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

July 25 – 28, 2005

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
401-462-0100 tty via 711 or fax 401-462-0106

November 2005

Table of Contents

TOPICAL INDEX

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

Monday July 25, 2005 3:00 PM- 5:00 PM
Newport Public Library, Lower Level Program Room, 300 Spring Street

Tuesday July 26, 2005 3:00 PM - 5:00 PM
Cross Roads, 160 Broad Street, Providence

Wednesday July 27, 2005, 3:00 PM-5:00 PM
Warwick Public Library Community Room, 600 Sandy Lane, Warwick
Wednesday July 27, 2005, 4:00 – 6:00 PM
Colt State Park, Barn, Bristol

Thursday July 28, 2005, 3:00 PM – 5:00 PM
Westerly Senior Center, 39 State Street
Thursday July 28, 2005, 4:00 PM – 6:00 PM
Arc of Northern RI, 80 Fabien Street, Woonsocket

Special Forum on the Concerns of People Affected by Household Chemicals
(Asthma, Respiratory Disorders, Chemical Sensitivity, Neurological & Behavioral Conditions)
Tuesday August 23, 2005 10 AM – Noon
RI Lung Association, 298 West Exchange Street, Providence

Comments may be made in person during the forums, 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.ri.gov (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 on July 26th; contact the CDHH (voice) 222-1204 or (tty) 222-1205 to confirm that other forums will have interpreters.
When making the ADA reservation with RIde to get to and from the public hearing, tell the RIde reservationists that this trip is for the Governor's Commission's Public Forums in order to guarantee your return trip, after normal RIde hours of operation. The ADA fare is still applicable.
For more information or to request accommodation needed, please call: 462-0100 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.

Governor Donald L. Carcieri

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

Advocates in Action, Kevin Delbonis, President;

American Lung Association, Lung Health Program, Tina Ragless, Director;

Arc of Northern RI, Dr. Robert Carl;
College of Pharmacy/URI, Donald Letentre, Dean;
Community Provider Network of RI, Donna Martin, Executive Director;
CranstonArc, Thomas Kane, Executive Director;
Corliss Institute, Mary-Ellen Baxter Breen, Executive Director;
Council on Assistive Technology, Jeanne Panarace, Chairperson;
Assistive Technology Access Partnership (ATAP), Regina Connor, Project Director;
Department of Administration Library & Information Services, Anne Parent, Chief;
Department of Elderly Affairs, Corinne Calise Russo, Director;
Department of Environmental Management, W. Michael Sullivan Acting Director**;**
Department of Human Services, Jane A.Hayward, Director;
Department of Labor, Adelita Orefice, Director;
Department of Mental Health, Retardation, and Hospitals, Katherine Spangler, Acting Director;
Governor's Commission on Disabilities, Paul Choquette, Chairperson;
J. Arthur Trudeau Center, Mary Madden, President/CEO;
Long Term Care Coordinating Council, Lt. Governor Charles J. Fogarty, Chairperson;
N**eighborhood Health Plan of RI**, Ernest A. Balasco, Interim Chief Executive Officer;
Ocean State Center for Independent Living, Lorna Ricci, Executive Director;
Opportunities Unlimited for People with Differing Abilities, Linda N. Ward, Executive Director;
PARI Independent Living Center, Leo Canuel, Executive Director;
Paul V. Sherlock Center on Disabilities @ RIC, A. Anthony Antosh, Director;
Rhodes to Independence @ the URI College of Pharmacy, Donald Letendre, Dean, Elaina Goldstein,Director of Public Policy;
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 Disability Law Center, Raymond Bandusky, Executive Director;
RI Coalition for the Homeless, Leigh Pagnozzi, Acting Executive Director;
RI Health Centers Association, Kerrie Clark-Jones, Executive Director;
RI Housing Resources Commission, Susan Baxter, Chair;
RI Public Transit Authority, Alfred J. Moscola, General Manager;
RI Rehabiliatation Association, Susan Shapiro, President;
State Rehabilitation Council, William Anderson, Chair**;**
Spurwink/RI, Raymond A. Arsenault, Executive Director;
Statewide Independent Living Council, Sharon Kimbriel, Chairperson;
Toxics Information Project, Liberty Goodwin

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 Working Group Themes and Recommendations

Convener - Paul Choquette- GCD ; Paul Klinkman- Toxins Information Project

Themes/Findings	Recommendation	Testimony on Pages
There are still areas throughout the state where there are a lack of/ or inadequate curb cuts. (Warwick, Cranston, Providence)	Continue to advocate for installation of curb cuts where they are needed with DOT and/or local municipalities	32,43,47
There are areas in the state that lack sidewalks or where the sidewalks are in disrepair	Continue to advocate for installation or maintenance of sidewalks with DOT and/ local municipalities. OR establish complaint/communication mechanism through GCD	34,52
Some existing ramps do not have adequate handrails	Provide technical assistance to entities installing ramps to ensure that existing ADAAG guidelines are followed	30
Some subsidized housing complexes lack automatic door openers resulting in lack of access	Provide education/technical assistance to management companies/public housing authorities in regards to their responsibilities under existing law to provide ADO's	35
Public facilities (theaters, restaurants etc.) segregate wheelchair users to certain areas due to "safety concerns"	Provide education/ technical assistance detailing the proper procedures in regards to wheelchair seating	45
People with chemical sensitivities are unable to access public buildings due to presence of irritants	1. Provide training to public officials regarding issues of chemical sensitivities Push to have State government use only non-toxic cleaning supplies in state facilities	35,38,44,75,80,86,87,89 91,98,103,104,105,107 110,118,119
There is a general lack of awareness about the issues of chemical sensitivities	GCD should specifically address these issues in training and outreach	Multiple pages
Lack of housing for people with Chemical Sensitivities	1. Educate building managers, realtors etc. regarding the issues of CS and accommodations 2. Establish preference for Section 8 vouchers for people with CS who live in subsidized housing complexes	35, 44, 76, 77
Many bus stops are not cleaned of ice and snow during the winter months making them inaccessible	Determine who is responsible for keeping bus stops open and inform them of their responsibilities (Newport does a good job with this)	40
Crossing signals are not working properly in Warwick, endangering PWDs when attempting to use them to cross busy streets	Work with DOT and/or local municipalities to establish better reporting/repair procedures	41

Assistive Technology Working Group Themes and Recommendations

Convener - Regina Connor – Office of Rehabilitation Services
Paul Choquette – Governor's Commission on Disabilities

Themes/Findings	Recommendation	Testimony on Pages
Lack of funding for internet	Recommend that legislation be introduced granting PUC authority too implement reduced rate for internet access for people with disabilities of low income	12
Complicated process for acquiring Assistive Technology	More funding made available to increase the capacity of clinicians (pre-service training and in-service graduate training) to do assessments	12, 13
Funding for Activities of Daily Living related Assistive Technology reduced by 40%, general lack of Assistive Technology funding	Increase State dollars Feasibility Study	31, 33, 106, 116
Lack of information on where to find Assistive Technology	Assistive TechnologyAP – OSCIL, EBEC, Tech ACCESS	13
Assistive Technology sitting in basements going unused	PARI/Assistive TechnologyAP reutilization programs	36
Lack of trial Assistive Technology resources for children who are not hooked up with ORS and funding as well	Assistive TechnologyAP device loan programs at EBEC and TechACCESS	68

Education & Employment Working Group Themes and Recommendations

Convener - Linda Deschenes – Office of Rehabilitation Services; Rory Carmody - CranstonArc; Regina Connor - Office of Rehabilitation Services; Jeanne Behie – Gov Comm on Disabilities; Paula Dewell

Themes/Findings	Recommendation	Testimony on Pages
Lack of housing/shelter for homeless individuals working non traditional shifts, e.g. 6P.M. to 2:30A.M.	Assessment of the prevalence of this concern through a venue such as the RI Coalition for the Homeless.	Pg. 19
Dissatisfaction with services provided through the Office of Rehabilitation Services. Lack of staff to meet demands, access to services and navigation of the system.	Continued advocacy for resources to hire and train staff.	Pgs. 39 & 57
Lack of employer incentives to hire individuals with disabilities.	Increase training and awareness to individuals with disabilities and employers on the various employer incentives through venues such as Department of Labor & Training's netWORKri Centers, Human Resource Investment Council, Office of Rehabilitation Services and community job development vendors.	Pg 57
Lack of access to assistive technology in the schools to try with students prior to purchasing an assistive technology device.	Advocate for State Colleges to include a course on assistive technology in their teaching curriculum. Advocate for the States Department of Education to offer a continuing education course on the topic of assistive technology. Increased education and public awareness through venues such as the local Special Education Advisory Committees on the resources available.	Pg. 68
Lack of access to choice regarding schools.	Increased education to parents and students on the resources available such as charter schools and the Sherlock Center.	Pg. 70
Lack of employer, co-worker and public awareness to chemical sensitivities resulting in job loss, increased sick days, behavioral concerns and difficulty learning of students.	Advocate for legislation to enact education awareness and guidelines for employers, and educational institutions. Advocate for the States Department of Education to offer a continuing education course on the topic of assistive technology.	Pgs. 85,89,90,97,104,117& 121

Family & Community Support Working Group Themes and Recommendations

Convener - Ken Pariseau, Neigborhood Health Plan of RI; Sharon Brinkworth, Brain Injury Association of RI; Karen O'Connell Lyons, Governor's Commission on Disabilities

Themes/Findings	Recommendation	Testimony on Pages
Concern re: current Mission Statement of MHRH	Consider incorporating the TASH principles into the MHRH Mission Statement	5

Sensitivity of disability support organizations to the wide range of disabilities		11
Lack of clarity re: basic questions such as “Do I need to put money in the parking meter”	Publicize information on SILC website. Incorporate into the “Point”	11
Formal state position to support advocacy and coordination.	Public awareness of the role of GCD as advocate	12
Lack of home-based support services for TBI survivors; delay in getting services.	Provide opportunity for survivors with TBI on Medicaid to enroll in a health plan.	14
No state agency to respond to issues of abuse of non-elderly persons with disabilities	KOL to review legislative or regulatory history	31, 35
Additional food stamp support for “medically necessary” diets		35
Financial planning support	Make Social Security materials more user friendly	38
Additional funding for services for persons with TBI	1.Provide opportunity for Survivors on Medicaid to enroll in a health plan 2. Reauthorize the TBI funding legislation	42, 56
The long wait for “Katie Beckett”	1. DHS is currently promulgating new guidelines and criteria for Katie Beckett 2. Mandate commercial coverage for children with special health care needs	68
The difficulty in navigating the service and support delivery systems for persons with disabilities and their families	Provide opportunity to enroll in a health plan	71
Lack of strong advocacy for persons with disabilities in areas such as disability insurance claims	Could this be a function of DBR or AG’s office? KOL to explore opportunity in AG’s office.	107

Health Care Working Group Themes and Recommendations

Convener - Kate McCarthy-Barnett – Rhodes to Independence, Paul Choquette – Governor's Commission on Disabilities, Janet Spinelli – RI Department of Mental Health, Retardation & Hospitals, Ken Pariseau – Neighborhood Health Plan of RI, R. Timothy Flynn – Shake–A–Leg , Liberty Goodwin – Toxic Information Project, Michael Spoerri – RI Department of Health & Marlene McCarthy – RI Breast Cancer Coalition

Themes/Findings	Recommendation	Testimony on Pages
	Legislation	
Families with commercial insurance coverage often are not able to access the same behavioral health services for children as families on RIte Care.	Commercial insurers need to be held accountable to provide the medical services their members need; particularly those with disabilities. Commercial insurers' practices shift costs for providing these services to the state; this is contributing to the rising cost of Medicaid. For example, prescription coverage, vision, dental and mental health services.	56
Difficulty accessing dental services under Medicaid. Poor reimbursement for providers.	Develop a better funded Dental Benefit Management (DBM) program for Medicaid beneficiaries.	64
Community based long-term cognitive rehabilitation service with support staff, financial management, counseling, and medical services such as neurology, neuro-psychology, vision, Neuro-optometry and assistive technology and family support.	Add legislate funding for expanding DEA volunteer guardianship program and to allow under 60 to participate in program or Develop legislation to fund a clinical coordinator for a statewide assessment team composed of residents, SW interns and student nurses etc. or Develop legislation to fund development and attendance to college credit/continuing education credit course (ie web based) on differential diagnosis, decision-making assessment, independence training, behavioral training, client empowerment, etc for providers. or Develop legislation and training for repayee services by provider agencies or Develop legislation to expand capacity for neurological, neuro-psychology, psychiatric services in hospital settings	5, 10, 15, 34
MS drugs are expensive and not included in RIPAE formulary, other drugs not in formulary	Determine if MS drugs are on any Part D formularies, if not, then include on RIPAE	10, 18. 46
Ombudsman for disability services across state agencies needed	Establish a disability ombudsman position	13
Kate Becket for underinsured	Legislation to improve underinsured grievance process such as Katie Beckett	56
The need for respite services.	Legislative funding to meet the need	56
The need for greater protection of those especially vulnerable to	Legislation or regulation to protect access to health care, nursing homes, schools and	Multiple pages of testimony

common chemicals, including people with asthma and other respiratory conditions.	other necessary services_for those sickened by chemicals in these places. (Might include requirements for in-service training, as per 3 b.) At a minimum, require institutions to adopt and carry out fragrance-free, less-toxic cleaning product and pest control policies.	
Young adults 18-21 experience difficulty accessing behavioral health services as they fall in the gap between two state agencies (DCYF and MHRH)	Increase funding for individuals who are dual diagnosis or have severe disabilities that currently do not fall under an existing MHRH priority diagnosis population. Young adults 18-21 experience difficulty accessing behavioral health services as they fall in the gap between two state agencies (DCYF and MHRH)	
Policy		
Lack of care coordination; customer service in Medicare and Medicaid.	Provide the option to enroll people with disabilities into a managed health care plan. Health plan would provide care coordination and customer service resources or access to the point or another central location.	32,
Six month Medicaid flex test for eligibility leaves consumers without coverage	Assist consumers in application process to cut down on lapses of coverage	20
Poor access to primary care under Medicaid. Poor reimbursement rates. Receiving primary care services at the ER	Provide the option to enroll people with disabilities into a managed health care plan.	21, 72, 83
No pediatric Rehab facility in New England area	Determine local rehab capacity in existing facilities and establish local facility or provide better information regarding existing resources	15
Income eligibility requirements in Medicaid are too low.	Propose increase in income eligibility	35,
Medicare takes a long time to approve wheelchairs	Decrease in waiting time	32
Lack of insurance for single males with no children	Medicaid coverage for individuals waiting for Medicare	18
Insufficient staff resources in programs such as HBTS	A state level strategy to address workforce development needs in health and human services areas	57
Difficulty accessing behavioral health services under Medicaid.	Provide the option to enroll people with disabilities into a managed health care plan. The health plan would have the responsibility of ensuring access to needed health care services. This would include the development of needed resources.	64
Difficulty accessing specialty services such as neurology, vision, hearing, podiatry under Medicaid	Provide the option to enroll people with disabilities into a managed health care plan. The health plan would have the responsibility of ensuring access to needed	64

	health care services. This would include the development of needed resources.	
The need for site-based behavioral health specialists.	Enroll persons with disabilities in a health plan. The health plan would have the responsibility of ensuring access to needed health care services. This would include the development of needed resources.	64, 69, 70
The need for greater protection of those especially vulnerable to common chemicals, including people with asthma and other respiratory conditions. For example, the lack of awareness and attention in public facilities like hospitals, schools, medical offices to the needs of persons with multiple chemical sensitivities.	Assistance with monitoring of any present or future protocols in service facilities. Possibly draw upon models from the work done by smoking ban advocates, especially the Substance Abuse Task Force.	89, 94, 98, 105, 111
Lack of access to health care for people with asthma and people with multiple chemical sensitivities	Forum on health effects of chemicals found in hospitals, day care centers, schools, workplaces. Presented by medical professionals to health care and school professionals and administrators. (Possibly also include affected person(s) as speakers.); Forum on how to replace toxic cleaners and deodorizers with healthier alternative products that are approved for hospital and institutional use; Sensitivity training for workers	82,99, 111
Out of state providers of treatment for MCS not Medicaid providers	Negotiate agreements with out of state providers for MCS.	83
Expand Governor's Commission on Brain Injury	Include more survivors, family members, treatment professionals on Commission.	5, 48
	Education	
Provide people with disabilities information regarding treatment resources. Make information available in different settings.	Develop outreach and awareness plan to educate the community about the new resource directory (the Point)	14, 15, 55, 58, 113, 114
The need for greater protection of those especially vulnerable to common chemicals, including people with asthma and other respiratory conditions	Education about the problems experienced by asthmatics and other chemically vulnerable populations, for health care and school professionals and administrators, as well as parents and the general public. Information on how to provide healthier environments.	89, 94, 98, 105, 111, multiple pages
Concerns about the proposed Federal cuts to the Medicaid Program.	Be prepared to advocate—stay education	38
Lack of information on Health Care resources	Utilize the Point or DHS Resource Guide	14, 113, 114

Housing Working Group Themes and Recommendations

Convener Arthur Plitt- GCD; Joan D'Agostino & Paula Parker – Department of Elderly Affairs; Paul Choquette - Department of Human Services; Marie Corcelli – Toxic Information Project; Kate Barnett- McCarthy – Rhodes To Independence;; Jessica Rutledge – Housing Action Coalition; Edith McLaughlin- RI Lung Association

Themes/Findings	Recommendation	Testimony on Pages
Available & affordable & accessible housing limited	All New construction should be visit-able w/ bath rooms on first floor. MLS listings expanded as with Rhodes T/I efforts. RI Builders Association made aware of universal design ready designs. Better placement coordination as wrong people in accessible units. Review of new programs like "Rent to Buy" for Independence and non isolation. Development & Recording Fees be used to support new efforts. Continued Support of NOP increased funding especially as a line item in budget or multi-year Bond funding of expanded NOP.	27,53,55,56,71,76
Housing Managers not listening to safety& Disability Needs of Residents	ADA and sensitivity-listening skills training for Housing Managers. Initial interviews for residents will have one page sheets for residents with rights and phone numbers for key contact people.	20,24,25,39,53,66
Housing Access improved with assistive technology for Independent Living and less expensive supports.	Social Workers and discharge people at hospitals/ nursing homes be trained to share one pagers - resident rights, assistive tech available w/phone contacts - like Tech Access, Insight & ORS and OSCIL/PARI. Use of Buttons for Door Openers.	39,53
Chemical Sensitivities of residents ignored by others including managers who fail to advise tenants of chemical usage (paint, cleaning, seal-coating)	Training of managers to include chemical sensitivities, revising apartment placements whether smoking or alternative cleaning chemical use. Green/Asthma Friendly Homes Explored(Mass)	113,88
Supportive Transitional Housing needed especially Brain Injury	RI Builders Association advised of needs and use of NOP funding to provide new construction. Social Workers at Hospital/Rehab Centers should give information on possible placements along with assistive technology referrals, Consideration of new programs as in other states.	43,95
Air Conditioning needed as a medical necessity	HUD/RIMFC changes to allow air conditioning added with some rent payment or Medicaid support. Also training sensitivities for managers.	45,95
Shelters lack accessibility in a	Funding thru NOP funds or other to reduce	various

growing population in RI.	the cost of complying by community group owners	
Confusion of resource availability and needs from residents who are disabled, providers and organizations. Acronyms and defining even accessibility confusion. (invisible, chemical, etc)	Training expanded as part of the 50th anniversary of GCD for all in different venues as well as empowerment training for individuals who are disabled for their self advocacy. Expansion of the "POINT" information hotline resource center at 462-4444 to a physical facility.	all
Chronic conditions expanding and needing preventative solutions.	Consideration of a White Paper for the Long Term Care Cabinet from the Governor's office.	all

Transportation Working Group Themes and Recommendations

Convener: Bill Inlow – RIPTA; Jeanne Panarace; Elaina Goldstein – Rhodes to Independence; Lorna Ricci – Ocean State Independent Living Center; Ralph Rodriguez – RI Department of Elderly Affairs

Themes/Findings	Recommendation	Testimony on Pages
RIPTA bus bike racks do not accommodate all styles of bikes	Allow customer to bring bike on the bus, and store safely	Page 7
RIPTA photo ID office doesn't visit Newport often enough	Use infrastructure of Registry of Motor Vehicles and AAA offices to process bus and ADA ID's	Pages 8 & 9
Not enough RIPTA bus service in Woonsocket and no service in Westerly	Need to address adding fixed route and ADA service in Westerly	Page 18
Funding for accommodations for personal vehicles (cars), currently uses assistive tech money	Explore other options for specific funds for assistive features on personal vehicles which are the greatest resource for mobility in RI	Page 31
RIPTA bus passes have to be renewed too often	Renewal process should be streamlined and period should be longer than 2 or 5 years	
Employment and transportation, routes don't go to some employers	RIPTA needs to review routes where there are employment opportunities of customers with disabilities.	Page 31
RIde service is not always reliable, too late or too early, especially important for employment	When customers have "no-shows" there are penalties, when RIPTA causes late arrival times, either refunds of ADA fees or free rides should be given	Expressed after transcript period
Payment for power assist for wheelchairs	Medicaid pays for more expensive wheelchair but should pay for this less expensive device	
Bus stops need to be cleared of snow and other debris	RIPTA should demand contractors and local communities comply with rules	
All gas pumps should be accessible all the time	Compliance with accessibility of gas pumps should be monitored better throughout RI	Page 43
There are too few trips on many RIPTA bus routes, too long between buses	Don't cut any more bus routes or trips	Page 49 @ 51
Traffic lights and crosswalks	All accessible traffic control devices should be fully maintained at all times	Page 40
Lack of sidewalks in certain areas, many people need to walk or roll safely	Conduct inventory of state and local codes regarding sidewalks and maintenance, and determine compliant avenues for consumers	Pages 34, 51 and 53
Lack of transportation for community activities to enrich lives	Legislation to increase the use of private entrepreneurial businesses for transportation, and making use of other vehicles like senior center vans, school buses, etc. to fully use existing resources in the community	Page 65
No courses in adaptive driver education	Make them readily available, State should create incentives to encourage use of	Page 70

	private accessible vehicles	
Needs to be “canary” devices on airlines (chemical sensitivities)	Federal policy issue, fragrant free flight attendants	Page 106
Dangerous safety issue when late or no ADA pick-ups at night	RIde needs a seamless back-up system to insure no disabled customer is ever stranded without a ride, especially late at night and in other hazardous situations	After end of transcript session

THE TESTIMONY

July 25, 2005. Newport Library, Newport

Sharon Kimbrel: I am the moderator for this afternoon and we have lots of panelists. So instead of my seeing how I can win or lose by remembering everyone's name and doing it wonderfully, what I'm going to do is allow the panelists to introduce themselves and start on the public forum.

Annette Bournniere: I am here today representing the State Rehabilitation Council.

Paul Choquette: My name is Paul Choquette and I am the chair person on the Governor's commission.

Tim Flynn: My name is Tim Flynn, executive director of shake-a-leg, and acting Chairman of the legislative committee on the Governor's Commission on Disabilities.

Eleana Goldstein: I am the director of public policy at Initiative of Rhodes to independence.

Alexandra Laplante: I'm from the Rhode Island Disability law center.

Linda Ward: I’m from Opportunities Unlimited and representing the private provider committee.

Diane Kayala: I’m from the Department of Human Services and Medicaid office.

Paul Autote: I’m from the office of rehab services.

Ken: I'm from the Neighborhood Health Plan.

Bill Inlow: I'm Bill Inlow from the Rhode Island Public Transit Authority and I also serve on the Legislative committee of the Governor's Commission on Disabilities.

Sharon: Well, welcome everyone. I'm supposed to start the meeting on time and I think with the parking out there, we've probably done about as well as we could. Everyone in here signed the attendance sheet? I'm to tell you that the purpose of these public forums is to identify the concerns of people with disabilities and their families in order to assist the state in developing programs to improve the quality of life of people with disabilities. This is not a conversation that we are going to hold. The panelists are going to listen to what you have to say and you are going to talk about the disabilities and what you want to say in your testimony. There won't be a question and answer periods. The CART transcript will then be taken back and gone over very carefully with the information that you have given that's needed and many of the agencies use this information. The transcripts will be posted on the GCD website. It says within a week they will be posted and then they will also be prepared and will go out to the different organizations and however long it takes them to do that. It says the recommendations will be used to develop policy and legislative initiatives for the next year or until they are accomplished. So I want to give everyone a chance to speak. We have a lot of people. I would say you are going to have about five minutes to speak. So, we will have about five minutes. Clearly state your name so that it can go into the transcript and then what you want to give testimony on. Panelists, are there anything particularly those that are from GCD, anything that you want to say Paul?

Paul Choquette: Let me thank everyone for coming. On behalf of the Governor's commission I want to let everyone know this is not just the Governor's Commission on Disabilities that are running these forums. Hopefully you had a chance to grab a handout on your way in if you didn’t; there are some on the table. There are over 30 sponsoring organizations this year, both state agencies, nonprofit agencies and disability rights organizations. Every one of those organizations is interested in hearing what you have to say because how we get things done in the state is by hearing from you even though we are up here on the stage a little higher than everyone else, we are still like you all here. We all have had challenges along the way. Because of these opportunities we had before, we have been able to make some changes and the main reason we are here is to hear what's going on out there so in the next few years we can work with our partners in the legislature to make some changes that will make things better for you. I want to take the opportunity to thank you for coming in, the panelists for coming today.

Sharon: Thank you, Paul. Well, the first sign in person on the list is Barbara and you have testimony you would like to give, Barbara?

Family & Community Supports

Barbara Kilkul: I'm on the board of Pow and in New England. I would like to say that I have a 37 year old daughter with a disability and I am concerned about the direction that things are going for families and people with disabilities. People aren't notified of the hearings in a timely manner except for this one and I also think the case in point is the former mission statement of MHRH showed clear vision for supporting other people with disabilities in a manner consistent with TASH and TASH New England. They will be coming out with a statement that resolves this particular mission statement and I hope the state will go back to the former mission statement because the current revised mission statement has deleted all essential personal statements and only addresses agencies that are interested in statutory obligations and fiscal management at the expense of individuals and families it's obligated to support. So, we are hoping again that the state will re-visit that and go back to the former mission statement. You know, on behalf of my daughter and our family, we hope that Rhode Island will continue in the direction it has in the past of being a leader among the states in serving people with disabilities and their families.

Sharon: Thank you, Barbara. The next speaker is Marika. Do you want the microphone, Marika?

Health Care

Marika Terleci: I'm a resident of Newport. Thank you for the opportunity to be heard today. I would like to also thank the Governor's Commission on Disabilities for their support in passing legislation to improve brain injury services over the past two years. I am a traumatic brain injury survivor. We are grateful that the Rhode Island legislation provides funds for brain injury services because of the significant lack of instate specialized traumatic brain injury programs and support services, the department of human services budget appropriations needs to be increased. The Governor's Commission on Brain Injury does not specifically include survivors, family members, or professionals specializing in rehabilitation community reentry processes. The Governor's Commission on Brain Injury should be expanded to include more survivors, family members, and professionals that provide services and supports throughout the continuum of recovery and community reintegration. The center for disease control estimates that there is a new brain injury in the United States every 21 seconds, approximately there are 5.3 million Americans living with long-term disability as a result of a brain injury. We believe that there should be a Statewide comprehensive brain injury prevention outreach program and general awareness campaign for education. There are no long-term community based programs providing long-term cognitive rehabilitation services and supports with daily living skills such as bill paying, budgeting, and management of personal affairs to individuals with mild cognitive deficits. Many of these survivors fall through the cracks but would have the potential to live more effectively in the community if they were provided long-term access to minimal supports. It would be beneficial if grants were provided for the development of these types of programs. There are economic barriers for individuals with brain injury in obtaining appropriate neurology, neuropsychology, counseling, vision and Neuro-Optometry, case management, and assistive technology assessment services. Quickly on a personal note, it's been ten years since my brain injury. I started off not being able to walk, speak, and hold a fork for 12 months to feed myself. I was in and out of rehab centers as a patient for three and a half years. It's been a long journey. So many people who see people like myself don't know that there is anything's wrong with us because I'm no longer in a wheelchair or using a cane or a walker. I was fractured in nine different places in my brain and prior to my injury, I was an international business consultant working with fortune 500 companies. I can no longer do that but I try to do other things. I have personally used the Rhode Island brain Injury Resource Center. I'm a strong believer in it because in my early years, both to myself as an individual and to family members, not only to myself but to other survivors, they are so helpful in providing and helping us make referrals They also provide information on where to go for help on speaking because now I can speak. I didn’t speak and I couldn't write a word. I had to trace the alphabet for two and a half years. That’s with a lot of education in the past. Places like the resource center have been tremendously helpful to people like myself. I hope that there will be funding to maintain the resource center in the future. In closing I would like to say I also just used the Brain Injury resource guide and the Brain Injury education materials that are provided to people through the resource center like myself. I now sit on the Governor's Advisory Commission on Traumatic Brain Injury and I'm a board member of the TBI Brain Injury Association here in Rhode Island. I used these materials to give of my time to work with other families and survivors who can't speak for themselves as I have been given the gifts to do. Thank you.

Sharon: Thank you. The next speaker is Cheryl Row.

Housing

Cheryl Row: My name is Cheryl and I would like to thank Marika, Terleci. That was a wonderful, wonderful presentation on how people with disabilities that are not completely visible because they have made significant transitions through some kind of occupational therapy types of things. All the difference it makes even though she can't go back to a six figure fortune 500 career, she is a functional human being because she has found services that helped her apparently through a lot of hard work in ten years. That being said, there are some disabilities that are still not being addressed and it's a very frustrating experience trying to find the resources, particularly if you have no caretaker assistance. If you are in an income range that doesn't allow you to get Medicaid or a caseworker or if you were a high income earner and you fall into everybody's gap. Then they treat you in a fashion like you are being difficult because you know, it's not that easy. You can't just give me a wheelchair ramp to my house and say, you are done. So, that being said, I am absolutely certain I'm going to offend some people in this room today and I apologize in advance. But I think that the very fact a meeting like this is being held in a location with two disability parking spots kind of incorporates everything that I would like to say about the organization of disability in this state. We might want to add some Dis's to the words that I say. With that being said, my most significant obstacle to the management of my disability, which is a very complex and systematic. It's not I just have a broken leg or something. It's one in the same with the most significant contributor to my health decline and that is lack of accessible housing for my disability. I want to read you something that I sent to the state of Rhode Island consolidated plan of course I heard nothing back, which is the history of my experience in this state in trying to get resources, just you ran a crack and they don't answer your phone call, okay. So this was submitted January 10, 2005. "Thank you for the opportunity to submit comment to the state of Rhode Island consolidated plan for 2005 through 2010. I am a former high income and taxed computer executive who was stricken with adult onset severe chronic physical illness. I'm physically disabled. I'm not blind. I'm not deaf. I'm not wheelchair bound as yet, not Rhode Island elderly nor developmentally disabled at age 52. I have no substance abuse, no AIDS, no criminal nor juvenile behavior or history. I have no caretaker, no personal care attendant, no homemaker assistance, although I desperately need them. I have already lost my water front home that purchased on my own in 1987 as well as over 100,000 dollars in IRA savings. I have been rendered unsheltered, homeless on the streets for extended periods several times. Shelters are not accessible to me due to the lack of accommodation for my physical disability. I am forced to live in HUD housing, which has no accessibility accommodations for my physical disability and have been forced to sleep in my car even while paying rent due to this lack of accessibility. No organization in Rhode Island has been adequate in providing support of services or adequate referrals for my special needs. My housing authority section 8 manager stated they have no accessible housing for my physical disability needs in this state. His associate suggested I move out of state, which is not feasible in my current state of health decline. The section 8 apartment I am in is an immediate and ongoing threat to my health and safety due to health hazard activity by tenants. I have been unable to find a stand alone unit under HUD payment standard restrictions. While I would be willing to move to a neighboring state if accessibility and supportive services would improve such measure, no one in the supportive services organizations that I have requested this information from has been able to help me access it. I receive SSDI at a level considered by HUD and heating assistance as low income, 187 percent of federal poverty level. Yet by Rhode Island standards, it's too high to qualify for legal assistance, Medicaid, food stamps, etc. I am not eligible for SSI or other qualifying programs for lower electric and telephone utility rates except when my heat is not included in my rent and I qualify for heating assistance. I am the person described in the state of Rhode Island consolidated plan draft report as a single adult who is not able to meet his or her basic needs until earnings exceed 200 percent of the federal poverty level of $17,960. There are no subsidies, food stamps, and EITC available at these income levels" end of quote. My health is declining as without access to Medicaid and prescription assistance. Medical and dental necessities and prescriptions are beyond my reach. My disability requires out of state specialists not accessible in Rhode Island. Just to give you an update since that, I did get out of that apartment. The hazard that I'm talking about is recognized by our legislators. A person has an option of not going to a restaurant because of smoke or a beach or a library. But not in their home where if they are a disabled person who is primarily bedridden is the most important thing to their health maintenance or lack of decline. It's simply an outrage. In this state which has the highest disability rate in New England, and above average national rates according to our health department. I think we need to get our act together and start getting organized and consolidating and addressing the fact that we are discriminating against populations of disability in this state. Thank you.

Sharon: Thank you, Cheryl. Next person is Allison

Sharon: Would you like an Mic?

Transportation

Allison Ward: Sure. I have lived in Rhode Island for my whole life. I am 28 years old and my disability is that when I was younger, I was diagnosed with speech problems and since then it's been…I went through high school with speech problems and I live in Rhode Island still. I would really appreciate it if the state of Rhode Island would be able to accept people's Medicaid or Medicare cards and be able to pay for something like a root canal or a tooth being pulled. Other than that, I don't know what to say. I mean, the person before me said mostly what should be done. I mean transportation is not good around Rhode Island when there's…
Sharon: That is fine, Allison
Allison: Someone just told me last weekend they can't even put their bike on a bus because of the tires. Now every bike should be able to go on a bus if they're traveling to work to get their money, to work hard for …to live in Newport, Rhode Island. Thank you very much.
Sharon: Thank you, Allison.
Bill Inlow: I understand the panelists have a right to ask a question, if there is a need for …
Sharon: For clarification. Right.
Bill: Allison, you mentioned that the bike couldn't go on the bike rack on a regular bus?
Allison: Yes
Bill: What was it about the bike that prevented it from being put on the regular bus so the person could go to work, which, of course, we want to help people do.
Allison: He said his tires were too small to fit on the rack.
Bill: Tires were too small to fit on the rack?
Allison: Yes.
Bill: I will look into that for sure. Thank you.
Allison: Thank you.
Sharon: The next person to speak is Steven Bowers.

Housing

Steven Bowers: I'm speaking here today in order to prevent certain subjects which I think are pertinent to the disability community. First and foremost, I'm disabled with multiple sclerosis. I'm also a care giver for my father who is disabled and lives in assistive living at COPD and emphysema and arthritis. Currently if you are living in assistive living, there is no supplemental income that can help you from the state. They consider you capable of self-pay. Therefore any situations that might have happened to occur with your health are not covered. But this seems to be in direct contrast to the efforts that are now being made to keep the elderly in their own homes with diverse mortgages and home health aid from various nonprofit organizations and even the state provided health in some cases. So I think it's kind of an oxymoron to say that, you know, just because someone can pay X amount in rent, you know, they shouldn't be able of getting something because they are disabled. I think this is one of the situations, again as one person that has testified already, is that the situations that fall through the gaps and I think this is one of them I think another situation that is really a need for is… I don't know how to put this. I guess education would be the best way. There's various organizations, there's providers, doctors that need to be sensitized to the concerns of the disability. I will give you a perfect example. For myself I had a terrible time relative to getting the appropriate health insurance and paying for the cost of my medications. For myself along Betaseron costs over $1,000 a month for me to survive and not go into a fast progression of the disease. If it weren't for the Betaseron foundation, I wouldn't be able to afford that. That's almost half of my income. When I went to them and said I was having problems, drugs …ostensively didn't have anything for me to do, no help. At one point I was considering going to the Medicare sponsored Clinic in Newport in order to be able to get free drugs. When I went to them they told me to go back to my interns because he can provide free samples, which I did. But the lack of sensitivity on his part relative to my personal concerns was appalling. This is only one case. I happen to be one of the assistant managers on MS people on-line and the antidotal stories with the insensitivity of neurologists and specialists with regards to this disorder again just shows a general problem with the knowledge and sensitivity that's needed for treating people with these disorders. I can go on with horror stories of things that have happened. Some of the specific recommendations, which I think that might be able to be legislative in the state, one is I think that from now on you should have legislation that makes cost of living increases long-term disability pensions be established and grandfathered it in because most long-term disability pensions, when you are disabled in the state do not include cost of living increases. I've contacted my federal representatives on this. As a matter of fact, Patrick Kennedy did get back to me several years ago but because of the lobbying efforts by the insurance companies, it never gets out of committee. Well, you might not be able to do anything about it federally, but in the state we should be able to do something about it locally. With regards to the Rhode Island department of transportation, I think one of the things that might make it easier for the disabled, especially in this time of high gas prices and the difficulty of private transportation is to be able to make access to the RIPTA disabled tickets ongoing rather than having just one or two or three periods of time over the course of the year and having someone go in one spot, be able to have people, you know, to go to one place and get it any time of the year. I also feel that if you have a long-term disability consideration like a handicap sticker, if you have a RIPTA disability Pass and you have a long-term disability, you should be able to do it on-line, you know, to get a renewal sticker. Slap it on rather than every two or three years, if you are not an elderly person having to go back and physically get a picture taken and physically do it again. I think that also …Depending upon what we see relative to the Medicare for drugs program that any aid that's going to be given for the disabled, the age be lowered to 50 because to be honest with you, if you look at the statistics, you are going to find that those people that are younger are going to be hurt more …are going to be hurt fiscally more than you would expect. This would be -- and basically I guess, I think the biggest thing we need right now is sensitivity. The paradigm for disability is such that I think Mr. Armstrong typifies it. There's a show that has a woman who had one leg and she did a strong man contest. That's all well and good and I applaud her and I applaud Mr. Armstrong for overcoming the disabilities and doing the things that show the excellent of the human experience. But at the same time, if the paradigm for disability is to be like the metaphor you see the three men going for the revolutionary war, hopping along, you know with one eye covered and everything like that. That's not the only thing that happens to you when you are disabled. You know, all of us have our own individual abilities and challenges. There's not too many disabled people I know that if they are not seriously depressed aren't doing the best they can to make the best out of their lives. As a matter of fact, I think probably we have been given these circumstances metaphysical basis because we are strong people and are able to meet the challenges. So I find it disheartening if you are unable to work, you know, people shouldn't be put in a situation where you know they are forced to feel guilty. For example, most of my symptoms are … you look at me, why isn't that able man body working? My job was a computer analyst. My cognitive abilities have been severely affected. My fatigue is such you don't want to be on the highway if I have to travel to a job and fall asleep. People don't see that, you know. They look at you and say Wow You really should be out there doing something good. They don't take into consideration the fact that the money that I'm saving the state by being a disabled care giver, I guess that's the final thing too. That's a specific niche. There's nothing fiscally to help me provide help for my father except for respites. There's nothing there. That's really kind of discouraging because I think I am saving the tax payers and the state a lot of money by what I'm trying to do. That's basically it. Thank you for listening.

Sharon: Thank you, Steve.

Diane Kayala: Could I ask a question? You mentioned your father was in assistive living but you are having trouble getting services. Will you be here for the whole thing? I would like to talk to you afterwards. There may be something that you are not aware of.

Eleana Goldstein: I also wanted to say one of the initiatives that the Rhodes to Independence project is doing after a couple of years finding there is a real lack of understanding for healthcare providers particularly for people with disabilities. Sometimes it's like a one size fits all or a bit paternalistic. You have uncovered other kinds of issues. Our efforts this year are hopefully going to reach many of the different provider organizations in the state and I would like to talk to you afterwards too to see if you would like to be involved in our outreach program.

Steven: Thank you.

Sharon: Thank you. Well, we have no one else on the list that wants to speak. We have a room full of people that haven't spoken. Is there anyone that wants to change their mind or didn't put their name down,

Annette Bournniere: There's one gentleman.

Annette: Stand up, Ellis.

Sharon: Okay. Thank you.

Transportation

Ellis: My only concern is that I'm a part of an… by Annette. She knows me and knows Steve. But my concern is this. The accessibility to be able to get passes is really impossible sometimes to get a hold of the people to come down from upstate so we can get those kind of passes. That's my only concern.

Bill Inlow: Can I ask this gentleman. Are you referring to a bus pass?

Ellis: Yes.

Bill: And you are saying that the fact that RIPTA sends somebody down every couple months or three or four months to Newport is not often enough?

Ellis: Yes.

Bill: Okay. Just clarifying, Thank you, sir.

Ellis: Thank you.

Sharon: Is there other testimony, something you thought of that you didn't have in your mind when you walked through the doors that you would like to comment on now?

Housing

Steven Bowers: Talking about the homeless. I think one of the clients did recently the bankruptcy laws have been changed. In terms of a lot of the information that politically pro and con, has found a lot of people that go bankrupt is because of medical bills and because of being disabled. It's like, well, if that's the case, what can we do either with private organizations, nonprofit organizations, state mandated programs, state law, whatever, to provide help for these people. Maybe, you know, we should take into consideration the fact of personal responsibility and maybe people have to take the knocks. But then again there are a lot of situations where people, you know, have done the best they can do and why is it that it's just the promise of the pursuit of happiness. If you don't stay on that high road, it's like, "See Ya. Don't want to be ya." I will give you a perfect example. When my father went into assistive living, I lost 50 percent of my income because my long-term disability company decided to cut me off. It took me 5,000 to get my benefits back. Total Bogus. On the same hand, I had to use the rest of my funds from my 401k to help my father get into assistive living. Consequently I went bankrupt. It was by the grace of God that I was able to get into an apartment because I have a long-term relationship with my landlord which is Picerne. Right now I can't move. I have no money. I have no assets left. I didn't do it …I wasn't going out and living the high life. I didn't go to Las Vegas. I don't want anybody to feel sorry for me because of what my father did for me. He put me through Brown University. Not that I can think not about providing him with my monies, relative to giving him assistive living, but there's nothing for me. As a matter of fact, the OSCIL, the organize. I didn't mention myself but I said, what if you happen to be in a situation where you have income with no assets, you kind of want to get to some place else, but oh, well those people are just been irresponsible. They don't, you know, oh, well. And just sloughed it off. For example, right now I would be in a much better position if there was somewhere I could get a short-term loan or a grant. Maybe I should go to Lesco, the guy on the commercials and be able to get the money to move. I would be in so much of a better fiscal situation. But I can't do it. It's nothing, I don't think I personally I have done anything to put myself in the situation. But that's really the fact when people find themselves with these financial burdens, high drug costs and the like, and have lost their income because when they go to the insurance and Social Security Disability, your income, drugs. There's nothing out there to help them.

Sharon: Thank you for your additional comments, Steven. Did you …Marika, I'm sorry. Did you wish to speak after Steven? You had your hand up

Health Care

Marika Terleci: Yes, if I may. Three things came to mind. One was listening to Steven here in front of me because I have a sister who has MS in Connecticut and pretty much she did everything about the expensive drugs, same thing, so forth. It just when you are talking about the sensitivity by doctors and therapists. The thought that came to mind is that some of our needs, although we may have different disabilities, some are common and the same across disability and where the Governor's Commission can use better resource allocation would be where needs are similar across disability, whether it's in prevention or in education, combine and be more cost effective in trying to provide the education not only to the person who's disabled but to the family members who need to understand because their lives change when someone's life is impacted whether it's through yours or mine because I was a bread provider not only for myself. But I'm the oldest of seven and aging parents. They were all used to me making money and taking care of them. I was highly independent and now, initially for five years I couldn't take care of myself after having the means but no longer having what was able. These kinds of thoughts reminded me that there can be some cost effective collaborative programs in education, in outreach where it's common. And because there's nothing more disheartening going into neuro…for us in my disability, neurologists test, neurosurgeons cut. But for someone to just sometimes listen and understand what you are really saying is worth more than a million dollars like that. So, you may have education on one level. But on another, we all can continue learning to help disabled people. And I will finish in saying one more time I guess to reiterate in a different way that I ask since you are the panel today and I know you are holding hearings throughout the state, is to also gain more understanding and sensitivity to disabilities that are not visibly seen. And you heard examples of that today, myself included, that’s what I mean when you cannot see that with all my education that I can't read past two pages. I have one page today and I had to practice five years to do that. You cannot see that I cannot maintain health needs individually, but need help. That part you don't see. You see that my speech came back. When you think of how many people are disabled and couldn't even come here today because they didn't get their speech back or they didn't get many things back. So please, I just ask, as a panel, as you hear throughout the state that there are voices that cannot be heard and they cannot speak for themselves, to be sensitive to that as you have been in the past. You need to continue doing because not all is visible to the eye. Many times that's what gets the money allocations and the services because visibly you see something's wrong. For the first five years people saw that in me and now it's, what's wrong with you? I'm just one of many different kinds of examples. Thank you.

Sharon: Thank you. Yes. Cheryl.

Family & Community Supports

Cheryl: I am going to have to borrow Marika to speak for me because she's further along with the cognitive rehab than I am. She says things so much more eloquent and can save me a lot of time. I think I would like to reiterate what she says about sensitivities with disabilities that the support organizations may not have experience with. I basically gave up on one of the referrals that I was asked to utilize because it was so stressful. I was put into seizures from it being told, oh, you don't need this. You don't need that. It's like, how do you know what I need? You never even met me. You don't know what my disability is oh, by the way I was given another diagnostic from this person, a diagnosis. But you know, so I would really stress the sensitivities perspective. And I would also caution that this whole pandemic of chronic illnesses, neurological categories, whether they are brain damaged through a TBI or MS or some other neurological condition, it's going to be huge. So the time to start learning about it and addressing it is today or yesterday or ten years ago. It's a really, really big deal and as we can see, there are people in this room that have very high intelligence, that with proper accommodation and accessibility perhaps could get a job, could get back into, you know if they had a lot of flexibilities, perhaps working out of their home or whatever. But that's not even considered in the state. I don't know if it is out of the state but it's not even thought about here. In getting back to the second biggest frustration that I had trying to work the system before I gave up was that there are common ailments, ailments of commonality that all disabled people kind of like disabled 101 guide like what is the deal about parking meters? Can I park at a meter without putting money in the slot? Well, I found out after…I don't know, ten some odd years a parking meter told me, you don't have to drive around for a disability parking spot, which there aren't a lot of. And you can just pull into a regular parking spot and put your tag up and don't have to pay the money and you don't have to run out in 15 minutes or two hours. Simple things like that. Why isn't that all in one little quick little guide to being a disabled person no matter what your Disability is.

Sharon: Good point. Thank you very much, Cheryl. We are going to be taking a short break. Say 15 minutes. People can use the phone if they need to. They can use the rest room. Come back in. Our panelists will be here and we will have an opportunity for you to speak directly to the panelists down in the floor area if you would like to. And we are scheduled for this meeting to last until 5:00. So, it’s what time now?

Female Speaker: Just after four

Sharon: Okay. Then we will be back at 4:20. And we will continue on with speaking with the panelists or asking questions of them and having more testimony. Thank you. Oh, yes, there's two things here before we take a break. The person that I kept saying I was waiting for that I knew she was coming was the executive director of the SILC program that is sponsoring this meeting.

Camille Panza: Hello. Thank you for coming. I want to respond to Cheryl and let her know that information is on the RI SILC website. Whenever we find out anything like that, we put it on there.

Female Speaker: I have been asking the question. For another thing people to know is if you are wheelchair bound or have problems when you go to a gas station, you do not have to do self-serve. You can have somebody put the gas in for you at self-serve price. You don't have to.

Sharon: What? Okay. So we will see you back here in 15 minutes.

(Return from Break)

Sharon: Panelists, would you like to join us. And nonpanelists, if you would like to take your seats. And the first thing that I would like to do is see if there is anyone here that's going to be giving a new testimony that should go in on the CART. New testimony that we haven't had today yet?

Steven Bowers: I was going to add further comments last time I was here last year that --

Sharon: That's Steven, right?

Assistive Technology

Steven: I'm sorry. That they had been talking about developing or suggesting the development of an ombudsmen function to advocacy and aid coordination for all the agencies that provide services for the disabled. I don't think anything has come up about that. Just making a comment about that. And also since a lot of the assisted living functionality involve now computers, I don't know if there's any state moneys available to help people connect to the internet in terms of, you know, moneys that might help to provide either regular service, high speed service for them. For some people that are isolated, it's a great social tool. Also you know just in essence a lot of assisted living devices are now computer operated that would provide service to the disabled.

Sharon: Thank you. Anyone else? Katie

Assistive Technology

Katie: The computer thing. I was given a computer, Sharon helped me with that. And for one thing, I can't afford the internet access, even the cheap one. I found out the people… somebody or whatever. Shows how much I know about computers. To get any technical support it's a dollar 99 a minute for technical support. I think it's $9.99 for the cheap people dot whatever. I know nothing. I don't even know how to turn this thing on and to get technical support the guy says a dollar 99 a minute so I hung up really fast. Yeah I found the turn on button but to ask anything to go from there it was like forget it. So to learn how to use it after I learned where the turn on button was a joke. And to learn how to do anything with one finger let alone to learn how to do anything besides turn it on, to get any kind of help with this stuff to find any kind of help would be wonderful.

Female Speaker: I didn't mean to cut you off. I apologize.

Sharon: Heidi, would you speak to the panel if it's testimony

Assistive Technology

Heidi: I just wanted to reiterate to Katie, in case she didn't know, that in Warwick there is TechACCESS and places like that that you can call and try to see if they can give you help. I've never used them personally. I know they work with people with disabilities and they give you different types of services and evaluations for technology and they do train you on computer based things. So you might want to call TechACCESS and see if there are any types of free programs available to you or you might want to also call the Office of Rehabilitation Services and things like that and see if there's any funding available to help you get the technology support. But TechACCESS I think would be a way to go.

Sharon: Thank you.

Cheryl: Just real quickly…

Sharon: Excuse me. Cheryl, someone here is speaking.

Assistive Technology

Barbara Kilkul: My daughter is nonspeaking and we have been trying to get a new communication device, personal communication device. Linda knows. Her agency supports my daughter. And it's been very, very frustrating. Right now we are in a situation we have gone through TechACCESS. They said in order to get a device to help her, first she has to get funding and these devices can be very expensive. She has to go to Rhode Island Hospital and be seen by their speech and hearing people and the last update I had, and you can confirm this, is they are still getting the run around. Not getting a response from Rhode Island Hospital in terms of getting an appointment. It's really frustrating for someone who can't speak not to have another avenue. She's able to get her point across most times. But not specifically and you know we've… It seems like TechACCESS is the only guy in town. I tried calling different other places and we haven't been able to find anybody that can help us with this. I went to a conference where I think it was people from Pennsylvania, their phone company has devices not just for the hearing impaired. The TDD which we tried but it's not… because of the relay function it's very difficult. They have devices that will attach to the phone that it's like a talking augmentive communication device that goes through the phone. Our phone company here does not provide it or whatever the agency is that provides this kind of support does not have things for people who cannot speak.

Sharon: Do you have a comment?

Paul Autote: I do have a comment. From the Office of Rehab Services as far as TechACCESS is concerned. Do you have that lady back? They do provide evaluation services to see what kind of augmentive speaking devices that are available for a person. And if at all, if there's a vocational outcome at all, our office can help with the purchase of augmentive devices

Barbara: We tried that too.

Paul Autote: Even to get to an evaluation stage, if a person needs an augmentive device in order to be evaluated, we can assist with that also. So, things like having difficulty to go to Rhode Island Hospital possibly if a person is involved with our agency and we did the authorization for the evaluation it might be expedited

Barbara: She had services for OCS. They have never been able to help, at least in the past. I don't know whether things have changed now.

Sharon: Diane.

Diane Kayala: Clarification. I'm with a Medicaid office and we do cover the devices. However I think it might be interesting for people to realize that Medicaid does not cover free state rehab. Medicaid can't pay for TechACCESS evaluation. We can only pay for a hospital to do an evaluation. that's probably what the issue is.

Barbara: She's also covered by my Blue Cross plan and she has, you know, again we have to go through the medical procedures first even though this is not something new. This is 30 some years of having this kind of disability.

Sharon: Yes. What is your name?

Assistive Technology

Margaret Shinners: My husband is 89 years old and he's deaf. And of course he's very frustrated and now he cannot hear on the telephone too well. Now he's completely isolated to talk to his sister or whoever he's involved. I called Verizon and they do not have any attachment to the phone. I'm not familiar with in talk so I called and I said who do I call? I know in Florida his sister calls and she says she has something on the phone that enhances her hearing. And so I said, who do I call? When I called Verizon, they said, well, I had to call and I didn't bring it with me. I was late. I'm sorry. The state has some sort of agency I was to call them. Well, there was no answer. I called quite a few times and there was no answer. So I called someone in the state and said I consider hearing a disability, a serious disability. And my husband is deaf. But if he could hear, I'm sure with this enhancement, I forget the technical word, on the telephone, nothing. So I spoke to Kathleen Connell who used to be Secretary of State. I'm in hello terms with her. She said she would try to find out. I called Annette one time

Annette Bournniere: I found something for you, but I lost your address

Health Care

Margaret: Good. And I thought it's a serious handicap. And I feel so sorry for people who have much more serious things. What do they do? What is the state doing for them? They should at least provide information to these people who ask where they can go. Fortunately I think I could pay for the service. So what's the problem? I think a person who has some hearing should be told where they can go for help because it's tough for him and It's tough for me and my daughter because he's completely isolated. And he's too good a man, too intelligent to be removed.

Sharon: Thank you, Margaret.

Margaret: You are welcome.

Sharon: Anyone else?

Housing

Steve Bowers: Yes. This is Steve Bowers again. There was something that happened to me that was interesting. I went to H & R block services free on-line for my tax return. And for some reason the property Relief tax in Rhode Island they didn't pick it up. And when I went to get, you know, an adjustment on my state income tax, it's like well, if you don't do it by the April 15th, you snooze you lose. I think it's an indication of the institutional handicap, no pun intended, that's given to situations that would affect people that are either disabled or elderly. With any other consideration relative to a tax return, you know, if you

have an adjustment, say there was an error on one of your forms or you made an error in math or something like that, you would be able to get a refund. I was out $250 and it wasn't because of anything I did. I did my return before April 15 but the state, if you don't get it in and meet the criteria disabled and under 65, you can't do anything about it. I think that's kind of wrong.
Margaret: Thank you for your time
Sharon: Thank you, Margaret.
Annette: Don't go away, Margaret.
Male speaker: Can I say something to Margaret? You made a beautiful point I think that your husband is too good a man to be isolated and cut off from other people in his life just because he can't hear
Margaret: He's intelligent
Male speaker: In his elder years.
Margaret: He has something it give to the community.
Male speaker: I think you are absolutely right, Ma'am, and thank you.
Annette: Just give me your name and address.
Margaret: I hate to run. Good luck.
Sharon: We will still have time for either talk with panelists. However I'm looking for unsaid testimony so far unsaid system.

Family & Community Supports

Katie: When I had my accident, my kids were eight, nine, and 13. It took me three years after being in the hospital and rehab and everything. My pastor had my kids for nine months. I was divorced at the time. When I came home, it took three years before any kind of agency came in and it was PARI that finally came in to give me any kind of help. That left an eight year old, a nine year old, and a 13 year old. And thank God my church family to completely take care of me and my house before anything fell into place. To deal with me, help me to deal with my household, everything that dealt with a severe spinal injury. And I really fear there's other young families that could be going through the same thing I went through. And there's really no state agencies that come forward to help with that. The VNA helped me for two hours, three times a week. But they came in to give me my showers and to do a little bit of housework. But it was up to my church to do grocery shopping, to take me to doctor’s appointments. It was up to my family to get me into bed, to do everything that it took to take care of a spinal injury person. There was no agencies. There was nothing. But a family and a church family and friends to deal with it. We got through. My kids are in college. My youngest is 17. They're wonderful. They're wonderful at this point. I think that maybe this made them the people they are. But how many other families are having to go through any of this because there aren't anything out there that fills in, that can step right in when someone is released from a rehab to take over. We will keep this family together. We will keep them home that will keep kids from going into foster care or whatever. If there's not a pastor or anyone that will step in, if there's not another custodial parent that can deal with it. But there was no state agency, no state anything, no state program right there that could go in and just take over when this all happened to me. And I just don't want to see another family have to go through that.
Sharon: Okay. Thank you, Katie.

Health Care

Steve Bowers: This is Steve Bowers. I just had one thought about this whether someone is disabled and going to continue to work or whether they are going to be home, there's three points of contact where like the brochure of information that's provided for this commission, might be of treatment use and that would be at the doctor's office, in the human resource department of where people work, and at the Social Security office. Because if someone's disabled that's the three places they are going to be. and I've gone to doctor's offices. I have seen advertisements for Viagra or Zantex but nothing for disabilities. How come you can find little brochures at any state agency and the Department of the Elderly Affairs when I never see any of that in the doctor's office. So it's just a matter of dissemination of information. If my human resources person had handed me, you know, a packet like this as I was going out the door, I might not be in the situation I'm in today.
Male speaker: I think Cheryl had indicated she may want to make some additional comment, did you not

Assistive Technology

Cheryl: I come from the computer industry and Katie, it sounded like you were asking for basic how to learn how to use a computer. And I understand libraries do that. It's generally free or for a nominal fee like $5 or something. Generally computer company's services aren't entitled anymore. They are expensive. They are not designed to teach basic how to turn on the computer and get to the internet. Just another option for you.

Sharon: What I'm going to do before we go into conversations amongst each other, which is going to the end now. And I am going to cut off comments except your name. Your name?

Mary Theresa Shaloc: My name is Mary Theresa Shaloc. Something she said brought something to my attention that I think should be included in the report that you are doing

Sharon: Okay.

Health Care

Mary: I have a problem, not only in Rhode Island but anywhere in New England. In the megacenter for healthcare that we have is there a place for a family to go if they have a child with a spinal cord injury except in Texas, Atlanta, or Georgia. There is a group in Boston with Travis Roy working trying to raise funds and to build such a facility somewhere in New England. I just would encourage the governor's commission that if anything is brought to any of their attention that they would support that and get involved in that so the families can be together. The whole family has to go to learn how to take care of this child. It involves the whole family. So, if something should come forward in connection with this issue, I would like to see the support of the state.

Sharon: Excellent. Thank you.

Paul Choquette: Just to clarify what you are talking about, rehabilitation, inpatient rehabilitation?

Mary: Yes.

Paul Choquette: Okay.

Sharon: Now, Alexandra, do you want to say something about what you brought with you. We are not ready to leave yet. But as you leave, there are a lot of different pieces of material on the table out there.

July 26, 2005. Cross Roads, Providence

Lee Pagnozzi: We're going to get started. My name is Lee Pagnozzi with the Coalition for the Homeless. In a minute we're going to have the panel introduce themselves. And the purpose of the forum is to identify with people and their disabilities and help the state to improve the quality of lives of people with disabilities. So we're going to start and the panel can introduce themselves. If anyone who speaks could say their name before they speak for the woman who is reporting. So if you could all do that we would really appreciate it. Do you want to start?

Dana Wright: My name is Dana Wright from the Rhodes to Independence.

Shelly Green: I'm Shelly Green with Brain Injury Association and I'm a mother and ex-wife of a person with a traumatic brain injury.

Kathleen Sherlock from the Disability Law Center. We're passing out our report and also giving you guys our priorities. We use these forums as part of our opportunity to get input on the kinds of cases we should take. If you don't speak up today or if you do, please complete the survey about the legal issues that concern you that you think we should be looking at next year.

Elizabeth Dalton: I Work at Rhode Island College in the Sherlock Center. I'm Representing that center today, it's A center that handles issues related to disability and is also representing the minds for technology access or actually, the ATAP Project. That's the tech act, a process that deals with technology and the issues related to that in Rhode Island.

Ken Pariseau: I'm Ken Pariseau from the Neighborhood Health Plan.

Bill Inlow: I am from RIPTA.

Lee Pagnozzi: Thank you everybody for coming we know the parking and the situation. We'll kind of go in order for who signed up to speak. We're going to try to keep it to a minimum also. I believe the first name is Manuel Alexander.

Housing

Manuel Alexander: I'm here, someone invited me here and I'm an apartment dweller in the section 8 apartment, Charles Gate, and I agreed to speak because I think sometimes people in the system that take care of these programs seem to forget, especially people that represent homeless people and disabled people from mental health. When somebody becomes an apartment dweller in subsidized housing, sometimes their credibility as a human being automatically goes down the drain whether you live on

Rochamboe Avenue or in a high-rise apartment. There are always problems between the owner and tenants. That's always existing, whether it's really negative or really positive. There's an interaction there. But the interaction between the people who take care of the high-risers and the people that own the high-risers, the people that work in them, there seems to be a tension that says I don't have any credibility because I live here. I'm a brain-dead individual, just follow the rules and policies and it's a struggle. It's a struggle to get out there to say hey, I'm living here because the government made this place available to me. It's an excellent gift so that we can live with the income that we get. But should it be that the people that take care of it push the humanity, the credibility of these people down or take it away from them? It's kind of hard to do with a personality like me. But there are actually people who live there who are afraid to come out of their homes and afraid to say something to the manager. I've told you three times my air conditioner is broken. I tell them call RIMFAC and they'll get it done quickly. But if they don't do it, the people will suffer through the summer without it. That's only an example. People who live in these high-rises are actually afraid they can be put out on the street like this, and it's not really true. But that's kind of the attitude of the people that run the apartments and even sometimes when you call RIMFAC. They're more an advocate for the owners and the business than they are for the people. The people that live in there really need more of an advocacy from I guess it's especially if they can get it from grass roots groups. I can talk a long, long time and I don't want anybody hating me, but that's what I wanted to speak about. There are some people here that live and maybe one day people in this room here will get to be in a high-rise subsidized government resident, and from being out in the world and being independent and being aggressive and taking responsibility, and you walk in there and you're kind of like running into a wall, you're nothing, your word has no value anymore. Your opinion doesn't matter. How could you have an opinion you're getting government subsidized housing that seems to be it. I've been in here for a long time and it's constant from the time I ever first got disabled until…that's about 25 years I've lived in one house or another. It's not a particular management. It's three different people so far that I lived. Three different real estate owners. But I think people in this grass roots area should know about that. The residents in the high-rise, sometimes they feel like nobody cares about us. They don't care about the laws. The people that run it. If you tell them this is how this process is supposed to go according to HUD and you have to take the time like me and go and read what HUD says, and everybody doesn't do that, and they say oh, we're behind schedule and they just put you off like it's okay to put you off. That's all I have to say before everybody hates me.

Lee Pagnozzi: no. We need to hear that kind of stuff so thank you very much. Next we have Charles Feldman.

Health Care

Charles Feldman: I thought I was third but that's great. Hi I'm Charles Feldman and I'm representing Mental Health Consumer Advocates of Rhode Island. I'm also the chair of the …(inaudible). I want to bring up a few issues. One issue is I felt this would be a chance to talk to a lot of disability rights advocates. There is a person sitting in the Governor's office in Tennessee right now. They're threatening to kick 719,000 people in Tennessee off the what's called TennCare which is their equivalent of Medicaid. And the longest sitting in the governor's office. They're asking people to hold vigils Sunday evening, let's see, it's the I believe it's Sunday evening, I can't find it, some anniversary of the sit-in, I can't remember what it signifies, but it's so many days they've been there. I was wondering if anyone is working on this issue. I think it's something that needs national attention. the governor of Tennessee may want to run for president. And he's threatening to kick off 719,000 people off the equivalent of Medicaid. I would like to pass this around. My e-mail address is on there. If you would contact me or any of your organizations want to help organize a vigil. They want us to ring bells and light candles at 8:30 central time which is 9:30 eastern time. That's all I have to say about that. If you're interested, e-mail me. The other issue is now getting back to the Rhode Island issues. Well, one issue that you know, I was talking about this with Joey and the executive director of AMCA before I got here. And the executive director Tony was saying we should tell our stories they're more interesting than statistics. I said I don't really have a story because for the first 7 years when I had mental illness I had the wrong treatment. After that I got good treatment. I was able to get a job when I looked for one, I was able to go back to school for a while and I realize that is my story. If things were different I wouldn't have recovered.

Health Care

Charles: At the NAMI conventions, the National Convention on Mental Illness, I met people with schizophrenia who have been psychologists with paranoid schizophrenia. Myself, I'm working part-time. I didn't do as well as though two people I'm thinking of, but when I was totally psychotic for 6 years in a row. At the end of the six years, I ended up in the hospital but before that I was in a holding cell in a town police station. Now, these days if that were to happen, I might have ended up in the ACI. Then, they were able to take me to the hospital where I finally got on a medication that worked for me and I was able to get resources and recover and get help looking for a job. I was able to get help. my parents looked into an apartment for me. But they would have given me help with that if I needed it. So I have access to treatment right off the bat. There are people who do not have access to treatment. Very often the people don't have health insurance and they're saying well, you know, you can get by and then their situation gets worse they end up in a crisis and it ends up costing more money for these people to get treatment early on when the situation could have been handled better. That's one important issue. And also Frederick Freedman who is the director of psychiatric services at the ACI spoke at MACA and he said the numbers have reversed themselves, there are something like three to four thousand people with mental illness in or maybe three or four thousand people total in the ACI where it was 300, but there are fewer people now in the state institutions and more people with mental illness in the prison system. So they say we have to stand up for our rights to refuse treatment. But if you're going to refuse treatment and end up in jail or prison that makes no sense. If someone gets treatment, then they are no more likely to commit a crime of any sort than anyone else. Also, if they have a substance abuse issue if that's treated at the same time.

Health Care

Charles: The other issues are choice in medications. Threats often come up to limit the medications that we have available to us. There is a bill for example to include you say in the state legislature, to do that to try to save money, but mental illness is very idiosyncratic because each individual may need totally different medications or a group of medications. So choice of medication is crucial because people find something that works for them. With Medicare part D, I don't know how that's going to work. It's going to be a big mess and also, housing is an issue.

Housing

Charles: Manuel mentioned sometimes it's hard to get through to management in public housing, or in subsidized housing, but there are some people that can't even get into subsidized housing. We have many homeless members and transportation.

I know there's someone here from RIPTA. Especially in the outlying areas like Woonsocket and Westerly, people who rely on public transportation, they can't get to the places they need to get to. So that's all I will say for now. Thank you.

Transportation

Lee Pagnozzi: Thank you Charlie. The next person is Joe Lynch.

Health Care

Joe Lynch: I don't get into the macro aspect of social reform, I'm more of an artist and I work at the grass roots level. I work for MHCA Oasis as their manager. I have had my brush with mental illness, enough to see some things. In '82, I had a nervous breakdown which lasted two months. For some reason I recovered I was an engineering manager for about 20 years. Then in between '95 and '99, I became bothered by aspects about baths. Which I don't have to go into but it has to do with sexual abuse. I was totally triggered by having a job with a church for about 8 years between '91 and '99. When I left that job, the usual events occurred between the person who was a survivor and the church and I was just numbed out. I couldn't function in a job situation and I've been blessed with a wonderful wife and I have 8 children. But my wife and I disagreed about a number of things but one thing being should I do something against the church and to cut a long story short, I never did do anything. But we separated in 2000. So my situation was that I was needy. I went from being on neighborhood health plan with a family of ten, to being by my lonesome without medical insurance. What happens to men when they're separated? I'm sure this happens to women, but I was a man and saw what happens to a male when separations occur.

Health Care

Joe: I think the system doesn't see what is actually happening, it's just set up to treat people in a generalist level or on a general level, excuse me. And so I went to a couple of community mental health centers, was turned down. Went to a church, was turned down. and then to make this brief, what I really needed was medication, and I finally, after having gone, with not having been told what to do, I finally found out that there was community free service at Rhode Island Hospital, thank god. And I got on medication. Slowly but surely I got stabilized and I was diagnosed with bipolar disorder as well as having BTST. So I went from a good situation working for the church and having medication through medical coverage, to having nothing. And now thankfully, the consumer advocates have hired me. I did go on SSDI for 3 years and then I got off of that. I'm getting off of that right now. So, I think that with our present system of

government we have in Rhode Island, there's an emphasis on people helping themselves. But I think that people are with help by others can greatly, can recover. That's all I guess I have to say.
Lee Pagnozzi: Joe was our last person to sign up. This is a public forum so we want people to feel free to speak what's on their minds about these issues. So, does anybody else here feel they need to speak?
Anonymous: I wasn't going to, however, there is an issue that's causing me some distress.
Male Speaker: Could we turn the air conditioner down? I would like to hear what you have to say.

Housing

Anonymous: I'll speak up. My name is …, I would like to speak basically briefly about my scenario as far as a place to stay for the time frame that I am "homeless" which should never have happened, but a lot of bad things have happened to me. I've been hurt at work, I've been discriminated against, having my hours cut and I work for the Federal Government. But anyway, the last thing that happened was me having this scenario. For me, it's temporary. I'm pig headed enough to get out of it. I want to get out of it, never thought I would be here. The wise crack be being able to project my voice. I was a physical education teacher. When you're in a gym you need to get your point across effectively. The issue for me, is there's one shelter for single women that's Welcome Arnold and it's run by the Urban League.

Education & Employment

Anonymous: When I'm working and I'm trying to get back on the clock I work 6 p.m. to 2:30 a.m. A couple of times some people have gotten injured and signed in before me and I've been bumped out. Both times were in snow storms. The second time the only clean clothes I had were shorts. I ended up coming here as I was going back. I need to know that perhaps the issue for those people trying to get out from under, perhaps someone can work with these people and it's not necessarily first come, first serve. I know it has to be an issue, but when you're handicapped you need to take that into account too. If I can't get there until 3 a.m. because I work from 6:30 p.m. to 2:30 a.m. There's a lack in the system that's one thing I feel and it has to be addressed. I know it sounds very selfish but there are other people as I've been told by the coalition, they've had opportunity to have employment and they couldn't take it or they attempted to but no shelter would accommodate. So therefore, they just stayed in the system of…which I've seen many abuse but we won't go there. Thank you for listening.

Housing

Anonymous: You know, it's not real comfortable sleeping in a vehicle. And I'm not saying that to invoke any empathy or anything. The situation is that I will get out of the jam that I'm in but for all the moneys that are being spent and I hate to say almost wasted in a lot of cases, to see the abuse daily and yet, there are needs. There's only three beds in this room, and that's a family room and that's a family room. If a family shows up you're bumped. Thanks. So if you could sort of address that, I don't mean to seem rude. I'm trying to get back on the clock at work and I have to get to the doctor's office to get my second doctor's note. Thank you for your time. For my personal sake would you leave my name anonymous. There are people at work that I don't want to know about this.
Lee Pagnozzi: Thank you for your courage.
Anonymous: I looked to see on the list of names and I heard his name as he introduced himself and I said for time-wise and everything. Some point down the road, I will have more input relative to the system and the way it's working and I will accept the challenge of perhaps sitting on a board or volunteering more information. At the present time, it's not to my advantage okay? Thank you.
Shelly Green: Sometimes things happen for a reason and maybe this is the reason so you can advocate for others. After you get yourself in a good situation.

Family & Community Supports

Anonymous: I said I will advocate after the things I've seen. It's a hurtful thing to say things happen for a reason. I've had a lot of people go for the jugular simultaneously and when you have your hours cut and you can't be part of that. I was totaled on the highway by a hit and run driver, it's just baboom, baboom and it's a revolving door. There's one issue I would express with you and that's besides getting back on my feet, if that happens which has to, it's the only thing that will get me going back, but I will be back to have more input and perhaps help in the planning.
Shelly Green: I say that from experience. I was a teenage mother. I have a brother who died from a brain injury who was institutionalized. I had my son very young, 14 years old. He was a gulf war veteran. I struggled my whole life. My son at the age of 21 fell asleep driving and suffered a traumatic brain injury. Brought him home in diapers. Quit my job and had absolutely nothing. Now I sit on the board of the Brain Injury Association advocating for rights and services. I say that in terms of compassion and support not flippily.

Anonymous: That one statement still hits right here.
Shelly Green: Me too, but it's also a support because there's a greater purpose for all of our lives.
Anonymous: That's when the inner strength come that you never knew you had. I said that was during my financial crisis. I was the kid that bought a house and had a sizable bank account and before I went and took my current job, I had money in the bank. I watched it go down to $0 a number of times. But be careful because I'm coming back and when I do, if you were on my side, you can have the shirt off my back. If you've gone against me and I'm not a vindictive person, I will drive by you on the highway. Lights perpendicular 95 south it hit the tree way off, and me with it. I would stop to try and help anybody but for the people that went out of their way to hurt me, good luck. Because I am going to come through this. Anyway folks I'm sorry for the delay.
Steve F: Take care.
Lee Pagnozzi: Would anyone else like to speak at this time?
Attendee: I can't speak that well. Would it be all right if she talked for me?
Shelly Green: Yes.

Health Care

Cindy Cagney: I have had CP all of my life and I've been trying to get an apartment. Every time I go, they take me for 6 months, aquatic therapy, and every 6 months, they tell me they can't take me anymore. So I have to wait for I can go back. Aquatic therapy is best for me because it loosens my muscles so I can move around better. Thank you.
Male Speaker: Who denied you the right to continue the aquatic therapy?
Cindy: Where I go.

Health Care

Male Speaker: Because the aquatic therapy place is full or is it a state agency that pays for it? Cindy: I don't know but where I go they tell me I couldn't go for 6 months. Part of it is actually, Ralph and I are here to really talk about Medicaid plans and to kind of. If I could just tell you what Ralph said, it's not that they won't take him anymore. Medicaid requires that every six months you have to go back for a reevaluation for them to could it again. And in reality aquatic therapy for Ralph is very important, and it's not really, like it's not something you can do without. It's not like in 6 months we don't need to do it anymore, it's something that's going to keep him moving. So that's really what it's about. It's about the fact that Medicaid will only pay for 6 months and you have to go back to be reevaluated and go back and do it all over again. By the time you get the OK to do it again it's like one step forward and two steps back.
Steve: So there's a time delay. And you're questioning the state Medicaid policy that requires that?
Cindy: Yes.
Elizabeth Dalton: How long is the delay usually?
Cindy: About 3 months.
Steve: During which you're not getting aquatic therapy, right Ralph?
Cindy: Right.
Steve: And it is not like it's going to cure you, it helps you.
Cindy: I move better.
Steve: Of course it helps you to be more flexible and move around.
Cindy: Right now, I am having a hard time because I'm in pain. I haven't been in the water.
Steve: This affects other people, as well Ralph. So you're speaking not only for yourself but for other people affected by that policy as well.

Attendee: Right. If I could add to that, I actually did my written testimony, but seeing as Ralph spoke up, I actually would just like to add to the fact that Medicaid is really, I guess I can read this to you.

Health Care

Deanne E. Gagne[1]: "Dear Governor's Commission on Disabilities. My name is Deanne Gagne and I'm writing to you to ask you to support the managed health care plan for people with Medicaid coverage. I am a person with a developmental disability and I have Medicaid. I've been very fortunate because my doctors have continued to care for me while not accepting any new Medicaid patients. Many people with Medicaid are not as fortunate as I have been. They have to go to the emergency room for routine care, most don't get the choice of their own doctor. This is discouraging. The doctors don't get the same reimbursement rate. Under traditional health care plans. Under Medicaid, they do not accept new Medicaid patients. The proposed managed health care plan will give me and others who have Medicaid the ability to choose our own doctors and have some continuity of consistent care. I support this bill and I urge you to do the same. Thank you for your time. Sincerely Deanne."

With that I would like to add that it would make it so much easier, I can't say this enough, it would make it so much easier for people to have Medicaid coverage to get the opportunity to choose where they would like to go and who they want to see instead of the person that they have to see. So, I think that pretty much covers it.

Lee Pagnozzi: Thank you so much. I think one of our panelists didn't get to introduce himself Steve Florio.

Steve Florio: Hello everyone my name is Steve Florio. I'm the executive director on the Commission for the Deaf and Hard-of-Hearing. I showed up early and my interpreter had yet to arrive. If there is anyone here that has issues related to hearing loss or individuals who are deaf and hard-of-hearing any of those issues please feel free to speak up and I will provide you with as much information and resources as I can. I really look forward to improving the system here in Rode Island to make it better and to advocate on your behalf and make it more efficient for all of you. Thank you.

Lee: Thank you. Anybody else? Want to be brave enough to speak up? Well, it's getting a little warm in here. We had to either have the air on or hear people. We'll turn on the air and maybe people can network a little bit. Is anyone interested in having the vigil about the ten care situation?

Male Speaker: No, but thanks for asking.

Lee: Folks, people, we have one more person who signed up to speak. So we're going to kind of call to order and let this person have their say. We are here until 5 o'clock. We have one more speaker and we'll stay here until 5 o'clock in case anyone else comes in and wants to have a say.

Housing

Donna Peterson: My name is Donna Peterson and I feel like I was discriminated against by the Cranston Housing Authority. I only lived in Cranston for two years because I drove a school bus for Cranston for 14 years so I figured move to Cranston. On January 14 of 2002, I was going down Vincent Way and I had another elementary stop I was covering. So I had their last stop, it was the little kids, the little ones. I had their last stop and my last stop and both monitors. So we were going down Vincent way and I saw a car coming out of the road and I had to stop on the right. This mom was an after school mom. We saw this car in Western Cranston, I don't know if you're familiar with it, the houses are set way back so you can see and that street is only like 4 houses deep. It's a short road and these kids were like drag racing. and they came flying out. I stopped the bus first of all. I said look at these kids, I said something is going to happen, you watch. We stopped. They came flying out of the street and didn't even stop. They came flying out into Vincent Way and they spotted the bus. They had an old bomber car one of them medal ones and it was three young kids and they spotted the bus. So they slammed on the brakes and spun out of control. I don't know how many times and slammed up against the curb. In the front of us maybe 20, 30, feet, probably 30 feet, and they slammed into the curb and then the car stop up on the lady's lawn right here on an angle. So the two kids with him got out and ran. I'm sitting in my chair and I had my seat belt on. I had a square metal box for my heaters and everything to run the bus. I was leaning over that and the windows only open halfway. I'm hanging out the window stretching trying to yell at the kids and you can't be rude so I said don't you run. I know what you look like and I'm watching them run down past the bus. And I wasn't paying attention to the driver because I mean, I never would have thought, he put it in drive and floored it. He was going to take off. But I guess he didn't realize he had two flats. So he couldn't turn. And I'm hanging over the box telling these kids not to run, he puts it in drive and floors it and I get a direct hit right where I was sitting. We have our own mechanics, it's privately owned by the City of Cranston, they fix the buses and they told me I got a direct hit. It was a large bus and you would think you wouldn't get hurt on a large bus. But he said where the driver's seat is he said the only thing between me and the car was the battery. So, I said to my monitor, are the kids okay? Is everybody okay. Yup everyone is okay. My monitor got hurt, because she stood up so she could turn around and look at the children. They were okay, they were a little shook up but they were all right. I called in to my boss that I was just hit and then the kid realized he had flats. He maneuvered the car somehow and backed up and took off. So he hit and ran a school bus with children on it. Little children, they were my kids and I had that same run for 14 years and I loved my job. They were so young and such kids I don't know if they even had a license. I don't know what happened to the two kids that took off, but the driver managed to back up and take off. He lived right on that street and this lady came running up with her cell phone and said, are you okay? Is everybody okay? She said, these kids have been drag racing through this neighborhood all day long. She said they almost ran me over. I said I think everyone is okay. I said my neck feels a little funny. I said look at my neck and my neck was like this, it was so deformed looking. I never seen anything like it in my life. It's still not normal and it's been since January 14, of 2002. It's almost like a pocket, it's all floaty. See the dent, that's the bone. That's as much as it went down in all these years. It was so bad, it was like this. And so the lady said I called the police. She said don't worry about nothing, they're on their way. I called into my boss and he said I will send another bus with an another bus driver out. So one could finish dropping off my kids and the other could drive my bus back to the yard. But the kid's car was totaled and he lived right on Vincent Way. So when the cop came, the lady was there, and she was a witness, she saw the whole thing and told him they were drag racing through the neighborhood all day and almost ran her over. The cop went up the street and the kid was standing right beside the car in the driveway. That's how young they were. You would think they would have hid or something. But he stood right there in the driveway. He was probably so young he was scared because he hit and ran a bus and knew there were kids. He was standing beside the car and the car was totaled. The cop put him in the cop's car and brought him up the street to the scene and made him sit there and watch them take me out of the bus on a board with a big enormous neck brace. My neck was so bad and my last stop was right around the corner on Kimberly Lane. Mother's knew this was time for the bus to come when we doubled because that was my last stop and every single mother was at that stop. It was a cul-de-sac and they were all there and when they heard the sirens and everything they came flying around the corner they were scared and I don't blame them. The kids my monitor started letting the kids off the bus. The officer made sure everyone was okay. He took a list of everyone that was on the bus. The kids if something happens, like in the night all of a sudden they feel stiff or whatever, you know, took everyone's name, address and phone number. When they saw their mothers they started crying. They took me out in the rescue. I went to the hospital, and I started seeing an Orthopedic doctor, Dr. McAndrew in Warwick on Tollgate Road. After about a year, he never did an MRI on me and I don't know why, but after about a year, he seemed to think and oh, my boss called me over the air and said Donna you're all set, I'm going to send you some paperwork. Just sign it, it was workers' comp, sign it and send it back to me, you're all set. He didn't tell me I still had to pay my union dues or any other kind. This has never happen to me before. I never got hurt, never collected workers' comp in my life. I'm 49 years old and I loved my job. I started out subbing and subbed for two years on that same run. Cranston has a middle school for the 6, 7, 8, and then #, 10, 11, and 12th and I did the outskirts of Cranston so I had to pick up my junior high with my high school and some of the kids that I had on the bus were in elementary school. They would bring in the match box cars and I had my high school kids. It just didn't seem right, but there wasn't enough time for me to get the junior high kids ride them back to Western Hill and go right back out and get the high school. I mean the high school first and then the junior high because I went through Cover Tree and then back into Cranston and up 7 mile, and that side of 7 mile is Sit Wait Avenue and my side is Cranston. I just really wanted to tell you I loved my job and I subbed on it, and I had it for 14 years. I had the kids from middle school until they graduated and they were so so good, they were like my kids and after he hit me, I couldn't work. I went to the doctor's at Dr. McAndrew.

Education & Employment

Donna: After a year Dr. McAndrew and worker's comp seemed to think I could go back to work as a bus monitor, light duty. Of all positions, I know other people that have gotten hurt and they put them in like city hall doing office work or something to that effect. He put me as a monitor. Up in the Western section. There's not a lot of bus stops, it's a lot of house stops because there are no sidewalks. So I would have to get off the bus, you know, climb off the bus, run to the front, walk, bend over, use my back and my neck, look underneath, after the kid got on the bus run to the back, and I have to run and look underneath the bus as I'm running to make sure they didn't drop anything or fall. I would look under the back, and if they were a cross up, I had to go back to the front and look underneath the front again and then get back on the bus. I did this for all my elementary stops and all my junior high stops and I did it for two weeks and I was in so much pain I couldn't do it anymore. On worker's comp. I was collecting 286.52 a week. And worker's comp. When they sent me back to work as a monitor, I believe it was February of 2003. I was drawing a paycheck from the school department so they cut my check down to 205.44. I applied for disability in July of 2002 and got accepted the first time which is unusual from what I understand. But I had gone into July and the worker's comp never brought my check back up to where it was supposed to be. I made fairly descent money. We did all the band trips to Connecticut, everywhere, the compete band from east high school and they were all day, all night trips. So I was averaging 41 do 42 hours a week. They had to pay, I don't know what they call it, not the full amount but maybe two thirds. I'm not sure, but I ended up with 286.52. And then I applied for disability in July, and I got accepted. And they gave me a partial SSDI check for supplementing the worker's comp of 279 once a month. And I went back to work when they said, you know, we want you to try this. I said, I'll try it, you know, I'm willing to try anything. And I did, and I couldn't do it. I did it for two weeks and I came home and I was in so much pain. It was terrible. So I went into Joel, my boss, and when I first went in to see him two weeks after the accident to show him my neck, and he couldn't believe it. Now, he's the Director of Transportation and this is exactly what he said to me, when he looked at my neck, he said holy …, I've never seen anything like that in my life. He couldn't believe what my neck looked like. I can't even describe it. It was so horrifying and now he's taking me out showing the three girls in the transportation office that take the calls. He showed her and said look at her neck, did you ever see anything like that? Oh, my god I can't believe it. Now he's taking me through city hall showing everyone my neck. It was horrifying. He couldn't believe how bad it was. After I went back to work for two weeks and said I could not do a bus monitoring position because I was using my injured areas.

Health Care

Donna: Everyone is telling me to go to Boston and go see a good spine specialists, they have the best doctors in Boston. So I did, I went to see a spine specialist in Boston. I called first to see what hospitals were out there and who was good as far as a spine specialist. So I ended up seeing Dr. Mike Eikler and he was affiliated with Brigham and Woman's Hospital and I just went there because it had woman in the title. Eikler did all types of testing on me, he did an MRI, a CT scan, x-rays, everything and everything. He wrote a letter saying I was severely disabled and you know, we're going to pursue this further and see what we can do to try to fix whatever could be fixed. So, they did cold needle treatments which was a procedure that I had to have done in the pain management center at that hospital and it's called a Disco gram where they lay you on your stomach and you have to go an hour prior were they set up an IV. You need antibiotics in you for an hour before the procedure and you need someone to drive you there and you can't even park there. You can't park. To park you have to park in the garage and pay or you have to have valet park. You can't park anywhere unless you're a resident of Boston. It cost me 8 to 10 dollars every time I went there. The first procedure was cold needle treatments where they inject needles into the disks. Being cold needles they could do both sides at once because I was telling them I had a lot of back pain down here and in my butt and my legs hurt. And then they tried a Cortisone shots and they gave me Lidaderm patches and nothing worked. Then he said we'll try the heated needles. Heated you can only do one side at a time. That was a two-trip procedure and that didn't work either. So Dr. Eikler said there's one more thing we can do and this test is either positive or negative. He said it's a Myelogram. If it's positive you need a procedure done on your back, if it's negative we'll look in another direction you know? So I had that procedure and of course it came up positive. So he said I needed either an IDET or a disk decompression and there was only two doctors that could do that procedure at the pain management center, in Brigham and Woman's Hospital. So he referred me to Dr. Edgar Ross and I went to see him, we had a consultation and everything. He had the referral paper from Dr. Eikler and explained what the Discography was and what they do is you have to be awake and they inject 22 centimeter needles into each disk and then they pressurize them. They then see which one gives you the most pain. That was, I will never have another one of them as long as I live. It was extremely horrible and it hurt so bad. The end result was oh, then last summer after we did that, he said okay, we'll reschedule for another appointment, and every time I had to make an appointment it took me like two months to get in there and they would call and cancel. One time there was all construction going on in Boston and I didn't know it, and I was late and if you're late they don't do it because you need the antibiotic in you for an hour. So, last summer, I had the first original Discography in October of 2003.

Lee Pagnozzi: Donna I want to bring you back to the original point you were trying to make about the housing.

Donna: I wanted to explain what my disability is.

Lee: Well, it's been a while.

Donna: I didn't know where to begin and I wanted to explain.

Lee: It's fine I wanted to let you know to get closer to where you started out.

Donna: Last summer I got out of bed, I had a floppy foot it was just dragging and wouldn't walk. He said I needed another Discography which I didn't have done until December 13th of '04. Just prior to that I got a letter from the Cranston Public School saying they were terminating my position and my health insurance because I was out too long. My daughter was in the middle of having bridge work on her teeth. She had one side and still needed the other side and my health insurance expired January 1 of '05. Now, I had two years after I got disabled. I had Medicare stuff coming in but I'm going to avoid all that and try to get right to the point. I ended up, this is my disability, I have two and three, three and four, four and five are all bulging disks. They are also herniated and it's pinching the root to my sciatic nerve. Which is causing the pain down my leg. I'm not supposed to sit or stand for any length of time, I can't push or pull, lift anything over five pounds, I can't walk for any length of time, I can't drive for any length of time. I feel like I can't do nothing. I feel useless. I feel like I can't even clean my house, the way I always did. Like the tub, you know, things like that. So anyway, I also have you know the disk bulging and it's herniated pinching the route to my sciatic nerve and it caused me to have the floppy foot. After that the doctor wanted to do another Discography when I had the floppy foot and he did another one and then he sent me right upstairs to have a CT scan to confirm what that test showed. And they couldn't do all the levels of the Discography because down here where it's really bad the crest was too high or something. So I had the CT scan and that's what revealed the two and three, three and four, and four and five, etc., pinching the route to my sciatic nerve. And after that, the doctor said if I had one bad thing wrong he could have went in and fixed it but because I have so many things wrong with my back I was not a candidate for surgery. I reached my maximum medical improvement and I am totally disabled from my bus job and all future employment. So that really sent me into a depression. You know, when this kid hit me, he ruined my life. He really ruined my life. He took my job away from me, which I loved. He ruined me physically and he ruined me mentally. I was very, very depressed and I was seeing a Psychiatrists, Dr. Leone at Butler Hospital who was treating me for depression. I worked all my life and I established credit. My dad taught me how to sign for a loan at this little finance company when I was 16 for one thousand dollars. I worked second shift and he said this is how you live. I was daddy's girl, the middle child so he always made sure I knew altogether the facts and he said this is how you live. You borrow money, you pay it back. You get a bill, you pay it. You pay it before or when it's due or after and I did that all my life. You know, I pay my bills. I had excellent credit until I got in the accident in January of 2002. I had like 7 visa cards and I continued to make minimum payments on it because I didn't want to ruin my credit. I'm 49 and I had excellent credit. I worked all my life to establish good credit. I paid minimums until April of 2003 which was a year and a couple of months after and then the rest of them I was running out of money. The rest of them number September of '03 and I know I'm dragging on and I'm sorry, but I just need to give you all of these details.

Male Speaker: Can you tell us about the housing authority issue you're talking about. That's really important to us.

Housing

Donna: I know that. Just this last quick thing. He ruined me physically, mentally,. financially. I couldn't pay my credit cards after September and they're in charge offs. I worked all my life to establish excellent credit. Where I live right now it's a house with 3 bedrooms and I have a voucher. You get them when you're disabled and I have a 3-bedroom house with a finished basement. About the same time a yard and I live in Cranston and I had a really severe problem with the Cranston Housing Authority. This would be my third year to renew my lease. Last year, when you have an adult child that lives in the home, they give you a letter to take home or have them come in, either or, and fill out their income because they're an adult and they have to include their income for your fair share of what you have to pay for rent. And I said to Marie Fisher, she's the one who writes up the contracts and everything and Elaine Luaguan is the executive director. I said Marie, Christine is a full-time student. Because the paper she gave me it was for her to fill out and there were four stipulations and one of them was unless you're a full-time student and I said my daughter is a full-time student. She gave me another paper and said tell her to take this to the college fill it out and bring it back. I was under the impression that's all she had to do and because she was a full-time student she didn't have to reply any income because she attends and she was unfit. She was unfit and only getting from FIP $400 a month. She had my grandson.

Male Speaker: That's FIP program?

Donna: Yeah, it's Family Independent Program through the Department of Human Services and she has Neighborhood Health. See, this is one of my problems.

Male Speaker: That's your grandson.

Donna: Yes, and the only one I have. My daughter was born with one kidney and one of them was a cystic kidney. She was five, or six.
Male Speaker: So you put this paperwork into the housing authority?
Donna: Yeah, but I was told that someone with one kidney would not be able to carry a child. When she got pregnant, it was scary because she had to go to the high-risk doctor because she was a high risk and you know, we didn't think she could carry the child full-time. It was like a miracle. He's the only highlight in my life.
Male Speaker: He has a good grandmother.
Donna: I love him to death.
Male Speaker: I bet you do.
Donna: I think he is the only thing that keeps me going at this point, it's him. Anyway, myself, my daughter and my grandson, we live in this three-bedroom house in Cranston.
Male Speaker: You did the paperwork for the housing authority?
Donna: I gave the paper to my daughter. My daughter is 19. And she said, ma, do I have to take this to the school I'm mortified. She said I doesn't want them to know we're on section 8. She's 19, a girl and that's how she was. She was like so embarrassed and kept putting it off. I begged her, I said you have got to go and get this filled out because we have to hand this in or I'm going to be in trouble. So then I got this letter from the housing authority. I have every single letter they sent me. And they were, when I first moved in the first year they were making me pay 30% of my income, which is the worker's comp and the partial disability once a month. The second year, she made me pay 40% of my income, and that was last year. My daughter did got a job at Dunkin' Doughnuts, but my daughter can't hold a job, she was taking business courses and accounting and she's excellent on computers.
Male Speaker: Good.
Donna: So I got a letter in March from the housing authority saying that I'm in jeopardy of losing my voucher as of March 31st because of nonreported income for my daughter and not supplying that letter from the school. And if I wanted a hearing I had to request it in writing within ten days. I did it right away, I wrote it out and brought it to the office. I had them make a copy it and have it stamped with the date. I said could you please stamp this, both of them because I already was having problems the way they were treating me. And I wanted to be stamped for proof that I did it within ten days. And you know, I would go down there and talk to Elaine and Marie and at one point, Mrs. Louagone the Executive Director. She literally through me out of her office, literally. I said I'm disabled and I don't understand how can I pay so much rent being on this program. You know, and Marie is the one that did the calculations and everything and I was paying 40%. This was last year and then this year, we had the problem and you know, this woman came in, they sent me a letter. My hearing date was such and such and Joanne Gregory came in, she was a hearing officer, independent from I don't know where, she came in to make a decision whether I was to be terminated or just make a decision on what to do. So I told her that my daughter was a full-time student, but she was mortified and she's 19, and she was very embarrassed. I know it's a legal document and I know she had to fill it out. And they were going to they were trying to say I was committing fraud, but I wasn't. I said my daughter did have a couple of jobs, I said but she don't stay there and they wanted me to go down every month, if my daughter got a job at Dunkin' Doughnuts so they could recalculate my rent for the month. She worked at Dunkin' Doughnuts, she wanted me to run down there, tell her my daughter is working here and makes this so much in pay and works this many hours. They would redo my rent for the month. I know my daughter doesn't hold a job. She'll quit in three days. I think the longest job she might have had was maybe two weeks. Anyway, I didn't go down and tell them she had this job because I know she don't hold a job and they were going to raise my portion of the rent and I wouldn't be able to pay it because I don't get that much money. Like I told you, they brought my worker's comp check back down to $205 when I took the monitor's job. I complied with all the requests that they had. I get the one month payment automatically deducted of $279 from the government.
Lee: I hate to cut you short but we have about 7 minutes left to the forum. So if you could make your final point.
Donna: I'm sorry.
Lee: We need to make sure we understand where you are right now, so we have a full break and a full understanding. But we are under a time constraint right now.

Donna: I'm just, my head. I'm mentally, I will right now, severely, I was being treated for depression like I said and we got the meeting, I got a letter and they requested that I pay back $2,040 to the housing authority because she didn't comply and submit the letter that she was a full-time student. I said how am I supposed to pay back that kind of money. Make her pay it back. Throw her out. How can I put my daughter and my grandson that's two years old out on the street. I said I can't and I won't. So they were harassing me so bad, they were rude to me, hung up in my face when I called. When I did call once in a blue moon they would talk to me and be really abrupt and very unprofessional and rude and ignorant when they talked to me and then they would hang up. I told you that woman threw me out of her office, I always left there in tears. I called back to talk to the hearing officer Joanne Gregory but I didn't have her phone number. I wanted to tell her that I forgot to tell them at the hearing that she was a full-time student because they had me such a nervous wreck. I was very depressed all right stressed out, anxiety runs in my family, panic attacks and I was under a great deal of stress. I didn't know what to do. I didn't know how I was going to pay back the $2,040. The fastest I'm trying to go, I can't get the words out because I feel under pressure because I have to hurry.

Lee: Have you talked to anybody at the Disability Law Center?

Education & Employment

Donna: Yes, and they said they couldn't help me. They said they could not help me. They said they handle if someone wouldn't hire them because they were disabled, that would be a discrimination case, they would handle that. If someone wouldn't rent to them because of their disability, or something like that, they would handle that. They couldn't handle my particular problem. Anyway, I was just under so much stress from these people and when I called to get the woman's number, they refused to give it to me, they would not give me her number. Elaine said to me, I will call her and give her your number and I will have her return your call. Well, she never called me. And I feel very strongly that they never passed on that message to this woman because if this woman was a totally independent person and then she would have called me back. I'm sure of that. So I believe they didn't even pass the message onto the woman. After that, everything just turned into a big nightmare. It got so bad Marie Fisher said to me one day, I said why do I have to pay 40%, I'm totally disabled and I only get this amount of money, I still have to pay my gas, electric, and all this other stuff. I know they don't count car insurance, it's mandatory, you have to pay car insurance. And at the time, I had to have full coverage. And I said, why can't I pay 30%, why are you making me pay 40%. She said we can make you pay whatever we want. Whatever we decide we want you to pay. And then I got a letter for June saying readjustment, interim, of family, contract rent, what they allowed me for my three-bedroom house was $900 and I was paying the difference.

Male Speaker: What is it that you would want this group to know or try to make sure this doesn't happen to some other people?

Housing

Donna: I was told that I wasn't the first one to complain about the treatment from Cranston Housing Authority and in June, I just want to tell you this because this is unheard of, they cut their payment down to 90 dollars and my payment was 110 dollars. How can they pay 10% and make me pay 90%? That's not, it's actually 30 to 40% based on a normal tenant voucher. I just got this packet in the mail the other day and it was about subsidized housing and HUD and fair market rent Every section 8 housing list is in there and public housing through the section 8, their own property, and it did state a regular tenant based voucher would pay between 30 and 40% of the income and in the bottom paragraph on the second page this was just updated February 15th of 2005. The bottom paragraph stated that the public housing authority, no, HUD.

Lee: Done, It's 5 o'clock. People have appointments.

Donna: Can you give me one more minute, please.

Lee: I do want to thank these folks for coming because they're leaving as you're talking. I think you have other cases that might be good to talk to other folks individually about them. I believe you have a strong case first with the hit and run and also with the housing. You may want to think of other options for their housing.

Donna: I'm trying to get out of Cranston.

Lee: It's a whole other thing you need to talk to folks individually.

Donna: One last thing please. The last paragraph said the public housing authority of.

Lee: I have to go too.

Donna: I'm sorry, they base their fair market rent, the HUD bases their fair market rent on similar units of the same size in the same area. Now, you cannot rent a three bedroom apartment for less than $1,000. A three

bedroom house with a finished about the same time and a yard, the rents have sky rocketed.
Male Speaker: Number one I have a grandson, a new one and I hope he gets a bus driver someday that's as good as a bus driver as you were. I mean that sincerely. Number 2, you're not useless, you've raised our consciousness and made us remember that people need to be treated with dignity and respect and that you know, there are rules and regulations under the housing authority and under HUD and all that but people still need to be treated with respect. We do have time constraints we've taken down all you've said and we're going to report this to DLC and other organizations that have to do with housing and other organizations. Thank you for your testimony.
Donna: Just one last thing, please, it's so important. They said that HUD matches the fair market rent for three bedroom houses in the Cranston area. Then it said in parentheses the public housing authority says 90 to 100%. Then 120% for those that are disabled and/or those that live in high rent districts. Now, I'm disabled, they know that, I'm totally disabled. They weren't paying. They were treating me like a regular tenant based voucher.
Male Speaker: We've listened to everything you have to say. We're writing it down and will take a look at it in the transcript and talk to people who care about the issues you care about it. We're going to stand up and leave and that's no reflection on our respect for you.
Donna: One last thing.
Lee: There can't be one last thing. I have to lock up.
Donna: The public housing authority caused me so much stress I couldn't even deal with them anymore. I had to hire a lawyer and then on June 9th I thought I had a stroke and I went to the hospital. They admitted me and took all testing I was there for a week and what I had was a historical paralysis due to stress brought on by the public housing authority.
Male Speaker: They've made things worse not better for you.
Donna: I'm so sorry I took so long. They put so much stress on me, I never heard of such a thing.
Male Speaker: Thanks a lot for conveying all this to us. Thanks.

July 27, 2005. Warwick Public Library, Warwick

Lorna: Just going to give people a few minutes. I know some people have been waiting a while. We will get started probably in about three minutes to see if we can have more of our panel and folks who wish to testify come before we start. So three more minutes.
I think we will get started. If our panelists could have their seat, if everyone is all set. Before I start, has everyone signed in? If you haven't, even if you are not going to testify, could you raise your hand and Jeanne will come around and get your name. Great.
My name is Lorna Ricci. I am the executive director of the Ocean State Center for Independent Living, I'm your hostess today. I'm the moderator. I am basically here to keep people moving along, keep the testimony going. The purpose of this forum is to identify the concerns of people with disabilities and their families in order to assist the state to develop programs and services to improve the quality of life of persons with disability. Our panelists today, our distinguished panelists starting with Dianne has arrived.
Dianne Kayala from the Department of Human Services. If you want to give a little hi sign. Next to her is Steve Florio from the Commission on Disabilities, oops sorry. Steve was blocking Anne. Sorry about that. Anne Mulready who should not be ignored from the Disability Law Center, wonderful center. Next is Steve Florio from the Governor's Commission on Disability. Make sure there's nobody missing. Sue Shapiro from the Office of Rehab Services. Also she's head of Youth Leadership Forum. If you heard about that organization, it's great. And Hal Fayweather from OSCIL. He's our housing advocate. And the last person but not the least is Regina Connor. She's in charge of the Assistive Technology Access Partnership or something we call ATAP. Steve?
Steve: Excuse me. I'm actually representing the Governor's Commission on the Deaf and Hard of Hearing.
Lorna: I'm sorry.
Steve: I just want to clarify that.
Lorna: My gosh. He is. Let's do it again. Steve Florio from the Commission on the Deaf and Hard of Hearing. Steve, I wasn't using my notes. And there I go, see. Got to use your notes. I'm sorry. We wish to take this moment to thank the Governor's Commission on Disabilities for their efforts in pulling the forums together. They are really the organization behind all of the forums that are taking place statewide. And with us from that

organization is Christine Botts and Jose Lobaton. If you want to give a hi sign. If you have any questions as to the forum or information regarding the Governor's Commission on Disability, they are here to answer your questions. I would also like to thank all the sponsors of today's event. It takes money to put something like this on. Advertisement takes money. All the sponsors are listed in this pamphlet that you received, information on the other hearings. If you know of people that may want to testify at some of the other sites, they are listed here and the times. Also right under the dark line in the middle is the Governor's Commission's website address as well as e-mail address. This is to be able to send further testimony or have others send testimony to that address. And also to view the testimony from all the forums at a later date. It will all be up there eventually. It does take time to compile all the information. So it won't be there tomorrow. But eventually, a few months from now you will be able to see all the testimony there. I would also like to take a minute to thank our interpreters. Brenda Petowski, is she here? I thought we had two interpreters. I know Maureen McEntee. I would also like to thank our Allied Court Reporter, Jen Moore. Rosa Norberg, our other interpreter, will be joining us. We thank her. A few housekeeping kinds of things. First of all, the rest rooms, should you need to use the rest rooms, as you go out the main entrance here, bear right. Should you need to use phones, they are to the left as you go out the door. Refreshments, if it gets a little warm in here and you would like a drink. There's a cafe. As you go out to the left, you probably saw it as you came in, Felicia's. Also I ask you to turn the ringers off your cell phones just so when people are testifying, it won't be disruptive to them. Has anyone arrived that wishes to testify that has not signed up? We are all good on that. Has everyone received a card? This blank card is for your use and your use only. What it is, it's first of all as you are listening to the testimony and thinking of your own testimony to jot down the topics that you are going to be discussing, just to remind you when you come to the table the things you want to address. We all sometimes have memory blanks. I mean, it happens when you get in front of a microphone you kind of go blank. Me included. It happens a lot. So what I've done is given you the card so you can jot down the topics you are going to be addressing and also have it in front of you as you listen to other testimony and you are thinking to yourself, wow, that applies to me too. I also, for instance, need a curb cut in my town at such and such a location; or wow, that issue on transportation, I feel the same way. Go ahead and put that down on the card. All you need to do is when you come forward to testify, say, for the record, I also agree with so and so. If you remember their name, fine. If not, at least the topic. I also agree that curb cuts, for instance, need to be in place; and in my town, could they please be added to my town. That's just an example. There may be other issues that definitely spark your own personal interest. This card is for you to jot those down. Again you don't have to go into a lengthy testimony. All you need to say is I agree. So it goes on record that there's two or three people that have the same issue regarding transportation or housing or whatever your issue is. Let's see. I would like to go over the procedures. First of all, all our panelists are here just to listen. This isn't a debate. They are not going to be debating whatever you say. They may though ask questions for clarifications. If you mention a name that's unfamiliar, they may ask for you to spell whatever that was; or if you mention initials, they may ask you to say what do those initials stand for. And please, panelists, if you do ask questions, please give your name because in the past testimony, once it comes months later in writing, all it says is audience asked question. We are not sure where the question came from once we read the testimony later. So when anybody, either panelists or even someone in the audience says anything regarding testimony, which you probably won't, but you might, please state your name first. I ask that everyone who's testifying state your name, the organization you are with, and your last name. And please spell your last name, even if it's Smith. You can spell Smith many ways. Please spell your last name for our CART provider. We ask that everyone be concise. I think the purpose of the cards may help to keep people focused on what you wish to say today. Again agreeing with someone previous is fine. Just state for the record, I agree with them. All testimony will be available on the Governor's Commission on Disabilities website at a later date for you to see. The testimony will all be reviewed by the sponsoring agencies and compiled into a nice booklet, which will be available to the public and available most importantly to our legislators. So we are beginning to tell our legislators some of our concerns. This is really a wonderful way to get on record some of the issues and concerns you have. Written testimony can also be sent, as I said earlier. The address is right on the front page. Again if you leave today and are beginning to talk about today's events with neighbors and friends and someone will probably say to you, I wish I knew. Boy, do I have an issue. It's not too late. They can send in their testimony. Again it doesn't have to be long. This isn't a contest of articulation or how well someone writes. It's important that you just get your main facts down on paper. And that testimony can be sent to the Governor's Commission prior to July 30th. I think that's it. Before we begin, do you have any questions? Okay. I think we can start. I need to know who will be testifying. Great. Okay. First up is Linda Bradley.

Independent

Linda Bradley: Hello. My name is Linda Bradley. B-R-A-D-L-E-Y. I am the Home Access Coordinator at OSCIL. And I thank you for the opportunity to speak with you this afternoon. Over the past five years, OSCIL has helped about 500 people to stay home, to stay out of institutional care by providing funding for home modification and assistive devices. The devices might be something as simple as a reacher. An indispensable tool for many people, may help you get dressed in the morning and not need help. May prevent you from falling on your nose so you can pick something up off the floor. Another example would be a simple kitchen device allowing a person to prepare food for themselves. We do see their independence on programs such as meals on wheels. Some folks are trapped in their homes or they are dependent on family members because of their inability to walk long distances. I brought a little device with me today. I thought it would be fun to show. These cost usually less than $200 and they can make a huge difference to a person. They can go out. They can visit a neighbor. They can go out in the yard with their grandchildren, watch them play. They can go to stores again. They can carry parcels or belongings in the basket in the front. And the nice thing about it is that if they are out walking and they fatigue, they have a seat. They can sit and rest and recover and then be on their way again. It gives them a nice stable device to hold on to. And really makes a huge difference. It's also nice in the home. A person can put a bowl of soup on this and transport it to where they are going to eat without the fear of dropping it and maybe slipping on the soup.

Transportation

Linda: OSCIL also does nonstructural vehicle modifications with the same pool of equipment money. We may do hand controls in a vehicle. So someone who has weak lower extremities may be able to drive. We also might put a lift in their vehicle to enable them to take their wheelchair or scooter with them into the community. Not everyone is on a bus route or they may be on a former bus route that has been cut. Their only means of transportation may be their own vehicle. And we help them to remain independent and less dependent on others.

Assistive Technology

Linda: My concern is last year the funding for assistive devices was reduced by 40 percent. The waiting list that I have as of this date already depletes the monies for next year. I anticipate that unless a significant increase in funds can be found, this list will just continue to grow. Subsequently, these consumers will have to remain dependent on the system for their supports and they will be unable to achieve independence in the community. Thank you.

Lorna: Thank you, Linda.

Fredericka Athanas: Good afternoon. My name is Fredericka Athanas, A-T-H-A-N-A-S. And I'm here speaking for OSCIL, NFB Rhode Island, and myself. I would like to publicly thank my Representative Mellow from East Providence and Councilman Cane who have been very helpful with issues concerning people with disabilities. I have three topics I would like to speak about OSCIL, RIPTA, and I would like to see an agency put in place on a federal and/or state level that would help people with disabilities when they have issues of domestic violence and abuse.

Independent

Fredericka: As far as OSCIL, I'm not sure where I would be without them. I would like to see increased funding. They've helped me with home visits, my now housing situation and support, financial planning, and everything like that. I would like to see that continue. And especially to get people out of nursing homes and into independent living and with the modification of the automobiles, which my hands are great but I still can't drive. I'm legally blind with maculate degeneration.

Transportation

Fredericka: And as far as RIPTA goes, I hope they don't cut any buses at all because if they cut the buses, then they cut, that cuts access to me using the RIde program, which I depend on totally. And as I get closer to looking for employment, there are three agencies that I would love to work for in Warwick. And they are all, I can't think of the name of the streets, they are all bus routes that RIPTA wanted to cut last year when I testified at the hearings. So that would just put me in my apartment full time.

Family & Community Supports

Fredericka: And the third issue is for a federal or a state agency that would deal with people with disabilities that are being abused at home. I tried every agency to get me help. Over the last three years, my ex-husband was not very nice to me. And it was almost like being the woman in the Alfred Hitchcock movie Gas Lighting where he was trying to make me insane. And again, there is DCYF for the kids. There's DEA for the seniors. I'm not a kid. I'm not a senior citizen. Nobody was able to help me. Examples of the abuse that I suffered, and these were not enough to have him thrown out with a restraining order. The tops of his razor blades were falling in the bathtub. I can't see them. And I would step on them. One time I did step into the bathtub and the razor was there. I cut my foot. From there on, I had to sweep with towel or rag or a sponge, anything and just constantly checking for razor blades. Another thing he would do would be to unscrew the light bulbs in the lamps so I would come into my home, flip the switch, you know, maybe have groceries, put my stuff down, whatever. I would still be in total darkness. And then there was the issue of the bank accounts that were emptied. I had nowhere to turn to. So I would be willing to work with an agency to get somebody to listen to the reports, respond to the reports and help the people because I'm not the only one. I have had conversations with other friends of mine. And they are like, well, maybe if you can do something Fredericka, you will be the last one. So I do have the support of the National Federation of the Blind of Rhode Island behind me as well. And that's all I would like to say.

Lorna: Thank you, Fredericka.

Health Care

Kathy Podgurski: My name is Kathy Podgurski, P-O-D-G-U-R-S-K-I. And I'm here to talk about Medicaid and Medicare. I have Medicare as my primary and right now I also have Medicaid. Last April 8, I was evaluated for a new wheelchair. This chair is beyond falling apart. And they said, you will have a new chair within four months. And I say yeah, okay. Four months later, I called. They hadn't even responded yet. Other than the letter I had sent, anything to them, but they hadn't even replied yet. Then it was getting to where I called every two weeks or every week. And they would say, two weeks. The problem is I don't need a full electric chair because I can move my arms. I have the strength to move it. But this chair is really heavy. I wanted a power assist chair, which would mean I could have the power when I needed it. But then if I went short distances like in the apartment, I wouldn't have to use it. And Medicare was saying, according to what Medicare was saying, oh, it's a new product. We don't know if it's going to work. We don’t have a code number. I don't care about any of that. This chair's miserable. This chair is hard to push. And it's falling apart. I got blue all over my apartment from the arm rest falling off. And I don't know what to do. Carrie has been a big help. PARI has encouraged me to keep fighting. I would have said, okay, just get me a wheelchair. I don't care any more. But that's not what I want. And I know, as well as anybody living, I understand me having try something that doesn't work is in their opinion a waste of money. But I'm just miserable in this chair. My arms, my back, my neck hurt and I know it's the chair because as soon as I lay down in bed, all the pain goes away. So, I don't know if I just keep calling. I asked PARI if I could write to Medicare and they said that wouldn't do any good because then it's responding to the render. So, I don't know where to go. It's got to stop.

Transportation

Kathy: And I do agree with Fredericka about the Ride. I depend totally on Ride. Where Ride doesn't go, I don't go. Thank you.

Lorna: Thank you, Kathy. I would like to take this opportunity to invite a couple of our panelists who haven't come up here to sit with the group. David Sienko and Sister Marietta Walsh, are you here? I heard you are here? Do you want to move up? Come on up. Didn't know you were on the panel. If there's anyone who needs a sign language interpreter, does anyone wish to utilize a sign language interpreter? Could you raise your hand? Okay. Great. Moving on. Next we have Tricia Whitehouse.

Accessibility

Tricia Whitehouse: My first name is Tricia, T-R-I-C-I-A, last name Whitehouse. I am representing Statewide Independent Living Center. But I have been asked to bring a concern by a consumer who spoke to me this afternoon and could not be here. His name is John Liston. And he lives in this neighborhood just off of West Shore Road on Pine Grove Avenue. He recently had a total knee replacement and was in recovery from that operation. He was temporarily using a power wheelchair for the first time in his life and discovered that he was unable to navigate this very neighborhood that we are sitting in right now with his power wheelchair because of the lack of curb cuts. He was trying to go West Shore Road, 117 A, Sandy Lane, and had to do a loop around and was unable at many, many corners to get off the corner. Only because he was able to temporarily stand and take a few steps was he able to maneuver his power wheelchair over a curb and continue on to discover how extensive this problem was. I would also like to, for the record,

agree with everything that Linda had to say. Thank you.
Lorna: Thank you. Linda Theburg.

Accessibility

Linda Theberge: Hi. My name is Linda Theberge, T-H-E-B-E-R-G-E. And when I saw this was going to be happening, I reserved a Ride yesterday and didn't think I would make it out. And realize if I stayed home, it's in triple digits at home, I would just be in a lot worse shape. So I'm glad to be here today and spend some time with you and be cool at the same time. I'm finding that people who have disabilities that aren't always clear and fully visible to those around them and those they deal with. They generally are dismissed and misunderstood, leaving a void and more closed doors. Communities themselves have great disparities in the differences of being open and inclusive to people with disabilities who aren't of certain ages. And that's especially problematic when I find I'm dealing with chronological ages. My spine has been aging about a decade a year. So, when I have parts of my body and system in their 80s, what good does it do to be told I have to wait so many years when that's just not going to happen. And I would like there to be some way to address opening some of those doors to be more inclusive towards people who are ill and disabled and don't meet an arbitrary number and age. Many people I know who are seniors, some of who are in good health, don't understand it themselves. Many of them enjoy very active lives and that's wonderful. But for folks who are struggling at younger and especially by themselves, it's very isolating and makes it overwhelming to not be able to access a number of things, you know. It's everything from forms of assistance and services to even, you know, whether dealing with, you know, purchase everything. I don't know if anyone here has any plug into an RSVP program that's used in different communities with volunteers to help people access needs. I know where I live things are not very disability friendly, you know, when it comes to anything that comes out of, say the senior center. So, it really closes a lot of doors when, you know, I'm not seeing many of them open at all anyway. I used to be involved as a very active care giver for all of my other family members. And there's only my mother left, who's very limited with her health and mobility issues. It scares me to think that she's down as my next of kin because I know she makes a point of not really getting involved too much in her own healthcare. So, I spend a lot of my time and energy trying to access things that I just can't do. Can't get there from here. But there are serious illnesses and things that I'm dealing with that, you know, are not going to be a sign coming out of my head, you know, I'm having a difficult time absorbing, digesting food, you know. There are no days I'm not ill. And often time's people will look at me and just make assumptions. I see horrible differences. But I have seen myself, you know, all along the way. And I used to work four and five jobs at a time and do a lot of volunteering and community things. And I really miss that a lot.

Housing

Linda: And I think with some kind of support and if I could better address my living situation, you know, maybe that in some degree of that would be possible again. But I instead am left very much isolated and, you know, not able to involve myself in things I really care about and, you know, thrive on.

Transportation

Linda: I agree that transportation is critical to folks. I no longer have a working vehicle, I can't get to a drugstore to get things. Every month I face a crisis in how to get my prescriptions. And every month it's like starting over because you know, I may spend days on end trying to deal with that. And everyone I deal with says, well, you must have people. I'm not Cher. I don't have people, you know, lining up to go here and there and do things. It doesn't happen. This is a very rare exception, you know, for me to be in the presence of so many people. So, you know, I wish that that was better understood by people all around. And I find that the toll it takes affects my health negatively so much. It makes it much more difficult. And unfortunately there is a tendency, you know. It's horrible to hear about domestic abuse. And a lot of that seems to be in the community in dealing with business, merchants, or things like that.

Accessibility

Linda: A lot of people seem to feel like you are fair game. And that makes it very difficult because, you know, I know there are things I purchased. There are certain merchants I later found out, you know, had really taken, you know, a handful of disabled people for a ride. You know, not given them fair transactions.

Assistive Technology

Linda: I feel it is important to restore funding whether it be for assistive devices, or for all of the services. And sadly the trend that we are seeing is very much away from that.

Independent

Linda: And the things that would be supporting people to be independent. I'm just seeing them disappear. You know, the budget doesn't reflect things like that right now and it's scary. I'm afraid of whether I'm going to have a roof over my head. I don't see options out in the community that are viable. And being at home means getting, you know, heat stroke on a regular basis too. I thank you for being here and again, I don't know if there's some way to address the chronological age thing because it just doesn't add up for a lot of us, you know, who have already been there without hitting the age yet. Thank you.

Lorna: Thank you, Linda. Thank you for coming out in the heat.

Linda: It's a relief to be here though.

Lorna: Joan Gardiner. While Joan's coming up, I am going to have to mention. We are going to have to keep track of time. We have a lot of people in who wish to testify. So if I kind of give, I hate to do this, but give a little time sign, that means I'm asking if you wouldn't mind kind of wrapping it up, just so we have time for everyone.

Health Care

Family & Community Supports

Joan Gardiner[2]: My name is Joan Gardiner and that's G-A-R-D-I-N-E-R. And I live in Warwick. I'm on the board of the Brain Injury Association of Rhode Island. I want to thank the Governor's Commission on Disabilities for your support these last two years in passing legislation to improve brain injury services. I also want to tell you my story, which demonstrates why it's important for us to provide services for those with disabilities. In October 2001 I sustained a traumatic brain injury in a motor vehicle accident. I was in a coma for ten days, in the hospital for a total of two and a half months. It is difficult to believe that I have a traumatic brain injury and have been told that by many people I have met these past few years. It is hard to understand the recovery from a traumatic brain injury is like. But unless you have an incredible support network of family and friends, there are many obstacles you have to overcome. In a recent Providence Journal newspaper, there's a story about how three people, each in different social class, had suffered heart attacks and have treatment, care, and recovery for each person was different based on the level of income and the life styles. The story explained why it's important to have services easily available to those that are recovering from major medical situation regardless of their social class.

When I was discharged from the hospital, I had a wonderful support network. A family and friends which I never realized was viable to my recovery. I did not drive again until almost a year later, after much needed driving evaluation.

Family & Community Supports

Health Care

I had a lot of help taking care of my children, who are four, two, and six months old when I got in the hospital. Because not only was I recovering from the brain injury, I had a shoulder replacement surgery six months after the accident. Because I was able to receive great care from family and friends and the medical community, I was able to work very hard at my speech and physical impairments. Not everyone is able to get help that way. Although I was very fortunate with my support network, there are many who do not have that kind of help after a brain injury or major automobile accident. I needed a lot of transportation services. I needed help taking care of my children. I also had excellent medical coverage, which is very important because my medical bills have totaled over $350,000 since the accident. There are many people who have not recovered as quickly as I have been able to because it is difficult for them for many reasons. It could be a lack of medical insurance or difficulty in receiving domestic help they need. That is why it is imperative to provide the necessary services to help others who are not as fortunate.

I also wanted to quickly mention, I noticed that there is a lack of sidewalks in certain areas of Warwick. Thank you.

Accessibility

Lorna: Thank you very much. Laurie Robertson.

Laurie Robertson: My name is Laurie Robertson. I am from West Warwick. I had previously lived in North Kingstown and in Warwick. My disability is that I have MS., multiple sclerosis. I was diagnosed in the year 2000 an I continued working as a computer programmer for two years until my diagnosis was upgraded to progressive, secondary progressive multiple sclerosis. I have five issues I would like to address today. Medicaid eligibility, food stamps, chemical sensitivity, equipment, and doorway accessibility.

Health Care

Laurie: On Medicaid eligibility, I make $11,000 a year. In order to qualify for Medicaid, I have to spend down $3,000. I would like to see the eligibility be raised to $12,000 a year for a single individual. With the way that food prices have gone up, I am having to make choices between my food and my medical services and frankly both are suffering.

Family & Community Supports

Laurie: My next issue was food stamps. I would like to see additional money given to the food stamp program in order to support the purchase of medically necessary foods for individuals on a special diet. For example, I'm a celiac. All my food has to be gluten free. This month I bought one loaf of bread. It cost $5 and change.

Accessibility

Laurie: My next issue is chemical sensitivity. I am allergic to pine cleansers. If I get any on my skin, like Pine Sol, I get an ulceration that eats right into my skin. If someone washes their laundry in pine cleanser, just being in the same room with them gives me a horrible rash.

Housing

Laurie: I would like to expand on equipment. I would like air conditioning to be considered a medically necessary piece of equipment. Please consider air-conditioning for subsidized housing, not just for people with MS where heat can cause exacerbations but also for the sake of the elderly. I do know some elderly have died.

Accessibility

Laurie: My last issue was accessible doorways. We need accessible doorways security cards in all subsidized housing. In some instances I cannot get myself through doorways that do not have handicapped buttons. I have given my five key areas that I would like you to consider. I don't know if you have any questions to clarify anything.

Family & Community Supports

Laurie: I would also like to say that I agree with Fredericka on us getting the disabled violence supporting agency. I agree with Linda on the need for equipment and I agree with Miss Gardiner.

Lorna: Thank you, Laurie. Betty Brewster. Come on over, Betty.

Accessibility

Betty Brewster: Thank you very much. I am Betty Brewster from Warwick. And first of all, I would like to thank the commission for having captioning. I have a severe hearing loss. I have had a cochlear implant. I wear a hearing aid. But without looking at the captioning, I would have missed a great deal of the presentations. And I do not look handicapped, as do most hard of hearing and Deaf people. I do not sign because I am a late deafened adult. Actually, as you probably are aware, approximately ten percent of the population in the U.S. is hard of hearing. Of that ten percent, only two percent are Deaf. Yet in the past, many commissions on disability, the ADA, has addressed primarily the Deaf portion of the population. I'm not questioning your need for interpreters present. But we can rather fall in a gray area. And one of the things that is not currently available in Rhode Island, but for which I was in a trial for almost two years, is the Captioning telephone (Captel). Is there anyone in the room that's familiar with it?
Steve Florio: (Motions).
Betty: I suspected you might be. You are not alone in Rhode Island by not having the service available. Many other states do not. But I think approximately 16 do. And the state where I live other than in Rhode Island has it through Sprint relay. And up here I would suspect it should be through Verizon relay. I do not know how you or the state make arrangements with that. My original contact was with the manufacturer Ultratech. And I can assure you that the captioned telephone is far superior to using a TTY, which I have never done, or a VCO, a voice carry over phone, because both of those have a great time delay. The Captel is virtually instantaneous. Even though with my implant I can hear much better on my volume control phones, I still have great difficulty with businesses that have long voice menus. It seems that almost everyone, including physician's offices and everything do today. And I sometimes just punch zero and hope that will connect me. But they've gotten tricky. Sometimes that won't work. Sometimes it's 8 I've learned. But anyway, the Captel is a tremendous technological advantage and I would like to see that pursued in Rhode Island.

Transportation

Betty: Another thing I'm not sure whether is available here or not is some sort of identification for the visor stating one is hard of hearing. You do have that? Steve, is that available?
Steve: No, we don't have that.
Betty: No. Again, not all states have it. But it is on the upper side of the visor. And if you should be stopped for speeding or whatever, you usually have time between the time you are stopped and you are approached by an

officer to flip the visor down. Some places also have a decal on the car with an ear with a slash through it. But most hard of hearing people do not want to be identified as such, thinking it would be a come on for crime. And I understand that. But we do not understand. Sometimes we hear but do not understand the spoken language. And that is something that the general population does not seem to understand. They feel like if they shout, we will understand. But that is not the case. Another thing, there may not be as many hard of hearing people appearing at this meeting because they tend to be reclusive. I'm fortunate because I'm late deafened that I speak well. But many do not. And they are reluctant to speak in public.

Assistive Technology

Betty: And then totally unrelated to the hearing issue, the people that I understand only too well are in need of new or wheelchairs. My late sister-in-law needed a wheelchair for a number of years and Medicare paid for it. But it's still sitting in the basement. And I would hopefully think, there is some place where used equipment from the handicapped could go. Thank you very much.

Lorna: Thank you.

Lorna: Regarding the used equipment, you may want to give your name at the back. PARI independent center accepts used equipment.

Accessibility

Steve: Just to clarify that, please. I just want to respond to that. You had brought up about the Captel and the new technology. The voice carry over service that we have now through relay, they have a person there who reads

Betty: That's the voice carry over.

Steve: Right.

Betty: Captel goes through a national center.

Steve: I'm aware of that. I'm giving a general description so other people will know what we are talking about. So I wanted to speak first about the voice carry over so people would be aware what that is. Voice carry over technology. We have that already. You have to understand the operator would be listening to the person speaking and then type it. So the technology is very different from a person who uses speech recognition technology. They hear the message and then type it. It goes much quicker. Hard of hearing people really love that most of the time because they can keep up with the Captel. It's more spontaneous. It's not the old technology that used to have a lag time when you had someone typing it. There are two different methods. Voice carry over with the Captel. With the Captel the relay provider is in the state. We have a contract here that will expire this spring. And there will be an RFP that will be distributed in the fall so that we will have the Commission on the Deaf and Hard of Hearing has already begun advertising. We would love you to come join us and serve on that committee to be looking at it. It's called the text relay commission. We will be analyzing how to improve the services for the next contract year for the relay services and through the bidding process. Captel could be included in that. We really encourage you to join that. We will be talk to go the PUC. And the chairperson will be responsible for developing the contract for that captioning service. We've already got it started and we will be waiting for the RFP to include Captel potentially. If you have concerns and would like to express those concerns, I definitely encourage you to become part of that committee. If you would like to contact me afterwards, I would be more than glad to welcome you to serve on that committee. Thank you for the comments you made today.

Betty: Could you just say what RFP is?

Lorna: Request for proposal.

Steve: It's for any contract. If you have a contract expires and you need to set up a new contract or new bidding to get dollar amounts. It's the bidding process. It's proposals.

Lorna: I need to just ask if we have a second interpreter? Sorry I can't see that far. I was going to ask if you need an interpreter break. But Rose is here. Moving on. Ann Nelson-Hartnet.

Accessibility

Ann Nelson-Hartnet: My name is Ann Nelson-Hartnet. And it's H-A-R-T-N-E-T. I was told about this get together just last week by Laurie as a matter of fact. And I had not received the announcement through the mail. I was like, why didn't I get it? I get all the stuff from the MS Society. That's what I have. It came in the beginning of this week. I thought it was a little short. So, she had been talking about it. I decided I think I should go. Walking in the building, I found one issue that just popped into my head. I said it's something worth mentioning. The ramps. The handicapped ramps work wonderful to someone who's in a wheelchair. I don't know whether this should be closer or further away. Higher? And you know that's great. But for someone like myself who is ambulatory. The ramps are impossible. They throw me off balance. And the handrails are what get me where I can pull myself up. But the handrail, if you notice when you leave, it's like eight feet from the beginning of the walk on. And I'm like going, okay, this is fine. A lot of times I find myself getting out of my car. Okay. Hold your breath. Take a few steps. If you can get to that point, then you can grab on it. You are fine and you can keep going. I don't know if there's an easy fix, you know. I congratulate them for having any handrail out there. You don't know. Maybe the rules could at least define them a little further and make them more all encompassing for the area they are designated to go.

Health Care

Ann: I'm also here because I'm the working handicapped. I have my own business. I'm a tax preparer and I'm also a register representative and insurance licensed. I'm creating my own business. There's got to be facilities out there. I'm doing a lot of reading about Social Security. I'm very fortunate. My husband has wonderful health insurance. I do have about $13,000 in medical expenses per year and I don't even take that much. It's not like I'm on a lot of medications. But I'm looking down the road. I'm reading the Social Security books and I don't where are we going to go when he retires? Medicaid is not going to cut it. It's like I am not poor. I don't have just $2000 in the bank. So, I'm not going to qualify for SSI. You know, I don't make $50,000 a year with my profession. It keeps me busy. You know, keeps my brain active. And I'm not really sure where I go, you know. It's not you know, I've got a wonderful house, a wonderful family. I also have a brother who has multiple sclerosis.

Independent

Ann: And I would strongly encourage you to increase funding to OSCIL. My brother has primary progressive multiple sclerosis. The only thing he can move is his head. He has been able to stay home through the love and the care of his sister and of his wife. You know, they have redone the entire house. And I know OSCIL has helped them with computers and things like that for him, just to keep his mind active and keep him going. He can actually answer a phone by voice control. So, I know the extremes, you know. I'm not in that bad a shape. And physically, he is.

Health Care

Ann: But he is on Medicaid. He doesn't have the finances. He doesn't have everything. So, I don't know if there are any quick answers to it. But I'm sitting there and I'm watching the news. And I'm watching them cut benefits. And I think there are a lot of people out there who really need the things.

Accessibility

Ann: Laurie Robertson comes to my home. We spend a day playing cards. She's absolutely right. I use pine sol on my carpet to clean up a dog stain. And she walked in the door and walked right out the other side of the thing because she just was like, oh my God. Who used pine sol. I had no clue. So, it's a very real thing. And it took her I would say four hours that afternoon just to get the puffiness going away, you know, it woke me up. Because I didn't know anything about it. Sorry, not to make an example out of you but. So those are my issues, you know, where I'm coming from. I know there's a million things that I know people really need help. I don't know how to help or how to lend.

Family & Community Supports

Ann: I think there's got to be some kind of blending with the Social Security system with financial planning. I don't think financial planning people have to be working on commissions and getting paid. I think they should be out there helping the people, helping to digest the Social Security system and helping come up with the plans. A lot of us, we can't walk. But we can read. We can go on the internet. We can hunt and dig through things. Our brains aren't gone. My brother who can only move his head is one of the most intelligent people I've ever met in my life. So, I thank you for listening. It wasn't that organized.

Lorna: Thank you. Allyson Dupont.

Transportation

Allyson Dupont[3]: My name is Allyson Dupont. I live in Cranston and I'm currently enrolled at Rhode Island School of Design. I am speaking on behalf of myself but also on behalf of a group of sort of alumni of the Rhode Island Leadership Forum who are unable to be here today. One of my main issues is transportation. Of the 26 alumni, only six are capable of operating a vehicle. And it's been a major issue that we are trying to work through, finding people. Transportation, be it paratransit or any way. I know personally taking the Ride bus, it's been very difficult on a number of occasions. Rides get cancelled. People out of the blue. And there's not always an alternative. If you find out the morning you are supposed to get a ride to class, for instance, that your ride has been somehow wiped out of their scheduling system, they don't have anywhere for you to go. On one occasion when that happened I would have missed a class. I'm paying almost $1500 to take the course. I would have missed a full day of it if my dad had not been able to give me a ride that morning.

I am testifying regarding the state of services available to persons with disabilities, specifically the Paratransit program and the Office of Rehabilitation Services. These services are, as most of the disabled community would agree, seriously flawed and unreliable at best.

A crucial part of an independent life for anyone. disabled or not, is transportation, yet those with the most sensitive need for it are those who find it most difficult to access. Although the process of applying for a Paratransit pass is fairly uncomplicated, the process of using that pass is anything but. Rules regarding scheduling a ride are strict, demanding that both the home and destination be within one mile of a regularly scheduled public bus route. If this is not the case, then one must find a way to the nearest bus stop to be picked up by the RIde bus. With RIPTA cutting more and more bus routes each year, it is getting increasingly difficult to obtain a ride from door to door. In Cumberland for instance, almost all bus service has been cut, and the bus stop nearest to Cumberland Hill residences ia at the Lincoln Mall, more than a mile away across a major highway. Residents of this area that I am acquainted with tried to do something about this with no avail. Ultimately, a young man with Cerebral Palsy and a woman who is completely blind were told by the president of the Paratransit program that it was completely safe to more than a mile across this dangerous highway to the mall. In order 10 maintain her employment, the woman with a vision impairment was forced to leave her apartment and move to Lincoln so as to have a ride to work—this was the only factor prompting the move. The young man, on the other hand, has no option but to stay in his current residence, so he is forced to pay a cab fair in the amount of $16 each way for a cab ride to the Lincoln Mall bus stop and then another $6 for a round trip on the RIde bus each day that he attends classes at CCRI. Yet, even if one can access the bus. as I can, there are still various difficulties in obtaining a ride. As has happened to me on more than one occasion, the ParaTransit schedulers will use their one-hour window to change a pick-up or drop-off time without notifying the client and regardless to whatever schedule the client may be trying to keep, often resulting in lateness to appointments, or, in my case, classes. Also, drivers sometimes show up to a pick-up early and leave before th^ designates time, reporting the client as a no-show and leaving them without a ride' on one such instance I was left on a sidewalk on the East Side of Providence and had to have multiple calls of complaint placed before the operators would send a bus back for me. On still other disastrous occasions scheduled rides have been completely erased from the system, and only sometimes have the operators been able to provide rides to whatever appointment is about to be missed. Although this speaks mainly of only my experiences, I know it to be a fact that almost all participants in the Paratransit program are equally inconvenienced by these scenarios.

Education & Employment

Besides the inconsistency of transportation, the Office of Rehabilitation Services is equally unreliable in providing assistance to Rhode Islander trying to work, attend college, or simply navigate the system. Entire districts of people with disabilities are without ORS councilors, meaning that they are also without ORS services. ORS is extremely tight fisted in handing out assistance to those people actually being serviced, referring any questions they can to other agencies rather than assisting; these are not even always the appropriate referrals, resulting in the person getting stuck in the system. Councilors are often inexperienced and unfamiliar with the services available in their own agency, as well as being difficult to reach and notorious for stringing clients along for days at a time. The fact of the matter that ORS is under-trained and under-staffed resulting m large numbers of people being completely unable to access the state services available to them. In fact. it took a letter directly to Jane Hayward for me to receive any attention at all from the Office of Rehabilitative Services and after a short time of attentiveness I find that my service is again slipping away.Although there are many problem areas in the systems designed to help the disabled community, I feel it is crucial that attention and reforms be directed at these programs as soon as humanly possible. They are the bases of the betterment of people with disabilities and they are not serving their purpose.

Also because of the cuts that RIPTA's making on bus routes, their entire geographical areas that are unable to access Ride. And this is the really backwards part. I have a friend who lives in Cumberland and there are a number of disabled persons in his neighborhood who are completely unable to access paratransit. He has cerebral Palsy. He has a neighbor or I should say had a neighbor who is legally and completely blind. And they could not access the Ride bus because they lived more than a mile from a bus stop. The closest bus stop was at Lincoln mall. And they went all the way to the president of Ride, who told them it was a perfectly safe walk, to go with cerebral Palsy and bad knees or to walk with a cane, across a major highway to Lincoln Mall. So, the blind woman actually had to move to Lincoln so she could continue her employment because she had no way to get to work. And the young man with Cerebral Palsy has to pay $32 a day for a cab ride to and from Lincoln Mall where he catches the Ride bus to go to CCRI, which he pays another $6. Honestly the fact that he goes through that basically hell every day to get to school. And he has been in school for two years now, It's amazing. And like I said, even people who are like me, I live in an area where there is access the Ride. I can access Ride. But it's so difficult to get places besides rides being cancelled. Drivers show up late. On one occasion I got out of class at 5:00p.m. and no bus showed up and I waited. And I waited. I called and asked. They said oh, you were listed as a no show and they left. I was outside before my scheduled pick up time. So the only way that happened was that the driver showed up early and left. And they weren't going to provide me with a ride home. I was stranded on the East Side of Providence. It took multiple phone calls from different people before they found me a ride.

And also on the topic of the power assist. I do know people who have had the same problem with that and it's quite a travesty and people should really look into it. Medicaid and Medicare are very picky about what they cover. For example, a person who doesn't have quite what it takes to use a manual chair, who would benefit greatly from a power assist, which is just a motor that attaches to the wheels of the manual chair. It costs pennies on the dollar compared to a powered wheelchair but they will not cover it. There are just so many cases of things like that. So, thank you for your time.

Lorna: Thank you, Allyson. Anna Martin.

Independent

Anna Martin: Hi. Thank you for having this conversation. I really would like to say thank you for supporting the legislation to give more money to the brain injury services and stuff. There are estimated that in every 21 seconds there are brain injuries. There are people that are disabled. They are disabled because of brain injuries. 1995, I was crossing the street going to the state house. If you have gone Smith Street and feel a bump, that's for me. But anyway I was crossing the street to go to the state house and a car came by and hit me. I was thrown to the top of the roof and down. I was in a coma for six and a half months. So I'm paralyzed and stuff like that. So there really should be I think, a way to tell other people that I'm disabled physically, not mentally. I don't know if people will agree with that or not or whatever. So I think there should be a publication or something to tell people that there are people in wheelchairs who are good people. It's just something we have to do physically not mentally. Thank you very much for talking to us, listening to us. Bye.

Lorna: Thank you Anna. Next is Alton Stuckey.

Accessibility

Alton Stuckey: Hello. Thank you for having me here. My name is Alton Stuckey. Spell it A-l-t-o-n. My last name spelled S-T-U-C-K-E-Y. I'm glad to be here again. I started riding the RIPTA bus in 1986. After that I have been riding it since. Most of the time now I use that bus. I get around in it. Sometimes I get a ride by cars, by taxis. But most of the time I do ride the bus. But in the wintertime, it can be my concern. These bus stops are not being cleaned because of ice and snow. It can be difficult for people with wheelchairs and the elderly and for other people that have disabilities that are not in wheelchairs because these sidewalks are not cleaned. We usually have to stand in the street just to wait for the bus. One day when it wasn't snowing, it was sunny out. And I was at the bus stop waiting in the street. I said to myself, I can't put up with, I'm not going to be climbing on top of that snow and falling down just to get on the bus. There has to be a way to figure something out, of getting these bus stops cleaned in the wintertime for easier traction for these elderly people, for people with disabilities that are not in wheelchairs, and for people that are in wheelchairs. They want to be able to get to those bus stops in an easy way without getting hurt. So I say these bus stops should be cleaned. There has to be a way. There has to be a way to get these bus stops cleaned. Figure something out how to get these bus stops cleaned in the wintertime for easier traction. It can be hard for people to go to work as well, volunteering or something else, or going to their appointments, just like me. It can be difficult in the wintertime with the ice, snow, and all of that. Very, very hard. So, there has to be a way. Thank you for my cooperation.

Lorna: Thank you, Alton. Next is Walter Judd.

Male speaker: I'm sight impaired and I have a lot of trouble crossing the street right in front of the Warwick Public Library. What's the reason why the light ain't working right? I have been asking the police department for over two months to get it fixed. They keep telling me they will have something down here tomorrow. And tomorrow is tomorrow. Tomorrow is tomorrow. Right now it's still isn't working. It works for the people coming out of the library as soon as they hit the bump out there, the light will change and then the light will change back to Sandy Lane again. And I can't cross. So I have to take a chance to run across. That's the way it's been happening every day for the last two months. Every time I call up and also my wife's called. They will be out there tomorrow. The lights are still not working. You can go out there right now. You can see the crosswalk light isn't working. You press the button. It ain't working. Only hitting the bumps to make the light change. That ain't the only lights. Because I take the bus a lot. I go downtown Providence. I go up Charles Street. A lot of places where I used to cross, some of them ain't working right either. Some of them are talking, and some of them don't talk. A lot of blind people can't see the light change. I can look at the light behind me and see it change. So that's my beef there. We would like to get it fixed, even kids can't even cross the street here to get to the library. I thank you for listening to me.

Lorna: Thank you for your testimony. Do we have anybody else that wishes to testify? Maybe something that was mentioned today that has touched your own heart and there's something that you could add? No one else? Anyone from the panel wish to step out of your role and testify for the record?

Assistive Technology

Regina Connor: Thanks, Lorna. My name is Regina Connor, as I had indicated earlier. I'm the program director for the Assistive Technology Access Partnership. We are the federally funded program that works to increase access to assistive technology for people with disability of all ages. We are currently in the process of developing a state plan for assistive technology, a three-year state plan. It's a new initiative for us with the reauthorization of the Assistive Technology Act. We are now required to develop a state plan, spelling out the activities that we are going to conduct over the next three years so that people with disabilities will have greater access to assistive technology. And if people have had experiences in attempting to obtain assistive technology, maybe want more information about assistive technology, might need technology for employment, for education, for community living. If you have any comments, any thoughts that you might like to give this afternoon, I would really appreciate hearing from you.

Transportation

Lorna: There's been some wonderful topics and areas of concern raised today. I wish there had been someone were RIPTA in the room because I think just the testimony regarding RIPTA services alone is pretty powerful. The good news is everything has been written down and this will be available when we begin to look at RIPTA cuts and people at higher places are looking where to cut or what to cut or where to get the money for additional services or for snow removal or the other things that were mentioned today. So, be assured at least we didn't have someone in the room hearing your testimony, but we will make sure the testimony gets to the ears and the eyes that need to see it. I thank you for all the testimony in that particular area because I know that's a major concern. Does anyone have anything else they would like to add? Anyone that's come today has any questions? Anyone from our panel?

Housing

Hal Fayweather: My name is Hal Fayweather. That's F-A-Y-W-E-A-T-H-E-R. I'm a housing advocate for the Ocean State Center for Independent Living. I just would like to second what Linda Bradley had to say as far as the cuts. Basically 40 percent for our part B program for equipment or assistant devices. The cuts takes away the independence from a lot of consumers. It takes away opportunities to stay in their own homes or to leave even a nursing home to go into independent living. They need this equipment, this assistive devices.

Hal: One of the things I noticed as a housing advocate for the last ten years throughout Rhode Island, which is a small state, 50 square miles from Woonsocket to Pawtucket. We have a lot of hotels, a lots of gas stations. We have a lot of, if you will, bars and package stores. But I don't see a lot of public subsidized housing. In a group last February I had an opportunity to go to Washington with Mr. Staples, who is here from Home Choice. A lot of the people from throughout the country, from California, Texas, New Mexico, and Florida, and all up and down the east coast, they are saying there definitely is a need for public subsidized housing, affordable housing. We see everyday in the paper and on television that there's a need for affordable housing. Going to Crossroads, people don't want to go to Crossroads. People don't want to go to shelters. They are living with sisters, brothers, uncles, whatever it takes until they can find something that's affordable. A lots of people want a quick fix. They want to get into public subsidized housing. There aren't any quick fixes. It takes time to file an application, to be on a waiting list, which may take even basically a year or longer. In most cases when they say a quick fix, we may get an opportunity that some one will call our organization and be from either Pawtucket or be from Woonsocket. Well, a lot of our consumers don't want to go to Pawtucket or Woonsocket. They want to stay in Kent County, or they want to stay in Washington County. It just takes time. As they said in Washington, a need for more high-rises, affordable public subsidized housing because we are dealing with people who's income is not high. One lady said, I'm fortunate I have a brain injury. Another woman says, I'm running a business. A lot of people aren't that fortunate, which they had said. They are on SSI or SSDI. And they need affordable public subsidized housing. Thank you.

Lorna: Anyone else have any comments? Pam Goes.

Independent

Pam Goes: Thank you. My name is Pam Goes, G-O-E-S. And I live in here in Warwick. I'm the parent of two young men with developmental disabilities. And I would like to see some way of increasing funding for the direct support people who work with folks with disabilities. There are waiting lists. There are unstaffed hours. There's a large group of folk who depend and rely on direct support staff to do their most basic needs, cares. There are waiting lists. My son has approval from the state for 20 hours of service and because of understaffed, we are receiving six hours. I would just like to see for a children program and for adult programs, some increase funding for direct care staff. Thank you.

Lorna: Thank you. Anyone else?

Health Care

Dianne Kayala: I'm not really testifying. But what I wanted to do was just mention two things that might be of interest. One is that we will be starting the Medicaid Buy-In as of January 1. It was from legislation actually passed almost two years ago. But for people who have any kind of paid employment at all, it's a much more lenient income and asset test for Medicaid eligibility. I want to make sure people are aware that's coming down. And secondly, that based also on legislation from last year, we are in the process of kind of trying to put together ideas for a voluntary managed care product under Medicaid. And we are actively soliciting people to participate in that activity and to give ideas. Even if you are not a person who's on medical assistance or on Medicaid, it would still be valuable to have any person with a disability have some input on to that and what kind of things would make it a better product. So, I wanted to make sure people knew that. If you want, you can be watching. There will be public announcements on both of those. But if you want to be sure to get a private, a personal invitation, if you give me your name and address, I would be happy to make sure that happens.

Lorna: Thank you. Does anyone else have anything to add? Linda?

Housing

Linda Bradley: Someone had commented about the handrails out front. And it made me think of a concept probably a lot of you have heard of the universal design concept. They now tend to call it inclusive design. And it's just basically a principle where if you are going to do something, do it so that almost anyone can use it. And when Hal was mentioning about trying to get some increased subsidized housing, I thought well, why don't we make it inclusive at the same time. Let's make all the new housing so that anyone can use it so that we don't get into the crunch again of trying to find affordable accessible housing. Everyone can use a walk in shower. And someone with a disability may need that roll in or walk in shower. Let's make them all that way. You know, if there's ever a committee to look at that, I would be glad to serve on it. I'm volunteering right now. I would be very interested in being involved with something like that. So, just another little thing to think about.

Lorna: Thank you, Linda. Anyone else?

Laurie Robertson: I did have a friend bring up one more issue just before I said that I was coming here.

Lorna: Laurie, your name again.

Transportation

Laurie Robertson: My name is Laurie Robertson. L-A-U-R-I-E Robertson. My friends that live in Florida, it is the law that when a disabled person goes to a gas station they can beep and have somebody come out. I have gone to a gas station myself and it was a full serve gas station, apparently only during certain hours. I arrived. I beeped. I waited. The guy pointed at his watch. And said, no. I drove off. I was not in any shape to gas that day. My friend had gotten out to gas her car. The

pump was the kind that you have to push in or it doesn't work. She was afraid she would be unable to. She had just enough strength to finish that day. That was all I wanted to ask. Thank you.
Lorna: Laurie, that's good. Anyone else? Okay. I will come to you.

Family & Community Supports

Joan Gardiner: My name is Joan Gardiner, G-A-R-D-I-N-E-R. Just have a tough time saying, what Hal said about a person with a brain injury has been fortunate. I have had a tough time swallowing that. It's not that I'm fortunate. I have been very fortunate.
Hal: You said, I'm not as bad off as others. That's what I meant. You can place that as fortunate compared to the others you had spoken about.
Joan: I understand how tough it is for a lot of people. I haven't had that because that's why I am fortunate that we still need the services.
Hal: Definitely.
Lorna: Absolutely
Joan: Okay. All right. That was a little tough for me to take that.

Housing

Kathleen Samways: My name is Kathleen Samways. I just want to add to what Linda said about the universal and inclusive design that if we moved toward making all units inclusively laid out and manufactured or actually constructed, it also reduces the isolation of the people who are living in the units because now we have folks who are in big high-rises who can't even get out of their own apartment. Or perhaps they can't go visit somebody else because they can't get in or they can't access the facilities in that. So if everything worked for everybody, then the problem of isolation wouldn't go away, but it would be reduced or minimized, just one more thing to throw in the record.
Lorna: I just need to add to that. If things are done to make a building accessible at the beginning, it's minimal cost. Sometimes the same cost if it's done at that time. Thank you for your comment. Anyone else? Our panel?
Linda Theberge: T-H-E-B-E-R-G-E. I think that is a really important issue. If one's needs do not necessitate it at the time, they may at a later time. And I think it really makes for a better community and a very more inclusive living environment for everybody. You know, people by choice don't necessarily flock to apartments made out of cinder blocks. So, I think, you know, by utilizing design that works for everyone, it will attract everyone. And it will open up people's lives really.

Accessibility

Linda: Also in my community, I know people are talking about curb cuts and things like that. I have seen people transporting along Elmwood Avenue at a very dangerous area where there are curves and very little traffic controls. Lights are few and far between going towards Warwick. And they have to go in the streets because the sidewalks are caved in in-places and not such that you can navigate whether walking or in a chair. And so, curb cuts and sidewalks would really be better maintained.
Lorna: Absolutely. Anyone else? It's funny you were talking about the access here with the rail. Our center was involved in all the renovations of this library when it was being done years ago. And we were real instrumental in getting things like the fact the lavatory doors can remain open, yet you still have privacy in the event you have some kind of event you don't want to have leaving the door as a barrier. Other things such as cubicles that have quiet areas for people that are really distracted easily and really need to have that quiet time. One of the biggest fights we had was that rail that was mentioned. In fact, my staff are laughing because I had to pull out the … I will attend the trustees meeting and explain to them why you need that, if you don't do it. The next thing I knew they were doing it. But I am going to make a call to Dave Pierce tomorrow morning because I noticed it looks kinds of sad. And I think maybe it's time to extend it. You are absolutely right. It should be extended all the way to the curb for those people that are really using it. It's kind of just not working for that need right now. But I laughed when I heard the mention of the rail because there has been a lot of issues on that rail.
Female speaker: I congratulate you.
Lorna: They weren't going to do it. They weren't going to do it. You know why? It wasn't aesthetically pleasing. The trustees thought that having a rail, it would just take away from the beauty of the library in that they didn't want it.
Female speaker: It takes away from the beauty of my leg but I still use it.
Lorna: I see another comment. Anyone else?

Hal Fayweather: I think that would come under reasonable accommodation. Under the ADA, that word "reasonable accommodations" that can be a little stressed, but definitely reasonable accommodation. I think Lorna will follow up on that one.

Lorna: Dave Pierce and I are friends. We have become friends over a lot of issues in this library. Anything else? I see a hand.

Accessibility

Bonnie Serdam: Hi. My name is Bonnie Serdam. Kathleen's aide. I am also the mother of two boys. They are now 18 and 16. But my youngest son has severe asthma. And he is also the type of child, odors, different things like that will trigger it. And people do not understand that just because he looks like a normal child, they don't realize that this is a disabled child. And I have been really fortunate that Kathy understands what I go through. I recently missed a day of work because he was at the hospital for 24 hours. They wouldn't let him to go home because he had such a severe attack that he could not breathe. So they kept him in the hospital for 24 hours and it was all triggered by a scent. And people just don't understand. It's a silent disability. It's not noticeable so they think, oh, he's faking. I actually had a doctor one time when he was five years old and he told me, oh, he shouldn't be here. What do you mean he shouldn't be here? I brought him here by emergency. And they put oxygen on him because it was so severe he was literally blue. So, I just wanted to say that. I understand.

Lorna: Chemical sensitivity has raised its head finally as a concern for lots of folks who are finally understanding that it can be very debilitating. If you know of people who wish to speak on that, that happens to be a forum that's being conducted specifically for chemical sensitivity. And that's going to be held August 23 at the lung association. Again, information as to where abouts and any information regarding that, you can talk to the Governor's Commission. But the address and the date and time are right on that folder that you have, the pamphlet on all of the sponsors. It's right on the front page. August 23. I encourage everyone that's testified today, should testify again. Or have other people that you know that have the same concerns. That is a specific forum that's targeting that new disability. I guess you can call it that it’s finally being recognized. Anyone else? Panel? Anne.

Anne Mulready: Thank you, Lorna. I just wanted to mention briefly. I'm from the Rhode Island Disability Law Center and your feedback is very useful to us. We are a federally funded law office that each year comes up with priorities of the different kinds of legal work we will do. I have left in the back surveys for people to fill out if they wish to about the kinds of legal issues that are most important to them in Rhode Island. So if you have a chance, please feel free to pick one up. I also have some with me. Thank you.

Lorna: Anyone else? We have a few more minutes, about 15 more minutes for this forum. someone over here. Allyson.

Accessibility

Allyson Dupon: Allyson Dupont again. I just have one more thing I thought of while we were sitting here, actually I thought of it when we were talking about the legal things. Being physically disabled obviously is much more obvious to other people. And something I have run into in public places is restaurants, movies, concerts, stuff like that is, simply because you have some sort of physical impairment or assistive or adaptive technology like a wheelchair or a walker. The employees of one of these places will insist that you are placed in a certain area despite what you are paying, despite what your personal wants and needs are. If you go to a concert at like the civic center, even if you can access numerous different areas, they demand that you sit in the designated area with the other disabled people, separate from your group of peers or family or whoever you may be with. If you go to the movies and this has happened to me before. I have gone to the movies and although there were the wheelchair spots were left open, there were no seats next to them and I was there with a group of friends. The employees at the movies told me if I did not sit in the designated area, even though I had a spot directly behind where my friends were sitting, if I did not sit in the designated area they would throw me out. At a restaurant once, I was told that I couldn't sit in the aisle. I had to sit in the back corner because I was a fire hazard. And this was before it was illegal to smoke inside. And they wanted me to sit in the smoking section in the back corner because I was a fire hazard, even though there was a mound of chairs stacked all the way up to the ceiling in front of the fire exit. But I was the fire hazard. I think people don't realize it's a violation of our rights. It happens very frequently and people don't do anything about it. I have a friend who just dealt with something. She went to a concert and was told she had to sit in the designated area, which was up a flight of stairs. She walked but they made her walk up a flight of stairs because

she had an apparatus. They actually said, you have an apparatus. You can't stand on the floor. She paid for floor seats but she ended up sitting all the way left stage up in the seats up a flight of stairs. This was in Massachusetts, of course. But she went to the commission and they have yet to do anything about it. When they went to their version of the Governor's Commission. They don't return phone calls. That just happens a lot. I think something should be addressed about the discrimination that people with disabilities face in public places.
Lorna: Thank you for bringing that up. I think it still happens a lot. It's just not talked about a lot. So thank you for bringing that issue up. Anyone else? Panelists? Well, I think we are done. I thank you all for attending. I thank you for your testimony. I think the panel has to stay here another 15 minutes if you don't mind just in case we have some latecomers. But we can definitely get a break at Felicia's if you would like and get some coffee. Please, I encourage those of you who have similar concerns talk. This is a nice comfortable cool place. Take a few minutes to get to know each other.

July 27, 2005. Colt State Park, Barn, Bristol

John Desautel: Does anyone want to speak about any of their concerns?
Gwen Reeve: I want to speak about my concerns.
John Desautel: Of course.
Steve Wright: I would like to begin now. My name is Stephen Wright, I'm the superintendent for state parks for DEM and on behalf of Michael Sullivan the director of DEM I would like to welcome you to Colt State Park. It's a little warm out there today. We would like to start by having the panelists introduce themselves.
Dana Wright: I'm from Rhodes to Independence and I'm happy to be here today.
Gwen Reeve: I'm the program director at MS Society.
Gary Weir: I'm the deputy administrator for the Blind and Visually Impaired.
Sharon Binkworth: I'm the executive director of the Brain Injury Association of Rhode Island and I would like to thank the Governor's Commission on Disabilities for their support for the last couple of years and some legislation that we were trying to get passed at the state house and we were pretty much successful with it, too. So, this is a good thing as far as we're concerned to have these forums.
Brian Adae: I'm an attorney with the Disability Law Center.
Steve Wright: Any other panelists. Since we have a small group, is anyone going to be speaking today? Does anyone want to speak besides the panelists?
John Desautel: I want to introduce myself. I'm not one of the panelists but I am on the staff of the Governor's Commission on Disabilities. I do plan review for state facilities and schools. I provide technical assistance for private facilities and I am also a staff person for the Accessibility Committee. The Accessibility Committee allocates state and capital bond funds for our state projects.
Steve Wright: I want to remind everyone that if you're speaking, speak up loud because there are air conditioners on it might be hard for other people to hear. I want to remind everyone to sign in and make sure you're signed in so that we know you're here. The purpose of these public forums is to identify the concerns of people with disabilities and their families in order to assist the state to develop programs to improve the quality of life of people with disabilities. These forums transcripts of the testimony on the Governor's Commission on Disabilities will be on the website, www.gcd.ri.gov and those will be available in about a week. Later this summer the sponsoring agencies you see here will review the testimony and prepare remss that will also be posted on the website by the end of the summer. The transcripts will be prepared and sent to congressional officials and the general assemblies and used to develop policies and legislative initiatives for the next year or until they are accomplished. I want to review the meeting process we're going to give everyone a chance to speak and at this point it will just be the panelist unless later on you feel you want to speak. This is a small group here but we will be here until 6 o'clock. Again, I ask you to make sure when you do speak, each time you speak to identify yourself and where you're from, and at this point, you can have as much time as needed because we have two hours. It's my job to kind of move the meeting along and I also want to point out at this time there is a water cooler here for everyone, we have restrooms and a phone. If anyone needs to use it, please let Walter Rocha who is the park manager, can assist you in those matters. Let's begin with the panelists. If you would like to begin, Gwen.

Housing

Gwen Reeve: Well, my name is Gwen Reeve and I work at the MS Society. Since I don't recognize anybody with MS here, I just wanted to say a few things about some concerns of people with MS. Some of the concerns we have are very general concern that many other people with disabilities have, affordable and accessible housing. It continues to be a problem for many of our consumers.

Health Care

Gwen: Adequate health care affordable health care is also another problem for a lot of our consumers. But one of the things we're very concerned about and we've tried to address the last couple of years is the fact that Rhode Island is the only state in the country who has state pharmaceutical assistance program that does not include coverage of MS drugs and we think that's pretty unacceptable. For the last two years we've been trying to get a bill passed, an amendment to RIPAE bill to include MS drugs into the plan and it has not been passed. We will be going for that again next year to try to get MS drugs included in the state plan. If you're not familiar with MS and the cost of some of the drugs they're incredibly high. The injectable drugs that people take for MS to slow the progression of the disease costs about $1500 a month for one drug. So you can imagine that someone who is disabled or is on a limited income really, really, needs assistance. So we're going to be shooting in again this year. We want to go on record of saying that it's not acceptable for the state to exclude MS drugs in their plan and we hope to get them included this year. Thank you.

Steve Wright: Thank you, Gwen. Next panelist.

Independent

Gary Weir: Again I'm Gary Weir deputy administrator for the Blind and Visually Impaired and representing ORS and the Department of Human Services. This is an important activity. We're here to listen. This information is used in many different ways. I serve as ex-officio of the State Independent Living Council and the council uses this information to develop its plan for the State of Rhode Island with regard to independent living. So the input that we get through these forums is used as a need assessment for Rhode Island to develop services that are needed in the area of independent living. The Office of Rehabilitation Services has a number of sources it uses to develop its state plan each year. We have a five year state plan and it's updated annually. We work closely with the State Rehabilitation Council which is an advisory group to the agency and in conjunction with them do customer satisfaction surveys and work with them to develop needs assessment tools, including the use of this kind of information to develop services for our agency to better meet the needs of people with disabilities. Some of you, are more familiar with ORS than others. One of the major focuses of the agency is the Vocation Rehabilitation Program which provides services to help people with disabilities train for, obtain and maintain employment. The agency, the unit that I work for services for the blind and visually impaired, is interested in the forum because it provides information for the development of services to provide the blind and visually impaired population that we try to serve. That includes things like Newsline where the commission supported that piece of legislation in this past year and in the past, and provided the opportunity for us to develop a program that allows people that are blind to read newspapers by the use of a phone. Simply said. So this is an important activity. We look forward to listening to the testimony today, and we'll use that information to help us develop our program further. Thank you.

Steve Wright: Thank you.

Accessibility

Dana Wright: My name is Dana Wright, I'm from Rhodes to Independence but I’m also representing myself as a consumer and other people that have shared physical disabilities. Since high school, I have noticed the barriers that were up against me. I just graduated from college in may of 2004 and this is actually the first year I've been on the forums because I'm representing Rhodes to Independence. But throughout the years I have taken an active role in trying to find ways to make places more accessible because I started to see all the barriers that were up against me. I was told by many people, my parents, teachers, and mentors if you need something, you need to go out and get it and talk to people. If you want something bad, you need to voice your opinion. And as I have tried to in the past years since high school, starting my own community service project, and trying to figure out how me and my closest friends could go about making places more accessible. I've been in the research part of really trying to further my initiative and one thing that I would like to put on record that I noticed throughout the years growing up in Providence, is the lack of curb cuts in the city especially in downtown areas and in Roger Williams Park, which I live very close to. I am very active, I was very active all throughout my life and me and my friends would go walk and many, many, many times I had to ride in the street. One year in particular, there was the Breast Cancer Walk in Roger Williams Park and I attend that walk every year. My mother is a breast cancer survivor and I go with her and support her. And the year it was held in Roger Williams Park it was very chaotic for me and my mom who was with me because there were no curb cuts in the sidewalks. The bike paths in the park were not accessible. They had to lift up my wheelchair to get it onto the sidewalk and put it down because at the end of the sidewalk there was no curb cut. So that would be one of the main things I would like to see Rhode Island try to implement is more curb cuts. Especially in the parks because the parks are beautiful and everybody should have access for being able to share with their family and recreational activities and going to the park and feeding the ducks. Little kids have wheelchairs too. One thing I was very impressed about in Roger Williams Park is the Hasbro no boundary playground. That was very impressive and that's all I have to say.

Steve Wright: Thank you. I'll take the moment to highlight something that DEM has done with the help of Governor's Commission on Disabilities over the last ten years. We've been fortunate to partner with those folks and they have been a big asset financially and also with the expertise. Roger Williams Park is a municipal park. We have a long way to go and I won't kid you we do have some areas that need some major improvements, but we have taken some steps over the last several years. We offer free of charge, first come, first serve in all of our state parks and beaches is surf chairs. They need assistance but we do have staff that will assist the person to go down right to the water's edge. They were purchased with financing from the Governor's Commission on Disabilities. We've had nothing but positive feedback from that. We've also been able to offer at Colt State Park ,which is adjacent to the 14 mile long East Bay Bike Path, recreational hand cycles which are also is free of charge. They are also on a first come, first serve basis. Again this is a very popular program. I also encourage you to stop on the way out at the new boat ramp that's has been installed since the past three years. The boat ramp was also designed with disabilities in mind. It was a beautiful project and DEM has been doing one project at a time throughout the state. The other thing is our restrooms. Some of our restrooms are historic buildings which are a challenge to try to make accessible. Again, with the Governor's Commission on Disabilities we started a year ago and got some money to widen doors and petitions and make things accessible. So we're very proud to offer these facilities to all people in Rhode Island. I would like to highlight since you brought that up.

Dana Wight: I didn't know any of those things that you just highlighted.

Steve Wight: Are website is www.riparks.com. You can view everything that's offered in the state parks. Having said that, Sharon, would you like to speak.

Health Care

Sharon Brinkworth: Can everyone hear me? When I introduced myself, I spoke briefly about a bill that we had introduced the last two years to create a Brain Injury Fund. This fund would provide services for people with brain injuries because very often the person with the brain injury occurs after their 21st birthday, after the 22nd birthday, and they have no insurance, they often fall through the cracks. There are no programs that they really qualify for because if the injury happens before the age of 22, they qualify under the children programs. Otherwise, there's really nothing for them to qualify for until they turn 65 and the elderly program. So as you can see, there's a big gap. We wanted the state to create a Brain Injury Fund for services and we asked them to add an additional assessment for $10 on speeding violations because most brain injuries are caused by motor vehicle disasters. And there is a commission on brain injuries the Governor's Advisory Committee. We wanted to expand that commission to include more people with brain injuries, family members, and the people who work with them. This was all a part of the same bill. What the legislature did, and we're very happy for that, is that they decided to put a line item in the budget and the Department of Human Services' budget, for traumatic brain injury services. That's the first time ever they did that and they did appropriate $250,000. So that's a start. It is the first time ever, and I know that our times of going up and speaking before the house finance committee and the senate finance committee, and especially having the Governor's Commission on Disabilities supporting this issue, it was a great help for us. So now, we'll start to see some services being provided. You might say our association is working very closely with DHS making sure they spend the money wisely on the right services.

Brian Adae: Just by way of introduction for those of you who are not familiar with or never heard of the Disability Law Center. The genesis of it is back in the 70s the United States Congress established funding for certain protective advocacies, actually created a protection and advocacy system across the country initially for developmentally disabled individuals and then for mentally ill individuals. Over the years it's expanded into 8 different federally funded programs which here in Rhode Island we are the designated administrator and provider of those. It's based on legal base advocacy either direct representation or doing policy or systemic issues for persons with disabilities on disability related issues. All of those 8 programs cover brain injury, developmentally disabled individuals, the ADA, and across a whole host of issues, whether it's vocational, housing access, or compromising their basic rights. If it's of any assistance and actually I would request anybody here if you're curious, we have a new annual report that's out and we're right now in the process of reviewing our annual priorities for the next fiscal year. Our fiscal year ends in September and we have a survey here that we would love to have anybody who is interested complete. This would be part of our establishing our priorities next year and on what we're going to address. Thank you.

Steve Wright: Are there other panelists that would like to speak at this time? Visitors, do you have any questions. You have a wealth of information here. It's a good time to ask any questions that may come to mind.

Janice Balasco: My name is Janice Balasco and I'm on the State Rehab Council along with Gary from ORS and this is my second three year term for the council and this is the second public forum that I've attended. I've previously been a consumer of ORS and they helped me through a very difficult time of having a disability myself. That's why I'm on the council now. I've seen a lot of improvements in my second term on the council. ORS has done a superb job. Attending some of these public forums, I only wish we had greater interest because I know there's a lot of interest in these issues. Making things handicap accessible. I know the publications are out there. I know there are a lot of concerns out there.

Transportation

Janice: Some people brought to my attention especially in this area, the RIPTA bus service. The bus service only has like maybe two routes a day, perhaps one in the morning and one in the late afternoon, I believe. So I wish the state would look into that a little bit into the RIPTA program. For other individuals to get out and to see friends or whatever reason they have I think it's very limited in this area, I would like to see that improved. I want to say thank you for any consumers who may be here and certainly if they have any issues at all to please bring it up. I can leave the minutes posted on the web and they can review them after each public forum. I believe there are several established in the next month I believe, Gary?

Gary Weir: This week.

Janice: I certainly hope you will focus on that and bringing certain issues to everyone's attention. Thank you. I wanted to make known that I am from the council and have a lot of personal interest.

Steve Wright: Thank you for sharing that with us. Anyone else?

Daniel Drake: My name is Daniel Drake. I live where there's no bus route and there is a bus that comes early in the morning and there's a lot of us who can't get anywhere because we have no cars and we're not in access to the bus route. We have to go to the doctors and we need to ask for rides. It would be very helpful if there was a bus in the afternoon going to Providence and coming back on Metacom Avenue. There are a some of us can't drive and rely on others and can't go anywhere. I think that would be helpful to us.

Sue Drake: There's two buses early in the morning, I think the last one is at quarter of 7, so if they need a bus downtown to go to the doctors or shopping there's no way for them to get back until 3:30 or 4 in the afternoon. That's a big gap in the afternoon. They need something in between. I'm not saying buses all day long but every couple of hours.

Daniel: Even at 11 a.m. or 2 p.m..

Sue: So that if they go to the doctor they can come back within a couple of hours.

Steve Wright: There's no one from RIPTA here today.

Dana Wright: At Rhodes to Independence we have a transportation subcommittee and there's always a representative from RIPTA there and I can get you contact information or bring it up at the next meeting for you. In this area?

Daniel: Yeah.

Gwen Reeve: Do you qualify for the RIDE program or the paratransit program.

Daniel: I believe I do.

Gwen Reeve: Because they would come directly to your home.

Steve Wright: Did you want to say something.

Housing

Sandra Braman: I'm Sandra Braman and my son has a number of disabilities and he's 30, and I'm been aware of what's been happening in the state for quite a while because I've also been trying to do some senior work because my mother has become very disabled. I actually came here to find out information about what kind of housing has been explored in this area in terms of availability, whether that's something that is going to be some of the forum work that you're doing and some of the outcome at the end of the forum whether you're going to be talking specifically about housing at all, anyone. I'm usually so involved with the state but I've been out of it for about five years now. So I don't know whether anything is happening at this point and this is all of great importance.

Steve Wright: Anyone from the panel that can address those concerns?

Sharon Brinkworth: Just the housing continues, continues to be a really big, big problem. Just across all disabilities.

Sandra: The other question is, is it a financial issue, or is it the lack of housing, or both?

Sharon: I think it's both. I think there's a little bit of both. There is a definite lack of housing.

Sandra: This I have seen in the senior area, but in the financial area. Have there been any goals set this year or next year for financially aiding people who have major disabilities to get housing?

John Desautel: That's my question.

Steve Wright: When you're talking, you need to give us your name and who you're representing because it's very difficult for the transcripts, when they're posted later on, it gets very confusing.

John: My name is John Desautel with the Governor's Commission on Disabilities and I've been in state service for almost 33 years now, but a good part of my governor's service was with housing. Specifically community developing block grants and so forth and I think there is some financial assistance through the many section 8 programs that are throughout our state. Usually they're affiliated with a local housing authority and there's also RIMFAC. I know that the state program was taken over by Rhode Island Housing Authority and I do know that they also provide an incentive to landlords of those units that are accessible. There is an increase in rent, it's Something like 20% more in their rent, based on the market area. So there are funds out there. I know there are waiting lists, some of them are quite lengthy. But, there is some recourse there.

Ben Quirk: I'm Ben Quirk with the Statewide Action, and I don't work specifically on disability issues, but I've been sitting in on the Housing Resource Commission meetings. They're in the process of developing a five year housing plan. They are taking into careful consideration ways to produce and develop housing that's appropriate for several different portions of the population including disabled persons. But I would strongly recommend if you have a personal stake and interest in this is getting in touch with someone at the Housing Resource Commission. As far as I know it is open to the public. It represents people from several areas but I haven't seen anyone there at this point with a disability. I think an advocate on those issues would be an asset.

Steve Wright: Thank You. Anyone else? For those who came in late, again my name is Steve Wright the Superintendent of State Parks and I want to read the purpose of this public forums are to identify the concerns of people with disabilities and their family in order to assist the state to develop programs to improve the life of people in the state with disabilities. We have a wealth of information to provide to you. These transcripts will be available on the Governor’s Commission on Disabilities website which is www.gcd.ri.gov and that will be available in about a week. Would anyone at this time like to ask a question of the panelists or? No one else?

Brian Adae: I know that it's been said but I wanted to make clear to everybody here my role here on behalf of the Disability Law Center is explicitly to hear the concerns, much the same as you were addressing about housing what the issues are out there, and as were discussed about the bus and the accessibility issues. We want to hear this. That's why I'm here. We're here to see what we can do about it. That's essentially why the Disability Law Center is here. To hear exactly what's happening with you, what the concerns are so that hopefully we can address them.

Steve Wright: Thank you. Any other questions or comments?

Transportation

Coffee Bell: I'm Coffee Bell, Chair of the Legislative Advocacy Committee of the Rhode Island SILC. As far as buses are concerned, I come from Jamestown and they're talking about cutting routes and that's one of the routes they're cutting. My concern is we have a lot of disabled and elderly that will have no transportation and will be out of the ride program. That's a big issue and

I'm really concerned about that.
Steve Wright: How is everyone doing? Cool enough in here? We're here until 6 o'clock. If there are no further comments, we're going to take a break and you can speak personally with anyone here in the room. Again I'm with DEM and if you have any questions on state parks or beaches, I can give you all of the information you need. So we're going to take a break unless you have other questions or comments. Thank you.
Steve Wright: If I could have everyone's attention please. It's 6 o'clock and unless anyone else has any comments or suggestions or anything else, I think we're going to end this meeting. It's officially ending at 6 o'clock. Please have a good night. If anyone needs directions out of the park please don't hesitate to ask. Thank you all.

July 28, 2005. Westerly Senior Center

Joan: If you want to move up closer, we can have a more intimate discussion.
Joan: We are going to wait a little bit longer because we have three more panelists that are to appear. I'm sure they are stuck in the traffic that I was stuck in.
Joan: I noticed from the sign-in sheet that no one has checked off that they want to speak. I know one person has already sent in her comments.
Joan: I am going to begin because I know some people may be held up in traffic but at least we can begin so those of you who are here and have to leave early. I would like you to have the opportunity to address the panel, if you so choose to. I think we all know why we are here today. And just as a reminder, the purpose of these public forums is to identify the concerns of people with disabilities and their families in order to assist the state in developing programs to improve the quality of life of people with disabilities. And we have a panel today that represents a number of different options and programs for you. I would like them to introduce themselves because I don't want to get anyone's name incorrect.
Joan D'Agostino: I'm from the department of elderly Affairs.
Michael Spoerri: Hello. I’m from the Department of Health.
Betsy Dalton: Hi. I am here representing the Sherlock Center at Rhode Island College and also the assistive technology access partnership, which is the State Tech Act Project. I'm interested in hearing people's concerns particularly with regard to assistive technology and equipment that's needed to support individuals with disabilities.
Valerie Shore: Hi. I am with Rhodes to Independence. We are an organization that helps break down barriers for people with disabilities, through housing, through different work groups, but mainly help to promote employment.
Ray Carroll: I'm representing the Department of Human Services, the Office of Rehabilitation Services. I've had the good fortune to attend many of these meetings over the years. It gives the public an opportunity to reflect needs and barriers. Our basic mission is to assist people with disabilities to reach high quality employment outcomes and to live independently in the community. We have a variety of programs available to the public to assist. We run the disability determination services. That means when people apply for Social Security Disability (SSDI) or Social Security (SSI), that the medical adjudication is done in our office. We get about 15,000 applications a year. We also have a vocational rehabilitation program whose goal again is to assist people to get a
good job. We run independent living programs. We also administer services for the blind. Betsy already talked about assistive technology, which is so helpful and useful for people with disabilities. Betsy knows that we are in the process of developing a new state plan for assistive technology for Rhode Island, which is due in about a month, August 26. So, those that use assistive technology, we would like to hear specifically from you.
Christine Derosa: I'm a staff attorney at the Rhode Island Disability Law Center. We are the designated protection advocacy agency for the state of Rhode Island and we like to come to these forums because we are federally mandated from our funding sources to get input from the disability community in order to set our priorities of the types of cases we can take. We offer representation, free legal representation to people with disabilities on various issues and those issues differ from year to year. We use these forums in order to hear from the community about the kinds of issues that people would like us to look into. I have with me today, if anyone has an opportunity, we these surveys. We would ask that if you could take a few moments to take one

with you, fill it out, and return it to us. Mark off those areas that you have concerns about and that will help us to set our priorities for fiscal year 2006.

Casey Crothers: I work for the Brain Injury Association of Rhode Island, primarily in the Brain Injury Resource Center. It's been operational for about two years. The goal of the center was to provide people throughout Rhode Island with brain injuries, but we also provide information to people with other disabilities. But to provide them with information and to help them locate resources and sometimes facilitate them to become linked with those resources. We also have educational materials and we provide educational training for professional groups that are interested in learning more about brain injury and starting to develop their expertise in working with people with brain injuries.

Bill Neirenowski: I am on the Governor's Commission on Disabilities. The commission will use the information you provide today to help formulate its future legislation package, in advocating for your needs on behalf of the state level.

Dianne Kayala: I apologize for being late. I'm Dianne Kayala. I'm with the Department of Human Services. I work in the Medical Assistance Office.

Joan: Okay. Would anyone…I know several people did say that they would like to address the panel. Would you like to address the panel?

Accessibility

Jeanine Wilk: Well, I basically have just one problem here in Westerly. The side streets have sidewalks that are broken or have no sidewalk. And that kind of limits me to take a walk, even with the walker. My granddaughter had to help me over the humps, the bumps. It's things that weren't there. Some way to get somebody to do the side streets. I mean they are doing route one, Fine, I don't go up to route one. The side streets are in deplorable condition. Some of them have no sidewalks. There's no curb cuts. If I want to cross a street, I have to use somebody's driveway and go way out in the road and then get up to the other side that way if somebody's got a driveway on that side or pick up my walker and that really is very inconvenient. It limits me to where I can go for a walk.

Joan: Well, I think that's a very valid comment. I think it's something that people from other towns and cities share. Hopefully…

Jeanine: But I don't know how to get somebody in town to do it. You know.

Betsy Dalton: Can I ask a question?

Jeanine: There's always some excuse it can't be done

Betsy: You are talking about the sidewalks themselves?

Jeanine: The sidewalks themselves are broken or you get to a certain point where there is no sidewalk so you are out in the road. And then maybe you can get another stretch of sidewalk so you are weaving in and out.

Betsy: There's no consistency to allow your walker to be able to be used

Jeanine: Yeah, but even somebody like my husband who walks with a cane. And he has to be extremely careful because of the way the sidewalks are. And they just seem to be doing route one, all the state highways, and forget about the side streets.

Betsy: Where people actually live.

Jeanine: Yeah. Where people actually live, exactly. Like I said, we have been unable to get anybody. We just say okay, we will do this street this month and that street next month or whatever. We are just not being done.

Ray Carroll: Our assumption is you have brought this to the attention of the local representatives and town council.

Jeanine: And…

Ray: Frustrated.

Jeanine: There's one excuse this week. There's another excuse next week. There's always some excuse why it can't be done. An empty promise of yeah, we are going to do it. Once you say you are going to do it, I have to stop asking. But it never gets done.

Christine Derosa: We at the Disabilities Law Center don't right that as an issue. This would be a great opportunity to fill out that survey. We don't even have a section for that but to write it in because it alerts us to a new issue. If we find there are several people sharing your concern, we can advocate to receive funding in order to address those issues.

Jeanine: Okay. Fine. That's good.

Casey Crothers: Would you like to give your name for the record?
Jeanine: Oh.
Casey: Keep a full record of this.
Jeanine: Jeanine Wilk.
Joan: Thank you. You had a question? Comment?

Accessibility

Barbara France: I'm Barbara France from Westerly, Rhode Island. And I e-mailed in my comments to the commission on disabilities so they already have that. What this lady was talking about. I took a walk around the block early in the morning back last week. And I said to my husband, I said, well, the sidewalks on the street up from us really are in a deplorable condition. They really need to be fixed. Well, we are on a street where I have lived since I was born in Westerly Hospital, brought home to the property we are living at. So I'm very familiar with the area. On our street there was only one sidewalk on one side of the street. I remember when that sidewalk was put in. The property owners had to pay one-half the cost of having the sidewalk put in the town covered the other half of the cost. Some property owners don't have the financial ability to upgrade the sidewalks anyway. Across the street from us, there is no sidewalks, never have been. Now my husband tells me that that doesn't have to be, that property belongs to whoever owns the house. And some of the people on the street have been planting flowers or shrubs or something, there's actually no sidewalk on the other side of the street. So here's the situation. Who do you go to for a situation like that? There are sidewalks in the town of Westerly that are in deplorable condition. And it would be very difficult for anyone in a wheelchair or with a walker to go through on the sidewalk comfortably. Now who do you contact? Can't you people give her that information as to who in the town of Westerly. I'm pretty sure there's someone in the town of Westerly who would listen to what she had to say and would make sure that everything would be done as could be done. Westerly can handle their own situations, many many times without having to go upstate for answers. If we know who to contact in the town, the Department of Public Works?
Dianne Kayala: It should be public works.
Betsy Dalton: It does sound, if the information you've given is correct, like what needs to be determined is who owns those sidewalks at first, you know. Is it the property owners? Or is it public works? So that would have to be determined first in terms of who's responsible for that area. And then if there's a problem with the way that it is, then that would have to be brought forth to the town in terms of providing some consistency about sidewalks. So, I'm not a resident of Westerly so I wouldn't know that information right off. But it sounds like that would be the question first because if the sidewalks are privately owned.
Female speaker: Why would the sidewalks be privately owned?
Betsy: I don't know.
Female speaker: When you buy property, you don't buy the sidewalk. You buy the house and the property on it.
Betsy: I don't know. I'm just listening to the testimony that was given.
Female speaker: That doesn't sound logical to say the sidewalk belongs to me.
Betsy: I don't know. But that would have to be, you know, the first thing to be determined. Does the town actually own all of the sidewalks or the areas where sidewalks should be? And then if it does, then the town bears responsibility for the condition of the sidewalks.
Female speaker: So then we are back to her question, who you go to and who does all of this.
Betsy: Right.
Bill Neirenowski: Did you try the public works department?
Female speaker: I…
Bill: You might try calling the public works department because they are the people that would oversee the sidewalks I'm sure. And I think Peter Carodeo is the superintendent of public works now.
Female speaker: I don't know.
Bill: I would try them at least to start.
Christine Derosa: You can always call the town council. That's usually a good place. They will have open meetings and you are welcome to submit your comments there. Often times, I'm not a resident of Westerly either. You can call up and express your concerns.
Female speaker: It seems every time I get a passive okay, we are going to do it or we will discuss it at the next

meeting. There's always some reason it doesn't get done. And I just sit here and I say, well, okay. I came here to you and maybe you can push it. I don't know. I can't push anymore. I've pushed long enough and I'm still hitting the brick wall.

Betsy: Even the responsibility of the town planner, you know. It seems like that's part of the town plan.

Female speaker: I just felt that perhaps somebody from upstate had more power and could say, okay. Look, this is the way it is and it's not done because they are ignoring all of us.

Accessibility

Joan D'Agostino: I'm not a member of the council here but I do live in downtown Providence and we are having the same problem. We are trying to have both sidewalks repaired because many of them are in disarray. Not the ones around water place park but other areas of the city. And we are attending city council meetings to express our opinion. So if you could get some people to contact your council person and let them know of your concern. And when they come around looking for voters, that's your time to really get them to commit.

Bill: It would also help if some of your neighbors would complain with you or people in the neighborhood affected by that sidewalk. Because it really is a lot of voices, the more numbers you have behind it. Going before the council if you take a couple neighbors with you, it tends to be noticed as just a single person speaking up because it tends to get lost in the shuffle sometimes, I suppose.

Joan: I know that this gentleman in the front. You had a comment. You wanted to ask, a question?

Health Care

Vincent Dejesus: This is, I am basically, I'm pretty familiar with all your organizations. First of all, I just wanted to thank the Governor's Commission on Disability for giving people like me, the disabled people, a chance to get their foot in the door, even get an internship to get their foot in the door. You know what I mean? I went to them twice last year and this year. And both years I got pretty good. I got a pretty good job working with people well, working through that, going through that organization. And I also would just wanted to say that I'm thankful for the Rhode Island legislators. I mean, it provides us the funds that have systems that help brain injury people, brain injured clients and people with disabilities. But I also think that we need like, there should be more things like, the Traumatic Brain Injury Association, even though there's like one of them. I think it's set up in a way that it's there's few of those like certain areas where people can go to find out more information about certain kinds of disability problems or even where they can get help, according to their disability needs. I know I used it, like I used it myself to find out more information about even my disability. But just other disabilities in general. I would use the resources there. And there's basically all I know of is there's probably one in the state. There could be two or three. But I don't think so. And just makes it harder for people to find information about certain disabilities or get their voices heard. And it's easier for certain people to fall through the cracks and not get the kind of assistance they require to become an upstanding citizen of the state of Rhode Island, even become a person with that can help the state of Rhode Island. I know I can say it's better in our state because I just like the other day came back from New Hampshire. That was, I mean, there was, it's a different state. You can be grateful for, I mean, even though we have like stuff like grandfather clauses and stuff, a lot in Rhode Island. I mean, you can really be grateful for other things because even the landscape itself makes it harder for people in other states to get around. It's also, other things like the buildings are older and stuff like that. Basically that's all I really have to say, I guess. I'm sure I left out like a million and one things. I will come up with those things.

Joan: If you think of anything as we continue, you are welcome to speak again.

Betsy Dalton: Can I ask this fellow two questions? First can we have your name for the record?

Vincent: My name is Vincent Dejesus.

Accessibility

Betsy: Secondly, Vincent, I was wondering if you or anyone you know ever used on-line resources, information resources about disability issues?

Vincent: Yes, I have.

Betsy: You do. Okay. Would development in that area be helpful?

Vincent: I guess. I used them like, I haven't checked them out thoroughly. I'm kind of like, even though on-line is, it's a good tool to get information across. It's just, it's hard to find out if you are going in the right place or whatever. It's like kind of frustrates me.

Betsy: It has some limitations.

Vincent: I would rather do it in person.

Betsy: Thank you for your comments.

Accessibility

Vincent: Thank you. There was actually one other thing I wanted to like mention. I don't know if this has any justification here. I mean, it's a proven fact that people with disabilities are like, do provide the community influentially a great deal. Well, one thing I took it from the Disability Law Center. In the front they have just pictures of people with disabilities and what they did to help the community or help their influence. It says stuff like, it has Theodore Roosevelt who had polio. But it also has stuff like Albert Einstein. He made a lot of the great theories, like influence American thought today, every country's thought. And he had a learning disability. And then Beethoven. He was a great pianist and he was deaf. Then it has stuff like Woodrow Wilson who also had a learning disability. And Harriet Tub man who had narcolepsy and Thomas Edison who also had a learning disability. And others. I didn't I just took out a few, you know, just as comment or whatever, just as a sample. That's it.

Joan: Thank you for your comments.

Vincent: You are welcome.

Joan: Yes, could you state your name, please.

Health Care

Jeanne Behie: Sure my name is Jeanne Behie. And I wanted to thank that young man for what he just shared about the need for access to information for people with disabilities. I see this as a very big need with people that I work with. I work for Washington County CASP providing services for families of children with behavioral and emotional disabilities. That I hear this time and time again too that families are overwhelmed. People are overwhelmed with just finding out what's out there. If there was a hot line, like one number that could be called in the state so that people could get other phone numbers and other information about the services that they need, it would be very helpful. This actually was a recommendation by the United Way Summit a few years ago. I don't know what's happening with that. But I would ask that you all take note of the great need for one place for people to call to get information about services that they need.

Family & Community Supports

Jeanne: And I also wanted to say too about the legislation that was passed for the Brain Injury Association. I'm very happy to see that there was additional funding allocated for that. And as a daughter of two parents who developed brain injuries as they aged, one from a stroke and that left my father paralyzed. And then my mother experienced a traumatic brain injury three years ago, which left her disabled. I do see the need for services for people with brain injuries because there's nothing like a brain injury to suck the finances from a family. The cost is so great and there really needs to be more emphasis on funding services for people with brain injuries. I do have a few other things I would like to bring up. I don't know if this is the right time now because I did…okay.

Health Care

Jeanne: I wanted to bring up some mental health issues that I see working in the field. Families that have dual insurance are penalized for services. They do not have the same amount of services as families that have Rite care through Katie Becket and this isn't right. For instance, services, comprehensive intense services are available for people, as I said rite care, Katie Becket. But people with dual insurance aren't able to access CIS. They are told that first they have to exhaust the funding through their private insurance. and the private insurance such as Blue Cross Blue Shield. They put up so many obstacles that many families just can't access this service. This isn't right. There really needs to be some attention on that. Why should families, middle class families that have private insurance not have the same access to service. Another thing is that there's a gap and I'm sure you are all aware, for kids 18 to 21, between childhood and adulthood, for instance kids in DCYF. We are finding that kids are aging out of services. They are not quite eligible for maybe adult services yet. So there's a few years where they are not really getting what they need. We are finding with DCYF that some kids are actually, at age 17, are losing services. So there's a need to address that gap. And I know that there is some attention to it now and some focus on it. But there needs to be more focus on it. One of the suggestions that has come up is maybe developing foster families for kids while they are working and enter either the work force or going to school. There are very few 18 year olds that are really ready to be totally on their own. So I do hope that be an area that we take a look at in the future. Some other mental health issues.

Health Care

Jeanne: There was a bill for the provider health index to have adjustments for salaries for people that are in that provider health index. This is in mental health field that has not passed the legislature this year. But there is a need for that because people that work in the field, it's not just mental health agencies like Perspective. It's things that provide adult services are not getting cost of living raises that other provide. Indexes provide such as the nursing home provide indexes.

Jeanne: There's also a need for respite. And it's very difficult to find, to find funding for respite for families. But I will tell you families are tired, and especially families of kids with behavioral problems. They need a break. Yet who is going to pay for respite? So, I hear this time and time again. I have one family it's a single mother. She has two young men who are 15 and 16 years old, both falling in the autism spectrum disorder. And she is with those kids when they are not at school 24/7. And she needs a break. We did find some funding for her for short-term for three months. But this woman needs it year-round, every day or every week not every day, but every week year-round she needs something like that.

Betsy Dalton: Can I ask a question, Jeanne, regarding respite. Is it just funding that's the issue or is it finding respite services?

Jeanne: It probably can be both because as you are probably aware, there is a shortage of workers for HBTS services, there's a new program pass. I've heard there's a real backlog of people and families are getting approved for that, but there's a lack of workers and things. So it's probably both. But the first thing is to find some funding because we do have some people we used community resources, which has provided some respite providers for short-term respite. But we are really talking about long-term respite for these families. Their situation isn't going to change. They have the same needs day after day, year after year. So something for three months isn't addressing the problem. It's putting a little Band-Aid on a really big wound. So funding I think is the first step. And then of course there are always the same issues, lack of affordable housing, especially in this area.

Housing

Jeanne: Many families are finding that they're just being edged out of their house and market. Families with limited resources when someone's losing a job or whatever the situation is. There needs to be more affordable housing and some of the town plans that have been formulated really aren't addressing the need. They are talking about five years from now on what we are going to do. That's really too far off. There a need to be more short-term solutions. I was at a meeting where it was suggested to a family that until they could find an apartment they should go camp at Burlingame. That's what people do. But it's not a solution. So housing really… and another thing is job opportunities.

Education & Employment

Jeanne: My son here just lost his job at Kingstown camera. He worked there for a year and was very happy there, right?

Male speaker: Yeah.

Jeanne: Yeah. But unfortunately they went out of business and everyone that worked there is laid off. He has been looking for a job. Right now he just started at habitat for humanities but as a volunteer doing computer work for them. There really needs to be some sort of tax incentives for businesses to hire people with disabilities. There are so many people looking for jobs. Why would they choose somebody who's visually impaired or has a disability when they can hire somebody able bodied. So, I think there needs to be more in that area too. Thank you very much for listening.

Joan: Well, thank you, Jeanne. Anyone on the panel like to address any of the points that Jeanne raised?

Health Care

Ray Carroll: Just a comment basically. Jeanne has provided an encyclopedia of issues and needs that so many of us have heard over such a long period of time. And it all boils down to a resource question and public policy and public priorities. And it's been so very frustrating to us who manage these programs who are well aware of the vast array of needs that are out there, have not been able to put together a compelling, I guess, influential case to assure that we get additional resources. I've just returned from a national meeting where we were talking about these issues. And we now, for example, we are in a war of time economy. We have a huge federal deficit. We have a huge trade deficit. And the governmental philosophy now is to cut back and cut out domestic programming. And the reality is the needs are great and the resources constrained. So we come to meetings like this and we are well aware of all of the documented needs that exist.

Education & Employment

Ray: And we also have presented over the years incredible cost benefit analyses that in a rather dramatic way, your son, for example, who becomes well employed and how he becomes a tax payer and doesn't need to rely on income maintenance programs and so on. And there is evidence based information out there. So the frustration from our point of view is, you know, how can we really impact the system to get additional resources.

Health Care

Ray: And you started off, Jeanne, with the information center, the information and referral center as it were. I go back so far that at one time in the 70s the governor had a, for lack of a better word, a hot line and that was incredibly well utilized by the public. And even in our office, we set up an information referral office that had dedicated employees that worked exclusively on that. And information referral is a rather complex thing. It's not just giving out a telephone number and so forth. Because the issues we hear are so complicated, they need to be researched and responded to. And we got at least a thousand inquiries a month. So you figure this times 12, that's 12,000. But the reality is that these programs when cost cutting comes around, these programs are one of the first to go. I guess using an analogy. It's like what cities and towns are coping with the school budgets and the like. And the first thing to go, a lot of enrichment programs and so on. We have tried to, with the assistive technology initiative, we have a one stop number to call for people that have issues around assistive technology. And even though that number, Betsy's been there for ten or 12 years now probably. Probably John Cupulic is unaware of it. Even though we try to do our best public education and so forth, my own department has a variety of hot lines and website information also available. But it is complicated for people. Even for us in the field, there are so many different programs and so many different eligibility requirements and definitions of disability that even with us in our job, it's kind of hard to fathom through a lot of these programs. So I'm impressed that you came back once again as the proverbial net to make us continuously aware of these particular needs. And one person has provided us with an incredible laundry list of things that will be part of the official record for, you know, these public meetings. That's just a commentary. I'm as frustrated as many of the customers and consumers are in terms of programming, our inability to acquire additional resources. We have wait lists in our own office for many of the programs we have as well.

Diana: If I could comment, unless somebody's waiting to testify. I wanted to just add to that a little bit in that to maybe have a more upbeat note, I guess it's true there's so much needs to be done however, maybe we ought to also think about all that has been done, you know, for example the brain injury fund, the resource center there, funding to be able to maintain that. It's been a huge asset to a lot of people. I mean, it's been well over 100 percent growth in being able to provide information referral to different people. There's the a-point it's called. The collaboration between the department of elderly affairs and they've invited in people from medical assistance and so on to try to develop better resources. We also have a grant through the department of human services in the Medicaid Office that we just actually finished with an RFP to develop a web base resource directory, which will be brought based in working in collaboration with traveler's aid or crossroads, excuse me, and others who are real experts on information. So, although there's way more to be done and everything else, I think there's a little bit incrementally being done and that by people showing up at hearings like this and at the legislature, when people are actually debating bills, that's the only way to keep things moving forward.

Joan: Thank you for that comment, Dianne.

Betsy: What agency are you with?

Diana: Department of Human Services and Medicaid.

Joan: Is there anything else anyone in the audience would like to talk about or ask a question or make a comment? Well, I really would like to thank all of you for coming today and taking time out of your lives to be here. And I also would like to thank our panelists for their input. And be sure to, if you didn't get any of the brochures on your way in, be sure to take them on the way out, especially that survey from the Disability Law Center.

Christine: Yes, please. Take extras if you know of other people.

Betsy: Can I just ask a question of the governor's commissioner? Will the governor's commission continue to take written testimony?

Bill: Oh, sure.

Betsy: And through what time?

Bill: That I'm not sure.

Diana: I think it was July 30 in the brochure.

Betsy: Through July 30, which is coming up next week.

Bill: Saturday.
Diana: Let me check.
Betsy: If someone wasn't able to make it here, they could still submit a written testimony.
Casey: Or if someone thought of additional points they forgot to bring up today, you can also submit additional testimony; or you've got inspired when you got home and suddenly decided you want to testify. You can also do that.
Diana: It is July 30.
Joan: Even your handout about the public forums. The e-mail address for the commission is there and the phone number. So I'm sure if you think of something that you wanted to say, you could either e-mail the commission or call them.
Betsy: It can be submitted electronically.
Bill: One person already has.
Betsy: Okay.
Diana: I would presume too maybe the governor's commission if somebody couldn't really write it down themselves, they could call and give it verbally.
Bill: Yeah.
Betsy: Information access.
Valerie: I would just like to add as a resource, I am with Rhodes To Independence. We have a website that has a benefits checker. It has a lot of links that might help you, which you should go to. it's constantly being updated. If you have ever been there, it's a good place to visit. Hopefully you find some good information.
Joan: Valerie, is that in your brochure?
Valerie: Yes. The website is on the brochure as well.
Joan: Well, folks, thank you very much for coming. Hopefully you can change policy and affect, make things happen for many deserving people.
Casey: We can't leave
Joan: The panel can't leave.
Casey: I'm blocking you. It was advertised until 5. Some people may be leaving work and planning to come here. You guys may leave. I am blocking us in.
Betsy: We are here.
Joan: Glad you mentioned that. I didn't know that.
Casey: We can have a break but we can't leave. In case somebody does show up at 4, 4:30 after work.
Joan: I'm glad you told me.

July 28, 2005 The Arc of Northern Rhode Island

Bob Carl: Good afternoon everyone. I think we'll go ahead and start this, there are a couple of people that still may join us, but I wanted to go ahead and get started today. My name is Bob Carl, I work at the Arc of Northern Rhode Island and we're honored to host this gathering. which provides an opportunity for people to give some advice from the Governor's Commission on Disabilities, which this is one of several Public Forums that are offered around the state, and there Are people that obviously the commission is looking For guidance, looking for suggestions, remiss and Commentary. We're planning ongoing today as late As 6 o'clock, I suppose if we go a few minutes Later, it won't break anyone's heart. So that Gives an hour and-a-half. We want to, I want to Make sure I do all of my house keeping duties. There are assisted listening devices available. Are we set with that?
John Desautel: I have one here, if anyone needs is.
Bob Carl: We have a device if anyone needs that assistance and interpreters for the deaf.
John Desautel: Should be here, they're not here yet.
Bob Carl: We expect an interpreter. It's a long ways up to Woonsocket for those of us who don't hang here all the time. I am going to read the purpose of these forums. The purpose of these Public Forums is to identify the concerns of people with disabilities and their families in order to assist the state to develop programs to improve the quality of lives of people with disabilities. So that's really what it's all about. We're looking for guidance. This material will be, as you can see, it's being transcribed as we sit here. The material will be made available

both the Recommendations and the transcripts from the Commission and from all the hearings, will be made available to the state officials and to the Congressional officials and members of the General Assembly and the recommendations will be used to establish new policy and new legislative initiatives. So if someone thinks we should spend money on something next year or in the years in the future, let us know. Everybody will have a chance to speak. But we're not interested in filibusters. We're interested in people giving concise, straight forward recommendations. Right

Now, I don't know how many people are planning on speaking. How many people plan on speaking? 1, 2, 3, 4, Okay so we don't have a lot of people who are going to speak anyway so we won't put any time limits out. I'll put the hook out if someone

Takes too long. (laughing) the only thing I'm concerned about is I want to make sure everyone who wants to speak has an opportunity to speak. So we just need to be aware of that. And it's my job to try to move the meeting along. We're privileged

to have some members of a panel up here, who are individuals who will help us, help pull out the testimony, but will also be able to provide input to the Commission itself. They represent a variety of agencies. I think what I'm going to do is have them in a loud, clear voice, I was going to introduce each of them, but I'll let them do that,

Give us their name and their affiliation, I think that's the best way for us to make sure you know who they are so you can keep an eye on them.

(laughing) Kevin, I'll start with you.

Kevin mcHale: Kevin McHale, Vice President of the Arc of Northern Rhode Island.

Jeanne Fay: Jeanne Fay, benefits specialist Ocean State Center for Independent Living.

Kate Bowden: I'm Kate Bowden a staff attorney with the Rhode Island Disability Law Center we provide free legal services to individuals with disabilities on disability related matters and we also use the information that we learn in these

Public Forums to set our priorities and projects within our agency.

Sharon Brinkworth: I'm Sharon Brinkworth, Executive Director of the Brain Injury Association of Rhode Island and we have a fairly new brain injury resource center located in Cranston and I just wanted to quickly say thanks to the Governor's

Commission on Disabilities for supporting in the last couple of years some legislative initiatives that will benefit people with brain injuries. So it's good to bring out what your issues are, because they really do end up getting somewhere.

Ken Pariseau: I'm Ken Pariseau from Neighborhood Health Plan. And in the last legislative session there was a bill passed by the Assembly and enacted by the governor that was a direct result of these Public Forums last year and that bill is that the State of Rhode Island is going to be offering a managed care health care option for adults with disabilities on Medicaid. So Neighborhood will be involved and working with the state to offer a health plan option for adults with disabilities.

Judy Drew: I'm Judy Drew representing the State Rehabilitation Advisory Council that's the group of people that provide input and advice to the Office of Rehab Services regarding the services they provide to people with disabilities related to

Work. I'm also the Vice Chairman for the Governor's Commission on Disabilities

Employment Committee. My passion is employment of people with disabilities and how to redue barriers. So I would really love to hear from you folks about some of those issues. And everyone who said this results in legislation is right. I've been doing this for many years and i'm seeing legislative changes coming about. Thank you for being here.

Doreen McConaghy: I'm Doreen Mcconaghy the director of PAL an advocacy organization for individuals with disabilities and we're a partner of Advocates

In Action of which Kevin McHale is one of the coordinators.

Elaina Goldstein: I'm Elaina Goldstein, Director of Public Policy and we're running an initiative called the Rhodes to Independence and I have some brochures back there. The initiative is in its fifth year and we're happy to say that through these forums and dominantly through these forums people were talking about having a Medicaid Buy-In pass. I'm happy to say with our grant and the people we were working with we got that passed

last year it's going to start january 1, 2006. It allows people with disabilities who are working to earn up to about $60,000 and still buy into the Medicaid program. We're working on issues to remove the barriers for people to get employment and to get transportation, housing health care,
Information about youth going to work, onset disability as an adult. So there are a lot of similarities about what we do here and in order to get the grant we use the testimony of you guys here, and we have continued every time we go for a continuation to say this is what the people in Rhode Islandneed and want and it's brought a lot of money and initiative money to help us get the things that we need to get done, done.

Bob Carl: Thank you very much. Each of these panelists may ask for clarification or may ask for other or try to pull more information from the speakers when they provide input to the panel. I would like to ask Ann the President of Arc of Northern Rhode Island, I know she's been pushing very hard op some of these initiatives, I would like to ask her to make just a brief comment.

Ann: I'm Ann, we're settling our folks, several of our board members were here today and several people we serve from the arc are here. Our board is focusing this year on two areas, of course it's development but secondly, it's advocacy. We really need to have strong vases. And this is wonderful because it allows us to begin the development of a statewide very strong voice. I've worked for the last ten years on the ricare program and seen how successful that can be because people get together and know what they want and sound off for each other and let their desires be known and that's the whole point of this. It's the beginning, a very exciting time forry I and our ability to serve people with disabilities and our arc wants to be leading it. Welcome to our house.

John Desautel: I'm John Desautel on the staff of the Governor's Commission on Disabilities. My primary function there is to provide technical assistance where we make state facilities ADA Accessible. This is Ron McMinn one of our
Commissioners and Doreen McConaghy who was our Chairperson last year and one of our commissioners as well.

Bob Carl: Thank you. Welcome everyone to Northern Rhode Island. What I would like to do is I know several people have comments or suggestions to make Arc, so I would like to ask individuals who want to make a comment, to raise their hand, and speak up.

Independent

Ted Sheverine: my name Ted Sheverine, a member of the Arc of Northern Rhode Island, I'm also a member of the state Arc board. What I would like to address is the problem we've been having for a number of years. I've been active in this chapter and also on the state level for the past 30 years. For the past 30 years, we've been trying to get adequate funding for our line staff, so that they can actually make a career out of doing this kind of work and helping people like my daughter who's being served here with developmental disabilities. We have not been able to do it. We simply doesn't have enough funds to pay our line staff an adequate wage, so that they can consider this as a permanent job for them to make a career out of serving our people with developmental disabilities. So we are looking for ways of getting that proper funding so that we can actually pay these people what they are worth. They are underer paid and overworked. That's been the ongoing discussions that we've been having for the past 30 years that i've been involved and yet, even though we get bits and pieces of money to fund them more adequately, we have not reached a level where they can consider this as a career program. Something they can stick with, and something that gives you continuity of service, continuity of wages for the person offering that service. That goes hand in hand. We can't continue to operate, if I go too long, cut me, we can't continue to brat in this manner because it does hinder our quality of service when we have people working for short periods of time and then they leave. Then we have to come in, retrain persons who take that vacancy and this goes on and on and on and we might as well put a revolving door in front of our services because of this particular problem. So we're looking for more adequate funding. Judy: I have a question for you ted, you say you're on the state council attendee: the state board of ri arc. Judy: have you done a survey among the different arcs to determine the turnover rate of line staff so that we have actual numbers to bring to the state legislators to say look it, these programs experience 50, 60% turnover, it's impacting the services that are being provided, we need help to make this a viable living wage.

Attendee: I don't have that particular information, but I think if you call the state arc, they can come up with

data that can support that.
Bob Carl: I'll make sure that this is Bob Carl speaking, I'll make sure those data are available to the Commission because we do have that information. It's not only for this agency but for all the agencies. We have it on a statewide basis. Just to clarify, many, many, agencies private agencies that support children, persons with disabilities, senior citizens and others in the state, came together in a coalition this year and sought funding increase in what was called an index, a provider index coalition to allow an annual cost of living increase for all of our direct support staff. The legislature in their collective and certainly inif I knit wisdom saw fit to give us a very small increase this year. I believe it's a 2.4% increase effective january 1. That's a 1.6% increase on the fiscal year. And we want to thank them for that. But, we know at the same time, public employees are getting somewhere between 4 and 8% increase. We know that the gasoline and oil and other prices are going up from last year to this year increment alley in large measures. We know that all of our costs are going up insurance costs and other kinds of things. We need some assistance to guarantee the continuity as there sheverine said of service. Because probably the most single most important thing we do for the people we support is we provide staff to support them. We can do without administrators like me. We can do without a lot of things, but we can't do without quality staff. We have a lot of quality staff but it's very challenging for them. So, thank you. Other questions of Mr. Sheverine.

Independent

Julie: I would like to add to his comment I'm Julie says and I'm supporting family living arrangements. A client lives in my home for almost 17 years and whenever there is a staff change, I know by the way she comes home, by the way her attitude is, she's very insecure because she doesn't know who is taking care of her. And then I can tell by her clenlyness that it's not a regular staff because the new staff probably doesn't know how to approach her, what her likes and dislikes are. So I think there should be higher wages and incentives for the staff if they do a caring job.
Bob Carl: Thank you. Ted do you want to add something.
Attendee: Yes, I received this action alert e-mail from the state Arc, from Paul Marshon who heads up the Government Affairs Section of the National Arc, and this message goes like this. This morning we all received a plea from Paul Marshon to help. Congress is required to generate a 10 billion dollar savings for Medicaid this year. There is a by partisan recommendation from the governors to increase cost savings for Medicaid, for Medicare, Medicaid i'm sorry, beneficiaries. The arc and other national disability organizations need our help to stop this. The arc is looking for stories about health-related out of pocket expenses, not paid by Medicaid that people are currently dealing with to help show that any increase in cost sharing will have a devastating impact on the health and we will being of our constituants and their families. Even a 1 dollar increase in cost sharing given the health related issues and prescriptions needed will drain people of the little if any money that is left over after paying for living expenses. Thank you.
Bob Carl: Other comment as soon as
George Nazaeth: my name is George Nazareth. Are anyway, one of the things I am's going to want to bring up is i'm also from the Arc of Northern Rhode Island, and have been active in the arc movement for a long time. Most of the funding for this our organization here, comes from the Medicaid fee for service based system and that does not adequately fund the programs for Rhode Island's developmentally disabled adults. Now, they do have in Rhode Island and we heard about this a little bit before the rite care for children which is a model program here in the state which does, in fact more adequately fund the services that we need. And it would behoove the federal government to use this as a model and try to do this type of funding on the national level. That's one thing that I wanted to bring up.
Bob Carl: Can you comment on that?
Ken Pariseau: what i'm hearing you say is that you're recommendations for adults with developmental disabilities a very similar kind of health care system that right care provides for children and their families.
Attendee: do the same thing on a national level for adults.
Ken Pariseau: In the Assembly this past year and the Governor allowed to be enacted calling upon the state to in fact develop a managed care health plan option a product very much like right care for adults with disabilities and so, the state Department of Human Services, will in fact be beginning to hold community meetings starting in September to hear from people what kind of health plan services they would like to have in that kind of program, and the plan is to develop a plan that could begin to enroll people as soon as next july. So you will not

only be getting more information about the program, but you'll be asked to offer ideas and suggestions in terms of what the program should be including. It will be a voluntary program so the adults will have the option of joining or not but the intent will use what they've learned from right care which you pointed out is a national model to inform the design of a program for adults also.
Bob Carl: That's terrific news that it's that far along. I think that's great.
Ken Pariseau: And one of the things I would certainly like to hear about today is what kinds of difficulties to people have right now in health care that you would like to see fixed by managed care health plan program. So if people have a hard time getting to a primary care provider or you need care management services, those are the kind of services that the state if they hear from people, will in fact include in this health plan option.
Bob Carl: Can I stop there for one second. We've got some people, you're all involved with securing health services. Can one of you comment on Mr. Pariseau's question. The access issue?

Health Care

Female speaker: We don't have too many issues for access with primary care, we have more difficulty with access with specialties.
Ken Pariseau: Like?
Female speaker: Like what kind of coverage –
Mary: Counseling services are very hard to come by.
Bob Carl: In terms of primary care, the we don't have too much trouble is because of thunder mist is that the reason or not?
Female speaker: No, we don't have too many people that go to thund are mist in the residential homes. But we have some programs in Rhode Islandthat have been willing to take on people and give them good quality care.
Female speaker: Any time anyone is in need of counseling type services, those are very hard to come by. Ken pariseau: when you say counseling services you're talking about mental health and substance abuse counseling.
Female speaker: not so much substance abuse.
Bob Carl: Can I ask Beth Lafond who does our case management or coordination of supports you deal with people from the community living at home.
Beth Lafond: I would have to reiterate what mary said is that counseling is a major issue that access to counseling services, the health coverage that they have is practically nonexistent. Judy: there's no medication issues?
Attendee: I have a medication issue.
Judy: Are you finding problems with getting meds filled at pharmacies because of the payment structure.
Female speaker: not right now.
Ken Pariseau: there are concerns about what happens next year.
Bob Carl: there are dual eligible issues. We're also concerned about issues around new departmental regulations regarding the distribution of meds that are seemingly conflicting and often times inappropriate. So we're struggling with it's a real nurse practices issues and whether we should have a nurse in everyone's backside. Which some nurses think we should have.
Doreen: Finding neurologists is difficult. I think they should have a neurologist of record, one that they chose.
Female speaker: Dentistry.
Bob Carl: Dentistry and eyeglasses is a little bit of a problem. I had a guy in my office today who had his sunglasses taped to his regular glasses because his regular glasses groek. Mary: hearing aids as well.
Attendee: What about dental?
Attendee: The ear doctor. Sometimes we might have to see him for hearing.
Attendee: Podiatry that would be something that people want.
Bob Carl: Okay. Dottie.
Dottie: i'm Dottie, Ted's wife. My daughter is in residential and she is getting wonderful care. But she could use special needs. She's nonverbal, and I would like to see my daughter with more of the behavioral specialists. I understand we do have an association called beacon behavioral, but it would be really nice if we could have these people more than like 8 hours a week. We're 365 clients in here. It would be nice to have a behavioral specialist work with my daughter to explain to the dedicated staff that works with tina, but help them to understand what she is trying to tell them because you can't expect people to be hired in here, and that you know, they just don't have the education that you know, a behavioral specialist has been through, and it would

be nice to have more of these people like this and counsellors and neurologists and everything. I don't have a problem finding a neurologist. I don't have a problem finding a dentist. What I do have a problem with is to have a behavioral specialist that can work with tina, with the staff, and maybe if he comes here soon enough, i'll be still living to explain to him or her what tina is trying to say. I'm 72 years old and how long is this going to happen. It would be nice if it's 2005 going into 2006, but if you wait too long, I probably will never live to see it.

Bob Carl: As a matter of fact, dottie, Diane and I and Bob Ross from Beacon talked today about that exact arrangement. So you're right. And that's something we should be able to manage. And so, that you should hold me accountable for that, I expect to deliver that.

Attendee: It needs more money too. Thank you very much.

Bob Carl: Certainly. George was still talking.

Attendee: There were some other issues I wanted to bring up.

Bob Carl: if you want to bring them up.

Attendee: I don't know if you're through discussing that.

Bob Carl: Two other people had their hands up.

Transportation

Attendee: Hi I'm Sheliveaguy from Coventry, the issue I have would be transportation for people with disabilities. My son happens to be very active because I don't work and I can take him everywhere, but if it aren't for me he wouldn't be doing half the stuff in the community, the advocacy work, the volunteer work that he does now. So I would like to see that addressed.

Bob Carl: Just to clarify, it's a huge, huge issue, across the board. We're having so many instances of people who, because transportation costs between the cars themselves, the insurance, the fuel, the repairs, believe me, it's a huge issue to try to keep up a fleet on the road and we're trying to do that. I appreciate the importance of that. You wanted to clarify --

Female speaker: We have restarted transportation work group on our project. Our work groups are sort of how we wind up developing the policy that needs to be changed and we work with the commission and the legislature. The issue on transportation, many other states have public private partnerships. Evidently in Rhode Island the law is such that you can't have private entities working to transport people disabilities and it's a component of the law that we're looking to see how we would be able to change. Because one of the very interesting things is that this is a great entrepreneurial business for someone with a disability that can drive to help other people with disabilities who can't drive and you doesn't have to go through ripta's program because they are really the funding for ripta has, as you know is problematic. So we're working very hard ongoing through a document that's about this thick on what's been going on in the rest of the states to come up with best practices for them to put a report together to give to the legislature to see what we can be doing to allow for innovating entrepreneurial to do transportation for people -- not health care related and maybe going to work, helping people get to work also. So I invite you to join our transportation work group because we love having actual experiences from people and suggestions and that's how we come up with what we come up with.

Bob Carl: We will get some people to join that because we run a program trying to transport people. We're a private agency, we transport people back and forth to doctor's offices, social things to work all kinds of things and trying to keep the fleet alive and be responsive to individuals is a serious challenge isn't it rachel.

Female speaker: A humungous one.

Health Care

Eleana: Obviously working for the College of Pharmacy, but also the project we're in, there are about 40 states that have this infrastructure grant to help people with disabilities get employed. About 75 to 80% of the people for buy ins are dually eligible and the majority of them have some type of mental illness and need some type of psychotropic drug. This is an issue of our state before the passage of the Medicare part D haven’t what CMS which is the government agency has done on this an a very positive movement because this was a concern for so many people. Whatever drug you're you know, you are on your son or daughter is on, will be no matter what prescription drug plan you are in, that drug will be covered, not an again eric, not a different kind of brand. That drug if that's the drug that works for you during a transitional stage and that transitional stage has not been defined yet. That took a lot of work to be able to get that accomplished, which means that because the biggest concern was that the drugs that people are on and the pmb dupt's have the drug on the list what's going to happen? So the transitional issues whether it's 6 months or a

year needs to be addressed. The issue that becomes difficult is that right now, if you have a Medicaid card and you go to a pharmacy, and if a pharmacy pulls up and sees that you're not on the list, okay, as long as you have that card, the pharmacist will dispense the medication to you. What happened with the Medicare part d they didn't really get into the operational, how you're going to get your drug at the pharmacy which is not a big surprise, that does not exist right now. So as people are moving and sign up for the pmb as early as possible. As soon as you can so that the pmb's have the opportunity and the time to get you in the system because if you're not in the system and you come to the pharmacist and you say I have this drug benefit and they pull it up, they're not required to dispense the drug to you.
Attendee: Does everyone know what that is
Female speaker: That's the pharmaceutical plan. Everyone has to join a pharmeutical plan before January 1, 2006 in order to have the Medicare pharmacy benefit. Some of the pharmacy plans, well, you're not --
Female speaker: You have one --
Female speaker: I don't know how many Medicare people you cover at this point. But Blue Cross, this is's a plan that covers the Medicare/Medicaid beneficiaries. So if you're in an hmo/ppo type of health plan that offers the drug benefit, you don't have to get a different one. But there's going to be ads up the ka z oo about the different plans to join. So what the department of elderly affairs has said is when you get a letter, you should be getting a letter from the federal government talking about drawing a plan, call the department of elderly affairs and they will help guide you through which plan would be best for you. But the point is to do that soon and get yourself covered way before the january 1st deadline because that way, you won't have a problem, it should be in the system, you'll be able to get your drugs when you need them.
Female speaker: also pharma care. If you're on Medicaid only and don't have a Medicare benefit this doesn't apply to you.
Ken Pariseau: This is just the do you livists.
Bob Carl: Which is a lot of our people. Mary.
Mary: I was under the impression that a provider hadn't been chosen yet. Is there a provider.
Female speaker: Oh, yeah, they've chosen a whole list of providers that are providing nationally and I don't know how many there are in rhode island, but there's a lot. You go on to the center for Medicare services website, www.cms.gov. Have you seen the ad?
Bob Carl: that's more than any of us want to know.
Female speaker: there are ads on television now, that if you want some understanding about the Medicare part d benefit call today. That's to get information about these plan not to join.
Female speaker: I was also under the impression you you could auto enroll.
Female speaker: You have the opportunity to you are you're going to be enrolled in something.
Female speaker: I didn't get the understanding it was more than one provider.
Female speaker: Auto enroll is one provider, you can select other providers.
Ken Pariseau: Even if you're auto enrolled and get information about another provider that you wish to enroll with you can disenroll from the person you enrolled with and reenroll with the new provider. Some plans are a provider and they won't know about it until september. So for example in addition to the pmb's blue cross and neighborhood will be offering a product for do you lives for january and we will be finding out about that in september, so there will be a lot of information that groups like Northern Rhode Island Arc will be getting September, October, that will help people make a big choice.
Female speaker: But I would suggest this issue about auto enroll and disenroll. That's where you're going to have the problem if the information -- and again i'm worrying about my graduated pharmacists here, who are so stressed, with that transition if you disenroll and reenroll, it may before if it's in the system. It's better if you can to do it upfront get the one you want upfront so you don't have to disenroll, reenroll. Judy: one comment for you all, if I were in your shoes sitting there, I would be right now, really confused.
Bob Carl: We are. Judy: what I want to share with you that those of us who are providers and work with this on a daily basis are also confused. The thing I need to emphasize for you the most from a practical stand point is that this is all about choice, no longer will you only have one way to do the things you want to do. So think of it as positive. Yes, it's more complex, but it's going to give each of you more choice in terms of the quality and level of services that you're entitled to. Is that clear to everybody? So even though it's more complex I think it's

really going to be a good thing in the long run.
Bob Carl: I think most of us are concern that had if it comes from this federal government it probably is not going to be a good thing. (laughing)
Judy: I'm trying to be positive here.
John Desautel: We have a sign language interpreter here if anyone needs that service.
Bob Carl: Would anyone like to have our interpreter?
Bob Carl: I guess we're okay, thank you. Mary, you still had another comment.
Female speaker: I wanted to, I just wanted to comment on the copay, the 1, 2, 3 dollar copay for medications. That doesn't seem like a lot of money but we recently did a survey in our homes and we had people, 6, 12, 17 prescriptions. So one of
My concerns obviously is people may be limited on their drug choice, but secondly, it's impossible for these people to pay what seems like a small copay but when you have that many prescriptions. It's a huge amount of money. Is there anyone working actively on this for people?
Female speaker: Who is paying the one everybody?
Bob Carl: That's prospective. Because for dual eligibles I didn't think there was a copay.
Female speaker: That's not the information I got.
Bob Carl: It's our understanding that when you go to the dual eligible program there's going to be a copay of 1 to 3 dollars per script, and if that happens, since a lot of our folks have very little disposable income and use it for little things like tooth paste and deodorant and buying underwear they don't have extra money for copays.
Female speaker: I believe the deductible has been waivered for peeped with disabilities. One dollar for again eric, three dollars for regular.
Female speaker: i'm not sure, but we can go back -- there are some parts of the law that give the state the flexibility to pick up some of the costs for certain populations. I'm not sure if this is one of those areas, it may be, but we can look into that.
Female speaker: That would be really important.
Ken Pariseau: I think it's really important that you raised a question and it's part of the record now. Clearly there's a need for information on the impact on do you lives. My understanding for do you lives you're on Medicaid and Medicare, so there may be a small copay related to Medicare, but because of Medicaid the Medicaid picks up the copay. My understanding is the issue is to make sure providers are aware of the fact that when a dual person comes in that they are not going to be charging them the copay that the copay gets billed to the state.
Female speaker: There's a precedent for that in the system right now, mary, it's called Right Share and It's for individuals because there are people that work who are eligible for right care, because their income is low, but because they have employer sponsored health insurance it's easier for them to take that insurance. The state does a couple of things. Because they're Medicaid eligible any Wrap around. So when they pick up their script at the pharmacy they give them their blue cross card Or whatever from their employer and give them the MA card because they can be 20 or 40 dollars in Some cases and the state pays for the copay. It is a full wrap around. When you go to the doctors, they also provide the Medicaid card so It's a full wrap around and the state pays all of the copays on a fee for service basis including any services they're eligible for but not included in The commercial plan. If it gets into legislation, You want to make sure state legislation supports the payment of copays that are being added on by the federal policy.
Bob Carl: Just to clarify matters this is the first sign of hope that i've heard that our folks were not going to face. A dollar one script who cares but if you have 17 of them and we've also been advised and again new information today, that the formula was going to be different, there was going to be very limited opportunities for certain kinds of meds and that the new, more effective, some of the new meds that are coming down the pike will not be approved for use under this model. Now, again, see, I believe all of that because I see who is passing that legislation, the united states congress, and I certainly don't believe they're doing things in the benefit of the citizens of this country, so that's just my concern.
Female speaker: so in putting together the state legislation what you want to make sure is that any gaps in the federal legislation is covered in the state legislation. Even if you moved out of state you wouldn't have the same benefit, but as long as you're in Rhode Islandyou have the same benefit. Bob Carl: that's what we're asking the

commission to do. This is a great forum. We've cut out some people.

Education & Employment

Kim Walker: I'm Kim Walker a teacher in the Woonsocket Education Department. What do they was saying kind of struck a little note with me that I see a lot of behavior issues with students that have communication difficulties and I would like to see some technology available to assist students. And it's a limited population, but my recent experience was I have a student who i'm trying to try some technology with before we invest the huge amounts of dollars and costs. So I tried Techaccess, I tried the Sherlock Center and the School department, and asked around and could not find material I needed to try with the student. I would love to see a library of this type of Technology in the state to be borrowed and also some kind of funding opportunities to get what we need for the students.

Bob Carl: Great idea.

Family & Community Supports

Kim Walker:And the second issue I see some parents have, I have students that are younger, parents are not, don't have access to any at-home support unless they are heavily invested and spend a lot of time investigating all of the things, again waiting a year on Katie Beckett. A lot of People doesn't know how to get the support service.

Bob Carl: You're 1000% right on that matter. I would encourage at least in this local if anyones has a need for in-home support I would ask them to contact this agency. We've been able to help a number of people obtain katy beckett eligibility. We have an insider that will help us with at least telling us who to contact. You've been very helpful. We've had great success. They've been very responsive from the dhs. We run a pass program which is a nonclinical social service support program for in-home for youngsters with disabilities and the home based treatment services program, and we've been trying desperately to work those lists so that people don't wait for one, two or more years. It's an absolute outraged that a family can be deemed eligible for a service and then told to sit and wait for one, two or three years until somebody decides to support them. That's unacceptable. And I would hope the dlc would start filing suit against anyone that does that. It's absolutely unacceptable. It's a sham and a lie to families to pretend they're eligible for something and then they can't get it. We're working very hard to overcome that and push us as hard as you can.

Kim Walker: Really, at the Department of Human Services, there has become an increased concern on the child side. There is an increase on the Katie Becket side. Bob knows how to link up. Sometimes it helps to get the right person in the right agency, it really works and I don't want to backlog her. Maybe I can talk to you later about the speech. I have a child with a speaking disability.

Judy: The student that you're referring to, is that student in high school or secondary elementary.

Kim Walker: Secondary, he's 7th.

Assistive Technology

Judy: That's really important in terms of access to services. Communication devices, assistive technology is more readyly accessible from the office of rehab services for children who are 16 and older who are transitioning to work and that may be one resource parents don't think about. The other is the State Independent Living Council or centers, most of them have access and some format to technology that you may be able to go after. This is the first time though, that I heard that techaccess doesn't have what you all need and that's something I will follow-up on.

Female speaker: they might have something that you have something in the center to see it, but not something to borrow to try with the student on an extended period of time.

Judy:That's become more difficult for them because of the cost. But you should have been provided some assistance to go to the manufacturer of the devices you wanted to look at.

Kim Walker: I'm in the process of doing that now. E-mailing.

Judy: You should have gotten assistance to do that. I will follow-up with that for you.

Kim Walker: There's also an excellent speech center at the URI. My son was a stutterer and he give his graduation speech with a device that was given to him.

Family & Community Supports

Darlien McGraua: I'm Darlien McGraua -- and we're also part of family support center here in the city. First of all I would love the name of the person working specifically with the families of children at DHS. The second thing I wanted to raise is in terms of families with children and aduments with disabilities one of the things we often see in early intervention is families where the adults have cognitive limitations and they're raising young children, and while they're in intervention they receive many supports but once they transition out, there's not much out in the community. I wanted to give -- make the audience aware and also to encourage and promote there are pilot programs being supported by the sherlock system, the money is limited and there's a far greater need for these parents with cognitive limitations because often times their only resource is for them to be referred to dcyf and that's not a good match for their needs. So I would appreciate the panel's support of the sherlock's center initiative as well as thinking about how the state might be able to continue with this program that is really going to save the state money in the long run but also support the family in a respectful and digfied way. Thank you.

Health Care

Attendee: The behavioral problems, I serve on the human rights committee of this organization and for many years i've sat there and read incident reports like you wouldn't believe and there are a great many individuals, well, at least a reasonable number of individuals, who repeatedly get involved with incidents such as shoving, hitting, banging at somebody and these are all written up and you have to read all of these they thinks and you can't help, but many of us on the committee have said there must be some way to have some behavior modification done so that these people would stop those incidents and it must be aggravating for those that are getting hit too. (laughing) so I didn't know if there are resources available to our employees that could assist them and guide them in the right way to stop some of this.

Bob Carl: Just to clarify, that's an agency kind of issue. Of course there are, that's why we've engaged in an across the board program with Beacon and try to get both individualized programs and more comprehensive approaches. But it's one of the realities that is tide to ted's comment earlier, when you have staff turnover and you have an insufficient pay roll to allow you to recruit a sufficient number of the staff at a highly trained level. It's much more challenging. And so I think those things are hand in glove. Absolutely we have that responsibility.

Attendee: you know, I would like to add to george being on the human rights committee and i'm sure a lot of those incident reports were for tina she's such a sweet girl. (laughing) I would like to share a story with you, just two years ago, tina was on a cocktail of psychotopic drugs that you would not believe for her own safety and it was, you know, she was diagnosed back in '84 that she was bipolar. That was the first time I ever heard of that illness so through the years we added more and more medication prescribed by the psychiatrists, because well, this will help and that will help, and that kind of thinged. But what happened is through the years, her kidneys were going to become close to being effected by the lithium, so tchs suggested that she be removed from it. So she had to be admitted to the hospital because by taking away the lithium, she went into a very high manic thing and they had to admit her. So when she went into the hospital, naturally, they decided to remove all of those drugs, the neurologist that came in, that landmark called routine to diagnose her, he said to my husband and i, he said she's not bipolar, she can't talk. She can't tell you that she has a toothache. She can't tell you that she's warm, she's cold, she's uncomfortable or the shoes don't fit and so forth. So we removed all medication and she's the most beautiful person you would ever want to know if you know what she wants when she has an episode, which it's not a big thing, they just really need to lighten up. As george said, you need these professionals to come in because the staff, you would be surprised, they'll know her in a matter of weeks, you see. But because of the staff coming and going like ted said like revolving doors, all that does is tina having more incident reports because the staff that knew what she wanted is gone you see. So that's where we need to look at these things. A lot of these drugs that you know, they're coming up with new Medicaid, I was trying to understand what you were explaining I don't even understand my own Medicare card. Judy: you also have to pick a plan.

Attendee: Maybe a lot of these people could do without being on drugs if we understood what we need to do.

Female speaker: As a clinical pharmacist he and this is something I had to learn, a clinical pharmacist is not a physician but if they're involved in the team looks at all the drugs that someone is taking and makes recommendations to actually take someone off drugs. So it's not like you need to go to a neurologist or that type of thing. So I don't know, there are a lot of different doctor groups within Rhode Island now they have clinical pharmacists working as a team with them being able to review a person's chart because of all of this. So –

Attendee: I understand that, I really do, it's just that i, you know, I just, i'm just hoping that you know, others will understand tina like I do, so that when we're gone --

Bob Carl: You're not leaving soon do they.

Attendee: He's worked 40 years. He started at Ladd School and he's still going to meetings. Sometimes I used to

wonder if he was really at meetings. (laughing) I thank you for sharing.
Bob Carl: Thank you.

Education & Employment

Tammy Bofalant: My name is Tammy Bofalant. One of my concerns is there aren't enough school choices for the child. The only school I can put my daughter in is the school that everyone is having trouble with, the middle school. She's in a great class and protected and doing well there, but I would like to be able to call which I did call a catholic school and see if they have a program. They told me there are no programs for a child like mine. I think that's discrimination. I would like to see different forms of teaching and that sort of things. Unless I spend my entire salary, I can't afford one or send my daughter across the state to get to another school.
Bob Carl: A couple of comments if I can, in terms of a school voucher program which some people have argued for, you get a lot of dispute about that, which you know, I think it wouldn't be eligible if they spent it at the denominational schools. The Sherlock center at Rhode Island College is a resource. I would suggest that you contact Dr. Antosh, Anthony Antosh who would be able to give you some guidance about school possibilities. And I think they would give you some good information.
Female speaker: That's good because you ask questions and nobody knows what to tell you.
Bob Carl: It's very hard for families and individuals out in the world to try to sort their way through this morass that we call a support system. I admire family that hang in there and keep pushing and keep getting to accomplish the right kinds of thipgs. It's a never ending battle as these folks will tell you, they're still fighting. And unfortunately, the environment is getting tougher now. We don't have the political support that we used to have. You know, it's a challenge. I'll be nice for a minute. But thr's just not out there helping us very much. (laughing) another commepts?

Family & Community Supports

Female speaker: A couple more comments. I would like to have like there are places offering first aid courses but there's nothing for someone who is a little bit under, I would like to have my child learn that type of thing in case she was in an emergency type situation. They don't have any types of things for you know, for children or adults to be able to learn stuff like that that I know of.
Bob Carl: Okay. Somebody here on staff must have a clue about that.
Female speaker: Driver's ed too.
Female speaker: We do have first aid for some of our folks. The nurses staff has gotten together with the physical education staff.
Bob Carl: so we probably can figure out a way to accommodate, if you'll help us get connected with some other parents of younger kids, we would be willing to run a program free of charge for your child and others.
Female speaker: really?
Female speaker: there is an adaptive driver's ed course. I'll give you a card and get it to you tomorrow.
Female speaker: that would be great.
Bob Carl: Any participate or family who has troubles getting something done, if they contact us hopefully, we'll help. But if we don't or can't, Doreen and the PAL organization was started up just for that simple reason. She is a parent and wasn't happy with the way things were when we first met, many years ago, and she's continued to push the state and push services. And it's worked reasonably well some of the time.
Female speaker: Absolutely.
Bob Carl: Anything else?

Independent

Female speaker: Yeah, one more. Like there's national honor societies, president awards for all should I say normal or average, but there's nothing, I mean except for special olympics and that's great, but there's nothing to recognize children, I don't know about adults because i'm not at that level, like in the school systems that my child say cannot be high honors but she does the best she can in her class. There's nothing to recognize that. You don't see it in newspapers or anywhere. Even national President's award for special effort or something.
Bob Carl: I think you raised a very good point. The ways to recognize the quality and effort and talent of people with disabilities who may not express those talents in always exactly the same ways as the rest of the population, but certainly have them and should be recognized for it. It's hard in this society. It's a tough society.
Attendee: Everybody has to be perfect.

Bob Carl: Other comments. you, Doreen.

Health Care

Doreen: I would like to go back to the proposed managed health care plan. There are a bunch of us that have been talking about this for a long time, and one of the things that we think Would make an excellent product would be if they Could build in some preventative care. We might Have a smoking sensation folks, lots of our folks Have dietary issues and some proactive education Around that would be helpful. We would like the opportunity for some alternative medicine. Someone spoke earlier about dentists. Having dentists that take a different card would be Wonderful. But I would like it to include things Like not having to have a tooth pulled out, but Maybe partially pay for a crown or a root canal. Right now the only option under Medicaid is if you Have a bad tooth, it gets pulled. More options Like that. Also many families whose sons and daughters who are pretty physically impaired and depending on the climate, sometimes there are Dollars to help with adaptations to vehicles and Sometimes there aren't. I would like a clearer Defined policy around paying for adaptations to Vehicles. I would like the policy to say yes, but I think paying attention to that because we have a Lot of families who's kids are not children, They're 19, 20, 35, they're at home and they can't Afford the vehicles. So these adults don't have Much of a life after 3 o'clock and certainly Nothing on the weekends because mom and dad doesn't Have any way to get them out.

Bob Carl: Yes.

Diane Brown King : I'm Diane Brown King Director of Services at CranstonArc. Everybody i've heard here is definitely statewide. Last month two physicians called up and said we can't take those folks anymore they have Medicaid. We don't take That coverage anymore. So we find other physicians for them. And we did a fine job at doing that. But then there's the copay piece. The podiatrist wants 20% of the visit, and that can be substantial. Mr. Pariseau is managed care going to effect this or help this in any way, if you could comment on it, please.

Ken Pariseau: Okay, I think one of the problems that we have been hearing about on the adult side, which was comparable to the problems on the child side is that because the fees are so low in Medicaid, there were a lot of providers, if they took children or adults on Medicaid, they really Restricted the number that they took. One of the Things that has happened in managed care under Right Care is because there is such a focus on getting children and families hooked up with Primary care providers and making sure they can Access the services that they need on the community level, we have been able to really reduce the number of kids going into the hospital, and so if children and families can get care in the community, you end up sending money on the In-patient side. You can use that money to pay Providers higher fees. So in right care, providers are paid a higher fee than in Medicaid. So consequently for children with special health Care needs, we're able to pay the providers a higher fee than under Medicaid. I believe there Would be a similar opportunity for an adult Medicaid managed care program also because the Effort would be to get the person into a primary Care provider, to exercise the preventative kinds Of things doreen was talking about. Because if You take care of the people in the community closer To home and families and they're less likely to go Into the hospital. If you pay providers more They're going to be more willing to see adults. The other thing that health plan brings to bear is That those providers are within our network and if One of our members needs a provider anticipate the Provider says no the health plan steps in and makes Sure there is he aa producter for the member. There is really no contractual obligation on the Part of providers to see folks on Medicaid. That's not the case if someone belongs to a health Plan. The health plan makes sure there are enough Providers that there are services the members need And if not, the health plan has an obligation to go Out and build that service.

Female speaker: One of the questions you could have Asked or if you come up with this again in the future, ask the doctor if he takes neighborhood Health plan. He's going to say yes. And it's The same thing except and ken is exactly right. Another thing some of the things you want to build in when you design this program, put prirments on the plan. For example we have a requirement that They have a primary care visit within 60 days of enrollment in the plan. A follow-up phone call When you're enrolled in the plan to let you know you need to have a primary care physician. Once a Year we go out to visit the health plans and we Have a certain set criteria, what are you doing About as mast ma, and this and that and if they Meet a certain criteria they get extra money. You Also have the f 2 hc there in cranston and they Will provide service. They get paid handsomely by The state.

Female speaker: It's usually not primary care it's usually the specialists.

Female speaker: They should have specialists on staff. But just to let you know that what Ken said is exactly right. When Right Care started 40% of the primary providers in the state accepted Medicaid and now upward of 95% accept Right Care.

Bob Carl: You need primary care services and specialty services.

Attendee: Yes.

Bob Carl: Basically, I think the answer is the primary care physician is supposed to refer you for specialty or more specialized kinds of services so one should follow the other as a rule of thumb.

Ken Pariseau: well, when the state designs a health Plan option like right care, there is a whole set Of services that are covered under that, it Includes primary care, specialty care, behavioral Health services, home care services, transportation sServices, medical appointments, all the in-patient Services and you have access to all of that if You're part of the health plan, and if there are Services that members need that don't exist, the Health plan's job is to go out and find providers To provide that service or to build a service if it Doesn't exist. So the whole range of health care Services would be covered under this health plan Option.

Female speaker: One thing you need to know is that Neighborhood Health Plan of Rhode Islands has been chosen to be the number 1 health plan in the country. So you don't have a shabby plan taking care of you.

Bob Carl: I think our transcriber needs a break. I think we're probably through. Is that correct. There's one more. I was worried about the transcriber. (laughing)

Ronald McMinn: Sorry, I wasn't looking. I haven't fallen in a long time. I'm Ronald Charles McMinn. Very good young lady. (laughing)

I'm a Commissioner on the Governor's Commission on Disabilities. And we take what you're questioning And asking about very seriously, we really do. And as you can see, we pull our hairs out trying to Come up with some good answers for you. (laughing) my mentor, doreen, took me under her wing almost 6 years ago.

Female speaker: Really?

Ronald McMinn: Yes, and although he she won't admit it, I caused her many gray hairs. (laughing) but the only way we can help on the Commission, anybody, is the input that we get out of these meetings. So I want to thank each and every one of you. And we're always looking forward to getting new, if you ever have something that you may think of in the middle of the night, call the Governor's Commission on Disabilities and one of the staff members like John, will take it and we'll pass it along to the Commissioners.

John Desautel: don't call us in the middle of the Night.

Ronald McMinn: No, but the majority of the time, our staff solves problems before it even comes to the Commissioners. So don't ever, ever be afraid of calling the commission if you have any questions whatsoever.

Bob Carl: Thank you very much. Folks I think that is the end of our hearing. Is there anyone on.panel that wants to make one final comment.

Female speaker: I would like to say we're going to be having a job fair at Network Rhode Island in Providence on November 3rd, and although we're not allowed to advertise that it's for people with disabilities, we are strongly encouraging all

people with disabilities to come to this job fair. We're hoping to get at least 30 employers in the state to be there and have resources and it's really exciting working with Network Rhode Island to make this happen.

Attendee: Where are you having it.

Female speaker: In the Providence Network Rhode Island Center.

Bob Carl: You'll have information.

Female speaker: Oh, yeah, we'll send out lots of information. This was just decided yesterday so you're the first to hear about it.

Ken Pariseau: Two quick comments, one, for folks Who are dual eligibles and are walking away or have Family members that are dual eligibles and walking Away feeling really nervous and overwhelmed by the Changes that are going to be happening for next January, there won't be a lot of information that You will be receiving and there will be a lot of Information sessions this fall. So there will be A lot of assistance provided to you and your family Members to help you make good choices, so you are Not going to be alone in that. The second thing Is a lot of the folks have raised concerns about Support services around behavior and around mental Health conditions. Neighborhood recognizes how Important behavioral health services are, and we Particularly have heard about for adults with Developmental disabilities because there is an Absence of good behavioral health services, adults Are often put on too much medication and when People join our plan, that will be something

that We will be paying a hot of attention to, because People should shouldn't be on medication unless They have to be. And there are a lot of Behavioral health interventions that don't involve Medications so there will be a lot of attention Paid to the issue of behavioral health services.
Bob Carl: We want to thank everybody for attending. I want to point out that nobody talked about one of the issues i'm concerned about which is the need For additional residential options not just more traditional group homes, we may not need that, but We have lots of people living at home with elderly Parents living in a situation where they need more Supports or different supports than presently Exist. So I would urge the Commission to push that agenda. We have for the first time in the State, in the recent history of the state, we have Waiting lists for people that required residential Supports and that's an outrage. So I hope you'll Address yourselves to that issue. I think this Was a terrific forum. I really appreciate the panel members, the Commission, the staff and Commissioners and your folks for coming with your commentary. This is a great feedback system. It's a very successful one and I for one really appreciate everyone's effort. Thank you. (applause)

August 23, 2005, Chemical Sensitivity Forum.

Liberty: Welcome all of you. Thank you all for coming. I am Liberty Goodwin. I am the Director of the Toxics Information Project, TIP -- turn this down a little -- and one of the cosponsors of this forum, along with the American Lung Association of Rhode Island.
Now, I think because we are late and because most of you will be speaking, I won't ask people to introduce themselves. I will introduce the panel. I will cheat and --
Chris: They can introduce themselves and talk about what they do.
Liberty: Let's have the panel introduce themselves.
Michael: I am Michael Spoerri. I represent the disability and health program in the Department of Health. I think just today we are interested in just hearing more about chemical sensitivity. It's an area that admittedly we don't really do much with and so it would be just to learn from you all.
Barbara: I'm Barbara Morin. I'm from DEM, Air Toxics Program. We are mostly concerned with outdoor air. But we are sort of -- responsibilities. And respond to odor complaints, kind of thing, you know, involved with people that are sensitive to odors that other people can't smell.
Susan: I am Susan Shapiro. I am with the Office of Rehabilitation Services and also President of the Rhode Island Rehabilitation. We are one of the sponsors of this forums and very interested in what you have to say. We are concerned.
Steve: My name is Steve Brunero. I am also with the Office Much Rehabilitation Services, the vocational rehabilitation side. I too am interested in hearing more about chemical sensitivity issues and how it relates to work.
Curtiss: My name is Curtiss James. And I represent the Rhode Island Commission on the Deaf and Hard of Hearing. Like everybody else, I too am interested in hearing your stories. As of yet, we've heard nothing as far as this issue in the deaf, hard of hearing, or interpreter community. But again, I am interested in hearing feedback from you all.
Eleana: I'm Eleana Goldstein. I'm the Director of Public Policy for the URI College of Pharmacy and the Project Director of Rhodes to Independence initiative, which is helping people with all types of disabilities to be able to work.
And I come to you as a person who has gone through an issue very recently. I have a sensitivity to mold. And I don't even want to tell you which department in the state was really adamant about me bringing a doctor's note, and though showing my allergic reaction. Does it help to see that I can't breathe? Is that helpful at all, you know?
So I am very much aware of this issue, as it relates to people and the workplace environment where you can work. So, I'm for it.
Liberty: Thank you. Okay. I hope everyone here has signed the --
Chris: I have it here.
Liberty: -- The attendance sheet. Put a check if you want to speak. There are assistive listening devices available. Chris standing there will help you if you need anything like that.

We have an interpreter, sign language interpreter for the deaf.
Public phone, the phone probably can be used. The rest rooms are back there.
Now the purpose of these public forums is to identify the concerns of people with disabilities and their families in order to assist the state to develop programs to improve the quality of life of people with disabilities.
The forums will be followed by -- there will be a posting of the transcripts of the testimony on the Governor's Commission on Disabilities website, which is www.gcd.state.ri.us in about a week, maybe a little longer.
Chris: A little longer.
Liberty: We are also going to put some of the testimony in our website to www.toxin.org later this summer or early fall at this point.
The sponsoring agencies will review the testimony and prepare recommendations which will also be posted on the website. It says by the end of the summer. I think it may be September.
The recommendations and the transcripts will be printed and sent to state and Congressional officials and members of the general assembly. And the recommendations will be used to develop policy and legislative initiatives for the next year or until they are accomplished.
So we are going to try to give everyone a chance to speak. We have two hours. If people are not too worried, we should be able to handle it pretty well.
The panel members are here to listen and gain an understanding of your concerns. They may ask clarifying questions. You will be asked to speak in the order of the sign-up sheet, which I have here.
So, that said, the first person who has indicated an interest in speaking -- let me just get a general idea of how long you are going to have.
Chris: Actually, Liberty, people can come and go as they please. So, you know, try to gauge your talk appropriately. In other words, if there's already seven people that Liberty identifies, don't say I have 30 minutes to speak or 20 minutes to speak. People can come and go as they please. We may see peopling coming in later.
Liberty: I think probably limit it to five to ten minutes is a reasonable goal.
Chris: That's fine.
Liberty: Closer to five, if you can. Otherwise try not to go over that ten minutes or so.
Russell.
Russell Irving: Yes, right here.
Liberty: Could you identify yourself.

Accessibility

Russell Irving:[4] Good morning.
My wife's life too often resembles that of a single woman. My sons have an involved, yet 'absent' father, living with them. Some co-workers do not know what to make of me. Some doctors are dismissive. Some of the others simply throw up their hands. Some of my extended family thinks that I am anti-social. Most folks simply cannot wrap their arms around the concept of someone like me, who has MCS (Multiple Chemical Sensitivity).
As a society, we struggle to understand what it must be like living with a disease or disability.
We have made great strides in accommodating many of these, with more steps needed.
Yet, despite over a dozen government organizations including the Department of Housing and Urban Development, the Department of Education, NASA, and the Social Security Administration recognizing the existence and need to accommodate those who are acutely chemically sensitive, life in the 'real world' has not begun to address the needs of MCS sufferers. Or even understand what it is.
During the dozen plus years since I developed MCS, my limitations have increased, along with the severity of reactions. Why? Because, increased exposure to life's accepted chemicals, causes increased sensitivity.
For myself, a single exposure can result in: severe body pain, head-to-toe; dizziness, making standing impossible; stomach cramps; loss of muscle and limb control; and more… An exposure can last minutes, hours, or even days. And, the more exposures that one has in a short period of time, the less able one is to withstand the next exposure, without a more serious reaction.
Yet, everyone is different in what triggers them and the reactions which they will endure.
There are no assistive devices available to help us. And, research money into chemical sensitivity is almost non-existent.

Now it is time to recognize the chemically sensitive among us.

We have a love affair with chemicals. Plastics, non-stick pots and pans, and even non-stick finishes for clothing. Particle board furniture. (I even saw a label touting the furniture as being made of 'genuine, artificial plastic'!) New fangled cleaning agents.

All wonderful products in many ways. But with anything 'good', there exists the potential downside.

Numerous studies have found residues of these chemicals in our bloodstream. In mothers' breastmilk. In organs of our body. Some last for years in our systems.

20/20 did a segment on Teflon, discovering that traces of it is in the bloodstream of most Americans. Pans with Teflon can emit gases which cause some people to have allergy and flu symptoms. Something doctors now recognize as the ‘Teflon Flu'.

Phthalates, a compound found in many plastics, hairsprays, and perfumes, has been linked to birth and developmental defects.

Our Food and Drug Administration allows cosmetics companies to conceal ingredients under the guise of 'trade secret protection'. Yet, we know that the FDA has received countless reports of folks experiencing dizziness, headaches, or nausea, from specific personal care products. Their response however, is that the complaints are small in number and severity. Yet, as every politician and media outlet knows, for every one complaint received, many, many more exist in silence by those too timid to speak out or uncertain of whom to address their concerns.

TV infomercials tout the wonders of a 'natural, orange cleaner'. However, upon scrutiny, you will see that the product is made of strong chemicals with perhaps 2% orange oil.

Our state and federal officials need to address the true safety concerns of many 'everyday' chemicals', to avoid a repeat of the horrors of smoking-related diseases, even for those experiencing 'only' second-hand smoke.

Back to the impact on my life, as a 'regular citizen' of Rhode Island.

How I loved book stores. Hours browsing through the racks. Now, after minutes my head spins, my muscles ache, and my stomach cramps up. No windows that open, patrons with perfumes and cologne lingering in the store's cafe or at the reading tables, and chemicals used to recycle paper are the cause.

I despise Wal-Mart and Target and the other megastores. Not because they are huge. But because of aisles filled with candles, perfumes, particle board furniture with formaldehyde, and…

When a store is new, it can take a year before I can go in and shop, due to the rugs, and paint, and 'whatever', off-gassing. Forget it when a store that I could tolerate decides to remodel.

Something as basic as getting your hair cut, can be a major dilemma because of colognes, scented talcs, and cleaning agents. Fortunately, I came across a barber who has MS and whose heart is big enough, that he takes me first in the day and contacts other customers, asking them to avoid wearing fragrances.

I live my life, in 'snapshots'. Small outings, if you will. It helps me to feel 'alive', instead of someone confined to the four walls of my home and a controlled workspace.

I have learned what stores I can tolerate, even for 15 minutes. If I can find what I need and get through the checkout by then, great! If not, I leave my purchase in my carriage and leave.

I know which theatres I can tolerate… maybe… for a matinee, because the odds of perfumes being in there are less than in the evening, when 'normal couples' often go out. Even then, I am often too dizzy to drive home, so someone drives for me.

Dining out is no picnic, either. Between candles on the tables, arguing with waitstaff about windexing our table or the ones near me… And, praying silently that the party sitting down nearby does not smell like a garden. Sometimes, I have to wolf down a meal and go sit in the car, leaving my family to finish their dinner, in a relaxed fashion.

When my sons were confirmed, I insisted on going to the church. But, waited outside, because of the incense, perfumes, and cleaning agents. And I know that my precious sons felt hurt.

I occasionally sit outside my place of worship and pray from within my car. Sometimes a security guard or neighbor looks over to see why I am parked out in front, for so long. Last year, I again tried sitting inside for the service. I soon found myself with little muscle control and great pain that lasted, far too long, afterwards.

Family functions often go on without me. Hosts need to clean their home. Besides, who wants to tell guests not to wear perfume or one of the ever-popular body sprays?

If my sons' friends come over and they have on cologne, I excuse myself, and eat not with them, but alone, upstairs. I dread the days when my sons will bring home dates. These women will probably think me 'weird' or anti-social, if they arrive wearing the latest designer scent.

At work, I might struggle through meetings. I hurry to explain to a new co-worker about my sensitivities and politely ask of (or is it plead for) them to avoid perfumes and air fresheners in their cubicles. I show them where a safe cleaning agent is kept. (One that I bought to make things easier for myself.) I often sit in my car, rain, snow, or shine, to eat my lunch because the lunchrooms' scents from fragrances and cleaning chemicals prohibit my socializing there with other employees.

A second income is needed, but finding another work environment that I could tolerate, is unfortunately not realistic, now.

Imagine, if you will, how I felt this spring when both my sons went to San Francisco to represent RI in a national academic competition and I could not be there to share this special moment in their lives. I had to look at digital photos and hear explanations upon their arrival home. A surreal scene. As if the roles were reversed and I was the child listening to my parents or uncles reminisce about special times in their past.

There is a social cost to MCS. Many with it are not as fortunate as I am. They do not have a supportive spouse or children. Marriages end in divorce. Other family members abandon them. The stress levels can get quite high, on all ends.

There can be guilt. When I said 'for better or for worse', I never intended to turn my wife's life upside down.

There can be jealousy. Of those who can come and go and stay places without problems. You know that you have hit a personal 'low' when you find yourself wondering, one day, whether you, the blind person, or the amputee has the better quality of life.

There can be anger and resentment, directed nowhere in particular.

There can be fear. As you watch yourself become more and more limited. And you wonder about any damage to the brain or vital organs.

And, yes, there could even be periods of depression.

Ultimately, you can reach out to the unknown future for hope. Guided and lifted-up by your inner strength, loved ones, and faith in God.

But perhaps, I digress.

This forum is also designed to discuss potential solutions.

First and foremost, there must be education.

I cringed recently when Tucker Carlson of MSNBC TV, 'poo-pooed' a community which banned perfumes and air fresheners from workplaces. And a popular, nationally syndicated radio talk show doctor has stated that those suffering from MCS are imagining it or are psychologically ill.

So, why would hospitals, workplaces, schools, and restaurants even bother to entertain the notion of accommodation?

Surprising is the number of workers who experience headaches, sinus problems, or muscle aches in the office or store, only for those symptoms to vanish after being home. If asked whether or not they might be caused by new carpeting, paint, or a closed-ventilation system, they will likely say 'no'. Some from fear of stirring up problems at work, others from not wanting to acknowledge the reality of chemical sensitivity because of the implications of so doing: loss of their income and ridicule. Employment discrimination for those with chemical sensitivities is great. Workers’ Compensation programs seldom acknowledge MCS.

However, do not be fooled! More employees than you imagine have some level of MCS.

Sick Building Syndrome is a reality. Recognized by even the Federal Government.

Imagine the shock when a federal office building was closed after renovations made countless workers ill.

We have buildings with windows which do not open. Air is essentially recycled, resulting in build-ups of VOCs (volatile organic compounds), perfumes and cleaning agents, off-gassing from rugs and cubicles…

We know the dangers of being in a locked garage with a car running. However, we allow workers to spend eight hours daily in spaces, where eventually these chemicals will probably have some type of effect on them.

Education.

Folks need to see those in positions of power and influence, recognize and explain the serious nature of MCS.

Public Service Announcements, news medias' health segments, hospital staff training, and school in-services are places to begin.

Public service announcements could tout the 'coolness' of good hygiene, without needing to mask poor hygiene with flowery smells. That boys could attract girls by being fun and with sincerity and kindness, instead of pheromone sprays.

Governor Cacieri could join the list of 16 states that have issued MCS Awareness Proclamations. He would be in the company of Governor Jeb Bush, Governor Mitt Romney, and Connecticut's Governor Jodi Rell, among others, who have issued proclamations for awareness of and sensitivity to those with MCS.

Our respected state legislators could push for perfume/fragrance-free government buildings. Now, realistically, you would not be able to eliminate the problem, but you could certainly reduce it. Cleaning could be done in 'off-hours', as much as possible.

The legislature could write laws prohibiting employment discrimination against the chemically sensitive. (Naturally, there would need to be practical guidelines.) The ADA, while covering MCS, is very difficult to get the backing of.

Some Rhode Island State employees could be allowed to join the millions of American workers, including Federal employees, who telecommute… work from home.

Unions must be willing to co-operate with the state in making this possible.

Both sides must work to enforce workplace consideration for those who are asthmatic or chemically sensitive. Why do we value an employee's right to wear perfume or have potpourri on their desk over a co-worker's right to be healthy and to keep their job?

Schools, already sensitive to children's nut allergies and learning disabilities, could ban fragrances in the classroom… all of the school's grounds.

PTA's could be instrumental in the education process of parents.

Health curricula could point out the issues facing the asthmatic and chemically sensitive in our communities.

Places of worship could have a space similar to a 'crying room' from where asthmatics and the chemically sensitive could safely participate.

I should point out that for MCS folks, it is not the scent itself that is the problem, but the chemical behind the scent. So that even 'unscented' products can cause distress. Labeling of products should be required to be clearer. A 'perfume-free' product simply has no added fragrance, but still has strong chemicals and their odors.

And don't be fooled! Most cleaning products on the market, today, have equally effective counterparts that would not harm many of those with MCS or asthma. A major consumer magazine, for example, found that lemon juice cleaned glass better than many retail window cleaners.

By the way, since when did filling our homes with the scent from plug-in, continuously-blowing, air fresheners replace the home's smell from cooking?

Natural, effective cleaning agents could be mandated for government buildings, including schools.

Tremendous is the notion of smoke-free restaurants. However, do we consider the affects on our asthmatic and MCS population, when it comes to perfumes, candles, and air fresheners on the tables? Why not at least, in larger eating establishments, have a scent-free section?

Hurt business? Why accommodating asthmatics and the chemically sensitive would be a boom!

Recently a national hotel chain began offering, at select locations, special rooms designed for the chemically sensitive. Not only because of the cleaning products used in them, but because of the type of furniture and rugs placed in them. - As it is, I don't go on vacation, in part because of the problem in finding a 'safe' room in which to stay.

Where businesses and governments look at 'bottom line dollars and cents', there is an economic loss, to consider.

Many of us, eventually lose the ability to work and collect unemployment or Social Security disability.

There is the cost of their healthcare.

There is the loss to restaurants, stores, theatres, bowling alleys, casinos, and other places where folks congregate and spend their money.

Doctors' offices. The place that you would imagine yourself 'safe', if asthmatic or MCS.

Nevertheless, I cannot tell you how many doctors' offices have air fresheners everywhere. And if they can post signs urging us to shut off our cell phones, why can't they ask us when making appointments, or post signs in their waiting rooms, to avoid wearing fragrances? My internist does. And, his practice thrives.

Chemically sensitive folks can readily share tales of physicians who, upon learning of the MCS, chalk up their complaints to stress, instead of conducting further tests.

Hospitals. This March I was hospitalized for an unrelated matter, but literally had to argue with the cleaning crew and their supervisor about not mopping my room, even when I was the only patient there. I had to struggle to get a nurse who was not wearing perfume and deal with other nurses explaining to me that their fragrance would not be offensive. (As if they knew what would be!)

Now, with asthmatics, other breathing-compromised patients, and MCS ones, how unreasonable would it be to enforce a no-fragrance policy?

I am shocked by the number of hospital staff who have told me that they have not heard of MCS. Staff who I have struggled with in the hopes that they would not use products, that would cause adverse reactions. For example, the plastic oxygen tube put in my nose will cause instant dizziness, breathing problems, and muscle pain.

Back when I was frightened by very severe reactions and went to the ER, I had a physician tell me that there was something obviously wrong, he knew nothing of MCS, and that I should just not return again for it. If I passed out and hit my head that would probably be the worst thing that would happen.

Again, education is the key.

Why couldn't hospitals, government buildings, and schools purchase 'chemically-friendly' paints and carpeting? They do exist! Moreover, they are often insignificantly more expensive, if at all more costly.

The California Department of Health did a large survey and learned that a significant percentage of their populations had some sort of negative reaction to everyday chemicals found in everyday places. There are many more people with MCS than most of us imagine.

For we are often invisible, by nature of ‘staying away' from public places. Or we suffer in silence, rather than face mocking or disbelief.

Multiple Chemical Sensitivity came to me, later in life. It has stolen much of my life. However, I refuse… Refuse to let it destroy my life.

Together, we can make a difference. We just need to care enough. We just need to act.

Rhode Island is number one, nationally, for many things.

Without much effort or expense, Rhode Island can lead New England, even the nation, in moving to not only accommodate those with asthma, allergies, or MCS, but to help our residents stay healthy. To be able to lead productive and active lives, alongside our neighbors.

I thank you for your time and understanding.

<u>Liberty</u>: Any of the panelists have any questions?

The next speaker will be Dori Blacker.

Accessibility

<u>Dori Blacker:</u> Thank you. I am suffering from one of the effects that I have from MCS that's -- I get affected emotionally. I get certain inhibitions. I can, much to my personal horror, wind up screaming at somebody who just doesn't know any better and I can be more offensive. I never want to treat another human being the way I sometimes wind up being put in that position. Or I just wind up uncontrollably crying. And it's really humiliating and it's embarrassing. And it definitely makes it more difficult to get people to hear you and take you seriously because you just look like a nut.

You know, this is one of the few things that we are sharing the air in this room. There's really no way. When people are asked -- I mean, I came here hoping I would be safe here. But there is -- there's so many chemicals in this room from the collective presence of people coming in here that I have gone to things where people said, I only put on a little. Well, I have to wear my deodorant. Well, it's natural -- well, I didn't mean to hurt you. And putting them at different places in the room, it doesn't help. And if this is one of the few forums on the planet where I can come to that I should be able to say, no, I need you to accommodate me. I can't accommodate you because accommodating you is killing me.

I have something written. I will try to read it as quickly as possible. If Liberty Goodwin hadn't pleaded with me to come to this hearing, I wouldn't be here. She begged me to give this one more try.

I have had a hard time believing that you care for my perspective. If you all chose to -- if you all choose to become irate with me and tell me your hands are tied and it isn't fair to blame you for inaction, I wonder why other places have successfully protected the rights of the chemically challenged.

I have expressed this problem at previously Governor's Commission on Disabilities hearings through the years, whose locations were chemically inaccessible to me, and to Bob Cooper personally. No, I am not well enough to draft legislation and pursue this on my own. I can't even enter the state house without becoming ill. I have been getting progressively sicker for the last 17 years. My life is getting smaller and smaller like a little dot on the old television set as it closes. I am winding up with no life. I've committed no crime. And I am dying and I am in prison. If you think that I'm being dramatic, I'm not.

MCS is the bastard child of disabilities. It is invisible, abstract in request for accommodations are dismissed, ignored, or met with hostility. I am treated like I'm crazy or have obsessive-compulsive disorder for germs. There is no public education.

I know you catch more flies with honey. But I'm at the end of my rope. If I offend anyone, it isn't intentional. I am running out of places where I can safely go.

Repeated exposure is taking a permanent seriously debilitating toll on me. We don't live long and we don't live well. We live in isolation. People become very socialized with us and tire of having to be aware of their surroundings when with us.

I have been told things like, I wouldn't have asked you to the beach but I like my sun tan lotion; what do you mean I can't use the bathroom here and get back in your car? Why do you have to move to another table again? You know, we can't control the world. Why don't you stay home. The Department of Health has been no help. The Governor's Commission on Disabilities hasn't been any help either.

The same barriers to disabilities that would be met with outrage and an outcry from the public have met -- would be met with outrage and an outcry from the public. I have met with the Governor to no avail. I got a letter that said thank you for your time. But we don't have control over the products used by the state governments.

It is a nightmare. To be sick, need help, and have no recourse. I have been told to try and pass legislation to try this. What is the ADA?

I keep -- passed the buck. We don't have control over the cleaners or we have to use these products. The injurious products are unregulated by the federal agencies that the public assumes is protecting us. Other countries demand that products are proven safe before being inflicted on the public. Here perfumes are trade secrets and deodorizing wipes are virtually unregulated. Candles, air fresheners deodorizers are not a constitutional right. My rights to equal access are denied daily. If people knew what was in these products and the long-term effects on all of our health and the impact on the environment that how ineffective and counterproductive really were, they wouldn't use them.

The advertising and sales aren't regulated for this modern day snake oil that a fear filled public feeling out of control uses to calm their fears. The proliferation of products in just the last few years is mind boggling.

The effects of an exposure can last for days. I don't even fully recover from exposures anymore and my health is deteriorating. My short-term memory is shot. I have trouble searching for words. I have trouble becoming comprehensible at times. I tire easily and I can't accomplish much. Each day I have to decide how much exposure I am willing to endure in order to have some semblance of a life.

I get headaches, suffer cognitive impairment, balance problems, asthma attacks, behavioral changes, nausea, severe muscle spasms, dizziness, hallucinations, lose bladder control, have chronic pain, swelling of the joints and brain, vision distortion, concentration problems. I get screaming diarrhea. And I become disinhibited. I can either be screaming or crying.

I cannot shop in most stores anymore. Stop & Shop, I don't know what they use in the cleaners. If you blindfolded me and put onions in front of me, I could tell you what onions are from their store. Shaws has decided as a service to their customers to now put scented disinfecting wipes at the entrance of every store. And I'm sick before I even walk in. The carts have the stuff all over it. And when I discussed it with them and talked to the EPA, their customers like it, they said. The stuff --

Audience member: You are supposed to wash your hands after you use them.

Dori Blacker: That's right. After I called the EPA that said that wasn't a federal regulation. They just put that on there. The problem is that they don't even work. They are supposed to be a service contact wet for ten minutes when you wipe it on there. It's not working. I don't know how many mothers don't realize they are not baby wipes and they are not wiping their children's hands which go in their mouths.

I can't shop at Shaws. I can't shop at Stop & Shop. Whole Foods to me is the worse because the public thinks that if Whole Foods is carrying it, it's safe. And Whole Foods has become the biggest perfume, candle store on the planet. I have been in a Whole Foods store where a deodorizing metered spray sprayed on me while I was in the bathroom, after I asked is this still working. They said, oh, no. We don't know why that's still there. And it sprayed on me while I was in there making me so seriously ill for days, it wasn't funny.

I can't go to a pharmacy. Think about that. A pharmacy. I can't use public transportation. I can't work. I can't live in contiguous public housing. I can't go to the doctor. I can't access physical or mental therapy. I can't safely see a gynecologist, a dentist. My teeth are rotting in my head and it hurts to eat.

Every moment of my life I am enduring physical pain that would probably drive most people insane. I am afraid of anything that will happen that I have to use an emergency room. I can't use that. I can't stay in a hospital for treatment or to even visit family and friends.

At my father's death bed, he lay there for three days dying. If that wasn't bad enough to endure watching my father die, they had to keep coming in and lotioning him every two hours.

And I had to ask them to stop that. I have no idea how that may have affected it. But they didn't have unscented lotion. I had to stop them from cleaning the toilet, even though it was a private room. And the respiratory therapist wore so much perfume I couldn't believe it. And she was so hostile that I couldn't get her to leave the room and she kept standing in the doorway. She kept coming back. It made a terrible experience even worse.

Rhode Island Hospital, I was going for physical therapy for my chronic pain. They decided to put in paint and new carpeting and then have the -- to send me the MCS sheets and say but this stuff is safe. It isn't safe for me. Which meant that my care was -- I was basically abandoned. I had abandonment of care yet I couldn't do anything.

I can't take my car to the mechanic. I can't go to the movies because even if I go to a midnight show, the cleansers that they use permeated everything in there to the point where I -- I can't stay there for five minutes. I can't go to the theater. I can't dine out. Handling money is a horrible experience. I cannot lobby as a United States citizen. I can't go and lobby anywhere because of all the stuff that's in the state house. And I can't participate in public forums. Just like I'm paying for being here today. Trust me.

I will be so sick for the next couple of days, it isn't funny. I can't take classes. I suffer dire consequences. Those handicapped accessible bathrooms aren't accessible to me. Deodorizer soaps, there are lotions in state offices in the bathrooms. Why do they need the lotions?

I can't ride the handicap access buses and shuttles that are new rage and outdoor festivals and events. One of the few festivals to enjoy they replaced handicapped parking. They say, you park two miles from here and we will ride you down on the bus. Then the police don't even listen to any of it.

Imagine having screaming diarrhea, not being able to use the toilet anywhere. Imagine being sprayed by a metered dose deodorizer against your will in a public bathroom. And I'm almost finished.

I have been asked, why don't I wear a mask and gloves? Well, they don't help. The products are out gassing fumes that cling to my hair and clothing and enter my system through the body's largest respirating organ, which is the skin. Burning my eyes and sinuses. Why should I have to wear a mask and gloves? There are ramps and curb cuts and rails for people with wheelchairs. But I'm being told that I have to do something differently.

There is no funding for treatment or assistive technology. We pay for everything we need out-of-pocket. Department of Human Services, Department of -- the Disability Law Center, the Human Rights Commission, ORS, PARI have been of no help. We fall through every crack imaginable. We get none of the legal technical support and emotional help available to other disabilities.

My loss of mobility and the ability to function physically and mentally is devastating. I'm tired of my disabilities being discriminated against. And not given the same attention and help as others. I'm so afraid that there will be no place left for me to go. Thank you.

Liberty: Questions? Thank you, Dori.

Health Care

Eleana: I have a question. What kind -- are there any healthcare providers in the state of Rhode Island that can treat you?

Dori Blacker: No.

Audience member: Did you go to alternatives by -- did you go to allergy alternatives? I haven't gone there myself.
Dori Blacker: I haven't heard of them. I'm unemployable and I have Medicaid. And places don't accept Medicaid. And the ones that do that are out -- the people that treat out of state you either have to get permission from the state to go out of state. And then they don't accept the Medicaid because it doesn't pay enough.
I have done internet searches for people in Massachusetts and Connecticut and I've called them and they don't accept my Medicaid.
Eleana: There are healthcare providers in Massachusetts and Connecticut who could be helpful but they won't accept -- is that --
Dori Blacker: Yes.
Male speaker: Part of the problem at least I've seen Harvard medical professor who's a National Institute of Health lead research on this. There's really very little -- it's not like diabetes. You can take insulin to prevent the symptoms. It's not like heart you can take natural glycerin.
There's really not a preventive treatment. Avoidance is really the only treatment. What doctors can do is give you medicines to try to deal with --
Audience member: Just cover it up.
Male speaker: But there's not a treatment per se to make it easier to go out.
Female speaker: That brings into the other problem we have a lot of problems with taking medications. I personally find that alternative methods have got to be the greatest. I have MCS also. I find holistic medicine in the state of Rhode Island is not friendly towards holistic medicine.
Female speaker: The other problem is it's not regulated. And so when you go to these places, a lot of times you feel like you are actually being treated like a Guinea pig. And there have been people who said, we are for MCS. And actually they got their study going that's actually trying to discredit you.
Audience member: Right. I agree with that.
Audience member: The other thing is the place like alternative healthcare or whatever --
Audience member: Allergy alternatives.
Audience member: Whatever their names are. They are healers. They are not Medicaid -- Medicare doesn't pay for it. And also you can't be officially documented.
Audience member: One of the --
Audience member: You don't have official documentation if you have to go to a medical doctor.
Audience member: One of the medical doctors that I went to for treatment is Dr. Jeanne Hubbit.
Audience member: She's extremely expensive and doesn't take any health insurance or Medicare.
Female speaker: Well, you know what. You have to balance.
Brian Adae: I'm sorry to interrupt. I just want get some idea. I didn't get a chance to introduce myself. I am Brian Adae. I was just --
Audience member: Could you speak up?
Brian Adae: My name is Brian Adae. I am a staff attorney with the Disability Law Center. I am one of the panelists, even though I don't have a name tag. What I was just wondering, just so that we can get some idea of who's speaking, if you could identify yourself if you haven't previously identified yourself.
Female speaker: I am Dori Blacker.
Brian Adae The other people who are speaking, as we got a colloquy going back and forth.
Female speaker: Every time I called your agency, I get a letter explaining why your agency can't help me. I'm amazed the amount of time that's spent by the staff -- (APPLAUSE) that can't help me. I'm not assaulting you. But it's just been the most frustrating experience.
Brian Adae: Allow me to, if I may, perhaps I can give you an overview of what the Disability Law Center does do and does not do.
Liberty: Can we keep it brief because we are running a little --
Brian Adae: Can I simply ask that the speakers identify themselves. That's all.
Audience member: By the way, I'm not scheduled to speak. But I just want to say one brief word.
Liberty: Your name is?
Rita Verone: What I hear her saying and -- a few others too. It's almost as if you are always on the defensive.

Now I'm much older than many here and yet I have taken some command of my life.

And I can go most any place as long as it's reasonable. What I do sometimes is I will take an 85 11 3 M mass and if I see -- if I detect something that I shouldn't be near, I have that. But I think if there was a resource that would help you initially take command of your life. The other things won't be quite as bad. I really do. But anyway, that's it.

Liberty: What is your name?

Rita Verone: My name is Rita Verone.

Liberty: Thank you.

Did you wish to -- can you, in just a few words, explain what you were going to say about what your --

Brian Adae: The disability and what's -- what was put out previously that there is no help. If there's sufficient medical documentation, there are a number of things. The Disability Law Center in Rhode Island is part of the national protective and advocacy system for persons with disability. We are essentially federally funded. We are a nonprofit organization. We do advocate through legal based advocacy on disability related issues on behalf of persons with disabilities. There are certain legal qualifications that are required for that.

If it's of assistance, and I would encourage anybody who is here, we have our annual report. In addition I brought along our surveys that we are now sending out that identify our -- that help us identify our annual priorities. And I would love to hear from you and have you complete some of these, if you would like to send them in. This will help us --

Female speaker: One of the hardest things to do is get medical documentation.

Liberty: Dori.

Brian Adae: If I could finish the story. I just want you to know – let me explain a little bit. I recognize that medical documentation, that the expert evidence that is necessary sometimes to go into the legal system is difficult to obtain. But once we have -- if there is medical documentation, we are able to do certain things. Now I'm cognizant there are people that have raised issue that they are going to alternative or holistic medical providers. Not all of those are recognized unfortunately by Medicaid, Medicare. But in the event that they are recognized or some of the medical treatments that are recognized by Medicaid, if they are not available in the state, it is possible to get a Medicaid waiver to go out of state. Those are some of the things that we can do.

And one of the earlier speakers was discussing accommodations at his workplace. While they are difficult to come by, that is something we can advocate for under the ADA, for workplace as well as access to medical treatment.

Audience member: How about funded housing?

Liberty: I suggest people should contact --

Audience member: Can I have your card?

Liberty: Contact the Disabilities Law Center for further information if you need it. Because we have a number of people waiting to speak, I want to be sure everyone gets their time. By the way, can you please correct -- Dori Blackman who's name is Dori, not Doreen.

Female speaker: Liberty, it's really important. One quick thing is it's really important to understand that you can -- it's difficult. But you can get permission to go out of state. But that still doesn't mean that a doctor will accept a Medicaid. They can refuse you.

Liberty: You did say that, Dori. We understand that.

The next speaker is Val Bruzzi.

Education & Employment

Val Bruzzi: All of the things that people have said so far I have to tell you, I feel the effects of because I am chemically sensitive with environmental illness. And fortunately for me, I am still working because I -- I've pushed -- I work in a school department. And I wasn't always like this. You know that. Because people tend to look at me and say, she looks very normal. And because I keep -- I work at being healthy. I work at keeping myself from getting sick because I have kids at home.

Like he said, I couldn't go to my son's graduation. I couldn't -- I can't go to church. I can't do -- I can't take them to the movies. And you know, I always seem to try. That's one of those things you do. You try to go to events with the family.

I went to Disney and -- which is a really bad thing for me to do. I can tell you, it was the worst thing. I ended up in the emergency room. I ended up -- they put a sheet on me with bleach, that was washed in bleach. I ended up being even worse than I had gone from going to Disney. You know, you have kids. That's one of their things. And fortunately, for me that the emergency room they took me to was aware of chemical sensitivity. And they realized. Took the sheet off. Gave me oxygen and put me in a room that they had just for people like myself.

Audience member: What hospital was that?

Val Bruzzi: In Florida.

Female speaker: Fortunately for me I didn't end up maybe dead because that's what could easily happen. It's like a bee sting. See, people who don't understand it. I can only relate it to as a bee sting. I teach school. And in fact one of the people work with me. And I can tell you, the kids understand it. My co-workers do not.

This year I was -- these past years I have been tortured by my co-workers because they -- I had to share a room. And they wanted the room to themselves. And they knew how to get me out was by opening all the windows, opening the doors while the kiln was running. Opening the doors where they know that the exhaust down the hall is from the shop, auto shop. This -- not only -- and also using rubber cement. If you know what rubber cement smells like, and you know what the chemicals are in rubber cement. I ended up in the emergency room again and having to be put on oxygen.

Audience member: Excuse me. She's not exaggerating because she took over my job. The exact same thing for me for eight years. And everyone said, I'm paranoid. I'm staying out here because I must have something that's bothering somebody. I apologize. I just wanted to get that in. She's not exaggerating. She's making light of it, as far as --

Accessibility

Val Bruzzi: I can just tell you, my family, my children have the hardest time because their friends -- I tell their friends. I have to say, like you talk about the cologne the kids come into, with on -- my kids' friends don't are -- are not allowed in my house if they have any scent on. And that's a fact. And they know it. They actually try very hard to keep a separate set of clothes to come hang out with my kids.

I want you to know that in the past two years, I've been actively trying to get help by the government. I called your office. I called your office. I called OSHA. And fortunately, unfortunately for us, there are two OSHAs. Okay. One for -- that handle all the people outside of the state departments, and the OSHA that takes care of all the state department buildings. And the one that takes care of the state department buildings is very lax.

And I can tell you that I would never be like this if there wasn't a faulty furnace in our elementary schools -- two of our elementary schools -- in the first place. I wouldn't be like this if they had done what they had done in New Hampshire with tools for schools to actually be proactive parents to get the schools healthier. Because maybe I wouldn't have been exposed as long as I was to low levels of carbon monoxide.

I have all my documentation from my doctor, who is a professional physician, who does both holistic healing – holistic medicine and -- alternative medicines as well. And I got his name from my friend, because we didn't know what was going on. Who was a professional with one pound babies in New York, Roosevelt Children's Hospital. And the pediatricians there gave the three names. One physician was in Canada. Another group was in Texas. And the other one because out of Boston.

He was helping the Brigham & Women's Hospital, women's hospital. The nurses there who had all that -- and they won that case. Recently this woman that's been totally harassing me at work because of it, I had enough. And I went and filed criminal charges against her because of what she was doing to me. In my workplace to try to get me out and get me sick. Because my students who were more caring than a teacher actually helped me out and said, this is wrong. Because they didn't want anything to happen to me.

Now when I went to your office and I called your office. They told me you had to be unemployed because they didn't handle that kind of case. When I called up the Governor's Disabilities Commission, they just shifted me around to everybody. Every office. I went to every office -- I'm going to tell you I documented every single phone call that I made because I keep a journal on this.

Now what happened with that -- I actually filed -- Paula, what was it? Restraining order. I'm sorry. I'm like everybody else. I'm bothered by the air in this room. I filed a restraining order and the judge gave me it. Okay.

Liberty: Val, we now have over -- we have one more hour. I am going to have to insist that people keep within five minutes. And I am going to ask someone to be a timekeeper. Will you do that, Chris? I'm sorry. I really want to hear. If you have more to say, the Commission will receive, you know, written comments as well. That

will be considered.
Female speaker: That's funny you say that we send written comments. We do everything. You know what? The people who are chemically sensitive, a lot of people are not here today because they can't be here today. This room is just a small little snippet of what is out there. And I'm talking about kids, adults, that are hurt by this.
Audience member: I actually have a suggestion. I think -- you are right for the rest of today. But I'm also getting emotional. I think -- access for us would be a recorder -- a nonperfume recorder comes to our homes and records what we have to say.
Female speaker: I agree.
Female speaker: Or in e-mail.
Female speaker: I think your right.
Audience member: I want to speak. But I don't know how to present myself in this environment and also I don't have time to write reports for you. I would like to help. I have a lot to say. But this is a very difficult -- it's like holding a hearing on disabilities access on a third floor with no ramp has.
Female speaker: That's exactly true. It's true.
Liberty: I really understand the problem.
Audience member: A suggestion to take care --
Liberty: We will be working with cooperation with the Governor's Commission. We and the -- the Toxics Information Project and the Lung --
Female speaker: Can we ask --
Liberty: We will be working in accommodation with them to do --
Audience member: It's a -- with home visits.
Liberty: I encourage everyone here to contact me, Liberty Goodwin, Toxics Information Project and there's some flyers over there.
Audience member: What's your name again?
Liberty: Call me. I will try to follow up.
Dori: I offered to videotape people's testimony because I think that's stronger than tape.
Liberty: We will try to make arrangements like that if we can.
Audience member: I didn't mean to interrupt. I just wanted to say --
Liberty: We will be focusing in 2006 a major part of our concern will be -- I'm thinking of calling it breathing is not optional campaign, to address these kinds of -- however for now, we have limited time. We just have to do --
Audience member: I hear that.
Liberty: I am going to have to ask the next speaker --
Female speaker: Can I just end? My conclusion is that my husband said to me, why are you going to this meeting? I said, well, I think I need to speak because it needs to be heard. But he said to me, nothing gets heard. Now you all are here on this board and you are hearing testimony from a smidgen of the population. And you need to really address it on a state level because it's not going to go away. It's going to get worse.
Liberty: There are estimates that the number of people affected by chemicals will go from -- it's about 15 to 20 percent now. It may go as high as 50 to 60.
Audience member: It's 30. It's going to go as high as 60.
Liberty: That's what I hear. Eventually it could be at least half the population.
The next person who signed up to speak is Cherly Grove.
Cherly Grove: That's me. Hi.

Accessibility

I think you all have gotten to experience the emotional – I have a problem with this word, anyone help me out. Liability, emotional. What's the word? Liability. That is oftentimes one of the adverse health effects of the fragrances which are no longer extracted from roses and flowers and things like that. The EPA and Stanford University have published numerous reports that state that its fragrances are primarily derived from a very inexpensive chemical called xylene, which is a known neuro toxic. So what you are seeing is a neuro toxicant reaction by people that are in the most susceptible population in our society.
Now, I don't use the term multiple chemical sensitivity, even though it's a very logical term. It is so biased and

discriminated against now. It is outrageous.

So I stick with EPA qualified terms. And they use the term chemical sensitization. You can be sensitized to a class of chemicals. For example, if you have been sensitized to formaldehyde. You probably have cross sensitizations to asataldyde, gludahyde, disinfectant in the hospitals.

That being said one, of the common building material off gassing emissions is called Tuline. If you pick up the NIAGE pocket guide to chemical hazards, it says symptoms, irritation of the eyes and nose; lassitude, which is weakness and exhaustion; confusing, euphoria, dizziness, headache, dilated pupils; lacrimation, which is discharge of tears; anxiety, muscle fatigue, insomnia, dermatitis, liver kidney damage. All of this data is readily available and readily accessible. There's a really nice one page summary -- pardon me?

Liberty: One more minute.

Cherly Grove: There's a really nice one page summary that was linked from the American Lung Association on indoor air pollutants and area health. It's not just MCS. It's related to people with diabetes are more sensitive to cardiovascular effects from air pollution. That's from the National Institute of Health. Women's health. Autoimmune diseases linking to the environment. Parkinson's, Alzheimer's, and other neuro degenerative diseases.

Breast cancer, estrogen, children, health, SIDS linked to nitrogen dioxide pollution. Breast cancer, thyroid. It goes on and on. So it's everybody's problem.

Now, here's the problem. Because the doctors aren't trained in this, and the legal community requires the MD, doctor expert opinion, we are running into a complete lack of accommodation for a disability, which is estimated at 11 million American citizens have moderate to severe chemical sensitivities. That was an estimation published in a well -- reputable national disability organization.

In Rhode Island alone, at the may -- better breathers meeting, over 50 percent of the people there with the diagnosis of COP, the chronic obstructive pulmonary disease, expressed a life altering -- life altering chemical reactions --

Liberty: I think we are going to have to stop.

Cherly Grove: I would like to have some equal time because – I heard a lot of other people. I need two more minutes.

Liberty: There are other people. There are 12 other people. We have less than an hour.

Housing

Cee Grove: Then I think we should extend the program. Give me one more minute. We've already wasted that much time. This is a nationwide problem that needs to be addressed here also. Attorney Generals are suing HUD because the properties are not accessible. Radio D J. Just won a 10.6 million dollars award in federal court against perfume Xylene. There's a lot of things going on. So why are we so alone?

The national green communities initiative has allocated 550 million dollars for 8,500 affordable environmentally friendly homes, also called asthma friendly homes.

In Massachusetts 209 million dollars, 1,000 green low income homes. Massachusetts has a toxics use reduction act. Massachusetts, Harvard Law just got a secondhand smoke person evicted from a property because of the drift of their smoke. What happened --

Liberty: Cheryl, I'm sorry. I have to ask you to -- yield to --

Female speaker: I couldn't get any support from any organization in this state.

Liberty: You have to submit any additional comments in writing because I have people who have a right to speak here. I'm doing the best I can.

Audience member: Can I just make a quick announcement?

Somebody has a red SUV. It is parked in the wrong place. You must have one of our pieces of paper in it or else they would not have come here.

Audience member: I'm in the lot. I don't have a red SUV. I don't have a piece of paper in it.

Brian Adea: I have a red SUV. Which lot was --

Audience member: When you --

Brian Adea: Take a left.

Audience member: It's all the parking on the right-hand side.

Liberty: The next speaker will be Susan Hurd.

Susan Hurd: That's me.
Liberty: We will have to keep it in the five minutes.

Accessibility

Susan Hurd: To help you folks out, I went and photocopied information that's pertinent, that could help you better understand the different statistics. I also have a letter that I couldn't get photocopied [i]. But if you would like to photocopy, it's all there. I have been disabled with multiple chemical sensitivity since -- for around 12 years now since 1994. I was 27 years old. I was very young. I'm now 39. And just like all these other people have said, I experience the same things. I've had my isolation. There was a woman here in the room. Someone in this vicinity. Numbness and tingling because of some laundry soap or fabric softener. This is a common occurrence that happens. Because I took the time to photocopy last night, I had insomnia.
I had burning cheeks that were all puffy right up to this morning. It was hard to be here. It's a miracle that I made it.
I appreciate you all coming and listening. It affects every part of our lives. I have been fortunate enough despite that I'm on disability, I receive a little over $600 a month, which is an insane little amount. I'm grateful that there's a little bit of money there. But it's not enough because when you have chemical sensitivities like people said. You can't always get adequate medical care, food. Personal products can cost more money. It's a lot of out-of-pocket expenses.
Fortunately I have doctors who have lowered, wavered fees, very good people. I am improving slowly.

Education & Employment

I am in school. I am in the holistic mental health counseling program at Salve Regina University. I am making progress. People try their best to be fragrance free. There are nights I come home from classes I have insomnia. I have digestive problems, rashes on my faces.
I'm doing the best I can. I have made it so far. I'm going to be in my third year of school. It has been a miracle that I have come this far.
It took six months for me to find an internship. All the typical counseling agencies would either say they didn't want to make an effort to accommodate me or they simply couldn't because of new carpeting and poor air quality.
I am going to be at the Rhode Island Rehab Hospital. Dr. Riffel has a wonderful integrative holistic model. And I once was in his program.
Another point -- a lot of people have severe food allergies. I have a severe peanut allergy. So on top of all of my chemical sensitives, I can't ever eat out. Someone pulls a peanut butter sandwich out, my throat tights up.

Health Care

Green care doesn't happen in the hospitals. It needs more education. Some hospitals are -- there are articles on green healthcare and websites in there for you folks.
One thing that happens when I go to the ER, Miriam has some very good doctors. However they do need education. A safe area in any of these public areas would be one way, just like we used to have nonsmoking areas. A safe area in the hospital is a good way to start. And in other places, public libraries, a safe area. It's not the ideal, but it's a beginning.
Having to think out of the box is what is --
Liberty: One more minute.
Susan Hurd: So when I go to the ER, doctors will be eating peanuts, peanut sandwiches. Peanut butter crackers are given to diabetics. I have a lot to deal with. It's amazing that I've come so far.
People don't understand the FDA does not regulate cosmetics and fragrances. Fragrances can consist of 4,000 toxic chemicals. 60 percent of what goes on to your skin is absorbed in the bloodstream. 30 percent of the U.S. population is chemically sensitive to one degree or another. And is predicted in 10 to 15 years, 60 percent of the population is going to be chemically sensitive. It's becoming an epidemic that we need to start taking awareness now and address. All the statistics and information are in your packets. I hope you take the time to read it and better understand.
We gave you solutions that could at least be a start. And addressing problems dealing with housing, working with vocational rehabilitation, ORS, et cetera.
Liberty: Thank you, Susan. I think we may have to actually cut down to four minutes because we have finding

more and more people. Olin, you didn't check --

Audience member: I meant to.

Liberty: Did you want to speak?

Olin: I think I will let other people speak.

Liberty: Will you submit written testimony, I hope. Laura.

Laura: There's too many people.

Liberty: Please do submit some comments.

Paula -- I can't read the -- Paula -- Dewell.

Education & Employment

Paula Dewell: I will just -- so you can see what I look like. I know some people are here -- I must -- I am chemically sensitive, but I must have something on – I apologize. I don't know what it is. Hopefully you can hear me from where you are. I was in a situation about ten years ago. I was one of the lucky ones. I've retired from teaching. I taught 31 years. And I vowed ten years ago the school was going under construction. And I became very ill. But I didn't know what the heck it was. I went to several doctors and they all told me oh, you know, it's asthma, which I never had.

I was extremely exhausted, forgetful, just feeling -- I couldn't even explain. And what I was out -- now and then, eventually the school nurse said to me, I think you have chemical sensitive. And I said what is that?

I found a doctor in Massachusetts. Because of him I was able to -- I am better. But I listen to these other people and I get very emotional because I remember being there. I remember not being able to go to church.

I have a young child that I couldn't do a lot of things with her. She was hospitalized at one time. I had to stay -- it was very difficult.

I guess because I only have five minutes -- the point I want to make it was a very sick building. It was under construction. Either five teachers had to retire, were fired, or I was the last one standing.

Once you become chemically sensitive, I was a person that they would look to for advice on curriculum and what to do in terms of safety because I was starting to feel some effects. And I really tried to clean up the classroom. I was an art teacher, which you can imagine. I can't even get -- when I was a kid, I used to wash my hands in it. I was exposing myself not knowing.

The school system once you become chemically sensitive, you are labeled as crazy. And nobody ever told me I was crazy before that. But all of a sudden I became crazy.

There was a wonderful chemistry teacher. They wanted my husband to take over the physics job. I said, isn't that the room that she was in that she got sick?

The guy said to me, Oh, she's just crazy, even though they had to carry her out of the school a couple of times. If they acknowledge chemical sensitive, then they would have a liability and they don't want that.

I'm still fighting it. I'm out of school. I still have people calling me in tears. When they couldn't get me out legally, I was pretty tenacious. They got -- they tried to -- they literally tried to poison me.

The then coordinator actually changed a proved school committee curriculum to say instead of closed doors, to keep toxic supplies -- the smell of fumes in, open the doors. It would -- they actually -- you have proof of all of this. It's amazing. It's so blatant.

And I see the kids that aren't feeling well. We -- they can't prove it. We are bringing up a generation of people. Some would go to hug me that wouldn't see me for a while, maybe had gone on to college. My face would blow up because they had perfume on. I tried to explain, you know.

Accessibility

My daughter was in college. She got married and someone, you know, I had to -- on the invitations, please no perfumes or colognes. It's embarrassing. You feel like you are so different. I'm not as isolated as I was. I can live a fairly normal life.

Thanks to a very good doctor. I spent tons of money getting well. And I mean ten, 15,000 a year for a couple of years. I had a very supportive husband. Most people get divorced over there. Their spouses think they are crazy or lazy or both.

I think especially important for school systems, schools are not safe places for kids. And you know, no one listens to you once you become ill.

So, I have quite more to say but, just to give an idea what people are saying here are things I felt emotionally. Most of -- they think we are crazy because we are in tears. We are emotional. But picture yourself in this kind of a situation. It becomes a very, very difficult thing. Again I feel very lucky to be not as -- I can be a spokesperson. I can work with departments. I can volunteer. I'm retired now.

I work at RISD. I'm very good. They give me special rooms. They give me air-conditioning. My students don't wear perfumes. Summer classes and evening classes. They treat me very well. Extremely different than when I was treated when I was in high school. Anyway, I will stop talking. Thank you for your time.

Chris: Liberty, next speaker please.

Liberty: I'm sorry. Okay.

Chris: Thank you.

Liberty: The next speaker will be -- is it Glen?

Glen Dewell: I'm Paula's husband. I will be a little cynical here because it's very nice of you to hear all this. But I don't know if it's anything more than nice.

Family & Community Supports

As Paula's saying, we went to the Department of Human Rights. We went to the Department of Education, Human Rights Commission, et cetera, showing that this person, this coordinator in Cranston literally falsified the art department safety procedures to try to create a situation where chemicals they knew would get my wife sick, would get into her room, and nothing is done.

So for you -- I understand what you are saying. The bullying that goes on is incredible. But if you can't even deal with someone in position in the City of Cranston, for example, won't even deal with what's going on, how can you expect any of these people to feel there's going to be help coming out of what's going on.

So it's extremely frustrating. I'm not chemically sensitive. I don't have asthma. But I see what's going on with the kids in the schools. And I see how irresponsible people are when they turn their back on people who deliberately harass. Deliberately harass, not by mistake, not -- I'm sorry. I didn't know -- but deliberately harass all the people here.

So that's my great frustration. I'm not going to take any more of your time. I would rather hear other people.

Liberty: Thank you. Eleona Bresler.

Accessibility

Eleona Bresler: I am going to try to stick to the time. I really want to emphasize what I said before. I really think someone should come to those homes, videotape or take information. I have enough trying to deal with my own life and my own problems, so I don't have a lot of energy to give, I will say. But there's a lot of us here and we are a wealth of resource for this. I have been frustrated in the past, similar kinds of situations where people say they will study something. They ask you once. Go off to be the experts. And they don't know what they are doing.

Everybody's hearing from us. But stay in contact with us. Keep asking us what we are learning. You know, we have -- like probably a thousand years worth of experience among us injured parties in the state. And rather than reinvent the wheel, ask us. Don't waste this experience.

I want to be very quick here with some points. First of all I believe the reason I'm sick is I grew up under the Laguardia Airport and the jet fuel was on everything. Also I lived in very poor housing. And we had cockroaches. My mother was clean and she sprayed all the time with Raid everywhere because she didn't like bugs. And I grew up with that.

Also there's a component that I had to mention because it's very sensitive. There's an element to emotional trauma to this disease also that children's -- small children who are severely emotionally assaulted, physically, sexually, losing a parent, whatever. Before the body is formed, when the defense mechanisms of the body are very unshaped, sometimes the body will attack a smell. It's like a memory associated with an incident. Very sensitive issue because you don't want to be going around accusing people of being emotionally damaged because they have a perfume allergy. But that is a possibility.

I have seen that a lot. That's an area that needs to be researched as well that there's a whole aspect of this. The body's a very complicated thing.

I have had incredible trauma in my life. I am getting better. Someone needs to really follow those of us who are getting better. There's no magic bullet. I do a lot of things that are recommended. But I don't understand why I'm getting better and the woman who was in the corner is still horribly tortured. It's very hard.

I spent a tremendous amount of my time cooking from scratch and know going here. And sometimes it works. Sometimes it doesn't. And we learn from each other. And -- it was like -- I was like half like talk myself into coming here because not only am I getting affected by all the smells in this room, but the emotional thing of remembering all this painful stuff I don't need.

I lived on a porch for a year and a half. I didn't have a bedroom I could sleep in. My downstairs neighbor would come out and smoke under the porch on purpose. The nature of our world is that the air belongs to everyone. The world belongs -- it comes out in other ways too. If you don't want to look at certain things, tough luck. Somebody's allowed to go down the street in front of you.

That's your luck. The air's the same way. People can wear perfumes.

You can't legislate everything. But we need to have more respect for each other and sensitivity. That's an intimidating issue. That's not modern society. People are afraid of legal liabilities, admitting there's an issue, afraid of admitting. It's a scary world.

You have no choice to breathe what came out of the truck that went by or the person sitting next to you. And -- I don't want to get off too much on that. We really share the air and there really isn't a tendency to do first and think later.

I worked in science. I was also affected in a laboratory accident. And, you know, you do the experiment, blows up. Everybody gets sick. Maybe there was something we should have done there. No one thinks first. They do it and then find out.

My current problems are -- I just want to try -- things people haven't already said. I live on Hope Street. When I moved here ten years ago, it was a relatively residential street. They built this Providence Place downtown and built up downtown for whatever the reasons they believe it will benefit the city. There's now so much traffic on the express way. Everybody gets off rush hour morning and afternoon and drives down Hope Street.

I can't breathe in my house anymore. We will probably have to move in a year if this keeps up. It's affecting my ability to think. Arthritis. I am more reactive to my environment again because my whole level of chemistry is up. I have just cardiac arrhythmia. I was hospitalized. It turned out chlorine is one of the big things that's contributing to that aspect of my problem and car exhaust is full of it.

Something I have not heard mentioned that I don't know if anyone tested. Those new energy efficient life bulbs we are all supposed to use. Some of those when they burn out, it smells like a melting insulation factory. I can't imagine what's in those.

There's one minute? Oh my goodness.

So those are two things I haven't heard. I encourage everyone to read Arthur's web, which is about chronic fatigue but explains a lot of the politics of these kinds of things.

This illness is heavily affected by women. Some men but many more women. And anything women get is not always treated so well.

And just to name three quick things that I think need to be looked into in search is beyond the politics and the consciousness raising and education is very little is being done about interactions between chemicals in the environment. This is safe. That is safe. What happens when they are in the same room? The virus component of things.

A lot of people -- understand more computers have viruses than you can have. A virus can insert a strip of DNA into your own genetic things years earlier. And then later when a situation happens that your body needs that area of energies, it opens it and brings out a reaction.

So this could be something that's implemented -- it's not just the assault of the chemicals in the environment. But it could actually be viruses implanting in our problems that are -- I'm not explaining this very well because I can't think in here. I'm sorry.

Another thing that I learned about -- I went to MIT. Someone there was doing research at something called electrophoresis that in a strong magnetic field the chemical nature of the cell walls change. So that -- this is another interaction as we live in a more and more electrical environment with cell phones and TV, a million signals flying through the air. The actual transport mechanisms of what your body allows to pass through your lung membranes or into your actual cell walls allows chemicals that would not normally go into you to affect you. And it may be why some people do better in the country even if there are still chemicals around.

Liberty: We have run out of time. I'm sorry

Female speaker: Thank you.

Liberty: The next person is Marie --

Marie: I think we should take a little break so your people can stay awake while they are listening to us.

Liberty: We don't have time to take any breaks.
Eleana: I would like to say something. In hearing all this, I have been involved in public policy now for almost 15, 20 years in Washington and here in Rhode Island. And a couple things I want to say to everybody. This is -- the same way you are feeling chemically overwhelmed, that's what this is, okay. I'm a kind of action oriented individual. The project that I have is a very action oriented.
The reality of life in public policy is change does not happen overnight. You have to have a strategy. You have to move forward. And you have to -- you have -- information materials that are understandable, really understandable. Overwhelming people with too much information, I think you -- makes people shut down because you just feel like it's so overwhelming, what are you going to do?
I will make a commitment to everyone in this room. Our project is in its fifth year of an eight year project. We have work groups. And what we do with our work groups is we create products and those products can take different forms. They can take the forms of policy papers, information, and the potentially legislation or potentially going to -- I think there was a lot of unbelievable suggestions here on what we can be doing that doesn't take any legislation. But you need to have an advocacy group of people in a formalized setting that can help push this forward.
I am right here saying to you, I am willing to do that. I believe that our -- I can conference in probably six people on a call. So for those of you who cannot come to a meeting, I could conference you in from your homes, if that would make it better.
Again, if you can tell me what we need to do to make a facility -- I know they said don't wear any perfumes here and look what happened. A lot of you are affected. I think everybody's affected by different things, which makes it more complicated. But whatever it is I can do to get more of you involved in this so we can have a product that can actually do something next year, whether it's legislation or if we can get the governor to -- I think there's one solution about changing the products that are being used to clean in the government agencies. I think he's -- governor that wants to be progressive. Wellness is a big issue for him. So I think that we have a very positive way of moving forward.
And if you want to take our materials -- yes?
Susan Hurd: My name is Susan Hurd. San Francisco has now implemented all public buildings to use nontoxic mud green cleaners in all of their public facilities.
Liberty: We are definitely going to follow up on this. I commit myself to working --
Eleana: I wanted to say that to everyone here.
Liberty: We will be working together -- excuse me -- with Eleana and the Governor's Commission. We will -- hopefully is a group that will get together and try to see what can be done. Marie Corelli, Percelly, I'm sorry.

Marie Corelli [5]: My name is Marie Corcelli and I have MCS - Multiple Chemical Sensitivity -I was diagnosis in 1986 - Prior to that I had worked 20 years in the medical field -13 years at Rhode Island Hospital so most of my life was focused on traditional Medicine - As a hobby I sold real estate and was a regional manager for a party plan gift company. I was married for 18 years and divorced 3 years before I got sick. I tell you this only to illustrate that anyone can become Chemically Sensitive. At times, a person can point to a particular thing or exposure that made them become sensitive but I can't. Although I do have a couple of things that I think may have caused it. Over the years I have had to fight many battles to get accommodations.
Today I am here to express my concerns and to share my personal experiences in having to use local hospitals and diagnostic centers.

Health

About 3 years ago -1 had to call 911 - My speech was slurred -1 had difficulty with word search and was experiencing numbness on my left side - My Blood pressure was 240/130 - The first horror of the day was that the people on the rescue was dress in rubber clothes — it was a fire truck that responded first because the rescue was not available - and I was not able to explain things to them -I was lucky that a friend was on the phone and could explain to then that I was not usually unable to speak. They questioned her as to me being able to understand. At the emergency room -1 told them I was sensitive to Latex - that was a mistake - they waited 3 hours for some cart to come from the supply room even before they would draw blood - they did do EKG and CAT Scan - It took them 2 hours to explain what they were waiting for -1 could have told them that my sensitivity to latex wasn't that bad ad they could have used a regular tourniquet to draw blood. This was all conformed and documented via a complaint afterwards. My other encounter was with Rffl emergency room -1 was having chest pain again Blood pressure was up but only slight slurred -1 called my primary doctor and she told me to call rescue and she would be at RM in an hour. I also called my friend (Gloria Stuart) and she came in from the campground - She works with people with disabilities and is trained in advocacy. She has my medical durable power of attorney and she is use to dealing with me when I am having reactions. But she is short and was dressed for camping. Dealing with the rescue and emergency room staff was more stressful to me because they would not listen about the smells of things bothering me. Their answers were textbook responding -1 tried to explain to them but "Well we have to take your Blood pressure" NO, we need to leave the cuff on you" - The smell of the cuff was bothering me. That in it self could bring up the Blood pressure. "No, we have to treat you first before your friend comes into treatment area." But she knows that I can react to my surroundings. Gloria is short and they my have thought that she was just a teenager. The security there escorted her back to waiting area a couple of times - Then she called another friend that because of her background knew enough to call the hospital administration - and the nursing supervisor. This again was the first week in July - there was a power play going on between the resident and the nurse - believe me - I've been in that position and I know how the nurses will let the new residents know what and how they run their unit. The resident OK my friend to cone-in and he was in touch with my primary -When my primary arrived she went and got my friend from the waiting room - They had threatened to remove Gloria from the from the hospital if she didn't sit-down and wait. But it took a lot of stress and commotion to finally let my friend in with me - and it was my friend that realized that the blood pressure cuff could be raising the blood pressure cuff - once the cuff was removed from the area along with a few another things the blood pressure finally started to come down.

I was admitted to the coronary care unit for overnight observation only after my primary doctor requested a private room and that Gloria would be allowed to stay with me. Knowing the hospital I did request "bum linen" and that all scented things be removed from the room. My primary decided not to allow me to be used as a teaching patient to avoid being exposed to a lot of residents. The room was OK - but Gloria did remove the soap and things -There is a book available written by someone with MCS and it may help if you if you were to read it. Another area in which I have had problems is waiting areas -1 happen to use RI Medical Imaging -1 get sick from them developing x-rays while I am having test done in the room next to developing room -1 have spoken to the office manager so now when I go in I wait in her office and they try not to make me wait too long. These are the high points and I do not want to hold up the day –

Housing

But housing is also a HUGE ISSUE - which I have had to fight also but I can leave that for another time - But I have a written agreement with management company as to when and how they will accommodate me. But, that is only as good as the people involved. If you have any questions or want any input on living with MCS I would be happy to share my experiences and thought.

Okay. Since that time, I was really, really bad. I have been very actively disabled community for a while. But then I backed off on the disabled communities. Then I went back to college. Since that time I've gotten my degree in business management and everything else.

But my battles along the way, the main battles have been -- I fought HUD, HUD uses my case history now for teaching people about accommodating people with chemical sensitivity. I do live in subsidized housing. It is a nightmare. But where do I go when I'm living on Social Security disability? Okay. Anybody with MCS, you living on disabilities, you know what I'm talking about. There's no money left for anything.

I was very fortunate that I was able to get to doctors. My doctors are 100 miles away. I am blessed that one doctor in the office is an MD. The other one is a P HD in biochemical nutrition. That's what got me going back in the right direction last year.

Audience member: They did.

Health Care

Marie Corcelli: It was another MCS patient that was at home. Thank God she was at home. She knew her way through the system. She knew what we were going through. She had the brains to turn around, call hospital administration, nursing services and everything else. In order for my girlfriend who has my medical durable power of attorney mind you to be able to get into the room there.

So happened it was July. It's new residents month. We were going through the power play of the nurse and the new resident and this is my turf nurse. My fear now is going back to a hospital. When my primary showed up, I again had been blessed. I finally found a local doctor. She doesn't treat the MCS. But she doesn't boohoo it. She has family members who have MCS. So she understands it. She doesn't mind me using holistic medicine. Her husband's a chiropractor. So therefore she's into all this medicine.

There is light at the end of the tunnel, but it does take every effort possible. I have fought ORS. I have very positive experiences with ORS. I have some negative experience with ORS. I got my bachelor's degree, cost me out-of-pocket $100 over seven years of school, but it's been fighting all the way.

You know, I didn't like what ORS denied. They said it wasn't -- usually paid for by ORS. Well, I'm sorry. I'm not your usual case. I file appeals. I fight them.

But it takes work. And I mean, one person -- I'm sorry. They left. They said --

Liberty: We are running out of time.

Marie Corcelli: They were saying -- I will close. One person can be heard, but it's harder. I have even filed a complaint against Bob Cooper, more or less tongue in cheek because I was taking classes. And I wasn't accommodated. I said I was going to file a complaint. He said, go ahead. And we both filled out the paper. So it can come about, but it runs slow. I'm finding every year there's more and more people. You've got to speak out. You've got to fight.

Liberty: Thank you. Kim Paul.

Kim Paul: Hi. I'm -- I get nervous speaking in front of people, but I do have chemical sensitivity. I tell people I'm just allergic to perfumes and chemicals. How it came about is I live across the street and I recognize your name. Across from -- it was a gravel operation who ran an unlicensed waste recycling facility with construction demolition debris. They have a variety of different chemicals.

Before I knew that was even there, I had some health issues. We just moved into a house. Within two years, I started getting flu like symptoms. Always tired, muscle aches, fatigue. Then I started getting muscle spasms. We weren't quite sure what was going on. Went through a variety of tests.

I get different symptoms, which I don't have enough time to go through all of that. Then I found out about what was across the street from my house. I got from DEM. What they found in the wells. We have well water over there.

The doctors tested me for what was on that property and several things came up. They found arsenic, mercury, lead, beryllium, Falom which has been banned over 30 years, only stays around for two weeks. And it's only used at NASA, nuclear testing, glass companies. It used to be used as rat poisoning, which was commonly used in the buildings that was demolished. There's still debate on whether or not they was on the property. That's another issue. But during that time of going through different doctors, I had hard times going to any doctors here in Rhode Island. I would be there and my symptoms would get worse. I would start having tingling, headaches, different chemical sensitivity symptoms.

And then they finally sent me to an environmental doctor in Massachusetts. And chemical sensitivity, which usually occurs from low exposures to toxins over a period of time that builds up in your fat tissue. And with the variety of -- that had been in there I'm not sensitive to other chemicals like -- acts like a sponge.

Anything I'm near. It absorbs quickly in me.

There is a hospital which I will have to do copies for you later that I sent to. It is all chemical scent free and all that because it's -- of the common chemicals that are in there that they don't know what it causes in your body.

I also had an air monitor at our house for a year. It showed that there wasn't one week that went by that the hydrogen sulfide was present in the air constantly. It was in our shed in back. I would be in the house and I would know, I would get tingling in my face and say that monitor's showing something. And it was at two. And I could feel it, which have very unusual that low.

It's usually -- I'm not sure what the numbers are. I know – I talked to you about it. But it's either the double digits usually before you feel it.

Education & Employment

My kids started having a lot of problems. And I was paying attention to what was going on because I figured if it was in my blood, it might be in theirs. That was in theirs. I talked to several neighbors because it's a rural area. Within 21 houses, there's 13 people diagnosed with cancer. Eleven children with learning and behavioral problems, and an additional child who is confirmed to have ADD. But the other children with ADD is a chemical imbalance. This is a different type. We are not born with it. We are exposed to it. So now we have this chemical imbalance. A lot of different feelings a lot of people get are similar to ADD.

When they started going to school, they were having, because I noticed the different feelings I had. I know I have a short amount of time. This is over -- since '98 this has been going on. With my kids growing up, when we moved there, my youngest he already knew how to add, multiple, all of that. Within a couple years he started getting tired and had a hard time concentrating. My youngest son was one at the time.

When he went into kindergarten, my youngest, and my oldest was in Third Grade, they had suggested both my kids had -- one had ADD and one had ADHD. That's what the school suggested. I read up about it.

It seemed like it was logical, but it wasn't all the time. So I started paying attention to when they act like it. When we go to some people's houses where they have a lot of perfume, scented candles, you know, a variety of different chemicals and cleaning stuff.

And then I noticed my kids would act up more or whatnot, not just normal battiness of kids when they were around that. Then when my youngest son was in Third Grade -- because the teachers, they wore perfume. The schools smell. I would go into schools and get headaches. It's the cleaning stuff. So I tried to avoid it. But I wasn't sure how it was affecting the kids.

And my kids were put in -- my youngest was put in special education. At each IEP meeting, we would discuss different things. I noticed that in the school, all the kids that lived on my street were in the same IEP class for learning behavioral problems. And since -- talking with research studies, different doctors and stuff, there's 98 people on our road who have symptoms to allergies which is a cluster.

But finally in Third Grade when I was talking to one of my son's teachers, he used to take temper tantrums in class. Be fine then take a temper tantrum. Break a pencil. He would be studying. All of a sudden, he can't think or he would start getting -- all right.

Liberty: So sorry.

Kim Paul: Let me just wrap up that part. When I went into the school for parents teacher meeting with my son in the class, we would do spelling at home. He would get them all right. He would get three or four right when it came test time. When I spoke to that teacher in the classroom, within five minutes I went in. We talked five minutes like normal adults. Within five minutes my words started slurring. I started getting tingling, distracted. I literally felt like I was getting drunk sitting in my son's classroom.

And I told her, I said, you know, no offense. I know I sound a little odd now. But it's your perfume. And I said, I can smell those black markers. They are burning my nose. Within two weeks they went back to chalk. She stopped wearing perfumes. Talked to people that we met in the special eds. Lessened with the air fresheners.

My son has reflexes that he is not aware of. When something is bothering him, before he can't concentrate or has a fit or something, he plays with his eyes, nose or mouth. And that's your body's natural response to something is coming to you, and you are trying to get rid of it.

Liberty: Could you just finish?

Kim Paul: Within two weeks we went from removing all that stuff. He went to getting three or four right in spelling, to 100s. No more temper tantrums in school. And my kids are doing better in learning. The special eds that our state has there are a lot of kids exposed to cleaning chemicals, perfumes, different public buildings they go to. There's so many chemicals just the -- of them is overwhelming.

Audience member: A lot of pesticides are used in schools too.

Female speaker: With chemicals in their body already. I can make copies and send them to you where babies are being born with chemicals in them.

Liberty: Thank you very much.

My husband and I put ourselves at the back of the line because we wanted to be sure everybody got to speak. You want to take a few minutes now, Paul. This is Paul Klinkman

Paul Klinkman: You have no idea how lucky you are. This is the smartest bunch of canaries I have ever seen.

Audience member: Do you have the illness or are you --

Male speaker: No. I am able bodied. My wife --

Liberty: This is the husband.

Health Care

Paul Klingman[6]:

Canaries and asthmatics both get sick quickly when they breathe unhealthy air. While the problems of asthmatics are quickly recognizable because they can't breathe, unhealthy air may cause canaries to appear to be normal people exhibiting inappropriate behavior. This testimony covers the known physiology and the social setting behind Canaries' behavior. The first inklings of trouble It seems suspicious whenever chemical exposures immediately make numbers of people sick at the same precise time, and then these same people stay sick for years. Here are two examples:

Michael Eash and his teacher both got sick at school on the same day in New Haven, CT. The school had undergone its monthly Dursban spraying that day. Michael stayed sick. Michael was home−schooled for much of the next seven years and is reportedly almost normal now.

Brenda Jones, RN, and her two kids were all three instantly sick after exposure to a normal application of lawn chemicals near their Florida home, and they stayed sick (for two years so far). The chemical atrazine was used on the lawn. In other cases, massive numbers of people in a particular group gradually become sick, and a single cause for the sickness was present.

Hundreds of workers at the EPA's own brand new national headquarters came down with what was called "sick building syndrome". These workers often have Multiple Chemical Sensitivity. 220,000 Gulf War Veterans complained of illnesses to the Veterans Administration. They were said to have "Gulf War Syndrome". These soldiers also often have MCS. 10,000 Gulf War Veterans are now prematurely dead. We live in a modern pandemic of reactions to chemicals. Asthma, allergies and chemical sensitivity are normal to the human condition, but never were they normal in the quantities seen in this modern generation. Given this disturbing weight of evidence, the government should restrict the use of chemicals which have been statistically linked to illness, until the chemicals are known to be safe. The politics of poisoned air I believe that chemically sensitive people should have civil rights. A canary should have the right to go to a hospital or a nursing home without having adverse medical consequences from cleaning chemicals in the hospital's air, or by heavy perfume worn by a nurse. Safer cleaning chemicals exist. Previous generations of nurses all knew better than to wear perfume around asthmatic patients. This generation of nurses needs to be taught not to do so.

Health Care

A canary should have the right to go to a public bathroom without being assaulted by bathroom fragrances. No class of disabled persons should be denied a bathroom.

A canary should have the right to go to a church, synagogue, mosque, temple or meetinghouse, the right to worship God, the right to belong to a community of worshippers, without the chemical solvents in the next worshipper's perfume, cologne or body scent putting her flat on her back for a week. Neighbors should protect their neighbors' kids from poisoning, out of a sense of both community responsibility and ethical caring. "Love your neighbor as yourself" is a Biblical commandment. I encourage churches and congregations to act in selfless love, and not to cast aside or wound members of their own communities that they love. Nor should they through thoughtlessness exclude anyone from worship with them. If one member of a community can't breathe the air, then perhaps in solidarity other members of the community shouldn't breathe the air. Once when my wife wasn't able to be in a workshop due to fresh paint fumes, I went to the workshop but silently wore a paint fume mask through one workshop session. At other times, when my wife couldn't worship with others due to contaminated air in a room, I've left worship with her. The air was medically hazardous for a number of people, so in my view no one should worship while breathing that air, even those that could be there. God demands that we be a community that doesn't throw away those members who are weaker than ourselves. The toxics in the air might also prematurely end the lives of any of the worship community's members, including its children.

A canary should have the right to use a public airline without getting poisoned on the plane or sickened in the airport terminal. People who were allergic to cigarette smoke once had no right to breathe on an airplane, but then the government made smokers move to the backs of the planes. This accommodation would work for chemically sensitive people. The privileges of fumers should now be weighed against the medical needs of asthmatics and canaries.

Canaries and asthmatics should have the right not to be physically assaulted with chemicals, nor to have a credible threat of assault. An angry man once threatened to spray my wife Liberty Goodwin in the face with his finger on the nozzle of a can of air freshener. He backed her out of a door with what essentially was a dangerous weapon pointed at her. It's possible that the perpetrator didn't believe his weapon would actually do medical damage, but he at least knew that my wife was as afraid of the wielded weapon as she would be of, say, a knife.

A canary should have the right not to be poisoned out of a job by a co−worker or co−workers, in cases where a department budget is shrinking and the co−workers stand to gain financially by hanging on to their own jobs.

An asthmatic or a canary should have the right to enter a polling place to vote without adverse medical consequences. An asthmatic or a canary should be able to attend any government hearing. Government offices should accommodate all classes of the disabled.

Schools should not make readily available to students any cholinesterase inhibitor chemical commonly used by kids for "huffing". To do so will facilitate drug abuse. Neither should these same chemicals be found in school air in trace amounts. Evidence exists that neurotoxic chemicals demonstrably affect the education of kids with ADHD, and therefore might be subclinically affecting other students also. Canaries should have many civil rights. I only mention the most basic human rights here, which canaries don't yet have.

Canaries and asthmatics have one recognizably enforced civil right. The United States Postal Service will no longer let fragranced advertisements and fragranced magazines be bulk−mailed to homes. In homes that use mail slots, fragranced ads would automatically pollute the air of asthmatics and canaries in their own homes. Therefore, no random recipient should receive fragranced ads. I believe that neurotoxic chemicals continue to turn formerly healthy people into canaries for life. Often these same cholinesterase inhibitor chemicals are statistically linked to asthma, to cancer and to multiple sclerosis. I believe that no one, healthy, asthmatic or canary, should be forced to breathe any unhealthy chemicals. The school of hard knocks has trained human canaries and asthmatics to sense unhealthy indoor air. If we value our healthy kids, we will not let children (or adults) breathe any air that a human canary or asthmatic can't breathe.

The enforcement of civil rights for canaries may in fact save the lives and health of other people, people who by rights should live a long life. Perhaps each healthy person's civil right to a healthy life is being violated too.

The Biochemistry of Chemical Sensitivity Many human canaries have lifetime concentrations of certain chemicals called cholinesterase inhibitors in their body fat. Some persistent cholinesterase inhibitors include lead, mercury, depleted uranium, pesticides and nerve gas in Gulf War veterans. These chemicals can build up in human fatty tissue over a lifetime, and aren't excreted. Cholinesterase inhibitors are so−named because they bind to the enzyme cholinesterase in the brain, rendering the enzyme useless. One theory holds that sometimes very little useful cholinesterase is left, on a permanent basis, in an affected person's brain. The introduction of even miniscule amounts of other cholinesterase inhibitor chemicals will stop the proper functioning of this little remaining cholinesterase. With all of the cholinesterase gone, neurons in the brain, and also individual muscle cells throughout the body, will start to fire uncontrollably. As the neurons use up energy from repeated firing they stop functioning. Sufferers often report that they feel both foggy and irritable. Sufferers can report headaches.

Because only neurons and individual muscle cells are repeatedly fired, no externally measurable early symptoms are manifested. Early on, the victim may look physically healthy. An air sample taken at the time of exposure might detect the offending airborne chemicals for forensic purposes. Perhaps an electroencephalogram could detect the unusual neuron activity. As the body's individual neurons fire and muscle cells contract repeatedly, they use up all of the body's available energy. The body gets fatigued. Flu−like symptoms within hours of exposure are common.

Cholinesterase inhibitor reactions are chemically different from histamine (asthma) reactions. However, both reactions are often triggered by exposure to the same airborne chemicals. How the nose−brain barrier works

Human pheromones will pass directly from the nose into the brain and set off chemical reactions inside the brain's mood center, a section of the brain which is right behind the nose. The transfer of these chemicals is quite fast. People can react within seconds to pheromones. Cocaine snorters use and abuse the same nose−brain barrier. Powdered cocaine, when sniffed, travels into the brain's mood center within seconds.

When a canary walks into a room full of petrochemical solvents, their first breath will bring a dose of toluene into the brain's mood center in seconds. In seconds the mood center's neurons can be out of control. An immediate mood center reaction of irritability, depression or hysteria can take place. Many long−time canaries have learned to compensate for this reaction once they recognize what's happening, but I've heard reports of canary children and Alzheimer's patients acting out. In another couple of minutes the solvents can work their way through the brain to the cerebral cortex. At this point the sufferer can also become foggy and disoriented. First Aid Responses to Hazardous Air Many petrochemical solvents can't be smelled. The solvents in perfumes are often chosen for their lack of smell and their ability to push fragrant oils into the air. However, canaries can learn, through year after year of repeated chemical poisonings, what a poisoning feels like inside. Canaries learn that if they feel angry, foggy or headachy for no reason other than being in a new room, they may be breathing toxins and a quick exit from the room may save them from enduring a long, slow recovery period. Smells come in groups. Healthy people can't smell carbon monoxide at all, but they can smell the hydrocarbon by−products of burned fuel oil or kerosene. If indoor air smells like burned fuel oil, smart people will open the windows or get out. In the same way, human canaries are vigilant for the smell of rose and lilac oils in perfumes. A little lilac in indoor air probably means to a canary that the air is full of the odorless but dangerous solvents so commonly mixed into perfumes. Non−canaries can also learn to be more aware of perfumes and other common scents. I regularly assist my wife on airplanes. On full flights we try to park non−perfumed people in the seats directly around my wife, with the idea that heavily scented passengers far away in the airplane will have most of their scents eventually vented out of the jet's contained air, and my wife will breathe relatively safer air in her section of the cabin. If a human canary has already reached the foggy, disoriented stage, don't expect him or her to take care of her/his most immediate medical need. Either you must take action or your canary friend could get really sick with a long health recovery period. Get him or her to fresher air. Don't argue with a canary in a toxic environment. Arguing with a canary in a poisonous room, or just outside of a fueled jet at an airport, is medical negligence. Low−cost Prevention of Toxic Air Canaries and their non−canary allies can learn to read labels. Certain marker pens conform to non−toxic standards, and other marker pens on the market don't conform and are hazardous. Washable markers are safest. Crayola makes washable markers, but they also make a second line of deliberately scented washable markers. Avoid these scented markers. Human canaries have a pretty long checklist of things to avoid. Almost all varieties of air fresheners are deadly. Anything with a built−in scent is probably dangerous. Laundry detergents, dish soaps and bar soaps are often scented. Perfumes, nail polish, hair spray and a several other cosmetics are hazardous. Cleaners based on chlorine or ammonia are hazardous. Unscented or otherwise safer versions of products usually exist and cost the same. Most new home construction uses chemicals or materials that emit toxic solvent fumes. A number of couples have reported to my wife and myself that they first closed their brand new home's windows in October, and then they moved out of their own home in November for health reasons. Sometimes new products have to be placed in a room with an open window or in a garage to outgas. We use our back hallway. The plastic on our newest computer needed maybe 5 months to outgas its toxic chemicals. Consider buying hazardous items in the spring, so that the house windows can be left open all summer. Consider finishing home construction in the spring to let the interior of the house outgas all summer. The EPA now recommends that every home keep a window open a crack even in the winter, to allow fresh air into the home. We notice how this suggestion will drive up heating costs and offer it tentatively, but marvel that the EPA would offer this suggestion at all. They don't usually seem to acknowledge the dangers of indoor air. Many plants are genetically predisposed to absorb formaldehyde, xylene and other petroleum solvents into their leaves as a source of nutrients. The book "How to Grow Fresh Air" suggests members of the palm family that tend to be the hungriest chemical−eaters. Hydrocarbon solvents in indoor air can also be absorbed by a charcoal filter or by a Volatile Organic Compound (VOC) filter. Generally, air is blown through such an adsorption medium by a fan. Such filters eventually become saturated with chemicals and need to be regularly changed every few months. My wife carries a charcoal filter mask for emergencies. The mask is a bother to wear for any period of time, but it does save her from a poisoning. The cheapest carbon filter masks are paint fume masks. Better masks that are slightly easier on a person's facial skin are available. However, we also know at least one local canary who avoids paint fume masks because they restrict her breathing. The politics of vague symptoms The longer−term effects of low−level cholinesterase inhibitor poisonings are many in number. They are often chronic problems, sometimes vague, and sometimes pretty bizarre. They include chronic fatigue syndrome and fibromyalgia. Sometimes canaries can be walking around and they look normal and healthy, but inside they can't find the energy to climb a flight of stairs. Each stair step up takes one minute, including resting time. The effect has been compared to climbing Mount Everest without oxygen. A woman with newly−diagnosed chronic fatigue syndrome played goalie on the U.S. Women's Olympic Soccer team in 2004. She could take the field, but had to be ultra−disciplined with her life off the field. Someone else had to carry her baggage through the airport terminal. She woke up, played soccer, went to sleep, woke up, played soccer, went to sleep and did nothing else. In Rhode Island we have a formerly athletic friend who has slept 20 hours a day for 10 years. A sick building caused her to lose so much of her life.

Fibromyalgia is a gnawing, terrible pain that again doesn't show on the outside. It can last for days or months, and it can move around. It usually leaves the sufferer feeling very fatigued. Despite its disabling nature, fibromyalgia is notorious for doctors not being able to diagnose the problem. The medical profession has a history of dismissing such chronic, vague, bizarre symptoms. 220,000 Gulf War Veterans were almost all told by Veterans Administration doctors that their illnesses were all in their heads. Only intense Congressional lobbying forced the Pentagon to look for likely chemical sources of Gulf War Syndrome on the battlefield, and to admit that 10,000 prematurely dead Gulf War Veterans is statistically significant. Death is in no way a psychosomatic or somatoform symptom. Millions of civilian Multiple Chemical Sensitivity sufferers are equally finding out in this decade that their HMO doctors are too quick to send them to psychiatrists. We have heard a canary speak of one doctor who claimed that no chemical could be absorbed through the skin. The teller of this story wondered whether the same doctor would turn around and prescribe a nicotine patch or a birth−control patch.

Liberty: Thank you.

Audience member: Thank you --

Chris: Liberty, before you introduce the next speaker, there's somebody who has already spoken who's asked for -- those of you who are interested to provide your name and e-mail and phone number so you can keep in contact. This is not associated with the Governor's Commission. If you want to provide the information, maintain contact, feel free to fill out the information. If you don't, that's your choice too.

Liberty: Okay. Thanks.

Audience member: While we are speaking about that, could we get emails of these people that say they want to hear from us?

Liberty: I think those should be available.

Eleana: From my perspective, I think if you fill out some kind of a paper that Liberty has, that will give me the information and all of you to contact.

Liberty: I will try to coordinate this kind of communication. Having very little time, with my own testimony in the dust, but I was asked to read this testimony from another person who – much more serious problems than I do. So I will do that.

Housing **Date:** 8/22/05 9:50PM

Subject: Re: Special Forum on concerns of people affected by household chemicals

To The Governor's Commission on Disabilities:

I am a 55 year old, RI woman with MCS (Multiple Chemical Sensitivities). I was chemically injured, 6 years ago, when I bought a house that had just been completely renovated. All the toxins inherent in products like new carpeting, with stain resisters, new cabinets with their laminates, glues, and formaldehydes, paints with VOC's, pesticides etc., conspired to permanently compromise my, already stressed, detoxification system. I was never able to move into the house. Within months I could no longer tolerate the minutest amount of toxins.

Everything was eliminated. All household chemicals, soaps, perfumes, art supplies, newspapers, etc. I could no longer work, go into buildings or the homes of family and friends. Save a plumber, no one has come into my apt. to visit, in 6 years, except a handful of times when other folks with MCS stopped by. I cannot ride in anyone else's car. I no longer have a doctor or a dentist. There are none that truly deal with or understand how to treat people with severe EI (Environmental Illness), here in RI. I broke a front tooth almost 2 years ago but cannot safely have it repaired. When neighbors use lawn treatments like TruGreen or Chemlawn, I stay inside with all of the windows shut. The same when someone paints a fence, leaves a truck running, uses their clothes dryer (w/ fabric softeners), lays down cedar mulch, light a charcoal grill, use citronella candles, use a woodburning stove and Heaven forbid someone seal coats their tarred driveway. Through avoidance, a relatively organic diet and a mountain of supplements, I have improved. I can now write with some pens, read a book (that took 2 years), go into Whole Foods Supermarket, and enter some places for a brief amount of time. I have but scratched the surface. There are more and more Chemically Injured folks out there and we need help! We need what the ADA refers to as "reasonable accommodation." It's a well intentioned law with almost no "teeth," with regard to MCS. We need to be able to have access to hospitals, public transportation, and even public restrooms, without being bombarded with a potentially lethal soup of disinfectants, masking perfumes and pesticides. For the past 2 years I have been paying my landlady double rent to keep her from renovating the apt below me. I ran out of time, after looking for several years, I had to buy a home that is less than safe. I have 5 weeks to fix major problems in the house, have little funds and almost no help in doing it. My landlady says she will have to start "doing things" downstairs next week as she can no longer leave the apt. idle. I am scared to death. Don't think for a minute that my situation is unique; that it couldn't happen to you.

I had a job as Sign Language Interpreter; before that I was a scene painter. I wore make−up, perfume; deodorant. I dined in restaurants; swam in chlorine treated pools. I attended meetings; flew on planes. I was "normal." I have since lost my job, my home, family, friends..my spouse. As someone with MCS once told me, "When you have EI it's like you are suddenly transported to a planet where you can't eat, drink or breathe." Unfortunately that planet is Earth.

Thank you for your time.

Feel free to contact me with any questions.

Sincerely,

Linda C Dugas

Liberty: And we are virtually out of time.

[7]

I will try to skim through the testimony that I prepared, which I will submit in writing.

Accessibility

My name is Liberty Goodwin, and I am a “canary”. I like this term because it draws a comparison to the birds taken down into the mines as early warning systems. When the canary keeled over, the miner didn’t say, “Oh that poor thing has some terrible canary disease”. He said, “I’d better get out of here fast – or I’ll be next.” Most of us were not born having bad reactions to common chemicals. Some were sensitized, by a major toxic exposure, to something like a waste dump, sick building, chemical spill or pesticide dousing. Others just finally could no longer handle the long term, low level exposure to many different chemicals, in combination with other stresses on our immune systems.

As the Director of Toxics Information Project (TIP) and a person who has personally had chemical sensitivities for around 20 years, I have a tremendous amount of information which I could share. In the interest of time, I will limit myself today to brief comments about my own experience, a mention of a few other situations that have come to my attention, and some suggestions for action to address the problems. Additional materials will be submitted in writing.

MY OWN STORY

I believe that in my case, some of my vulnerability started in babyhood. I was premature, and was brought home to being kept warm for a while by the gas stove in my parents’ apartment. Also, as a child I had sensitive skin, could not tolerate wearing wool, only cotton. I was sensitive as well to the sun, and nearly passed out at a field day event. However, until around 1973, I appeared otherwise healthy, and even used perfume and make-up without incident. Around that time, I developed migraine-like eye symptoms due to hormones in birth control pills, which I had to discontinue. I also got divorced and involved in a four-year custody battle. Under all of this stress, I wound up with hypoglycemia, candida, was even diagnosed at one point as pre-diabetic. Later, while living in Florida in the mid 1980s, I was so depleted by my symptoms that I could often could barely get up and walk across the room. I had my first reaction to laundry detergent at that time – a terrible rash and a jumpiness that prevented me from sleeping.

The first problem being in a building that I remember was at a chiropractor's office. It seemed strange that I should become headachy and disoriented when I had been in the same waiting room the week before without such a reaction. The mystery was solved when I realized that, although the newish carpet was there before, the second visit was on Monday morning, after the office was closed up all weekend collecting fumes. In 1988, after they built a new building at my graduate school, the only way I could attend class was by taking an electronic air cleaner into the room with me. I was not able to participate in the life of the school in any other way. The worship room had new cushions and carpet, the place where students ate was too large for my air cleaner to handle.

Education & Employment

After coming to Rhode Island, I was able for a while to work as a phone research interviewer, then found employment in the Community Policing Bureau of the Providence Police Department. It came to an end when they moved another employee down from the third shift to mine. She was reeking with fragrance, and applying some product while sitting at the desk up against and in front of mine. I got a headache, became dizzy, and had to have an officer take me home. Since there was only one room in the unit, and since she had valuable bi-lingual skills, I was then out of a job. The next job, phone interviewing at Memorial Hospital, was okay for a while with my air cleaner in the cubicle – but when they moved operations to a renovated facility elsewhere, I was not invited to continue, because they knew I couldn't tolerate the new quarters.

Accessibility

I hope that the Commission can understand the extreme insecurity this disability produces, just in everyday life. We canaries never know if we can be somewhere, or will have to leave, will become ill. We never know from what we may next be threatened. We don't even know if we will be able to use a public bathroom! At home, I had another bout with detergent reaction when my landlord's daughter used our washing machine with something nasty. Outside, the pervasive use of lawn chemicals is a constant threat. I went to the bank to make a deposit, and was confronted by the sight of two men applying something to the front lawn. Thinking to simply avoid them, I quickly dashed into the bank , only to find the one story building was completely permeated with fumes from whatever they were applying, and got one of the worst headaches ever. When I came out, I ran over to their truck to read the label on the container they were drawing on – it said "Round-Up" and also the name of another common lawn pesticide beginning with "D". I escaped as quickly as I could, but, unlike the brief recovery time after a perfume headache, this one lasted for days.

I don't mind so much not being able to go to the theatre or any other entertainment spectacle with lots of people for which you have to buy tickets (knowing that if the wrong person sits next to me, I'll have to leave). But it is a real problem having to run the gauntlet to see my three grandchildren in California. My husband and I fly on Southwest because seats are not assigned. I put on my "I Can Breathe" mask – used to use a latex paint mask – and we try to screen out the people wearing fragrance and encourage safe ones to sit near us. Usually it works. However, once a woman reeking with perfume switched with someone in front of me, and after useless argument with a "disability expert" for 20 minutes, I was forced to keep the mask on all the way to Kansas City. Another time a perfume wearer refused to sit further away from me – again the mask – in which I cannot eat or drink, by the way. On a previous trip, a flight attendant wearing fragrance refused to have someone else serve our section – and stood talking to someone right in front of me for about ten minutes, although she knew it was making me ill. The worst was the time I was threatened with the police as personnel tried to remove me from the plane after objecting to my asking people to accommodate me. Fortunately, a calmer head appeared and I was able to resolve the problem without being stranded in Arizona. Ironically, the airlines routinely ask people to voluntarily change their seat to allow families to sit together – the same action that would meet my needs just fine.

The greatest fear, however, is that I will become ill and be taken to the hospital – one of the most threatening environments a "canary" can face. Most are a toxic stew of employee fragrance, sickening cleaners and disinfectants, and a variety of other chemicals. It is a terrible thing to be faced with the unanswerable question – is it more dangerous to fight my illness on my own, or to expose myself to the uncontrollable fumes in a "health care facility"?

STORIES OF OTHERS

Health Care

Whatever problems I have had myself, even more heartrending are the tales of woe I hear from people calling my organization, or find on internet sites. I've not enough time here to discuss these. There are those unable to utilize medical or nursing care, who cannot find housing that doesn't make them sick. There are children who are diagnosed with ADD – some of whom are found to have dramatic changes in their learning ability when chemicals are removed from the classroom On the playing fields, kids have asthmatic attacks, are even taken to the hospital in anaphylactic shock. In the workplace, vulnerable people are mocked and even attached by co-workers – who douse themselves with perfume to make the "canary" sick. One group of kids even assaulted their teacher with fragrance. A friend's elderly mother with Alzheimer's had to be moved to 3 different nursing homes because she reacted to fragrance and cleaning chemicals by becoming violent. The problem went away when personnel were persuaded to remove the chemical triggers.

WHAT TO DO?

The really important thing is, what actions can reasonably and realistically be taken to improve the situation of this vulnerable group of people? I have a few suggestions.

Accessibility

PROTOCOLS & POLICIES in all **involuntary** public facilities – those which people must have access, and cannot just avoid. This would include health care providers, nursing homes, schools. All should require fragrance-free employees, alternative, less toxic cleaning products, low or no-VOC paints, rugs, etc. Public bathrooms should be free of toxic "deodorizers" or "air fresheners" (actually pollutants per the EPA). These kinds of requirements are being used and enforced in many hospitals and other places, in both the U.S. and Canada. Policies could be instituted voluntarily or, better, be statewide by regulation or legislation. In schools, toxin-free environments would benefit not only those with conditions like ADD and asthma - studies indicate they might reduce aggressive behavior in some and enhance the learning abilities of other students as well.

EDUCATION. The Commission can provide information to employers, medical people, school personnel, on the health effects of chemicals and on the alternatives available.This could involve developing a database of such effective measures, healthier products and accommodations that work, as well as a possible speakers' bureau.

LAWN PESTICIDE LEGISLATION. Support the two bills to protect Rhode Islanders from toxic lawn pesticides, introduced in 2005 and coming back next year. One would ban the use of such products at schools and day care centers. (A similar bill was passed this year in Connecticut). The other would permit towns and cities to pass ordinances restricting cosmetic lawn pesticide use within their borders that were more stringent than those at the state level. They had this power until it was taken away from them in 1990. This might allow, among other things, some kind of response to the growing number of people who are sickened in their homes – or driven out of them - by pesticide drift from neighbors' lawn applications.

Transportation

ENCOURAGING FEDERAL ACTION ON TRANSPORTATION. Although the Commission does not have power to change regulations for airlines, perhaps the Governor, in cooperation with counterparts in other states, could call upon federal authorities to address "canary" accessibility issues on planes. A simple provision requiring fragrance-free flight attendants and the right to request that someone change seats with you would be a Godsend to the chemically sensitive, asthmatics and those with other respiratory or health conditions.

In closing, I wish to say that I am very grateful for the Commission's willingness to take this concern seriously, to give it their time and attention, and to consider ways to improve the lives of Rhode Islanders for whom chemical exposures can be health and life-threatening. I look forward to helping this effort in any way that I can.

[ii]

Blessings

Chris: Thank you for moderating, Liberty. Thank all of our panelists for participating and listening. And hopefully we can take some action on this.

And thank all of you for coming and sharing your stories with us. I know it's not easy to talk about the pain that you deal with on a daily basis. But we certainly do appreciate it.

This is the first public forum that we have held on chemical sensitivities. And believe me, we all heard quite a bit and a lot to take back and work with. So thank you.

Audience member: Thank you for trying to make a safe environment.
Liberty: There are materials over here about our organization, please take it.
Audience member: I guess we are out of time in this room. But if anyone has any questions, I would be more than willing to spend some extra time in the parking lot.
Audience member: Anybody who wants to share the web addresses with other people, it's time we set up a website to talk to each other.

Emailed and Written Testimony

Date: 7/19/05 11:05AM
Subject: Public Forum Comments

My name is Susan Eleoff and I work at the Ocean State Center for Independent Living (OSCIL) in Warwick as an Information and Referral Specialist. I would like to address two issues about which our agency receives many calls.

Assistive Technology

First is the inadequate funding for equipment (assistive devices) to keep people living independently in their homes. Many persons calling OSCIL are living on fixed incomes and can not afford to take loans to purchase equipment. We receive requests for equipment for cars and vans, such as scooter lifts or hand controls, as well as for alerting devices and baby monitors for persons who are Deaf, for railings, walkers, and bathroom equipment such as tub transfer benches, and for many other items that can keep folks independent. There is a need for more grants and funding allocated for equipment and aids to daily living.

Housing

Secondly, OSCIL is seeing a large increase in requests from persons with disabilities who are homeless or facing eviction and who can not find decent, affordable housing. Most subsidized apartments have very long waiting lists. Some persons who are on SSDI used to be able to afford moderate−priced apartments (apartments in the $500 to $700 range) in the private sector. Landlords are selling the rental properties for large profits and new owners sometimes double or triple the rents and evict the previous tenants who are unable to pay the huge rent increases. As a result, persons who had been renting in the private sector are now adding their names to the already long waiting lists for public subsidized apartments. Some of these persons also need accessible apartments. The older apartments do not have enough handicapped accessible units. There needs to be more affordable housing and more handicapped accessible housing in Rhode Island.

Date: 7/22/05 12:19PM
Subject: Disability Concerns

Housing

I am in support of affordable housing. There is an enermous need for affordable housing for people with disabilities. The wait time varies so much to up 2−4 years. This is unacceptable.

I also am in support of affordable prescriptions. People on Disability cannot afford the high cost of prescriptions, neither can the elderly.
Mary Willis

Date: 7/22/05 12:44PM
Subject: Disability Concerns

Housing

As a mental health consumer I am concerned about the lack of affordable housing in the Kent County area. People with criminal records cannot get into subsidzed complexes and I only earn $630.00 per month. How can I afford a $850.00 per month studio apartment and eat too?
Also, the waiting list for subsidzed apartments are 1−2 years long. Please HELP!!!
SharonTanner

Date: 7/22/05 3:41PM
Subject: Forum on Chemical Sensitivity

Accessibility

Unfortunately, although i would like to, i will be unable to attend. i would like to bring to your attention, a problem i have with chemicals. i suffer from copd and in some places on grounds here, bleach is used for cleaning during our work day. while they are not to use it on my floor, it would make sense to me that it not be used at all for cleaning while staff is present. there must be others who suffer from asthma and copd, and bleach is an irritant. also, i have noticed that, on occasion, the inmates have not mixed the cleaning chemicals properly (eg. pouring directly from the bottle when it should be mixed 1:5 or 1:6 with water) it does not happen that often, but i wonder if something could be done to eliminate it entirely, and insure they are used properly. there are other chemicals that could be used instead of bleach.
Diane Nawrocki

July 24, 2005
Re: Long Term Disability Insurance - Lack of Advocacy

Family & Community

To Whom It May Concern:
As a result of an operation in 2002, which resulted in the removal of over two feet other small intestine, (along with essential parts that, among other things, control the ability to control her bowels) XXXXX attempted to return to work. After a short period of commuting and often having to start and stop only to start over, on multiple occasions, and much difficulty she was placed on short term disability in 2003 by her doctors. Initially her insurance company. Liberty Mutual, denied her short-term claim because it was related to Crohn's Disease, which is "not recognized" by the insurer as being a disabling disease. Fortunately, the Federal Social Security Department accepts the medical diagnoses, which Liberty did not. In brief, the Short Term Claim was denied, overturned by her employer (Fleet Bank, N.A. Bank of America) with the Short Term Benefits paid - done with the assistance of an attorney. Those benefits were paid only "after expiration of the STD benefits" (the attached two page summery of the resulting problems gives additional insight). Shortly after that settlement Social Security accepted her claim and she received Social Security Disability Benefits. While one attorney was retained and paid $1,000, he declined to continue representation, as he "did not have the time" to devote to the case, others refused when they reviewed the underlying facts. The employer, Fleet, sold Long-Term Disability Insurance to it's employee's with promise of certain benefits. The employer then purchased an insurance package from Liberty (without consent or acceptance by the employees) where-by Liberty assumed all claim decisions, etc. They denied her claim. The Federal ERISA program "overseen" by the Federal Department of Labor has no regulatory power; only the Federal Court can review complaints and resolve questions of fact. Attorneys in Rhode Island will not take the case - as Social Security offsets make the case "non-profitable". The Rhode Island Department of Business Regulation, Insurance Division will not consider the matter as it resolves on an ERISA matter, even though sold to employees in R.I. by a R.I. employer and the separate agreement with a licensed insurance company clearly impacts on Rhode Island residents. The Massachusetts Insurance Division has accepted the complaint and has had the item under review for three months. Long Term Disability Claims require that the State of Rhode Island have an Insurance Division that will address issues of this type when Rhode Island Employers and Licensed Insurance Companies are providing benefits sold as Long Term Disability Insurance.
Edward H.Baifour and Suzzanne E. Balfour

Finite Risk Insurance the impact on an "insured"

XXXXX has had an operation which resulted in what is medically described as a "short gut" in essence she has lost the ability to control her bowel movements which presents difficult social problems. In addition, because of Crohn's, the disease that was discovered as a result of the initial operation resulting in the short gut, she has a continual distress as well as diarrhea, creating a situation impacting on everything and which has disabled her. It was from this problem that we found ourselves dealing "first hand" with: finite risk insurance/coverage.
Background:
Her employer was Fleet Bank. Fleet had originally provided a group "self-insurance policy" for Short Term Disability administrated by The Hartford Insurance Group. XXXXX, in 1997 purchased Long Term Disability Insurance, which, according to her employer was to provide protection when and if she should suffer a disability under which the Short Term Disability benefits were exhausted. After her surgery (in 2002 -she was

allowed STD coverage) she attempted to return to work only to be placed on STD by her doctors.

It appears after 1997 that Fleet had acquired Bank of Boston and while continuing it's self-insured STD program changed "administrator's" engaging the service of Liberty Mutual. Additionally, Liberty had earlier divested itself of it's financial subsidiary. Liberty Investments which would become part of Quick and Reilly the Fleet Boston financial firm. Fleet Boston also then obtained approval for a Long Term Disability Program through the Mass. Dept. of Health with provisions designed to satisfy Federal ERISA requirements and acquired Liberty to administer and service that program. Today, Fleet is part of Bank of America.

It appears that the "approved" LTD program in Massachusetts was extended into all other jurisdictions where the employer did business. Fleet then acquired a "financial risk contract" from Liberty under which Liberty was to provide 100 coverage of claims and was also the claims manager, etc.

In XXXXX's situation Fleet of Rhode Island was provided an insurance certificate for the program, which was never submitted nor approved as an insurance product in Rhode Island.

Fleet continued the sale of, LTD coverage to its employees (including XXXXX) through payroll deductions and would also collect premiums while she was on medical leave of absence due to the claim. Liberty would allege it had "no fiduciary responsibility" to the employee prior to acceptance of a LTD claim as attempts to acquire benefits were made by correspondence.

XXXXX's STD claim of 2003 (after being treatment required her to be medically removed from work) was denied by Liberty - after retention of an attorney her employer received the information as to the impact of the "short gut" and overturned the denial in late November 2003. However, that was after the STD benefits had expired in October the claim for LTD was then given for review to Liberty. Liberty did not even assign a LTD claim number until April of 2004 when it both accepted the claim and issued a denial of future benefits but would provide benefits while the claim was reviewed - such benefits would not be required to be reimbursed if a non-favorable decision were rendered.

At about this time XXXXX was granted Disability by the Federal Social Security Program, Liberty then deducted as "offsets" benefit payments for the very claim they contended was now not covered even though they had quoted language in the "Fleet Policy" which said offsets would only be taken for benefits received from like claims for which they "Liberty" paid.

The insured questioned how if the claim were denied offsets could be deducted? For a short period benefit payments were received and a partial acceptance of the claim appeared to have been made. Then in December of 2004 a ftill denial was issued, even as XXXXx was undergoing cancer surgery. Her Gastroenterologist received assurance from Liberty's Doctor Millstein that the denial would be reconsidered. It was not. Consequently she was forced to again seek an attorney to assist.

Her past attorneys declined the case as one did only Social Security and the other did not have the time available to handle an EBR.SA Court Case. In middle January an attorney said he would review her file.

She was advised in February that the time for appeal would expire shortly but he would accept a retainer and court fee and proceed if she desired. The attorney also advised that most cases required resignation to achieve settlement. As XXXXX was a vested employee in Fleets/Bank of America, retirement program the "resignation" to relieve Liberty of LTD benefit payments certainly would not be in her best interest. The attorney was so advised but, he was not very encouraging not withstanding the obvious medical history.

Current Position:

We see where Fleet (now Bank of America) obtained a "financial risk contract" from Liberty. Certainly, Liberty might prefer that the claim disappear. Thus the claimant's attorney's position that most matters require a resignation to settle can be appreciated.

Settlement would avoid long tail transfer of risk and associated records and/or any undisclosed side agreements between the parties as documented in the ceding insurer's underwriting folder (including the employer's loss history, comparable quotes (if any) rate history [information from the prior Hartford A&I program] from being reviewed. Also avoided would be any inquiry into the original intent of the transaction -including agreements as to the satisfaction of obligations to employees to satisfy ERISA and all pricing information having to be disclosed or produced should discovery be instituted by either a claimant or claimants attorney or other regulatory officials - all items that the carrier would prefer be avoided if possible.

Indeed, if shown as a valid LTD claim with an order of the court to provide payment I would assume long term financial reports would be produced and show this is, in fact, insurance and thus a product never approved in the jurisdiction where it was sold.

Additionally, if a court review were made, query into the intent of this product being to produce misleading financial statements by either or both parties (Liberty &/or Fleet) might be made leaving open a possible conclusion that such actions then violate the Saroanes - Oxie Act. The very fact that such issues might be required to be addressed, as opposed to just being limited to supplying benefits for employees m satisfaction of the ERISA act should not be overlooked. If regulators were to review complaints as part of a market conduct exam additional factors might also be found.

July 27, 2005

Dear Sir,

Housing

After moving to Florida from Warren, R.I. in 1991 with my children and husdand, I have since moved back to R.I. 7 weeks ago due to a pending divorce. My 18 and 15 year old children are temporarily residing in Florida and unable to move up here with me due to my housing situatiojn. I've been totally disabled since June 2003. Temporarily I am staying with my brother in a small 1 bedroom apartment because I've been unable to find affordable housing for myself and 2 children. Monthly, I receive $856.00 in disability payments and all Section 8 and subsizised housing in Warren or Bristol area are on hold for the time being due to long waiting lists. Hovever, there is no assistance for a 46 year old who is disabled; many of the agencies and/or organizations I have called have openings only for senior citizens. What about families? All landlords wat 1st and last months' rent, along with security; plus a 3 bedroom apartment with no utilities includes is definitely out of my budget. I cancelled my Medicare, Part A in January 2005 because I could not afford it; plus I am requ9red on a daily basis to take my necessary breathing medications which cost me approximately $300.00 per month 2nd I go without most times. My main concern at this time is to find an affordable apartment for myself and 2 children. There has to be some kind of low income assistance available in the Warren or Bristol area for families without a place to live. Recently I've been in touch with Dorothy Furlong, the Houseing Coordinator for the State of R.I. and she gave me a few numbers to call, but there is no available low income housing for a disabled person at this time. I think disabled citizens should be on top of the list when it comes to housing, especially when there are children involved. Mrs. Furlong also sent me a list of the Section 8 landlords and an online printout of "finding an apartment" which did not assist because of the high cost of rent and nothing available for a disabled person. If there is any way you could assist me, I would be greatly appreciated. Thank You

Sincerely,

Cheryl Parrish

July 27, 2005

To Whom it May Concern,

Accessibility

I lived in Providence, RI from January of 1995 through August of 2004. Soon after my arrival, I went on disability for the disabling illness Chronic Fatigue Immune Dysfunction Syndrome (CFIDS), which I had contracted 2 1/2 years earlier. Later, I developed a secondary condition called Multiple Chemical Sensitivities (MCS), which caused me to get extremely ill from exposure to common chemicals found in body care products, laundry detergents, cleaning agents, pesticides, and building materials. Like others with severe MCS, I risked permanent injury or death from exposure to ubiquitous chemicals, and had to practice nearly total avoidance of them to keep from getting worse. I was already generally homebound and mostly bedridden, and sorely without services or practical help, so any worsening of my condition was a terrifying prospect. While CFIDS made my life very restricted, MCS threw me into exile.

I suddenly found that almost no venues were accessible to me due to the copious use of fragrance−containing body care products, toxic cleaning products, and health−threatening building materials. This meant that all basic human services were denied me −− including legal services, health care, and home care. I could not pursue medical care in Rhode Island, except for on rare occasions when I found a fragrance−free* (see terminology below) care provider to do a home visit, or when I educated one doctor to make his office fragrance and chemical free so that I could go to appointments. My reactions to chemicals became so severe that I could suffer a permanent worsening of my condition from one exposure, often leaving me bedridden for months at a time (even years). Despite having one of the most disabling conditions around (CFIDS has been found in studies to be more functionally disabling than heart disease, other chronic illnesses, and HIV), I found it nearly impossible to get home care services such as visiting nurses or PCA/homemaker services to accommodate my secondary disability, MCS.

Health Care

For example, I was approved by a program in Rhode Island for funded homemaker services that were direly needed: however, the agency would not allow me to seek out an attendant who could be fragrance and chemical−free, and thus I had to forgo this much−needed help. Similarly, my doctor ordered potentially helpful visits from a Visiting Nurse, but the VNA would not provide me with a nurse who accommodated my disability, so I had forgo those services as well.

When I had abnormal tests −− such as abnormal EKGs −− I could not see specialists for the most part due to the toxic office spaces and nurses and technicians using fragrance−containing products. When I had breast surgery to remove a lump, I could not go for my follow−up visits due to the toxic cleaning products used in the facility. Specialty appointments −− such as gynecological care or dental care −− were generally impossible. None of these offices made efforts to accommodate people with MCS, and I could not enter their facilities without risking severe reactions. Emergency medical care was my greatest fear. Although Miriam Hospital was just blocks from my house, they did not have any provisions in place for the treatment of patients with MCS.

I could be severely injured from hospital cleaning products, latex, sanitizing chemicals, and −− mainly −− the staff and their personal care products. Ironically, doctors and nurses made me ill to the point that I could barely even talk and advocate for my own care, due to the fact that they all wore scented products and washed their hands frequently in scented soaps. Chemical reactions caused instant cognitive dysfunction which made me lose memory, stammer, have breathing problems, and lose the ability to form sentences. I knew that if I had a situation requiring emergency medical care, I was in big trouble.

One such occasion occurred when I began to have symptoms of acute appendicitis. I suddenly began to have unbearable abdominal pain (especially when I tried to eat or drink), a high fever, and other symptoms that were unusually severe so I ultimately needed to go to the ER. I figured I would be out of there in no time, but after running some tests the staff wanted to admit me for two days. Due to my symptoms and tests, they thought I had appendicitis (though the tests were not fully conclusive) and wanted to wait for the staff surgeon to arrive to decide if they should operate immediately or simply keep me under observation. I was so delirious that I signed my name on the admission papers. When I fully realized what had transpired, I begged the nurses to let me leave. I was getting sicker by the hour, but not from appendicitis −− from nurses hovering near me with hairspray, deodorant, and scented soap. Thankfully, once I put a call in to my physician (the one with the scent−free office), he advocated for me and got them to release me, against their better judgment. They told me I could be in a life−threatening situation, that my appendix could rupture, and that it was against their better judgment to send me home. They did not comprehend that it was even more life−threatening for me to stay in their care. Fortunately, one of my neighbors was a scent−free acupuncturist who was willing to do a home visit, and she treated me with alternative medicine (in China, acupuncturists are often the first line of defense against appendicitis). Miraculously, her treatment cleared up my symptoms, even though I spent well over a week unable to eat solid food. Since so many people suffer adverse reactions to chemicals in fragrances, and since children and others are increasingly vulnerable to chemicals in cleaning and building products, it is imperative that health care facilities address these concerns. For those of us with MCS, CFIDS, and related conditions such as Gulf War Syndrome, these chemicals can be life−threatening or can cause permanent neurological damage. Very few hospitals and medical facilities take into account the underserved population of chemically vulnerable people. We need facilities we can go to for health care, and providers who make a commitment to use fragrance free products so that their clothes, hair, and skin won't make patients sick.

I believe all health care facilities in Rhode Island −− and particularly those that are state−funded −− should implement chemical and fragrance−free staff policies. Staff should be fully educated on the risks of their personal care products and laundry soaps for patients with asthma, MCS, and other conditions. Additionally, RI hospitals should implement safer cleaning policies, such as those recommended in Deirdre Imus' "Greening the Cleaning" or in the Health Care Without Harm guidelines (see references below) to minimize the use of harmful chemicals in health care settings. State−funded programs such as those provided by the VMA and Centers for Independent Living should always have provisions for those who are chemically vulnerable. In addition, hospitals should keep on hand special guidelines and "crash carts" for patients with MCS. Staff should know to isolate MCS patients from others patients, keep them near open windows if possible, make sure they receive fragrance−free bed linens, provide them medical oxygen with nontoxic tubing, and ask them about their specific needs. In addition, staff should be made aware of the special carts for MCS patients, and these carts should offer latex−free gloves, adhesive−free bandages (or bandages utilizing natural adhesives), tygon oxygen tubing or specially treated cannulas, hydrogen peroxide swabs, fragrance−free Castile soap wipes, and other items that will create a non−injurious environment for the chemically vulnerable. In addition, signs should be available to place near the rooms of the chemically vulnerable, to warn doctors and other staff not to bring in toxic products, flowers, and other items that might cause a reaction.

Thank you for listening to these concerns.

Best wishes,
Peggy Munson

P A
R I
A Resource Center for Independent Living

Governor's Commission on Disabilities
41 Cherry Dale Court
Cranston, RI 02920-3049

July 28, 2005

Dear Commission Members:

I was unfortunately unable to attend the public forums held this week, but did not want to miss an opportunity to express my concerns for the individuals I work with tlirough PARI.

Independent

Currently, I am actively assisting people who want to transition from nursing homes and other restrictive settings back into the community. A major obstacle we have encountered is lack of affordable, accessible housing. I realize tills is an issue you may hear year after year, but because of that, it requires your attention. In reality, services and resources exist to support someone to transition once they find a place to live, however, they spend 1-4 years in a nursing home or state hospital until it's found. Thedetrimental effects of this institutionalixation are easy to see and ultimately make it harder to succeed once in the community.

Health

Furthermore, I would like to say that I've seen the Dept of Human Services make great strides in providing comprehensive Medicaid services dial make it possible for people with disabilities to transition from nursing homes back into die community. However, I feel strongly that we need to do more to assist those individuals who are not Medicaid eligible. People who have worked hard all their life, purchased a home, sent their children through school, contributed to society, and experience a disability later in life, are often excluded from necessary resources. One way of addressing tills would be to expand the current State funded Personal Care Attendant Program in order to benefit more people with disabilities who want to manage dieir own care needs.

Housing

Another area of concern involves the lack of supportive/transitional-type housing for people with brain injuries. In my experience, individuals who sustain cognitive disabilities are not given tlie opportunity for effective, comprehensive rehabilitation across tlie board, regardless of severity.They are forced to leave an in-patient setting well before they are thoroughly prepared to function independendy. As a result, individuals and their families are left to struggle with daily needs and are at risk of further injuries. Then-recovery is inhibited and often completely interrupted. Transitional living that offers a specialized habilitative approach with an opportunity to continue to improve and re-leam skills will result in more independent outcomes and more fulfilled lives. I hope the Commission will continue to be open to innovative ideas and programs, which also support more self-directed models of services for people with disabilities. Thank you for your time and attention to these concerns.

Sincerely, Rosemarie Coffey

Independent Living Counselor

Date: 7/28/05 10:40PM
Subject:

Health Care

First I do not think enough information is given to people that are disabled as to the help that is available for them. When I became disabled no one told me of the services available. I struggled for three years and then by accident I found out about PARI that are able to help in many ways. Long term care gave me some help for around my home but the quality of the people they send is awful. One of the people they sent told me she smoked pot before coming over. I was very worried about having her here. Another clogged up my toilet and the group that sent her would not be responsible for what she did. I had to stop the service and this put a tremendous stress on my daughter who had to do everything for me. PARI has helped me hire people I can trust and I am confident with this has been a big help. But for the years in between we had to struggle.

Also I found a treatment called prolo therapy that was helping me to be more mobile and in less pain. My daughter paid for a while for the treatments, but we could no longer afford them. No insurance will cover it. So even though there is some help out there I cannot get it due to lack of money. I have now been housebound for almost a year trying to get help to get a wheelchair and a lift to be able to get out. I have been approved by the PARI group, but things take so long and meanwhile I am still stuck in the house. I know things have to be checked and approved, but with all the modern computers there must be a way to make these processes move more quickly, but meanwhile I have to be locked in my home with no way out if there is a fire or other emergency I will die. I need medical transport to even get to a doctor. I had an emergency and had to be rushed to the emergency room at Rhode Island Hospital to get home I needed another ambulance as I cannot get in my own home. I may have to pay all or part of the bill. I am trying to find help for this because I am below poverty level on SSI and don;t know how to pay for this. They told me I have to be preapproved for medical transport or it is not paid. I can see that for a doctor's appointment or dentist but in case of emergency what are you supposed to do. I had no way to get back in my house without assistance.

Overall I think there is some decent help out there but it is not organized well and no one gives you the info and when you are disabled you can not go around looking for help if you can't get anywhere. I find most of the offices are not truly handicapped accessible. They are in areas hard to get to and hard to manuever. Then when you get to the office there is nothing to make it easier for the handicapped. I would love to come but without

wheelchair and a lift I am homebound which is why I am sending you this instead.
Antonetta Stanzione

Date: 7/28/05 11:11PM
Subject:

Health Care

I recently heard about the disability forums happening and was advised by someone at PARI to write in and tell you my feelings.
I have three big complaints. One lack of info on resources available for assisting the disabled, I am not disabled myself but my mother is and the red tape is horrendous to find out a single stitch of information on assistance. Two lacking flexibility in medical care. If a treatment is not approved there is no funding for it. My mother tried a not approved treatment and it was working she went from unable to walk to walking with a cane but we ran out of money she is now housebound and unable to even bathe comfortably. I still can not get her a wheelchair thou I have been pushing with her for well over a year, what would happen if there was a housefire? Third is some of the help given for home care is drug addicts. These people are handicapped and should be given trustworthy assistance from the state not drug addicts! PARI an organization I found when I was laid off helped in getting my mother a Personal Care Assistant that we hired and is not a drug addict. The down side is it is only 20 hours. I work close to 50 she is unable to get out of the house. By not giving more help and the system moving slow you are jeopardizing peoples lives. This is a tragedy.
Dawn Stanzione

Date: 7/29/05 11:35AM
Subject: Testimony for GCD Public Hearings

Hello Commissioners −

Independent

Thank you for the opportunity to express my opinions here. I am the parent of a young woman with significant developmental disabilities. My daughter, Hannah, in spite of disabiliites, that not thirty years ago, would have relagated her to a place like Ladd School, holds two part time jobs and serves her community in three different volunteer sites, bringing joy to many whom she encounters every week. She is currently supported in this full, meaningful and contributing life through combined state and federal funds which flow through RI's Department of Mental Health Retardation and Hospitals (MHRH), specifically its Division of Developmental Disabilities. Her supports and services were developed several years ago under the leadership of MHRH whose mission statement focused on the "dignity of people with disabilities" and supporting their "inclusion in the fabric of society," ensuring that they "experience valued status and full membership in their community." That mission statement spoke of "empowering individuals to exercise choice and take charge of their lives." I was very distressed to learn that recently under new leadership, MHRH has changed its mission statement to the following: "The mission of the Department is to fulfill its statutory responsibilities to fund, plan, design, develop, administer and coordinate a system of services for identified citizens of Rhode Island with specific disabilities. MHRH is dedicated to achieving the best possible results for its consumers and the taxpayers of Rhode Island within its legislated, annual budget." This pedantic, restrictive, bureaucratic statement is a step backward for the people served by MHRH. Gone is any mention of the dignity of people with disabilities or the goal of supporting them to be valued and meaningful contributors to their communities. They are seen merely as "consumers" of a service system and the focus here is clearly on statutory and budgetary limitations to those services. While, of course, budgetary constraints are a reality in any state agency, its mission statement should be expansive and focus on what it hopes to accomplish, and not those limitations. I fear what will happen to the nature of the supports available to those Rhode Islanders with disabilities served by MHRH led by this new mission statement and it's authors. While the former mission statement may have been a little rambling and unfocussed, its values and vision were on target. Other states have succinct, to the point mission statements which reflect similar values (e.g. Massachusetts − "DMR is dedicated to creating, in partnership with others, innovative and genuine opportunities for individuals with mental retardation to participate fully and meaningfully in, and contribute to, their communities as valued members.") I strongly suggest that the Governor's Commission recommend to the

Governor Carcieri and the appropriate leaders in his administration to revisit MHRH's mission statement and develop one that reflects the values, thoughts and ideas of the people whom MHRH serves as well as their families. Under the current mission statement and the restrictive values it reflects, individualized supports for a meaningful life that contributes to society such as my daughter currently enjoys will disappear before long and we will be on the road backward to the days of Ladd. Thank you for your consideration.
Sincerely,
Claire Rosenbaum

29 July 2005
Dear Darlene:
Though enabled to be discrhaged from a nursing home in November 2004 I was still very vulnerable and weak [iii]
.

Independent

I felt then that you, your staff and other residents at Sunrise House were suspect – the recent stabbing death and rape at another assisted living facility confirm this sitrust.
Your response to my fear then and now is inappropriate as XXXXX assistance in this regard was totally inadequate.
Kingly remove my name from your wating list.
In closing, I suppose somebody has to do your job(s)
Robert Jurich

Date: 7/29/05 3:24PM
Subject: Forum testimony
Commissioners:

Assistive Technology

I believe it was over 25 years ago when the GCD conducted a study at Zambarano Hospital to determine the effects of providing simple assistive devices to patients. Not surprisingly, patients maintained or improved function, and reduced their dependence. A more recent study ("AT for Health,") conducted by the Health Department through community contractors, had similar results. Yet AT (assistive technology) still remains little known to the general public, and is often out of reach for those who most need it.
I recall the experience of "Mr. M.," an elder with severe hearing loss, who has a very low income. As part of the AT for Health study, he was provided with a (free) "Pocket Talker," with significant results. This device enabled him to listen to television without disturbing his neighbors, converse with friends, and importantly, understand to his physician's information and instructions. It improved his outlook, as well as his functioning. And so impressed was his physician that he planned to obtain one for use in the office, with other patients...
Neither Mr. M. − nor his physician − knew about the existence of this device. On his own, Mr. M. probably could not afford it. Yet for a relatively small investment (about $200), there were many returns.
Rhode Island needs to invest in AT − through a revolving loan fund, direct state appropriation, and human resources. Perhaps there are also Medicaid waivers which might help? This is an investment that can actually save health care dollars, not only for persons in the community with disabilities, but those in chronic care hospitals and nursing homes.
In addition, RI needs to institutionalize AT education for those who serve persons with disabilities − social service staff and medical providers at health facilities, staff of public housing facilities, assisted living facilities, etc. Continuing education on AT is always well received by professionals, but has been limited due lack of financial resources.
We hope that RI will decide to make an investment in AT! Not only will this improve the health of persons with disabilities, but will promote the best use of our health care resources.
Sincerely,
Jeanne M. Panarace

Chairperson, RI Council on Assistive Technology
Chairperson, Adaptive Telephone Equipment Loan Program
(Retired) Manager, Disability & Health Progam

Public Hearing of the State of Rhode Island:
To identify the concerns of people with disabilities and their families.
July 29, 2005;
Marcia Liss, Ph.D.
Rehabilitation Psychologist
Angell Street Psychiatry
1351 South County Trail, Bldg 2
East Greenwhich, RI 02818

Independent

Good evening. I am Dr. Marcia Liss, and I am a rehabilitation psychologist in private practice. I have been involved in medical rehabilitation and disability for twenty years, in both hospitals and community settings. In this testimony, I would like to speak about my perceptions of the needs and concerns of individuals with brain injury and their families

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 <u>family system</u>, such as changes in marital and parental relationships, the loss of a primary breadwinner or primary child care provider. The process of rehabilitation involves continuous measured experimentation, or risk taking, by the individual and family in order to relearn skills and gain independence. The time period may be measured in years, and it is often difficult to accurately predict how long it will take a person to reach a level of optimal functioning.

Throughout my clinical experiences, I have seen a wide range of responses and outcomes. I have seen individuals, whose future was initially underestimted in terms of their potential, achieve quite significant and noteworthy vocational and social goals. I have witnessed the effects of under – or un-employment, and the devastating implications that 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. I have seen <u>families</u> feeling isolated and in pain; because of the ensuing behavioral stressors and their difficulties in obtaining respite. I have seen marriages fall apart because they were not able to adapt to the changing needs, and I have also watched as relationships become stronger, and more resilient.

I would like to turn my attention to addressing the needs and concerns of the individual, the family, and finally; their integration within the network of social programs.

I..The Individual

One of the single most important predictors in rehabilitation outcome is the personality of the individual; their desire, their passion, to "get well," if you will. It is our responsibility, as members of the rehabilitation community, to do everything we can support that hope, or as I discuss with my clients, to keep that "fire in the belly," and their inherent belief in that possibility. We can do this, within our provision of services, by taking the time and effort to understand the person, as they are, and were, prior to their brain injury. <u>We need to know, we need to ask, we need to include it in our evaluations, who were they, what were their hopes, dreams, life goals, prior to the injury.</u> <u>This does not mean that we deny the existence of the injury, but rather that we look for opportunities; not solely limitations</u>.

II. The Family

As previously noted, families are of crucial importance within the process of a person's rehabilitation. While providing a stable and familiar environment for the individual, the family can often provide an additional, and very important perspective, regarding the individuals mood, outlook and progress. We need to educate families, re: the comprehensive range of support services available to them and the individual; both locally, and within the greater New England area. These include, but are not limited to: case management, outpatient rehabilitation programs, structure day programs, assistive technology, support groups and counseling. As necessary, families may need to learn how to become advocates – both for the individual as well as for themselves.

III. Finally, the third component in addressing the needs and concerns of the individual and the family is the collaboration and incorporation of the external support system. In times of tight budgetary constraints, we need to focus energies on making the optimal use of existing resources; including, but not limited to, our centers of rehabilitation, our government sponsored social services, our private service providers and voluntary civic and support organizations (such as the Red Cross, the RIBIA, the United Way) and our religious, and community centers (such as the YMCA, and community senior centers). Our clients and families need to know the range of services available to them; what are the programs, what do they offer, where are they, in which facility, which facilities are accessible, and how might the range of services change, depending upon where they are in the rehabilitative process. A person does not need to know all the answers, but they need to know how to go about obtaining the answers. Our method of information dissemination needs to be multifaceted, where the information is available from several different resources; e.g., from the acute care hospital, from the rehabilitation inpatient or outpatient program, from our local agencies and organizations, from educational systems. We also need to assist in access; both in the availability of health insurance benefits, and transportation to ensure that the client and their family can actually get to the services.

As a person begins to move toward school or vocational reintegration, we need to work with these institutions and worksites. For example, when a person with a disability enters the college setting, he or she should know the particular administrative office that can facilitate reasonable accommodations, and the point person in charge of doing so. Upon return to place of employment, the client and his or her supervisor need to have a realistic perspective on tasks and schedules, in order to maximize success; and have a process in which problems can be responded to effectively.

This more comprehensive and integrated approach can provide grater support to the client and family, while making the best use of the available services and service providers.

Thank you for your time.

August 3, 2005

To Whom it may concern,

Independent

My name is Howard Erickson. I have been paralyzed for 17 yrs., from the neck down. I have been w/ PARI for 12 yrs. And living at Matthew 25 Apartments in Warwick. I am next to the Malls and frequent them often in my wheelchair.

I'm afraid that I will loose my PCAs if any changes are made in the current program. I would then be forced to kill myself rather then going into a nursing home.

I value the PCA's that I have and trust them w/ my life.

I asked that no changes be made. Please consider my complaint.

Sincerely,

Howard Erickson

This letter is a testimony in regard to the August 23, 2005
RI Governor's Commission on Disabilities and Concerns of People Affected by Household Chemicals.

Education & Employment

I speak on behalf of myself, who has been affected in the workplace by both fragrance and toxic cleaning products. My diagnosis by my primary care physician was asthma, and chemical sensitivity. Company's who would not institute policys to protect people afflicted by such conditions forced me out of the workplace. There are a very high percentage of toxic chemicals in fragrances, which have never been tested by the FDA for safety in humans. And there are a growing number of people with such conditions.

Employers should make every attempt to protect all employees; especially to limit exposure related sick days, health costs, undue stress and medical leaves.

I worked for an insurance company in the 1990's and was greatly affected by the perfumes and colognes of co-workers. I also left work most days with migraines, breathing problems and fatigue. The fluorescent lighting there also had an effect on my overall health. All fluorescent lighting should be changed to full spectrum lighting for optimal work environment. Years later, I worked for a health insurance company and lasted there only several months because they had a full reconstruction project going on only about 8 ft. from my desk, including knocking down walls, glue and paint. I landed another job several months later at a healthcare industry. At this homecare agency, the employees wore perfumes, lighted scented candles at their desks and washed the lunchroom down with Clorox wipes. For people who are sensitive, the chemical Dioxin in Clorox is outright dangerous. I left this job only months after being employed.

At this point, I became frantic, I could not remain unemployed and wondered how I was going to survive. I went to my doctor for help with disability. He flat out said he could and would not help me because he wasn't sure the chemicals I came in contact with was the true cause of my illness. I felt I had no support system, for my primary care physician did not have any proper training in medical school for chemical sensitivity. I tried to search out other professionals in Rhode Island who might be able to help, but there were none.

Accessibility

So, I continued looking for a safe place to work while out on unemployment. The stress of it all was overwhelming. I finally got what I hoped would be the right job with caring, understanding folks. What I found was just the opposite. This was a mental health facility where I worked as a medical records clerk. I encountered strong perfumes on many employees again. And in this facility they would wash down pretty much everything with bleach, to kill any kind of germ that might be taken in by the patients.

And they would constantly spray antiseptic spray in the air. I heard it was actually sprayed in through the vents in the ceiling. They also had reconstruction going on inside during working hours. Once again, I did not last here more than a few months. I would again get all the same symptoms, go to my doctor and he would tell me again, the best thing to do was get out of the environment so I could get my breathing back to normal again. And time and time again, unemployment had to pay monies out to me. Needless to say, not of my own accord, I went through quite a few jobs in a short period of time. There is no excuse for this.

Something must be done to help those of us who are hard workers and want to work for a living, not be on disability! Environmentally safe-cleaning products must be used and naturally safe antiseptic sprays only in medical environments. Policies at all work places must institute "0" tolerance for anything scented and/or toxic. No more scented products, including candles, bathroom deodorizes, cleaning products and health anti-bactenal/anti-viral sprays, perfumes and colognes. There are many other safe alternatives. Therapeutic essential oils would be one. Or the great natural cleaning products at Whole Foods Market, which are the best thing that every happened Just walk into a Whole Foods Market and just see, feel and breathe in the difference If they do it all chemical free, everyone can. Everyone will be healthier and isn't that what we all strive for!

This is definitely a workable and solvable problem if only someone would take the time to help this group, which by the way grows daily. Something must be done not only so the asthmatic and chemical sensitive don't end up on the streets but also to help one another out, because if this hasn't happened to someone in your family, chances are it will soon. We must keep in mind the future, for our children and to give them an environment in which they can thrive. And we would be also helping out the skyrocketing healthcare costs in numerous ways.

I would like to be of any help possible to get legislation changed and follow suit as others already have, to make for a healthier workplace in Rhode Island.

Sincerely,
Deborah A. Pina

Date: Sun, 21 Aug 2005 14:13:10 −0700 (PDT)

Subject: Troiano to Governor’s Commission on Disabilities (GCD),
Governor’s Commission on Disabilities (GCD),

Accessibility

To whom this Concerns, My husband, Domenic, and I became very ill shortly after moving into in a new residence. Unbeknown to us, toxic chemicals were leaking/outgassing and taking over our air space. We didn’t know at the time that we were being exposed to formaldehyde, toluene, mold, asbestos, fuel oil and many other toxins.

We started to experience adverse reactions to perfume, gasoline & the detergent isle in the grocery store. Deodorants, soaps, shampoos, clothes, household & cleaning products that we had used before were now causing us adverse reactions. We’d break out with rashes, hands would crack open & bleed. We both experienced great difficulty breathing. It felt as if an 18−wheeler had parked on our chests. We became so ill that we could no longer enjoy going out to eat, shop or socialize. That home & its toxins turned our lives into a living hell. It became a daily struggle just to survive, like walking on minefields. Life as we once knew it was gone, forever amputated! As time went by more & more debilitating symptoms developed including but not limited to: severe head, body, joint aches & pains, skin rashes, non−ending flu−like symptoms, dizziness, extreme fatigue, respiratory problems, mental confusion & short term memory lapses, increased sensitivity to sound & light, intestinal problems, heart palpitations, lack of coordination, stroke−like symptoms and the list continues. As one can imagine, during & after these exposures, unfortunately, we found ourselves in desperate need of proper medical diagnosis & care. While fighting for our lives we endlessly sought such help. . . to no avail. Just as physical barriers prevent wheelchair access, chemical barriers including toxic chemicals, pesticides, scented products, mold and more prevent entry & use of public facilities, including schools, places of employment, medical & dental care facilities, emergency, assisted & residential housing as well to those with Toxic Injury.

We experienced great difficulties attempting to enter “public” buildings due to people (including employees & employers) smoking while standing at entrances to hospitals, medical clinics, doctors’ offices, grocery stores, etc.

On rare occasions we managed to access these “public” buildings only to be blown away by scented personal care products or strong cleaning disinfectants used by doctors, nurses, other patients, clerks or maintenance crews. We often had to leave without ever being seen by the doctor returning home more ill and without groceries or supplies due to the devastating consequences of yet more un−necessary scented products, pesticides, chlorinated cleaning products "air fresheners" (petrochemical derivatives) and other toxic cleaners and chemicals or mold. To add to our misery we constantly had to try & dodge toxic fumes from buses transporting the elderly to stores & doctors’ offices & some delivery trucks often left idling at entrances to these public buildings. Toxic fumes from these types of unnecessary exposures added yet another nail in our coffins while completely immobilizing us. On more than one occasion we had to stagger back to our car, rest until we were well enough to drive home ~ without the medical care, supplies and or groceries we had been put in harms way to try to get & needed.

Unfortunately, these sad events are true & added much pain, stress & discomfort to us while further damaging our already over−burdened bodies. Some of these chemicals are listed on the EPA, RCRA and CERCIA Hazardous waste lists. Many are known to be carcinogenic, endocrine/hormone disrupting, respiratory irritants, and/or a sensitizer capable of having serious, adverse health affects on the human body and the environment.

Toxic Injury may include multiple, often disabling illnesses, affecting the respiratory, central nervous (brain), immune, musculoskeletal, porphyrin, energy metabolism (energy generation for function of every body cell), and endocrine systems & can be life threatening. Toxic injuries can also include but are not limited to reactive airway dysfunction, toxic encephalopathy, some cases of Parkinson’s & other neural degenerative disease, gulf war illness, attention deficit disorder (ADD) attention deficit hyperactivity disorder (ADHD), increasing chemically related cancers (like brain and neurologic cancers, leukemia, lymphoma, etc), as well as some cases of multiple sclerosis (ms), autism, immune dysfunction, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), migraines, irritant asthma, chronic/recurrent sinusitis and/or laryngitis, autoimmune disease, and more. Widespread aching from toxic injury is sometimes labeled “fibromyalgia.”

Toxic Injury is a chronic debilitating condition for which there is no known cure. It causes serious financial, employment, learning, housing, health, social and other consequences. Once sensitized, our bodies adversely react to more substances at less, even minute levels, which can instantaneously cripple us.

Unnecessary toxic exposures are robbing millions of children, (our future leaders), the right to an education. Their precious childhoods, goals, dreams & hopes for a healthy & prosperous future ~ all dashed! Doctors are finding it medically necessary to withdraw children from school & adults from places of employment because these environments are making them ill & the medically required reasonable, “special accommodations” that would allow children their right to an education & adults their right to work & support themselves & their families, while creating a safer & healthier environment for all, are being denied.

The constant danger of additional toxic exposures & the serious adverse health reactions (some which are life− threatening) stop many of us from doing the very basic daily errands & activities necessary for survival. Attending school, church, work, shopping, dining out with family & friends, attending, sporting, school & other social events, interacting with others are all fast becoming faded memories.

As our health issues worsen, many become unable to care for themselves and increasing numbers of very ill individuals & families are becoming homeless.

We were shocked by the doctors, nurses & other public servants' lack of concern & professionalism, their unwillingness to listen, to accommodate us or to even read important articles on toxic exposures and illnesses that we provided for their viewing, to refuse to pick up a phone & call specialists in other states that we provided phone numbers for in order to help properly diagnose & treat our very serious health issues.

After years of watching Domenic struggle with the senseless pain & suffering caused from what could have & should have been avoided, tragically & unnecessarily Domenic's life was prematurely ended on January 3rd, 1999. Many tears have been shed ~ tears for what was & will never be again ~tears for all the hopes & dreams that were permanently destroyed ~ tears for all that was so precious to us having been senselessly taken away ~ tears because this tragedy & so many others could have/ should have easily been prevented. Don't let this happen to Your Child or Loved One − Get Involved − Become Aware − Make Safer Choices and please, provide the special accommodations now medically necessary for those with toxic injuries/illnesses and disabilities!

Sincerely,

[iv]

Peggy Troiano

Date: 8/22/05 5:28PM
Subject: Special Forum August 23 Response

Hello:

Sorry for the last minute response but I just got word of Tuesday's forum a short time ago and am unable to attend the forum.

Education & Employment

I work for the State of Rhode Island and have a sensitivity to perfumes, colognes, scented soaps, cleaning products, paint, etc. It is very difficult for anyone to "see" this disability/sensitivity because I will just get very nauseous and sometimes the scent will trigger a migraine. Sometimes I start to cough and feel that my throat is closing. It is hard for people to understand what a scent will do to me. Many times when going into an unknown situation (new job, carpooling with different people, dates) I have to take aspirin just to avoid a migraine. I don't like to do this, but it is usually necessary.

I work in cubicles with no windows that open. I am in a large room with many women and it is very difficult because of the many different soaps, hairsprays, deodorants, perfumes that are used. I have asked co workers to not use perfumes, but of course they get angry because they feel they have a right to use that expensive perfume as they please and it's my problem. It has strained many office relationships.

I don't think legislation or regulation will help because people will resist being "told" what to do. I think education would be great, or make this type of thing a real disability so people understand how it is not different from a physical disability that can be seen.

Many times I have to move seats or go outdoors for air or sit by a window when I encounter these scents. Sometimes it is easier for me to decline an invitation rather than stress over whether I will get sick or not. That is not the way I want to live.

If there are any after office hour forums being planned, I would like to know about them and try to attend.

Thank you for addressing this issue.

Linda Curtis

---

[1] The text includes Ms. Gagne’s written testimony

[2] The testimony includes the text of Ms. Garnder’s written testimony

[3] The testimony includes Ms. DuPont’s written testimony

[4] Text includes Mr Irvings’ Written Testimony

[5] The text of Ms Cocelli’s remarks includes her written testimony

[6] Text includes Mr. Klingman’s Written Testimony

[7] Text includes Ms. Goodwin’s Written Testimony

---

[i] Attachment to Susan B. Hurd’s Testimony

August 23,2005

To whom this may concern:

My name is Susan Hurd. I am now 39 years old. In 1994 at the young age of 271 fell very ill with Chronic neurological Lyme Disease, Multiple Chemical Sensitivities, (MCS), and severe potentially life threatening allergies to some foods,- especially to peanuts and some other nuts- even to minute traces of peanut fumes wafting in the air from peanut products being eaten, baked, or foods cooked with peanut oil like some Asian foods, or movie theater popcorn, or that I come in skin contact with, is enough to trigger a frightening allergic reaction requiring medication and a trip to the ER. I also am allergic to molds, to many medications and common antibiotics, to sulfites used as a preservative in some foods and medications, to other preservatives and dyes used in foods and medications, to latex- including breathing the fumes wafting and skin contact, and to some other things. It is an extensive list of allergies that I now must contend with. It is very complex. I must be aware of a lot of things that most would never think about and take for granted. Things that most people do and take for granted like eating out in restaurants, traveling on airplanes, entering any public buildings they please, walking down a city street, going to school, getting a job and working, taking public transportation, and living in homes, visiting people, and getting proper medical treatment become a serious challenge or impossibility for me and others with MCS and severe allergies, and Chronic fatigue conditions such as Lyme Disease and CFIDS. I am now legally disabled and receive SSDI/SSI and live on a little over $600 a month. I have HUD assistance, and Medicare, too. Despite it all, I have managed to slowly improve and convelesce and rehabiltate myself. It has been a very hard upward hill struggle that has taken much courage and perseverance and help and support from the government, family, friends, and doctors, healers, and others. I am now pursuing my MA degree in Holistic Mental Health Counseling at Salve Regina University in Newport, RI, and have some assistance from Voc Rehab/ ORS in making this a possibility. I am very grateful for this opportunity which has taken over 12 years of hard work for me to have come this far. It has taken 6 months alone for me to find a conducive counseling internship since most typical counseling agencies won't educate themselves in how to be comfortable in making simple accommodations so that I can counsel patients, or because their buildings are simply not conducive due to new carpeting, poor air quality, and other building materials, or scented candles refused to be removed from the work place. I found an internship at a hospital with an integrative holistic medical model being implemented here ein the state, so I will counsel patients with fibromyalgia. Chronic Fatigue and other chronic health conditions.

I lived in Sonoma County, California when I fell ill in 1994. Sonoma County is part of the Northern San Francisco Bay Area, and it is also Wine Country. Much neuro toxic spraying occurs in Sonoma County due to the vineyards, tree farms and from agricultural farming. Recent studies show that Sonoma County was becoming more toxic than the Central Valley where most of California's produce is grown due to the wine and tree farm industries, which can get away with lax regulations in toxic spraying since wine and trees are not considered foods for consumption. They also have powerful lobbies. I have since learned that genetics, exposure to neuro-toxic chemicals,as I got exposed to, toxic molds that were abundant in the homes of that coastal area of California, as well as^serious chronic auto-immune conditions as I contend with all can trigger MCS. Formaldehyde is a leading cause for triggering MCS and it can be found in perfumes, fabric softeners, perma-press clothing, shampoos, carpeting, wood glues, cigarettes, pressed board building materials, urea foam insulation, and other materials that are used in common personal and home products. Any word with aldehyde in its name is a form of formaldehyde. Formaldehyde is neurotoxic and carcinogenic and is also labeled under what is called VOC's or volatile organic compounds, as are found in paints, stains and other building materials. Unfortunately, there are not strict regulations, and there are powerful lobbies.

Senator Ted Kennedy said in a 1997 speech to Congress that:

- Cosmetics are broadly used by Americans, more so than most prescription drugs, medical devices, or biologic products, and Americans routinely assume that these products are safe.
- The cosmetic industry is a $20 billion industry, loosely regulated by the FDA. Federal law overseeing cosmetics regulation has not been updated since 1938.

- The FDA has no authority to require cosmetics manufacturers to register their products, or to file safety data on the ingredients used.
- A recent study by the general Accounting Office(GAO) found that more than 125 ingredients commonly used in cosmetics formulations are suspected of caricinogens.
- Ingredients in cosmetics can cause sever allergic and asthmatic reactions, central nervous system damage, potentially even birth defects
- The FDA bears the burden of demonstrating by its own testing that a product is hazardous to consumer's health, a burden which is unlikely and prohibitive.
- Fewer than two FDA employees work full time on labeling and packaging cosmetics
- In the absence of federal regulations, various states have attempted to require manufacturers to properly label cosmetics, and warn of hazards- as for example, California has done with industrial products. The cosmetics industry spends 70 of its lobbying dollar fighting these efforts on the state level, and are suggesting that they're unconstitutional.
- We've known for over ten years that fully one-third of the most common ingredients in cosmetics are toxins, but have done nothing to strengthen consumer protections.
- In the Federal Food Drug and cosmetic Act there are 126 pages devoted to pages of regulation to drugs and devices; 55 pages to food regulation; fully eight pages devoted to definitions; and a mere two pages devoted to regulation of the cosmetics industry! It clearly has not been a priority.
- Other countries, most notably, Canada, the European Union, Denmark, Sweden, and Malaysia, lead the way in initiating consumer safety in cosmetics and proper labeling of hazardous substances.
- (A footnote regarding labeling. Cosmetics activist Linda Chae remarks that the word "fragrance" can indicate the presence of up to 4,000 separate ingredients, most of them synthetic.)
- the most common chemicals found in a study done by the EPA for 31 fragrance products were amongst: acetone, benzaldehyde, benzyl acetate, benzyl alcohol, camphor, ethanol, ethyl acetate, limonene, linalool, methylene chloride, a-pinene, g-terpinene, a-terpineol,many of which were they not worn on the human body in the context of fragrance, would be classified as neurotoxins, biohazards, or hazardous waste, with stringent requirements for proper disposal. (see: Townsend Letter for Doctors and Patients, January 2001, pages 42-45, "Making a Stink" by Lily G. Casura.)

For your awareness, 60 of what touches your skin will be absorbed into the blood stream. This is why the patch medications used are effective. Also, the olfactory system is one of the bodies oldest developed systems and is directly wired to the reptilian brain area. The blood/oxygen brain barrier is most permeable to the brain through the olfactory system. This is why nasal spray medications, and also cocaine and glue addicts prefer to inhale their drug of choice. The drug will be delivered the quickest into the blood stream throughout the whole body and affecting the brain chemistry. Children don't have fully developed blood/oxygen barriers to the brain making them more susceptible and permeable. Because of these reasons stricter laws are applied in children using non-toxic art supplies in the classroom. Also, oil based wood stains are now outlawed on wooden playground equipment and more states are outlawing oil-based stains in general, including Massachusetts. RI is in the process of phasing the oil-stains out for sale.

People with compromised immune systems, as I have, are also more vulnerable to the various neurotoxic and carcinogenic products mentioned above. Under-funded research is now being done at the Washington State University showing how people exposed to stressors from illnesses such as Neurolgical Lyme Disease, to neuro-toxic exposures, or those exposed to ther stressors that can include trauma resulting in Post Traumatic Stress Disorder can cause very real physiological changes to the brain and making the blood/oxygen barrier more permeable which could explain the heighten reactivity those experience who contend with MCS. (See: Townsend Letter for Doctors and Patients, August/September 2005, "Multiple Chemical Sensivity: Towards the End of Controversy" by Martin L Pall, PhD.) Other doctors have done research that now documents through fMRI's, Spect scans, and PET scans that very real changes takes place in the brains blood/oxygen flow when exposed to various neurotoxic triggers. This can cause altercations in neuro-cognitive functioning, the'autonomic nervous system that regulates blood pressure, heart rate, respiration, and other vital functions that disrupt the homeostasis for one exposed to a trigger. Respiratory functioning is affected and can trigger asthma attacks that can be potentially life threatening. It can disrupt the endocrine system and hormonal regulation. Because the brain is directly and quickly affected it can also trigger vertigo, dizziness, nausea, headaches, migraines, confusion, spacyiness, insomnia, exhaustion - requiring 12-15 hours or more of sleep and bed rest and requiring one to basically have to live from bed after a serious exposure, or for some even a minor exposure, and not be able to live a life of quality. Petrochemicals for years have been known to be able to cause injury to the brain, immune system, and nervous system and to the, whole body. Just as happens when one bangs their thumb or toe well, injury s^fi inflammation will happen. For those assaulted by toxic overload injury any inflammation to the whole body will happen, impairing vital organs like the brain, lungs, liver, kidneys and skin functioning. A general auto-immune response sets in. MCS is an auto-immune condition. It is a serious and complex condition that can affect any of us if we have enough toxic exposure to large amounts of neurotoxins, such as can happen with pesticide spraying, lawn spraying, working with petrochemicals, etc. One's genes also make one more vulnerable to MCS.

Currently 30 of the US Population is now chemically sensitive to various degrees. Some are aware and others aren't that their asthma, or migraines, or vertigo, or digestive problems or skin problems or hormonal imbalances, or infertility, or ADHD/ADD, or insomnia, or mood swings, depression or anxiety etc have a direct correlation with their being exposed to daily common products used in their homes, offices, and in building materials, or personal products, or cleaning products used. It is predicted that within 10-15 years from now that 60 of the US population will be chemically sensitive to various degrees, the worse suffering with full blown disabling MCS. 72 of those suffering from asthma are triggered by chemical exposures, including to fragrances, perfumes, sample perfumes cards tucked into magazines and mail, and to household cleaners. Because of these epidemic statistics occurring as we speak, leading hospitals, medical schools, and HMO's such as MT. Sinai Hospital, NY,NY; Harvard Medical School and teaching hospitals, and the Hmo-Kaiser-Permaente, CA. are all instituting Fragrance-Free policies and Green health care policies that use non-toxic disinfectants and cleaners, low VOC paints and carpeting, and more Green building materials and medical supplies. One leader in offering information and being a Green medical supply warehouse is right at U. Mass-Lowell, The Sustainable Hospital Project: www.sustainablehospitals.org More info can also be found at Health Care Without Harm: www.noharm.org; Hospitals for a health Environment: www.H2E-online.org; Canadian Coalition for Green Health Care: www.Greenhealthcare: Healthy Building Network: www.healthybuilding.net; Clean Med Conference: www. Cleanmed conference; Physicians for Social Responsibility: www.psr.org; also see Healthy Schools Network: www.healthyschools.org.(See: UTNE Nov-Dec,2002, "The Greening of Health Care" by Karen Olson.) Also see for more health related info on fragrances and MCS see: www.fpinva.org.

I strongly believe that RI needs to become more aware of chemical sensitivities and how to accommodate those already disabled with MCS and how to prevent more from becoming seriously disabled with chemical sensitivities. I live near Miriam Hospital, I commend the caring doctors and nurses that have tried to accommodate me when I have had to make a trip to the ER for one of my serious allergic reactions to Peanuts/nuts, or other exposures, or illness needing medical attention. Unfortunately, not much education has been given to these caring people in how to accommodate a person disabled with MCS. First, just like a disabled person in a wheelchair needs wheelchair access to at least enter the hospital and ER, so does the person with MCS need safe accessibility to the ER and hospital. Simple things like instilling a Fragrance-Free policy with all workers can help one with MCS greatly in getting the medical care they need and in an emergency situation. Second, a safe waiting area free of others waiting with fragrances on, or eating peanut candy snacks, or other food triggers.and free of other triggers like cleaners, could help with easier access. Third, the ER needs to have a separate area free of fragrances, toxic overpowering cleaners, non-fragrant, hypoallergenic sheets and sprays used on the ER beds, and free of food triggers. Fourth, all ambulance workers need to be fragrance-free so that they won't complicate problems with their fragrances, like triggering a serious asthma attack or worsening one in place. (I once had to turn an ambulance away when I had a case of vertigo because the workers ignored rules of eating food and ate peanut butter on the way to my home. The fumes lingering in the ambulance and the oils lingering on the EMTs touching me etc, could have triggered more serious problems for me. Ambulances also run on diesel which is a major trigger for those with asthma and MCS.) Non-toxic/least toxic cleaners need to be used at least in designated safe areas in the ER and hospital, and ideally the whole hospital should follow these same policies. Hospital rooms need to be made available to those with MCS. Again, if they are put in a room with others, people visiting or their hospital caregivers may be strong of fragrances. Safe rooms are needed or private rooms need to be reserved. Organic, preservative free, dye free whole foods are crucial for the chemically sensitive person because they are so reactive to minute traces of chemicals. I was fortunate when I had to stay in the Miriam Hospital for a week that I was given a private room, and the cleaning people had strict instructions to not come in and clean my room while I was there for that week. However, many of the hospital workers did not read the sign on the door that it is a latex free or fragrance-free room, and would come in with latex gloves or materials to put on me for my IV, and smell strong of fragrances. I could not eat any of the food and my family had to cook food to bring in for me to eat daily. The hospital food delivered daily I could not eat, and workers that served it had latex gloves on their hands touching my food, and eating utensils, which made it impossible for me to eat even if there was something on the tray I might be able to eat, since I am so reactive to minute traces of latex contaminating my skin, and what I breathe etc. Latex free gloves are now used in the ER, but they are still in abundance on the hospital floors, and in handling towels sheets, and food trays. I could not even visit my father when he had major open heart surgery because the late'wJtTng ^h in0.01118 was t00 'Tr for me triggering an B"61^ asthma^ reaction g swelling my airways and throat to various degrees requiring medication Some Se areTTthe country ^ use Iatex ^ more becLe m(:e^ Z. people are developing serious allergies as I have developed. Also, some o'rf^T pltals do ".T Green cleaning P^^8' and off" organic food options. It is not impossible and is cost effective. I have read articles on schools and hospitals serving organic whole foods and they have been able to serve nutritious foods at the same cost, and even cheaper than some of the ma^or food services can offer conventional foods that are less healthy for any of us to eat.

Another major concern of mine is my severe peanut/nut allergy, which sends me to the ER usually once a year or so due to my being at the wrong place at the wrong time and getting a whiff of peanut fumes from a peanut butter sandwich or peanut butter cookles baking or nut coffees roasting and permeating the air, or someone touching me that forgets they have traces of peanut oil on them from foods eaten or skin care products used It's a difficult allergy to live with. Currently 2 % the US population suffers from peanut nut allergies. The percentage is higher in children and growing. Many children have severe peanut/nut allergies as I have. Because a growing increase, many schools now have banned all peanut products in their schools, or they have safe lunch room areas for those with peanut allegies to eat in. If peanuts were a medication the FDA would have pulled it off the shelves to sell to the public due to too many allergic reactions taking place. Peanut allergies worsen with exposure so that smaller and smaller amounts can trigger an allergic reaction. Those with MCS are triggered by minute amounts and get more and more reactive to triggers too. Many people with MCS have serious food allergies. Many people with Chronic Lyme Disease which also has reached epidemic proportions, develop many serious allergies, especially to high protein foods like to nuts, legume eggs, etc. as I have developed. Many also develop MCS. It is mind boggling with the high increase to peanut allerigies, latex and to chemical sensitivities that hospital and ER s are not taken more precautions and educating their workers better. In the ER waiting room a vending machine with peanut snacks are offered, and in the ER treatment area peanut butter crackers are offered as a snack to patients, and to diabetics. The doctors and nurses often will have a jar of peanuts/nuts sitting at their work station to nibble on and take handfuls in between treating patients, or they will have peanut candies to nibble on like peanut M&M's Paicnts next to me with only a curtain dividing us may be offered a peanut butter sandwich or peanutbutter crackers to eat. I always have to let everyone know, but I fear the day I go into the ER with an already severe allergic reaction to peanut exposure that I am going to seek their help, and I can't talk because my throat is already swollen and I am struggling to breathe, what will happen then if I can t advocate for myself. If schools throughout the country are banning peanut products, then surely can the hospitals and ER's where people are going to seek help and preserve their life. The hospital needs to be safer place. Safe areas need to be made available at the very least!

60% of the population will soon be chemically sensitive, and wearing fragrances will become politically incorrect as has smoking has become and being banned in public places. Public hospitals, medical clinics, and other public meeting places need to make more accommodations and need to request their places be fragrance-free. Major large churches of 10,000 parishoners now offer fragrance-free Sunday schools and fragrance-free safe areas for those with chemical sensitivities. Some schools and colleges are now implementing fragrance-free and Green policies. I have heard Burriville High School here in RI has a fragrance-free policy and will send strong smelling fragrant students home. Some towns and cities across the country now request fragrance-free policies to be honored at public meetings. Places like Santa Fe, New Mexico it is common for Green and fragrance-free policies to be honored and in use. In California, Oregon, and Washington State, and in pockets of Massachusetts and Vermont it is common to see fragrance-free signs posted at hospitals, performing arts centers and other public institutions. RI could also be paving the way with other more aware states. Fragrance-free policies, removing automated air fresheners from bathrooms is a start. Automated air fresheners are known to be highly toxic, and can trigger serious reactions including asthma attacks, headaches, confusion, burning rashes to one's face and other adverse reactions from seconds to minutes of exposure. These automated air fresheners serve no real purpose. They don't disinfect or clean the air on any level and only pollute the air and prevent accessibility to those with MCS and to those with asthma triggered by chemicals and fragrances. Having access to public bathrooms in hospitals, theaters, shopping places, airport terminals, etc should be available to those with disabling MCS. The automated air fresheners are known to have neuro-toxic and carcinogenic chemicals in them that aren't good for any of us to be breathing in.

Proper air ventilation and/or air purifiers can offer clean air that does not smell offensive, and can eliminate the need for air fresheners. Air purifiers also disinfect and purify the air as well remove odors. More buildings should install adequate air purification systems, including schools, and work environments where people spend a lot of their time.

Safe-areas that are fragrance-free, etc. could be made available in schools, public libraries, theaters, performing arts centers, work buildings, and restaurants, and on public transportation, and ambulances that are made also diesal free. It could be a partial solution in providing some partial accessibility to those with chemical sensitivities, and would be a similar concept to public places that offered no-smoking areas. These toxins, perfumes, chemicals, high VOC paints and carpets, and diesal buses and ambulances aren't good for any person to be exposed to. It serves all of our health and well-being.

In Time Magazine April 25,2005,page 59, "The Eco- Friendly Home", by Lisa McLaughlin, wrote that "Studies indicate a baby crawling across a carpet can inhale the same amount of carcinogenic materials that it would if it had smoked three cigarettes a day. You can change that by vacuuming regularly, using non-toxic cleaners, and buying special flooring, that has low VOC's"

More public places should be made peanut free, too. I, for example, love films, and cultural events and I have BA degree in Mass Media with a concentration in film/video/TV. I also am a talented musician and oboeist and have been recorded on various collaborations. I often can't attend movie theaters like the Avon theater, or Cable Car, and film festivals held in RI because of peanut oil being used in popcorn being served. I can't attend Waterfires because there is a nut vendor that frequents this event and other RI arts events. I once used to play my oboe to the Waterfires crowds as they strolled about until the nut vendor came. I can't attend events at the Civic Convention Center because of nuts being served.

Another major concern is safe affordable housing for those disable with MCS. I am disabled and I receive around $600 a month from my SSDI/SSI check. HUD won't allow me to exceed $650 for rent. I, however, can't live in an apartment building due to food fumes wafting, nuts being cooked, cigarette smoke wafting and seeping through the air systems and walls, new carpeting and building materials and sprays being used. I need to have an individual dwelling with old out gassed carpeting and materials, wood floors, and washer/dryer hookups. I can't use a laundry mat, its impossible. I can't be exposed to sprays, lawn sprays, pesticide sprays, and other toxic materials used at large living complexes. An exposure can cause a major relapse and set me back weeks, months or years, debilitating me back into bed needing to sleep 12-15 hours a day and needing naps every two-4 hours on top of it. I have had to live on pureed soups for months due to serious digestive and liver problems from chemical exposures, that for many would seem minor. Just one spray drift that I breathe or that gets into my home is enough to make me very sick. Currently where I live the air becomes more polluted with a laundry factory that spews fragrance into the air. I must keep my windows closed and keep the airpurifies on. I must cover my face and run from my car to my home when I go outside when the factory is spewing its fumes. There is a coffee factory that also violated air code regulations and spews coffee roasting fumes into the air. When the air blows my way and they are roasting it will seep into my home and affect me when they are roasting a nut coffee. I have been awoken out of a sound sleep at 7:00 am or earlier with my throat tightening from nut coffee fumes seeping in. I must flee from my home, groggy covering my face with a towel and go to Miriam Hospital a mile away to seek help and clean air. Even at Miriam Hospital the Excellent Coffee factory's fumes can be smelled over two miles away. Yet, if these factories honored ventilation codes and kept their vents cleaned and adjusted properly the air would not wreak as it can. When I first moved to my home I actually used to sit outside on occassion and keep windows open, and the factory was not so strong. Also, they didn't keep it open so many long hours and days. It is full of Hispanic workers, and I suspect it is an illegal alien sweat shop going on in there since when they have had multiple fires shutting them down, the place clears out and the hours of the factory hours are reduced.

My relocating and finding affordable and more or less conducive housing is near impossible. HUD workers don't try to help and understand and follow only their regulations. Yet, my right to accessible, safe, affordable, conducive housing that will accommodate my disability is being violated. I am at the point where I will have to file a complaint with the RI Disability Law Center to help me relocate and find conducive housing. HUD won't allow roommates and I must be the sole person to live in my dwelling, or if I should live say with a boyfriend/husband then I am required to have a two to three bedroom place and his income would be included, however my boyfriend also has Chronic Lyme and chemical sensitivities and only has SSI of $400 a month. They would combine our incomes. Rents would be out of our league. We figured out we would have less than $200 a month to pay all our bills once we paid the rent amount. Medical expenses and other accommodations are not taken into consideration that is mandatory for our health conditions. I have severe allergies and must eat an organic whole foods diet which is expensive. I can't buy what's on sale. I must buy foods and personal products that I am not reactive to. Sometimes I may be only able to find one brand. I can spend $300-400 alone for food and personal supplies each month. I qualify only for $10 in food stamps despite medical doctor letters and appeals. I can't find a place for $650 that will meet my specific needs. I and my boyfriend can't live together or marry because combining our incomes will actually penalize us. Studies show that for people to heal and improve and rehabilitate themselves they must remove chronic stressors, eat a well -balanced nutritious diet, have basic needs met, avoid triggers from chemicals, and have a strong support system. Isolation and living alone contributes to more illness. Studies on orphaned babies show they will not survive beyond three years in institutions, and single or divorced men who have spent years alone will develop more health problems and die prematurely once they pass the age of 50. Living with others and having loving support improves health and well-being. Those with MCS and living in poverty can become very isolated, and contend with chronic stressors that make improving their situation very difficult. Housing programs, and other programs are needed to keep the basic needs met of those with chronic disabling conditions. Public buildings, and social services must be kept conducive by offering fragrance-free safe areas at the least, and hospitals absolutely must become more informed so as to accommodate those with MCS, and offer safe areas, safe waiting areas, safe treatment areas, and safe hospital rooms that will be kept fragrance-free, and more Green and less toxic, latex free, and offering organic whole foods meals that will not be tainted by latex, or peanuts, or other preservatives, or chemicals.

I am grateful Voc Rehab/ORS is helping me pursue my MA degree in Holistic Mental Health Counseling, however, improvements are needed with them as well. Little advocacy and no counseling has ever took place on my behalf. Fortunately, I am intelligent and can advocate for myself. No one told me whatever was put down as my original goals, would hold with only what they would pay for, except after the fact. I had no Voc Rehab counselor to go over goals or inform me prior how the rules work. Fortunately, I am a fairly wordy detailed person, so I'm not being terribly penalized. I requested that I would need a home computer to work on in the safety of my own home since using public libraries is difficult to impossible for me. I can't be in newly renovated libraries or other buildings. People's fragrances can harm me and send me out the door, as can people eating peanut snacks. I requested to Voc Rehab/ORS in August 2003 for a computer and printer and financial assistance to put me on-line while I am in school so that I could do necessary research and communication with the school. This is considered an adaptive tool in my case, as would a voice activated program to help me write, which was denied to me. I received in Nov. 2004, over a year later a Dell computer, and no printer. I had to shut off my den to out gas the new computer for months. I never received a printer though it was paid for. I was denied funding to put me on line. I'm still waiting for a printer two years later! I have had to take incomplete grades extensions in order to do research and write papers and must go to others homes. I fatigue, and have MCS so it's not an ideal situation. I was supposed to have a computer in my home to help me do well in school and to reduce stress and fatigue and environmental triggers to my system. I am not able to just take a CD copy to print easily other places. I am not proficient in my computer and there are no services through Voc Rehab that offer for someone to come to my home and help teach me how to more effectively use my computer. When a private party buys a computer through Dell and others, they are offered 6 months of free internet service. Yet, this isn't offered for those going through Voc Rehab even though they pay top dollar for the computer system! Voc rehab will pay for a 4 year BA college education and room and board and personal assistants if needed, and other adaptive tools for one in a wheel chair and physically disable in obvious ways; yet, they can't find money to help ends meet to pay for internet service, get me a printer, or to pay for books or travel expenses, or help with dental and out of pocket medical expenses. They say in their policies that they will help make ends meet with medical and dental etc when it is paid out of pocket. I live on a little over $600 a month. Voc Rehab abruptly stopped paying for books this past Spring Semester. I have to find a way to pay for my Spring and Summer and Fall books. I owe $300 for books and haven't bought my Fall books. I won't be able to take Fall classes until my debt is paid. Voc Rehab won't pay for books now, though they did for a year and a half. I try to buy books ahead of time so I can let them outgas, which is important for me to do. I have no extra money to pay for this unexpected expense put on me. I must pay for food, living, housing, travel all on my meager $600 a month! It's insane! I am allowed $3 per a trip in travel reimbursement and this is based on a bus fee, which I can't take due to my MCS and severe peanut allergy. Also I fatigue and have physical limitations that makes taking a bus and spend many extra hours on a bus and changing buses an impossibility. I can't carry heavy loads. I must carry my books, and a back pillow and other things when I go to classes. I must pack all my own food and can never eat out. It costs $12-15 for me to drive myself from Pawtucket to Newport for classes for a round trip covering gas and bridge tolls. When I finally get a travel reimbursement I see it perhaps a year later. I constantly must borrow to make ends meet. It is very stressful!! It has contributed to relapses that I have had and has not eliminated stressors in helping move forward and pull myself out of poverty. With conditions like MCS, fibromyalgia, chronic fatigue, chronic Lyme Disease and other auto-immune health conditions like Lupus, removing stressors, having basic needs met, getting plenty of rest, not over doing one's physical limitations and needing to do less before soreness and fatigue set in is crucial. Avoiding triggers is crucial too. Chronic stressors like living in poverty and never having basic needs completely met, and having unexpected expenses like having to buy books last minute and being on the phone for hours with government services going around in circles and being cut off adds stress and cause serious relapses that can last weeks, months or even years for some. I am doing everything in my power to help myself and live a quality healthful life. I do my best to reduce stressors. I seek healthcare practioners that will take Medicare, or who will waiver or reduce fees. I am trying to pull myself out of poverty and support myself at least part - time if not more and not be so dependent on government services, it is a near impossible situation I and others are in and more awareness and financial help and other kinds of help is needed desperately if we are to have a chance to live a quality life and a safe, healthful life. Please do what you are able to do! Thank you for your time and interest.

Sincerely,
Susan B. Hurd

[ii]
Attachment to Liberty Goodwin's Testimony

Open Letter: Perfumes Contaminate Our Classrooms

A perfume power-struggle is being played out in schools across the country. Some students and teachers believe it is their civil right to be able to drench themselves in an assortment of scented products. Another equally passionate group reports experiencing adverse health effects on exposure to perfumes and they are requesting scent-free accommodations. They claim that perfumes contain many of the hazardous ingredients we typically associate with cigarette smoke. Is it possible to satisfy both these vying factions? Education is the answer.

The nose is a chemical receptor. When you detect an odor, you are really detecting the **chemicals** that make up that odor. You might be surprised to learn that as many as **600** separate chemicals may be used in a single fragrance formulation. The majority of these chemicals have had minimal or no toxicity testing (84%), according to the National Academy of Sciences. In 1989, from a list of 2,983 chemicals used in the fragrance industry, the National Institute for Occupational Safety & Health (NIOSH) recognized **884 toxic substances**. Some of these are capable of causing cancer, birth defects, central nervous system disorders, allergic respiratory reactions, skin and eye irritations and provoking chemical sensitivities. Approximately **95%** of these fragrance ingredients are **synthetic** , in this instance meaning that they are derived from petrochemicals (a class of chemicals very often implicated in hypersensitivity reactions). These include benzene derivatives, aldehydes, acetone, ethanol, methylene chloride, and many other toxic and sensitizing agents. In a 1991 US EPA report, toluene was detected in every fragrance sample collected and tested. Toluene is a potent solvent used in gasoline, furniture wax, tires, ink, glue and paints.

In a study reported on in the American Journal of Medicine (January 1986), 72% of asthma patients had adverse reactions to perfumes (pulmonary function tests dropped from between 18% and 58% below baseline). In a Louisiana study (November 1993) 25% of asthmatics exposed for only 5 seconds to scent strips, showed a decline of 10% or more, in their breathing function.

According to a perfume survey conducted by the Candida Research & Information Foundation in the winter of 1989-90, the following scent-provoked symptoms were reported: watery or dry eyes, double vision, sneezing, nasal congestion, sinusitis, tinnitus, ear pain, dizziness, vertigo, coughing, bronchitis, difficulty breathing, difficulty swallowing, asthma, anaphylaxis, headaches, seizures, fatigue, confusion, disorientation, incoherence, short-term memory loss, inability to concentrate, nausea, lethargy, anxiety, irritability, depression, mood swings, restlessness, rashes, hives, eczema, facial flushing, muscle and joint pain, muscle weakness, irregular heart beat, hypertension, swollen lymph glands and more!! Even just a brief look at these reactions would lead a reasonable person to conclude that scents have no place in school.

And even the U. S. Food and Drug Administration acknowledges that the incidence of adverse reactions to perfume products appears to be increasing, as a result of the rising popularity of stronger, and sweeter fragrances. Additionally, the chemicals are being manipulated to increase “hang time,” so that the scent will linger in the air longer.

Let me introduce you to Tracey, a bright, seven-year-old, environmentally hypersensitive child in Australia who had to contend with asthma, tachycardia, multiple food and chemical sensitivities, hyperactivity and learning difficulties. Tracey was labeled a non-reader at her school until her mother requested perfume and solvent accommodations. Two weeks after her classroom teacher stopped wearing perfume and banned solvent-based marking pens, Tracey began to read fluently!!

Judy Sanderson, a chemically sensitive Culver City high school biology teacher (20 years), reported having been the victim of “fragrance assaults” by some of her students on more than 90 occasions from 1993-1997. In November 1997, she won some precedent-setting accommodations after a collective bargaining agreement was issued by arbitrator, Ronald Hoh (California State Mediation and Conciliation Service Case # 96-3-740). In this landmark decision, student pranksters caught dousing the teacher or her classroom with fragrance-based products will be punished as they would be for any other physical assault on an instructor. And the school was directed to install oscillating surveillance cameras both inside and outside of Ms.Sanderson's classroom to deter students from engaging in further assaults.

James Cone, M.D. M.P.H., a Berkeley based indoor air quality consultant and former Chief of the Occupational Health Clinic at San Francisco General Hospital, describes fragrance chemicals as **one of five major contributors to indoor air**

pollution. He suggests a regulation be adopted to govern IAQ saying: “no person shall discharge from any source whatsoever such quantities of air contaminants or other material which cause injury, detriment, nuisance or annoyance to any considerable number of persons or to the public, or which endanger the comfort, repose, health or safety of any such persons or the public, or which cause, or have a natural tendency to cause, injury or damage to business or property.”

When students and teachers complain of reactions to perfume, they are often dismissed as hypochondriacs, ignored, demeaned and ridiculed. All this evidence makes it hard to understand the general lack of appreciation regarding the undeniably strong association between perfumes and illness. At a time when schools everywhere are struggling to improve the Indoor Air Quality in their facilities, it is important that they not overlook the fact that **perfumes pollute**.

An endorsement for perfume accommodation has arrived from a most unlikely source - Nancy Tuckerman, co-author of The Amy Vanderbilt Complete Book of Etiquette. In an interview with the editor of the Heart Institute of Wisconsin Newsletter (October 1997), Ms. Tuckerman is quoted as having said: “It is no longer considered considerate or ‘correct’ to wear perfume, cologne, or after-shave to the office, move theaters, religious services, meetings, or social events where people with fragrance sensitivity / allergies may be present.” Isn’t it time we add SCHOOLS to this list?

School-based perfume accommodations are working successfully in Upper Musquodoboit, Nova Scotia and Kitchener-Waterloo, Ontario, Canada; at the Challenge Charter School in Phoenix, Arizona; and at the University of Minnesota’s School of Social Work. I think it is time to ban scents from schools nationwide. We just might be stunned by the improvements in behavior, academic achievement, attendance and occupant health!

Let’s clear the air in our classrooms....

Irene Wilkenfeld

http://www.head-gear.com/SafeSchools/perfclasslet.html

ATLANTA, GEORGIA – SOCCER FIELD EXPOSURE

ChemLawn made promises did not keep them, sprayed just before kids came on field. Friend arrived at school with child and they were spraying. Two girls were rushed from the field with anaphylactic reactions. Now have breathing problems when go near the field.

Details from a story in the local paper recently:

One such exposure was experienced by 15-year-old Kelsey Langworthy last fall. She came home lightheaded after practice at the city’s Highway 74 Baseball/Soccer Complex with a bright, emerald green substance on her shoes and socks and on her feet. The healthy and athletic teenager began rapidly manifesting labored breathing, chest pains and other problems that landed her in the emergency room. Since that time Kelsey has experienced three other occasions of similar symptoms, including one just over a week ago. On every occasion, the common denominator was her presence at the Hwy. 74 Baseball/Soccer Complex. For Kelsey’s father, Bill Langworthy, her first-ever episode was something he will never forget.

“The fear was etched in her eyes,” he said. “As a parent you are there, but there is nothing you can do. You are helpless.”

Risch said research on pesticide exposure shows that chronic exposure includes worsening of asthma, headaches, dizziness and flu-like symptoms. Other exposure levels can be much worse.

“Pesticide exposure is very serious and can include asthma attacks which can obviously be fatal, serious allergic reactions like Kelsey experienced and even cancers, which we do see in our soccer population and the children in Peachtree City. The specific cancers associated with pesticide exposure are leukemia, non-Hodgkins lymphoma and brain tumors.”

“I’m a nurse so I believe an ounce of prevention is worth a pound of cure. And if it has happened in the past it will happen again,” Risch continued, recalling her children and others covered in a blue-green substance on one occasion after soccer practice. “The likelihood is a whole lot greater that a lot of other children have been exposed and we want to avoid having one more person experience this.”

Risch said the company that applied the pesticide would not release the names of the specific chemicals used to treat the fields. Applications made as recently as last week were claimed by the company to be benign, though parents could not obtain the names of the substances. In the mean time, Risch said, Kelsey had a a fourth reaction while at the soccer fields.

“This is completely unacceptable,” she stressed. “A couple of parents have noticed a pattern where they would bring their kids home from practice and two or three times during the season they’ll be very sick, needing breathing treatments or perhaps needing to go to the doctor.”

PROBLEMS WITH HEALTH CARE ACCESS

September, 2004 – Dorothy P.

We have a safe dentist office but after being poisoned by ozone at a doctor’s office, I went in search of a safe place. A couple of doctors were suggested by a clued-in friend. One was my folk dance teacher. I did not want to blur the relationship so I went to the other: The office of a doctor who allegedly specializes in "environmental medicine" was suspect. The staff looked at me like I was from Mars when I told them I was looking for an environmentally safe office. They suggested I talk to the office manager. She extolled the virtues of the Dr. and explained that what I smelled was from the massage oils. May be OK. And finally, she said a new carpet would be installed "next week". When asked what material it would be, she had not a clue.

Another doctor was suggested: His office was in a newly renovated building and was totally intolerable. When I asked if he would have an air cleaner, I was told he was "just starting out" but if I wanted to donate one, he would be delighted.!!!!! I left the office. I had on a respirator. The staff had suggested it! Try going to a doctor effectively wearing a respirator - because the doctor is too ignorant to have clean air. I guess I would not have been so upset if I were not spoiled by the dentist. I went ballistic and gave up looking for a doctor. I had already given up looking for one who could help my environmental problems. I just wanted one where I would not be poisoned.

Physician's Referral can only tell you where and what specialties --- environmentally safe office/healthy office??? What on earth is that?

At the hospital - for tests on two occasions - I had to stand or sit on the floor, as there were no chairs in any moderately safe place. The air was disgusting - to me. At least I know when I am being poisoned, usually. At a workshop sponsored by a hospital Wellness Clinic, I could tell there was something in the air. Only the next a.m. when I woke up sick - symptoms of carbo-phosphate poisoning - did I realize how right I was. I managed to call the office of the doctor who had given the workshop and got the name of the building manager but have not had the energy to make that one more call. Sick of being made sick by the health care system, I consider myself fortunate that I do not have any REAL illness! Heaven forbid that I should be hospitalized. It would probably kill me.

So what is being done to educate the AMA, hospitals and physicians before they kill us all off???????????

A man who works for the EPA asked ME to call him if I find any help - covered by insurance - because his wife is also environmentally ill and they cannot find any help. Once in a while, I have the time/energy to do something useful. Mainly, I am still trying to catch up with my life after almost five years of being made ill by the air I breathe.

Occupational Acute Anaphylactic Reaction to Assault by Perfume Spray in the Face

http://www.familypractice.com/references/referencesframe.htm?main=/journal/2001/v14.n02/1402.07/art-1402.07.htm

James E. Lessenger, MD, From a private practice.

[J Am Board Fam Pract 14(2):137-140, 2001. © 2001 American Board of Family Practice]

Case Report

A 21-year-old woman was working as a medical assistant in a family practice office. She had no history of rashes, wheezing, allergies, or reactions to fragrances, soaps, or perfumes, and there was no history of asthma or eczema. She did have rhinitis caused by pollen allergies for which she took loratadine. She was gravida 1, para 1, and with no history of surgery, hospitalization, medical illness, or allergies to medications. She had never smoked and rarely used alcohol. There was no drug use history. Her son had no history of asthma, allergic rhinitis, or eczema. There was no family history of asthma, eczema, rhinitis, or wheezing.

On the morning in question, the employee was taking a female patient from the waiting room to an examination room. She noticed the strong odor of perfume on the patient and commented on it. The patient said she had sprayed on extra perfume so the physician would not notice she had been smoking. The patient then turned on the employee, said something unintelligible, and pumped three sprays of a perfume into her face.

Immediately the employee experienced shortness of breath and a suffocating sensation. She felt her throat and face swell and collapsed to the floor. Coworkers took her into a treatment room, where she was found to be hypotensive and tachypneic. The physician-on-duty examined her and discovered wheezes throughout her lung fields and generalized urticaria. Epinephrine, diphenhydramine, oxygen, inhaled metaproterenol, and steroids were administered, which reversed the respiratory distress.

The urticaria and wheezing persisted, however, so the employee was transported to the hospital emergency department. In the emergency department she was again found to be hypotensive and tachypneic and was administered intravenous steroids and aminophylline. She could not tolerate spirometry. She was admitted into the hospital and started on intravenous steroids and aminophylline. That evening her spirometry reading was normal. The following day she was examined by a pulmonary specialist, who could hear no wheezes. A second spirometry test was normal. She was discharged 2 days later with tapering doses of steroids and oral bronchodilators. She returned to work 2 weeks later still using oral bronchodilators.

When seen on consultation 2 months after the incident, the patient complained of a persistent shortness of breath, relieved with twice daily bronchodilators, and a persistent sensitivity to all perfumes, but not all fragrances. She found she could not use perfumes but had no problems using soaps and other scented toilet articles. Findings of a chest radiograph, chemistry panel, and a pulmonary function test were normal. An odor challenge test was considered to be too dangerous to offer to the employee.

Eventually, the employee was weaned off the oral bronchodilator but insisted on keeping one with her at all times in case she came in contact with any perfumes. Although her assailant was arrested by the police, the disposition of the criminal case is unknown.

****

Students Suspended for Endangering Fragrance-Sensitive Teacher

7th-Graders Raise Stink at School

Wednesday, March 22, 2000, 01:57 p.m. Pacific
by Frank Vinluan
Seattle Times Snohomish County Bureau

Marysville School District officials are trying to clear the air about the suspension of three students who wore cologne in a classroom, an act officials say could be perceived as harassment bordering on assault. Despite requests that students refrain from using fragrant products because of the severe allergic reaction they cause teacher Jeanne Bartlett, the seventh-grade boys still "doused" themselves in cologne before entering her classroom at Cedarcrest Middle School, said Mary Fears, spokeswoman for the Marysville district.

Last Thursday, four boys went to the bathroom and poured cologne on themselves before entering Bartlett's classroom, Cedarcrest Principal Harlean Mailloux said. One boy reconsidered and washed it off. He was not suspended. But the others wore the cologne to the classroom, which bears a sign warning of Bartlett's sensitivity to fragrances and chemicals. "That's harassment, if not assault," Mailloux said.

Mailloux said teachers have seen Bartlett experience breathing difficulty after exposure to fragrances. Bartlett's allergies are so severe that cologne, hair spray and even deodorant can trigger a respiratory attack, she said.

Bartlett's students and the teachers who work with her have been asked not to wear anything scented. The request was honored without incident until this year. In January, a boy put on cologne before entering Bartlett's classroom, Mailloux said. He was suspended for three days. The three boys in last week's incident also received three-day suspensions, a punishment reduced to one day after two parents appealed. Fears said the parents contended the boys may not have been aware of Bartlett's allergy. One boy served his suspension Friday because his parents did not appeal. The other two served their suspensions Monday.

Bartlett, who has taught in the district for more than 10 years, declined to comment. But Mailloux said letters describing Bartlett's situation have been sent home with her students for several years and, with the exception of the two incidents, students and teachers have accommodated her need for a fragrance-free environment.

The district does not have a policy banning scents, Fears said. The request for a fragrance-free environment is made only in Bartlett's classroom because of her severe allergy, she said.

**"The issue here is *responsibility and consequences*," Fears said.
"This is no different than any other situation where you put a
fellow student or teacher in jeopardy."**

(Archive no longer available online)

[iii] Attachment to Robbert Jurich's Testimony

AIDS Care
Ocean State
18 Parkis Avenue
Providence, R.I.
02907-1408
(401) 521-3603

October 28, 2004

Robert Jurich

Dear Robert,

I received your letter and have placed your name on the waiting list. You are presently # 15 and it appears to be at least 12 months before we have another opening unless someone is evicted. I have filed the three spots already and have 15 people waiting.

I fully understand your desire to be independent and to be in familiar surroundings and we wish you well. It is our job to provide the exact safe, environment you sought so we know how hard it is for our residents.

Just be aware that whe your name comes to the top of the list you will be offered once more, if you decline at that time you would have to start the application from scratch.

Good luck and hopeful holidays.

Sincerely,

Darlene A. Cowan, MA, CAGS

Director

[iv]
~~Attachment to Peggy Troiano's Testimony~~
SOME WAYS TO ADRESS THESE URGENT ISSUES: Through the teaching and practicing of better stewardship, and implementing the precautionary principle "better safe than sorry" many could avoid becoming ill in the first place. Making safer choices, raising awareness & education and taking a preventative approach to health care (ounce of prevention is worth far more than an pound of cure), improving the quality of our indoor/outdoor air, protecting our water supply, forests and other natural resources along with working to keep our food chain pure and implementing truth in advertising would go a long way in creating a healthier, brighter and more prosperous future for all.
Utilizing simple precautionary measures could also help reverse/lessen some of the symptoms thereby restoring/improving the quality of life to those struggling daily from Toxic Injury as well as reducing the overall cost of healthcare not only in Rhode Island but worldwide. Given environmental controls (less toxic materials, & procedures) & reasonable accommodations, many of the chemically ill could once again be self−reliant & financially independent & not forced to go into the welfare system. Less toxic measures for user− friendly medical & dental care facilities, emergency assisted & residential housing is urgent. Existing ones are filled with so many dangerous, heavy duty cleaning products, disinfectants, pesticides and other irritating toxins that they are rendered off limits to the chemically ill. The very basic, human rights and needs necessary for survival are currently being denied to those needing them the most.
The prevalence of these illnesses and the lack of qualified doctors clearly calls for further education in this field for the public in general, practicing doctors, dentists and rescue personnel alike & for the medical and dental schools to implement this study into their required curriculum.. Other health care providers, social workers, counselors, vocational rehabilitation workers also need training in diagnosis & prevention of harm from chemical exposure. MSDS sheets & ICD Diagnostic codes for toxic effects of many chemicals found in our everyday environment & surroundings are readily available.
Building maintenance personnel need training in less toxic building management. Pest control personnel and farmers need training in the need for safe pest control. For West Nile Virus, the CDC has determined that pesticide spraying for adults is not effective and efforts should focus on larval control. Recent research shows that spraying increases mosquitoes because it kills their predators. Pesticides also exacerbate migraines, emphysema, allergies, neurological and autoimmune diseases, autism, attention deficit and many more illnesses. I would suggest contacting Beyond Pesticides:
701 E Street SE #200, Washington DC 20003 · phone 202−543−5450 · fax 202−543−4791 · info@beyondpesticides.org
To view the letter sent to all governors visit: http://mcsbeaconofhope.com/2005%20Governor%20Letter.htm It is imperative that those with Toxic Injury receive the same rights, acknowledgment, respect, support and help allotted to other illnesses and disabilities. They/we deserve to have understanding from our government, families, friends, & society in general as they/we struggle with the restrictions and isolation now placed on them/us.
"Knowledge is Power" and that Power can save precious lives!
STATISTICS AND CODES FOR YOUR VIEWING:
According to the National Academy of Sciences, 37 million Americans suffer from environmental illness. Its estimate further holds that as high as 15% of Americans can no longer live comfortably in this post−industrial world and by this it is meant in their own homes. These awful statistics are also supported by a WHO strategy meeting on Air Quality and Health held in Geneva in September 2000 where it stated, "As many as one billion people, mostly women and children, are regularly exposed to levels of indoor air pollution exceeding WHO guidelines by up to 100 times."
From: New York, Dec. 23, 2003 JOEL SHUFRO, executive director, New York Committee for Occupational Safety and Health (NYCHOSH). For each worker killed on the job as a result of traumatic injury, 10 workers die of occupational diseases. An estimated 66,000 workers die each year from occupational disease and their employers are never prosecuted. Standards exist for only 500 of the some 70,000 chemicals used in the workplace, and those standards are woefully out of date and inadequate.

According to the American Lung Association 20.3 million Americans reported having asthma in 2001 & that 72 % of asthma attacks are caused by perfume. It is also reported that 155 million people worldwide have Asthma & an estimated $1 Billion is lost annually in productivity by working parents caring for sick children due to asthma in the United States alone. 95% of chemicals used in fragrances are synthetic compounds derived from petroleum. They include benzene derivatives, aldehydes and many other known toxics and sensitizers − capable of causing cancer, birth defects, central nervous system disorders and allergic reactions. Neurotoxins: At Home and the Workplace, Report by the Committee on Science & Technology, U.S. House of Representatives, Sept. 16, 1986. (Report 99−827). A National Cancer Institute study found that children whose parents used store−bought home and garden pesticides are up to seven times more likely to develop childhood leukemia. Studies have also linked pesticide exposure to breast and prostate cancer, Parkinson’s disease and immune system disorders.

Accordingly to David Pimentel, PhD, Cornell University entomologist, less then one hundredth of one percent of sprayed pesticides reach their intended target. Pesticides cause serious health problems including deaths, toxicity, neurological effects, reduced immune responses, learning disabilities, and others (Pimentel, 2004). Each year worldwide there are 26 million pesticide poisonings with 220,000 deaths (Richter, 2002). In the U.S., NCFH (2004) reports there are 300,000 nonfatal pesticide poisonings.

ENVIRONMENTAL AND ECONOMIC COSTS OF THE APPLICATION OF PESTICIDES PRIMARILY IN THE UNITED STATES, DAVID PIMENTEL College of Agriculture and Life Sciences, Cornell University, Ithaca, NY 14853−0901 Tel:(607) 255−2212; Fax: (607) 255−0930; email: dp18@cornell.edu

Abstract: An obvious need for an updated and comprehensive study prompted this investigation of the complex of environmental costs resulting from the nation's dependence on pesticides. Included in this assessment of an estimated $10 billion in environmental and societal damages are analyses of: pesticide impacts on public health; livestock and livestock product losses; increased control expenses resulting from pesticide−related destruction of natural enemies and from the development of pesticide resistance in pests; crop pollination problems and honeybee losses; crop and crop product losses; bird, fish, and other wildlife losses; and governmental expenditures to reduce the environmental and social costs of the recommended application of pesticides.

The major economic and environmental losses due to the application of pesticides in the U.S. were: public health, $1.1 billion per year, pesticide resistance in pests; $1.5 billion; crop losses caused by pesticides, $1.4 billion; bird losses due to pesticides, $2.2 billion; and groundwater contamination, $2.0 billion. Key words: agriculture, costs, crops, environment, livestock, natural resources, pesticide, pesticide resistance, public health.

Toluene can effect you when breathed in and by passing through your skin, may cause mutations, may damage the developing fetus. Handle with extreme caution. Exposure can irritate the skin nose, throat, and eyes. Higher levels can cause you to feel dizzy, lightheaded, and to pass out. Death can occur. Repeated exposures can damage bone marrow, causing low blood cell count. It can also damage the liver and kidneys, can cause slowed reflexes, trouble concentrating, and headaches." New Jersey Department of Health, Hazardous Substance Fact Sheet Right to Know Program. CN 368, Trenton, N.J., 08625−0368. "The evidence is strong that formaldehyde is a carcinogen. It is a mutagen; namely it is capable of attacking the genetic materia of cells, and producing permanent genetic damage. 95% of chemicals that show mutagenic activity are carcinogenic. That formaldehyde is a demonstrated carcinogen in animals is now undisputed.

The National Institute for Occupational Safety and Health reports, "the results of individual studies suggest that formaldehyde exposure may be associated with increased risk of lung cancer, brain cancer, and leukemia."

U.S. scientist Samuel Epstein, author of several books on cancer, say 80 to 90 percent of human cancer is determined environmentally. Dental Amalgam Mercury Syndrome “DAMS” Scientifically Proven Facts about Mercury & Dental: Dental Amalgam contains about 50% mercury. Mercury has been scientifically demonstrated to be more toxic than lead, cadmium, or even arsenic.

Mercury vapor is absorbed at a rate of 80% through the lungs into the arterial blood. (31, 55)

Mercury is cytotoxic −− i.e. it kills cells.

There is NO harmless level of mercury vapor exposure. (63)

Mercury vapor is absorbed directly into the brain. (34, 55a)

A few Diagnostic codes for your convenience:

506.3 Other Acute And Subacute Respiratory Conditions Due To Fumes And Vapors

506.4 Chronic Respiratory Conditions Due To Fumes And Vapors: {Emphysema (diffuse) (chronic)} {Obliterative bronchiolitis (chronic) (subacute)} {Pulmonary fibrosis (chronic)} due to inhalation of chemical fumes and vapors

975 Poisoning By Agents Primarily Acting On The Smooth & Skeletal Muscles & Respiratory System Injury & Poisoning

980−989 Toxic Effects of Substances Chiefly Nonmedicinal as to Source

987.9 Toxic Effect Of Unspecified Gas, Fume, Or Vapor
989.3 Toxic Effect Of Organophosphate And Carbamate Carbaryl; Dichlorvos; Malathion; Parathion; Phorate; Phosdrin
989.4 Toxic Effect Of Other Pesticides, NEC Mixtures of insecticides
989.6 Toxic Effect Of Soaps And Detergents
995.66 Anaphylactic Shock Due To Food Additives