasty one.
Speaker: Charles, maybe you can have some other ideas of ways to bring a complaint like that to city hall. Is there a person for that?
Charles: I think you actually advised her right way to go which is to start with the city. I would actually start with the mayor.
Speaker: that's who I have in mind.
Charles: and I know he's a busy guy and also -- I’m not a Providence taxpayer, so I can talk a little differently about him.
Speaker: feel free.
Charles: he's a very busy individual. I think he tries very hard. What I would do if you can't get him on the

phone because there's no guarantee that you are going to, I would write him.
Speaker: well, they also have a tendency of filing letters in the waste basket.
Charles: well, I would start with that. And what I would do when you write your letter is to keep a copy. And if it's not too much out of your pocket, then send the letter certified or return receipt because that way you will have -- you will know --
Speaker: proof that he got it.
Charles: not only will you have a copy of what you sent, but you will have proof that it was received in city hall.
Speaker: someone is going to have to write it for me because if I wrote the letter it would be more than 40 pages long.
Charles: if you have -- if there's a social worker or caseworker who works with you, maybe that person can help you write the letter. What I would also say is to put it in your own words.
Speaker: oh, believe me, it will be.
Charles: okay. You don't have to sound like a lawyer yet. But I would put that in your own words and if you can document specific places in the city --
Speaker: well --
Charles: and dates and times I know that's hard. For example --
Speaker: I lose track of dates, times, years, even months.
Charles: but if you can say to the mayor, I was in Providence last week and on the corner of Westminster and Dorrance --
Speaker: I can't read street signs.
Charles: ask somebody where you are. It's okay. The mayor will have an idea of where you were.
Speaker: It doesn't matter where it was. It's the bricks itself.
Charles: but the mayor needs to know what you are talking about because --
Speaker: anywhere there are bricks.
Charles: if you can be more specific with him. I know bricks all over the city because as you pointed out it is an old city.
Speaker: Very old.
Charles: and people like to preserve a lot of its historical charm.
Speaker: You know, keep the buildings but get rid of the damn bricks.
Charles: I think the mayor needs to know that. I think if you put your complaint in writing and you could be specific where exactly you have the most difficulty. I think that could be a good start.
Speaker: what's the mayor's name?
Charles: can I write it down for you. It's David Cicciline.
Speaker: Sounds like a sneeze.
Charles: I will write it down for you.
Patti: something you may want to consider is having a throw-away camera with you and document what you see and where you are. And obviously if you've got a picture, you've got it.
Speaker: good idea.
Patti: there are some throw-away cameras that are very inexpensive. Get it developed locally. I would do that. Then you have proof 16 positive.
Speaker: Good idea.
Patti: I can appreciate the problems with that. We are seeing that now in Westerly because we decided to go back in time and make everything look wonderful here. And they install bricks and every time you get frost, the little buggers go up and down like this.
Speaker: tell me about it. Patti: so you know, not a good thing. If people were thinking ahead.
Speaker: I mean, someone's going to have to read that to me.
Charles: read what?
Speaker: what you are writing.
Charles: they are my own notes.
Speaker: okay. Even down here.

Patti: I have seen it.

Accessibility Snow Removal

Speaker: Yeah. I mean, am I behind? I don't want to run anybody over. I do that enough with my own feet. In the wintertime here, the first winter I was here, idiots who plow the streets left a whole bunch of snow on me one night. And this is before the chair. Apparently they weren't paying attention to what they were doing and it was -- wait. Here's Babcock, the back of it. And I'm right here behind the factory or some kind of factory. It was late at night. I was coming back from shooting pool. I should have been wearing bright colors. But next thing I know a whole bunch of snow was dumped on me.

Patti: can you clarify Babcock? Babcock school or --

Speaker: village. Did I say that?

Patti: I don't think so. I think you said Babcock.

Speaker: what ear do you have trouble hearing in?

Patti: both. Without this I won't hear a bomb coming off. I would feel it, but I just wouldn't hear it. (laughing)

Donna: Sky, are you all finished? We -- since you started three more people want to testify

Speaker: no problem.

Donna: Okay. So, Denise I think you were --

Health Care Professional Development

Denise: what is it that you want me -- I mean, I've moved here two years ago. I moved here two years ago and I used OSCIL a lot. They put a ramp in the house and they put -- widened the doors, done some things in my bathroom, put hand controls my -- hand controls in my mother's car for me to drive. There have been a lot of things -- OSCIL -- more people need to know. And I keep telling my doctors, do you know if there's something out there that's going to help? I keep leaving their number and giving your -- I get something mailed to me every month and I -- I don't have any left because I keep giving them to doctors and to people I see. Call them. They are the ones that can help. Ocean State Center for Independent Living, OSCIL. I learned that one right away.

Donna: so you are suggesting that they have more of an outreach and educational program for the medical community?

Speaker: yeah, exactly. The doctors don't know. I tell them. I give them the numbers and I give them everything. They act like they've never heard it. And I know you guys want them to know. It's not like they are trying to hide it.

Anne: there's also another independent living center called PARI. Independent living center. That's in Pawtucket. OSCIL is in Warwick. They both operate statewide.

Speaker: that's the Connecticut one?

Anne: one's in Pawtucket. They do both operate statewide. There's also the statewide independent living council which I didn't identify myself as a member of that. And they have been planning to do an outreach campaign to medical offices. They just haven't gotten it off the ground yet. I agree that is needed.

Speaker: So there's PARI and I know over the border in Connecticut there's Easter Seals. There's a lot of Easter seals stuff. And that's basically the same thing as you guys in Rhode Island. So, a lot of people don't know about that either. So you would have to ask me as far as what else.

Casey: did you have any trouble with -- not that OSCIL gave you any trouble -- but was there any trouble with getting your home modifications or your ramp?

Speaker: No.

Casey: did you have to wait very long?

Speaker: not at all.

Casey: You were able to get it right away?

Speaker: I was able to get it right away. I was so surprised, you know. They came to the house and they were -- this is when Joan -- she's who I worked with in the beginning. Now I am working with Linda. But it's just the right place. I came from Minnesota. And there's a place like this in Minnesota but you have to found out they don't want to be found. And they are not as good as you guys are at all as what they provide. As long as you find them, you guys aren't that way. It's just great. All I do is read -- not even knowing what you offered until I read that newsletters that were coming to my house. It's worth it. I post it. Any other questions because -- I have -- that worked. I have gotten out everything I need so far. But I will let you know what else.

Donna: thank you, Denise. Do you -- is it Carol?

Family Support Resource Directory

Carol Pratt: Yes. My name is Carol Pratt. I have a son who acquired a brain injury due to an assault. My concern being it happened a few 20 years ago. And I realize he was getting worse. And I did call the Brain Injury Association and they put me in touch with a good doctor but I think he fell through the cracks because he was a resident of Connecticut and I brought him into Rhode Island. And I just think there should be like some kind of clearinghouse that would -- could have filled me in, a social worker, somebody I could have gone to tell me what help there is out there for someone like my son. You know, somebody, you know, to diagnose him, how bad is he, somebody to keep an eye on him. We had his social security reinstated right away, so we got his medical. But like I said he fell through the cracks, not getting the proper help because I was given wrong doctors to go to. If there was just -- at the time I didn't know what the -- about the Brain Injury Association or I could have gone to them. But just like one place. I didn't know about this OSCIL and that sounds like it may be helpful too.

Casey: actually if you are looking for services for somebody with a brain injury, you may want to call PARI Independent Living Center and I can give you their information later. They have several programs that could be helpful. There's a limited amount of programs available within Rhode Island. But I can give you their information because they do have two programs that are available to help people that are eligible that have acquired brain injuries that got them after they were 22.

Carol Pratt: thank you very much. I will speak to you afterwards. Thank you.

Donna: and let me add that the adult -- the aging and disability resource center that I mentioned earlier, were you here when I mentioned that?

Speaker: yes.

Donna: we will have information of the type you are looking for about the Brain Injury Association, about OSCIL, PARI, all of those organizations will have information on the website and at the physical site at the center itself.

Speaker: I will be looking forward to that.

Donna: we are beginning with services to elders in the first year and in the second year we will be adding the adults with disabilities. So it's in the planning stages now. And we should have something a year from now that brings everything into one place as you just said.

Speaker: that's great. Thank you.

Speaker: and you are talking about OSCIL or you are talking about PARI or --

Donna: I'm talking about a new -- I don't think you were here when I mentioned it. Let me say again that the department of elderly affairs and the department of human services has received a federal grant to design and begin to implement what some people call a one-stop center. We are trying to get away from that terminology because it's so overused. But its one place where you can get all the information you need for services. So it will have a virtual component through a website, and it will also have a physical site on the Pasture Complex in Cranston. And there will be people there from both departments. There will also be information and perhaps some people from some of these other agencies like OSCIL and PARI. We haven't finalized the disability portions of it. We are starting with the elderly and we are moving next to the adults with disabilities. But it will be all in one place and we are launching a website in October that will be like a test website that will get people accustomed to seeing it. And then it will be finalized in the winter. We just want people to be alert for it. We are aware of that need, and we will be giving organizations an opportunity to put their information on that site.

Communication Access Assistive Technology

Speaker: I won't be able to read it because I have a computer, but I can't use it anymore, and I can't find anything that will enlarge the print. And I'm told you have something on a computer that can enlarge the print, you know. But you go to a different section or whatever to look something up and it disappears. You can't get it back up and it won't stay up.

Donna: we were discussing that at a recent planning meeting.

Speaker: she needs to talk to TechACCESS.

Donna: TechACCESS.

Speaker: who?

Speaker: technical problems that you have with the computer, which I haven't got yet but I am going to get it. I

know I'm on their mailing list too.
Donna: can you give her that information?
Speaker: I don't have it with me. But –
Casey: I can get it for her. I can send it in large print if I just get her address. I can talk to you later. Donna: she will get you some information about tech access.
Speaker: what is that?
Donna: I don't know. But she will tell you after the hearing, okay.
Speaker: okay.
Donna: you had a comment?

Housing Assistive Living

Speaker: yeah. My husband and I had a motorcycle accident. My husband -- I feel he fell through the cracks also. I had him home for some time, but he's been in and out of the hospital periodically and his last stint he was in Eleanor Slater for over a year. And now he's up in lake view. But the time that he was in Eleanor Slater all he did was stare at the ceiling. There was nothing for him to do. And he's very physically fit and could do lots of things but there was nothing, nothing available. And I just thought he was wasting away so now he's in lake view, New Hampshire. It's a four-hour drive and I'm in hopes that he can get rehabilitated and come back home to a group home situation. He wouldn't be able to come back home to me because he's very difficult to handle. But it doesn't seem that there are any group homes here.
Casey: can you give your name for the public record?
Carol Compton: Carol Compton.
Casey: Thank you. You are correct in that there are no group homes in Rhode Island that are devoted to adults with traumatic or acquired brain injury.

Transportation RIde

Carol Compton: I mean, he could do a lot for the community. But there's nothing available. He did work at stop & shop for a little while back in 2000. But if I was working, he would have to walk to work or take a cab if it was raining, and that would be $6 one way. But he couldn't get that RIde program because we were too far out. That was hope valley. Now I'm in Westerly. It's just -- you keep batting your head against the wall.
Casey: You experience many years of not being able to find programs he would be eligible for.
Carol Compton: Right.
Speaker: You just have to keep being verbal. You have to be your own advocate because otherwise there's nobody there for you if you are not. You will find them, but you have to keep being your own advocate.
Donna: I believe the woman sitting there had a comment too. Did you have a comment?
Speaker: It's long gone.
Donna: I'm sorry. I called on the wrong person, forgive me. Let's see. Did you want to speak?
Speaker: Yes, I did.
Donna: and your name is also Carol.

Transportation Disability Parking

Carol Perez: Carol Perez. I'm new at this game. And I have found I do all my shopping, one of the things -- let me go back a little bit. I became disabled last year. I have a progressive disease. I have -- fearful with the ramp and most places you cannot get in or out. They make -- the handicapped spots are great for people that have handicaps, which is fine.
Speaker: But people in cars don't pay any attention to them.
Carol Perez: Van accessible. It says van accessible. It doesn't say van accessible only. And tons of time I have gone to the store and in order for me to get out of the vehicle, my husband has to park way down, drop me off, so that -- then I have to drive up. Cars can't see me, which is dangerous. And I was hoping that they could change the van accessible to just van accessible and not cars.
Speaker: exactly.
Carol Perez: I see many people in cars that I'm sure they have a problem of sorts but they can walk. I can't.

Accessibility Snow Removal

Speaker: they don't care about things like that. They really don't. If they did, they wouldn't park in front of ramps, and the idiot who does the plowing in the wintertime wouldn't push the snow in the front of the ramps or anything else. They are sitting on their brains keeping them warm.

Accessibility Stores

Carol Perez: Another thing that I was concerned about is that stores. I don't know what

the law is as far as is it just that they -- for disabled people they put the lines there and that's a disabled -- that’s it. Disabled people can go there and park. But they can't get in the stores because they can't open the doors. There's no way --
Speaker: What stores are you talking about?
Carol Perez: JC Penny, TJ Max.
Speaker: There are many, many stores.
Carol Perez: there are a lot of stores.
Speaker: the thing of it is --
Carol Perez: they should be automatic.
Speaker: I’m in this. How am I going to open the door? I can't do it. And I just don't understand why they don't have at least one door where you can at least push the button.
Charles: So what you are saying is these stores don't even have the automatic door opener?
Speaker: No.
Speaker: Not at all
Charles: do they have -- is there a door that's wide enough for a chair to pass through?
Speaker: yes.
Charles: but there's no way to open the door?
Speaker: no way to open it.
Charles: and other stores do you find they have the revolving door entrance --
Speaker: like hospitals, that's about it. There are a few stores that do but there -- it's not that many that I have come across.
Charles: you really can't even enter the store because there's -- the door --
Speaker: I can sit there and wait until someone comes. Or I have to have my husband with me.
Charles: these stores, are they major stores?
Speaker: yes.
Charles: you identified one. Some place like stop & shop?
Speaker: they have the automatic doors.
Speaker: but TJ Max?
Speaker: TJ Max is one. Pier One Imports. I went there the other day. That's another store.
Charles: have you ever addressed this with the manager or anyone?
Speaker: well, I did at Wal-Mart about the van accessible. And he was going to get back to me. And I called and he never got back to me.
Speaker: still waiting.
Speaker: I’m still waiting for that.
Charles: how long ago was that?
Speaker: I would say about a month ago.
Speaker: they are tied up with another lawsuit right now. Class action, thousands and thousands of women minorities. You and I can talk after. I would be very happy to talk to you 28 about doors.
Speaker: another thing I noticed when you go into the stores, you can't get around them. I went into jc penny which I go into quite a bit and they did have some sales. I have quite a few grandkids and --
Speaker: it's hard to get in between the clothes.
Speaker: there's no way. You can't even get near them.
Charles: are the aisles are too narrow.
Speaker: narrow isn't the word.
Charles: I know a lot of stores have a very bad habit of putting merchandise on the floor.
Speaker: but I thought there was a code. If there was a fire there and I hit something and knocked it -- I would never get out.
Charles: there could be a fire code issue. I don't know that off the top of my head, but I could find that out. But there is -- for example, in Massachusetts, CVS was sued because the aisles were not wide enough for people with wheelchairs. So people who use chairs couldn't even maneuver to get down the aisles let alone -- getting into the store was fine. But that's as far they could go was the entrance because they couldn't maneuver.

Speaker: I did that -- excuse me.
Charles: they settled with the people who sued them. So they are supposed to be widening I think their aisles and doing something with the things at the end I will refer to as end caps. I think they were also getting in the way.
Speaker: but the racks of clothes. I can't even squeeze through them.
Charles: I know that's a problem.
Patti: that's true.
Speaker: what's the sense of going to the store if you can't shop?
Charles: I lost my son there once because he ducked because he was small. I know what you are saying because you can't see anything. You can't maneuver through it. And it does get very difficult. It could be a fire hazard.
Speaker: And I went into Pier One yesterday and I got in the door but that was it.
Speaker: you couldn't go through --
Speaker: there was nowhere to go. I would be knocking -- I would have been knocking glasses and dishes. I mean, the store is so packed. There was another store I went into yesterday also, and they had so much stuff in there.
Speaker: you couldn't move.
Speaker: I mean it's a danger even if you brought a child in there. And these boxes were all stacked up so high. If somebody ever hit them --
Speaker: what store was this?
Speaker: it could hurt them. And kill them.
Speaker: Pier One --
Speaker: it denies you the accessibility of shopping for goods. You can't shop. We had to leave a few places without the items we were looking for.
Charles: okay. That was simply because you couldn't maneuver through the store.
Speaker: you are not trying to take anybody's living away. Naturally if you own the store yourself, you can easily see you would want to put as many things for sale as you could. But there's a balance in there somewhere where you have to have access to the merchandise on the shelves. And we just simply can't find it. I'm Frank Perez. I'm Carol's husband. And you know, I know there are different things to do. If I could make a suggestion. You folks are looking for ideas. I might suggest that you have the state grant you all a wheelchair for a day and take a ride around, you know, for a whole day.
Speaker: I'm with you on that.
Speaker: and you know what? You wouldn't have to -- it would really open your eyes to the problems. Now I apologize for being late. We wanted to be here on time, but I don't know what I missed and I don't want to be redundant and mention something again. But somewhere in the planning stages in licensing when you make access to a building. Now you mentioned earlier about keeping the town quaint and good looking and that sounds great. But we have doctors, a lot of doctors in the state and they rent like old colonial buildings. This town is full of them. There may be two or three or four doctors in the building. You go through the main entrance and there could be three doors, all facing you opening the other way. You go in the door. Picture the colonial; you know how wide that is. All the doors to the other doctors' offices open towards you. You've got to stop there, try to figure out how to maneuver, get in everybody else's way to open this door here. what I'm suggesting is somewhere in the licensing that, you know, if there are colonial buildings, you want to keep the charm and make access, at least the entranceway should be so you wouldn't get trapped in there or it would be easy to get to all the people in the building.
Speaker: in other words, be able to move around.
Speaker: it seems like -- you know, before the problem, so it's not another expense to face afterwards to fix it.

Transportation Disability Parking

Patti: I agree with you on the majority of the things that you have said. I know from my own experience with the school district here in the community that basically when they put down a handicapped parking sign, it's not necessarily nearest the entryway. they have moved them from the back of the high school where it was behind a dumpster now over to a regular parking area, which means the wheelchair person has to get out of the car, either go in the road or go between cars that are parked to get to the ramp which puts you in the back door, which is so outrageous.

Speaker: I know.

Patti: I can appreciate what you are saying on there. And I think things need to be done and I think people need to be held accountable.

Speaker: Yes.

Patti: accountable should be before now, but we need it now.

Accessibility Snow Removal

Speaker: I know what you are saying. Before Carol got into a power chair, we had a regular push wheelchair. And there's a difference between the two. We can go places with this chair that you can't go with a push chair and a lot of the establishments have weather barriers, thresholds that stick up to catch the cold air. Well, they just -- you go with a regular wheelchair, it's like someone mentioned earlier about the bricks. They stop you cold. And more than once I had to hang on to the back of the chair when it's going forward. Because I was going too fast. But I mean, it's -- it seems like somewhere in the beginning, in the building inspectors that that would not be allowed. There wouldn't be these built-in stops when they remodeled or whatever. They could put a different kind in.

Patti: you know,

Accessibility Stores

I would also like to add to what you were saying about shopping in the store. I think you mentioned j c penny. That the thing that used to frighten me using -- go up in a wheelchair in the past was the racks themselves are at the height if you turn around in a wheelchair, you are going to get it right in the eye.

Speaker: Exactly.

Patti: It's a very -- you know, they just don't -- first of all, there’s not enough room. And we are not talking about the regular pathway that's all tiled and smooth. We are talking about once you leave that to go and look at a rack of clothing, you can't get your wheelchair through there because they put everything so close together that there's no maneuverability. And that presents a problem. But the eyesight business scars me to death especially at the height that you are and the height that you are in your wheelchairs that -- it's not safe for you and I’m worried about that.

Speaker: When I go in, I wear my glasses.

Patti: yeah.

Speaker: That way if something hits it, it won't hit me in the eye.

Speaker: I think to that -- like I said, I never -- and I think there's a majority of people out there that never gave -- you see someone disabled and you feel bad for them but you don't give it a second thought. You think about it for maybe a little bit and you look at them and you feel bad. But --

Speaker: But they don't want to bother giving you a hand with anything.

Speaker: well, not just that. I think the thing of it is, is that there just aren't enough -- I don't know if it's laws or things spelled out properly so that handicapped people can be like regular people, go into a store.

Speaker: What I think, I don't think a lot of people know how to read or they just don't give a damn.

Accessibility Rest Rooms

Speaker: Or another example is we've had an awful time because I can’t walk the bathrooms they put in. These little -- they're little -- what do they call them?

Speaker: Safety bars.

Speaker: safety bars with the toilet is a regular toilet. You might as well be sitting on the floor.

Speaker: they think putting bars in it makes it accessible.

Speaker: exactly.

Speaker: that's not --

Speaker: Why can't they put a high toilet in it? Why can't they put bars not just on one side, all around it? I mean, in a place where when you go into the bathroom that's handicapped that you can go in with your chair and turn around. I have been into some of them you would have to be a magician to get in there.

Speaker: Oh, yeah and a lot of times people who are not handicapped are using handicapped bathrooms. I think whoever does that should get a fine at least because, you know, they are in there. And they are taking their sweet time and I’m turning inside out. Anybody would be turning inside out. A station at Kennedy Plaza or anywhere. I mean it's not right. They've got their own stalls and we have ours. And they bring their kids in there with them to either change them or something. But there's changing places in the bathroom sometimes. But they don't bother using them.

Accessibility Disability Parking

Speaker: And on the van accessible, my husband came up with a good idea that maybe when you do get your sticker, it should have your picture on it. Because there are so many people that -- in fact that Wall-mart it just happened recently that this man was using his father's sticker. He got out of his vehicle, walked right in.
Speaker: In a handicapped place?
Speaker: and he walked right in, did his thing, and came right back out. But he got caught, police apparently was called. I --
Speaker: that's something you don't see too often.
Speaker: I'm saying to myself, maybe if the picture was on there.
Speaker: Exactly.
Speaker: People would give it -- people -- I know somebody that had a handicapped sticker from her husband. He's been dead for 15 years, and she still parks in the handicapped spot. Nothing wrong with her.
Speaker: A photo would eliminate that whole issue.
Speaker: That just doesn't make any sense.
Speaker: You know, pardon me. When you get your driver's license, they take your picture. The same building when you get your handicapped sticker can put your picture on it the same way. You know, a little different adaptation, you know what I mean. Instead of the little card for the license on your handicapped card could be done the same way.
Speaker: But it also has to be waterproof.
Speaker: So it would eliminate a few problems. And if you ever adopted the van only or whatever things like that, when you are applying for your license, that would be part of the instruction that you received, you know. I didn't know that it would be in your license -- you don't park so close to a fire hydrant. You don't park so close to a corner or do this or that, that it would be in there that there are van accessible only spots or whatever the situation called for. I'm certainly -- this is not the only –
Patti: no. But I tell you what. I'm a member of the disabled American veterans association here in westerly. And one of the things we asked the police a long time ago is would they give us the right to give out tickets so that if we were driving and we happen to want to get into a handicapped situation and we could not, we wanted to be able to say, I hope you realize you have taken someone's spot and here's your ticket.
Speaker: Like citizen's arrest?
Patti: absolutely. And I don't see anything wrong with that. Take a picture. Have a little camera with you. Take a picture of the car, where it is. Write them a note and turn it in. It's too often you come out and say, I was there for five minutes. I don't care if you were there for 30 seconds, you don't belong there. There has to be a way if the police department is shorthanded and they don't have the time to do that, maybe an organization should be able to help out in situations like that where they shop all the time.
Speaker: you know what I think part of the problem is, and it goes back to money, stores -- forget the handicapped parking. Just go to stop & shop and look at all the cars parked in the fire lane. And there's no room, there's no room for two rows of traffic and people walking with children, let alone the handicapped in the chair and not seen and everything else. But you don't see any police in there moving cars out of the fire lane because it's bad for business. There's no phone calls made. You know what I'm saying?
Anne: I'm going to just chime in while we are talking about parking in areas where you shouldn't. It's a big problem for the buses too with people parking in bus stops, which means we can't deploy a lift properly or if there's no curve cut someone has to go down the street and come back in the middle of the street to get on the lift. We have a big problem with not parking -- no parking signs not being enforced in bus stops as well.
Speaker: On -- what was your answer to the request of ticket?
Patti: as far as I know, the answer that we received -- I didn't have -- I didn't get it directly but through another member was that they would think about it. Now we are two different police chiefs away from when this was asked, maybe even three at this point. But I --
Speaker: Three years ago?
Patti: I didn't think there is anything wrong with people that do have a handicapped parking permit in their car to say you have parked illegally. I have been given the right to give you a ticket. Here it is. Maybe next time you will think twice. I think that's an issue that should be brought up especially if you have an organization,

which we do have --
Speaker: I will join it.
Speaker: You have to be a disabled American veteran to join that particular one.
Speaker: because I'm in a wheelchair, I don't have to be a veteran too.
Patti: this particular organization is called chapter 6 group, disabled American veterans.
Speaker: That's –
Patti: that's about as tight as I can tell you on that one.
Speaker: Okay. So in other words, you have to be a veteran from the war to –
Patti: you have to be a disabled American veteran to be a member of that group or the spouse of one to be in the auxiliary. I am not an auxiliary member.
Speaker: can you have people looking out -- pardon my language but assholes that do that?
Speaker: where I live in Minnesota --
Speaker: a camera with me when I go out.
Patti: that's wonderful. Do it peacefully. You don't want to get in a position where someone is going to come and get you or something. Take a camera.
Speaker: If I saw somebody in trouble, I will intervene.
Patti: take a camera with you and take pictures, perfect. Nobody can say, no, I wasn't there. If you have the picture and you have the sign in front of that and you are taking the picture from the rear of the car, you have the license plate and you have the place in front that says handicapped parking.
Speaker: And also take a picture of the windshield proving there was no sticker.
Accessibility Stores Speaker: And one other thing I wanted to bring up, even like going to Wal-Mart, there is plenty of area between -- aisles. But you have somebody coming the other way, I mean, forget it. There's just -- they're not wide enough.
Speaker: the aisles aren't wide enough.
Speaker: no, they don't make them wide enough. And then you get the people that just leave the carriage there and walk around and come back and get it. And by the time I have to pull in, I'm able to back up, back out, and I have to watch that I don't hit anybody.
Speaker: Like you were saying about the eye in the rack.
Speaker: It is.
Patti: I thank you -- excuse me. I think one of the issues that people do the minimum, minimal to meet any standards. Many times they are not even doing that. They have to take a blue sign, stick it on the bathroom door and say that's accessible. Well, gee, it isn't accessible. If you expect to get in there and turn around, that's b s. Sorry but it is.
Accessibility Rest Rooms Speaker: I go to Mass General and I go to the old navy yard because that's where my doctor is. We had to use a bathroom there.
Speaker: Nightmare?
Speaker: It was horrible. Totally horrible.
Speaker: This is in a hospital?
Speaker: This is a hospital
Speaker: What?
Speaker: Oh, yeah.
Accessibility Disability Parking Speaker: What are they thinking? And like you say, it is minimal. They put those blue stripes out there. I did my thing, disabled. They're all set. Who cares if they can't get into the building? You sit out there and wait, someone will come along soon to open the door for you, you know.
Patti: I can match you on what that used to drive me crazy with the school department here in westerly that would be if it snowed, there was no longer a handicapped parking spot there. Anybody could park there and everybody in the world knew it because they taught in that building for years. Once it snowed, space is none available.
Speaker: that's not right.
Patti: no.

Speaker: that's why I'm saying, I'm new at this. I just think that there's got to be more done. There really has to be more done. And to help disabled people, I just can't imagine why it hasn't been addressed before. And it seems like the only people that address it are disabled people, and I'm one of them. I never thought about it last year when I was walking around and I was fine. But I definitely think it has to really be pushed and pushed and pushed. And something has to be done.

Accessibility Government Services

Patti: you know I can't speak for the state because I don't work with the state in particular, but just as a resident of Westerly, I think we need to have an ADA person that is part of our government structure here in Westerly where you can go and say okay, here I am. I would like to take you around to places I have had difficulty so you can take action and correct this. And I think what we need to do is have somebody go out there. We did it in the school department. It was kind of -- oh, we have to change this? Yeah, you do. It says so in the book.

Speaker: Everybody gives you a look like –

Patti: Oh, yeah. But you know, like you said, take the reigns and do something. Find out who the ADA person is in the community here, if we have one and say, would you spend the day with me? I'm going shopping. Come with me and let me show you some of the things that I have to do that's wrong.

Speaker: And does Westerly have an ADA?

Patti: I don't know. You would have to call the town hall and find out. I'm not sure.

Casey: For -- if there is a church or any kind of public building that is interested in whether they are accessible or not, they can contact either OSCIL or PARI independent living center to have accessible assessments done. They can also contact the Governor's Commission for the same thing. So there are people within the state that can provide them. I know that PARI has done them and I'm assuming OSCIL has done them in the past. And I know that there was a project through the Governor's Commission on Disabilities that did accessibility assessments for different, you know, different venues and things like that. And the other thing is to, you know, do what you are doing today, which is to come and bring up problems.

Speaker: I think this gentleman over here in the red shirt had a great idea. Hurt the people who make these bloody rules. Put them in a wheelchair and let them go through what we go through for a month.

Speaker: How about statewide political wheelchair day. Provide all politicians with a wheelchair.

Speaker: Exactly.

Speaker: Why not?

Speaker: Stay for one month and try to get into the bathrooms that we try to get into that aren't big enough to get a wheelchair in. If you can't trust your legs, you have to pull yourself up and hold on at the same time and move. Sometimes if your leg doesn't want to move, you have to force it to move. If somebody's in the bathroom, you know, you have to stand there until they come out if there's only one stall.

Speaker: If you can get in there, you sure can't close the door.

Speaker: what did she say?

Donna: you can't get in the bathroom. You can't close the door

Speaker: I know if you are acrobatic you can push one --

Donna: okay. Let me just make one additional comment about the Commission on Disabilities. I know that they not only have a program that will do the evaluation for accessibility, but they have a person who will actually work with an architect when the building is being renovated. So we had that -- we called on them for one of the senior centers that needed a lot of accessibility work and they were very, very helpful working with the architect directly.

Speaker: I wish they did that with Babcock village. I wasn't planning on ending up in this thing.

Donna: Cecilia Murray.

Family Support Resource Directory

Housing Assistive Living

Speaker: I just had something to say. Eight months ago my son had a stroke at 28 years old. And there was no place after we got through the initial hospital part in the short-term rehab. There is no place in the state of Rhode Island to go for long-term rehab. Absolutely none. The only places that there are, the closest one would have been in New Hampshire. And we are a very close family and I strongly felt that family involvement was going to help his recovery. And if he was in New Hampshire that wouldn't have been possible for us. the only option that we had after a month at the Rhode Island rehab center, because once again I was told by them that they're short-term. By a month they meant are short-term. A month at the regular hospital. The only options that we had then were at 28 years old is send him to a nursing home for four months. At 28 years old, a nursing home is not an appropriate placement for someone with brain injury. He -- he stayed four months. They didn't know how to handle him. They didn't know -- they just didn't know what to do. They had never had anybody that young come in with a brain injury that -- and they weren't prepared for it. After four months he came home and he's doing well now. He's involved with Sargents. but the point is there was no place, absolutely no place in this state of Rhode Island. I know the state's small. But -- that we could send him where we could have all been involved as a family. And a nursing home to me wasn't an appropriate placement for a 28 year old person. He didn't have anything in common with anybody there. It just wasn't appropriate.

Speaker: and the people there didn't know how to take care of him.

Family Support Resource Directory

Speaker: the people there didn't know how to take care of him properly either. They weren't trained to deal with brain injuries. They weren't trained to deal with 28 year old people that had a stroke. His needs were different than the needs of an 89 year old lady or, you know, an 89 year old man. He just had different needs. And they didn't know how to deal with it. and I just really feel that in this state of Rhode Island that they need -- believe me, I never thought that I would be -- I never thought that I would have to come and do something like this. I just -- in the state of Rhode Island, there's got to be some place where you can send people with brain injuries long-term. Even North Smithfield was an hour ride for us, an hour up and an hour down and we went every single day. That was the closest we could get him. And even some of the support systems, no one ever told us. We had to find out from friends and I found out myself. I found out through a friend about PARI. I didn't know about that. There was -- there needs to be some way or somebody that's a contact person that can say this is what you need to do. These are the resources that can help you. And then give them a call. I just -- I just think the state is way behind on those kinds of situations. We are way, way behind. Because there's more and more people out there that have brain injuries and there's more and more people -- and there's younger people.

Speaker: Unfortunately.

Speaker: Excuse me, younger people that are out there with no place to go. And they either end up in state hospitals, which was also an option for us, which was not going to happen; or they end up in a nursing home. And it's not fair to them, and it's not fair to the family. So I just -- I just thought it was important that you know that there's nothing in this state. And I think we are very backwards when it comes to that.

Speaker: believe me, this is not the only state that's like that either. Take your pick.

Speaker: I just think it's very important that everybody know that there's nothing in this state.

Bill: have any of you who are looking for resources tried calling the Governor's Commission on Disabilities? I can suggest that as an alternative. The person who answers their phone most days is called Terry Carr. I have -- she maintains a list. Everything that was mentioned here today: PARI, OSCIL, she knows those contact people and can funnel you.

Speaker: But when this happens to you, you don't know about these things. You depend on everybody else.

Speaker: There should be -- the social worker at the hospital --

Health Care Resource Directory

Speaker: We had a social worker in the hospital. She never sat down and did a discharge plan for us. She never sat down and said this is what she is going to do, what you are going to do. These are the places you can call for help, never. Absolutely never did she ever sit down with my husband and say and say these are the organizations that can help you. I didn't want her to call. I was going to call when my son was at the nursing home, I did his discharge planning. I did it. They didn't do it. I did it. I made the phone calls. I set up the appointments. I went to the meetings because after seeing what I saw at the other hospital, I wasn't going to leave it to anybody else. If I wanted it done, it was going to get done by me. If I made a mistake, it was my fault. It wasn't going to be anybody else's.

Casey: I just have a question. So neither the acute hospital nor the acute rehab gave you community resources that you might need down the line?

Speaker: I found out about PARI through a friend of my son's, and that was how I found out about PARI. And they have been very helpful but I -- nobody, nobody sat down with us with brochures, which I saw 100 of

afterwards. No one sat down and said, this is what you can do. These are the options.
Casey: How did you find out about the Brain Injury Association?
Speaker: on the internet.
Casey: On the internet. So basically you think it had been brought up before but probably PARI, OSCIL, the Brain Injury Association, and other organizations. We need to do better outreach.
Speaker: Definitely. But it's not -- I don't think it's up to PARI to do that or if it's up to any of the other organizations. It's got to start at the hospital because that's where the crisis is.
Bill: there is -- I know they just started it inside the front door of the hospital, a resource room with all sorts of brochures on illnesses and any kind of health related issues. I think they're trying to make an effort to do that, whether they have the appropriate stuff there, don't know. But the next time you are in the hospital you might bring that up -- I think Dianne Brown is the person to -- the contact person there for that resource center. they have a couple terminals in the room for internet access. you can sit there in the hospital and get the information. The room is full of brochures on health related information. It may not have exactly what you want, but a good -- good word in for them. I'm sure they would like that to be a complete resource center as possible. please feel free to do that.
Donna: Before you came in I was talking about the aging and disability resource center that is in -- under planning and design phase right now. And I'm glad to know you used the web because it will have a website. It will have information for elders and for adults of disabilities like your son. we at the department of elderly affairs have over the years made a lot of attempts to work with hospital discharge planners with limited success, and we're not sure exactly why. But when we -- what we have tried to do is talk to them about elderly people who have needs other than just to go to a nursing home, who have mental health challenges, who have addiction problems, who have brain injury that goes beyond the type of dementia that most nursing homes are equipped to handle. I'm not sure what it is. There's a lot of turnover in discharge planners for one thing. And we're aware that's a problem for the elderly and now I'm aware that it's a problem for the adults with disabilities as well. But it's very much a problem.
Speaker: Because you have to remember that the family is almost still in a crisis. It had only been two months for us when he was at the rehab hospital. I mean, the information that people were giving us, we were on overload. Some of the information that people would say, you don't remember it. You are exhausted. You are driving an hour every day back and two hours every day. And it's just -- you need someone to sit down and really take the time to really make sure that you know what's available out there because I didn't know. and even.

Transportation RIde

We just had a disagreement with the RIPTA people over the bus scheduling. Now I was under the assumption and so was everyone else when he started Sargent's he would be eligible for the RIde program. Well, when I called back two months later and I gave them the start date for Sargent's, they informed me that he wasn't eligible because we didn't live within three quarters of a mile of a fixed bus stop.
Anne: The Sargent -- there's -- I need to explain the RIde program.
Speaker: I know. I don't mean it -- but I -- we were under the assumption for like two months that that's how he was going to be getting to Sargent's because there's a bus that goes by my house every day at 3:30.
Anne: Is he working with voc rehab?
Speaker: Right now he just finished his ten-day evaluation.
Anne: Steve, could you talk to her about the transportation options under voc rehab?
Speaker: I can talk about voc rehab. That's an organization that helps individuals with disabilities to return to work. If your son has already applied for services and found eligible, he can work with RIPTA to help provide transportation for him, for training, for work sites, et cetera.
Speaker: when my husband was -- don't mean to interrupt. When my husband --
Speaker: Did I answer your question?
Speaker: In a way. But it doesn't pertain to him right now. We did end up finding out through PARI there was another service that would come and pick him up. But otherwise I would have had to bring him to Warwick every day and then pick him up, which -- in a working family doesn't work. We did end up getting -- because he has Medicaid.

Speaker: He's all set now?
Speaker: He's all set now. But it's something else to put a panic on you all of a sudden because you think, okay, it goes by my house every day. He's eligible. He has a disability. It's okay. You are going to do this and then you hear, no. And it's like okay, what do we do now. All set. It just adds.
Donna: Go ahead.
Speaker: That happened with my husband too when he worked at Stop & Shop. He was two miles from work but he couldn't get any transportation either.
Donna: This is Carol Compson again.
Anne: where was that?
Carol Compson: In Hope Valley. We couldn't get any transportation.
Anne: there's no transportation in hope valley.
Speaker: It would seem to me and make sense to me the people in rural areas need it more than people that live within three quarters of a mile of a bus stop because if you live within three quarters of a mile of a bus stop --
Anne: Let me take a minute to explain that because it's confusing to a lot of people. First, the RIde program is a number of different services. Voc rehab pays for some trips. The service you are talking about is the Americans with Disabilities Act and that mandates complementary paratransit service for people near a fixed bus route whose disability prevents use of that bus route. That's why it existed within three quarters of a mile. It's for people who could use the bus but because of their disability they can't get to and from bus stops because there's no curb cuts. They can't cognitively 51 navigate the system. They would have access to the system but their disability prevents it. It's not in addition to fixed routes. The theory is if you have no access to transit then you have no access to transit. ADA 's only to pick up the difference between -- for the people who are near the fixed bus route. What we need are options for people who don't live where our bus routes can go.
Speaker: It shouldn't matter where they live as long as it's within the state of Rhode Island.
Speaker: To get appointments
Speaker: The help should be there.
Anne: We need better transit in the system period. But ADA is specifically for that purpose to provide the transit service for people who could have access to it if their disability didn't prevent them accessing it.
Speaker: I did send an e-mail to jack reed. And I got a very nice letter back and he did contact Doug Wood who is the administer and you know explained --
Anne: Doug worked for RIPTA.
Speaker: He explained about the rules. That's how upset I was at the time.
Anne: it's understandable. Our rural areas do need some kind of service, particularly people with disabilities or other people who don't drive for whatever reason. They need services in rural areas. we don't have the funding for it. But the ADA service is specifically -- it doesn't serve anybody with a disability. It serves people whose disability prevents use of a fixed route system. and you have to be within the corridor to get those trips because it has to be equivalent to the fixed route.
Speaker: Buses -- the bus I see going by my house are for like seniors or to medical appointments.
Anne: In Westerly there's no ADA service because there's no fixed bus route. Department of Elderly Affairs pays for trips for adult daycare, pays for some trips for medical appointments. MHRH pays for trips to the Olean Center. The RIde program coordinates all these different programs so we can use the same vehicles and get more bang for our buck basically. But the ADA service, it is contentious because -- but that's what it's for. What we need is more service all around.
Speaker: It's almost like he's being discriminated against because of where he lives because we live in Ashaway. You live in a rural area so, you are not eligible for the RIde program.
Anne: right.
Speaker: Because of where you live.
Anne: if you are eligible for --
Speaker: It's not discrimination. But it's if I lived in the city of Providence I could take the RIde bus.
Anne: You could take a regular bus too. The whole thing is if you can take the regular bus you can take the ADA service if your disability prevents use of -- it's equivalent to time and place. it's -- because we can't fix all the streets, so people can pass them to get to our buses. We can't fix other things. This is the federal

government's way of saying everyone deserves access to the transit system you have. It doesn't create more service than what we have.

Speaker: May I speak? I haven't seen my doctor, my family doctor in eight -- maybe eight months, a year. I lost track. Because I can't get there.

Anne: Is your doctor in Westerly?

Speaker: he's at the -- what's the word that was -- valley something.

Bill: Hope Valley

Speaker: Thank you. I knew there was a valley in there. I can't get there because the bus doesn't go there. Also cabs will not pick me up anymore because of my chair. So I haven't seen him for almost a year.

Anne: The only other option for medical trips for people with disabilities under age 60 is through the department of elderly affairs transportation. But you have to be Medicaid eligible to take advantage of that if you are under 60.

Speaker: Well, I don't think I am going to reach 60 because I’m dying.

Anne: are you Medicaid eligible; do you have Medicaid?

Speaker: Well, I’m not 60, I’m 42.

Anne: but do you have Medicaid?

Speaker: For now I do.

Speaker: Then you can get --

Donna: You are eligible.

Anne: Then you are eligible for trips through the RIde program paid for by the Department of Elderly Affairs for medical purposes.

Speaker: To Hope Valley?

Anne: For medical trips.

Donna: That's correct.

Anne: How she would get certified for that.

Donna: I don't know how she would get certified. I know where she can call and find out.

Anne: It's in those green books

Health Care Medicaid

Speaker: I don't even know if I will have medical or anything else covered because social security decided that I’m no longer disabled and that I’m able to go back to work.

Casey: If you have Medicaid, it's just based on your income.

Speaker: Which is $460 a month.

Casey: So you are Medicaid eligible. It has nothing to do with whether you have been declared disabled or not.

Speaker: I get my last check in August because they are cutting me completely off from everything.

Casey: From disability?

Speaker: They tell me I’m no longer disabled.

Casey: Medicaid is a separate medical program and it's with income eligibility. So it has nothing to do with your SSDI whether you –

Speaker: I don't get SSDI . I just get plain Social Security.

Casey: Medicaid is a separate program and it has nothing to do with SSI or SSDI. But we can talk to you about that later.

Speaker: okay.

Anne: But there's a number in that book you can call to get trips for medical appointments.

Speaker: I can't see that.

Donna: This isn't big enough?

Speaker: my -- I –

Donna: I will write it even bigger for you.

Speaker: Do you have color coded?

Donna: I will write it in blue, will that do it?

Speaker: If you use another color afterwards. If you use the same color all the time, the page will look that color. Donna: okay.

Speaker: I did a lot of experiments when my vision started going south.

Kristen: Carol Compson.

Employment Job Training

Carol Compson: Yeah. I had a question for Steve. You mentioned voc rehab and they provide transportation.

Steve: Individuals who are interested in going to work or maintaining work.

Speaker: That's -- my husband got the job at Stop & Shop.

Steve: Voc rehab.

Speaker: Yeah. That was in 2000. But then he still couldn't get rides.

Steve: He couldn't get transportation. Is --

Speaker: Not now.

Steve: You can certainly call us. Did he lose his job?

Speaker: Well, he wasn't able to keep a job.

Steve: We can help with transportation. We can talk afterwards.

Housing Assistive Living

Speaker: He's in New Hampshire now. I don't know if he will ever come back because you know, he's up there and they are going to try to get him into a satellite home, a group home. But my idea is I would like him in Rhode Island so I could see him.

Steve: Right, sure.

Speaker: But there's no group homes here for that situation.

Steve: Housing's an issue.

Speaker: Yeah. If he does come back.

Speaker: Thank you.

Donna: We are through all the people who signed up to speak. is there anyone else who wants to say something who didn't sign up? or any other testimony, even if you have already spoken. Any other comments? Yes.

Transportation Disability Parking

Speaker: I think someone who gets a handicapped sticker, I think there's a lot -- just getting a sticker is enough. There's a lot that you need to know with that sticker. This is how you use it. this is how you do not use it. This is how people who know that you always carry one think they can park in a handicapped spot when you are not getting out, which I keep telling people you can't park there because I'm not getting out. You can't park there just to make it easy for you. So, I have to reemphasize that. And I think they finally all get it now. not everybody knows that. There's a lot of different rules that would make it easier if people who have the sticker would follow the -- you know, the rules. I mean it's a whole bunch of them.

Speaker: If I may make a comment on this lady speaking. Gone to a parking spot, van spot with the ramp area and had a guy park right where the ramp comes down. I said, you can't park there. It's a handicapped spot. He said, no. You are in the handicapped spot. this is not a parking area. He walked in the building.

Speaker: I see -- if I’m going into any stores or anything, no matter where I’m at and I see somebody pulling in to a handicapped parking, and I see them getting out and they are not handicapped. I say look, that's for people who need it. You don't need it, so move it. I speak my mind. I don't care if I’m talking to --

Speaker: On that comment. I think the normal person without disabilities doesn't understand -- I drive a special needs bus so I do drive wheelchair students. And I understand that not only do you need room for that ramp to go down, you need room to get that wheelchair off of the ramp and the lay person doesn't understand that. You know, I know that at Chariho, at the middle school they redid our handicapped parking because when they first did it, they didn't have it wide enough for that. And they realized their mistake and over the summer they fixed it.

Speaker: Wouldn't you agree -- going right back to the state level in the manual getting your drivers license if that were printed in there, then there's no excuse --

Speaker: The lay person needs more education on that and on school bussing, yeah. Yes.

Casey: I think there are instances where people that have a handicapped placard may not technically look disabled to one of us and we don't really know that. There is a possibility they stole it. there's also a possibility that they have an extremely bad cardiac condition and they can only walk a very short distance. I would say we should be angry at people with no sticker that is going in there but not jump to assume that somebody doesn't have a more hidden less obvious disability. there's also people that have wheelchairs and need the same amount, maybe not quite as much but the same amount of extra space just like a van does because they have

wheelchairs, but they happen to drive a car. But they need room to toss their wheelchair in and out and things like that. So they also do need the spaces. but there are people that have more hidden disabilities with that placard.
Speaker: absolutely.
Casey: so I think we need to be angry at the people who have no placard first.
Patti: I thank you for that because that's a very good point. It really is.
Speaker: That is true.
Speaker: Can I ask?
Speaker: I wanted to add to that Casey. Thinking about the cardiac. You can't outwardly say the person is handicapped. But when my husband and I first had the accident, he was really out of control. And when I first took him home after he had been in the hospital for 14 months, I had to take him to doctor appointments. So I had a handicapped plate for him. And I'm sure that people saw us walking into the doctor's office, you know, parking in a handicapped spot. But I needed to have that so that we could get in quick and get into the doctor's.
Speaker: Absolutely.
Speaker: That's the same with my son because he's -- he does have physical disabilities and he does walk. Casey, you have seen him. his walk is funny. His gate is funny, but it's more in his hands. but we do have a handicapped spot -- plate. But I don't -- people have starred at us when we have gotten out of a car because here's this young boy who, yeah, he's walking with a little bit of a limp but so what. And there's another woman that doesn't look handicapped and we actually had people stare at us. What are they parking there for. but there are reasons that people need that spot that don't -- aren't in wheelchairs. And the other thing is when he gets out of the car because of his cognitive deficits he will walk right across the street. So I need some place that's close where I can coral him to get into the store safely. so you can't always see a deficits and it makes the person feel funny, feel strange when they are being stared at.
Speaker: When they stare, tell them to take a picture. It will last longer.
Speaker: I agree with that as far as that. My main concern was the van accessible. I mean, there's got -- maybe it has to be more.
Casey: more --
Speaker: There's like two or three. I think there has to be more. and just what you said, I have seen people with wheelchairs in small vehicles get out and that's fine. But I have also seen people and there's tons of handicapped spots where they can park and they get out and like you say, can't walk that far. That's fine. I have no gripe with that. The only gripe I have is I have to go down to the end of the place where there's no cars in order for me to get out. then I have to drive up and worry if I will get killed. Nobody can see me. And I think, you know, maybe there has to be more. And it's not just in Rhode Island. I think --
Speaker: It's all over.
Speaker: It's every where.
Speaker: The whole country has to get on the bandwagon.
Patti: I can give you another side of that story as well. Let me think. Bradford school system when you first pull in there, they don't have signage out there that tells you where the office is and where you need to go. But they do have a spot that says van access, van access, not a regular parking area without the van. the problem is you get out, you get yourself all ready, and you go to that door. That door's locked because the office is now way down at the other end of that building. But they don't have signage to tell you that. That is irritating for people. You know, I asked them to please do something about that. I think they are waiting for me to go through the building with them and show them, this is where you need to look, et cetera. but the school systems in westerly are -- they need a little bit of an adjustment, big adjustment actually. Those are two sides. You have to have other things other than van signs as well.
Speaker: Exactly.
Patti: A lot of good information today.
Speaker: Is it --
Donna: Denise

Accessibility Rest Rooms

Denise: Is it a law that for accessible bathrooms. Isn't there a law for that?
Patti: In a public building? I believe there is a law that you have to have a

handicapped access bathroom. The problem is sometimes people think they get away with a room that looks big enough and slap that blue sticker on. They don't even get the pieces underneath the sink that have to be coded so you can't get burned when you are under there. They don't have seats high enough to shift from the wheelchair on to the toilet itself. They are too low.

Speaker: What kind of places -- is it somewhere -- wherever you spend money?

Patti: I think it's public in particular. I could be wrong. You can check with Bob Cooper at the American's with Disabilities Act, commissioner for the governor here in the state of Rhode Island.

Speaker: Because you check any beach, on the beach and you go there for a concert, you go there for whatever. You are not going there to reuse the beach. Not have handicapped accessible bathrooms. So if you are there for a concert, don't stay long.

Accessibility Recreation

Casey: For the beaches -- I can give you this too. I may have to get your address and send you stuff. For the beaches, some of them are private or town beaches but they're through the state beaches, you can go right on the net and get information about what beaches have wheelchair accessible boat docks, wheelchair accessible facilities. And there are some state beaches that also have accessible like chairs for people that use wheelchairs so they can go out. Some are self-propelled, some are that. But they are within the state, within the state beach system. There are some accessible facilities.

Speaker: But then you have to watch for the town beach that has a ramp, has the chair, the blow up chairs where you can go out on to the beach, whatever. Just don't use the bathroom because the bathroom is not accessible at all. So I mean, it's really weird. they got all this stuff but they don't have everything.

Patti: Is that from the state or from the town that's not accessible?

Speaker: Town beach in Westerly. Town beach has a beautiful ramp. The bubble chair that you can -- you have to transfer out of your chair into the bubble chair and that's when you go on the beach. You have to have another chair to stay in because the bubble chair won't stay with you and that's fine. That's great to have the beach. people say I never knew they had that. Yeah, they have that. But don't try to go to the bathroom because they ain't got that.

Bill: have you tried talking to the department of public works in town?

Speaker: No.

Bill: That would be a point of contact there. The beach comes under their domain.

Speaker: There's something -- excuse me --

Donna: Carol Perez.

Family Support Case Management

Carol Perez: I wanted to say you are saying call this person and call that person. And being handicapped, especially in my case, I mean, between going to the doctors, having people come in to help me, trying to visit with my children, grandkids, and I have been on the phone to different people. And oh, yes, we will get back to you, no problem.

Speaker: And they never do.

Carol Perez: It's just like a revolving circle. It just keeps going around then you finally get to the point, you know, what are you doing? You are beating yourself up. And nobody gets back to you. it's like -- oh, yeah. You ask their name and everything. They call back -- I always ask the name. And nine times out of ten, a lot of places or a lot of people don't want to give their last name out.

Speaker: Yeah, they don't.

Carol Perez: I don't know what the secret is. They are working for the state or the town. I don't know -- they don't want to give their full name out. If you call back and say, I talked to Patti. Well, which Pat? I don't know.

Speaker: In other words, they swept you under the rug.

Carol Perez: Yeah. There's so much. There has to be more -- things put out to help.

Casey: I think it's -- I think when the one-stop shop center is open that can be more helpful so you are not chasing your tail. I think the other thing I learned because I hate writing letters, but I learned that my phone calls -- if I don't keep a record and I don't write letters, it's meaningless. So I have learned to write letters when I feel strongly about something and to keep records. I never used to. and there's some things I think -- because having a disability is a job in itself, you do have to decide how you are going to use your time because it's kind of a job in itself. And I think picking the battles that are most important to you but also kind of keeping records. I went there. I did it appropriately. Now I can move to the Governor’s Commission on Disabilities and do this.

But kind of streamline your approach and do your record keeping, or decide that you don't want to spend that way. But I'm really happy whenever I see people come to something like this. That I think there are times when you can end up kind of all over the place. I think that's one reason like sending letters and keeping a record of them is a good thing, even if they are handwritten.

Speaker: And I do try to do that. And -- but it seems to me that all this record keeping that I keep and nobody calls you back. It just with Medicare alone. If I have a problem, I have one daughter that takes care of my car insurance because there's always a problem. and I have one daughter that tries to find clinical trials that are in Boston. I mean, I was trying to do it. I just couldn't keep up with it. There's so much. With the disease I have, I have to rest quite a bit. I have to rest during the daytime. And like get in a shower. People, we take it for granted. For me to take a shower, I'm wiped out for two or three hours. And that's hard because -- like you say, that's great in theory and I can't hold a phone too long and I bought all these different devices and it still doesn't work right. And -- but there has to be like you say some place that has all this so that people don't have to get overwhelmed by it. I mean if I wrote letters to everybody that these things are upsetting to me --

Speaker: It will never end.

Speaker: I would never be done.

Speaker: I have to say it's very hard in the beginning when you are trying to find all the information. When you are trying to reach people that you need to reach because as you say, people don't call you back or -- in my case I was working. So people would call me at work or people would call me at home and leave voice mails and I would have to call back. And very frustrating. When you are trying to run as normal of a family as you can in the meantime, it's very frustrating to have to go through all that. If there was one main -- like she said one main -- one-stop shopping that it would be much easier, much easier.

Donna: We have about 10 minutes left and I know that there are several people who wanted to get information from specific panel members. Would you like to do that now or does someone else have something in general they want to say? I don't want to cut anybody off.

Accessibility Rest Rooms

Speaker: Well, I would like to add one thing to the bathroom situation. One time I was in a regular wheelchair stall. And when I was lowering myself down, the seat moved. I mean, I almost ended up in the toilet because they -- people who take care of the bathrooms don't keep making sure that the seat ain't going back and forth on you.

Donna: Okay. what is your name?

Speaker: I didn't sign up to testify. I testified before to the commission for the deaf and hearing impaired when they were here in Westerly Library and I voiced my concerns. On very different experiences. I myself -- right now listening -- reading through here. It's very tiresome for me to sit for any long period of time reading, which naturally through education comes better understanding and when you -- hearing loss reaches the threshold and deafness. And you cannot understand voice in an educational environment; it becomes extremely difficult to learn when all you have is your eyesight to read and have to learn through reading. it's a proven fact that when you hear that information is taken into a different section of your brain than it is when you read. And that's, of course, a reader, it makes you a different person. You view the world from a different perspective than you do when you go to music concerts and you are taking music and everything naturally, of course. You have to make changes and remove yourself from various different things that were one time, very relaxing to you. Now the information is in place here, my –

Employment: Job Training

I came in here. Salve Regina University has now a professional program in rehabilitation counseling. The program at the 48 credits program providing the skills for graduates to empower people with disabilities to successfully find employment. And that is something that is desperately needed in the South County area because I for one went to vocational rehabilitation process in Providence and could not find paid employment in my hometown.

Speaker: Discrimination.

Speaker: I put up with five different volunteer positions that could have been consolidated into a paid position thus making me financially independent. And because one out of three of my daughters shared the same type of hearing loss, that is hereditary factor involvement. And I saw her go through local schools and she did not reach her potential in the westerly school system because again through better understanding, through better -- more education comes better understanding. and we need more people with better listening skills in this area. People who will listen and understand what we are trying to say so that no child in this country is left behind. And this is what happens because we did not receive the information and everything again another generation and the same thing happens over and over and over and over again. That we need to focus on what we have and we don't have, and stop labeling people because they wear a hearing aid or they are in a wheelchair or they come from the wrong part of town.

Speaker: She hit the nose --

Transportation RIde

Speaker: And I will tell you this goes all the way to Providence. I have personally e-mailed for information and received absolutely nothing from Providence. And my question is why. Why do the people in south county, Rhode Island, because we pay as many state taxes as anybody else, why we do not have the transportation that we need in this area. And we do not have the help that people in the northern part of Rhode Island have. And this has been going on continuously, continuously, continuously and continuously. We have absolutely nothing. You cannot tell me that when -- a catholic college in Newport, Rhode Island, is offering a professional program to people. it is time we get some of these young people going and develop their listening skills so they can understand that just because a person wears a hearing aid doesn't mean that they are not qualified to hold a job. Or because a person is in a wheelchair that they can no longer function. There's such a thing as a personal care attendant, if I believe so, right?

Speaker: Exactly.

Speaker: Sure. That is available to people who cannot do things for themselves. That information should be put out to people who are being exacerbated or exhausted by trying to do the best they can because these people are trying to do the best they can. And if everybody in this country tried to do the best they can, then we would have a much better country.

Speaker: Before I moved down here to Westerly I applied for a job at -- what was it? CVS or Brooks. It was a long, long time ago

Speaker: I’m tired.

Employment Discrimination

Speaker: and that was before the chair. So, I go in, way before anybody else is in there and talk to the manager. I hand them my application. We talked. And as I’m turning around I’m hearing him say, I’m not going to hire a freak. There's nothing else going on in the room. I can hear everything. And I turned around and said, who are you calling a freak? He didn't think I heard him. It's his word against mine, you know. I mean, people judge you because of -- the color of your skin, the way you hear, the way you see. It's not right. Especially people who run a business shouldn't judge you. Right now I don't have the energy to even get a job right now.

Donna: anybody else? I believe we have some people who want to talk individually to our panel. I want to thank the members of the panel for being here and, very valuable insights and information. And I especially want to thank each of you for coming today. Thank you for coming, for sharing.

Speaker: I’m glad I found out about it.

Donna: Okay. So the hearing's over now. And feel free to continue to talk.

July 30, 2004 - Salve Regina University

Dimity Peter: We might get started. I was under strict instructions to start on time but I know it was a difficult location to get to, to find the building and the location like this, so I would like to welcome you all here today and there's a few things we need to go through. The bathrooms, the corridor at the end and of course, you found the elevator or the exits that are on either side of the building. What I would like to do is to start the meeting by mentioning that the Governor’s Commission on Disabilities would like to announce that the purpose of this forum is to identify the concerns of people with disabilities and their families in order to assist the state, develop programs to improve quality of life for people with disabilities and they ask me to read that formally today to you.

So what's going to happen in a moment, I am going to invite the panel members to introduce themselves and then I would like to ask the audience to just briefly introduce themselves as well. And then the next move will be to ask people to speak about any issues related to the purpose of the forum. I would like to let you know that there's a hearing device available if you need some assistance with hearing. And we have a microphone that we will need to use to facilitate that and we have different interpreters as well. There is going to be a transcript of this meeting and these transcripts will be posted on a website that is available in your information pack. And then a series of recommendations will be posted coming out of these transcripts. And then hopefully any issues that arise will be developed into policy issues of the coming 12 months in two years. So I think I covered everything. So the next step is to ask the panel members to introduce themselves briefly for two or three minutes and then just -- however they would like to introduce themselves and start from there. Can I start with you?

Bill Inlow: Bill Inlow, I’m a member of the Governor’s Commission on Disabilities’ Legislative Committee. And I’m also representing Al Moscola, General Manager of RIPTA, Rhode Island Public Transit Authority.

Dimity Peter: Thank you. That's great. Perfect.

Camille Pansa: Camille Pansa, I’m the executive director of the Statewide Independent living Council and we are -- while I’m a paid employee, it's an all volunteer council appointed by the governor. What we do is we develop and monitor the state plan for independent living and we do that in conjunction with the Office of Rehabilitation Services.

Dimity Peter: Thank you.

Rod Titcomb: Rod Titcomb, I’m a member of the council.

Annette Bournbonniere: Annette Bournbonniere, I’m a representative of the State Rehabilitation Council. I'm also a member of the independent steering committee and the Newport accessibility advisory committee.

Dimity Peter: Thank you.

Coffee Bell: Coffee Bell, I am vice-chairman of the Statewide Independent Living Council.

Larry Grimaldi: Larry Grimaldi, Chief of Public Relations of Elderly Affairs.

Colleen Polselli: Colleen Polselli, Office of Disability.

Dimity Peter: Thank you very much. We do have some panel members who are obviously running a little bit late. So they can introduce themselves when they arrive. Can we just do a very brief introduction along --?

Kim Warnamark: I'm with the Veterans Affairs Rehabilitation employment division.

Mansfield “Pro” Lyon: My last name is Lyon nickname is Pro. I'm a Newport resident and here just to understand and discover.

Dimity Peter: Welcome.

Sheila Collins: Hi. My name is Sheila from Portsmouth, and I have a young adult with special needs who's transitioning to adult services.

Mark Aubrey: My name is Mark J. Aubrey, traumatic brain injury survivor and a member of the Rhode Island Brain Injury Association.

Missy Koch: My name is Missy Koch and I am a rehab counselor. Here from Office of Rehab Services, and I’m here as a listener.

Gary Weir: Hi. I'm Gary Weir. I'm deputy administrator of the Office of Rehab Services, Services for the Blind, Visually Impaired. I’m also here to listen.

Cheryl Grove: I’m Cheryl Grove, I’m disabled and I am here to find out what's available.

Bud Cicilline: I'm Bud Cicilline. I'm a CEO at the Newport --
George Levesque: I'm George. I'm transportation manager for the Jamestown Center.
Paul Bohac: I'm Paul, survivor of traumatic brain injury.
Dimity Peter: Thank you very much. And welcome, everybody. So the format is that if there are people who would like to speak about any issues, challenges, experiences that they would like to have the commission look into, now is the moment to do so. So I invite anybody to have the floor.

Family Support Resource Directory

Paul Bohac: Hi. I'm Paul Ohack. I sustained my traumatic brain injury 18 years ago. There were not at that time many services available for me at that time. I'm a member of the Rhode Island Brain Injury Association. And through a grant I'm finally getting some counseling that I need. When you usually suffer a brain injury, there's -- everybody's different. I'm deaf in my right ear. There are people that I see they have problems with their vision. Basically the problem -- I graduated from Bryant College before my injury. I was lucky I was able to attain my education. But hurting my head and impaired my memory. That's one of the traits that go around with the left frontal lobe and basically I make bad impulse decisions and I run into a lot of complications. I didn't have any counseling. I ended up in jail. It's not fun. And basically the reason that happened is I didn't have anyone to throw problems at. Now finally after a great deal of time, there's a grant and I'm getting some services through the Paraplegic Association of Rhode Island to pick up -- there was a grant available and they took my case and since then, I'm with another agency. I'm finally getting the -- some counseling and some help that I need. So I hope that the state government will fund any grants for the Brain Injury Association or any other grants for people who are blind or anything else that need it because there's a lot of problems with brain injuries are a hidden injury. I don't look like -- people look at me and they think everything's okay. Well, yeah, it is okay because I worked really hard. I hope other people they don't have to work that way because there are programs available to them. Thank you.
Dimity Peter: Does the panel have any clarifying questions they would like to ask?
Bill: I would like to express the Commission's gratitude for your coming and speaking up not only on behalf of yourself but as an advocate for other people that have similar challenges. And it's also good to hear some positive comments as well as obviously, hoping that things will get better in the future. Thank you.
Dimity Peter: Someone else.
Pro: I'm curious. I'm wondering, talking to several people and listening just now and how many instances in this room would the solution come in financial form. In other words, how many of us here see the solution if there were sufficient funds available. Is it as simple as a function of bucks or is it more than that, other than that?
Dimity Peter: I'm not sure that that's going to be something that somebody can answer in two or three or four minutes. But maybe after the meeting, I might link you up with somebody who might volunteer to answer that question.
Paul Bohac: I heard one incidence -- you had to struggle to find a grant.
Speaker: Yeah.
Speaker: And having found those moneys, things are happening that are good right now. What I heard you hope is state support going on after that to make that happen.
Speaker: Correct.
Speaker: There's one incident in the first Speaker -- I spoke to someone else for who money would be the answer. I'm not looking for simple answers but I'm betting that is a common thread.
Coffee: I would like to say that there are constant efforts to get monies from both the state and federal government through many agencies and in the state and they are all separate grants. Everyone's best bet is to find out what services they need in particular and go to that agency. And there are advocates that will help you as much as they can with the monies that they have.

Health Care: Medicaid

Sheila: I guess my question would be having -- I just have gotten nowhere with finding where I can go to ask for help. That's one thing. And responding to this fellow, personally I'm not sure finances would be -- I'm not sure I could say yes or no, you know, it would be the only thing. But it would certainly help. I'm in a position where I had a very good job and I lost everything. I lost my home. I lost everything and now I make too much money to get Medicaid so I can't -- to get Medicare so I can't even go to the doctor because I can't afford the co-pays. I can't afford the rent. I mean, I’m getting sicker and sicker because I make too much money and now I’m in poverty conditions. And, you know, I have been in abusive situations and not found any one in the state to help me. Or, you know, even if it's outside of the state, I don't care. I mean, I will move to Alaska if there is, you know, better assistance. The other side of it I’m finding is I’m also in this catch-22 in that I’m not old enough for senior discounts and senior services. I'm not 55 yet. And so I’m in this gap. Wait a minute. With my disability I lost my home. I lost over $100, 000of my IRA my life savings, every single thing that I owned. But I don't qualify for senior discounts because nobody’s addressed it. It's pathetic.

Annette: What kinds of services are you looking for or do you not know what kind of services you really need?

Sheila: I need everything. You know, I have not been able to find anyone to help me with anything.

Coffee: What is your particular disability?

Sheila: I would rather not get into -- it's physical and it's all encompassing.

Coffee: There are certain organizations that handle, you know, blind, deaf, MS.

Sheila: That's the problem. I'm not blind. I'm not deaf. And I'm not in a wheelchair.

Coffee: You fall exactly into my life. So I would love to talk to you later.

Sheila: That would be super.

Coffee: Because I -- the same exact thing has happened to me.

Sheila: Okay.

Coffee: There are people out there. There are advocates out there. It is hard to find them.

Sheila: I’m delighted to hear that because everyone that I talked to has said don't waste your time with your organization. I'm sorry. That’s why I haven't called you yet.

Coffee: Never listen to them.

Sheila: Okay. I will hold you to that.

Coffee: -- The statewide independent living center --

Camille: What organization? The Statewide Independent Living Council?

Sheila: That's what I am told.

Coffee: Not to bother to call us. I would love to know who said that.

Camille: The Governor's Commission on Disability?

Sheila: No one even mentioned that.

Coffee: We will work with you

Sheila: Thank you.

Larry: Just a point of clarification for you. Once you are receiving your social security disability for two years, you are eligible for Medicare. That has nothing to do with income.

Sheila: I have Medicare. I can't afford the co-pays.

Larry: You mentioned Medicare. I wasn't sure

Sheila: I have Medicare, I need Medicaid.

Coffee: You don't qualify for Medicaid?

Housing Assistive Living

Sheila: I don't qualify for that. I don't qualify for assisted living. I need that. I don't even qualify for paying $580 a month to get assistive living. You know, I’m being penalized because I had a good career. And I was a very responsible person. And I’m not a drug addict. I'm not an alcoholic. I'm just physically disabled.

Annette: I know that too. I lost everything too.

Sheila: At least people can see you. When I drive my oxygen around, I get some sympathy from people.

Coffee: Right.

Annette: But unfortunately the system doesn't harbor -- before you can get any help. That's not unusual. It's sad but it's not unusual. And I’m sure that they will hook you up the best they can.

Coffee: Whatever is available we will make sure you get hooked up to it.

Sheila: Thank you.

Speaker: I work for the Office of Rehab Services. We would certainly love to try to work with you. I think there is some help out there to find the links that you need. A lot of them are around the state.

Coffee: A lot of people just get so discouraged and so overwhelmed because they are dealing with a disability and they are dealing with bureaucracy.

Sheila: When you are sick you don't have the energy to survive never mind get a Ph.D. in social services to figure out how to find it out. I'm sorry.

Coffee: That's right.

Bill: I think this gentleman over here wants to say something.

Speaker: Please and then I will call you for the next one.

Mark: Thank you.

Mark: My name is Mark. I'm a traumatic brain injury survivor, and I have a family -- not Rhode Island. But when I was injured a little over 10 years ago I was struck and brushed by a backhoe while I was working. There were no services in Rhode Island. I finally got to go to In Motion Therapy that referred to me rehab.

Health Care: Medicaid

All these services are decided by the funding sources, with me it was Workers' Comp insurance. But it's not fair that the funding sources decide what services you will get, what doctors you see, what therapy you will get, how much they will pay for. You are working really hard at it in therapy. You are doing great. All of a sudden funding stops. They are not paying for it any more. What do you do? You go home and you are devastated. And then you have to sit around and wait for that whole bureaucratic process to get up again so you can actually fight to get more services. So the whole problem is that there are abc's out there to help, state, government, even some private ones. There's money there to pay for services. For one, that's basically for traumatic brain injury because there really isn't any and there needs to be. But it's not being delivered properly. Who knows what's out there. Nobody advertises to anybody, to the public at all. You have to work really hard to call this agency. They refer you to that agency. And that agency refers you to this agency. And then you say okay. We can help you with this and this. Then you have certain guidelines you have to fall. With me I’m poor. I lost everything too. Everything. My daughter was one and a half at the time when I was injured. So just trying to be a good father was tough enough and trying to survive, just -- you get caught up in survival. That's the whole issue of disability. I don't want to get off track with the health issue. You have to think the major issues, you know, the toughest parts that we have to deal with in our lives is getting healthcare, being able to pay for it and not feel like a loser because you can't pay for it. That’s the biggest issue. Without your health, I’m nothing. I mean; every one of us in this room is going to become disabled. That's the fact of life. It's going to happen. And when something is inevitable, there shouldn't be excuses being made for something that already -- that happens in life anyway. You know what I mean? It happens. It's all about the quality of life. It's all about how we live. What makes us comfortable? And being disabled its like; it takes so much energy to live your life now. I mean, you finally got to the point where it's like I have to live like this. Well, with me I have had seven mental -- and four surgeries in the past year and a half. Medical problems that have come up. But they have come up because I couldn't get into therapy that the doctors prescribed. I couldn't take the medication that the doctors prescribed because I couldn't afford it. I don't qualify for Medicaid. If I move to Massachusetts, I do. They have a fund that bridges the gap between qualifying, you know, for the federal guidelines that they bridge that gap. And there should be a fund in Rhode Island that should bear that. It's already there in Massachusetts. And Maine I believe has the same program for Medicaid. The federal government supplies the money for Medicaid. The state manages that money. But the state to me is mismanaging that Medicaid

Money because they are not providing Medicaid to people that really need it. The people are getting worse. They have to go to the doctors. The doctors don't get paid. I have so many bills right now that I can't pay and they are calling, collection agencies calling. I mean, just the stress in that alone is -- would be enough to overwhelm anybody never mind having to deal with, you know, health problems, just trying to live your life and get through to the next day. Not even thinking, you know, two months, six months, 12 months from now, when you should be because there are all these programs in place, you know what I mean? But it's just the delivery systems have to be worked on and it's tough enough for the people working in these programs to do that because they are already doing their job. But the kind of change that system, there has to be more employment offered in order to change that system. Because people already in these programs like yourself, you are doing your job. But sometimes you are doing, you know, two jobs; three jobs because the system, you know, it's constantly evolving. And that's just not enough back up for the issue. The major issue at hand and that's quality of life, how do we live? How do we live? How do we live our lives? I mean that's pretty much the biggest issue that faces everyone each day. So it -- to get people like myself out of survival mode, that is the biggest issue. How do we get this person out of the mode for survival instead of put them in back in. Bounce off these different programs that you don't qualify for. Then you are back to square one with more health problems. You have aged. You know, that takes its toll too. Instead of being Medicaid

Caught up in the system, we should, you know, find out exactly what is needed. For Medicaid, people with disabilities should automatically qualify because they are disabled. They have more health problems than the average person so they need that insurance more. But that's not realized. They kind of lump everybody in with the healthcare system, you know. It's bad for the economy because doctors don't get paid. Service providers don't want to come into the state because they don't get paid. How do we attract more business for Rhode Island? How do we make Rhode Island, the economy better, and everybody wins? How do we do that? We just have to get these barriers down, you know. The first barrier is Medicaid. How do we get, you know, services for insurance?

Housing: Assistive Living

The second is housing. I mean they have all these programs that we qualify for housing but it's like, there are all these loopholes that you can fall through, especially with having a traumatic brain injury and trying to keep up with everything. For me its like -- I have had section 8 for four years. I mean, I waited for it. I finally got it. I couldn't use it because the rents are too high now. The rent standards haven't been raised enough to meet the specifics of the program. So what I found out is that over 85 percent of the people who have section 8 can't use it. They can't use it. Why is that? Because they are already disabled? They already have problems. So, you know, what are we supposed to do? The rents are getting higher. You are trying to live. All of a sudden we are homeless. That's happened to me three times since I have been injured. I was a successful person before I got hurt. I always worked. Now that's the problem right now. What's wrong with me? Well, he's not working. That's the problem. We need programs in place that gives us an incentive to work on, gives us things to work on. So what will we work on now? What will I work on today, to not only improve my life but to get through the day? You know what it's like -- with Medicaid, if there could be something, you know, that bridges that gap of eligibility, you know, with section 8 or whatever type of housing program. There should be some type of automatic process that kind of funnels persons with disabilities where they need to go instead of struggling with the stress that you are put under. You are supposed to be out work -- trying to work and live your life but you can't do that because you are caught up in this whole process of trying to just survive. You know, and that process is disabling in itself. So there's no -- you really can't complain about it. Work has to be done. Just work. And it just -- people in the right places need to have that information in order to, you know, get that work done, to kind of you know help the whole situation. Traumatic brain injury I mean that would be a huge boost to Rhode Island's economy just to have those types of services in place, not only for me. I went through them. I was educated in these services. But what these services are providing is an education about life itself, about the human experience of how we behave, how we react, what is a typical human being. I mean, it's the brain. That's the final frontier so to say in the medical field. But Rhode Island's not getting on the bandwagon. So Rhode Island's going to miss out on those economic boosts as other service providers choose other states and I have to leave my family and move to another state to get better because Rhode Island doesn't have these services. We need incentives to bring these service providers in and what the incentives would be is to make it easier, to make these programs easier to deliver to people and individuals that need them, and more than qualify for them. Thank you.

Coffee: Thank you.

Annette: Thank you so much.

Coffee: May I say there isn't anyone on this panel that doesn't understand exactly what you are going through.

Mark: I don't mean to come across like I'm angry or anything.

Coffee: We have all been there

Mark: Nobody's complaining. It's just how it is.

Coffee: I understand.

Speaker: This is the reality of my life situation. Somebody else that I heard it's just a similar situation. This is not right.

Health Care: Medicaid

Sheila: And I will reinforce what he has to say is Medicaid. I can't understand why somebody with a disability doesn't get the Medicaid so they can get the medical assistance because they are making too much money. $700 or $1,000 a month that's bizarre. And I would very much like to talk to you about which states do provide it because I will be out of here very quickly.

Housing: Safe and Affordable

The housing, section 8, you know, frankly I can't live with criminals and drug addicts. I can't deal with the stress of that on top of all the physical survival challenges. And I had a very bad experience with administrators of section 8 who, being in a situation where I had no heat under the legal law --The law states that they have to -- if its owner supplied, owner controlled heat that they have to supply it at 68 degrees. I called the state health department. I called the police officers. I called the housing authority. I called legal assistance. I was told unfortunately, quote "what the law says and what really happens are two different things." I went through winter without heat, trying to live at the library and a coffee shop to stay warm. That really helps someone with physical disability. Nobody cared. And that's not the only housing nightmare I have had. So you know, if people are hearing these stories, I don't understand why, you know, if its Rhode Island law, if there's a document that states that that's the case that landlords have to comply to certain laws, then why is someone who can't afford a for profit lawyer put in this position?

Speaker: Section 8 program, I mean you can move anywhere you want and live anywhere you want.

Sheila: You can't find anything that qualifies.

Speaker: The rents are too high unfortunately right now.

Sheila: Or landlords that will deal with the administrative nightmare, which it is.

Speaker: There aren't enough educated landlords. The benefits to renting for section 8

Sheila: Yes, there are. But the bottom line is it's an administrative nightmare. I have a very extensive sales background and I'm a good salesperson. I've sold the section 8 program now to three different landlords. And they were just appalled by what they were put through to get on it. It was a nightmare. Despite me pumping out a 30 page presentation for them that showed them all the paperwork and talking them through it with all the best fortune 500 training that I had.

Speaker: That's true.

Speaker: Just a comment first. There is I think a traumatic brain support group. I don't know where it's located.

Speaker: There is. Some throughout the state through the Brain Injury Association.

Speaker: Do you go to them?

Mark: Yes, I do.

Family Support Resource Directory

Pro: And I don't know what your disability is. It's a good thing to point out that a lot of support for myself. I am bipolar and I have multiple sclerosis. I'm starting out with that state where I'm coming from. I will also state there's a strong possibility -- I don't know if anyone knows about multiple sclerosis being bipolar may have been the first incident of having multiple sclerosis. Some think that multiple sclerosis, although it is an auto immune disease, may be caused by a virus. And there is a subsection of the multiple sclerosis population that is bipolar. And they are thinking that subsection that there may be a viral connection. But that's not what I wanted to bring up. One of the things that I mentioned last year to the commission, which I'm bringing up again is some form of states -- I think many of the problems I heard in the last ten minutes that someone to go to other than just wanting state agency, like the department of business regulation or the American Disability Law Center that can coordinate and bring things together. Sometimes you just need a government representative to say hey, what's up for a person in a difficult situation.

Health Care Insurance

Another thing is that I'm 51, going on 52 next month. And AARP is not -- I'm not able to buy AARP indemnity insurance in the state. I may have taken Blue Chip in some form if I were capable of not having $2000 out-of-pocket if I wind up in the hospital, you know. I can't afford to do that. I can't take that risk because I live so close to the edge. I think it's unfortunate when I look at United Healthcare, you know, just a few miles away. Bristol County offering a fantastic HMO I couldn't get to it because I live in Aquidneck Island. This is a 20 by 50 state and I think as you well addressed you go right to the border and it's a different world where they come from. And it's sad. There is talk I know from the department of business regulation of a health insurance consortium that would allow health insurances from Massachusetts to freely be able to sell insurance in Rhode Island. This could be a very good thing. But the downside is that they have made I think mandatory certain forms of insurance and then a lot of insurers are pulling out of Massachusetts. Someone mentioned it to me. But in any case, it's a thought.

The other thing I was going to mention too is that -- and this goes into my own personal experience -- this week has been out of the twilight zone. I have antibodies in my spinal fluid that are indicative of the MS I have in my brain. I have neuropsychological tests that show my cognitive disabilities are directly associated with the -- with the disability structural changes in my brain. I had a neurological visit. You have them every six months with a neurologist with MS. He tries to throw me in a whole different auto immune paradigm which essentially gets no treatment. I was talking about stopping my interferon treatment which would stop my plaque development. I went through a bit of a change. I went back to the wars. The first neurologist I saw when he got the MRI told me to see another neurologist. Let me repeat that. The first neurologist I saw told me to see another neurologist because of the problems I had. This week I decided to have closure. He told me very tersely on several occasions throughout the interview being bipolar and having MS is a difficult case to deter. Even though I in front of me, even though I had the confirmation of six neurologists stating that I have multiple sclerosis, he didn't want to treat me, even not take me my recommendation is this. You have many advocacy groups in this state with regards to disabilities, specifically relating to neurological disorders. We do have a medical school here. Let the tail stop wagging the dog. We have to get doctors treating patients. I don't walk into their office with a piece of neurological tissue and say treat it. I'm a person. When I stagger, when I have incontinence, when I have cognition problems, it's not because I have a bad day and I feel bad. It's because I got a neurological broke --And how dare the audacity of someone who takes an oath refuse to treat someone because they have a personal problem with mental disability. It's obscene. But time and time again it was an epiphany, the troubles that I had for the last eight years sat around the fact that bipolar. It took me a long time to get a diagnosis of multiple sclerosis because every time I was having a symptom it was saying it's because he's depressed. Oh, it's because he has emotional difficulties. Now I stagger, I have incontinence. Does that make any sense? The worse oxymoron is if I was an average Joe Blow and I go in with multiple sclerosis and I get the a.b.c.'s.

Health Care Prescriptions

Drugs, guess what the big side effects of interferon's are? Suicide ideation and suicide. So I can bounce off the walls a couple of times in Butler. Never had a past psychiatric history but I'm fine. But if you walk into any psychological, even if they might be associated with the initial stages of multiple sclerosis they don't want to look at it. They have limited attitude and in some cases they don't want to treat you. What kind of sense is that? And these are doctors. This is not laymen. These are doctors. I had my benefits cut off in 2001 Benefits cut-off because of the fact that being an honest Joe I wanted my boss and to complete my medical records for my former employer. I gave my neuropsychiatry exam to them. They gave it to my private disability insurance for my company. They cut off my benefits. I had to spend $5,000 to get them back. And the horror stories I had throughout the process of having to go to a neurologist you wouldn't believe, actually had got disability from social security and gone through that whole process which you know is very exacting. He acted as if I was going to work the next day. I wonder if -- a lot of them have m s. It's really silent. I look as Billy Crystal would say "marvelous." But you don't want to drag your behind going to Providence every day. You might -- I was falling asleep. I was a programmer for Textron Financial Corporation dealing with electronics. You can't stop billions for billions. It doesn't work out that way. I would love to work again. But with all the things that I need to maintain myself emotionally and physically, I Unable to work can't do it. And besides that I'm a disabled caregiver.

Housing: Assistive Living

My father is in assistive living. We were living together. I was diagnosed in 1998 to 2000, was taking -- sorry -- 2002, I was taking care of him and myself as best I could. But after cut of 50 percent of my income because of stress and us, you know, he had to be placed into assistive living. I no longer have any life savings because the life savings went to put him into assistive living. I'm barely managing. I'm scraping by. I'm using some creative accounting. Hopefully I will be able to get in some form of assistive living or reduced rent in the not too distant future. I got hit badly this month because I had to buy a new car. I don't want to drive any more. I really don't. But if I give up a vehicle, it's not that my father doesn't have convenience. He dies. I'm maintaining his independence. And a man that was born in the 1920s, his independence is his life, if you understand what I'm saying. Don't cry for me Argentina. That's not what I'm saying. But we do need help. I find it curious too. As I was driving over, the high rollers In Las Vegas do excellent treatment. This is one of the states that have the highest per capita of elderly. I don't know about disabled but definitely elderly.

Health Care Insurance Why is it that the consortium of the insurance power for the hospitals, the drug companies, everything isn't used to our advantage? Cities and towns do it. You know, State of Rhode Island does it. Teamsters do it. But it doesn't seem like any advocacy groups try to get something Consortium of advocacy groups together for those people with disabilities or the elderly even together. We are the ones going to doctors. We are the one using the hospital the most.

Health Care Prescriptions We are the ones spending the most on drugs. I don't understand that. That's wild. We are the ones who are taken the most advantage of, yet we are having our pockets dug in Betaseron is $1,000 a month. My full income that's about 50 percent. I can't afford that. If it weren't for orphan drug programs, forget it. I'm on plan 65. I was in blue chip, but I can't go out of state for certain conditions they won't or can’t treat here. And so I stick with Medicare until I’m 65. I pay the rest of my drugs out-of-pocket. That's between anywhere $250 to $300 a month. But even if I went and got a doctor to write for exemptions to go to Mass under HMO, blue chip, it would still be dicey with the money when you buy -- you pay the diagnostics office co-pays. You wouldn't believe how it kind of pans out. But when you are in a fixed income and you don't -- a lot of times with private insurance, disability insurance you don't get cost of living increases. You are really kind of stuck. Beans and rice. My father used to say crabs and ice water. The only other thing I can say is help. We really do need some attention put into housing. We need something done in regards to Health insurance. It's killing us, literally.

Speaker: I notice you go to the pharmacy and you pay the full price of a prescription. But does the insurance company pay that full price of the prescription? No. They pay a percentage of that full price.

Pro: Why can't I get the same discount from the pharmaceutical companies?

I asked the pharmacist this. He said that would be nice but unfortunately I don't do that. I said do you have discounts for people who are disabled? No. we have people for discounts who are elderly. I'm like, that doesn't make sense. That's kind of discrimination in a way because everybody hopefully they're lucky will become elderly, you know. They get discounts. That's -- they deserve it. But you are not lucky if you become disabled and you know, the life you are supposed to be living and you are not. You are trying to live and survive yet you are getting beat on by everybody out there trying to make money. When they can be making a lot more money helping us instead of hurting us. Whether it is intentional or not intentional, either way. For me it's -- it goes for a question of, you know, what we are as human beings.

Mark: For me with a traumatic brain injury, every activity -- well, I don’t know if they know about activities of daily living. You get dressed, breakfast, you do all the normal things, laundry, stuff like that. But each one of those activities is amplified to the fact where I even have to break down in certain levels to be able to accomplish it. It's like you know what happens when you over think something too much. What happens? You screw up. You make a mistake. So that’s kind of the syndrome that person with a traumatic brain injury is. They are constantly making mistakes and dealing with the frustration from that. And then, you know, it's just -- you forget who you are, what type of person that you want to become. There are so many different levels of disability when it comes to traumatic brain injury. There are services out there that can help that person to lead a normal life as a traumatic brain injury survivor but the services that we need aren't being provided for in the state of Rhode Island.

Speaker: I was going to say too, not to cut you off, if the state Of Rhode Island legislature were to mandate that private disability Insurance would have to have cost of living increases as a clause that would help tremendously. It really would because some of the policies actually cap over the amount you get from social security and deduct from it which actually pushes you into poverty.

Health Care Prescriptions Another thing is it might be -- it would be a gesture just like Howard -- I have to commend the state legislator for approving importing of Canadian drugs. If they were to make a resolution about developing some form of universal healthcare, I mean, we can't do it for the rest of America. But I think it would make a strong statement if it came from at least one state that resolved. We believe for the health of our economy and people that we need a universal healthcare system. I think that would mean a lot. Politically that could mean a lot. We do have Senator Reed in the state. He carries a lot of weight. So the state of Rhode Island said something like that, maybe people would take notice.

Employment Tax Credit Pro: There should be -- I had this idea for a while. Corporate sponsorship program for people with disabilities. The state gives tax breaks to corporations for any number of reasons. Why can't they do it for a corporation to sponsor a person with disabilities, to kind of fill in the gaps that we usually fall through and try to get services, to kind of prompt us up so our lives aren't -- don't completely fall apart before our eyes. There should be some type of sponsorship program, to kind of help pay for services. It would be good for the economy because all of a sudden this person who is disabled is working now. And they are putting back into the system and they are helping other people going through similar situations. It just gets better from there. It is all of our money, I mean, if you have money, if you have family support; you are going to do great. But if you don't, then it's just -- the roll of the dice and how much you can dig in as a person and just grins and bear it. Say I’m happy to be alive. Even when everything else is completely wrong and devastating in your life. There just needs to be more work done on these types of issues. There needs to be more of these types of meetings. Thank you.

Speaker: Would you like to -- thank you.

Sheila Collins: I apologize because there are Speakers here you can just talk from your heart. I have to go by a script. It took my heart to write this. I appreciate the time you are taking as volunteers to listen to concerns we have as a community here in Aquidneck Island. First, I would like to introduce myself as Sheila Collins. My oldest son Michael is 20 years old and has a chromosome disorder called brain syndrome. Advocating for special needs has become a passion of mine. And I sit in several committees, local special education committee, east bay transition council, and the state special ed advisory committee. First, I would like to comment on having this meeting here at Salve. I'm an alumnus and just recently Salve will be hosting the second site for transition council, transition academy which is for kids 18 to 21 that are now for the first time in east bay getting services on a college campus. It's just a really neat experience these kids are having. And I applaud the school system for making this happen. Unfortunately my son missed the gun on this because of his age. But he's in Massachusetts in a place called Burke Music Academy.

Housing: Assistive Living

What my concern is he's 20 and he will be coming home next year. So I just will give you a little bit. We applied to the Division of Disabilities when Michael turned 18 to get the paperwork started. January 19th of this year we submitted a request for funding when Michael turns 21. Just three days ago we finally heard that Michael will be granted level 3 funding yet there is no money available. Currently in Rhode Island there is no money available to open any group homes in the upcoming year. This is what my Developmental Disability council has told us. Younger -- older adults with special needs must live with their parents until they are in a crisis. Families are being penalized because they are an intact family. People with special needs are being placed in group homes only when one parent is dead and the other is terminally ill. Needless to say this is unacceptable. Last month a group of 15 families and I’m sure there are many more gathered to proactive in this issue. We are looking at options to develop owner based housing for our loved ones. We as parents are willing to go and pay the mortgage, but there needs to be funding available to support and make this dream a reality. We need to look outside the box and develop housing options that will be a win-win for everybody, the state, and our children, special needs and young adults. Our school system and parents work diligently to get these students ready for the real world. We are extending to “college.” But adult services need to be there when they graduate. We cannot let these students sit at home and be nonproductive and dependent. They and their families deserve better. We look to your help as citizens to find how they can be truly as independent as possible. In summary I would like to help the school systems for developing transition academies to prepare these individuals for the adult world. However the adult service world needs to step up to the plate to provide services for these individuals when they cross over to the adult world. We have invested too much in these individuals to let them fall through the cracks. And I know that an independent living council representative is here. I would welcome any suggestions that you have. I will be leaving shortly. I have to pick him up at 4:00 because it's a two and a half hour shift. But we are at a loss of what will be available. We need funding not only for Michael but all these other kids that are living at home and when the door -- people tell me, there's nothing there. It's not fair. We worked too hard to get these kids to be independent to where they are. They deserve a better lifestyle. They deserve to be with peers and make friends with peers, have a recreational life, still be as independent as possible with the supports they need, but be contributing members to our society. And with a little bit of money we can make them productive citizens. So I ask for your help and support. My hats off to the rest of you who are working this battle too.

Bill: I have a question. Could you elaborate a little bit on owner based housing? I think that's how you described

it.
Sheila: It's a new concept. It's happening right now in Boston, probably other places in the country. There's a group out of Boston called specialized housing. We had them come down a month ago and talk to 15 families. They have ten homes in the Boston area. And what happens is parents, families buy the home and they kind of rent it out like a condo. So you own one-tenth -- whatever the group home consists of. You own that component. But then they are looking for ways to support parents and looking for ways to support and provide the support that these children -- adults excuse me need once they are in the home. So it's a neat thing. It's a win-win. There's -- the parents will be in this home that they own. Some stability. For one part of it. There's another concept home getting funding from banks. I don't know where else. I'm just beginning to do the research because my goal is in a year or two this will be a reality for my son and several of his peers, people on this Island. The fact that my son goes into a group home from what I understand, that group home could be closed if it's a state run -- There's no place. If the home closed and he's moved I -- I want to know when I’m gone he has a place and he's safe and secure.
Bill: So, Pro, you know more about this than I would. The families pool together their equity value in their own homes for collateral and then they take some of their own earning power to guarantee that the mortgage would be paid.
Pro: Right.
Bill: Sounds like a pretty interesting idea.
Pro: It's a win-win I think for the state and for the families.
Bill: I like the idea because it doesn't say, well, I will just run up to the state housing department and ask them for the land. You have done that. The rest is pretty dry. I like the idea you are thinking of something creative and use a resource that's there. And tremendous equity value in our homes it seems like we don't take advantage of it very often.
Sheila: Maybe when they are older they can do a reverse mortgage to help get some of that support -- pay for the supports that they are using
Bill: Yeah.
Sheila: And maybe there's some ways we can get a group going that can look at what's available in the state. You people have the expertise. I'm the new kid on the block, what is out there that the state already has in place.
Pro: The services you can't find that aren't available.
Sheila: The services are there. Who is going to pay for those services?
Pro: Okay.
Sheila: That probably -- what burning question for parents if I put up this money and I get a home for my child, then where is the money going to come from.
Pro: It's less than affording a facility than it is affording services.
Sheila: With this group of parents we -- but apparently they are doing it in Vermont with people that probably don't have the money. I don't know how that's working. Because my Michael can never have more than $2000 in his name. And I said is there a way -- because he needs to buy into this. He somehow has to contribute to this fund and have ownership of this house whether its $10 a week or whatever, he needs to be able to do that. So I would love to hear options of people already doing this in Rhode Island and how we can make it a reality here. I will submit some paperwork to you. My name and address is on it. I do have to run and get him. I thank you for your time.
Coffee: Thank you very much.
Speaker: Anybody else who would like to speak to the panel?

Transportation

Speaker: I too want to thank the Commission for coming to town hearing concerns, the concerns from others. I recall when you came in last year it was at the library, was that -- and I work for an organization for persons that have mental illness. And there's a range of services that there are, and there are things available. The state of Rhode Island does a pretty good job of being supportive. But invariably they have problems. Other people with disabilities have problems. George can attest this. He has been a state representative in the past. We know about things that almost everyone with disabilities, transportation is a major issue. And every so often we read about the RIPTA budget. And that is so critical for a lot of people, particularly the people with disabilities who just want to get around. They don't want to be locked in. I just would want to put that on the table as a major issue for people with disabilities to see what we can do about supporting public instead of figuring how we can -- and often with so many hours cut down and people with disabilities most need it. That's on weekends. They may have plenty -- some activities during the week but there's this other phenomenon about activities, recreational activities, things to do to improve and enhance the quality of their life. And they don't have access to transportation.

Health Care Prescriptions I mentioned -- this is a problem all around but it can also affect MS. -- high cost of prescription medication. Going to Canada. I think the whole disabilities enterprise get on board and promote and push for low -- it's so crucial for so many people. And we should join that initiative and identify -- because there are plenty of people with disabilities who don't always have the adequate prescription coverage to afford co-pays. And often they are reducing the medication intake, halves to stretch it out twice as long but its half as effective. So they don't benefit as well from that. That's a major problem.

Housing: Safe and Affordable Housing is -- seems to be a problem all over the state and particularly in this area. There are people with disabilities who just can't afford to pay the rent and also buy food and pay for the heat, just as much -- we talk about the elderly. In fact, George can tell you that there have been efforts within the general assembly and they're our friends. They generally are to increase the programs. RIPAE, Rhode Island Pharmaceutical Assistance Program for the Elderly, but we have been -- that's been working -- it's been extended in so many directions interests in legislation to reduce age level to 55. I know it doesn't take care of everybody. But there was -- making more of our people eligible for this reduced cost for medication access. And I think the, we can advance the idea of enhancing that program, making sure it is much more available. But housing I want to mention and then employment, Employment

Employment Job Placement There are some employer friendly organizations or businesses that will work with persons with disability but not enough. The extent to which there could be an initiative for the Commission to cultivate more of those relationships with area businesses, saying people with disabilities can work just as hard and be just as effective and efficient, all of that. In many cases they very well can. Some because of some limitations may not be able to work a full workweek and all that. Probably when they are working is probably doing better. They can be creative about how they employ people so there could be job sharing kinds of situations. People could come in; two people would work a full shift or something like that. Just to get them to be thinking about that and bring them to the table. I don't know if they are represented on the commission already. If they are not, get them on board and put -- hear the story because I think -- at one point everybody's going to suffer some kind of disability. How debilitating remains to be seen but it's true. And I think why -- it seems like a catch-22. When it touches home, it's touching plenty of homes around here. I think we should get people to be mindful of it. Again, thank you for coming and hearing our story.

Coffee: Thank you.

Pro: Just one final comment. It's interesting. Sometimes it's like when you talk about our priorities in society; we look at athletes' salaries versus what teachers are paid. And I think a lot of them aren't even physically spent in the state. And this has no political connotations. But I know if I was from another country right now and I came in here legally as a legal immigrant, I would have a place to live, and I would have Medicare immediately, you know. Right now -- the person could work. If I took the job that that person was working at, I would lose a lot of my benefits and my income. Something's wrong with this picture. Social security disability is a benefit I got from working a number of quarters. Good hard one by the way. But a lot of people had the opinion and impression that you are -- not that this is something that's entire -- joined Social Security early and maybe some public relations. has to be done with regards to people that aren't working because it's not like you are sitting back watching Oprah all day or want to. I don't think any sane person wants to sit around and be nothing where their lives. And even though I am disabled, you know, being involved with my father's life and allowing him grace in his golden years is very rewarding. I'm getting much more back than I'm getting, but it's tough. It's hard work. It's rewarding too. I guess the overview is maybe some of the things we have to do are better public relations. To question our priorities because I think as society stands and falls on how it treats its weakest members, it's young, the disabled, and the old.

Speaker: Thank you.

Speaker: I just had a question. Maybe I missed when I was out of the room. But you mentioned something about trying to lower the RIPAE to the age 55. I guess my question is why is there even a question? If disabled people are trying to live on less than seniors, why is there even a question as far as an age restriction?

Speaker: It's money. I don't disagree with you. Extending that program, it just has to do with what resources. When you go to the state governor, I just got this much money. Do all these other things. For us this is the highest priority. There's no question. Some of you heard one Rhode Island program out there, talking about funding certain things. The feeling for some of us, that should be funded first not if they find the money. And I agree with you. This should be funded first. But you will have others that come in and say we have to fix the roads. We have to make sure we get this. It's one of those things a lot of times same pocket of money.

Pro: Well, let me ask you the next question. Why is someone who didn't pay the amount of taxes that I paid as an executive qualify to get full medical, dental, and prescriptions and I can't even afford my Medicare co-payments? I'm one of these people. I haven't halved my medication. I have thirded it or done without it. I can't go to the doctors because I can't afford -- why someone who didn't work as hard as I did, didn't pay into the system as much as I did, why are they getting -- if it's a matter of money, why are they getting everything and I'm getting nothing?

Speaker: I'm not going to defend the eligibility requirements that are there. I can -- I don't have a whole lot to do with -- but that's something as individuals. It's an election year. We have people running. We should make our point and answer the question. Ask people who are running for state legislature, the congress, and whatever else; what are you going to do about this? I don't defend that.

Speaker: Would you like to have the floor?

George: I think I fit into about four of those categories that you just mentioned. I would be remiss in saying that certainly -- I try to be -- where what was known as tax and spend liberals, you know, and we never saw a social program we didn't like when we were there. It wasn't because of what we were accused of. It was because we believed in those things and that's why we are here today. I used to be a state representative. I worked for the Maher Center now and I'm running for state representative again, but that's neither here nor there.

Transportation RIde

The issue transportation, which Bud brought up, is very important one. And it's close to imploding right now, okay. We have a transit system. I mean, in the papers a couple days ago, RIPTA's talking about cutting back. I work a lot with the RIde program. We don't have enough buses. We don't have enough routes. We are in some ways being held responsible for our success. This is a very small program ten years ago. It has gotten very, very large. And there has not been the money there that was promised to grow with it. And when you have a politician running around saying let's cut 10 percent from every department, okay, not looking at what their budgets are or anything, but saying to each department head, cut 10 percent. Well, that means cutting 10 percent from MHRH. That means cutting 10 percent from the Governor's Commission on Disabilities. That means cutting 10 percent from every program that you are talking about. If that program's under funded to begin with, you are saying get 10 percent less services than you got before. And they continue to demonize. They don't demonize the people who use the services. They demonize the people who provide the services. They are overpaid, that they don't work hard. State workers don't work. And it's troublesome.

Housing: Safe and Affordable

I have workers that have all the same problems that you do and they are working more than full time for me, that can't find an apartment on this Island with what I'm paying them. The section 8 in southern Rhode Island is a joke. Okay. Jamestown where I live is in the process of hiring a town manager. The salary they are advertising the town managers job at, that person could not afford to live in Jamestown if he was coming in to buy the place at the time. Luckily I happened to buy over there when it was nicer to live in Newport than it was in Jamestown. But it's -- they have these rates set and they are set by the federal government. And they have no application whatsoever in southern Rhode Island. Most landlords that you go to now with what they are willing to co-pay on section 8, would just laugh at you, especially for all the paperwork that they have to do just to qualify. Why would they do that when they can go out and they can rent to somebody without a disability or without three kids and get twice as much money? Why, why would a person do that? We run about 13 group homes. I think its 13 right at the moment. But those go out too. In a community -- when the prices of property go up, obviously our costs go up. Not necessarily in the taxes but to buy a place, a place that we could buy for $100,000 even ten years ago is now a quarter of a million dollars, okay. Bud was one of the heroes of the housing movement and trying to get housing for the homeless. We put in a pittance and we had to fight for that. And basically inflation in the housing market has made what we did almost nothing. Okay. When you talk about putting a quarter of a million or a half a million dollars or a million dollars into a housing market in Southern Rhode Island, which buys you one decent place with maybe six apartments at best. And there is a limited amount of money. And until we turn government around to say these are the things that are important to us not giving tax breaks to financial institutions, not giving tax breaks to gambling institutions, not giving tax breaks to hotels. But giving living wages to working people to providing good housing for people with disabilities, to provide group homes for people that need them. Until those become our priorities again, we can sit around in these groups and talk forever. You know, Bob with the Governor's Commission, Bob Cooper is one of my favorite people. We talk these things all the time. But unless the money's there, it's not going to change. And unless the government changes, the money's not going to be there. It's been a generation, a half a generation since we closed that horror place, the Ladd Center. That's how we treated people with mental disabilities up until the 80s. There's a guy retiring from state service right now, Bob Kohl who was heroic in that fight. And now he's going up to the Northern Chapter of Arc and he will be a fighter for those people again, for people with disabilities, not that he ever stopped being. But we need more people to fight, people to speak up, and people to demand from the governor what is their rights. I'm sorry I have been on the soapbox. But thank you.

Speaker: I would just like to ask if -- I mean, I would happily do that, but I don't know where to go or who to fight with or that sort of thing.

Speaker: The first place to start is with these five people up here because these people have been doing it and fighting for peoples with disabilities. And they're on commissions and they will tell you where to start.

Speaker: Because I just think it's horrible. I had fully expected to be able to get back to a six figure computer career. And because of the struggles with just surviving that have been talked about today, I have gotten sicker and sicker. I have given my hope so far as becoming functional again and I don't think that's fair.

Speaker: I will go there. I'm a private citizen. I'm not running for office. You know the whole Blue Cross fiasco this year. Okay, resolve it with a sacrificial lamb. But Senator Montalbano has no conflict being head of the board. The whole thing it's ridiculous. How can someone -- when you talk about changing the structure. I mean its right there. It's before all the people. This is a situation with regards to health insurance.

Bud: I think you are mixing up three different people there when you say that. Senator Montalbano is not on the board. Representative Montanaro is not on the board. His father is on the board. His father is the president of the AFLCIO and he is now.

Speaker: He was a member.

Bud: He is president of Blue Cross or president of the board of directors, whatever.

Speaker: Also the head of the committee.

Bud: No. He is the head of the AFLCIO in Rhode Island. President of the AFLCIO. He doesn't see any conflict with that. I think a lot of people do. The question is, are his people are biggest buyers of Blue Cross Blue Shield. So he doesn't see a conflict of interest there? He's looking out for his workers.

Speaker: Wasn't he on the committee for health in the senate?

Bud: No.

Speaker: He never was.

Speaker: Is that an elected official?

Speaker: No. He has never been in the senate. I think you are thinking of -- whose North Providence? John Celona was on the committee on health and he was -- or he did so much --

Speaker: Even the senator -- the director --

Dimity: Excuse me. I think this is an incredibly interesting conversation. And I think you two should have it in just a little while when we close the proceedings until somebody else. That's not to discourage discussion, debate. It's a very important thing. But that clarification isn't quite what the Commission is looking for.

Speaker: All right.

Dimity: Is there anybody else who would like to take the floor to make some point that hasn't to date?

Bill: I would like to ask Pro if I could a question.

Dimity: Please.

Bill: Is it just a question of more money? We have made great strides in dealing with mental health disabilities. We have a system of group homes and support services for people with disabilities. We have an incredible commitment from their family members. We have an imperfect under funded transportation system for people in general, especially for people with disability. But we know how to provide these services. You asked whether it was just a question of money. And I think you meant -- I thought you meant money for services not just money for income. But it seems to me the question -- is that what you meant? Money for services or money for individuals?

Pro: I think both. What I'm hearing is that there are a lot of issues. And the journey of 1,000 miles starts with one step. If that first step were in the form of currency, I have a hunch that a lot of the rest of it would fall into place. If your income were sufficient so you didn't have to worry about screwing around with petitioning agencies and so forth, you could then address some of these other terribly important issues. So it's that. I guess I'm concerned about services also. I'm thinking of primarily in terms of the people I'm hearing here today. Were there more money available for them to be provided in the form of services, I think a lot of good things would happen. I don't think its going to happen and I don't think money's the only issue.

Bill: I would like to ask -- you are involved with the faith community, right?

Pro: Correct. Interfaith.

Bill: Why is it that the faith community, which I am a part too, espouses? We testify at all these high ethical values. But why is it people have to scrounge around and beg for bare existence in an incredibly rich country like this one. I mean that to me seems to be the questions. Why, why do these problems exist? Why don't we as a country, as a culture, as a society make the commitment that's necessary to do that? I mean hell, if we want to go to war in Iraq; we just get the credit card out, stick it in the machine and go. But every place else, well, we don't have the money cut back. I don't get that. In a society that claims to have some real sound values. And -- If I had to answer your question, I would be sitting in a pile of money myself. I don't know the answer to that. Certainly articulating the problem, bringing the problem home. I lost a daughter who was arthritically crippled and blind at the time of her death. Great human being, she was doing great things. But I'm sensitized to the issue because I lived with her. Part of the problem is there's a lot of nimbi going on right now. They don't see it and they may very well be an educational component we have to pick up on and make it clear when the people read its real blood that's being bled. I don't think -- I think that's part of the problem. Indifference or indifference because of ignorance or ignorance because of lack of education.

Speaker: I would have to support that. I just left a church that I was trying to do some advocacy to get some funding for disabled people, specific disabled people that were in that church community. And they had no problem approving money to send a kid to New Zealand for a vacation. But when it came to the disabled people, well, we will give them a blanket. No money. You can't trust them with money. And the attitude was, you know, they are just looking for a free lunch and they are getting plenty. So I think it comes down to education.

Speaker: Not only that. There are a lot of disabled people that are unable to go to church. You know what I'm saying. You are capable. You can do anything. But they don't believe it. If you look at church by church denomination on this Island alone, you do not have generally people to go out to the church or seek out, have an outreach to whatever, or the people. It doesn't exist.

Bill: I wasn't just talking about the churches and faith community, but ethics and values as a society. Why doesn't our society feel Responsibility to not only -- I mean if education's a right, why isn't healthcare a right? Why isn't decent housing a right? Why isn't good quality mental healthcare or transportation a right of all people? I don't get it.

Pro: It's the American dream. It's not necessarily -- the American dream is a promise. When you have beautiful models, when you have athletes that are supposed to be strong, when you have all the images that are associated with success, why do you think you have a society that emphasizes that and makes an idle out of the work ethic want to feel positively with someone who isn't all of those things. It's part of our cultural -- it's the under side. It's -- you won't -- it's the shadow. It's the shadow of a successful society. When you are not successful, they don't want to look at you. Someone had mentioned death too. It's not like people are running out and -- always seeking life insurance when they are 20 years old. They don't want to think about death. They want to live forever. If you are successful and prosperous and you are making $500,000 a year, the last thing you want to think about is being in a position where you have nothing and you are scrounging around every day wondering how to pay rent. It doesn't come to people. And that's a cultural paradigm. How do you change it? I think its public relations. It's education. It's letting people know what your routes are. Because ultimately the people that are hurting hurt the people that are successful because we are all the same country. I don't get it.

Coffee: I would just like to add one thing. We as service people are trying our best to do everything that we can. And it's true that there is a phenomenal lack of money. And I think one of the things that you can all do is to help us to help you is to go out and vote.

Speaker: Who are the good guys?

Annette: That's a little tough to figure out. But we do live -- you know -- we live in this very perverse society. If you have a disability, you truly have to impoverish yourself to be eligible to do better. It's sad. The people that have worked real hard and thought they had a grip on the American dream are the ones that totally lose out. There's something really wrong. We've got to do a flip on this. We really do.

Pro: Bill's point still is going to resonate. The money is there.

Annette: Yes, it is. That's why it's a perverse society.

Coffee: That's why you have to vote.

Bill: It's how we spend it, all of us. If we let our politicians, our government makes those decisions and don't hold them responsible, it’s partly our fault too.

Mark: People are suffering. I mean, myself -- not just from the accident just from trying to attain services. And I don't even know what I’m entitled to. What am I entitled to? How do I feel about what I am doing applying for different services, where's my confidence? It's gone. Because I’m being introduced as not Mark Aubrey, he was -- I’m being introduced as Mark, brain injure survivor, problems. People that know me say he's gone. He's gone now. Its like can there be a type of services that kind of instill confidence in the person that you are delivering the service to. Given me something to work towards. And it should be the process of work. None of these things should be handed to anybody. I mean, there should be some adversity because it creates a positive environment for that person, to get through that experience and feel good about it. And once you get through it, then you have that feeling of accomplishment like you do something. That’s a step by step process I think that could be initiated in the delivery of types of services. I mean, I would like to ask this gentleman a question with regards to mental health. The services that are being provided to persons with mental disabilities, are they automatic? I mean, does once you start you go to the emergency room, okay. You get mental health services. Are those services that are provided after that is they automatic? Who initiates those types of services?

Speaker: There's criteria to determine whether a person --

Speaker: Right.

Speaker: Then there are some other tests or evaluations to determine whether this person has any means to pay for the services.

Speaker: That process is automatic.

Speaker: Yeah. We have had people who -- every year we assess and see whether they continue to have this disability.

Mark: You do follow up with people.

Speaker: We check on it every year. But we had people in service; mental illness is one of those things that don’t go away. We have people 20, 25 years or more.

Speaker: Right.

Speaker: And we have new people all the time. So it's -- but they are assessed each time. At least once a year the treatment plan is developed to make sure it's a service that's needed.

Mark: Do they have someone they can call to say, I’m not doing too well today. What do I do?

Speaker: Yeah. Every person that's in our -- has a case manager and we even have people that -- when they desire this, help them to manage their money and we have --

Mark: Social workers and so forth.

Speaker: And we have what we call mobile treatment team. Some people provide service 24 hours a day, 7 days a week if needed. Call us and we are there. There's a lot -

Mark: That's wonderful. That's excellent.

Speaker: Intervention.

Mark: Do you treat anybody with a traumatic brain injury? Is there anybody --

Speaker: Not often. You are right. Not often

Speaker: Really?

Speaker: No. There are some in our case load, yeah. Some of the time they are referred to the Braintree and other places outside of the state. Adversity affects physical functioning and capacity is a difference. More cognitive in all that we have seen continuously --

Speaker: Right. But they don't get the same type of -- they are not allowed to get those same types of services because they don't fit into that specific criterion.

Speaker: They are in the mix. They are receiving the same kind of services.

Mark: See, I was denied services because I had emotional problems after my brain injury. I couldn't control them. I cried for no reason. I didn't know how to act or react at certain situations. I would be in a group, do I leave now? Do I stay here? Is the conversation done? The point I'm trying to make, a person with traumatic brain injuries needs to have an automatic system in place. Go to the emergency room. Get assessed, treatment, follow through. There's no follow through. The person has to initiate themselves or the family members have to really fight to get some type of services. And by that time, their lives are completely devastated. They lost everything that they worked for. Whereas they could have gone through this automatic process and still kind of retained some of their -- part of their life that made them successful and hopefully will make them successful again. Can there be some type of process of services for people with traumatic brain injury, cognitive speech therapy, which is the most important. Clinical psychotherapy which is kind of holds everything together.

Bill: Why don't we ask the head of the mental health -- who has been a splendid advocate for people with disabilities in the state legislator? Former state senator, Bud, can I ask you a question? Could your organization, your 501 c 3 nonprofit expand to provide services for traumatic brain injured individuals? If you had the resources?

Speaker: If we had the resources and the personnel --

Speaker: Of course. This gentleman just described what he needed and what all people with TBI need. It's not magic. It's a question of whether society is going to give a qualified organization like in the resources to provide those services that that individual easily can describe is needed. The issue is whether or not the government with our tax money is going to spend our tax money for that kind of choice, the way to spend it or some other way. And -- are you familiar with Sergent Rehab?

Speaker: Yes. I have been there.

Bill: A great organization that deals with people with traumatic brain injuries. I get across my desk at RIPTA sometimes a description of a person with a tbi. Every time if see a little kid on my street in Middletown without a helmet on or a bicycle, I tell them, do you know what a TBI is? No. It's a traumatic brain injury and that's what's going to happen to you if you fall off your bike or get hit by a car without a helmet. Sargent rehab can help.

Transportation RIde

Do you know one of the routes that are going to be cut if RIPTA's budget doesn't get increased by the federal government? It's the route that goes by Sargent Rehab and RIder vans won't go to Sargent Rehab if that cut occurs. That's -- if you think things are bad? They could get a hell of a lot worse. And I really think people need to realize that and make some decisions about the way government goes state level, local, and certainly federal. It has a hell of an impact, a tremendous impact on all of us. And I think -- it just -- you know, obviously I care or I wouldn't be concerned. But sometimes we talk to the wrong people. We talk to each other or we bitch and moan because the mental health center won't provide the services. Of course, you would like to do that. Right, Bud? But if we as a society made the resources available, and I really think that's what we need to think about in this country a lot is what are we doing to ourselves. And you are right. The longer you live, the more likely you are to have a disability. And if you live into your elder years, you are damn near certain to have a disability or more than one. And so we are talking about our own selves, our own family members. I think need to do a better job of communicating that to the decision makers in our society.

Speaker: That's --

Bill: Sorry, folks, I apologize.

Pro: You said something about self-esteem. My hope, my dream is if I have the opportunity, I want to do a motivational speaking course that will help disabled men and men that are recently retired for several reasons. One, because men often define themselves by what they do by who they are and what they do, okay. And two, if you are disabled, it can be a golden opportunity for you to try something new that you never thought about before. Not going to all the details. The bottom line is I was bipolar since 1975. I was hired by over five fortune 500 companies. I worked with three. I worked for Blue Cross Blue Shield for over 13 years. I ended up with Textron Financial Corporation. I changed careers from being a counselor, psychiatric intake counselor to being a senior programmer working with the electronic Textron Financial Corporation. I was disabled during that period of time. I wasn't disabled so I couldn't work. Now I am disabled and I can't work. But that doesn't mean that I still don't have plans for the future, that I still might be able to make a fruitful contribution to society. You know, there's one thing that my mind gets skitsy or crazy. Computers, internet, connections. MS Support group worldwide for MS.com perhaps if some monies can be made available for those that are disabled to have internet connections or cheaper internet connections, there's a lot of support groups out there. I'm talking to people from Canada, Israel, whatever. And it’s wonderful. The advice you get, the suggestions you get, just the support and being able to share and give. And they're out there for traumatic -- for brain injuries and any kind of disorder you can think of. There are people out there that are sitting in rooms and being able to get a lot of support and information out to. That's a very practical and cheap manner in which perhaps they might be able to help the disabled. Although I read something in the paper right now, universal money might be even harder to keep the libraries and schools on the internet. One can hope.

Speaker: What is needed --?

Speaker: Sorry. One more for you in the middle here.

Gary: I just want to say two things. One from the Office of Rehab Services, you know, I wanted to make sure you would know we thank them for their participation. We are going to take the information in conjunction with our state rehab council, not only from this forum but from the five that were held around the state, and use it to try to improve our program, anyway. And just on a personal note, the comments really touched me. You know, I wouldn't be in this field if it wasn't important to me as Bill was mentioning. Thanks for coming.

Speaker: I would like to read out a letter. Perhaps what I would like to do -- I know people still have questions. If the panel wouldn’t mind just staying for the next while and answering some specific questions that you have, that would be really helpful because we seem to be more in question -answer dialogue. Perhaps giving of information. So I will just read this letter for the record. It's from Tom McMahon, MD. And he's written to the panel to say "to who it may concern, I’m aware of the forum to be held next week but am unable to attend. I would like to draw to your attention a problem which I think needs to be solved. I have a daughter with cerebral palsy in a wheelchair. In order for us to provide transportation, we had to get a wheelchair adaptation to a minivan. It cost $18,000. I think that people who have disabilities should have the right to a wheelchair adaptation for their vehicle."

Dimity: I would like to thank everybody for coming today, for your participation. I encourage you to dial up with members of the panel. And I hope this information was -- will go to the website, be analyzed, and recommendations will go to the governor. Thank you very much for your time.

Emailed and Written Testimony

Governor's Commission on Disabilities Public Forums
Warwick Public Library
July 28, 2004
Submitted by:
Sharon K. Brinkworth, Executive Director

Insufficient services for individuals with brain injury include:

- Case Management- only available for those identified as requiring extensive 24 hour programming or basic ADL assistance secondary to motoric limitations. There is a significant lack of case management services for those who require Cognitive assistance or manual assistance with Incidental/ Higher level ADL and life skills/personal management.
- Current medical assistance rehabilitation options limit access to the most appropriate outpatient rehabilitation, cognitive rehabilitation, assistive technology assessment and services, neuropsychological assessment and services, and neuro-optometric assessment and services.
- The affordable housing shortage is having a negative impact on individuals with brain injury as it is with those from other disability groups
- The Brain Injury Resource Center in Cranston was established by the Brain Injury Association of RI, Inc. through a 3-year Federal TBI Implementation grant that DHS contracts to BIARI. By the end of 2003, the Resource Center had a 400% increase in call/walk-in volume since opening in December 2002. The resource center provides information/educational materials on a variety of brain injury topics, prevention and medical/community resource information for brain injury survivors, families and professionals. A funding source will be needed to continue the operation of the Resource Center after 3/2005
- Legislation to create a brain injury trust fund was introduced in the 2004 General Assembly. All 3 bills had public hearings with one bill passing committee and making it to the House floor for a vote. That bill was sent back to committee. There was great interest among the legislators and we have been assured that they will work with us again next year. The brain injury trust fund bill would have created a fund by assessing an additional $10 on all speeding violations. The bill would have expanded the membership of the Governor's Permanent Advisory Commission on TBI. This bill would have provided for the above-mentioned brain injury services, and provided funding for the continuation of the resource center. We appreciate the support for this legislation from the Governor's Commission on Disabilities, the RI Disability Law Center, and the many survivors and family members who testified and wrote letters of support.

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Subject: OSCIL and The Gift of Hearing Program

Communication Access Oral

My name is Ida May McCarthy and I am from Warwick, R.I I wanted to give testimony at your meeting at the Warwick Public Library but I was unable to make it. I was watching my Grandson Sean. I wanted you to know that because of OSCIL and The Gift of Hearing Program I am able to hear everything Sean has to say to me. Up until I received my hearing aids through the programs, I always had to tell Sean and his friends to talk into my better ear. Life was not easy; I could not have conversations with people unless they looked at me and spoke clear and loud. I went to see Dr. James Healey an Audiologist and he told me hearing had deteriorated in both ears. I was told I needed hearing aids. My husband and I do not have medical coverage that would help me. Dr. Healey stated that he could give me basic hearing aids for about $1000.00 each. I told him I was not in a position to get them at this time. I bought some volume control phones at Radio Shack and a listening device I found for $10.00. The device was not perfect but it helped till I could find help. I finally found the help in November of 2003 when I was told about OSCIL. I took a chance and called. Donna Lee a OSCIL representative. She came to my home and interviewed me and helped fill out the paperwork to see if I qualified. I was so happy, when I was told I did and to call URI Department of Communicative Disorders. I was told I had to wait till after the Holidays till their break was over. I was thrilled when my appointment came and I was fitted for my hearing aid. Roberta Singer and her staff were wonderful to me they even let me pick out the style of hearing that I would be comfortable with. I feel I was lucky to find out about the hearing program. I hope in the future the program continues and more people can learn about and benefit from the program. I believe there are a lot of people who could use the program because of lack of funds and have no where to turn. I hope the program can be more publicized so more can benefit.

Sincerely Ida May McCarthy

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Emailed Testimony for 04 Public Forums

Transportation Disability Parking

I am unable to attend one of the Public Forums but did have some comments. We recently moved to Rhode Island from Florida and I have been astonished with the frequency I see cars without handicap stickers parked in handicap spaces. People, also, park in the yellow crossed out space between or beside a handicapped space making it impossible for a wheelchair to navigate between the cars and get in the car. I was, also, surprised by the low cost of a ticket in some towns....sometimes posted at $25.00. Additionally, I have seen police officers ignore cars parked in these spaces and never ticket them. It would be nice if the posting was enforced and the fines rose for violators. In Florida many municipalities charge $1000.00 fines for parking in these spaces and violators are ticketed by police that are always checking the spaces....even in private parking lots.....for violators while they are doing their routine patrols. It is amazing how infrequently you see people without a sticker parking in those spaces when they know they will get ticketed. It is hard enough for the wheelchair bound individual to get around without having parking problems to boot.

Susan R. Little, East Greenwich

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These comments are regarding issues for the disability forums. Both of us are disabled and retired, but unable to attend any of the forums.

Housing Safe and Affordable

#1 Affordable and Accessible Housing: We were fortunate in that we were able to buy a condo in West Warwick last November, 2003. We searched all over the state for something. There is very little to choose from, especially if one is handicapped physically. This condo is not even designed for handicapped, but is on 1st floor, where we could install a ramp so that we could enter the condo using our scooters.

Transportation Curb cuts

#2 More curb cuts. Places like Newport are difficult to visit because curb cuts are so absent. In West Warwick (downtown) it's the same.

Transportation Disability Parking

#3 More handicapped parking spaces + wider ones Leave more space in between parking spaces

Russell & Joan Kokernak, West Warwick

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My name is Brian Hennessey and I am from Narragansett, RI. In September of 2000, my wife Christine was hit in the head by a large buck on her way home from a routine day in Narragansett. From that day forward, my wife's life as she knew it, would change dramatically as well as the lives of those that love her. At first, neither of us knew what we were in for. Shortly after the accident, we both knew something was wrong but had no idea as to what that something was. Eventually she was diagnosed with a mild traumatic brain injury. Let me assure you that there is nothing mild about it. The next several months immediately following the injury were extremely frustrating. From the time she was driven home by the ambulance and over the next year we were told it was just a matter of time…….the best cure was the simple passing of time. At first this seemed acceptable given our lack of knowledge but over time it quickly became more and more frustrating and unacceptable. During this time of waiting my wife was experiencing serious cognitive and executive functioning issues that were not being addressed. She was experiencing fatigue like never before getting tired after what used to be the simplest of tasks. She was having difficulty managing her daily life from getting up to make herself breakfast to brushing her teeth before going to bed. Everything seemed to be chaotic and out of control. She was unable to enjoy those things she enjoyed before the accident……taking long walks on the beach, dining out, taking day trips, writing poetry, preparing nice meals, enjoying get togethers with family or friends and other interests. It was painful and maddening at the same time to see my wife change before my eyes and being given no direction or instruction as to what to expect and how to provide the best support I could but rather just being told….give it time. Overtime we had to redefine our roles in our marriage. As a result, I took on more of the household responsibilities such as shopping, cleaning, cooking, paying the bills, writing and sending out the birthday/anniversary cards etc. and I know at the same time this slowly took away Christine's confidence, in her mind, wanting to be a more contributing member of the team. Eventually, after our pushing and prodding, Christine was referred to rehabilitation services. These services proved valuable, teaching her sequencing skills and helping her to acquire strategies to develop and better manage daily routine.

Health Care Insurance Unfortunately, even though Christine was showing progress, the health insurance carrier would allow only a limited number of visits per year. In an effort to increase the sessions, Christine's primary physician wrote a letter indicating additional visits are needed but the request was denied. This certainly would not have been the fix all but it certainly would have assisted with additional progress. Currently, Christine is seeing a behavioral optometrist specializing in vision therapy. It was not until we attended the MA Brain Injury's annual conference that we learned about Post traumatic vision syndrome which is associated with traumatic brain injury. Christine has shown considerable improvement in this area which has helped significantly in her daily living. Unfortunately, these services are very expensive and our insurance company does not consider this therapy a necessity and only pays a very small portion of the cost. This surprised us given the significant improvement we have seen. What also surprised us was that many folks in the medical profession were unaware of such therapy for brain injury survivors and the impact a head injury can have on vision.

Given all the above, I see services needed for the brain injured in several areas.

Health Care Rehabilitation First, revenues are needed to subsidize specialized therapy that some health insurance carriers do not pay for.

Health Care Professional Development Second, it seems some medical professionals need to be better educated on various services offered to the brain injured. I'm sure the RI Brain Injury Association could use additional funds to continue to improve brain injury awareness throughout RI.

Health Care Case Management Third, given our experience, it seems medical professionals such as neurologists, neuropsychologists, primary physicians, psychologists, behavioral optometrists and cognitive therapists have different perspectives as to what the best approach would be in response to treating a brain injury. These different perspectives can be conflicting and very confusing to the injured person and their loved ones. As a result, I think additional case managers are needed to coordinate the best approaches of treatment for the different brain injured.

Health Care Counseling Fourth, I know my wife could benefit from peer support groups if they were closer to Narragansett. Unfortunately for my wife and I'm sure others, it is difficult to drive long distances. For this reason it would be beneficial to locate more of these services and others on bus routes.

Your attention to this growing need is greatly appreciated. Thank you.

Brian Hennessey, Narragansett, RI

Ms. Rita D. Alderson
172 Plain Street
Rehoboth, MA 02769

July 24, 2004

Sent via email and U.S. Mail
Governor s Commission on Disabilities
John 0. Pastore Center
41 Cherry Dale Court
Cranston RI 02920

Dear Members of the Commission:

Accessibility Chemical Sensitivity I noticed your recent advertisement in The Providence Journal for the upcoming public hearings. The reason I am writing to you is to commend you on stating in your notice that you “request people wear unscented products ...“I am a person who has asthma and is also very affected by perfume and other scented products. There are many people who are not understanding, or sometimes do not truly believe, this health issue. It is very important to me that people are made aware of how perfume and other scents can affect other people.

Employment Discrimination I recently found it necessary to resign from my job of many years as a legal secretary, because of two newly hired secretaries in our office who thought they should have their right to wear heavily perfumed products, no matter how negatively it affected others. After six weeks of this situation, I personally felt for my health that I must resign.

I recently submitted a claim to the Rhode Island Department of Labor requesting the possibility of collecting benefits while I continue looking for a suitable job to support myself. I have been out of work since February. My claim was denied by Ms. Carol Gibson. When I was giving my statement over the telephone, I tried to explain that even though I resigned, it was these circumstances that forced this decision upon me. However, I was under the impression that the person I spoke with did not fully understand asthma and/or how perfume can affect other people. My claim number is 04-12700.

If at all possible, it would be wonderful if “information bulletins or letters” could be sent to various offices/businesses throughout the state (beginning with law firms!) to be copied to their employees -- or some other type of request along these lines.

Thank you so much for taking the time to read this letter and my best wishes to you in your efforts in making people of Rhode Island as aware as possible of issues like this.

Sincerely,
J D. Alderson

Governor’s Commission on Disabilities
John 0. Pastore Center
41 Cherry Dale Court
Cranston, RI
02920-3049
fax 401-462-0106
email: disabilities@gcd.state.ri.us

To Whom It May Concern:

The following is intended to share the concern, both, my wife and I have expressed to each other on numerous occasions over the past year concerning several observations we made through the process of helping our “disabled” son get into the system and receive some benefit from what we initially thought was a safety net for the unfortunate in our society. As an outsider to the system and not having any experience with the process required to gain access to the very much needed resources of the system we as citizens have paid for over the years, we found the task extremely frustrating and cumbersome to say the least.

I recognize there are many types of disabilities and services that may be required for each of the various situations that are obviously complex and difficult to administer. I am obliged to discuss what relates to our experience with the system.

Family Support Resource Directory 1. Entry into the system of disability: We need to focus the system on the beneficiary of the services that are to be provided The array of benefits that apparently is available should be administered from a single location, geographic and with a single intake contact or coordinator. The complexity and confusion of having many access points for various services is overwhelming to someone who’s life has been turned upside down and who is easily confused with day to day activities. Without the constant support of my wife and I, our son would have easily become the guy living in the wood’s in a cardboard box. I have the sense that the system is far more intended to screen out the needy (thus eliminate the expense) than it is to help the needy get the services they require. SSI, SSDI, FOOD STAMPS, WELFARE, MEDICARE, MEDICAID. A lot for even an average citizen to appreciate never mind someone with limited income and/or mental capacity or confusion brought on by an unanticipated and debilitating disease. These people need help, not a run around, or an unfriendly process of achieving support.

Family Support Case Management 2. Awareness of available service: once a person has gone through the daunting process of getting into the system, he or she still doesn't know what will happen to them. There is a concern about loosing what has been achieved by getting into the system. The review process is overwhelming and difficult to maintain. The level of resource is very unrealistic (discussed later). The person in the situation of disability doesn't have the knowledge of what is available to him or her to help them with their day to day living requirements or where it will come from. Medications, transportation, living quarters, food, education, rehabilitation, socialization, it's as if we have allowed them into the system and that is all we need to do to feel ok about it. Medical assistance, is it Medicaid or something else?

Health Care Medicaid 3. Medical assistance: If a person has no insurance and is an adult, decisions are made for him by medical staff and he sometimes has no ability to control what happens. Services provided by an ambulance company, ordered by a doctor, to transport an unstable (physical or mental) individual for more appropriate care in another hospital, should be paid for under medical assistance. Placing the financial burden on the patient elevates the stress and causes him or her to try to do without. It discourages them from seeking out treatment when they need it most.

Family Support Case Management 4. Coordination of treatment/rehabilitation: The assignment of treatment to a facility and social worker, by way of exiting the hospital and being directed by social workers, presumed to be state workers, into a treatment environment that isolates the individual from family members without a process of information flow, even though permission papers were signed, is inconsistent with a reasonable and expected treatment philosophy based on professional recommendations. Insufficient coordination resulted in an occasion where specific medication was not attainable by the patient, which would have caused extreme consequences, but averted by coincidence because a family member happen to be picking up the medication at the time. If the patient was picking up the medication, the ridiculous price of the medication would have made it unachievable by the patient. Several months later and we are observing that the same lack of coordination seems to be leading us to another crisis by the end of this month. No standing prescription with an appointment on the 30 of the month and enough medication to last to the first. If the Doctor is absent or the appointment is cancelled for some reason, the patient needs some way to assure that he will have what he needs.

Health Care Medicaid 5. Medical assistance: After filling all of the requirements of medical assistance and having many Doctors (5) document the patient has a disabling and debilitating mental or medical problem, It is inconceivable that a "RN" nurse, within the state system, would have the power to override the diagnosis and determine that eligibility for medical assistance should be denied on the basis of no disability. Again, without family involvement, this would have put the patient at extreme risk of becoming homeless or worse. But for the appeal of this decision and coincidental approval for social security disability the decision was reversed. It is inconceivable to think of what would have happened if we were not involved. The system needs to take care of these people not make them fight for the benefit, a lot are unable to fight such a system. They need our support and help, not more paper to fill out or they shouldn't have to get a lawyer, which I am sure most could not afford.

Health Care Professional Development 6. Social Worker: Because of a lack of knowledge about what they do or what is expected of them. I find it difficult to understand the requirement of a social worker. In our situation, even though signed approval of release of information forms for the family doctor and family members, no information is forthcoming. The patient has a monthly meeting with the social worker to discuss something. It seems that pressure is applied to the disabled person to get back into society, find a job or something else. I don't know the credentials of the social worker, but find it difficult to accept that they are better trained than the doctors that gave the initial diagnosis. The results of the pressure, the opposite of what is needed, are to create a unpleasant and stressful situation for the patient. It seems that confusion about the patient's situation and diagnosis exists and is extremely unsettling. There seems to be too many reassignments of individuals. Our son has had four different social workers in the course of less than a year.

Family Support Financial 7. Financial support: Social Security provides $599.00 per month for all expenses the individual has. I find this grossly insufficient to permit an adult individual to live anywhere. No specific alternative to help with living expense is allowed, If he has any income it is taken directly off of the $599.00 which therefore only adds expense to his situation and does nothing to enhance his living conditions. We must ask if we individually could, in our own situation, manage our life with such resources.

There are numerous other issues with the system as it exists. I am hopeful that this input will be given fair consideration and perhaps it will help some needy person in the future. I don’t understand the system enough to offer specific solutions to the above sited conditions, but my sense is that the system needs to be completely eliminated and redeveloped to support the person in need, not the individuals in the administrative side of coordinating the system. It is far far to cumbersome to be much help to most of the people who need it!

If I can be of any further assistance, I offer to be interviewed, discuss or assist in any way I can at you request. I feel obligated to share these opinions and I am hopeful that our experiences are not the same as others who have had to deal with the system.

Jim & Marilyn Lannan
Foster. RI

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The Governor’s Commission on Disabilities

Testimony

Good afternoon, my name is Sheila Collins and I reside at 68 Colonel Christopher Green Road in Portsmouth. I am the mother of four children and my oldest son Michael is twenty years old and has a chromosomal disorder called Williams Syndrome. Advocating for children with special needs has become a passion of mine and I sit on several committees including our Local Special Education Advisory Committee, the East Bay Transition Council and the State Special Education Advisory Committee.

Education Transition to Careers

First of all, I would like to comment on how fitting it is to have this discussion at here at Salve Regina University. I am an alumnus of Salve and I am extremely proud of it being the second site in Rhode Island to house a Transition Academy for students with special needs ages 18 to 21. For the fi4t time, in the East Bay, these students are being offered vocational and life skills on a college campus with age appropriate peers. Salve’s administration has reached out with open arms to embrace these lucky students and help prepare them for the real world. We are entering very exciting times indeed.

Housing Independent Living

However, my son missed this “at home” opportunity and is in an out of district placement at a wonderful place called the Berkshire Hills Music Academy, in South Hadley, Massachusetts. It is the only place in the world that teaches to special needs children that learn through music. Michael has learned some wonderful vocational and life skills through this program, and we are delighted in his progress. Our goal for Michael is that he will be as independent as possible and be a contributing member to society. Our plan is that when Michael finishes another year in the program, he will return to Rhode Island and have a place he can call his own with the appropriate supports.

We applied to the Division of Developmental Disabilities when Michael turned 18 to get the paper work started. On January 19 2004 we submitted a request for funding when Michael turns 21. Just three days ago, we finally heard that Michael will be granted level 3 funding, yet there is no money available. Currently in Rhode Island there is no money available to open any group homes in the upcoming year. Young and older adults with special needs must live with their parents until they are in a crisis. Families are being penalized because they are an intact family. Apparently, it seems that people with special needs are being placed in group homes only when one parent is dead and the other is terminally ill. Needless to say, this is totally unacceptable.

Last month, a group of 15 families (and I am sure there are many more) gathered to be proactive on this issue. We are looking at the options to develop owner-based housing for our loved ones. We, as parents are willing to go and pay the mortgages but there needs to be funding available for support to make this dream a reality. We need to look outside the box and develop housing options that are a win for everyone. Our school systems and parents have worked diligently to get these students ready for the real world. We are sending them to “college”. Adult Services need to be there when they ‘graduate” We cannot let these students sit at home and be nonproductive and dependent. They and their families deserve better. We look to you to help us find ways that these citizens can truly be as independent as possible.

In summary, I would like to thank the school systems for developing transition academies to prepare these individuals for the adult world. However, the adult service world needs to step up to the plate and be ready to provide services for these individuals when they cross over to the adult world. We have invested too much in these individuals to let them fall through the cracks. Thank you for your time and attention to this matter.

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Date: 7/25/04 1:21PM

Subject: Re; Lack of work for the disabled

Employment Job Training

To Whom it may concern, I'm a 47 year old married man, whose wife is also totally disabled. I'm writing you because of my concern for "legitimate work from home opportunities". Since becoming disabled 17 years ago, I've worked the "system"...Vocational Rehabilitation, I've been able to acquire licenses and work independently on a commission basis. But, my condition has worsened over the last 5 years forcing me to seek work from home and it's been very discouraging. I have never sat back and looked for hand-outs, but it's so hard for me to believe in this time of telecommunications such as, PC's, cell phones, etc. ,and with companies hiring temporary workers as to not have to pay them benefits, and here I am, as well as millions of other tax paying Americans, where these companies aren't even advertising to hire the disabled with all our technology it should be a no brainer! I'm asking that if someone can please get back to me with some information on companies that are willing to hire the disabled. We are bright people, we just have "obstacles". My other is subsidized housing. I live in a complex with my wife for 3 years, and every year our rent goes up, but no improvements are implemented, they just make sure, when HUD is about to come around that the outside of the buildings look appropriate, but the insides of our apartments, and by the way, I know they have to follow certain conditions in order to continue getting their funding, if it were not for people in our situation, they wouldn't get the be befit! Our rent keeps be raised, yet our apartments are being allowed to be runned down. Frankly, I feel this is unjust and we would like something done, either at the state level or federal. Our medications keep rising, yet less in medicals are being taken into account. Has HUD changed its standards, or possibly just the landlords?

I'd really appreciate it if someone can help me, and give me some answers. I'm not alone, I vote and we're just one of many registered voters who expect our representatives to look out for us, that's why we voted for you... it's called TRUST.

Thank you

Sincerely,

Paul

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To: <disabilities@gcd..state.ri.us >

Date: 7/22/04 7:30PM

Subject: THE DEAF IN RHODE ISLAND contact Michael D

Hello,

Communication Access Education

I know that you will be having a meeting on July 26. The meeting will be on the same grounds as where the Perspectives Office is located. I have a child that lives in one of their homes. My son has missed out on his education from the years he was 18,19,20 and 21 .He is on a second or third grade reading level. However, he has had subjects like history math science etc. at the Learning School for the deaf. The last couple years he had been hospitalized and he missed out on completing his education. The problem always goes back to his deafness. RI doesn't offer enough services for the deaf. I hope that in the near future that my son will get a GED, high school diploma or a special education certificate. I hope that there will be someone at your meeting that can help my son complete his education in ASL and receive his diploma.

Thank You,

Robin (mom)

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07 11:06 FAX

UNIVERSITY GASTROENTEROLOGY

29 Powel Avenue
Newport, RI 02840
July 22, 2004
Panel of the Public Forum on Disabilities
To Whom It May Concern:

Transportation Private Vehicles

I am aware of a forum to be held next week but unable to attend. I would like to draw to your attention a problem which I think needs to be solved; I have a daughter with cerebral palsy in a wheelchair. In order for us to provide transportation, we had to get a wheelchair adaptation to a minivan. It costs us $18,000. I think that people who have disabilities should have the right to a wheelchair adaptation for their vehicle.

Thomas P. McMahon, M.D.
TPM/jll

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Dear Commission

Accessibility Government Services

I want someone to know about certain public buildings that are difficult in enter for people with disabilities. There are no handicap access to the entrances and the doors are heavy. I use a cane and I hate to complain. Sometimes I feel embarrassed, stressed, and weak!

We are being punished for out health problems. I know money is an issue but a little change can help.

Health care and insurance are so costly. Why?

How can, we keep paying these prizes?

Sincerely,
D.L. Groce
Warwick

Index of the Concerns of People with Disabilities and their Families