



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



July 25 – 27, 2006

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

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November 2006

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

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



Monday July 24, 2006, 3:00 PM- 5:00 PM

Newport Public Library, Lower Level Program Room,
300 Spring Street, Newport

Tuesday July 25, 2006, 4:00 PM - 6:00 PM

Eleanor Slater Hospital- Zambarano Unit, Auditorium,
2090 Wallum Lake Rd., Pascoag (at the end of Route 100 N)

Wednesday July 26, 2006, 11:00 AM-1:00 PM

PARI, Independence Square, Auditorium,
500 Prospect Street, Pawtucket

Wednesday July 26, 2006, 3:00 PM – 5:00 PM

Independence Square II, Large Conference Room, 25 West Independence Way,
Kingston (on Route 138, just west of the URI Campus)

Thursday July 27, 2006, 4:30 PM – 6:30 PM

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

Comments may be made in person during the hearing, or you can mail, fax or e-mail them by July
31st 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,
contact the CDHH (voice) 222-1204 or (tty) 222-1205 to confirm which forums will have
interpreters.

When making the ADA reservation with RIdE to get to and from the public hearing, tell the RIdE
reservationist 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.

Donald L. Carcieri, Governor

Public Forum Sponsors

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

Brain Injury Association of RI, Inc.

Sharon Brinkworth, Executive Director

Community Provider Network of RI

Donna Martin, Executive Director

J.A. Trudeau Memorial Center

Mary Madden, President/CEO

Ocean State Center for Independent Living

Lorna Ricci, Executive Director

Opportunities Unlimited for People with Differing Abilities, Inc.

Linda N. Ward, Executive Director

PAL

Doreen McConaghy, Director

PARI Independent Living Center

Leo Canuel, Executive Director

Rhodes to Independence @ the University of Rhode Island, College of Pharmacy

Donald Letendre, Dean, Elaina Goldstein, Director of Public Policy

RI Breast Cancer Coalition

Marlene McCarthy, Chair.

RI Commission on the Deaf and Hard of Hearing

Steven A. Florio, Executive Director

RI Department of Health

Dr. David R. Gifford, Director

RI Department of Human Services

Ronald Lebel, Director

Assistive Technology Access Partnership

Regina Connor, Project Director / Assistant Administrator

Center for Adult Health

Dianne Kayala, Chief, Family Health Systems

Office of Rehabilitation Services

Raymond A. Carroll, Administrator

RI Council on Assistive Technology / Assistive Technology Access Partnership

Jeanne Panarace, Chairperson

Services for the Blind and Visually Impaired

Ronald Racine, Deputy Administrator

RI Department of Mental Health, Retardation and Hospitals

Ellen Nelson, Director

RI Disability Law Center

Raymond Bandusky, Executive Director

RI Governor's Commission on Disabilities

Paul Choquette, Chair

RI Public Transit Authority

Alfred J. Moscola, General Manager

Spurwink/RI

Raymond A. Arsenault, Executive Director

Statewide Independent Living Council

Sharon Kimbriel, Chairperson

RI Department of Administration Library & Information Services

Beth Perry, Acting Chief

Purpose of the Public Forums

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

Procedure following the Public Forums

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

Community Concerns and Recommendations

Below are the community concerns, as raised by people with disabilities, their families, and others at the 6 public forums and recommendations developed by the forum sponsors in response to those concerns. After each “concern” are citations of the pages in the transcripts related to this concern. Even if each of these “concerns” does not match reality, the misperception indicates a need for better outreach / awareness of services and coordination among providers to ensure families in crisis are able to quickly and effectively access the appropriate services.

Accessibility Concerns	Recommendations	Testimony on Pages
1. Public buildings, institutions, health care facilities and public and non-public housing are inaccessible to people with Multiple Chemical Sensitivity	Implementation of the Senate Resolution 2006 Chapter 276 Urging The Department of Administration To Use Environmentally-Safe and Health-Friendly Cleaning Products In State Facilities and Workplaces, using the State House as a pilot project Based on the results of the “pilot project”: in the future consider training for property managers, realtors, and health care practitioners specific to Multiple Chemical Sensitivity Ocean State Center for Independent Living should include chemical accessibility as a criteria in the statewide accessible housing registry	3 , 4-5 , 31 , 57 , 58 , 66 , 71
2. Lack of accessible housing	Support Bond Referendum # 9	9
3. Accessible rest room stalls are often used by persons who don't need them, tying up the stalls	The Governor's Commission on Disabilities should assist Patients for Progress in their advocacy efforts	14
4. Disability parking placard difficulty (tests??)	The Governor's Commission on Disabilities' Disability Parking Committee should meet with Motor Vehicles on policies, practices and procedures for getting a parking placard.	40
5. Lack of sensitivity to deaf &	The Commission on the Deaf & Hard of	53

Accessibility Concerns	Recommendations	Testimony on Pages
hard of hearing from police	Hearing should conduct training for police departments	
6.		
7. Lack of Automated doors at medical facilities	The Governor's Commission on Disabilities recommend the use of automatic doors when providing technical assistance	61
Community Supports Concerns	Recommendations	Testimony on Pages
8. The need for additional "job coaches" for persons with disabilities	Opportunities: <ul style="list-style-type: none"> • MT Team per diem includes voc rehab • Grants 	63
9. Lack of respite for parents with a child with severe disabilities	The Governor's Commission on Disabilities should advocate during the budget hearing for funding of respite services for parents with a child with severe disabilities;	64
10. Inadequate in-home based behavioral intervention services, community-based psychiatric services and other support services such as speech and language specialists	The Governor's Commission on Disabilities should sponsor legislation to create a loan repayment plan to keep newly trained community-based psychiatric and other therapeutic services providers in the state	64
11.		64
12.		
13. Teachers are often poorly prepared and supported to understand and manage the needs of children with special health care needs in their classrooms		64
14. Poorly developed and inadequately enforced Individualized Educational Plans (IEPs)	1) Contact RI Department of Education 2) Contact RI Parent Information Network for support 3) Opportunity present as RI needs to develop regulations to comply with new IDEA regulations. A more frequent review of school district compliance (current policy: every 5 years)	65
15. Lack of appropriate school-based accommodations. Poorly enforced accommodation requirements.	Same as above	65
16. Lack of sufficient number of teachers at Zambarano in the summer	RI College and the University of RI should offer Summer internship opportunities for teachers and other rehab interns at Zambarano	15
17. Poor client treatment at the <u>Eleanor Slater Hospital</u>	Notices should be posted outlining the Long Term Care Ombudsperson's responsibilities were extended to include the both units of the	16

Community Supports Concerns	Recommendations	Testimony on Pages
	Eleanor Slater Hospital	
18. Lack of family supports (i.e. recreational activities) for families with young adults with special health care needs.		8
19. Lack of awareness of available resources for Persons with disabilities	<u>The Departments of Elderly Affairs and Human Services should improve their Better outreach – awareness of resources:</u> The Point ¹ Ask Rhody ²	19
20. The need for additional resources to help transition young adults with special health care needs from school into community network supports; employment opportunities; transportation		17
21. Confusion regarding guardianship issues	The RI Disability Law Center should conduct: 1) Family education re: guardian process 2) Ensuring protection for Persons with Disabilities in the guardian process	36-40
Health Care Concerns	Recommendations	Testimony on Pages
22.		
23. Instate support for persons with brain injury need administrative funding	The Governor’s Commission on Disabilities should sponsor legislation to amend the comprehensive instate services for individuals with traumatic brain injury legislation to authorize up to 10% of funding for DHS administrative expenses.	23 , 24 , 56
24. Need for more Habilitation waivers “slots”. 25. Waiting list for Home Based Treatment Services (HBTS)	The Governor’s Commission on Disabilities should advocate during the budget hearing for funding of: The habilitation waiver should be expanded to include all eligible recipients who would benefit from physical therapy, occupational therapy, speech/language therapy, psychological therapy, rehabilitation services	24-25 , 45-48 53 , 56
26.		
27. Inappropriate placement of younger people with disabilities who need to be in long-term care facilities.	Assessment of how many younger people in Long Term Care facilities who might benefit from placement in more age appropriate setting. Feasibility study.	35 , 56

¹ THE POINT (401 462 4444) provides information, referrals, and help getting started with programs and services for seniors, adults with disabilities, and their caregivers. <http://adrc.ohhs.ri.gov/>

² Website work funded by a Real Choices Grant from the Centers for Medicare & Medicaid Services and the RI Department of Human Services
<http://www.dhs.ri.gov/askrhody/>

Health Care Concerns	Recommendations	Testimony on Pages
28. Limited care coordination services available in commercial health insurance for families with children with special needs.	The Governor's Commission on Disabilities should monitor the implementation of the budget article on mandated care.	25
29. Group home receiving Social Security funds instead of consumer.	The Attorney General's Medicaid fraud Unit should conduct under investigation	12, 35, 36-38
30.		
31. Disappointment and dissatisfaction with CEDARR Program	The Department of Human Services should implement Public Law 2005 Chapter 400 ³ that requires Rite Care Health plans to develop additional home and community based services	45-46
32. Lack of adult specialty providers for persons with disabilities.	The Health Insurance Commission should ensure that managed care health plans should be responsible for developing provider network needed by its members.	47
33. Costs of co-pays for dual eligibles are too high.	The Department of Human Services should establish a monthly cap on co-pay and modify the-deductions according to a person's income	55, 59
34. Inadequate or no payment by Medicare for power assisted wheel chairs.	Education and advocacy with Centers for Medicare & Medicaid Services. Medicare issue	55
Housing Concerns	Recommendations	Testimony on Pages
35. Lack of funds for home modifications	Modifications to homes/apartments owned or rented by families with disabled members (expand to include Medicare only recipients) and create flexible funding plan such as cash and counseling for families to modify home or yard;	51
36. Limited housing that is accessible and affordable	The Governor's Commission on Disabilities should support bond issue (Question #9) that	52

³ **42-72-5.2. Development of a continuum of children's behavioral health programs. –**

The departments of children, youth and families (DCYF) and human services (DHS) shall cooperate to develop a design of a continuum of care for children's behavioral health services that encourages the use of alternative psychiatric and other services to hospitalization and reviews the utilization of each service in order to better match services and programs to the needs of the children and families as well as continuously improve the quality of and access to services. The departments of children, youth and families and human services shall present a report to the governor and the general assembly no later than January 1, 2006 that fully described this continuum of services and outlines a detailed plan for its implementation, including resource requirements, responsibilities, milestones, and time frames, as well as a set of indicators and program metrics that will be employed to evaluate its clinical and fiscal effectiveness over time. The report shall also describe any and all changes proposed in program oversight or budgetary responsibility for specific services. An important step towards the development of such continuum of care is to assure the appropriate management of psychiatric hospitalizations. To that end the state shall:

(1) Amend contractual agreements with Rite Care health plans to reflect complete responsibility for the management of psychiatric hospitalizations, specifically the development of hospital diversion and post discharge services; and the utilization of crisis intervention services as a requirement for authorization of a psychiatric admission for all children enrolled in Rite Care; and

(2) Issue a request for proposals to identify a contracted entity to reflect complete responsibility for the management of psychiatric hospitalizations, specifically the development of hospital diversion and post discharge services for crisis intervention services as a requirement for authorization of a psychiatric admission for all Medicaid-eligible children not enrolled in Rite Care. The request for proposals shall include a dispute resolution process.

<i>Housing Concerns</i>	Recommendations	Testimony on Pages
	will increase the availability of affordable housing. Pending passage, closely follow implementation and seek to integrate accessibility. The Housing Resources Commission should determine the level of compliance with affordable housing mandate requiring each city/town to have 10% affordable (low-income) housing	
37.	•	3 , 31 , 71
<i>Transportation Concerns</i>	Recommendations	Testimony on Pages
38. Disability Parking lacking in Newport, especially following construction projects	The Governor’s Commission on Disabilities work with RI Department of Transportation and the City of Newport to ensure Disability Parking is restored and usable during and after construction projects	3
39. The process for getting hand controls restriction placed on driver’s licenses is overly stringent, applicants for disability parking permits and drivers’ licenses –are given strength tests for driving if apply for disability parking permits, jeopardizing their drivers’ license	RI GCD Disability Parking Committee should expand its responsibilities to include the rights of drivers with disabilities and meet with Motor Vehicles on policies, practices and procedures	49-50
40. RIde does not cross state lines	The Paratransit Task Force should review alternatives or modification of policy especially if the trips are employment or medical care related	54
41. Enforcement of Handicapped Parking is lax, and there are not enough van accessible spaces	RI Governor’s Commission on Disabilities’ Disability Parking Committee should review of enforcement activities to find/share best practices and advocate with local police departments	40 , 61
42. Differing scheduling requirements for RIde if disabled vs. elderly and also too early or late or 5 AM vs. 5 PM pickup	RIde needs to do some revision & education of dispatchers as to scheduling for disabled vs. elderly. Regulations / Policy changes possible as well as better dispatch confirmations of time before. Flex routes perhaps for some like employment	62
43. Accessible transportation to and from the airport is very limited and difficult to locate, there isn’t any wheelchair accessible taxi service in the rest of RI	The Governor’s Commission on Disabilities sponsor legislation to require a percentage of each taxi fleet be accessible (modeled after the Louisville City Ordinance) Require the Airport Corporation ensure that information on their website and at curbside pickups/monitors and Johnson &Wales	61 , 62

<i>Transportation Concerns</i>	Recommendations	Testimony on Pages
	information booth distribute information about the RIde and other accessible taxi and shuttle services.	
44. High School transition programs are not able to utilize the RI Public Transit Authority bus in for travel training. They only provided one bus with only two wheelchair hookups. The class has more than two students using wheelchairs, the students need to learn how to utilizing their community	RIPTA and the educational collaborative should establish travel training programs to foster transition to community and employment	16
45. RI Public Transit Authority – bus rides from Zambarano for visits long and bumpy and w/o communications to driver in front of the bus		8
46.		
47.		

The Testimony

Monday July 24, 2006, Newport Public Library

BARBARA ROSULE: Good afternoon. I am Barbara, Treasurer on the State Independent Living Council Good afternoon, again. Can you hear me? My name is Barbara Rosule. I am treasurer on the state independent living council, okay. The purpose of this forum is to have people identify the needs of people with disabilities and their families in order to assist the state to develop a program to improve the quality of lives of people with disabilities. We have here before us members that represent several facets of the government. I will let them introduce themselves.

ALEXANDRA LAPLANT: I am Alexandra LaPlant. I work at the Disability Law Center. I am a legal advocate there. We are a federally funded nonprofit agency. We deal with all disability related issues. Actually in the back there, the yellow sheets. I brought a bunch of surveys. Every year we come up with a list of priorities that we account to our funding sources -- priority cases that we take. So we wanted to get consumer's ideas and what they thought would be beneficial for the community. If you feel like filling out a survey and leaving it for me, that would be great. You can also take it home for you and put it in the mail. Thanks

LINDA WARD: I'm Linda Ward, Executive Director of Opportunities Unlimited. We are a small nonprofit agency located in Cranston that provides services to adults with developmental disabilities.

CATHERINE GORMAN: I am Cathy Gorman. I work with the Department of Human Services. I work for the center for adult health which is involved with Medicaid or Rhode Island medical assistance. I have a lot of experience though working with adult service and long-term care programs.

BILL INLOW: I am Bill Inlow and I'm a member of the Governor Commission on Disabilities Legislative Committee and I live in Middletown.

PAUL CHOQUETTE: That's it?

BILL INLOW: That's it.

PAUL CHOQUETTE: I am Paul Choquette. I am the chair person of the Governor's Commission on Disabilities. I am I also work at the Rhode Island department of services in the center for child and family health where I work with programs that serve children with special healthcare needs. And I'm very anxious to hear what's on people's minds today.

BARBARA ROSULE: Postings of the transcript of this testimony on the Governor's Commission on Disabilities website will be available in about a week. If you want to write the website down, it's <http://www.gcd.state.ri.us> I guess that's about it. I guess we can start. The first person who signed in for testimony is Annette Bourbonniere

PAUL CHOQUETTE: Can I just add a couple of things first? We have -- as you can see, we have real-time captioning, open captioning available. We also have sign language interpretation available if needed. And there is an assistive listening device here in the room if it's needed as well. And I also want to point out that there are handouts at the back of the room. Some information about the forums and its sponsors and also some information on what has resulted from some of the forums we had in the past. So anyone wants to grab those, they are more than welcome to.

COLLEEN POSELLI: I am Colleen Poselli from the Rhode Island Department of Health

BARBARA ROSULE: Everyone has introduced themselves already and Paul helped me with the stuff I forgot to mention. Annette, would you like to stand up and make your presentation?

ANNETTE BOURBONNIERE: I don't. I would love to but that's not an option today

BARBARA ROSULE: Just mention your name.

AUDIENCE MEMBER: The first thing I really want to talk about is being in -- having meetings be accessible. I don't understand why we have this meeting here where it's an organization that has only two handicapped parking places. There are places on the island that have many more parking spaces that would be, you know, would have at least as much space and would be as easy to go to. So, I would really

**Accessibility &
Transportation**

like to request that in the future we look at other possibilities. The other public meetings in the city of Newport want to always schedule its public meetings to be held in the city council chambers. If you want five people with disabilities to go to that meeting, they actually have to start about an hour and a half before the meeting to be able to get up there. And there's also no bathroom on that floor that's accessible. So this lift would be going constantly. And again, it would take that much time to get people down. There was a big meeting recently on transportation issues. That is a real concern to people with disabilities and we couldn't go to that meeting. So I really would like to see a law be that all public meetings have to be not just accessible with one person being able to go up on a lift, but they have to be able to accommodate groups of people with disabilities. That would be I think protocol. And then the third thing is on parking as well. We've talked about it on the city level and we are told that on a state level it's been okay and I'm not sure it is. But the courthouse downtown Newport in Washington Square when they've been redoing Washington Square, they've taken away the three parking places that were there. And they've now replaced it with two -- what in very -- very different locales, none of which make it very easy for someone to get into the courthouse. In fact, I think that people should be concerned that we are some day going to not have somebody be able to get into the courthouse and have them get arrested. And it will be the fault of whoever is paying for all of that rendition down there. Those are the things I had to say.

BILL INLOW: Can I ask a question?

BARBARA ROSULE: Please introduce yourself.

BILL INLOW: I am Bill Inlow. Did you say there are only two parking spaces for people with disabilities in this library?

ANNETTE BOURBONNIERE: Yes

AUDIENCE MEMBER: If that.

ANNETTE BOURBONNIERE: There are only two

AUDIENCE MEMBER: I couldn't tell you where they are

ANNETTE BOURBONNIERE: I can tell you right where they are. They are in the parking lot. They are two spaces

AUDIENCE MEMBER: Could you tell me --

ANNETTE BOURBONNIERE: They are right near the door.

AUDIENCE MEMBER: The back door or the --

ANNETTE BOURBONNIERE: The back door. It's on the middle level.

AUDIENCE MEMBER: So Spring Street side?

ANNETTE BOURBONNIERE: No. The parking lot side. There are two parking spaces there

AUDIENCE MEMBER: Oh, you are talking --

ANNETTE BOURBONNIERE: That's here for this --

AUDIENCE MEMBER: Oh, here I thought you were still --

ANNETTE BOURBONNIERE: I think he is talking about here, right?

BILL INLOW: On behalf of the Legislative Committee, I apologize --

ANNETTE BOURBONNIERE: There are only two parking spaces and --

BILL INLOW: That's unacceptable. We apologize. We will make sure that doesn't happen again next year. Thank you for bringing that to our attention

ANNETTE BOURBONNIERE: If you want, we can discuss later some really good alternatives that have great parking. It would make it a lot more accessible

BILL INLOW: That would make it very helpful

BARBARA ROSULE: Thank you. Cheryl, Cheryl Grove.

CHERYL GROVE: Yes. First of all I want to thank Annette for the comprehensive writing that she does about wheelchair accessibility in Newport Daily News. She gives them heck consistently. I think that's great. I would like to see that expanded to more than just wheelchair accessibility. I know from time to time there is a blurb -- there's a disability that's not recognized apparently in this state and that's breathing disability. The other thing before I leave is three years ago, we had this meeting over at Salve Regina and there was tremendous parking. It was a

Accessibility

wonderful room, wonderful facility. And since I believe they still have a disability masters program, I would think that it would be incredible to continue that relationship going there. And I pointed that out last year. But apparently it wasn't heard. And as far as the parking down at Washington Square, I mean, how many spaces did we lose there? It's ridiculous. And I've gone to the police department and I've asked for a map. Well, where are the parking spaces for disabled people in this city? And I don't know if there is one that I -- but anyway, so that's just all those issues. Now I'm going to mine, which may not leave a happy set of statements to people that have worked very hard for wheelchair accessibility in this city. But I want to put -- title my presentation accessibility, how accessible -- how it is more than a wheelchair ramp and signage. As wheelchair accessibility non-optional locations housing seems officially understood, perhaps the parable could help in understanding a life threatening disability that continues to be superficially and ineffectively addressed within the state despite ongoing health and safety risks and result in preventable decline in a few well defined severely disabled, MD documented, SSDI constituents, including myself, who are financially confined to restricted housing, inaccessible to pollution related breathing disability and other complications. Right to protection from neighbor news since VOC numbers including secondhand smoke and consumer product VOC fumes through walls,

Housing

ceilings and floors and in common areas is unenforced and unaddressed in the state. To my parable, imagine a poem becoming an adult on set wheelchair, you found according to your own experiences a 14 moves in seven years and informed by the state housing authority, "There are to be no housing accessible to your disability in the state." There were signs including in Braille. But no wheelchair ramps or garden egress to provide accessibility into any HUD assisted housing units in the entire state. Several officials advised me to move out of state during the six years you have actively sought assistance. After years of suffering preventable declining health, directly related to the same inaccessible housing including new complications from sleeping in your car despite co-paying for inaccessible housing, you are asked to accept what a GCD representative stated was, "practical." Your state legislators were being asked to mandate the study of voluntary wheelchair ramps in schools and hospitals, not non-optional primary location HUD assisted housing for the next year, despite the fact that these were well studied and implemented outside the state. When the state health department declined, due to claimed budget constraints, the next "practical" concept was to translate educational materials for the general Hispanic public, something which was again already readily accessible to anyone with internet access to out of state resources. You remain at the mercy, not of technologically unacceptable solutions but of ignorance and lack of commitment to the GCD pledge of disability equanimity funded

Health Care

by our tax payers. One would presume this would prioritize the most at risk cases, particularly when they number so few without private resources to address this housing inaccessibility in this state. As any reasonable person has -- example voluntary and educational programs don't protect susceptible non-offenders. Rhode Island statute 23 health and safety concluded, "It has been determined that smoking is the leading cause of preventable death and disease in this country. More people die from cigarette smoking and related illnesses each year than die from alcohol, traffic accidents, cocaine and heroine, AIDS, murder, and suicide combined. "Secondhand tobacco smoke alone causes up to 53,000 deaths per year in nonsmokers." As quoted by the center for disease control, "Secondhand smoke is the third leading cause of death in the United States Today "A recent U.S. surgeon general report survey 20 years of scientific evidence about the effects of secondhand smoke and found that even trace amounts causing immediate and damaging effects in nonsmokers. Surgeon General Richard Carnona said, "There was no safe level of exposure to secondhand smoke and no amount of air filtration can eliminate the health effects of secondhand smoke." These same VOCs, which stands for volatile organic compounds, and carcinogens, cancer causing compounds, are causing preventable health and safety decline through floors, walls, and ceilings, and in common areas in HUD assisted housing from VOC consumer products to promote that these few severely disabled susceptible constituents need education on this matter is to promote your ignorance. They likely wouldn't be alive today if they had not taken it upon themselves to become educated by current responsible out Of state authorities, including CDC and Global Threat in Societies. People die from pollution related respiratory and other, including heart diseases. We lost one at 61 years old last year. How many die from

wheelchair accidents from improper ramps? Perhaps you can reflect on this when you set your priorities this year. And on public record, I am requesting to be the GCD constituent on the housing legislative committee this year as well as any other pertinent associations. Bob Cooper knows how to contact me. And you can also contact me at my e-mail address, it's Seagrove62@Yahoo.com. Thank you.

PAUL CHOQUETTE: Thank you, Cheryl.

BARBARA ROSULE: Thank you, Cheryl.

CHERYL GROVE: You are welcome

BARBARA ROSULE: Is there anyone else here who would like to give testimony? Beverly, would you please stand up and state your name. Do you want to give testimony, Beverly? No. Okay.

BEVERLY: I can't hear. Not now. Maybe later.

BARBARA ROSULE: I guess that drops it off then.

PAUL CHOQUETTE: The meeting is not over. We will be here until 5:00. So if nobody wishes to give testimony right now, they don't have to. But we will be here until 5:00 to take testimony. And any testimony given will be recorded up until 5:00. So if there's nobody else who doesn't need to give any at this time, then we can just take a recess actually. We can take --

BARBARA ROSULE: Take a little recess.

PAUL CHOQUETTE: Take a recess.

BILL INLOW: But anyone can speak if they do decide to.

PAUL CHOQUETTE: Absolutely.

BILL INLOW: You can stand up and tell us your name, express their opinions about the issues that we are talking about.

PAUL CHOQUETTE: This is an opportunity to really let -- maybe I should just mention that the transcript of this, along with the other four public forums that will be taking place around the state, will be given to the legislature, the executive branch, and all the departments and the sponsors of these forums. So this is an opportunity that if you are having anything that you feel that you want the state government to know about, this is the opportunity to do so again, it's just one of those -- it's something that we use it every year to try to come up with what we are going to be advocating for legislatively as far as the Commission goes. But the Governor's Commission was once part of the advocacy system in this state. And the other organizations that are represented here and at the other sites will also be taking this information to use that in their advocacy efforts as well. So again, it's not just the Governor's Commission on Disabilities that is taking the ball with this and running with it. I've learned over the years is that it's when we work in partnership with each other that we actually can make some change happen. So, please, don't just think that just the Governor's Commission is going to hear this. A lot more people are going to hear this than just the Governor's Commission on Disability. So, take some time. We will be here until 5:00.

(Return from break)

BARBARA ROSULE: Excuse me. We are going to try to reconvene the meeting again. Does anyone else have anything they would like to say because we are going to be here until 5:00. Any new thoughts that have come up in the interim? No?

PAUL CHOQUETTE: Because Annette, you are always worth a couple extra comments that are always very cutting -- if you don't have anything. Well, we will be here until 5:00. If people -- people don't need to stay until 5:00 except for the interpreters and the people on the panel. Thank you very much for coming and for your input. I do appreciate it from the Governor's Commission on Disabilities. Again we will be here until 5. If there is no one presenting any testimony at this moment, again, if you want to wait until 4:55 to do so, go right ahead. Thank you. I guess at this point, if there's something you wish to say, just raise your hand or indicate that you want to say something. If not, we will probably just talk amongst ourselves for the next 20 minutes. Thank you.

(Return from break)

BARBARA ROSULE: I would like to thank you all for coming, and representatives from various organizations in government. And hopefully we will see you back here next year.

AUDIENCE MEMBER: Not here.

PAUL CHOQUETTE: I would like to thank everyone for coming. In the back table there is some information if you would like to take away. At this point we are going to officially close this forum. Thank you all for coming. Drive safe.

Tuesday July 25, 2006, Eleanor Slater Hospital- Zambarano Unit

JERRY MENOCHÉ: Good evening.

It's going to be that way here. The acoustics are very bad. So anyway, I'm Jerry Menoche. I will be moderating the panel. I work -- if you want to come closer, you can. It's a rather big room. I guess some of the residents in the hospital may come down later. But basically what we will do now is kind of read the outline and ask the panelists to introduce themselves at this time. So I will pass the microphone down.

JANET SPINELLI: I am Janet Spinelli. I work with MHRH in this campus. I worked in the Cranston campus and I work in the community of neighborhood health.

CASEY CROTHERS: I am Casey Crothers from Brain Injury Association of Rhode Island.

BILL INLOW: Can you hear that? You have to speak right into. Some us have bigger mouths (LAUGHING). I could sing a song with this mike that way -- the few people we have here. Can I go ahead, Jerry? I am Bill Inlow. And I am the disability services coordinator at the Rhode Island Transit Authority, RIPTA, all the ADA (Americans with Disabilities Act) application for RIDE Program come through my office. And that's how I got to know Jerry Menoche, social worker here, a good friend of mine. We just met for the first time today face-to-face. I was here two or three years ago at the privilege of hearing a lot of testimony from the residents of this place. I was very moved from the folks that come down -- for our benefit as well as theirs, their concerns about issues of people with disabilities in the state. I'm glad to be here and I certainly welcome all of you folks here. I help you make known your opinions about issues for people with disabilities.

ARTHUR PLITT: I am Arthur Plitt, commissioner with the Governor's Commission --

LOUD SPEAKER: Can I have your attention. The Governor's Commission on Disabilities is now being held in the auditorium. The Governor's Commission on Disability is now being held. The public forum is now being held in the auditorium. All who would like to attend.

ARTHUR PLITT: Okay we will try again. Arthur Plitt, Governor's Commission on Disabilities. I have been a commissioner for a number of years and I also serve on the -- (loud speaker) and I'm not sure if Elaina will be here later. But she directs the Ocean State independence -- we are missing one other panelist. I should read the purpose of this 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. These public forums will be followed by posting the transcripts of the testimony on the Governor's Commission's website in about a week. The website is

www.disabilities.ri.gov. Later this summer the sponsoring agencies will review the testimony, prepare recommendations, which also will be posted on the website at the end of the summer. The recommendations and the transcripts will be printed and sent to the state Congressional officials, members of the general assembly, and recommendations will be used to develop policy and legislative initiatives for the next year or until they are accomplished. If you will note some of the past records, a lot of comments that you and other Rhode Island citizens have submitted to these public forums have become law or have made administrative changes. So thank you very much for your past comments.

BETH PINKHAM: I everybody. I am Beth Pinkham, the transition and the real choices at the Department of Human Services.

ROBERTA GREEN: Good afternoon. My name is Roberta Green. I work in the Office of Rehabilitation Services for the Department of Human Services in the training coordinator and supervisor. I also worked as a counselor there, rehabilitation counselor. And up until about three years ago, I worked at the Disabilities Law Center. I was an advocate for 13 years.

BRIAN ADAE: Good afternoon. My name is Brian Adae. I am a staff attorney for the Rhode Island Disability Law Center, one of a number of staff attorneys. The Disability Law Center is part of the national protective and advocacy system for persons with disabilities. We are the state designated P&A, protective and advocacy agency, for the state of Rhode Island. One thing I do want to do in addition to telling you about our website for those of you who do have access, internet access, our Website is found

at ridlc.org. R I D L C -- for Rhode Island disability law center -- dot org. We do -- on an annual basis; we take a look at the forthcoming year. We provide assistance, legal based -- free legal based representation and advocacy for persons with disabilities on certain disability related issues. One thing we are in the process of doing as we speak is setting up priorities for the next coming year on what cases, areas involved we are looking at. A lot of times we like to look at systemic, policy based issues, issues that we do take individual cases. I brought along with me our annual survey, which I would love to get some audience participation from everybody here, in addition to hearing your comments. I would love to have everybody here take one of these. And if you have the opportunity, fill it out this afternoon and return it to me so that I can take it back. If not, put it in the mail and send it back to us at a later date. Thank you.

JERRY MENOCHÉ: I have another microphone over here. This one will be used for the audience as well. I thank you all for being here. I thank the audience as well. Just a few other little things. Reminder is that we have a sign in attendance sheet. And so if you have not signed in, please sign in at the table over there. And also designate it if you wish to speak today on that sheet. That way we will know you want to testify. We also have a group of handouts that you probably already have. If you haven't, they are at the table. I want to make one correction and that is on one of the handouts I passed, the state website as www.god -- that should be gcd. So you can make that correction on your handout so you don't get the wrong Website. If you go to the -- it might be interesting, but it wouldn't be correct. So, we read the terms of public forum and we also have that on the handout as well. When you speak -- when you do speak, we would like you to introduce yourself and to just let us know where you are from. And - - since we have a small group, I will pass the mike around and ask you to say your name and where you are from. I will start over here.

FRANK MOLLA: My name is Frank Molla. I am from Charlestown, Rhode Island.

JANICE HARRISON: My name is Janice Harrison -- to the department of community preference.

JEANINE LOGE: My name is Jeanine Loge. I am from Elmwood.

BARBARA ANGEL: My name is -- Barbara Angel from Burrillville.

CHRIS PARKER: I am Chris Parker from Woonsocket School Department and I live in Glocester.

JESSICA FRACHETTE: I am Jessica Frachette also from the Woonsocket School Department. I live in Woonsocket.

JERRY MENOCHÉ: These two people are interpreters. Right now we only have a couple of people who have signed up to speak. So, you have an amount of time to speak and ask questions. As more people come in, we may have to divide up at -- set a time line to -- so everybody gets a chance to speak. We would like to wrap it all up by 6:00. And obviously we want to leave some time at the end for questions. So, at this point I guess we will start with our first speaker. And that person would be Jeanine Rue.

JEANINE RUE: Hello. I am a mother of a son who suffers from severe Asperger's syndrome and **Health Care** anxiety. And I seem to be running into stone walls as far as getting services for him. I have a medical doc and what I haven't been able to find a psychologist, psychiatrist nor dental services. He has the state of Rhode Island insurance and it seems that many providers do not -- Rhode Island insurance, I was wondering if there's -- help me get good competent doctors for my son.

JERRY MENOCHÉ: Any questions at this time?

BILL INLOW: Did you say your son has Asperger's syndrome?

JEANINE RUE: Yes.

BILL INLOW: That's on the scale of autism?

JEANINE RUE: Socially dysfunctional -- he often says inappropriate things. He loses jobs. He got himself in all kinds of trouble in high school because the staff didn't understand where he was coming from basically. And students just would pick on him constantly. It was just a horrible situation.

BILL INLOW: So now he's out of school?

JEANINE RUE: Yes.

BILL INLOW: So the challenge is you are going after the school system -- is imperfect to give adequate support. On your own --

JEANINE RUE: Right. He had a childhood psychologist from the time he was about eleven. And this doctor was kind of -- in Bradley Hospital to keep him on. Your son is an adult now. Really this is more another area that he should go into a regular psychologist. He had -- no. That was a psychiatrist. He had a psychologist while he was in high school provided by the school. And we kept up with him for a while. But he also -- my son is 24 now and he basically fell -- his, you know, his need to move on.

BILL INLOW: That's a good -- we heard before. With children, especially when they enter the school system, children with various disabilities, at least in the school system and under professionals within that system are supported. But once that person becomes out of high school, when you are in your 20s and becomes an adult, services are not near as easy to find. Is that --

JEANINE RUE: That's correct. He has no outside activities. He has no friends. He's basically home most of the time. He has a couple of part-time jobs that ORS is trying to get placement for CDL trucking, but he doesn't have experience. It's a little bit tough. But he's very capable as far as intelligence and skills. He delivers the newspaper. He works at Target. He's -- other than that --

Community Supports

BILL INLOW: Thank you for sharing that with us. We will certainly make note of it.

JANET SPINELLI: If you want to see me after, we can talk. See if you -- some of the avenues we have.

JEANINE RUE: This thing on the web as far as doctors that are subscribers to the state of Rhode Island?

JANET SPINELLI: I don't know that DHS has an answer to that on their web.

ARTHUR PLITT: I believe there's a hot line number that you can access and they can give you vouchers in your area. I'm not sure what the number is. But we will put it in the transcript. Have you talked to PARI or OSCIL in regards to independent living activities? A lot of times they are able to provide some of the services that they know the resources that are out there.

JEANINE RUE: No.

ARTHUR PLITT: OSCIL is based in Warwick. And PARI is based in Pawtucket. And --

JEANINE RUE: Are they listed on here?

ARTHUR PLITT: I think they would probably be on the Governor's Commission website, I believe. But also one other resource might be Sherlock Center at Rhode Island College. There's a lot of resources they can put you in touch with.

BETH PINKHAM: Definitely I can meet up with you afterwards and we can talk about some of the provider issues and maybe other avenues that you might pursue.

JEANINE RUE: Great. Thank you.

ROBERTA GREEN: I just wanted to clarify what your -- as you presented them. From what you said is that there are just not enough doctors, choice of doctors available that would accept Medicaid?

JEANINE RUE: That's correct.

ROBERTA GREEN: So that was one concern we had. And another concern I think that you mentioned was lack of other type of services for recreation activities?

JEANINE RUE: Right.

ROBERTA GREEN: And then also -- I work for the Office of Rehabilitation Services. You mentioned that. So some type of vocation goal

JEANINE RUE: He's had that. I'm not sure if it's an IEP but it's considered --

ROBERTA GREEN: IEE.

JEANINE RUE: We met with his counselor and they set up a job placement service for him. She's working -- trying to find him a position in the area that he would like to be in. So that's good.

ROBERTA GREEN: I just wanted to make sure we understood what your concerns were.

ARTHUR PLITT: This is Elaina Goldstein from Rhodes to Independence, would you like to --

ELAINA GOLDSTEIN: I am sorry. I had to take a tour of our state at this point. And I do apologize for being late. I am Elaina Goldstein. And I work for the Rhodes to Independence. There's a major product to help people with disabilities become self-sufficient and dependently employed and working are -- you name it. We work on the issue of healthcare, transcription, housing. I'm sure there are many other issues that you are bringing up today. And we use this forum as a means to figure out what we are going to do for next -- the issues, problems that you are experiencing right now that we will help you work through.

ARTHUR PLITT: Jeanine has a son who is 24 who has severe Asperger's. He has a problem getting services and recreational activities. Do you want me to comment?

ELAINA GOLDSTEIN: Let me just --

ARTHUR PLITT: Okay.

JERRY MENOCHÉ: Okay. I was -- I just thought I would throw out -- maybe you will mention this. Have you been involved with developmental disabilities trying to get services through them? Have you heard of them?

JEANINE RUE: I don't think so.

JERRY MENOCHÉ: That's another resource. I have some other ones too. I have a packet of all of that stuff. I can give you some of that afterwards.

JEANINE RUE: Thanks.

JERRY MENOCHÉ: The next person that's going to speak is Janice Garrison.

JANICE GARRISON: Hi. I have two things actually that I want to address. First one is accessible housing. And it seems like the lists are long. There -- but even longer when you get there and find out you could never use that apartment anyway. So -- in other words --

BILL INLOW: Can you hold the mike closer?

JANICE GARRISON: Oh, okay. I stayed on a list for three years. And every once in a while they go -- find some excuse why -- oh, well, so and so didn't move out or that didn't pan out, whatever. But I never get to use the apartment anyway. I do have -- I did file a grievance with the Rhode Island Disability Law Center, which I plan -- I have a place now. I will be moving next week. But in the

Accessibility

meantime, I've had no reason to be in the facility. And that's a lot of money wasted as far as I'm concerned. And I'm also -- my independence. So it would seem like there has to be a better way to set up the lists in terms of what's accessible. You can't go and see them until you reach the top of the list. It could be two years by then. And that's exactly what happened to me. It happened with two different places where they don't have roll in showers. And a good -- you know, some of them have systems where you can transfer on to a bath chair and the arms rest. But they are not good options. They are even building some new ones that do not have roll in showers, which is crazy. I mean at least if you build them with the roll in showers and people don't use them, that's one thing. Anybody can use a roll in shower. But when you try to convert the other way around -- at this time I know when one place that's in the process of being built. And they are claiming to be accessible. But they aren't. So, that was one part. The other one was to do -- I was talking to Bill about the RIPTA buses. The trips especially from here are so long. You know that. And I bet you know how bumpy the roads are. Most of the time -- I've

Transportation

had more of the older buses since I've been up here for longer trips. Sitting in the back of one of those buses is -- no one should have to do it, first of all. And the other thing is there's no way to contact the driver if you need to. There's no pull cord, no nothing. And it isn't safe. And it isn't comfortable. Another thing too is the scheduling of it, of the buses up here. I know they pear down the schedules at some point. But if I want to go to something, say in Providence in the evening, I can't go because I can't get back. And forget -- I've heard people around here wanting to go just to -- you know, maybe a family gathering that's around this area. And there's no service on the weekends. So being that the RIde program follows the regular bus service doesn't seem to make sense because sometimes when you need -- when you need them is when there is no bus service. When I was in Cranston, I used to have to pay every holiday to go home. And my family was about ten miles from there. But it would cost us a hundred dollars every time. So, a lot of it is just the routes in where -- that's not a good bus route anyway. East Greenwich bus route doesn't carry through to North Kingstown. And it's a little bit too far for me to get off there, especially in the winter. Take my little chair -- another while. But those are basically the issues that I had talked about. As Bill was saying to me, they -- they are trying to replace the RIde buses, you can see that. In fact, I have asked them to check to give me a bus that's -- that I can ride in the front. Supposedly it's in my chart. But I have hardly ever seen one up here, maybe once or twice. So, I don't know if they don't have that many that they came up here or they just don't go by that. But you almost -- the other thing too is there's almost never anybody else on the bus with you. So to use the 16 seat bus, it doesn't make any sense to me, anyway. That's all.

ELAINA GOLDSTEIN: I got my bearings now. Two things. One, on the housing issue. I just want to let you know what we have been doing. About a year ago, maybe a year and a half ago, we worked with the Realtors Association. And Realtors Association now has in their multi-listing a much better definition of accessibility, various different types of what we mean by accessibility. One of my staff people is very, very exceptional at dealing with this and saying you can't just say you are accessible. You have these specifics. And they have that. Now that's in the home, multi-listing. That was a good thing. The next thing that we wanted to be working on, I think what you were trying to allude to, which is a registry, a Rhode Island registry of apartments that are accessible. And I -- we were going to be working on that next -- this coming -- this year and next year. There's another organization, housing organization that wants to take that on. I think they will have the wherewithal, the money to be able to really get it up and running. And we are going to be working with them. Right now I can't for the life of me remember the organization. It was Peter from -- anyway. I am supposed to have a meeting with them sometime at the end of the summer so we will figure out who is going to be responsible for that so we can get that registry created and up and running. Third thing that we did, we tried to do this year, tried to get a piece of legislation passed. Fortunately, we have a really good piece of legislation. That's a good thing. But it didn't pass. We will try to do it again next year. At home modification loan program and this is if you are in a specific house and that house needs to be modified; or if you are renting an apartment and the landlord can also apply to get the loan, modify the apartment. Say you found an apartment. It didn't have the shower that you are talking about. It's possible that this landlord could apply for this loan, up to \$25,000, and actually renovate that bathroom so there is a stall shower you would be able to use. So it's for senior citizens, people with disabilities. We are going for a bond as a means of financing, a \$5 million bond to buy more home modification services to people in Rhode Island than we currently have. There are home modification programs, OSCIL, PARI, ORS, but the money is -- all together it comes to maybe 5 -- \$600,000 which is not enough to really do anything sufficient. So that's our -- the agenda that we are working on with housing. The agenda on transportation is a barrier. Bill will sit here and tell you RIPTA has been going through -- forget disability transportation. RIPTA, the program in general has been going through a lot of trials and tribulations dealing with the legislature. There are a lot of people who have made a lot of noise, especially the senior citizens, I tell you. And this is their number one policy issue to get moving next year. The good news is that we actually got a grant, RIPTA, Easter Seals, us, we have a senior organization. Trying to get a lawyer to come too to come to a week long strategy and planning grant. We are going to Washington next week to sit there with -- is it the Community Association for Transportation? And it sounds really great. They are really -- part of it gives you that time way to actually plan for all these different courses and the kinds of things, innovative things we can be doing that other places have done to be able to address the transportation issue, specifically for senior citizens and people with disabilities. So it's not the big broad transportation issue. It's specifically speaking about people that need the kinds of services that I believe that you need. So, probably everybody else here needs. Hopefully. We are really excited about this. It's a lot of time initiative but they will be giving us support afterwards to come back. One of the -- I think the senior citizens and people with disabilities, advocates for people with disabilities working together next year and really with RIPTA, really hopefully make some major head way in this issue. Just to let you know that's one -- we are having your comments saying it's important that people know, this is a real, real major problem

JANICE GARRISON: Yes. Especially as far as signaling the driver. That's something that should be done immediately because I have had times where -- in fact, they were going to bring me to Weeden Street in Pawtucket and I wanted to go to Weeden Drive in Warwick.

ELAINA GOLDSTEIN: And you knew you were going the wrong way.

JANICE GARRISON: And I had three times. I had made it clear when I made the reservation. Since then the reservation department has gotten a lot better.

ELAINA GOLDSTEIN: That's a nice thing.

JANICE GARRISON: Much better. But I couldn't -- I was yelling to the driver because all of a sudden I had dozed a little, I guess. I woke up and was on Thurber's Avenue curve going north. So, it took me

three or four times to get him. The radio wasn't on or anything. It's just noisy. Or sometimes you have the lift banging or -- any number of things could happen. But I -- you know, I would hate to have a medical problem back there and not be able to contact anybody.

BILL INLOW: Janice, as you and I talked about, all new RIDE vehicles are going to have wheelchair securement positions in the front for wheelchair lift van. The wheelchair lift itself is in the front. Positions of people with limited mobility in wheelchairs will be in the front of the van right near the driver. That's going to take about three more years because we are replacing vans when they become five years old. You are right. We should have done it that way in the first place. But we have learned that lesson because people like you who use a wheelchair and others spoke up loudly to us. Even though we are all bureaucrats, we finally did hear that message that the person with the least ability to move around in a van ought to be closest to the driver; and that the most comfortable -- least uncomfortable position in the van is near the driver, not in the back of a 16 passenger van. It took too long but we did hear that message and we are making progress. In the next couple of years all the vans will be front wheelchair position vans. Thank you for that input, Janice

JANICE GARRISON: In the meantime, I still say there should be some way to contact the driver.

BILL INLOW: I will convey that point to leadership at RIPTA. We are certainly making that part of our hearing here that we will review. That's a very good point. Thank you. CASEY CROTHERS: I just wanted to clarify something in terms of the accessibility. You went to certain subsidized housing or public housing to look for an apartment and it wasn't truly accessible for your needs. As part of your concern, would you like to see the codes changed for when that type of housing is built; that the minimum requirements are that they improve it or raise the bar on it so that -- because what happens right now is, I think, there's a minimal requirement and they build to that and it's obviously not good for the people who need roll in showers. So would you like to see that change over all as far as the buildings go?

JANICE GARRISON: Yes. And I think some of them it's not -- maybe it's not -- some of the places, this particular place was an older place. And it may not be financially worth it to do that. But it should be coded so that people won't waste their time, as I did, for three years and pay -- the state pays for me to stay here for a day than -- you know somewhere else for a month. That's no real secret to anybody. So, I would think it's in their best interest to figure that out. And yet -- certainly be issued to reflect -- you can't say it's accessible when -- it might be accessible if I had a hearing problem and maybe not even then. You still have to do things. They weren't willing to do very much. Other places were willing to. But -- and it's -- I believe it was RIHMFAC mortgage. They don't have any problem taking federal money so they should do something with it. At least put a front door open --

JERRY MENOCHÉ: I guess we are getting a little bit of a list here. We probably have to set up -- did we want to introduce Colleen?

COLLEEN: I am Colleen from the Rhode Island department of health. I am very happy to be here. I am Colleen from the Rhode Island department of health, office of research with special healthcare needs. And within that office is disability and health and services for children. The disability and health program works with adults and children. Thank you.

JERRY MENOCHÉ: Okay. We are going to move on to our next person who wants to testify. And his name is Frank Martin.

FRANK MARTIN: . Hello. My name is Frank Martin and -- testify -- I had some dealings with Roberta years ago. I was here in this facility from I think it was July of 2000 to April 2001 and I come from Cranston. Rhode Island rehab, Rhode Island hospital for a while. This time I had a quiet -- I had rip a quiet -- not knowing I had it. Help showing up. And I would sit with nursing home center recently used

Health Care

certain nursing homes because supposedly they know how to use all the dressings and machine that they had me hooked up to. The nursing home had a lot of problems. I laid there in bed for the first three days just watching what kind of neglect was going on. And once I got up, I found out how bad it actually could be. And I thought that their social worker, I asked to come back here. So when they finally got in touch with them, the staff here went up there and talked to them first. And they said that I was drinking, smoking pot, taking other drugs other than I was

allowed and trying to elope. And it was all a lie. I would -- the grounds -- but the grounds consisted of a little platform to sit on, one table or a parking lot. They would chase me along the parking lot. So it got worse. People didn't know how to apply the dressings. It got so bad that I really had to leave there. When they came in with their staff, they relayed all these hospital -- I was thinking here I was put on a lot -- I tried. I explained to them that none of that was true. They never really did any background check. In order to have smoked marijuana and have them know it, there had to be a test, you know. There had to be an alcohol test. As far as an eloping goes, there's no such thing of eloping a nursing home. I wasn't sentenced to a nursing home. I was sent there to get better. All did I was get worse because the nurses didn't know what they were doing. They went as far as plugging the thing right into a hole in my buttocks, up through my rectum at a certain time so that -- filled with feces oftentimes. But then the nine months I spent here, I got a lot -- if you want to go up there and spend a whole day and a night there, you will find that it's not really a comfortable place for somebody like myself. And no matter what I did, it seemed not good enough. I was trained here to use people's -- scissors because the nonuse of my hands that I have weak dexterity or any strength. But they would take these things from me and -- so I would make up for it by using other objects. And every time they found something else, they would take it away, keep me on there longer. But for Christmas, the staff brought me a toolbox full of tools. I had them for a whole hour and they came in and took it away. I haven't seen it ever since. In fact, I haven't seen a lot of my belongings since. I really think they should have went a little further and looked to see what they were saying was true. But I had -- they had helped me, with some of the things I needed. 2003 I was hit by a car. I was living in independent living housing. I needed to have some operations. I had noticed -- I just had -- and the next thing on the list was I was to leave again. So it doesn't take too long because it took a while last time. And I remember when I was leaving, they introduced me to my community social worker. I don't remember his name. It was John something. A little slip of paper with his number on it. Said if I ever needed anything to call him. But a little slip of paper I lost. I never had it. Who to tell you where to use when to use. I was with PARI where they saw to have some counseling of who I should call. But I called the disability center this time. I talked to Bob Cooper. Somebody up here in the next week to check out my situation. And nobody ever came. It was just like banging my head up against a wall. Very frustrated. As far as the nursing home went, I wasn't physically abused but I was mentally abused. I watched one roommate after three months I talked him into going to therapy. He was a double amputee. Somebody had spilled -- on his first prosthetic and he had yet to get a new one. But I kind of got a pressure to go to therapy. Once he was in therapy for a week, the administrator started to come in the room every afternoon for about an hour badgering him to sign over his Social Security check, which he had sent to the bank for his daughter's schooling trying to be a veterinarian. She went to school. And within a week, the administrator bashed him over and over, threatening. The managers lost - - life in five days later he died. And there was no reason to have to go through that. It was a nose dive that I saw that. You get to a point where the owner actually called me one night and thought that was all they could do. They did the best for me and they wanted me to leave, which I wanted to from the seventh minute I was in the place. I think that it was looked at the way people are treated more often have some kind of -- so that when people do have -- they have someone there to talk to and they don't have to wait for an appointment and then call them again and in my case, because I could call at certain hours. So times I need to be in bed were always the times that people asked me to call them. I wouldn't have access to a phone. I would be in bed and they wouldn't make one available. I got my -- I had a lot of anger and it's just -- I haven't found myself capable of letting go of trying to look at -- closer. I just -- I think they should be -- a whole lot of rules and regulations they have here. I mean some of them are so idiotic. Over and over again why do you have to do this. Because you have to wait for a doctor to change the bandage and the leg to a different sore. One that you know would be better. What happens if the doctor is on vacation or your social worker and you need to get in touch with somebody? They have the paper and that is when I became aware a lawyer had -- statute of limitations. I don't believe that three years -- I wasn't allowed -- they thought take care of myself feeding, just medical. I didn't have power of attorney for my legal rights. My father got sick by the way and died and he was really an advocate for those sorts of things. And I really would like to have -- term of statute of limitations. By the time I found

out some of the things that had happened to me would cost me the rest of my life, it was too late. It went pretty far in hiding some of them, some of the facilities. And I really didn't like the fact that they knew they had hurt me and they never ever offered therapy. That's part of it. I just had to get this out of my -- so. I don't like living in anger. I don't like having to hide hinges so that I can make things easier for myself. My hands can't -- pick a scissors, a pack of sugar, put things that I had to learn how to use there. This time here I am caught with -- I get in trouble. Silly. That's all I have. Thank you.

ARTHUR PLITT: Anyone want to comment?

BETH PINKHAM: First of all, as someone who works on a nursing facility transition, I can certainly relate to a lot of what you are saying. I definitely would like to speak with you after. But there also -- it's probably the -- like closing the door -- but there does exist in the state an ombudsman program for individuals in nursing facility program. It's known as it's alliance for better long-term care.

FRANK MARTIN: I called.

BETH PINKHAM: There are things that can help in those kinds of situations. I guess, me being in a nursing facility something -- is that a plan you have?

FRANK MARTIN: It's always been. After six months you have to give up --

BETH PINKHAM: Right.

FRANK MARTIN: That's where -- grand theft -- stupid word -- I would have taken -- up to six months.

BETH PINKHAM: Okay.

ARTHUR PLITT: The next speaker -- have you signed up?

JERRY MENOCHÉ: We do have another person that signed up. We are going in the order. We are going in the order. You are having difficulty hearing? You are having difficulty hearing?

MALE SPEAKER: What?

FRANK MARTIN: It's not the hearing. It's just when it goes to that speaker --

JERRY MENOCHÉ: We don't really have too much of another option. If you want to feel more comfortable speaking like this, you know, without the microphone and everybody can hear you, that's fine

FRANK MARTIN:: I will use the microphone to talk, if you want.

FRANK BEASLEY: There's a list.

JERRY MENOCHÉ: The next person who signed up is Frank Beasley.

FRANK BEASLEY: My name is Frank Beasley. I am president -- here at Rhode Island . hospital. And

Community Support what we have - we always have teachers here in the summer. We have the teacher here that's on vacation right now. But the teacher was always filled in the summer. The patient that wanted to be here today had to be in bed at a certain time. So she asked me if I would speak up about a teacher here in the summer because some of the patients, they like to teach pupils. Every year they always had one or two teachers coming from Cranston. But this year it seems as if the way the budget is and everything that they wouldn't supply one or two teachers for the summer. And we are lucky -- take that to Governor Carcieri because there's another thing too that myself, at the state house many a time fighting for -- cable. Took a year and a half to get it. But we finally got it to all the patients. This is what I am, very heavy advocate for the patients that are in the hospital. I have been here for 39 years and I can't complain. We always have to fall -- no one can take that and say they didn't. Patients are here, out every day. They are in the programs. The most programs that we -- I have two. We love to have our art program. I understand that we need someone -- the money that these -- the art program would like to have because what happens is they work one week or two weeks. They have a week off. One week, two weeks, a week off. And the same way with the music program. We haven't gotten the full funding for the music program yet and we haven't got the funding for the therapy, the whole thing. When I was at the state house, governor Carcieri, which I did bring -- I was right in his office. And I looked at him face-to-face and I told him over ten percent of the cuts were hurting us. He wasn't aware of it. I said well you are aware of it now. Because I said you know, I said it's a shame because I mean, you give -- now you get a bunch 3.7 billion dollars budget, 3.7 billion dollars. I'm sure they can come up -- and give us some programs back that all the patients loved to have here. I know we do have a lot of -- but still patients love to do artwork. They love pet therapy, and they love fun

things to do. It's the same way. Patients here, they love to learn computers but we have to have the teachers to -- in the summer to offset the teachers that are on vacation for the summer, teachers from the schools. So I would like to carry that so that we can maybe go back and I will be glad to help. I'm very heavy -- they all know me down at the state house. I have been down there many, many a time, doing this vice president stuff for a good many years out of the hospital. It's like we always say, I don't think 39 years that I have been here, to find a better place because they do give the care. They do give what the patients do want. And no patient is tied down and no patient is -- arms around their back since I have been here. I thank you very much.

ARTHUR PLITT: Thank you.

JERRY MENOCHÉ: Our next speaker is Christopher Bur.

FRANK BEASLEY: I have two things to say or complain about. This place is there are more people in wheelchairs here than walking around people. You go into the bathrooms. There's no handicapped stalls. They are like three bathrooms with handicapped stalls. And those get filled up. A contest playing

Accessibility

chicken where the next bathroom that you can use. One time I was seeing a guy walk into the handicapped stall and out -- I said, you know, this is for handicapped people. Can you get out of there? He gets up -- punch in the face.

Now could it be possible to put more handicapped stalls in the bathrooms or make new bathrooms or something like that? That's about it.

ARTHUR PLITT: Thank you.

JANET SPINELLI: We can't answer a lot of the questions a lot of the things that you guys are looking for, but we are taking notes of it. And other people will be listening to your issues. Thank you.

ARTHUR PLITT: I know the governor's commission has some accessibility funds, very limited, actually have been cut in some years. I know that we spent some money at Sam Burano. I will take it back in terms of the handicapped stalls. If there's -- rectify that, we will. Thank you.

JERRY MENOCHÉ: Okay. I guess -- do we have anybody else that is signed up? Okay.

TERI PRIOR: Hi. My name is Teri and I graduated CCRI on Friday with my LPN license. I am here because I completed two weeks of my nursing clinical at Eleanor Slater. I worked in the Virk's Building.

Community Support

And I have to say that I noticed, first thing I will say is the patients were clean and the -- they were fed. And the facility itself was clean. But I have to say I'm truly disappointed with the way the staff treated the patients. I actually am appalled. As a nursing student going into a new facility, I am so sad for those patients. I think about them every day that I have to leave them behind. I can tell you that I've witnessed the staff sitting down, watching television, reading the newspaper. The activities director did not move off her rocking chair. That is so sad. The patients just like attention, to be talked to, to play a game. I can tell you that I was in the last -- with two other students and three patients. And the radio channel was on. And it was on 92 Pro FM, which I thought was inappropriate. I got up and I changed the channel to an oldies station, which the age of our patients were in that age range. And one patient that we were told that had severe brain injury knew verses to two of the songs that came on the radio. I was elated. I was so thrilled that I could make this patient's day. One of the CNAs got up from her chair and came and turned the radio off because it interrupted her story. I am appalled. As a student we are taught to observe. I couldn't believe what I was seeing, how the doctor was screaming at the patients, threatening to take away their cigarettes, threatening to take away a person's shoes because the doctor didn't think they were appropriate. This is all they have. It's appalling. It wasn't just in front of me, it was also in front of my instructor. It was terrible. I got to sit in two of the team meetings and that's all the doctor did was yell. I felt so terrible. I had to leave those patients behind. I feel awful. I think about them every day. How can I help those patients? As a nurse, as a brand new nurse, how can I help them? Tell me how I can help them? That's why I'm here. How can I help them?

BRIAN ADAE: Teri, may I ask, you are talking about Flex's one?

TERI PRIOR: That's correct.

BRIAN ADAE: Thank you.

ELAINA GOLDSTEIN: Brian, do you work for MHRH? Disability. I would contact the director of MHRH. Anybody know her name? Ellen Nelson. She's a Dr. -- Dr. Ellen Nelson. She is the new director of MHRH, which Eleanor Slater is. The administrator of Eleanor Slater reports up to her. I would contact her and let her know what happened. I mean, she is the one -- the one above her is the governor, okay. She -- again, she's new. And I think it would probably be a good opportunity. Obviously it's going to be in the record here. This is going to take a little bit of time. That would be my suggestion. I don't know if anybody else has any other suggestions on who you can actually call to contact to give this information to.

TERI PRIOR: While I was there, I did notice there was a bulletin for the patient advocacy phone number. And during my clinical instruction, we did have a lecture by Reed Cospers. But these patients don't have access to a telephone. Here they are getting threatened that their cigarettes are going to get taken away. Do you think the staff is going to give them a phone so they can report? It's terrible. And I feel bad for these patients. If I ever saw a woman yelling at a five-year old in the market the way the staff, the way the doctor was yelling at these patients, I would have gone out and taken the mother's license away. The way the staff treats the patients, I'm telling you, is terrible. Nobody, nobody should be treated like that. Thank you.

COLLEEN: I will also check with the department of health. I'm not sure they have some jurisdiction over that. So, what unit was that again?

TERI PRIOR: Flex's one.

COLLEEN: Okay. Thank you.

BRIAN ADAE: Teri, may I speak to you afterwards?

JANET SPINELLI: All facilities are licensed by a state agency so that's -- when you talk about -- with the department of health, they license hospitals. So any hospital or department of mental health.

BILL INLOW: You asked the question of how can you help them. I think you have already taken the first step by having the courage to stand up and speak up. And you saw something that was wrong and unjust, and I admire you a great deal for it. Not only feel you for those persons who were abused, but for coming here today, speaking up in front of other people and making it a formal part of this record. So I think the answer to your question is what can you do to help them? You've already taken the first step, which is to speak up loudly and with compassion and with courage on their behalf. And I can assure you, we will look into that situation. Thank you very much for speaking up or some people who are not able to speak up for themselves. And I'm sure that the young woman that you have, if that's your daughter, is certainly -- if this is your mother, you should be very proud of her. You should be proud of yourself. Thank you very much.

ARTHUR PLITT: Teri, do we have your last name just for the record?

TERI PRIOR: My last name is Prior.

ARTHUR PLITT: Thank you. Thank you very much.

JERRY MENOCHÉ: Do we have anybody else? Well, we can do one of two things --

BILL INLOW: I think anyone else who wants to speak ought to be able to -- anyone who is here.

JERRY MENOCHÉ: Is there anybody else at this time who would like to speak?

CHRIS PARKER: Oh, the second thing. I mentioned two things. The second -- how can somebody get a house to live in? You see these things on TV. I bought this house for a dollar. I bought this house on my good looks and top real estate taught me how to do it. How do they get a house to live in? I don't want to live in any special community apartment or special zone for the special people, the special ed people. That's what I want is stuck with another label on my forehead. So, how does somebody get a loan to get a house and walk in? I had a stroke. Unfortunately I don't have much money right now. Primary income is Social Security, you know. I keep hearing about these houses that the government has with tax relief they are selling people for a dollar. I've never seen them. You know. And how do you know when they are going to go on sale? I read the papers in the real estate things. And I don't see them on there.

ARTHUR PLITT: If you think it's too good to be true, it probably is.

CHRIS PARKER: Well no, they keep mentioning, the state of Rhode Island is going to sell these houses for a dollar. They sold one house to Brown University for a dollar. The only kick was they had to move

it. They moved it down to South Providence. A nice big Victorian house. That's the only house I have ever seen that was sold for a dollar. A big monstrosity you have to move. It probably cost them 150 grand there. But I'm trying to find out where I am going to live now after I am done here. I don't want to wind up in an old folks home. I was there one time. It was horrors

ARTHUR PLITT: Hopefully with the 50 million dollars bond that will be passed –

CHRIS: I want to live in a regular house in a middle class neighborhood. Not a special zone for weird people, you know. Special people go here. You can't walk. We will put you in the special Olympics where you can win a gold medal. I don't need that crap. Who's next?

JERRY MENOCHÉ: Is there someone else?

AUDIENCE MEMBER: This is for Bill. I'm a special education teacher at Woonsocket high school and I'm actually working on transition for six of my students. And we actually are trying to utilize the RIPTA flex bus. Unfortunately it only hooks up two wheelchairs and sits. I was just wondering if RIPTA has any plans of making accommodations in the future for more than just two wheelchair hookups at a time?

Transportation

BILL INLOW: To be honest with you, I don't know of any such plans. But I can assure you that I heard you when you made that suggestion. Thank you for making it on the formal record as well. It is certainly something that -- a part of this material doesn't get written up and put up on a shelf. We have other -- after all of these hearings are held, we go through all of this material. And we pick out points like that and we make sure that they get sent to the right part of state government or RIPTA or some other part within state government. So that's an idea. I heard a lot about -- but certainly it will be conveyed to the people at RIPTA who make those kind of decisions. And I think it's a very good point.

AUDIENCE MEMBER: We try to utilize the RIPTA bus in Woonsocket and they told us to use the Flex- service. We went. But they only provided one bus with only two wheelchair hookups. Now I can only send two kids out at a time. I have six. And I would like to go as a group. I want them to start utilizing their community, utilizing the services that they are providing. And they all have RIPTA bus passes and fortunately they are not all using them at this time.

BILL INLOW: Well, it's a fair point. Just because you use a wheelchair, it shouldn't be the case that you can only travel with one other person. If you want to have a right to travel with several other people who need wheelchairs, you ought to be able to do that. I think that's a very good point. It will be documented. We will pick it out of the material and we will convey that to the leadership at RIPTA because you are right. Right now every one of our regular fixed route buses and every one of the RIDE, every one of the Flex- buses only has positions for two wheelchair positions. But we are going to make note of that. You made a good point. Make it here, make it often. The squeaky wheel gets the grease, right? You have been down at the general assembly many times. And you know sometimes you go to the general assembly, you raise a good point. And they say, okay, we will think about it. And then the next year you go back again, right? And you make the same point and they think a little more. And the year after and the year after. And finally they get tired of seeing you and maybe it gets through and there's a little change that occurs, right? You got to have some patience and some stamina and this guy and -- right here. We are -- fortunately there are young people -- this fine young woman -- here who are going to speak up and be an advocate for making some changes in the future. Thanks a lot.

ROBERTA GREEN: I have a question. Part of the solution is finding a solution. So I'm just curious when you take your six students on field trips, do you have the capacity within your school department to take all six at one time?

AUDIENCE MEMBER: Yes.

ROBERTA GREEN: How do you do that?

AUDIENCE MEMBER: We actually go through valley transportation. But we only go on I think two field trips a year. All the other times we are actually walking out in the community. And the reality is

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these teenagers are getting older. They are getting 19, 20 years of age. We have bigger wheelchairs. They weigh more. We physically can't

push them around the community anymore. Our way of doing transition for them and getting them out in the community as much is to have them actually start utilizing what they are going to utilize when they leave at 21 years of age, which would be the RIPTA Flex-

ROBERTA GREEN: There is a bus company that does have the availability?

AUDIENCE MEMBER: During the school year.

ROBERTA GREEN: I think RIPTA could take a look on that.

AUDIENCE MEMBER: That would be great.

ROBERTA GREEN: Thank you

AUDIENCE MEMBER: Bus number 20.

BILL INLOW: We certainly will take a look at that. You raise the point. You know the person who spoke used to work for the disabilities law center. As you probably know, Americans with Disabilities Act is a civil rights law. People with disabilities have the right in that federal law to give equal service. Well, if a group of five teenagers who don't use a wheelchair can get on a RIPTA bus and go down to the mall as a group, right? Then you can make the argument that a group of five teenagers or young adults in wheelchairs have the same civil right to be able to do that. And maybe RIPTA ought to find a way to fix and -- we've heard that. And you keep talking and we will hear it more.

AUDIENCE MEMBER: I will.

BILL INLOW: Finally we will do something about it like you. We will get it done, right? Thanks.

FRANK MOLLA: It's not only going to the state house. I mean the idea is -- I'm with the developmental disability council. We have a council here -- patients for progress. But any organization that you can go up any time. There's meetings or anything else and you go up there and you sit there and you listen because that's where -- they will either hear you. You have to go back. Like you said, you have to go back. You have to go back until they do hear you because I mean it took a year and a half to get cable here for all the patients in the rooms. A year and a half. But finally, we got down there in that budget committee there and that's what happened. We told -- why are we so backward with the technology out there today? Why are we so backwards? Not because people out there can go across the street. They can jump in the car. They can go to a movie. They can go see a sport. Here, you just can't go out and jump in a car any time you want to go to a movie. Today they have cable. They can see any kind of movies they want, American -- all the old movies they love to see. We have our sports, everything else. This is the thing. I don't speak for myself. I can tell you I became an American citizen. I came from Nova Scotia. I became an American citizen to speak for people who can't speak for themselves. I was in an orphanage for 12 years. I was born in an orphanage. I know what life is. I can say one thing, life here, life here is a joy from where I was. But you do what had to be done. Today in the army. I came here in 1953. I came here as an American citizen to do the thing that should be done is fight. Like you said, the squeaky wheel gets the grease. But you have to keep fighting until they do hear you. I know the governor heard me and he heard me well. He came and whispered in my ear, you got your cable. 1200. What do you know. I was at the house Senate finance and -- said Mr. Beasley, I am sure -- 14,000, to give these patients their cable in the room. All the sports and everything. But it's like I say, the buck doesn't stop. It just has to continue. We have to continue. This is why now I would love you to go back and get the programs, try -- the full amount of the money back for these programs that we, all the patients, love to do. And I assure you everything is there. But -- it's some of the patients do. So that's the way I look at it. We one time here we had nothing. We had nothing. Today, thank God for the administrator that I admire. That person Benedict opened up -- all the patients because he had a heart of gold. And he knew that he understood what a handicapped person is. And he always said, I don't live here. I can go home. You people live here. But I want to know what you want. I want you know your needs because I can't do it unless you come up front and tell us. Well, there. That brilliant, all the programs and I thank you very, very much.

ARTHUR PLITT: Is there anyone else who wants to speak? I also mention if you think of something and you are on the computer, you can always send to disabilities@gcd.ri.gov an e-mail indicating any additional comments. They will also be included in the transcript. Disabilities@gcd.ri.gov.

ELAINA GOLDSTEIN: I want to mention Teri, there was a piece of legislation that the commission worked on very hard this year that has passed. I really don't know if it applies to care givers that are in a facility. But it's an abuse and neglect piece of legislation that when people with disabilities are being abused, there is an avenue which they can be going know. Really, I think the commission did an unbelievable job getting this bill passed. It was very difficult. I don't know if it addresses an issue if the person is in an institution, if abuse is happening there. But I think what Arthur is going to do is go back and double-check that, see if that is in the law, just to -- I thought about that.

TERI PRIOR: My question is, if nobody is -- the CNAs certainly aren't going to tell on each other. It's up to me to advocate for those patients.

ELAINA GOLDSTEIN: I understand. But there's a law that something has to be done if there's abuse. Teri: So there's a law. It's a printed law. Who is going to tell on each other?

ARTHUR PLITT: It's a brand new law.

TERI PRIOR: Is somebody going to go in with a hidden camera? I saw it because I was there. I would never know.

BRIAN ADAE: Teri, one of the reasons I asked to speak to you afterwards, as a protection and advocate system for Rhode Island, we are mandated to investigate an abuse and neglect situation. I wanted to get more information from you regarding that because I can't tell you we are going to initiate one. But we may. We can initiate an investigation. We can certainly communicate our concerns, take necessary actions if they are warranted with MHRH. Not only -- not just with the director but with the legal staff as well as the quality assurance individuals. I have something in particular in mind because -- I can tell you right now we have existing clients on that ward. I would like more information about it. I want you - - I personally want to investigate this.

TERI PRIOR: Thank you

BRIAN ADAE: That is why I would like to talk to you afterwards.

ARTHUR PLITT: I realize as I was going through some of the handouts that the information on OSCIL and the information on PARI are included, following the copy of the public forum. So it does list OSCIL being in Warwick. 738-1013. And PARI is 725-1966. But if anybody should -- there are a few more copies at the table of the handouts. And so you have a number of the sponsoring organizations for these forums as well as good resources for you to follow up on.

CASEY CROTHERS: Also on the papers table is a yellow flyer for the brain injury resource center. We have a lot of different resources and things that I can send out to people so people can either e-mail or call. We have explanations about some of the things that PARI and OSCIL do and all of their contact information and about the loan program that OSCIL works with a lending institution. And they are very creative financing. We have a lot of different disability things, rec. programs, things like that. So anybody that wants to pick up the yellow fliers, if you want info on PARI or some other program whether developmental disabilities programs, you can call me and I will send you out a nice little info sheet.

JERRY MENOCHÉ: Frank would like to just mention something.

FRANK MOLLA: Is this website somebody told me about. I guess was www.abledata.com it's just a roundabout. Anybody you need for disabled people, 5,000 of us.

BILL INLOW: Frank, is that accurate? Is that [abledata.com](http://www.abledata.com)? Thank you.

COLLEEN: The contact information I will bring that to the director's office and have them contact you, Teri, thank you.

JERRY MENOCHÉ: Janice?

JANICE I was stretching. Thanks.

JERRY MENOCHÉ: Is there anybody here who would like to say something? Barbara has a mother who is ill right now. They are not sure exactly what is wrong. They suspect she has dementia. And I

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guess that she's at a loss as to what to do with her. And I think that the mother is exhibiting some type of pent up anger. She was wondering if there are any resources that can help out and particularly maybe

someone -- psychology, somebody who works maybe with people who may be dealing with this type of issue who could maybe, you know, help her out.

BETH PINKHAM: I just want to mention there is one resource in the state that I think would be a good place to start. It's known as the point. It's a disability resource center for elders and others with disabilities. And you can reach them at 462-4444. And they are basically there to provide resource information and steer you in the right direction. Also the department is working on -- one of the grants I'm working on -- establishing an on-line resource directory where people will be able to go in on the internet and find things that they may be looking for. So be watching for more information on that, coming out soon. I think if you gave a call to the point, you could get some good information that can at least get you going. 462-4444 is the number.

ARTHUR PLITT: Also wanted to mention another resource that actually will be a full table of resources on rhodestoindpendence.org.

BILL INLOW: Is that the accurate?

ARTHUR PLITT: Rhodestoindpendence.org.

ELAINA GOLDSTEIN: The resource center, they decided a name for it. It's hard to kind of -- resource center. It will be called ask Rhody. You will be able to go in -- it's sort of like ask Jeeves. It will be easy to access this -- I just heard -- we worked on this like months. One of these things you work on and you work on. We just brought -- people were at a table kind of brainstorming for a good name for something like this. But it's -- it really is coming pretty shortly. We are talking probably within the next three months you will be able to be at your computer. Go on ask Rhody, your Zip Code, information you want.

BILL INLOW: How is it spelled.

ELAINA GOLDSTEIN: I don't know. So the point is actually a place where you call. You will get a person. And they will have satellites in the future. Ask Rhody is something you can do on the internet.

ARTHUR PLITT: Also in relation, a lot of that came from crossroads data and that is going to be updated. But one of the things that was part of putting together this resource was that it was to see what facilities were accessible because many of the facility resources, you have to go up a step, or you have to go through doors that are too small. So there's a lot of checking and double-checking. So ask Rhody will be very valuable for everybody.

ELAINA GOLDSTEIN: One of the things Rhodes to independence project did when we were bringing people with disabilities around the table to see what kind of places and information, recreational, a whole lot other people with disabilities would need to know about. We found out really quickly that this issue of accessibility is huge. You have healthcare facilities. You have outpatient clinics. And they make -- same thing -- they may say they are accessible, but it's not clear what kind of accessibility it is. So what crossroads agreed to do is they sent out this year, they sent out information to all their -- all the people in the crossroads data base. They have to fill out -- they should be filling out a section that relates to accessibilities. When you get into -- you have -- these people have to return it back with this section filled out. Assuming people do that, these organizations do that, where you go on to ask Rhody, you will be able to find out if the entity you are looking at going to is accessible and how it will be accessible.

BILL INLOW: I would like to pick up on what Beth said for you. We gave that phone number. You can call. It's in the department of elderly affairs. A real life person is going to answer the phone. No machine. You will not have to push any buttons. And when you tell them about your elderly mother who has some confusion, maybe dementia and is also acting angry about that, that's very difficult to deal with when a loved one you are trying to help is actually getting angry at you. The person there at this phone number 462-4444 is going to know about that. They are going to listen to you. They are going to know some of the resources in the community, places where you can go where they can give you some more information to get you some help with that. I know that's a real challenge. You can talk about all these programs, but push gets to shove, it's your relative. And you are looking at them and she needs a lot of care. And you want to give them care but you just don't know what to do. That can be really frustrating. But people at that phone number are pretty well trained. And they are also people that have family members, as we all do, and know that it's difficult to deal with an elder parent, especially when they are

showing confusion and dementia and when they are getting angry at the very person that is trying to help them. So I think you will get some help with that number. I appreciate you talking through Jerry and referring you.

JERRY MENOCHÉ: Just a suggestion too is I have had success with dementia, Rhode Island chapter of the Rhode Island Alzheimer's association. Even though -- they have Alzheimer's in their title, actually it's for all forms of dementia. They have been very helpful with us in the past.

ARTHUR PLITT: I believe the number is 421-0008. Somebody has a question? Stretching.

COLLEEN: Hi. I wanted to ask if your mom has had any services at all at this time?

AUDIENCE MEMBER: No. She -- she's currently --

COLLEEN: She is in a facility?

AUDIENCE MEMBER: We are in the process.

COLLEEN: The other thing I wanted to say, this gentleman brought up about activities here at the hospital. A great way to explore would be volunteer. I'm just -- this idea through RISD, west bay art program. I will look into this. But colleges and that was just a thought. How we would present that? I just thought of that. I was thought community service.

JANET SPINELLI: I just want to add too the department of elderly affairs also has a program for self-neglect. So if anyone meets that and you can find more information on that also. Department of elderly affairs or the point can give you information on that.

JERRY MENOCHÉ: I guess what we could do now, if no one else has anything, we do have refreshments. We do have the opportunity to make go with -- you can kind of talk to them one-on-one if you would like. I think this gentleman here has something else to say ARTHUR PLITT: I just wanted to also mention that the survey that determines the bills agenda for next year. That's available. So please fill it out. I'm sure that he would be happy if you took a couple of them for friends or other people who would like to fill them out so that they can get a picture for their agenda for next year.

BRIAN ADAE: Thank you.

BILL INLOW: Somebody said once -- a couple of times there. Zambarano hospital is one of Rhode Island's best kept secrets. And I agree with that. And I want to thank you all for coming out and reminding us that this is a long way from a lot of people in Rhode Island. But it's an important place, filled with some really wonderful staff. Jerry, wonderful residents as well. Thank you for hosting us here today.

JERRY MENOCHÉ: Thank you. And we thank all the people on the panel, the governor's commission for all of the work that you do as well.

JERRY MENOCHÉ: Thank you everybody for coming.

Wednesday July 26, 2006, PARI, Independence Square

LEO CANUEL: Good morning, folks. Welcome to this governor's commission hearing. My name is Leo Canuel. I am the executive director of PARI independent living center who is hosting this hearing today. I will be the moderator for the hearing. A little bit of housekeeping tips before we get started by introducing the panel, having the panel introduce themselves. If you need to use the rest room, the best way to get there is out this door to your left and take a right. The bathrooms are right there. If you need some type of nourishment, food, drink, what have you, again go back out this door to your right this time, first right. They have vending machines in there, a little cafeteria, and real food. So whatever you would like to do. We are going to go along, accept any testimony that we have to offer, and just go all the way through to 1:00. So we are here if you want to talk to us. We can now start by introducing the panel. I will have the panel introduce themselves and I will go to my right first. Down at the end, Brian.

BRIAN ADAE: My name is Brian Adae. I am a staff attorney with the Rhode Island Disability Law Center. I am not Christine Miranelo. This is no fault of the governor's commission who prepared this. I am subbing for Christine today. I can promise you she is much more attractive than I am, but you are stuck with me. For those of you who are not familiar with the Disability Law Center, we are federally mandated, state designated agency for the protection and advocacy of persons with disabilities. We actually have eight separate programs which are legally based. They are for persons with disabilities who have disability related issues in a number of areas. In addition to policies systemic work, we also do free legal representation on an individual basis on a limited number of cases. And as long as I have the floor here for a moment, if I can take a second. At the front table, I have a plug for these yellow sheets. We are right now in the process of setting up priorities for case acceptance for the upcoming year. And I would love to have everybody take one of these and check off areas of interest you are concerned about. If you could return them to the front table or to myself afterwards, I would be delighted to take them back. It's of great assistance to us. If you don't have time to fill one out today, take one with you and you can place it in the mail. Thank you.

REGINA CONNOR: Regina Connor from the office of rehabilitation services. My position there is as assistive administrator. My principle responsibilities are for Assistive Technology Access Partnership and also for transition services for youth with disabilities. I'm particularly interested hear the comments from any of you related to assistive technology needs for people with disabilities and also for vocational rehabilitation services for individuals with disabilities in general.

HANNA KIM: I am Hanna Kim from Rhode Island department of health. We are funded from -- federally funded (phone ringing) actually I am here to hear your concerns and issues to direct our program for people with disabilities.

PAUL CHOQUETTE: Paul Choquette from department of human services center for child and family health. And also your representative for the commission on disabilities. I want to thank everyone for showing up.

ROSEMARY COFFEY: My name is Rosemary Coffey. I am the project coordinator for the personal choice waiver, which is a consumer directed program and my office is located within the department of human services on the center for adult living.

STEVE FLORIO: Hello. I am Steven Florio, executive director for the Deaf. If anybody needs an interpreter, we do have two interpreters in the front as well as CART services for access to Deaf and Hard of Hearing. We focus on a variety of issues to improve the quality of life for the Deaf and Hard of Hearing people in Rhode Island. Often the Deaf are considered an invisible disability, not easily identified just on the surface, often overlooked. It's a challenge to educate and raise awareness. I am very interested to hear your concerns and issues and looking forward to working with you to make things better for everyone in Rhode Island. Thank you.

JUDI DREW: I am Judi Drew. I am a commissioner with the governor's commission. I am in private practice as a rehabilitation counselor and I'm also on the faculty of Salve Regina University teaching in the master's rehabilitation counseling program. My issues that I would like to hear from you about are issues related to equal access to education and to employment. So if any of you have testimony in those areas, I would be particularly interested.

LEO CANUEL: Okay. Now let's get to why we are here and that is hearing your testimony. I'm just going to ask Christine if we have a sign-up sheet back there. Do we have a sign-up sheet? I am going to ask that you keep your testimony short as possible. The panelists may have some questions for you. But it's not our job here to get into a debate about policies or programs. We would ask clarifying questions. And if there is something available that we know about that you may not know about, we will probably talk to you about that. But we will try to keep it as succinct as possible. Please, you can testify from where you are seated. You don't need to come forward. We ask that you speak as clearly as possible. State your name, if you are with a particular organization, and the city and town that you are from. The first person to testify is Ms. Casey Crothers.

CASEY CROTHERS: I am Casey Crothers. I live –

LEO CANUEL: Maybe if you can stand up.

CASEY CROTHERS: Project. I am Casey Crothers. I'm from Warwick, Rhode Island. . You can read

Health Care

 that too. And I work for the Brain Injury Association of Rhode Island in the Rhode Island Brain Injury Resource Center. I have two concerns. One of them is a program that was developed to serve people that have significant cognitive disabilities, such as those that can happen after a brain injury. It's also known as the habilitation waiver, called habilitation community based services program. The waiver was started four years ago. It has been very successful in serving people that were not being appropriately served or who were denied services based on they had great cognitive needs and perhaps not as much needs with motor activities. At this point, the program is near full. There was legislation that was introduced last year that was requesting slots being increased. And I'm in hopes that in the next legislative session that legislation will be introduced again. I think it's an important program and it's really helped the quality of lives. The consumer satisfaction reports have been very good. So that would be my one issue. My second issue is this year there was legislation which was passed -- do you want the bill numbers?

LEO CANUEL: Sure.

CASEY CROTHERS: I have them. All right. S 2604 sub A and H 75 -- I typed wrong -- I think 46 sub-A. They were enacted -- I can't even read that even -- on 7/7/2006. That legislation was a follow-up to the prior year's legislation. In the previous year legislation had been introduced suggesting we should have a restricted receipt trust fund for brain injury issues to better develop programs and infrastructure and so forth. At that time the legislation didn't pass, but the general assembly did appropriate funds specifically to DHS for that purpose. This last legislative session, there were some other important issues that had been addressed in the prior bill. So it came back to address those issues. One of them being to expand the governor's commission -- governor's permanent advisory commission on brain injury because it was certainly not representative of the continuum of care. And in particular it didn't specifically state that a survivor of a brain injury or family member should be on it. That was taken care of. And several other issues establishing a consultant or advisory capacity to the governor's permanent advisory commission to DHS and how they would use the funds. There was however an omission I believe to -- inadvertent omission. They had removed the language used in the original bill that said DHS could use some of the fund monies for administration. It's a fairly complex program. Someone has to administrate the money. So I would like to see legislation that would amend this year's bill so that there is some administrative money. There's a lot of things that goes on behind the scenes to get the money out to people to -- for program development and other things. So it's really kind of a necessary thing. Thank you very much.

LEO CANUEL: Casey, I have a question. Do you remember the legislation this year, the number -- the number of slots on the waiver?

CASEY CROTHERS: No. But I could supply that to you.

LEO CANUEL: Supply it to the governor's commission, please. Any other questions from the panel? I want to take a pause for a moment and ask Arthur to introduce himself

ARTHUR PLITT: Arthur Plitt, governor's commission on disabilities. I'm sorry I'm late. On other important mission somewhere.

LEO CANUEL: The next person to testify on the list is Heather Sprague. Heather, please stand.

HEATHER SPRAGUE: Hi. My name is Heather Sprague. I'm from Warren and I work for PARI Independent Living Center as an IL counselor or independent counselor. Two programs that I want to **Health Care** advocate funding going toward to reiterate the half waiver that Casey had stated because there is definitely a need there and with the limited slots. Right now we are at full capacity. And we are getting calls each day for more. I'm working particularly with a habilitative waiver so I know that from experience. The other program that I'm interested in increasing slots is for the PCA state program because that enables people that don't meet the Medicaid criteria or that are over the economic criteria to get PCA services. And again there is more need than there are slots. So if we can consider that.

LEO CANUEL: Any questions from the panel for Heather? One clarification. The state PCA program is not a slotted program. It's a funded program. So what we need is more money so we can put more people on the program. Just a clarification. Next person to give testimony is Vincent Dejesus.

VINCENT DEJESUS: Hello. I am Vincent. My concerns basically the habilitation waiver that was **Health Care** started up about four years ago from basically -- it's -- a certain amount of people that are allotted to fill -- be qualified for this program, which helps brain injured adults, people that acquire a brain injury after the age of 22. And basically just my concern is that the waiver's almost filled up now. And I was just bringing this to the attention. The waiver's almost filled up. Thank you, I guess.

LEO CANUEL: Okay. Dawn -- we have a question mark. Where's dawn? Okay. Dawn -- have we answered your question yet?

DAWN NORDEGA: I didn't -- it's Nordega. I just have a couple quick points. It has to do primarily with children with special healthcare needs. The biggest issue has to do with commercial -- kids who are **Health Care** given commercial health insurance and have no mechanism to become eligible for Medicaid for a backup or wrap around services. As many of you have -- not all of you know -- the door into Medicaid is closing tighter and tighter as we speak. And there are children out there who have significant special healthcare needs. I spoke to a family yesterday who has a child, seven month old baby with a significant cardiac condition as well as some other genetic syndrome that developmentally at least so far this child is fine, but has significant health issues. Mom is a schoolteacher and her leave of absence is due to expire. She is supposed to come back to school in September when school starts up. It's a two earner family and they require both incomes to maintain their household. Mom's been told by the child's cardiologist that the baby is not -- cannot be put into any kind of a child care setting where there are other children due to the threat of infection and the impact that may have on the child's cardiac condition. So, this is a family who has at this point in time only commercial insurance, may or may not qualify for Medicaid. We are kind of working through that process to see if that happens. But none the less, even if the child qualifies for Medicaid, there are not any services out there to help support the child care for that particular child because he can't go into a daycare setting or a home. So there are real strict limitations due to that. So that's one example of some of the commercial insurance issues kids that are covered by commercial insurance. Those that are covered by commercial insurance and also fall under Medicaid run into a limited -- a very complex and confusing care coordination benefit. Supposedly the commercial plan's responsible for taking care of that. I say supposedly. Nine times out of ten the family winds up having to do it on their own because through the Medicaid benefit, the family won't qualify for the care piece because they have a -- it's a third party issue that services in any case. The -- another point around coverage for this particular population of kids and families is that if a child with special healthcare needs has commercial insurance and does not qualify for Medicaid through any mechanism whatsoever, and there are plenty out there that fit in that category, they currently have no access to some of the good public programs that have

been developed over the last five or six years in the state for kids who do have Medicaid. So, in a sense, they are almost better off without commercial insurance. And I really don't think that that's what we ought to be promoting as a state. So there's the access issues for those kids who qualify. And my last point really has to do -- goes back to that family example I gave you in that it was a really hard discussion that I had to have with the mom yesterday about what her options are. September will be here before you know it. She's supposed to be going back to school. She has no child care, no access to child care for her seven month old baby, and her plan was to go back to work. She had a baby in December, so her plan was to go back to work in September. She cannot go back to work because she has no child care for that baby. That family has no other access. They cannot supplement their income any other way because at this point mom's been forced to -- any parent who is being forced to either reduce their work hours or leave their jobs all together to be able to stay home and to care for a very ill or disabled child. Those families have no support. And the adult system, if you will, there are some set ups and support those families -- those individuals with disabilities in the community. The same stuff does not apply to the pediatric community because obviously a seven month old is the responsibility of their parents. Their parents may be perfectly able but they may not be. So there is that whole economical equation basically is if a family is in that situation where they can't return to work. They have to reduce their hours. How can we help support that family to stay in their house, if that's what the case may be? And I'm not sure what the answers to these questions are. But these are some of the pressing issues, the more complex ones that we have not been able to work out with families. I didn't mention it earlier. I work for the Rhode Island Parent Information Network. So those are some of the significant issues that I was hoping the commission would take a look at

PAUL CHOQUETTE: I have one quick question, Dawn. What program on the adult side are you referring to? I think which one you mean --

DAWN NORDEGA: Some of the -- some of the -- I don't know what they are called, choices or what, because I'm less familiar with the adult system. But in this particular case, my initial reaction was if this family qualifies, or this child qualifies for Medicaid, this could be a perfect fit for the CASP program on the children's side because in fact that would allow that family to determine what it was they needed and if what they had to do was hire a child care provider to come into their home that he would have that mechanism to do that. If it's an adult with a disability, there are day programs. There are other kinds of mechanisms which will allow the family care giver to go out and take care of a job and everything else that you need. So it just leaves that family out there. It's really hard to have to tell that mom that the first thing you ought to focus on is getting your -- because you will not resolve this quickly, and in terms of trying to gain access to Medicaid so they can access some kind of support.

PAUL CHOQUETTE: My five weeks of being on the children's side, I found out that it's better to be -- better on the adult side for something. That is quite amazing. It's true.

DAWN NORDEGA: I think you may meet more families.

LEO CANUEL: I think we are talking about two issues here. One is dealing with medical issue and one is dealing with the child care issue. The question I have on the medical side is, is this family eligible for Katie Becket?

DAWN NORDEGA: We don't know. That call came from this mom just yesterday. So we are in the process of maybe -- because this child is, so far anyway at 7 months old, developmentally sound, there could be a question as to whether or not that child qualifies for Katie Becket.

LEO CANUEL: The next question the program that you envision through Medicaid, would it be something like a Medicaid Buy-In program?

DAWN NORDEGA: Umm, well, actually I will tell you right off the top. I am a firm believer in the development of the Medicaid Buy-In for many of these families. This case I told you about is an extreme case. There are less extreme cases where kids have special healthcare needs, disabilities where medical needs are above and beyond anything that commercial insurance is going to cover for those kids. And out-of-pocket expenses for those families can be astronomical. So the concept of a Medicaid Buy-In for wrap around services for this population would fully support. I would be happy to work with you guys on it.

LEO CANUEL: We already have many models across the country of Medicaid Buy-In programs for kids from working families. And that's one issue. The issue regarding child care, I guess the question that I would have is a program that pays for child care support that would be a center that cannot be used in any private means by hiring a private child care program.

DAWN NORDEGA: Exactly. The program that is currently in existence, which is wonderful compared to what we had years ago. This particular case, because of this child's risk of infection, that child can't go into a center. And that program is not set up to send –

LEO CANUEL: My next question goes to two of the panelists, Brian and Paul, regarding with that particular program. Would it be -- would we be able to look at a reasonable accommodation under the ADA for that particular program to get services for this family paying for child care? In the legal aspect, Brian?

BRIAN ADAE: Something occurred to me when they were -- aside from you asking the first question was Katie Becket eligibility occurred to me. Schooling certainly at least as a partial fix would be a 504 combination or perhaps even -- it's hard to say without looking at the individual -- IEP, at least as far as the schooling takes care of part -- maybe, maybe.

DAWN NORDEGA: This kid is an infant though.

BRIAN ADAE: How old?

DAWN NORDEGA: Seven months.

BRIAN ADAE: We are not going to have her in intervention.

DAWN NORDEGA: The child is already enrolled in early intervention.

BRIAN ADAE: That's excellent.

DAWN NORDEGA: But the child -- provision of individual child care in the home setting doesn't fall under early intervention.

BRIAN ADAE: No, it doesn't. At this point as far as Medicaid and equal bit accommodation, 504 combination at this point I can see the argument but I'm not sure the liability at this point.

PAUL CHOQUETTE: I would say from the center for child and family health side I think two things. One is that I will certainly bring this issue back today when I go back. But the way I'm thinking of it, the concern -- the way to address this maybe the standards we have for the existing program that the kids can program to see if it's possible to alter those to allow for individual providers to be in that sort of case. It would be an individual provider within, you know, still having some standards, but having it set up in a one-on-one basis -- that's just off the top of my head. I don't necessarily -- take that as gospel because I am –

AUDIENCE MEMBER: That's a bit -- you are talking about the modification for the kids can –

PAUL CHOQUETTE: Right.

DAWN NORDEGA: The only other thing in this particular situation, if we can -- if we can get this kid eligible for Medicaid through Katie Becket provision, in fact this child might qualify for nursing –

PAUL CHOQUETTE: That's what it sounds like without knowing too much -- taking too much time here I think -- we can talk about it off-line. But it sounds like if it's a medical need is that -- certainly private -- do -- fill up –

DAWN NORDEGA: Exactly.

LEO CANUEL: The question that I would have, PARI works mostly with adults with disabilities, providing personal care assistant programs. But if a person needs a PCA there for health and safety, just monitoring them, we can't use the PCA program for that. We assume Medicaid is going to be the same issues. There needs to be a medical service there for that particular child.

PAUL CHOQUETTE: It --

LEO CANUEL: Heidi had a question or comment.

HEIDI JOSEPH: I just have a quick question for you, Dawn. And that question is obviously we want these kids and their families to be able to get the best of both worlds. We want the mother to be able to work. We want this child to be able to get the care that it needs in a comfortable environment. For the child it would be in their home. Are there bills pending right now that in the legislature that we can help

support -- you have numbers of bills that we can contact Congress and get them supported on behalf of this child and the families in that situation?

DAWN NORDEGA: This particular case is so fresh to me, but it's not the first time I have heard this kind of an issue. I guess maybe it really struck a personal cord for me because it brought me back to a time in my life when I was in a very same situation. And in terms of whether or not there is any pending legislation, this is -- this is, as most of us know, in most families you need two people working to just -- just to survive. And this family is no exception. So they don't have what I would call the luxury, if you will, for mom to take an extra year off, if that's what she needs to do. And hopefully the baby will be stable enough in another year because the baby's facing cardiac surgeries, that type of thing, that he can go into a daycare center at that point in time. So this is, I mean, potentially a temporary situation. But who really knows?

HEIDI JOSEPH: I'm also thinking of other families where it's already been documented that it's going to be a long-term situation.

DAWN NORDEGA: Right.

HEIDI JOSEPH: And how can we help these kids and these families live as normal as comfortable a life on both sides --

DAWN NORDEGA: I do think there's daily available. In terms of where you can research -- there is daily available, not necessarily Rhode Island specific but on a national level, about the fiscal impacts of raising a child with a disability. In particular there's questions about whether or not parents are able to return to work or even have to cut their hours to be able to care for the child.

LEO CANUEL: I -- can you identify yourself for the record and clarification?

HEIDI JOSEPH: My name is Heidi Joseph and I am -- I represent the RISILC I am the -- a lot of things that we try to do is to help

LEO CANUEL: Can you speak up a little louder so the CART reporter can hear?

DAWN NORDEGA: A lot of the things that we try to do is to help to reach out to the needs of disabled people and their families and provide services for them and help to try to advocate either through educational workshops or through physician papers to help to get legislature passed.

PAUL CHOQUETTE: Heidi, I will address a couple of your concerns. Currently the state legislature is out of session. They will not be back in session until January. So there is no current state legislation that's out there addressing the needs that Dawn brought up. I will say that during the last session, there was an attempt made to add an article to the budget to compel every commercial provider in the state to provide services that Dawn spoke about, specialized services that -- as available to Medicaid eligible people, that being home based treatment services, past services, services rendering the Cedar or family center. Unfortunately that did not go anywhere. It went somewhere but it didn't go to where we want it to be. The result was that there is now a what's called a child's health fund. Children's health fund, which the insurance companies will pay a certain amount of money. That will be put in that fund which will be used to pay for those type of services for people who have dual coverage. But, you know, I think next year again the attempt will be made in the legislative session to try to get the commercial carriers to pay for some of these services. Again but that's always an uphill battle because we are asking the insurance companies to spend more money. So when it comes -- when the time comes, his commission will be outreaching to people for support. So, sign up for our newsletter so you can get information.

LEO CANUEL: We have come to the end of our list of people that identified themselves as wanting to give testimony. So, I know want to open the floor and ask if there is anyone else who is interested in giving testimony or if this discussion has prompted some other things to -- up to your brain and you would like to discuss that. So is there anyone who wishes to provide testimony at this time? Yes. Can you identify yourself, your organization, and your hometown, please.

VICKI KAUFMAN: I am -- my name is Vicki Kaufman. I am in the office of civil rights for the federal department of human health and services. And we are the federal agency that's responsible for enforcing section 504 and title 2 of the Americans with disabilities act. We seem to be

somehow a well kept secret. That wasn't our intention. We are trying to make sure that people do know that we are here and we exist. We accept complaints on discrimination by -- discrimination based on disability as well as other issues, national origin, race, color and age by any agency or program that -- under 504 that receives funding from the department of health and human services. So that includes healthcare programs, social service programs, and under title 2, the disability act and the state and local government agencies that provides healthcare services. We are here. We are small. And understaffed I'm sure that's how -- sounds familiar to all of you because that's what happens to all the agencies, I guess, working around these issues. But please, we are here. And we welcome complaints, if there's anything we can do to assist. ROSEMARY COFFEY: How do people get in touch with you?

VICKI KAUFMAN: There's -- we have -- these -- cards

LEO CANUEL: Can you also verbally say the address and phone number so we get that into the record?

VICKI KAUFMAN: Yeah. The address is office of civil rights, U.S. department of health and human services, John F Kennedy federal building, Boston, Massachusetts 02203. And the phone number is 617-565-1340. Thank you.

LEO CANUEL: Thank you. Is there anyone else that would like to call for testimony at this time? What we will do is take a pause and come back in 15 or 20 minutes. If others show up, we will be able to do that. The rest of the panel will be here until 1:00.

(Return from break).

LEO CANUEL: We are going to call the hearing back to order and ask if you have any other testimony from the audience? Hearing none, I will officially close the meeting and thank you all for participating. And Paul is buying lunch for everyone who stayed. Just kidding. It's money from Bob Cooper.

PAUL CHOQUETTE: Thank you guys. Thank you.

Wednesday July 26, 2006, Independence Square II, Kingston

ELAINA GOLDSTEIN Okay, everyone, welcome to the Governor's Commission on Disabilities forum here today at the Briggs Campus. On behalf of the Governor's Commission and Rhodes to Independence, of which I am the director, Elaina Goldstein, Rhodes to Independence is the sponsor of this particular forum today. Just to kind of understand, the forum's purpose is to identify the concerns that people with disabilities and their families have in order to assist the state in developing programs and policies to improve the qualities of lives for people with disabilities. I wanted to explain a little bit about what happens after today. After everybody testifies, there's going to be a posting of the transcript, and Shelley is taking the transcript for us. Testimony will be on the Governor's -- the Commission's web site, which is www.gcd.state.ri.us in about a week. Later this summer, the agencies will be reviewing all of the testimonies and prepare recommendations which will be posted on the web site by the end of the summer. The recommendations and transcripts will then be printed and sent to the state congressional members, and members of the General Assembly, then used to develop policy and legislative initiatives for the next year or until we have accomplished all of the tasks. This is a really special day today, I don't know how many of you know that the commission decided to have the hearings the week of the anniversary of the American with Disabilities Act. Today, July 27th, is actually the actual anniversary, and it's the 16th anniversary of the ADA, so I can't think of anything more appropriate than to have a forum today. Sixteen years after the passage of the ADA we can look back and see a lot of progress that's been made, but there's still a lot of work that needs to be done, and we can look forward to commemorating by receiving your input, advice, and suggestions, and whatever you feel is important to tell the policy makers in Rhode Island about the concerns and barriers that people with disabilities are finding in the state. The ADA has changed all of our lives and promises a better future for equality for all. I have a great staff, and Kate McCarthy, who happens to also be a commissioner, I guess she got a copy of this. For those of you who know who Justin Dart was, he basically, he didn't do it single-handedly, but he was an amazing man who, without his leadership, the ADA would never have become a reality, and his wife. There was a song that he created, and it's called Lead On. And, not that we're going to sing it, but I think it would be nice if we all kind of just read the words and got a little inspired. Steve Brunero of ORS will be passing this out now. It's kind of a gospel song, I don't know if we're ready for that here. I can just see them reading the transcript now -- what did Elaina do. But I think it's important that we commemorate.

STEVE BRUNERO: Lead on, lead on, lead on, lead on, lead on. Live the dream, lead on. Fight for freedom, lead on. The world is watching, lead on. Lead on, lead on, lead on. Now's the time, lead on. We can win, lead on. We have the power, lead on. Lead on, lead on. Love for all, lead on. Have the vision, lead on. Save democracy, lead on. Lead on, lead on. We are able, lead on. Truth in action, lead on. With liberty and justice for all. Lead on, lead on.

ELAINA GOLDSTEIN All right, happen anniversary, ADA. Now, how do we go beyond that. All right, what I'm going to be reading are the required things I need to read. I'm going to have everybody on the panel introduce themselves, tell you who they are and what agency or organization they're representing.

ROSEMARIE COFFEY: My name is Rosemarie Coffey, the project coordinator for the Personal Choice Waiver. My office is located within the Center for Adult Health at the Department of Human Services.

ANN MULREADY: I'm Ann Mulready, a supervising attorney at the Rhode Island Disability Law Center, and we are the nonprofit law office designated to protect and advocate for the rights of Rhode Islanders with disabilities. I left on the table over there, our surveys. In addition to participating on this panel, every year, we seek input from people about what legal issues related to disability are related to them. So, if you want to hand it to me, or leave it.

JEANNE BEHIE: I'm Jeanne Behie, Governor's Commission on Disabilities. I work for South Mental Health, working for families of children with emotional behavioral issues. I am also the parent of a young adult with disabilities and I was the daughter of two parents that acquired disabilities as they aged. So, I'm glad to be here today.

STEVE BRUNERO: Good afternoon. My name is Steve Brunero, Office of Rehabilitation Services, deputy administer of the vocational program. I'd like to thank you all for attending today. I'd be happy to speak with anyone afterwards to discuss issues relative to the program.

LAURA JONES: Good afternoon, my name is Laura Jones, I work at the Department of Health in the division of family health. I'm a parent consultant there, which means that I'm a parent of a child with disabilities, and sort of bring that perspective to the Department of Health. I also work for the Rhode Island Parent Information Network, which is a nonprofit advocacy/education agency in our state that supports families who have children with special health care needs.

CURTIS JAMES: My name is Curtis James, and I work for the Rhode Island Commission on the Deaf and Hard of Hearing. Pamela Zellner was supposed to be the representative today, and at the last minute, she was not able to attend so I took her place. I am the sign language interpreter, I set them up for Rhode Island. The Commission is happy to be here as a representative, and if anybody has questions in regards to deafness or the Commission, please see me after the forum. Thank you.

ELAINA GOLDSTEIN Okay, there are assisted listening devices if anyone needs one. Okay. And also, Curtis is our -- are you going to be interpreter if a person --

CURTIS JAMES: Paul and I.

ELAINA GOLDSTEIN Okay, we have two interpreters here, great. If anybody -- if you would like to move up, you're more than welcome. If you're happy sitting there, that's fine, too. But, how about we have everybody in the audience introduce themselves.

PAUL: I'm Paul, sign interpreter.

DANIEL ARRIGAN: My name is Dan Arrigan with Perspectives Corporation.

VICKY HALFMAN: Vicky Halfman with the Office of Civil Rights.

DIANE HELEN: Diane Helen, and I'm here because of my sister.

JOHN DESAUTEL: John Desautel on the staff of the Governor's Commission of Disabilities.

PAUL: Paul, man on the street.

LAURA: My name is Laura, Diane brought me.

CAROL NEESO: Carol Neeso, registered nurse in home care and the sibling of a disabled individual.

SALLY: Sally, chemically sensitive, and don't know how I can stay in this room because I'm tanking already.

ELAINA GOLDSTEIN Okay, Val, do you want to tell everybody where the rest rooms are?

VALERIE SHORE: Just go to the door and they're just to your right.

ELAINA GOLDSTEIN We also have cookies over here, feel free to take them whenever. And if anybody has cell phones, please turn them off so we don't get interrupted. For anybody who would like to testify, we have the sign-in sheets. I have four, or is it five people that want to testify here? We have, I guess five people. Basically, we're here until five o'clock today. So, since we only have five people to sign up, I was going to say everybody has at least five minutes, but, I think what we'll do is, we can maybe have a bit of a discussion, also, or if you need more than five minutes, I think we could swing that here, we want to be sure everybody has a chance to speak. And our role here is really to listen and to gain an understanding of what your concerns are. But if you would like a response from anyone on the panel, we would be happy to respond, but you need to let us know that. What we were going to do -- I'm sorry, Sally, would you like to go first?

SALLY: I would like to.

ELAINA GOLDSTEIN Why don't we have Sally go first.

SALLY: I'm just going to tell you what my day has been like. I was up at__ because my landlord gets up at and does his laundry. The fumes come in to my two-room apartment, and the fumes come in there, and I ran outside. I was confused, my throat was sore, I was having trouble breathing, my eyes were swollen, I had to use eye drops that cost over a hundred dollars a bottle. I told them before I moved in, I can't tolerate this, and I don't know, we didn't understand each other, or they just don't care. All throughout the day, I went home later to try and, to just take a shower and stuff, and the dryer is going. And they've got Bounce dryer sheets going, so I ran back out of the house again, and this goes on until eleven/twelve o'clock at

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night, randomly through the day, and frequently. I don't smell the stuff, but it affects me. First hint I have it's going to bother me is I start feeling dazed and out of it, so that's my cue to run outside and I never know when I can come back. I go in and out probably a dozen times a day, hoping I can stay in my apartment. Prior to this, I tried staying in a shelter last summer, but that didn't work at all because they use a lot of cleaners in there and there's a nine o'clock curfew, and you have to be in by nine, and everybody is cleaning the house after nine, and I'm getting really sick. Before that, I lived in a rental that I found out after I moved in was contaminated with mold. It wasn't obvious in September, it was obvious in the winter. Before that, I spent the summer living out of a tent; before that, I lived in someone's house, begging to get him to clean his furnace, because the fumes from the oil don't bother other people, you can't make somebody clean their house for you. And I'm in an abusive relationship but I stay with this man because his house is a filthy pig pen and I can deal with dirt better than chemical cleaners, and he doesn't clean. I know I look fine, I'm starting to kind of lose it in here. But normally, I can hold on a conversation, but I can't even -- the other day I was trying to fill out a form to order some organic health and beauty stuff, and I had it so mixed up, I said to my friend, you have to do this for me, I can't do this myself. I've lost a lot of my cognitive function. I am in desperate need of a home, a place where I can go to where I'm safe and not going to be assaulted by chemicals at random times. And this is like five o'clock in the morning until twelve o'clock at night, that's five hours of sleep. I went out and spent money on an organic bed and now it reeks of Tide and Bounce and Glade Plug-ins. That all comes up from my landlord's house, and no amount -- I'm in desperate need of housing. I don't know where I'm going to go after this, I'm at a loss. When I was diagnosed, my ex-husband took me to court and had my children taken away from me, disability is not supposed to be a reason. If he had left me alone, I had enough finances at the time, I could have bought a house and made it safe. When I went to court, the lawyer said, 'I don't know what to do, this should be a cake walk,' because I was a soccer mom. I lost my house, my children, my ability to move freely in society, there are a lot of places I can't go. I won't stay in here for too long. People laugh and think it's a joke, it's not funny, I've lost my life, lost everything. There's no seeing eye dog to make people see what's wrong, I just look like a smart person who acts stupid.

LAURA JONES: Sally, anything you can suggest, some sort of policy?

SALLY: A Home, I just have to have a home, and it has to be specifically for us because, if you put us in general housing, people are still going to use Tide, the Glade Plug-ins, Bounce dryer sheets.

LAURA JONES: A place where you could go and other people like yourself --

SALLY: To live, a place to live.

LAURA JONES: That is chemically free, a chemical free zone.

SALLY: Yes.

ELAINA GOLDSTEIN If I remember from last year, there was a whole forum on chemical sensitivity. From what I understand, I believe the Commission set up -- we were going to do something at Rhodes for Independence, but the Commission set up a subcommittee on health issues, and I believe it's the Department of Health and the Commission, and I am -- I don't know if anybody here knows what's been going on with that subcommittee to deal with -- I know housing was, for sure, brought up last year.

JEANNE BEHIE: Actually, this was a very big issue last year, a tremendous amount of testimony on chemical sensitivity. You're not alone. And, but there's a number of issues you identified, the chemical sensitivity, homelessness, housing issues, abusive relationship, and your children was issues. But right now, you want to focus on housing?

ELAINA GOLDSTEIN That would solve a lot of the problem.

JEANNE BEHIE: The Legislative Commission looked at legislation about this, and I think one of the suggestions that came out of it is possibly having legislation that there's going to be some chemical free buildings in the state, and that's just the beginning, but it's such a minuscule thing compared to what your needs are. But I'm wondering if that group that comes to the legislative committee meetings who deal with sensitivity issues might be a good person, a good group to -- there's a couple of people.

ELAINA GOLDSTEIN She deals more with like pesticides on your lawn -- No, they're dealing with all chemical sensitivity issues. If I understand correctly, there was a piece of legislation passed, I think it had

to do with hospitals and making sure they were chemical free hospitals, so if you go to the hospital -- I think that's what she was working on this year. But I know last year at a couple of the forums, people were specifically talking about the housing issues at the various forums I went to, so, I don't know what the -- I came late onto the legislative committee, so I'm not sure what was done on the housing issue.

JEANNE BEHIE: Nothing.

ELAINA GOLDSTEIN So maybe that becomes, you know, well, you're here, and you're recommending, sort of like a group home for people who are chemically sensitive, that would be really --

SALLY: My own home.

ELAINA GOLDSTEIN Your own home?

SALLY: It's not simply a matter of, this is what I feel like, it's like a desperate need. I'm out in the middle of winter at five o'clock in the morning, I'm sleeping in my car at ten/eleven o'clock at night, not because it's what I feel like.

ELAINA GOLDSTEIN I mean, I don't know how you could get your own home.

ANN MULREADY: Well, there's Section vouchers.

SALLY: That's just another apartment.

ANN MULREADY: Sometimes not, it depends.

ELAINA GOLDSTEIN There is a program, Fanny May, and I think Citizens Bank, with a relatively low down payment, people with disabilities can purchase homes, but, who is the gentleman from -- do you know the gentleman's name that -- can somebody --

JEANNE BEHIE: You need to be able to apply for a mortgage and a down payment to cover a mortgage.

FEMALE SPEAKER: The down payment is only \$, it's applying for the mortgage.

SALLY: How do you pay a mortgage on disability?

ELAINA GOLDSTEIN That's what I'm saying, I wish I could remember this guy's name. I don't know what kind of financial help they tell you about, I don't know, I mean, it depends on the house, I guess, how much the house costs.

SALLY: What agency is this?

ELAINA GOLDSTEIN It's Citizens Bank and Fanny May are in partnership, have a program for housing for, housing, buying houses. OSCIL, Ocean State Independent Living Center. If you call them and ask them about this program.

JEANNE BEHIE: Also Habitat for Humanity, although I think they're having trouble finding land, but for families with low income, and it's based on your income, the mortgage rate is.

SALLY: I've known people several years ago to try and work with Habitat for Humanity, but the problem is, they want you to work, if you can't hold down a job, how can you work for them?

JEANNE BEHIE: Are you saying you cannot work whatsoever, because I know they do require you to do some work on the house, and to find people to work on it.

SALLY: That's why I'm on disability, if I could work, I wouldn't be on it, would I?

JEANNE BEHIE: There's a lot of people on disability who can work, but it may be limited because of their disability.

ELAINA GOLDSTEIN What we do is try to help people who are on disability who want to work be able to get jobs, and try to remove barriers for people about getting jobs. You know, I know a problem for someone with chemical sensitivity is the actual place of employment sometimes is the problem because you have a problem working in that environment, but there are a lot of changes in the laws that have really become in favor -- Steve can probably talk about that, but I don't know if that's your issue right now, anyway. I think your best bet is, at least to start, to call Citizens Bank and find out about this program because maybe there is something -- okay, thank you.

SALLY: Thanks.

ELAINA GOLDSTEIN Okay, Virginia Davis. (NO RESPONSE)

ELAINA GOLDSTEIN Maybe she left. Is it Diane Owen? Okay, Diane.

DIANE OWEN: I came because I have a sister, and this really is a family

thing, but even though this is a public forum, I am so exacerbated by the runaround I've gotten from everybody in this state. I even called the long term care coordinator's office, and their right hand doesn't know what the left is doing. They say they can't do anything, somebody else says they were supposed to call, 'Roberta Hawkins is out of the state,' I say, 'Fine, good for her.' It's the Department of Health, it's, everybody gives me such a runaround. I have a sister who has been incarcerated in Woonsocket, and I need to help because it's a mockery. She's been treated worse than an animal in captivity, she doesn't belong there, and I can't get her out. This is killing her in there. Even Miss Morgan, I mean, back in May, I talked to her, I was there last week. She says she's on the top five priorities and Morgan still can't tell me whether you'll take her case or not. I said, 'How much time do you need?' 'Well, I can't tell you that. I can just say that we're investigating it.' This is ludicrous. I ended up, I walked to the police station to file a complaint because I don't have a car, and they told me I need to file a complaint in Woonsocket, they can't fax it. It's just round and round I go. Meanwhile, my sister has lost weight. Kept incarcerated, she can only walk a hundred feet from her bed to elevator, no fresh air, no sunshine, no proper brain nutrition to get well. She fell on the bike path in December, frozen tar, they released her for a little while, and my two evil sisters put her away. She's been there for two-and-a-half years. That's why they have group homes now, so people don't need to be institutionalized. She's, she's in with year-old people, nothing against them, but they're screaming in the middle of the night. This is an atrocity. It's not even human to be treated like this, and there's no reason she's there. That's where I am.

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ROSEMARIE COFFEY: Does she have a place to move to?

DIANE OWEN: She can come with me. I brought some of the paperwork because there's something the state calls a DMAT, I don't know, Decision Making Assessment Tool, and a document from South County Hospital, didn't need to be notarized or second opinion or anything, he decides. Which, I don't know, to me, he pulled it out of the air, not treatable/reversible, so that gives Mount St. Francis the right to treat her like a vegetable.

ROSEMARIE COFFEY: What do you need to take her to your house?

DIANE OWEN: I already went to the Rhode Island resource exchange web site and asked for a donation of a chain link fence, like fence worth of fence. She's totally functional and can't get well where she's at because she has like eight to ten hours of TV everyday, so her brain can never get well. It's like they've done everything opposite of what she needs to get well. Then I read the intent of the legislature is to help people get well, and PARI, and all these good things that are supposed to come with ADA, she's not getting access to any of those. She hasn't had access to a telephone. I sent her mail with a green card to be sure she gets it, and the nursing home rejects it. That seems like some federal violation if you can't receive mail when you're a resident in a nursing home. ROSEMARIE COFFEY: You mentioned PARI, both independent living centers have the ability to come out and work with you. Have you initiated getting in touch with them?

DIANE OWEN: I just found out about PARI two days ago. I called the brain injury association in Cranston, and they're the ones that told me to call PARI.

ROSEMARIE COFFEY: They have counselors that would come out and try to identify what the barriers are, work with you on removing those barriers. There's also access to funding, you mentioned, like a fence, I'm not sure if that's an item that would be covered, but there are many nontraditional items that, if it assists somebody getting out of a facility, it will help with funding.

DIANE OWEN: She has filed two sexual assault -- and my evil sisters had her in Butler before Woonsocket, and she filed a sexual assault complaint there, too, they have Woonsocket police investigating this now.

ROSEMARIE COFFEY: They could come in and work with you on some of those things that are so overwhelming, and help with the steps to get her out.

DIANE OWEN: It's not overwhelming to me because I know what needs to be done.

JEANNE BEHIE: You mentioned your sisters, do either one of them have health care proxy over your sister?

DIANE OWEN: That's this DMAT thing, they had a guardianship hearing without notifying me, these two evil sisters did this. One has it over financial and one has it - it's all tangled up. But how can somebody be so deceived that they think they're helping her by putting her away in a zoo like this?

JEANNE BEHIE: We should back up then, if they have guardianship -- and you would be best to answer that, right?

ANN MULREADY: I don't want to speak since -- I didn't know you had been to our office, so -- If they have guardianship, then they have the decision making over where she goes.

DIANE OWEN: Well, I finally got to see her in May, once I got a car, they brought her out to the parking lot, I got to go inside the building and see -- I had hand-carried books for her to read and pictures for her wall. I thought it was a rehabilitation facility, I brought seeds and dirt to make a garden, they had taken everything away. It's like, you know -- I lost my point because of the guardianship thing, but there has to be some way I can -- I know when I went in May to see her, all I did was lay hugs on her and I wanted to sit in front of her bed and not let anybody come and be mean to her any more, but they told me I had to get out because, 'If you stay, you can't get her out.' The two evil baby sisters filed a domestic abuse summons against me because I went to see my sister. So now I have to go to court. I went twice already and it got postponed to December 12th. I mentioned one time to my son, this is worse than a TV soap opera, he said, 'Where do you think they get the scripts?' A domestic abuse summons against me because I go see my sister, because I love my sister, you know, it's too weird for words. So that's where I'm at. I think it's criminal to have her in there, because my sister was an officer in the Navy, she has two boys. The town of South Kingstown would call her up and she would take them in. She's the sweetest spirit you would ever meet, and it's criminal. There ought to be something that, you need a second opinion before you can put someone away, there's nothing here. What Debbie and Peggy have done is given Lindy a lifetime sentence with no hope of parole. And this is what happened, I called her, we used to call two or three times a day, and after I went to see her, now they won't let her come to the phone and talk to me any more, or get the mail. And I said to her on a Thursday, because she had said she wanted out of there, and I said, 'Okay, we're coming to get you,' and this was going to be a Monday, some holiday. I just said to go down to the office and treat it like a hotel. I was told if you sign yourself into a hospital, you can sign out. I said, 'Just tell them I'm checking out tomorrow.' She said, 'Fine.' 'What do other people do when they sign out of there?' She said, 'They don't.' So, whatever ward they have her in, there's no way out. So they've put her away, it's a sin, it's an atrocity. I thought for sure the Disability Law Center was going to be a God sent.

ANN MULREADY: I don't know anything about your sister's case, but she would be our client.

DIANE OWEN: How long does it take to decide whether you're going to take somebody as a client?

ELAINA GOLDSTEIN Can you get back to her?

ANN MULREADY: You're not the person with the disability, so I'm not sure whether or not I can share with you --

DIANE OWEN: I'm advocating for my sister to get her out of that joint.

ANN MULREADY: There would be issues.

ELAINA GOLDSTEIN It sounds like she does not have a sense of where things are, if you could just contact somebody to contact her?

DIANE OWEN: I can't wait any more. She's going die in there. Somebody told me it will take a year to get her out through the legal channels. She won't last a year. She doesn't belong in there.

ELAINA GOLDSTEIN Okay, Vicky Coffman. Do you need a mic.?

VICKY COFFMAN: No, I don't. I'm from the Office of Civil Rights within the Federal Department of Health and Human Services, and I came down to let you folks know that we exist. We somehow seem to be a well kept secret that no one knows that we're there. Every federal agency has a Civil Rights Office that's responsible for enforcing the civil rights laws for any program that receives funding from that department. So, in that case, we're the Department of Health and Human Services. So, hospitals, health care programs, social service agencies, we receive funding from Providence Health and Human Services, so anyone that receives federal funding has to agree they will not discriminate on the basis of disability. And a , it's actually and the Americans with Disabilities Act, and our office investigates

complaints of agencies over whom we have jurisdiction that, you know, there's a complaint that that agency is in fact -- there's discrimination going on. Typical complaints we would receive would be a hospital that didn't furnish a sign language interpreter, for example, for someone who was deaf or hard of hearing; a nursing home that wasn't accessible that had stairs but no ramp; rest rooms weren't accessible. Those are typical kinds of complaints that we receive around disability issues. So, I'm kind of here to let you know that we do exist, and if it's all right, I'll put some cards on the table. It has the number on it.

ELAINA GOLDSTEIN If anybody wants to talk to you afterwards, you'll be here?

VICKY COFFMAN: I just wanted to see the issues raised here.

ELAINA GOLDSTEIN Do you know how to get in touch with the Commission of Disabilities?

VICKY COFFMAN: I do now, I didn't before, but I do now.

ELAINA GOLDSTEIN Thank you. Laura.

LAURA: I'm not talking.

ELAINA GOLDSTEIN Okay. Is there a Virginia who wanted to speak? I think we had the wrong last name.

VIRGINIA DIANO: A year ago, my year-old brother who has Down Syndrome voluntarily left a group home, amidst reports of -- a year ago August, my brother, who is year-old and has Down Syndrome

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voluntarily left a group home and came to live with me, indicated he wanted to stay with me and live with me. And he's been there with me ever since. For almost a year, his Social Security funds have been withheld, they've gone to the group home. The center that is responsible for the group home never contacted Social Security to say that they were no longer representative payee and held onto his social security check. A few months ago, I called Social Security and reported the incident and it is now under investigation. I have since been made representative payee. However, there are funds that he is entitled to that have not yet been recouped, and I would like to know what the Governor's Commission can do about that. And also, I'd like to know what the council can do to recoup funding that my brother is entitled to that has been filtered into the center where he is no longer a client, and is still receiving funding for a nonexistent compliant. I have been in contact with the acting director for the Department of Developmental Disabilities. I left several messages for him toward the end of March, never had my phone calls returned. I finally did e-mail him, and before I e-mailed him, I spoke with his secretary and told him if he did not respond to me via e-mail or telephone call that I would contact the Governor's office, and within ten minutes, the phone rang. I'd like to know where those funds are, the state deserves to receive those funds as a reimbursement, they do not belong to the center for the period of time that my brother was not there. My attorney has sent two letters to this individual that have gone un-responded, and I'd just like to know what can be done about it. And I feel his civil rights have been infringed upon. Thank you.

CAROL MUSSO: There is something I can say. Carol Musso, M-U-S-S-O. This is under litigation

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because there's a guardianship that's being contested. Also, for my brother, which was taken out, I use the word illegally because it was filed for in a town where my brother, Tom, was not living; it was done without notification to my mother or my sister and I; and seemed to be something going on between the Judge and the individual who is the guardian, my older brother, who is also an attorney. We have been in court over this for three years, the guardianship. It's like we're spinning our wheels because nothing gets done, and in the meantime, my sister has taken in my brother, and he wants to live there, and she has provided for him out of her own pocket. And there's funding going to a center that shouldn't be going to a center; social security check that went to a group home that shouldn't have been going to a group home, should have been going to my sister's home where she could use it for his benefit, and she can not even get services for him at another center because the money is still tied up in the one he left a year ago. So, there's more to this, it's very convoluted, but also very disturbing because my brother is quite articulate and he can say where he wants to live, who he wants to be with, where he wants to work, and yet, there are documents sent to court saying he has an IQ of , it's impossible. If you ask him if he knows anything about stealing things and he'll say, 'I'm not a thief.' I don't think someone with an IQ of

can tell you that stealing and being a thief have something to do with each other. And it's very frustrating because we want him to get the services he deserves, and nobody can seem to help us. It's bogged down in the judicial system in the state, and he goes a whole year without the proper services. So this is why we decided to come here and see if we could get some help with this issue. Thank you.
ELAINA GOLDSTEIN You said you've got social security involved, right, because that check, it really is, you know, the social security check that was not going -- if it was going to the wrong place and not getting to him --

VIRGINIA DIANO: By law, that center was supposed to notify social security, it's right in their rules and regulations of social security. By law, either the guardian, who is presently guardian of finance, was supposed to notify them and never did, and neither did the center. They knew that that check did not belong to them.

ELAINA GOLDSTEIN But Social Security is now involved in this because it is fraud.

VIRGINIA DIANO: Yes, it is.

ELAINA GOLDSTEIN Then they will be the ones that need to recoup, you know what I mean?

VIRGINIA DIANO: I understand that, but I'd like to know what happens to the funds appropriated from the state to my brother, where are those funds?

JEANNE BEHIE: You're talking about funding to provide -- It would be through DD -- you said you've contacted them, too?

ELAINA GOLDSTEIN I would contact the new director of MHRH, what's her name, Dr. Ellen Nelson, she's brand new. I think she was appointed a month ago. So, this is, and she is the new director, Ellen, I think Nelson. She should be aware of this.

VIRGINIA DIANO: Do you think the acting director would have passed along the information?

JEANNE BEHIE: No, they're up here and the people dealing with it are down here, on the individual cases.

ELAINA GOLDSTEIN I think you should call her.

JEANNE BEHIE: Most probably, your brother had a social worker. Did you contact the social worker?

VIRGINIA DIANO: The social worker is involved in the litigation.

JEANNE BEHIE: Okay, all right.

VIRGINIA DIANO: There's a stumbling block to us getting services.

CAROL NEESO: The social worker has been a stumbling block, yes.

ELAINA GOLDSTEIN I don't -- I don't know if there's something that your office does about things like this?

VICKY COFFMAN: We're not involved in the financial end of it, but I would say, yes, social security does have a broad unit, that would be who I would --

JEANNE BEHIE: I will tell you from my own personal experience in dealing with social security and SSI, that contrary to most places, I find I get better service when I go to the office in person rather than trying to talk to them over the phone.

VIRGINIA DIANO: I have spoken to a woman who has been extremely helpful. It's one individual that I have spoken to exclusively to anyone else in the department, one person.

JEANNE BEHIE: Okay, good.

ELAINA GOLDSTEIN Does the Commission, if there's a problem like that, is there an area in the Commission or someone in the Commission that gets complaints like this, or not really?

JEANNE BEHIE: I don't think we have an actual department that handles things like that, accessibility issues.

VIRGINIA DIANO: Well, the funds are being filtered into the center where he was no longer a client is what concerns me, not Medicaid funds, these are funds for day services, residential services that were being --

ELAINA GOLDSTEIN But they may be, I'm just saying that may be Medicaid funding that goes to that. Is that Medicaid?

STEVE BRUNERO: Could be.

ELAINA GOLDSTEIN Medicaid program is a federal/state program, so, if it's Medicaid funding, and if it is, you may want to contact -- John Young? He's the director.

VIRGINIA DIANO: I spoke with his office and got nowhere, in the Department for Developmental Disabilities.

ELAINA GOLDSTEIN No, John Young is the director of Medicaid. Or Ron Label, who is the director of the Department of Human Services, which is, Medicaid is under the Department of Human Services.

JEANNE BEHIE: Probably the same, John Young.

ELAINA GOLDSTEIN The other person in charge of the whole kitten caboodle, Jane Hayward.

JEANNE BEHIE: Is this a state run group home or private?

VIRGINIA DIANO: State run.

ELAINA GOLDSTEIN Do you want to know what the center is, will that help you figure this out? I think all we can probably do here is try to give you people that you can contact, who -- they would need to know the name. There must be something within the state that if there's a problem with the facility, then there's something that you need to do. But again, it might be -- instead of SSI, or SSA, it's state Medicaid funds.

VIRGINIA DIANO: I know part of the social security come from Medicaid.

ELAINA GOLDSTEIN Medicaid is the health and social service piece.

VIRGINIA DIANO: And the SSI?

ELAINA GOLDSTEIN SSI comes partially from the state and the federal government. The other place, and I'm not sure, the Attorney General's office also has an area on Medicaid fraud that they go after different, I guess, facilities, as well as individuals on Medicaid fraud. Anybody else have any -- you have a list now of more people. It sounds like you're formidable though, I'm glad I'm not getting the call from you.

CAROL NEESO: Well, some of these people have been contacted, and here we are a year later. That's why we decided to come here.

ELAINA GOLDSTEIN This is a public record at this point, I mean, you've made it public versus having made the calls to these individuals, you know. I don't know if you want to mention who or what, you don't have to.

CAROL NEESO: I'd love to.

ELAINA GOLDSTEIN You're the one testifying.

CAROL NEESO: Craig Stenning, we were told he's the acting director of the Department of Disabilities.

ELAINA GOLDSTEIN I don't know who he is. Steve, do you know?

STEVE BRUNERO: He's the state administrator for MHRH.

ELAINA GOLDSTEIN Dr. Nelson would be his boss now. So, when you contact her, she probably knows who he is.

CAROL NEESO: Correspondence has been sent to him.

ELAINA GOLDSTEIN Hi. You came in a little bit late. I don't know if you want to introduce yourself, if you'd like to provide some testimony, ask any questions.

FEMALE SPEAKER: Just listening.

DIANE HELEN: On this guardianship stuff, how does the guardianship relate to a bond? How do those fit together? Either the state pays the guardian a bond or the guardians pay the state a bond, there is some type of guardianship/bond connection.

JEANNE BEHIE: What do you mean by a bond? When someone gets a guardianship of someone's estate, the courts often, depending on how big, the court will ask anymore to post the bond so that if later on, there's some question about, was the estate money really used for the benefit of the ward, they have the bond as sort of an insurance policy if the court later decides that the money, the ward's money, the estate was misused. So that's part of what probate court does in requiring a, they have buy a bond, like buying an insurance policy.

DIANE HELEN: Just a one time thing?

ANN MULREADY: Kind of works like an insurance policy, it exists for the duration of the financial guardianship.

ELAINA GOLDSTEIN Anybody else? Did you want to say anything or ask any questions? We're here for another hour.

DIANE HELEN: I have another one. I'm grateful for what I've heard, as for the ADA and all this effort in the last years, but once you label somebody -- I can see this, you can see ramps on the sidewalks and everything. But once somebody has been labeled disabled, how do you get unlabeled? I mean, you know, how do I get my sister to -- first of all, who do I have to prove it to, that she doesn't need a guardian? How do you get unlabeled, for lack of a better way to put it.

ELAINA GOLDSTEIN See, the people behind you seem to be going through a similar issue with the guardianship.

ANN MULREADY: The law is supposed to look at whether somebody has the capacity to make any decisions at all. And if they are, that kind of autonomy is supposed to be preserved. But we have as many courts as there are cities and towns. They're all interpreting that law, and sometimes people are very maternalistic in interpreting the law and take away people's autonomy when perhaps they don't need to. And courts are also supposed to look at if somebody has trouble making decisions or finances, is there something less restrictive than a guardian that could help, a joint checking account with someone, could they have a representative payee from Social Security if that's all the money they have. So, the process is supposed to work like that; it doesn't always. And that's how the law sets out guardianship, and people have misconception about what guardianship law does. Some family members are told that it's a way to protect their loved one, and it doesn't necessarily do that. So, I think there's a lot of misconceptions about what guardianship will do for someone, and I think there's, you know, there's many, many different ways of interpreting that law. And I think the disability community, it's still of concern that we take away probably more autonomy than we need to from people, and that we really need to find ways to support people's decision making as opposed to finding someone else.

DIANE HELEN: I do a lot of home care and have had a lot clients, different diagnosis and stuff, but you don't just put them in a box and cage and stuff like that. It's a nurturing thing, an encouragement thing, to let them know they can still function. I'm in shock over this. I read the paperwork from the probate court and I'm in shock that a country that is supposed to have the rule of law would do this. Anybody could put an X and X in the box, it doesn't say they investigated, you know, the one that says other, they didn't check any, why couldn't she live with me kind of thing. It's just shocking to me that this could happen.

VIRGINIA DIANO: My brother was assessed by a physician who spoke broken English and whose presence my brother had been in maybe minutes his entire life. He filled out an DMAT for my brother.

ELAINA GOLDSTEIN So, this is the paperwork that says someone need a guardian?

CAROL NEESO: It's what probate court takes.

ELAINA GOLDSTEIN I think, from a legislative policy perspective, we've heard this now twice. We need to be looking at this DMAT and how it's working.

DIANE HELEN: It's awful.

JEANNE BEHIE: Could you talk about how people go about reversing guardianship? I guess it would have to be the person who is appointed a guardian over, but you must --

ANN MULREADY: State law does give the person called the ward a right to petition the probate court to be released from guardianship, but in most instances, it requires another doctor to fill out a DMAT saying the circumstances have changed or the original circumstances never existed, but an expert to dispute what the original doctor came up with.

CAROL NEESO: I didn't catch your last remarks.

ANN MULREADY: You'll need another DMAT to be filled out by a medical professional to say that either the first doctor was wrong in that assessment of the person's decision making ability or that the person's decision making ability has changed. So, either one. But that is really what --

DIANE HELEN: If I get a doctor to visit her at the nursing home, she can petition to get rid of the guardianship stuff?

ANN MULREADY: That's certainly an avenue.

DIANE HELEN: She wasn't even present at the hearing.

CAROL NEESO: It isn't that simple. I mean, getting another doctor to do a DMAT that contradicts another one isn't simply going to make the guardianship go away. We can testify to that fact. We have been for three years trying to make a guardianship go away.

ANN MULREADY: Could you get another doctor to see your brother?

CAROL NEESO: For a second opinion, no. We have an expert on Down Syndrome.

ELAINA GOLDSTEIN Can I clarify something, because I'm confused -- I didn't realize, and maybe I don't understand, you can help, but you both have a, like a number of family members, so, a family member, one of the family members went to get the guardianship and other family members don't need to know?

CAROL NEESO: They're supposed to.

ELAINA GOLDSTEIN Is that the what the law says?

CAROL NEESO: -- not filed where my brother was living.

ANN MULREADY: I think, which town in Rhode Island does the person have residency in and where is the most appropriate place for the guardianship to take place -- because these are city and town courts, not state courts. So, it is possible to make those arguments, and to take a lot of time making those arguments.

ELAINA GOLDSTEIN But there is supposed to be something across the board that all family members are supposed to be notified prior to the guardianship.

ANN MULREADY: Same hierarchy as you would go to when someone dies, next of kin.

ELAINA GOLDSTEIN Then the next of kin can testify?

ANN MULREADY: They can appear, that's the due process.

DIANE HELEN: To add to that, right before my mother died, I had financial and medical guardianship of her and that was done in the hospital. They brought a lawyer in the hospital to fill out the papers and my two brothers were notified of it, also.

ANN MULREADY: It is possible to get an exparte guardianship. If people ask for a temporary guardianship, there is a process that allows that, even the person of which guardianship is being taken to not get notice. In some circumstances, they may be not giving the person themselves notice. I'm not saying that's a good practice or that all courts would do that, but theoretically, it's possible.

DIANE HELEN: So the probate court that awarded guardianship is a city and town court, not a state court?

ANN MULREADY: Yes.

ELAINA GOLDSTEIN Guardianship here.

DIANE HELEN: Well, it made someone a prisoner.

LAURA STEELE: I have something on the lighter side. I used to have a sticker for a handicapped driver and it was good for a year, and I talked to my neurologist about getting another one. They changed the

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laws now. I know people who have stickers for life and they can hardly walk -- I know one who uses two crutches and still needs help, can hardly get in her car, and has a handicapped sticker -- not a very good driver, but does get around. When I went to see about getting my sticker renewed, I found out they

have all these tests you need to take now. My neurologist told me he had trouble with some patients that were turned down because they didn't pass the tests. I said, 'What are the tests?' He said, 'Don't worry about it; you're not strong enough to do it.' They have tests now for handicapped drivers that a handicapped person could never pass. Basically, he told me, you have to be not handicapped to get a sticker to pass the test, and since you're handicapped, you don't get the sticker.

ELAINA GOLDSTEIN This is just for parking, right?

LAURA STEELE: Yes, before you had your doctor put down you were handicapped and deserved to have a sticker, then they'd send you one in the mail, but now, they have you take these power tests, strength tests, and he said only somebody who's not handicapped could pass these tests.

ELAINA GOLDSTEIN This is not a driver's license, just a sticker?

LAURA JONES: Seems like they'd give you the sticker if you failed it because you didn't have the strength, no?

LAURA STEELE: I had a sticker to park in handicapped and wanted it renewed and went to my neurologist because he wrote the diagnosis, which doesn't keep me from driving, I'm still driving. And he said, 'Because the last two clients I sent there whom were perfectly capable of driving, didn't need any extra things on the car or anything, they couldn't pass the test, and they wouldn't give them a sticker.'

ELAINA GOLDSTEIN Maybe they're requiring a certain level of disability. I'm just figuring.

LAURA STEELE: They were the same. They had had stickers for ten years.

ELAINA GOLDSTEIN But the test is some sort of strength test?

LAURA STEELE: The test they're requiring to take, my doctor went down to find out about it, you could only pass it if you were not handicapped.

ELAINA GOLDSTEIN But, it's a physical?

LAURA STEELE: Physical test, but you can't pass it if you're handicapped. A handicapped person is not capable of exerting the power to pass the test.

JEANNE BEHIE: And you have to pass it to get a sticker?

LAURA STEELE: Yes.

JEANNE BEHIE: Where is this being given?

LAURA STEELE: I don't know, I didn't ask, it's a state of Rhode Island test.

ELAINA GOLDSTEIN So, you haven't gotten your sticker renewed?

LAURA STEELE: No, I don't want to lose my license because they took the license away from the people who took this test. And, you know, they were perfectly capable of driving. Isn't that a little weird? Should somebody look into that because there are a lot of people who can drive who are not getting a parking sticker. I think they did it because it was being abused a lot, but they got way overboard.

CAROL NEESO: Now we have the weakest people walking the furthest.

ELAINA GOLDSTEIN: Maybe the same implementation may –

LAURA STEELE: Takes me twice as much energy to walk as it would you, and I can't get a parking sticker any more.

ELAINA GOLDSTEIN: This is not a city or town thing, this is a state thing. This is being done throughout the state. What is the new policy/procedure for people to get their parking stickers. And then, what's happening is that people seem to be losing their license because they're not passing some test.

LAURA STEELE: Before, your neurologist or doctor could fill out the paper and you get your sticker. They were taking the doctor's word for it, I guess it was being abused so now you have to take this test, and if you take the test and don't pass it, they take your license away

JEANNE BEHIE: Because you're not capable of driving.

LAURA STEELE: It's not a driving test. It's a strength test, they make you lift weights.

ANN MULREADY: I don't know about the test, but there is a question on the bottom of the form that your doctor fills out to get a handicapped parking permit. It asks that the doctor signs off, does he think that this person is capable of safe driving. If he signs yes, the DMV, by law, is not supposed to require further.

LAURA STEELE: But he wrote yes, they are capable on all of these.

ANN MULREADY: Sometimes doctors sign off no. Hopefully, that's a conversation they have with the person before that.

JEANNE BEHIE: They probably don't.

ANN MULREADY: If people are denied, they have a right to appeal that decision. They're not supposed to take their license away until they have an option for a hearing.

JEANNE BEHIE: I'd like you to repeat what you just said because I don't know if everyone heard that.

ANN MULREADY: If people are denied a handicapped parking permit, they have a right to a hearing, and if their license is denied, they have a right to a hearing before their license is taken away, unless they are immediate, unless they will immediately jeopardize the public safety.

LAURA STEELE: I don't know if these people appealed. I know they still do not have driver's license and still don't have stickers, and this was two years ago. So, I presume they appealed, but it sounds to me that they lost if they did. But isn't this strange that they would have you come down for a strength test? The people aren't passing unless they're not handicapped.

ANN MULREADY: The law does provide that if they determine -- it sounds as if they've made inquiry into the person's ability to drive, either because the doctor checked off the box and might have said he's not sure if the person can drive safely.

LAURA STEELE: I know my doctor very well, I asked if he checked off the box saying they could drive safely and he said, 'Yes, of course.' But they went down and couldn't pass.

ANN MULREADY: One of the things, when you ask for a hearing, if they think you can't drive and you ask for a hearing, one of the things you can opt to do is do a road test,

LAURA STEELE: Don't you think that's a little odd that they would have a test like that all of a sudden that only someone who's not handicapped can pass.

ANN MULREADY: Do I think it's odd if it's a lifting test --

DANIEL ARRIGAN: I just sort of would like to hear what the process is for, after these forums are finished, you know, some of the things that were brought up, what would then happen when you're reviewing the transcripts, and when this is presented in the fall, and is there a follow up, you know -

ELAINA GOLDSTEIN: Basically, the transcripts will be on the web site and there's a group of people that are on the Commission, I guess it's predominantly people on the Legislative Committee.

JEANNE BEHIE: Different committees are formed to look at different testimony, and every bit of testimony is reviewed by a committee. And what we look for are concerns, especially similar concerns. So, last year we heard a lot of concerns about chemical sensitivity, and that was an area we wanted to even form a separate committee on because there were so many concerns about it. But we look at the concerns and then decide what issues we're going to address during the following year. And we can propose legislation pertaining to those issues. So, everything that people have spoken about today, you know, isn't going to be shelved and forgotten. We will take a look at all that and hear what other people have said and decide what issues we're going to be working on. But I can tell you I will make it a point to bring up some of these things mentioned today, too. If you didn't verbally testify or if you go home and think of other issues you're concerned about, you can mail in those concerns or e-mail them to us, and that's on this information that was given out, too. Or if you have friend that has some disability concerns, too. You all should have been given one of these, and if you didn't, we'll be sure you get one before.

DANIEL ARRIGAN: Just following up, when you make these proposals for the legislation, in the past, what is the, sort of success rate of getting these proposals passed?

ELAINA GOLDSTEIN: I guess they knew that was coming. There's a single page here, "Concerns raised in previous forums," it's a single sheet. Do you want to read through what became law from last year's --

STEVE BRUNERO: Anybody else need a copy?

ELAINA GOLDSTEIN: I must say, what happens is, these are the only ones that have become law. I think if I can remember from the last legislative meeting that we had, Bob said that the success rate this year, do you remember what the success rate was? It's not percent, but it's a pretty nice success rate. But there are other things the Commission was working on that maybe didn't pass this year, that they want to look at again to help push through next year. So, the process, and again, this was my first year in the Legislative Committee, I've been involved in the forums and involved in going through transcripts, but I had never been on the Legislative Committee, and what they do is they look at all of the issues that they were trying to help push through this year and see what hasn't happened, they look at all of the new issues that have been brought up. For example, this guardianship issue, from the few years I've been involved, I don't really remember that as an issue. But we had two people here out of the, you know, eight or nine people that are here mention that. That is a high percentage in one forum. So, I'm sure, if there is something that can be done within the changing of the laws and looking at how the laws are now -- and that is sort of, that's sort of the kind of things that I believe the Legislative Committee takes on. If

there is something legislatively that needs to be changed, then that becomes a high priority, I guess, in the Legislative Committee. If there's issues that come up that are not basically legislative options, I guess, those where they can't really do anything about –

JEANNE BEHIE: We brain storm ways to deal with the issues. It may be a legislative direction, but it will lead to something else, too. We definitely look at ways we can deal with certain issues.

ELAINA GOLDSTEIN: Do you ever get back to the people?

JEANNE BEHIE: Well, it's open to the public, so anyone is welcome to come to the meetings. You can go on the web site and see where they are and follow what's going on, too, so, you're all welcome to attend our meetings, and I want to give a plug. Here in Rhode Island, I think it's one of the only states that you can really have an issue, you can let your friends know and have your friends come out and voice concerns, and it can being a legislative bill the following year. Here in Rhode Island, you can really make a difference in what you see as needs.

ELAINA GOLDSTEIN: Absolutely, I've been involved, again, first year with the Legislative Committee, to see that process go. But I've been involved in coming to these forums for the last, maybe four years. And this, to let you know from the Rhodes to Independence perspective, if there's anything that comes up within the purview of the project we work on, housing seems to be an area, it's helping people with disabilities become employed, so -- actually, we're going, next week, the transportation issue, although it was not brought up here is a huge issue for people with disabilities and senior citizens who can't drive and don't have a car but still want to get to work and other places. It's a huge problem. And we were fortunate enough to get a strategic planning grant and we're going to be in Washington, D.C., four of us, next week to help with ideas about what's going on around the country and planning a better transportation system in Rhode Island. So, and again, I have heard, although we didn't here it at this forum, I have heard in previous forums that transportation is such a big issue, that when I saw this grant opportunity, I said, even though we got it kind of late in the game, and spent a day-and-a-half and worked really hard to get that grant in, and we got it in. And it is sometimes frustrating why other people who may have seen this grant and seen the need, or whatever, but we were lucky enough to have it, and we're working with Easter Seals, RIPTA, the senior community, and hopefully with the legislators and state agencies, and I'm sure the Commission will be working with us on that. But it's been a huge issue for people with disabilities year after year. So, because, you know, we've become aware of that, you become aware of the issues when things come up, at least from my perspective that's sort of what I do. I like to be sure in our grant that we're working on those issues specifically that we are about here. And the guardianship one, actually, would not pertain to our grant, but certainly to state law that is out there. Anybody else that would like to say anything? Does anybody want to say anything exciting that's happening in any of your agencies that might be informative?

LAURA JONES: I can say at the Department of Health and Division of Family Health, we just completed an autism guide for families and providers, so it will have all the resources available, and just talks about all the different treatment options for autism. And those will be going out to all the pediatricians and will be available to families. And also, a deaf and hard of hearing guide that will have the same, all the resources in our state. So these are two guides that we just, you know, published and will be available. So, that's something new.

ELAINA GOLDSTEIN: Will they be on the internet or can people call up and get a copy?

LAURA JONES: They are going to be on the internet. I don't think they are yet, but they will be on the Department of Health web site.

ELAINA GOLDSTEIN: Great. Steve.

STEVE BRUNERO: I'm with the Office of Rehabilitation Services. ORS, for short, has three programs. Services for the blind/visually impaired, second is disability termination services, adjudicate social security decisions, and the other -- there's three different programs within the office of rehab services, ORS. First is Services for the Blind and Visually Impaired, second is Disability and Determination Services, and third is Vocational. I'm the deputy administrator at the Vocational, and it's a program designed to assist individuals with disabilities to obtain employment or maintain employment in the community. We work with folks from years old, on. Last year we serviced about, individuals in Rhode

Island and assisted over become successfully employed. So we offer a wide continuum of programs and services, and I'll invite you to visit our web site, or if you would like more detailed information, I'll speak with you afterwards.

JEANNE BEHIE: As I mentioned before, I'm Jeanne Behie, and I work for a children and adolescent program, working with families of children from birth until who have emotional behavioral issues, helping the families' access resources and information in the community that can benefit the family and the child. I work with the family on understanding what their rights are under the law for education. I attend IEPs with families if they want, and, you know, just help them get resources that they may need to make their lives easier. I am also a graduate student becoming a teacher of students with visual impairments. So if you have any questions about family members who are visually impaired, I'd be happy to speak with you afterwards. As I said earlier, both of my parents acquired disabilities, both brain injuries, so, I feel I have a lot of knowledge about brain injuries, too. So, I'm glad you all came today.

ELAINA GOLDSTEIN: One thing I'd like to say about the Rhodes to Independence project, it's Rhodestoindependence, all one word, .org, and that will tell you a lot of the issue areas we've been working on over the last six years. A lot of youth transition issues, helping young adults go from high school to work, or from high school to college. One of the things that we've produced this past year, and hopefully it's getting around the state, being distributed by the Department of Health, the ORS, Department of Ed. is an interview tool, and it's actually a very nice little booklet that gives you step by step on what to do in getting a job, in helping you get a job. We've worked on the, as I said, we worked on a housing issue. We had a bill that Representative Eileen Naughton introduced on a home modification loan program, and although it didn't pass this year, it's one of those areas -- this was one of the pieces of legislation that the Commission really wanted to help get passed. And working with the Legislative Committee, it was a bill that got improved dramatically and we are hoping to reintroduce it next year, and hopefully it will pass. And its purpose to help people at various income levels, not just low income levels, be able to get home modification loans. So, if you're in your own home, you can get a home mod. Right now, ORS has money and it gets distributed, and I think, totally, it's about maybe or for the whole state, which is really not a lot of money when you talk about all the people that would need it. So this was going to be a \$ million bond issuance, and that would do a lot. So hopefully next year, we'll move that along. The other areas we are he working on, there's the health care area, that's one of our big accomplishments we have felt was getting passed, a Medicaid buy in called the Sherlock plan here in Rhode Island. We're having -- it's been something that was actually started January 1st of this year. Unfortunately, there is another program that many of you may know about called Medicaid Part D that also was implemented on January 1st which took a lot of resources from the state agencies to really help people get in the Medicaid Part D programs, and understanding Medicaid Part D, so, unfortunately the Sherlock plan has taken a backseat as far as outreach. But if any of you belong to any organization that would like to us come and talk about the Sherlock plan, we'd be happy to do that. You can contact our office. I should have probably brought Sherlock plan brochures here but we didn't, so you can contact our office. My number is - in Cranston, that's probably the best place to contact us. We are finding out through the people that are attempting to become eligible for the Sherlock plan that we are definitely going to have to go in and modify this bill because the premium rate for many people is just too high, so we are going to need to modify that. But hopefully, through this year's experience, we'll be able to show that a lot of people aren't eligible because of the premium rate. The other thing, there was a bill passed this past year called -- or, was it last year -- the Medicaid Managed Care Bill for people with disabilities. I know, I think it was passed last year and it was supposed to start to get implemented this year, and this was a piece of legislation that the Commission had moved forward. The problem for a lot of people with disabilities is they feel, especially if it's a person newly disabled, that it's very hard to find the right kinds of providers to take care of their specific problems, and they felt that the RItecare program and how it's been designed has been very helpful, especially for kids with disabilities that are in it. So they wanted to pretty much try and emulate the same kind of health plan for people, adults with disabilities. And so, we're working with DHS, and people with disabilities are working in a group to try to be sure that the plan that gets developed is one that is going to be a good plan and addresses the issues

and concerns of health care accessibility for people with disabilities. I'm trying to think. If anybody would like to be part of our Steering Committee on the Rhodes to Independence, we love bringing in new people every year. We don't really have a set number of people that are supposed to be on the Steering Committee, and I'm trying every year to get more and more people with disabilities or family members with a person with a disability because I do believe that the only way we're really going to be able to make change is to understand what the problems are and that's sort of what you guys have done here. You came out and have been very courageous and stood up and testified about very personal things so that the problems that people are experiencing -- I'm sure you're not the only ones experiencing the problems that you addressed here today, but a lot of the problems are very personal and it takes a lot of courage to come out and say this in testimony so we can hear about them and actually go and do something about it. So I personally want to thank you for sharing all of your concerns and issues because it is very courageous.

ANN MULREADY: As I mentioned before, I work for the Rhode Island Disability Law Center. We are a not profit law office funded by the federal government to represent people with disabilities on disability related issues. And every year, we try to get as much information and input from people with disabilities and their family members about, what are the pressing legal issues facing people with disabilities. So, the testimony that is presented at these forums is very helpful to us. We also do our own survey which I hope you'll take the time to fill out. I just noticed guardianship isn't on this survey, but you're welcome to write it in. We do represent people with disabilities who want to contest guardianship. I think this forum has been very helpful to us, the last one was on criminal justice and I remember some very persuasive testimony two years ago from some adults with mental illness who were concerned about people with mental illness getting caught up in the criminal justice system. So we now are representing, or we're trying to set up some advocacy services within the prison system in response to that. We also, occasionally, unfortunately, represent children with disabilities who get caught up in the criminal justice system, as well. So, although we don't do criminal representation, our goal is to try to get people out of the system and get them converted if getting them in the system is related to their disability. So, thank you for your time and you can either hand these in to me or leave them here. That would be helpful.

ROSEMARIE COFFEY: A program I think is important is a project called Personal Choice. It's a Medicaid program, initially put together with a grant through the Robert Wood Johnson Foundation. It's a consumer directed program in the sense that individuals with disabilities are making choices about the services that they're receiving under the program. We already had a similar self directed program through PARI Independent Living Center to provide personal care services. But this is a way of really enhancing that and opening it up to a broader population. We're hoping that seniors who would like to have, possibly, family members work for them, maybe friends, neighbors, someone that they're comfortable with instead of an agency who makes all those decisions, that this would really respond to that need. The program was initiated, began implementation in March, and we hope that we'll have at least a hundred people on in the first year, and eventually expand to over four hundred. So there's a phase-in process going on now. Other programs people have been receiving service from, they may come over from those programs, they may be in a situation where they've never had services and this is a program that finally fits them. So that is something to be aware of, too, with the Department of Human Services. Again, I'd like to emulate what was said earlier about, really the good that comes out of this testimony because I've seen it first hand, too. If issues are brought up here today and they're heard over and over again, it really does give the Commission some concrete information to go on, to listen to the public and move forward on changes for the better. Thanks for coming.

ELAINA GOLDSTEIN We're being pretty informal here

DEB HARBIN: Can I speak up, then? My name is Deb Harbin, I have seven children, my oldest daughter is and has at turrets syndrome and gets services at home, fortunately, my husband and I have been able to keep her at home with support of day services. We've also been lucky to adopt three special needs children of younger ages. So I really have a lot of experience. By the time I finish my IEPs, it will be years of IEPs. First thing, was day services which I

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know we avoided a big cut. My daughter has only been getting day services for four years and already the number, the agency has divided by has shrunk those hours. So, I'm wondering, in ten years where will I be in hours, then increasing mileage, health care, never mind raises, just the cost of doing business, and there's no built in. Even a one percent or any kind of cost of living raise to keep that chunk of money every year that comes every year, it buys less and less every year. So there should be some consideration to just making a minimal -- and I know -- I'll say the state of Rhode Island is extremely good to this population. I've lived in other states and wouldn't be able to do what I'm doing here without the support. My next bone of contention is I've had HTBS services or day services. I have one still involved with those services. I've had one that's sort of graduated, and I had initially felt the Cedar Centers would be a great idea, really good idea to have a clearinghouse for people not quite as savvy at maneuvering the system, to have one stop shopping. I've come to rue the day we're wasting our money on CEDARR centers instead of the services they're supposed to provide. My son is with Down Syndrome. If he was as big as he should be, he'd be in Bradley, so, it's still like a toddler. I was persuaded through the agency I work with to go ahead and start the HTBS services because I know we're going to be up against the wall when he does grow, or hits puberty. Much to my chagrin, the whole idea of going through CEDARR centers when I've already been with an agency for years and years and years was, would put me off for several years to do that. Why go and tell all my business to strangers to put him out to an agency when I'm already well known to an agency, seemed insane, no grand fathering clause in there. I did go, partially, through the intake process to have my insurance bill for the intake process to be told they're not doing intakes because the waiting list is too long. So why they even started the procedure, and this was the Hasbro center. So I assume they see quite a few people -- why they even started the process. When I saw it showing up on my insurance bill, I am obviously complaining about that, but why they would start that process when they're putting a hold on intakes. They said the waiting list was over five years, so why pay intake counselors a salary if we cannot pay for services. So the whole thing seems like it's now another agency where we're paying a zillion people's salaries and there's no money for respite. He qualifies, obviously, but there's no dollars, and he has the G tube. I could give you all sorts of insight about how to do the little umbrella that the MHRH people try and delegate to not pay an R.N. to do respite, but that's a bigger ball of wax. But, those are my two. I could talk about diapers and not being able to go to Walmart, but I've talked about that for years and it seems to be a hard place to get, so those are my two big things, the Cedar centers are driving me crazy, because they seem to be not providing the services that they're supposed to be there for. That money should be spent on families.

CAROL NEESO: I can absolutely second. I have almost an identical procedure with the Cedar center. I'm on a three-year waiting list and we went to the CEDARR center two years ago to be put -- my son is already , so, by the time it comes up --

DEB HARBIN: Which CEDARR --

CAROL NEESO:: Hasbro.

JEANNE BEHIE: I would try the others because I haven't heard five years. What we've heard is two years for the other ones.

DEB HARBIN: I will just say, when you have a family, especially a family who doesn't have a lot of expertise or even education, being faced with the idea of having strangers come into the house and help you with your child who you're supposed to be able to raise by yourself, and you build up the gumption to go to strangers and put our your personal history, and you're asking for help, I can't handle this child, a two year waiting list is too long because they've already reached the place they need help. People don't come proactively. You don't get it if you haven't been -- families wait until the last minute, until they really feel that they're up against the wall. So, even a two-year waiting list is ridiculous. Probably thinking about hospitalization at some point -- puberty, I can only imagine. So, even two years is ridiculous. I could try, but I wonder if my insurance would pay for two intakes in a short amount of time. That would be interesting to see if that goes through.

ROSEMARIE COFFEY: Thank you for bringing those issues up.

JEANNE BEHIE: You came late, but I do want to say, I work for families with emotional / behavioral issues and Down Syndrome is actually, is in that category, and we do not have a waiting list like that. There is no cost to our services and if you want to speak with me afterwards, I can talk to you about that.

DEB HARBIN: I would be happy to do that, thank you.

ELAINA GOLDSTEIN: Do you work for family voices?

LAURA JONES: Family voices is one of the programs within our –

ELAINA GOLDSTEIN: I don't know if you know about RIPIN?

LAURA JONES: One of the projects I work with at RIPIN is, it's called the pediatric practice, what we're doing is, we have consults across the state and the ones around in this South County pediatric group and Wood River, they work with the families who have kids with special health care needs, and really, it could be any family, in helping them navigate systems and getting resources they need. So, that's another thing is, you know, if you like to have pediatric practice that has parent consultants in it, you can do that, or call RIPIN, and they will help you with some of that. But as far as, you know, the waiting list, I think even if you went to another Cedar center, I don't think it would matter because you're still on the same list for the agency that's going to provide the HBTS. So, I mean, you could go to other HBTS and go on a different list, but usually, I think, don't they put you on all the lists?

DEB HARBIN: I've been involved for years and I can't imagine, by sending staff to my house for other kids, they're the ones nagging me to go to the intake.

JEANNE BEHIE: But they can't expedite the process.

LAURA JONES: I don't know if I'm allowed to have something be on the transcripts? I had a family member who recently came to me who had moved into town, had had their child put on an HBTS list.

ELAINE GOLDSTEIN: Just for anybody who doesn't –

LAURA JONES: Home Based Therapeutic Services. And this family member just this week called me in a panic because she said that her child had been on the list to get HBTS services and she got a phone call saying that because her child was turning five, now her child had to be, and her child was like, had been on there for two years, because her child was turning five and she was like fifth on the list, now they told her that she had to go on a different list because he had aged out of the first list, and now he had to go to the bottom of the list, which does not make any sense to me.

ELAINE GOLDSTEIN: Which -- is this an agency?

LAURA JONES: Perspectives. So I don't -- understand, if a child, they knew that child might age out and not come to the top of the list, that they didn't put him on the other list, as well, or the people aging out of the first list aren't given priority and moved to the top of the list. But this parent was told, no, you have to be put on the bottom of the list now. This child is autistic and she had moved here from California and was getting, you know, a lot of services there, and was not able to get this, and hasn't for two years. If you know anything about autism, it's, the earlier that you get the services, the better. And the longer you wait, the harder it is.

ELAINE GOLDSTEIN: Part of the early intervention program?

LAURA JONES: No.

DIANE HELEN: I have the same as I go around and round with my sister, talking to Woonsocket, they have you call back and they can't help because they only do elder things, so she doesn't qualify, so these arbitrary age things don't help anybody.

LAURA JONES: Another thing with the HBTS that, you know, some of it is lack of funds, but a lot of it is lack of personnel. What I don't understand is why couldn't we have like a certificate program like they have for nurses or paraprofessionals in a school that someone could do this as a career and they would get a certificate that would have them become, either they could be certified to be a respite worker, Home Base Therapeutic Service worker, and we could have something through, like CCRI, where we could then train folks to have this as a career so that we aren't just, you know, constantly saying, we just don't have the personnel.

JEANNE BEHIE: A number of years ago, I was on a committee that brought that up, too, and I don't think anything has been done. But that same suggestion was made a number of years ago when

personnel shortages were so evident. And even if they trained respite providers, there's no money for that.

LAURA JONES: I'm actually sitting on a respite Committee, and they are looking for funding for respite, it hasn't happened yet, but it is being discussed. They're getting closer. Because it is such a need for families.

DEB HARBIN: Let me add, too, you have to use an R.N., but I don't need an R. N. for daily services, so, and I have to tell you, for years I've used the same R.N. who can't do it, so now **Health Care** I don't have a person who knows her who can do the services, but the staff I have in my house are totally qualified. They've known her for years but because they're not an R.N., they can't get respite money for the same things they get the money from for her day services. And that's insane because you, the state spends so much money for those hours for R.N.s when you could get so much cheaper, and I'd feel better about the people she's staying with because I don't want to send her out with a stranger. It seems kind of a little insane that just because the money come from this pot, I mean, it all comes from the same pot, but the regulations from respite requires an R.N., and they don't for day services. It just seems to be really a waist of money.

ELAINA GOLDSTEIN: Anybody else? Three more minutes.

DIANE HELEN: This pertains to the state bureaucracy giving me the runaround. When I wanted to file a lament against the nursing home, they said they would have a team there within three days and get back to me. Three days came and went. I eventually got a helper saying they had so many complaints that it would take many months to investigate. Now I'm asking for a history on this one nursing home, which, to me, you should hit one button because it's the state's job to monitor these things. Well, they're trying to say they need to charge me a hundred bucks for a report on the deficiencies and fines given. So, that's part of the state bureaucracy.

ELAINA GOLDSTEIN: That's the Department of Health.

DIANE HELEN: They're the champion at giving me the runaround.

ELAINA GOLDSTEIN: I'm exhausted just hearing everything.

DIANE HELEN: One comment in response to your children, as a Registered Nurse, I did a lot of home care with the birth to three population, and I have such great respect for you folks dealing with this day-to-day because it is an enormous task to be taken. The task of keeping these individuals at home. I'm appalled and sorry you're going through that because it would seem that we should have been watching this all along, knowing what services we had in place for little children and being prepared for what happened to those individuals as they got older.

DEB HARBIN: I do think that's why the legislation had passed on managed care for adults with disabilities because there is a disparity system for children with disabilities and then when you hit a certain age, a lot of services that you had, because you were a certain age, you no longer have, and that, I think, the issue is that because our health care system has gotten so much better, a lot of these children, you know, are surviving and making it, and I think, I hear what you're saying, we have not really kept the supportive services. And to tell you the truth, people are telling me that there's adult, there's pediatric doctors that will take care of kids with disabilities, but there aren't the specialists when they get older. So I've heard that a lot of people that could be / are still going to their pediatrician.

DIANE HELEN: My daughter's pediatrician said she wouldn't kick her out, she's .

ELAINA GOLDSTEIN: As I said, having coming here and giving the testimony -- when you came in, that's what we were saying. This gentleman asked, what happens next, is that all of us here have been able to make use of a lot of what we hear are problems, because if you don't hear of the problem, you can't make the change to the problem. So, we want to thank you very much for coming twice. Thank you very much, and the issue, I mean, with Cedars, again, when you hear it multiple times, it will definitely be one that gets highlighted in the transcripts. So, thank you all for coming.

Thursday July 27, 2006, Warwick Public Library

SUSAN SHAPIRO: Folks, good afternoon, everybody. We are waiting for a microphone because some people may not be able to project and I want to make sure that we hear everything that is said. So if you can bear with us for another minute or two and we will start the forum, okay? I can probably start with some of the housekeeping rules. Bathrooms, important things; out this door to your right. They are right on the right. If you would like coffee or something to drink, there is a snack bar. If you go out the doors again, it's to your left, right before the exit of the building. All right, folks. Good afternoon.

I am Susan Shapiro, I am with the -- can everybody hear me okay? I am a member of the board of Ocean State Center for Independent Living and I am pitch hitting for Lorna Ricci, who could not be here today. We are here today to talk about issues that are important to us. And I just want to explain a few things so that you understand how the forum is going to work. We are here to listen to what you folks all have to say. If you are interested in speaking today, I would ask that if you haven't already checked off your name on the list or if you haven't signed in to make sure that you do because that's how we will be recognizing people to speak. When your name is called, I would ask that you come up to the front, if you can. If it's a problem, just let me know and I will give you the hi sign and I will bring the mike to you. We have a panel here and they represent a number of different agencies and organizations. Their role here is predominantly to listen. And if there is a point of clarification, they may also meet with you afterwards. If you have something you would like to speak with them specifically about, they may have information to share with you. So we will make arrangements for that. We must be out of this room by 6:30. So we are going to have to stay to a tight schedule. So I appreciate folks' cooperation on that. If any of you have cell phones, I would greatly appreciate it if you would turn them off so they don't ring in the middle of our event. I am going to ask the members of the panel to introduce themselves to you so you will know who is represented here. And I would ask that they identify themselves by name, by their agency, and the city and town that they represent. So, if you could start, John.

JOHN TOLENTO: Yes. Stand up? My name is John Tolento and I represent the Commission on the Deaf and Hard of Hearing for the state of Rhode Island. That's predominantly why I am here. I got an e-mail yesterday that Steve, our director, would not be able to come. And he sort of thought that since I lived the closest I would be the best substitute. So that's why I'm here. Thank you. (LAUGHING).

KATHLEEN BURRELL: I am Kathleen Burrell from the Office of Rehabilitation Services and we provide services throughout the whole state.

RORY CARMODY: I work at Cranston Arc as a rehabilitation counselor coordinator specialist and serve as a commissioner on the Governor's Commission on Disabilities.

SUSAN SHAPIRO: Can everybody hear that?

KEALLY DEWITT: Good evening. My name is Keally DeWitt and I work with the Rhodes to Independence which operates out of the URI College of Pharmacy. And we look at how systems in the state of Rhode Island can be improved to support people of disabilities transitioning to work.

LINDA MCMULLEN: My name is Linda McMullen and I am here from the Department of Health and we are here representing everyone in the State of Rhode Island.

DIANE KAYALA: I am Diane Kayala with the Department of Human Services. I work in the Medicaid office for adults and I'm here representing Medicaid office.

SHARON BRINKWORTH: I am Sharon Brinkworth, director of the Brain Injury Association of Rhode Island and so therefore we represent the whole state. And also I serve as a commissioner on the Governor's Commission on Disabilities.

SUSAN SHAPIRO: Thank you. There are assistive listening devices if anybody needs those. If you do, please see someone in the back of the room. We have interpreters for the Deaf here with us and we also have CART to help. If you have other needs, please let somebody in the back of the room know. We will try to accommodate that, if we can. As I mentioned earlier, the purpose of this forum is to identify the concerns of people with disabilities, and in order to assist the state to develop programs, to improve the quality of life for people with disabilities. What happens is that all of the testimony that you folks

give is recorded, put together, and reviewed for need in terms of legislation program needs. And last year, quite a bit of legislation resulted from it. I don't have that list with me. I thought I did.

LINDA MCMULLEN: Right here.

SUSAN SHAPIRO: Thank you. Last year there were a couple things. Mandated benefits in insurance for infertility treatment under the neighborhoods opportunity program. There was a bond issue for support of housing programs for people with disabilities. And a fund for a neighborhood opportunities program. There was also a bill related to traumatic brain injuries in regard to adjudication of traffic offenses. And there was also a bill to prohibit parking upon the cross patch of the parking spaces, the handicapped parking spaces, because people were parking in those. So all of those resulted from the things that were heard last year. In addition, programs made some modifications to the way in which they are providing services and looked at the way in which they address the various populations of people with disabilities. So what you say today is important. It will be heard by many people besides those in this room. And it will be studied. And where appropriate, it will result in some kind of an action. Because we have a large number of people here today and a number of people that want to speak, I'm going to ask folks to stay to a specific time limit. I'm going to allow folks who want to speak to talk for five minutes and I will give you kind of a sign to wrap it up. I don't do it -- don't take it personally. It's a way to keep this going. If we find that we have time at the end, there will be another opportunity to raise other issues. So people will be afforded an opportunity to speak again, if time allows. But please try to stay with that five-minute time span. The other thing to keep in mind too is that if you have written testimony or you want to submit testimony afterwards, you can do so and you can send that to the Governor's Commission on Disabilities. And if you like, we can give you that address after the event. Any questions about what's going to happen here today?

RORY CARMODY: Sue, voter registration.

SUSAN SHAPIRO: Voter registration forms are available in the back of the room. I believe the deadline is August 11 for the primary. If somebody isn't registered to vote and would like to register to vote, those forms in the back of the room as well as some other material you may be interested in. Feel free to take any of those materials that are back there. To make sure I did all of the stuff I do -- after the forums, the transcript will be available at the 11 governor's commission website. And that website is www.gcd.state.ri.us. It should be up there in about a week. Later this summer the agencies will be reviewing testimony, as I said before, and preparing recommendations that will be forwarded to state Congressional officials and to the members of the general assembly. The recommendations will then be used to develop policy and legislative initiatives for the next year or until they are accomplished.

AUDIENCE MEMBER: Is there any other way to get the testimony? I'm probably the only person on the face of the earth that doesn't have their own computer.

SUSAN SHAPIRO: That's fine. If you don't -- you don't have to -- you can do it in writing and mail it. Okay?

AUDIENCE MEMBER: No. I mean to get the testimony heard today.

RORY CARMODY: You can request a copy in print --

SUSAN SHAPIRO: -- by calling up the Governor's Commission. So everyone will be given an opportunity to speak. The panel members here, as I mentioned earlier, are here to listen. And we will just keep this meeting going. So I'm going to start right now with the first speaker. And ask that Maureen Tanguay. Again I remind you, your name, agency if you are representing an agency, and your city or town.

MAUREEN TANGUAY: Hi. My name is Maureen Tanguay. I am from Coventry. I don't represent a state agency or other. Sorry for being nervous. I didn't know I would be called first. Back in 2000, I had to start receiving disability. My disabilities are hidden, many of them are hidden. Prior to that, I was taking care of Ronald, who is behind me, who is in a wheelchair. We both sort of reside together. We have separate apartments. We are in the same house so we can keep an eye on each other. However, it's sort of become a nightmare for us. Nobody knows that I have disabilities and obviously everybody knows that he has disabilities. We don't know -- we don't know why the agencies behave why they do rather than come in to -- they are supposed to be helping. He is in great

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need of a bathroom . And the agency did come in -- an agency, I don't want to name the agency. An agency did come in. And they're putting in what they want and what they said they had funds for. This does not matter that about a year to two years down the road that he is going to have to request this all over again and wait another five years possibly for another bathroom. What he does beyond that, I don't know. Within a year to two years, maybe even three, if God is with him, he will not be able to get into his shower. One inch. That's all it has to go down is one inch or a new one put in. And they will not do that because of money. Now let me tell you that the money was there and it was for a kitchen so that Ron could access the kitchen. Ron does not use the kitchen. I use the kitchen and it had to comply to my disabilities. But because I was not the one that applied for this, then the money got thrown out and left just for the bathroom. I don't know where the justice is in it. I don't know what he is expected to do in a year to two years. I just noticed today there was a certain thing that he was unable to reach because little by little his arm reach just isn't there. And it goes gradually by the day. I just -- I don't know where to turn to, what to do. I've been his spokesperson for as long as I can be. When we saw the notice for this meeting, it's like we've got to go because we need help some place. We just don't know what to do after this bathroom is done . I also would like to know is -- when a federal agency is doing rehabilitation in your home for accessibility, handicapped accessibility, are they required to put in handicapped materials? I should -- should the floor be handicap -- should the shower be handicapped accessibility? Every dollar that they put in there, should it be handicapped accessible because they are using federal funds? Should everything be handicapped accessible instead of being replaced? Because what they are doing right now is they are taking this same shower out. They are replacing it. Hopefully it doesn't break because we don't know who is going to get stuck with that bill if the shower breaks when they pull it out. They are putting it back in. He has a vinyl floor now. They are putting a vinyl floor back in. I already had to have neighbors come over twice because he has slipped coming out of the shower. He has slipped on the floor and his doctor has said -- Dr. Parker has said, "Absolutely do not touch him if he falls because you can break every bone in his body. Call 911." My concerns -- like I said, my handicaps are hidden. I can get by. And my concerns are for him because I see what's going on. I know what's going on. My concerns are for everybody in this room because I want to touch about one other thing and it's handicapped parking, which might be a minor thing to a lot of people. But myself, to all of us in this room, I bet we could go to Rhode Island mall right now and not find enough parking for all of us that have disabilities in this room. And I think that's shameful for the disabled. Thank you.

SUSAN SHAPIRO: Thank you, Maureen. Ron -- is it Ylitalo? Okay, thank you. Gary Brandberry?

GARY BANDBERRY: Hi. My name is Gary Bandberry. I am from Wakefield, Rhode Island. I recently **Transportation** stopped being able to drive using my feet and had to get hand controls in a new van that I purchased. . When we did that, we learned that the legal way to do this is to get trained and then go and get a new license. Part of being disabled is suffering with embarrassing moments. We all know that here in this room. It just goes with the territory. I had to get a driving instructor and learn how to drive with hand controls. She told me I need to surrender my license and apply for a new one with a restriction for hand controls. To do that, I had to go to control central, which is next to the ACI, and see a hearing officer to get an application for my doctor to sign. She warned me that it can be a difficult place to get through and advised me to bring her with me, which I did, at \$80 an hour. I entered the room which probably had 40 or 45 people sitting around waiting. I had to go by an armed guard to get into the room. When I went up to the counter, we told them why we were there and they told me to take a seat. My wife and the instructor were able to do that in the back of the room. And eventually, I navigated my wheelchair back to where they were before I had to stand up and get out of the way. The aisles were that thin. I'm sorry to say that this was the dregs of society that were in this building. When I say we were near the ACI, I felt like I was in the ACI. Everyone who had violated the law due to drunk driving, driving under drugs, too many accidents, too many tickets, et cetera, were there trying to get their driver's license back with their attorneys to try to plead their cases with officers. About 90 minutes went by at \$80 an hour when my name was called. We went to the hearing -- we went to the counter and told the hearings officer what we wanted. And he said, oh, you just need a form. He handed me the form and sent us on our way. I was humiliated. My wife was so

angry I could hardly even contain her. In Massachusetts and in Connecticut, they send you the form in the mail. My question is why are we treating the disabled like they've broken the law? A few weeks later, I got an appointment to go back to the same place and take my driving test. Again, an armed guard is at the door. The reason for the armed guard is because they've had fights break out in this mock ACI between people who are tired of waiting their turn and jumpy. I waited. I took my test, which took about maybe ten minutes. And now I have to see a hearings officer. I waited and was called in about 15 minutes. He took me back to his office where he informed me now I need to go to a regular DMV to get my license issued because they don't do that there. I see you smile. We were smiling too. Why are we singling people out who are disabled and making them jump through hoops just to be able to drive when I volunteered to do this. Should we drive with hand controls without getting a new license? There are many people in this state that are doing just that. If I was to go into a regular DMV in my wheelchair and get a license in my wheelchair, they would allow me to take the test, get my license, and truck right on out of there. They would never ask me if I'm driving in the chair or using my hands or feet. They would just rubber stamp you a license and send you on your way. So it appears as though we are rewarding those who don't abide by the law and punishing those who do. Something's backwards there. And I think it sounds like it's something that could be -- easily be fixed. Nothing special happened at the ACI. It didn't do anything in particular other than hand you a form the first day. And I took a driving test just like people do at regular DMVs every where. But for some reason we are singling out those who are handicapped and saying, well, now you have to go to this place, the only one place. And then when they are all done with you, they send you back to the regular DMV just like a regular person does to do exactly what they have to do. Something is wrong there. I think it needs to be fixed. Thank you.

SUSAN SHAPIRO: Thank you, Gary. Melony Hebert.

MELONY HEBERT: Hello. I am here regarding affordable disability housing. I called several places and they say there is a waiting list for section 8. But the section 8 list is closed. I expressed I am handicapped. I need a first floor apartment. I can't afford it. My -- is \$1001. I pay \$800 in rent, not including gas. I get food stamps for a family of three. I talked to some people about different agencies. And they say there are programs for people who are reformed prostitutes, reformed this, reformed that. And I say to them, that's their choice of lifestyle. I was born the way I am and I have no choice. If did all what I listed above, maybe I would have somewhere to live. Maybe I would be able to afford a little extra. And they say, sorry. We can't help you. It's closed. I finally get into Cumberland list for section 8. And I was 200 when I first applied. Then they put me at 100 so I would say progress. Within a year I went up 100. When I get my list, I'm 30. The following year, I get the list. I'm back to 200 something. So I was very upset and asked them how come? They said, you do not live and you do not work in Cumberland. I said no, I can't work. I'm physically disabled and I don't live anywhere because at this point I'm homeless. You know, thanks to my parents, I got back on my feet with my own apartment but the same situation. How do you afford it? Then you get Social Security and that income is coming in. And time gets tough. You need 26 to pay the gas bill or electric bill. And you make a few dollars to make ends meet and they whack you. They take half the money away for taxes. Then you are done paying your taxes. At that point it was union fees and union dues. I was walking away with \$25 working 35 hours a week, which I couldn't handle. My hip collapsed. The doctor says, you can't do that kind of stuff. I say, well, you have to lead somewhere. And I have no options. I'm homeless now. My kids are living with my parents and I have nothing. I have to sleep out in my car at night because if I live with my parents, they will kick the parents out of their house. I have gone to several agencies. I have been to several programs and it seems like nothing works or it takes -- see you next month. See you next month. Where do I eat and sleep the next few months, you know. Why are my parents, who are retired, you know, their food and their income. It's limited to begin with. And not see my kids because I can't sleep there. I have find elsewhere to sleep, go to a shelter by 7:00. Right now I work -- I don't get out until 9:30. That's not an option. I don't feel people who are disabled should have to go in shelters. Those are for people who are drug addicts and prostitutes, not your own person who has no ability to control their circumstances besides people who do control their circumstances. Thank you. That's all I had to say.

SUSAN SHAPIRO: Thank you. Pam Costello?

PAM COSTELLO: Thank you. Hi. My name is Pam Costello from North Kingstown, Rhode Island.

Health Care

And I am here to help support the need for additional slots concerning the habilitation home and community based services program, also known as the habilitation waiver, and to speak on how this helped my family. It's always very devastating that you or a loved one has sustained traumatic brain injury due to an injury or disease. For my family, it was my son Jason who received a severe traumatic brain injury when he was involved in an automobile accident nine and a half years ago at the age of 22. The doctors gave Jay less than one percent chance to survive. If he did, he would remain in a vegetative state. Jason's injuries left him in a coma for three and a half months. Throughout I never wavered from the belief that being home was the key to Jason's continued recovery. I believe that home provides the family smells, activity, and family that cannot be experienced in a state facility. The choice to care for Jason at home was easy. But the act of caring for Jason was difficult and it quickly became apparent that my husband and I could not do this alone. We definitely needed help. As I started the search for help, I learned that because Jason was injured at 22, funding sources are very limited. And throughout, through persistence and a chance connection with PARI, he was accepted on the habilitation waiver. With this waiver, we were able to get personal care assistants for Jason, which truly made a difference. We both were able to keep up with our full time jobs, our home, and Jason's rehabilitation. And Jason was able to relearn how to walk, communicate, eat, dress himself, bathe, all with the help of constant cueing and direction. This couldn't have happened without the help of the waiver. I know that we are not the only family who has been faced with this devastating reality. This brain traumatic injury will not be the last. It could happen to any of us at any time. The habilitation waiver not only needs to continue, but there is need to accommodate for additional families and individuals who will have no other choice but to go to a state facility without the support of the habilitation waiver provides. Thanks.

SUSAN SHAPIRO: Thanks, Pam.

AUDIENCE MEMBER: Short and sweet.

SUSAN SHAPIRO: Bonnie Abols.

BONNIE ABOLS: Good afternoon. My name is Bonnie Abols. I hope you can hear me. I cannot hear

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my own voice, but I am glad you can hear me. Okay. I work for Ocean State Center for Independent Living. I am the independent living specialist. I work for people who are Deaf and Hard of Hearing. The problem I have encountered, many, many times when people have problems with the police. I have an emergency card. That card is for accessible for communication only. But it's really worthwhile to have it. But the only problem that is when a person goes into a police station and the police officers say, please empty your pockets; means his wallet, his money, everything. But the problem is this card is in his wallet and he needs someone to tell him I need an interpreter to communicate with in sign language. But the police often ignore the problems. They don't care. You take your position. In jail overnight and you get this back in the morning. I don't think that is right. Because every consumer I work with has a right to have an interpreter for communication access, accessibility. It really is a problem. Many times that happens with the police people organization. They do not understand how this works. We did train these people and say this card is for only people to use if they show the police. Read this. It's for legal -- it could be anything -- medical reason. But I feel the police people, all the state of Rhode Island should be trained. I hope this will be solved very soon because I'm tired of it, people calling me for problems going to the police station. Come to the court. It's so hard for me to advocate for these people. But really, this works. But the police don't work. Thank you very much.

SUSAN SHAPIRO: Thank you, Bonnie. Norma Lovegreen.

NORMA LOVEGREEN: Hi. Excuse my back.

SUSAN SHAPIRO: It's a strange set up.

NORMA LOVEGREEN: Yes, it is. I -- my whole family has mental illness. I have a major mental illness. I have a seizure disorder. I have had two strokes. I have been homeless. My mother has dementia. And it's hereditary. The Medicaid billing all the time is going down. People are paying much

more for the medication than they can afford. I hear people all the time saying that I don't know if I can have enough money to eat until the rest of the month. My friends worry about their medication and how long it's going to last; that all these things are going to keep happening. We are paying more and more. The place that I go for services is Hillsgrove House in the Kent Center. I come from West Warwick, Rhode Island. I'm 56 years old and I struggled all my life. And I'm really tired of struggling. I'm really tired of not having the ends meet. And it's getting worse and worse. When it comes down, I have diabetes. If I don't have food, I'm in real trouble. The only one in recovery is myself and my sister. So I've suffered all my life with my illness. And I'm just tired of struggling. Thank you very much.

SUSAN SHAPIRO: Thank you, Norma. Lorraine Botts.

LORRAINE BOTTS: I have a member -- I'm a member of the MS support group out of Seekonk YMCA there. We have a member, Nancy Ryan, from Rumford, Rhode Island, who used to come to our meeting. She is totally disabled. And the happiness wagon, I think it is, used to pick her up. They lost their funding. They can't afford it because of the gas prices so now she's house bound. She can't come to our meetings. And I believe RIDE doesn't leave Rhode Island. I think they stay in Rhode Island so she can't even get to where we are right over the border. And another thing is too, she can't get to her doctor in Massachusetts unless her husband takes the day off of work to take her. That's all I wanted to say. And I know she's not the only one that is probably having that problem. There's probably a lot of people with disabilities that can't get out. They can't get their -- she can get to Florida by airplane but she can't get from Rumford to Seekonk.

SUSAN SHAPIRO: Thank you. Tina Abrams. Is Tina not here? Oh, she's coming. Okay. Take your time. Would it be easier if I come to you? Why don't I do that then.

TINA ABRAMS: Hi. I am Tina Abrams and I live in Rehoboth, Massachusetts. I am the one that needs **Transportation** the MS meetings in the Seekonk YMCA. We have a problem because we live in Massachusetts. Central Massachusetts MS society says that we belong to them. But when they have all these programs, the programs are so far away. And most of the people that are in my group are either from Seekonk, Rumford, East Providence, Warwick. So because we are right on the line, it has made it so difficult. Most of the time I do work with -- Cathy mentioned from the Rhode Island society. And we have one man who lives off Blackstone Boulevard who always came faithfully. He was a professor at Brown University. Now that he has lost his wife, he can't drive any more. But he still wants to come to the meetings and there is no way that he can come from Blackstone Boulevard to Seekonk. The map is a straight line. But coming from his house, he would probably have to go downtown Providence and then take the Taunton bus or whatever. But it's a difficult situation when you are living right on the state line and don't know who you belong to. Thank you.

SUSAN SHAPIRO: Thank you, Tina. Cathy Podgurski.

CATHY PODGURSKI: Hi. I have a problem -- kind of the same one I had last year. I'm still looking for -- my name is Cathy. My last name is P-O-D-G-U-R-S-K-I. I am from West Warwick. And I can -- like I said, I'm still looking for Medicare to fund a new wheelchair. The problem is I know I can get around all the time in a manual chair. But I don't need a fully automatic chair all the time. I want a power assist

Health Care chair and that costs more money so, even though it makes me more independent, Medicare doesn't want to pay for it. I've gotten a letter held from PARI, which is People Actively Reaching Independence. But it's been a very uncomfortable. Everything hurts. The only time I am comfortable is when I am laying down and I'm not going to be laying down all the time. It's just not me. So, until -- PARI has tried it. I -- people have told me you need a new wheelchair. I say, I know. They say, why don't you get one? And I say I feel like saying, oh, all right. I will just go to the bank and set \$600 out of my millions in the bank and I will buy myself a wheelchair. But that's not going to happen either. But I don't know. I'm just so uncomfortable in this thing. I'm so frustrated right now.

Transportation I do have a positive thing to say about the RIDE program. I go every where on RIDE and the drivers are terrific. The people who make the reservations, he gets them wrong every once in a while. They're like -- but that happens every where. But without them, I wouldn't be here today. So, that's one positive thing I have to say about them. That's it.

SUSAN SHAPIRO: Thank you, Cathy.

CATHY PODGURSKI: You are welcome.

SUSAN SHAPIRO: If there's anybody here who wants to speak and hasn't already signed up, please let the folks in the back know. The next person is Michael Sicard.

MICHAEL SICARD: S-I-C-A-R-D. My name is Mike Sicard. I am with the support group in Woonsocket. And I'm also the vice president of the Manic Depressive and Depressive Situation. I live with bipolar disorder myself. And the reason I'm testifying today is because of Medicaid co-payments and the proposed preferred drug list. People living on supplemental security income make approximately \$600 a month. A third of that, if they are lucky enough to live in disabled housing, goes towards their rent, leaving them with approximately \$400 a month to live with. Co-payments of \$3 for brand names and \$1 for generics might sound like a small amount to most people. But to someone with \$400 a month spending money, it's a lot of money. These people quite honestly at the end of the month, a lot of times don't even know where they are going to get the money to eat. What will probably happen with the preferred drug list is that the cheaper medications are probably all that is going to be allowed. I was promised at one time psychotropic medications were not going to be included in the PDL. But from what I have seen, they are not harboring that out now. With this happening, people who have psychiatric illness, basically one medication doesn't fit all diagnosis. I myself have changed medications on several occasions because they -- medications have stopped working. My depression put me out of work in 2000. I'm just lucky enough now to start working again as a peer advocate and it's only part-time. What I'm afraid of is that people are not going to be able to afford the medications or not get the medications that are going to keep them stable. What will happen then is in the front end you probably save money on Medicaid. But in the long-term, it's going to cost a lot because these same people are going to end up in emergency rooms, long-term hospital stays, possibly prison, and ultimately there will be suicides in the course of the life. You can't put a price on that. And I'm really afraid that people are going to have to try to make the decision, am I going to eat this month or am I going to take my meds? That's a tough, tough position to put someone in. Thank you.

SUSAN SHAPIRO: Thank you, Mike. Fredericka.

FREDERICKA ATHANAS: Good afternoon. My name is Fredericka Athanas. I am a member of the national federation of the blind, Rhode Island Ocean State center for independent living, and ATAP with the RIPTA board. And Leah is my girlfriend and she is going to read my testimony.

LEAH for Fredericka Athanas: Good afternoon. My name is Fredericka Athanas. I stand here today to publicly thank all the family, friends, agencies, and organizations who listened to me speak in the two previous forums sponsored by the Governor's Commission on Disabilities. I really need to thank everyone for taking my private concerns seriously enough to have a new law signed by Governor Carcieri on June 20, 2006. This is entitled an act relating to criminal offenses, assaults, protective services programs for severely impaired persons. Before this law was signed, there was no reporting agency for people with disabilities between the ages of 21 through 65. Prior to 21 years of age, there is the department of youth and families. For those over 65 years of age, there is the department of elderly affairs. My goal was to put into place a reporting agency for people with disabilities so no one after me - - I'm sorry -- so no one after me has to suffer the emotional, mental, financial, and humiliating abuse I suffered from. But I am a strong survivor and I am willing to do any work that needs to be done to get this agency up and operational. So without any further ado, I would like to thank Governor Donald Carcieri, Attorney General Patrick Lynch, Representative Eileen Naughton sponsor of the house bill; Michael McCaffery sponsor of the senate bill; Bob Cooper, Governor's Commission on Disabilities; The National Federation of the Blind in Rhode Island; The wonderful staff at the Ocean State Center for Independent Living, SHICA -- Insight and last not Terry and my Thursday girls; wink, wink. Thank you.

SUSAN SHAPIRO: Thank you. I guess that's testimony to say these forums really do bring things to the forefront. Thanks. Shelley Green.

SHELLEY GREEN: Hello. My name is Shelley Green. I am the mother, sister -- first sister, mother, ex-wife of a brain injured survivor, all from unrelated at birth injuries or accidents. I am here to ask for

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support for the bill that bill S 2604 sub A and H 6544 sub A. They were passed in the General Assembly in last segment hundred session. It's -- excuse me -- is on 7706. These bills were based on portions of the bills introduced in 2005 that would have established a restrictive receipt for the trust fund for traumatic brain injuries. That legislation did not pass. And the General Assembly, however, designed a line item for \$250,000 in the Department of Human Service. We are asking money be allowed to be presented for the administrative cost in this bill, although it hadn't passed. The \$250,000 that had passed, there's no -- these ten percent needs to be accountable for legislation -- excuse me -- for administrative fees. And we are asking that that be put forward.

Health Care & Housing

The other thing is my son right now is living in elderly handicapped housing and there are so few services out there. It's a horrendous situation when you are in this position as the other mother -- is it Pam? Who testified when your child comes home. My son is a Gulf War veteran. If it wasn't for the fact he was a veteran, he would not have received any services beyond rehabilitation. And at that point, you are only a mother. Although I took him home a year later at 22 in a wheelchair and diapers and brought him back with the supports of many services, including hospital, Sargent's Rehabilitation Center, and the VA hospital, once they get to a point of walking and talking, it's over in many situations. And there's a multitude of problems, physical, mental disability, delusional behavior, impaired judgment. It's not a situation that you can handle by yourself. My son would get up in the middle of the night and I could find him walking down the middle of the road. And you cannot restrain somebody by chaining them to a chair, nor would I want to. But the supportive services are so important to be in place, as all of our services that we are asking for are important to be in place. But when the person has a physical disability and a mental disability, they are really vulnerable. And they need the support of our society and of our government. Also with these supports, you really can help reduce some of the cost by providing basic needs. Then you don't have people either homeless, living in prisons, or in institutions where they don't need to be. The other -- the program I'm talking about is the -- I can't even say it -- say it for me, Sharon -- what do you call it --

SHARON BRINKWORTH: Habilitation home

SHELLEY GREEN: Community based service program. That is a program that's down in Charlestown. I believe it's for people ages 22 to 65. And there's no funding for that. It didn't make legislation. There is no funding for that. It would have been -- if it had been passed, there would be have been a number of people that would have been able to be in that housing. Because it was denied because of time restraints they are homeless. Thank you.

SUSAN SHAPIRO: Susan Herd.

SUSAN HERD: Hi. My name is Susan Herd, and I have multiple hidden disabilities. My biggest concerns deals with -- I felt completely disabled in 1994 with chronic neurological Lyme disease, which weakens my immune and nervous systems. This created severe, potentially life threatening allergies and chemical sensitivities. And I am now disabled with multiple chemical sensitivities, also known as MCS.

Accessibility

I have been very fortunate that despite all my challenges, I have been able to somehow, with a lot of angels, to be able to move forward. And I now have -- as of recently my Masters Degree from Salve Regina in holistic mental health counseling and I have received services. It's been a big challenge. All of my rooms have had to be kept fragrance free and also peanut free. I have a severe life threatening allergy to peanuts. And that's -- where even minute traces of fumes or I come in contact with can trigger severe and collapse reactions. I also can have serious allergic reactions or sensitivities to many fragrances and common chemicals that are used in common building materials. A lot of these things could be easily remedied and give more accessibility not only for me but for the 2 percent of the population that is dealing with MCS. And the 2 percent of the population that's dealing with serious peanut and nut allergies. Having more awareness and refraining from foods. Just when I walked into the library, automatically there was a cafe. And immediately I held my breath as I walked by because I don't know if there could have been nut poppies or some kind of nut product wafting in the air. I have to do that walking down my street as well. Because if I pass a Chinese restaurant that is cooking with peanut oil, I am in the ER. When I go to the ER, in the waiting room, there are peanut butter snacks in the vending machines. And when you go into the exam room for

treatment, peanut butter crackers are there being served to other patients. And the medical staff, doctors and nurses often will have a jar of peanuts sitting on their medical station, grabbing handfuls as they go from room to room. Of course, with me just getting a whiff of even something like an M % M candy peanut can cause an allergic reaction or if I just get touched. They don't belong in emergency rooms or hospitals. And they are being removed from schools because of this serious -- there has been a lot of awareness happening with airlines because of this. I think that it needs to be taken into serious consideration as far as with chemical sensitivities. Even a room like this is hard for many people with MCS to be in because of the newer building materials, the carpeting, the sealed windows. And simple things making a room more green, using low VOC building materials, VOCs include things like formaldehyde, Benzene, acetate. By having no or low VOC paints in carpets, using sealants could make a room much more accessible for not only me but others. Using better air filtration systems. Many public buildings including -- I don't know if it's in this library or not -- but the bathrooms will have air fresheners. Air fresheners don't do anything with sanitizing the air. The air fresheners are known to be neurotoxic and carcinogenic. And they trigger not only reactions for me but for the 72 percent of the population of asthmatics who are triggered by fragrances. Many people get migraines triggered by fragrances. Fragrances are known to have 4,000 different ingredients. Many that are neurotoxic and carcinogenic. And they are all lumped under the very innocuous seeming word fragrance. Yet they are causing very real neurological problems 57 for myself and others. When I get triggered by something like an air freshener in the bathroom, which is not allowing me accessibility into a public building. But if I have to really use it, what am I supposed to do? I try to hold my breath. Put a scarf over my face and come out dizzy. I can have blurred vision. My muscles will weaken. I can be spaced out. It can cause poor coordination, making it difficult and not always very safe to drive. When I was going through my program at Salve Regina, some of the bathrooms had air fresheners, which they repeatedly tried to turn off. And someone would come back and turn them back on. It -- I'm a very intelligent person and -- but when I get exposed to fragrances, I have a lot of difficulty in retaining and learning. I despite that did beautifully in my program. And I'm proud to say I had a 3.71 GPA when I was given time accommodations. And people did honor me having no fragrances around. When I was in a building like a library or another place where there were fragrances, it can be different. It can trigger insomnia or fatigue. Right now I can't live in my own home. I live in a condo. And the condo association did not honor my request for low VOC water based stains to be used on the condo fences. I have not been able to live there in two months. I don't know when I will be able to live there. And of course, on my disability I'm low income. Try finding a place that will allow you at \$650 a month for rent. I need a separate dwelling. I can't use public laundry facilities because of the high fragrances used. I need to have filtered water, filtered air, out gas wood and floors and old out gas building materials. This is a common theme that goes on for people with chemical sensitivities. Ideally a small cottage or home is what I need to be renting. But try to find that on \$650 a month. That's all I'm allowed for rent. This -- I hear this repeatedly. Yet my rental exception is not honoring some kind of accommodation. There are many, many ways that MCS impacts a person that just are not well understood. So, I'm here today to bring a little bit awareness and hope that more consideration will be made in starting to have Rhode Island change. Rhode Island has been a leader over the years in being progressive and I hope that we can continue to be a leader. Massachusetts has already outlawed oil stains, California has outlawed oil stains. And supposedly Rhode Island is phasing out oil stains. Children's playground equipment. It's illegal to use oil stains. So, the -- using water based low VOC stains are what are used in children's playground equipments in other states like Massachusetts and California. So something like that needs to happen here, as well as with the other green accessibility things I mentioned. So thank you very much.

SUSAN SHAPIRO: Thank you. Is there anyone else here who would like to speak? Is there anybody that wishes to expand on what they have already said? You have a little bit of time left.

SUSAN HERD: I would. But right now I just can't face you because I've listened all night to many people -- all the people -- all the people in this room and my stomach is sick. I cannot -- it's very hard for me to hear what's happening in the State of Rhode Island. And what's happening to people in general. When I just listened to that lady talk about how difficult it is for her just to live in a house or in an

apartment. People that have a hard time getting food because they only get so much money a month. People that can't see. People that can't hear. Are we to let the people that have disabilities go without help? Should we increase it so much that no longer can they live a respectable life? It's just really hard to get through the day. And I hope the people in this room get the help that they need. And I'm not just thinking of myself. I'm just thinking of everybody that's in here. And all the people that help people like that, because it -- for my program or other people's programs, where would we be? I would be stuck home alone. I don't know where they would be. But I assume they would be in their homes by themselves getting worse, feeling really bad about themselves. And I just think it's so important that we have a sense of worth; that the state views us as every individual is important. And I just pray to God for this. Thank you.

SUSAN SHAPIRO: Thank you for those words and kind of summarizing what we've heard here. I know the panel has listened and will thoughtfully review all of these comments.

SUSAN HERD: Could I say a little bit?

SUSAN SHAPIRO: Sure.

AUDIENCE MEMBER: Again my name is Susan Herd, and I didn't want to take up too much time and hog what I have to say in case there were other people.

SUSAN SHAPIRO:: It's all right.

SUSAN HERD: I don't think I said that 30 percent of the population is now chemically sensitive. Maybe

Accessibility not with severe disabling full-blown MCS. And it is going up to 60 percent. So many of you may have some more mild chemical sensitivities. You may notice someone's fragrance or some other thing like when a new carpet comes in you get burning eyes or you start to get more wheezy or a bad headache. Those are all chemical sensitivities that are happening or skin rashes. So I would like you to be aware of that. That's a pretty big statistic; and that leading medical facilities right now are making green accommodations and fragrance free buildings. And just having things like fragrance free and safe areas could make a world a difference. Just like we have smoke free zones. Having just fragrance free zones or buildings. I had requested Salve Regina to make a safe room, study room for me to be in, which never really happened unfortunately. So, even things like using a computer in the library. If someone has perfume on their wrists, then when I touch the counter top or the computer, I get it on me. Or it will be on the keyboards and then I'm all spacey and loopy. Or if they came along and they ate peanut butter and then touched the keys. These are all kind of things to be more aware of with the fragrance. I'm now doing my clinical training in counseling other people with chronic health conditions at the Rhode Island Rehabilitation Hospital in the fibromialgia -- many people with fibromialgia have chemical sensitivities and food allergies. Many people I see are low income like myself and trying to find their way on a very small modest income. Common things that I'm hearing that are heart breaking are -- many people who receive \$800 or less a month are only getting \$10 in food stamps. Now one of the things the fibromialgia is promoting good nutrition. How can you get good nutrition on only \$10 a month and you are living on something between 4, 5, \$600 a month. It's very difficult for a person to do that. I have one woman who is choosing between toilet paper, toothpaste one week for her boys and herself. And again trying to find safe housing. She couldn't make it. Other people -- I see -- they can't afford drivers insurance and the expenses of driving. So they try to take buses. And I have one woman with the RIDE transportation program. One week they came 5 a.m. instead of 5 p.m. to pick her up. Other weeks they are running 45 minutes to an hour behind schedule so she misses her time that she needs for some counseling support. And this happens also with seeing her psychiatrist and doctors. She has missed appointments and it's crucial she gets to these places, which of course this creates more stress. For people dealing with autoimmune chronic health conditions, whether it's MCS, fibromialgia, MS, rheumatoid arthritis, Lupus or Lyme disease, it's crucial for them to reduce stress and chronic stresses and to eat healthfully. Of course, how can you reduce stress when you have so little money and the systems are not always working? Of course, this creates more inflammation. It weakens the immune systems of these people. And it creates more health problems in the long run. So, and as well as emotional, mental, secondary depression is common because of all the stress. So those are some other things I want you to take into consideration. And understanding why it's important that basics are

somehow found to be met for people living on low income with such serious chronic health conditions. Thank you very much.

SUSAN SHAPIRO: Thank you again, Susan. Okay. If there's nobody else who wishes to speak –

MELONY HEBERT: One more issue I would like to address, Melony Hebert. It's a standard deduction

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Department of Human Services. They have deduction down I pay \$300 a month. My standard deduction is \$800 for rent, and then they don't give me deduction for my utility bills. As I explained to them, Section 8 or affordable housing my electricity and my gas would be included. But seeing gas and electricity ain't included, they want to give me \$25 gas reduction. Not even my electric bill is \$25. And the gas bill is way -- obviously the prices today are over \$25. And I think the deduction should go according to the person's out pay and in pay instead of just a standard deduction because not everything for everybody is standard. Everyone pays a different amount for rent, different amount for income, and also bills. Some people heat and hot water is included. Some people is not. So that's just one issue that I would like to address also. Thank you.

SUSAN SHAPIRO: Thank you. And there was one other person who wanted to –

MAUREEN TANGUAY: Hi. My name is Maureen Tanguay. Disabilities, I think it's fair for me to say are on the rise. I don't know how else to say it. I don't remember when I went to school, I don't remember seeing wheelchairs. I don't remember seeing people with glasses. There was time -- some people with glasses in school. Sometimes would go behind the room and we would snicker. Now today it's a big thing. Oh, wow. You got glasses. Wow. You got braces. Wow. You are in a wheelchair. You know, that's the attitude today. And now we hear all of this testimony. And it's very depressing and brought tears to my eyes and a couple of other people here. If we cannot properly take care of the disabled now properly, and with the disabled people that we are getting as time goes on, not to mention the wars that are going on right now, and the men and women that are going to be coming home or have come home disabled, how are we going to handle this? How are we going to do it? Where is it all going? Everything is run backwards. All the testimony here is stating that it's running backwards. It's running wrong. It has to be done right. And that's just the bottom-line. It has to be done right for it to work for everybody. Thank you.

SUSAN SHAPIRO: I would reiterate that's the purpose of the forums is to identify those things that we can do better with, and to plan for ways in which to effectively address the needs of people with disabilities. Rory, did you want to say something?

RORY CARMODY: Rhode Island has started a project called the Rhode Island Disability Vote Project. And it's an opportunity to get agencies and individuals involved in the electoral process. Voter education, awareness. The tragedy is only 20 to 30 percent of people with disabilities vote. And it's the only time we are on a level playing field with everybody else. One person. One vote. You need to get out to vote. You need your families and friends to register and get out to vote. There are roughly 45,000 unregistered Rhode Islanders with disabilities. We need to get all of them registered and all of them out to vote for whoever they want to vote for. But if you want more information about the Rhode Island disability voter project, you can call the governor's commission on disability. They can direct you or your agency, if you are supported by an agency, in how to get involved because that's -- we saw from last year some of the legislation we were able to get passed -- you have something there? Great.

SPEAKER: We have brochures in the back on that topic.

RORY CARMODY: It's how it has to be. We have to be collective as a group. If we fight for chemical sensitivities separately, instead of with the mental health community or the DD community, we are one group. We are one family of disabilities. And we need to mobilize our vote and our voice that way. And I think that's a critical issue, especially now when we think of the disability community voting at 20 to 30 percent. That's -- we are not going to get anything. We are not going to get anywhere with a voting record like that.

SUSAN SHAPIRO: Thank you, Rory. If folks who have no more comments to make, want to leave, you can. We will be here until 6:30 in case other people come who couldn't be here earlier. They are all in the back, I think. Identify yourself.

JAMES DEBOER: I am James. I have business cards about the Rhode Island Disability Vote Project. Thank you, Rory, for discussing it. If you have any questions about voting, you want to get involved, we have brochures back there, voter registration forms. And I also have business cards on me and also brochures and more information as well. Come find me

SUSAN SHAPIRO: Thank you.

Written & E-Mailed Testimony

Governor's Commission on Disabilities

I can not attend the forums but I would like to address a couple of issues.

Transportation

I am disabled and have seen positive changes over the years but there are a few things that never seem to change. Parking for the disabled doesn't seem to be taken seriously in this state. I can't count the number of times there are no space available and the cars using the designated spaces do not have placards. Are there ever tickets given? The other problem is there are very few if any wheelchair van parking spaces. Are there any laws dictating such things and if not why not?

Another issue I am constantly faced with is the inability to get into buildings because of no automated

Accessibility

doors. I realize that not all businesses can afford to do this but medical buildings should have to. Almost every time I go to a doctor or the dentist I find myself sitting outside for long periods of time sometimes just waiting for someone to come by and let me in. Some buildings have the first door automated and then have a second door to enter the building and that one is not. An example of this is the new medical building at 1539 Atwood Ave in Johnston. In the same area of town if you go over to the Atmed Treatment Center to get x-rays, again you have one automated door but once you get in you are faced with a set of double doors you can't open. I find this with every doctor office and dentist I go to. You would think the medical community would know better. I assume the laws of the state are written so you only have to have access to the foyer but that makes no sense to me. I was once told that the building couldn't be changed because of fire laws. I assume this is not the case and if it is something should be done to change it.

The last point I have is with the RIPTA bus. This is a great service and I am very grateful for it. What I

Transportation

don't understand is that there is a distinction between the elderly and the disabled that are using the service. If you are disabled and have a doctor's appointment you must give an exact drop off and pickup time when you make the appointment. If you are elderly you can designate your drop off time but you have a will call time available for pickup. I am told to tell my doctor I have to be seen and out by a specific time and they will comply. I don't seem to have any doctors that run their practice that way. If they have an emergency or a patient needing longer care they are taken care of and everyone else waits. This is the reality of doctor's visits. I cannot use RIPTA for doctors visits for this reason so I am left with taking a cab and most cab drivers do not want to take disabled people and they cannot handle the wheelchair so end up missing appointments. There seems like there should be a better way.

Thank you for offering me the chance to voice my opinions,

Sincerely,

Theresa Rello

July 31, 2006

Public Forum Written Comments

Transportation

Susan Eleoff: I work at the Ocean State Center for Independent Living (OSCIL) as an Information/Referral Specialist. I am requesting the legislative committee of the RI Governor's Commission on Disabilities look into accessible taxicab service from our airport. Specifically, should this service be covered under the ADA?

Years ago OSCIL advocated at the PUC for the issuance of additional taxi cab licenses for accessible taxi service from the airport. We have referred numerous callers over the years to Airport Taxi, which offered wheelchair accessible taxicab service.

Recently I have received several calls from the public looking for accessible taxicab service. Last week I had a call from three stranded travelers from Colorado who were stranded at their motel in Warwick because they were told Airport Taxi no longer offered accessible taxi service. I called Airport Taxi to

verify this and was told they no longer had an accessible vehicle and to their knowledge no one was providing accessible taxi service from our airport. A dispatcher suggested travelers in need of accessible taxicabs contact an ambulance service.

The state of Rhode Island is promoting tourism and needs to offer accessible taxicab service to tourists and to Rhode Island residents. This service is available in many other states.

From: John J. Dybala
190 E. Highline Circle #107
Centennial, CO 80122-1034
(303) 347-8684

Date: July 26, 2006

To: The Honorable Donald L. Carcieri, Governor of Rhode Island (via e-mail)
Mark P. Brewer, President and CEO, Rhode Island Airport Corporation (via US Mail)
Ladies and Gentlemen of the Governor's Commission on Disabilities (via e-mail)
Governor Carcieri, Mr. Brewer, Members of the Commission:

It was my great pride and joy to bring two visitors to my home state of Rhode Island this past weekend: **Transportation** my fiancée and her son. Not only was it my joy and privilege to introduce them to my family, but I also had the pleasure of introducing them to the state where I was born and raised. The source of many fond memories ... the source of the strange accent that, after 12 years in Colorado, still comes out when I try to say certain words ... the place that, even after those 12 years, I still call "home." "Home" was, however, not terribly welcoming to my fiancée, who uses a wheelchair full time due to severe cerebral palsy. First, I was surprised to discover that no one in Rhode Island rents lift-equipped vans. I had three companies to choose from, all in Massachusetts, and two of them at least a two-hour drive (Billerica and Brimfield, Mass.) The third company is in Seekonk, but they had no vans available for this past weekend. This meant my father had to drive to Brimfield – a two- to three-hour drive each way – to procure an accessible vehicle. Second, I was dismayed to discover that visitors to Rhode Island have one, and only one, option for accessible transportation from the airport, specifically, Airport Taxi and Limousine. Third, I was rather perturbed upon discovering that Airport Taxi's one wheelchair-accessible vehicle had broken down. Not only this, but by their own admission, the vehicle has been broken down for some time and is not expected to be back in service for some time. Further, the best description I could offer of their attitude in conveying this information was a shrugging of the shoulders. To be a bit more blunt in stating the situation: they simply didn't seem to care. This left me, my fiancée, and her seven-year-old child sitting in the airport for nearly three hours after our arrival ... after a cross-country journey that had started at 3:00 in the morning ... waiting for the rented van to arrive because the only company in town that could have taken us to our hotel just didn't care. (RIPTA's Ride Program was not an option due to the various requirements of that program, including residency, pre-registration, and advance notice.) Poor customer service aside, I find it reprehensible that people with disabilities who visit our state are placed in such a situation. I would go so far as to call it a clear violation of Titles II and III of the Americans With Disabilities Act. I request that the Governor, the Commission, and the appropriate representatives of the RIAC investigate this matter and seek a more viable solution for the lack of wheelchair-accessible transportation from the airport. I also request that Airport Taxi and Limousine be considered for any applicable and appropriate sanctions with respect to their utter disregard for their stated commitment to service people with disabilities, by advertising the availability of accessible transportation and failing to provide it. (I will be filing a formal complaint via the appropriate channels, however, I am aware that the Commission is meeting this week and wanted to present my complaint in a more informal manner for possible review during said meetings.) If you have any questions or concerns, or if you require any further information from me, I can be reached at (303) 347-8684. Thank you for your time and your consideration of this matter.

Sincerely,
John J. Dybala

cc: The Honorable Rep. James R. Langevin

Dear Governor Carcieri,

As an Employment Specialist with an area non-profit, I often find it difficult to place some of our **Community Support** "members", (i.e., individuals/clients with mental illnesses), due to the need for job coaches. We are a smaller organization and are unable to finance such positions. ORS can pay for this about 6-9 months, but some people need coaching for the duration of their employment. Also, ORS does not provide coaches. It is the responsibility of the requesting agency to hire, train and supervise job coaches! Since I am the agency's sole Vocational Counselor, and also a Mobile Treatment Team Case Manager, fulfilling this need for our members is nearly impossible. Some of the larger agencies in the State provide this service to their clients. Job coaching can be a part-time employment option for parents of young children or for those wanting to transition off welfare. It can also be an opportunity for the unemployed to learn new skills, of which can later be applied to full-time positions in human services, training, etc. What do you think? Thank you for your time and this opportunity to speak on behalf of our members.

Karen J. Marsh
Emp. Spec./Case Mgr
Riverwood Mental Health Services
(401) 247-0173

GIFTED RESOURCE CENTER OF NEW ENGLAND

Deirdre V. Lovecky, Ph.D.
11 Whiting Street
PROVIDENCE, RI 02906
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Governor's Commission on Disabilities
John O. Pastore Center
41 Cherry Dale Court
Cranston, RI 02920-3049

Dear Members of the Commission:

I am writing to offer comments on children and adolescents with Developmental Disabilities and **Community Support** psychiatric disabilities. I am a clinical psychologist licensed by RI and I work with children with Autistic Disorder, Asperger Syndrome, Nonverbal Learning Disability, Juvenile Bipolar Disorder, ADHD, Major Depression, Anxiety Disorders, and others. Many of the children I currently work with are intellectually gifted (IQ over 120), and some are more average or below average. I have worked extensively with all age ranges, disabilities and mental health problems in my more than 30 years as a psychologist. I have worked in schools, in community settings and in private practice.

I would like to address my comments in the following areas: children and adolescents with severe disabilities, children and adolescents with milder disabilities, problems resulting from nonexistent and un-enforced IEPs and problems resulting from nonexistent and un-enforced 504 Accommodations in schools.

Allow me to start by saying that while I am addressing issues in services available for children and adolescents with disabilities, I have met many outstanding teachers and other school personnel who have championed the needs of the disabled child, and gone well beyond any required plan to help that child feel safe, and accepted at school. They have done wonderful things to allow all children to feel

valued and challenged, whatever their ability level or degree of need. Nevertheless, it is the other teachers and school personnel that are the problem. It is the parent's lack of resource when things go wrong that is the issue, and it is the fact that things can change so much from one year and one teacher to the next in how well any disabled child fares that is the question.

Severe Disabilities: Children and adolescents with severe disabilities in Autism, Asperger Syndrome, Major Depression, Anxiety Disorders, severe ADHD with Oppositional Defiant Disorder, and Juvenile Bipolar Disorder are underserved. These families need four services to manage these disabilities.

1. First is the need for trained respite care workers so that families are able to develop supports and bonds away from the immediate and overwhelming needs of the disabled child. Currently in RI respite care is limited and many middle-income families have none. Respite care is needed on an on-going basis for all families dealing with severely disabled children.

2. Also needed by families are in-home workers with appropriate training who can help families implement behavioral programs including ABA, TEAACH, and cognitive behavioral interventions. It is very hard for middle-income families to find access to these services.

3. Families need more access to psychiatric services. Most middle class families who work are allowed 20-30 mental health visits a year. Many need weekly visits to psychologists and social workers, and also access to supportive specialists that are not currently covered by insurance such as speech/language specialists, specialists in behavioral services such as ABA and occupational therapy specialists.

4. Families with adolescent children on the autistic spectrum need to work with Department of Vocational Rehabilitation to help their children develop life plans that will allow for learning employment skills. Since people with autism often need breaks from jobs, they may need several interventions from DVR over several years. North Carolina has an exemplary program in this regard.

Milder Disabilities in the areas of: Autism, Asperger Syndrome, ADHD, Nonverbal Learning Disability, Depression, Juvenile Bipolar Disorder, Anxiety Disorders, etc.

1. Access to teachers and aides who have been trained and have knowledge of the disability. Many of these children are attending school with no one understanding their disability and no one offering any accommodations for their needs. Not only are they deprived of needed services because no one recognizes the symptoms of their disability, they are often punished for their problems.

All teachers and aides should have training in the needs of children with disabilities even if these children are in the regular classroom with no "official" accommodation plan. Good teachers are able to be flexible and allow for social needs—only with the necessary knowledge though can they do it. Currently there are some educational services available if a school requests them for children with autism spectrum disorders. There are no services available for parents to provide education to their child's teachers who have not been provided it.

2. Access to services with milder forms of a disability even if academics are not currently affected. In my work with gifted children, I have found that those gifted children with high IQs who one would expect to attain high grades, perform well in college and establish themselves successfully in the work world, are unable to do so because of their disability. There are so many otherwise gifted adults with autism spectrum disorders and/or ADHD who are unable to make it through college or hold down a job. They end up not contributing to society by paying taxes and instead are on disability. The reason for this was that they did not learn the skills that would allow them to function in society. I have witnessed too many schools denying needed services to children with bright futures but who have a disability because they are at grade level. Well, they can be the academic stars of the class but without social skills training, training in executive function skills, and daily living skills, they are unable to function in life. Some, who have been denied any services, have IQs in the 150 plus range but adaptive functioning skills in the 40 range. My recommendation is a focus on assessing all the needs of the child, not only the academic needs up to grade level.

3. Families need more access to psychiatric services. Most middle class families who work are allowed 20-30 mental health visits a year. Many need weekly visits to psychologists and social workers

to help their children learn needed skills and deal with the associated problems of anxiety and depression that often accompany many of these disorders.

Problem of IEPs:

1. Many of the children with whom I work do not get access to school services because they are not doing badly enough academically. To obtain services they need to be well below grade level. The problem with this approach is that it deprives children of services needed until they fail. Current performance based assessment should taken into account the potential of the child, not just the lowest possible standard. Adhering only to the lowest possible standard deprives these children of an appropriate education and lowers the expectations of everyone.

2. Inappropriate assessment is done in some cases – for example, a child age 10 who thinks that 4 dimes is more money than 2 quarters might have a math problem or he might have a language problem. He doesn't see that quantity is different from value, but it could be because he doesn't get the idea of equivalency (math problem) or it could be he only has one definition of "more" in his mind (language problem). These two problems require different approaches. I've seen too many schools not take the time to see which is the problem but give very superficial evaluations in math and then say it is a math problem.

3. Un-enforced IEPs is a huge problem. Parents can get goals written but it is really hard to get them actually carried out. Thus, children with goals that they will have a Lunch Bunch for lunch each day end up most days sitting on their own with Lunch Bunch once a week. I've had children skip lunch everyday so they would not have to be in the cafeteria and their IEP has stated they should have lunch with an aide and a friend or two in a smaller room but the room was taken over for testing all year, and no one provided an alternative. Children have had written into their IEPs the use of a computer or Alpha Smart but no device was provided so the child produced little and was graded poorly. An IEP states parents are supposed to get a weekly report via e-mail of missing assignments and behavior but nothing comes despite repeated requests, until warning notices are sent out and the child has 3 notices of impending failure. Accountability of services provided for children with disabilities is desperately needed.

Problems with ADA 504 Accommodations:

1. Despite documented need, some schools resist giving accommodations. Some accommodations are simple to achieve: providing access to computers, allowing extended time on tests, preferential seating, less visual clutter on a page, reduced work load, study notes, a second set of texts at home. One parent recently reported that her child was denied an accommodation despite the fact this accommodation had been previously provided, was successful and is well known in the literature. The reason for the denial? A new SPED director who had different ideas about what accommodations were allowable.

2. Accommodations are not followed. As with IEP goals, needed accommodations such as assistive technology is not provided though it is written into the 504 Plan. It can be difficult to get teachers to follow the plan - for example, allowing less practice work instead of sending it home for homework along with the regular homework for a child with a Processing Disorder and slow work speed.

3. Social goals are often put under ADA to avoid writing an IEP. Then the child's needs are not met and the parent has to beg for the accommodation of a Circle of Friends or lunch space.

4. Teasing and bullying are not seen as ADA 504 issues though more than 90% of children with autism spectrum disorders report bullying. Without either an IEP or an appropriate 504 goal the child has no recourse. Teasing and bullying are school-wide issues and education of teachers, aides and peers about bullying in its various forms could help many disabled children tremendously. Teacher training and peer education, formation of support and friendship groups throughout schools can bring more community feeling to schools and help children with disabilities feel more like they belong. There is nothing like being bullied long term, with teachers turning a blind eye, to make an already disabled child feel defective and unwanted.

I would suggest the following remedies:

1. Respite care services and in-home training and behavioral management services for all parents with severely disabled children.

2. Required education of all school personnel about the disabilities of children in their classes, emphasizing what is reasonable to expect and how to accommodate for problems in milder cases, even without an IEP or 504 Plan.

3. The creation of a lunch and recess friendly environment for children with problems with social interactions, or sensory overload. This means providing smaller rooms at times for some children, working to build friendships, and encouraging acts of friendliness within a school.

4. The education of teachers and peers about bullying and the establishment of a state-wide effort to produce effective plans for schools to implement on bullying prevention and intervention.

5. The establishment of a statewide office that would be available to parents of disabled children to assess the efficacy of IEP and 504 implementation and follow through. This would provide some accountability that does not currently exist on follow through and efficacy.

I am available for further comment at the above phone number.

Thank you all for your efforts on behalf of children with disabilities.

Yours truly,

Deirdre V. Lovecky, Ph.D.
Clinical Psychologist

Susan B. Hurd
July 25, 2006

To whom this may concern:

My name is Susan Hurd. I am now 39 years old. In 1994 at the young age of 27 I fell very ill with

Accessibility

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 build 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 convalesce and rehabilitate 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 and post master's certificate in mental health counseling 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. In May 2006 I received my MA degree and now continue on with post master's work. 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 in 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 carcinogens.

Ingredients in cosmetics can cause severe 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, hominine, 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 Neurological Lyme Disease, to neuro-toxic exposures, or those exposed to their 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 heightened reactivity those experience who contend with MCS. (See: Townsend Letter for Doctors and Patients,

August/September 2005, "Multiple Chemical Sensitivity: Towards the End of Controversy" by Martin L. Pall, PhD.) Other doctors have done research that now documents through MRI'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 alterations 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 and inflammation will happen. For those assaulted by toxic overload injury and 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 depression or a infertility, or ADHD/ADD, or insomnia, or mood swings, 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-Permanente, 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.orjz ; 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

Health Care

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. Currently the hospital is under remodeling which makes it impossible for one with MCS to be in if Green materials are not used that don't outgas toxic VOCs, like pressed board, paints and new carpet and glues outgas. Simple things like installing 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 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 latex wafting in his rooms was too reactive for me triggering an allergic asthmatic reaction swelling my airways and throat to various degrees requiring medication. Some hospitals through the country don't use latex any more because more and more people are developing serious allergies as I have developed. Also, some progressive hospitals do use Green cleaning products, and offer 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 major 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

Accessibility

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 cookies baking or nut coffees roasting and permeating the air, or Asian food or popcorn 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 20/0 of 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 of the growing increase, many schools now have banned all peanut products to be served or eaten in their schools, or they have safe lunch room areas for those with peanut allergies to eat in. If peanuts were a medication the FDA would have to pull 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, legumes, eggs, etc as I have developed. Many also develop MCS. It is mind boggling with the high increase to peanut allergies, latex, and to chemical sensitivities that hospitals and ERs 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 ajar 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. Patients next to me with only a curtain dividing us may be offered a peanut butter sandwich or peanut butter 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 ERs where people are going to seek help and preserve their life. The hospital needs to be

Community Support

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 parishioners 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 diesel 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 diesel 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 nontoxic 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 oboist 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 Water fires because there is a nut vendor that frequents this event and other RI arts events. I once used to play my oboe to the Water fires 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 air purifies 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 occasion 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.

Recently, the condo association where I lived decided to ignore my requests for water-based low VOC stain to be used on the fences that surround my home and patio. I had to flee on June 5 with no warning and got exposed to toxic oil stain which gave me neuro-cognitive setbacks. I have had to stay at

a home for the last two months which has caused me setbacks because it isn't conducive for me to live in for two months. The people who let me stay can't do a kitchen renovation project because I have no where to go and I can't be in a home under building renovations like a wall being knocked out. My rights are being violated and the ADA and Fair Housing Act is ignored for reasonable accommodations. Oil based stains are outlawed in Massachusetts and California and other states and outlawed to be sued on playground equipment because they are so neurotoxic. RI is phasing them out. I pointed this all out to my condo association and they ignore this request and the fact that water-based low voc stains are a reasonable request and easily found in hardware stores. I get nowhere with the RI Disability Law Center and haven't had a phone call returned in over a month. So I'm on my own to try to make due or to find a cottage for under \$700 a month that meets my needs. Housing for those with MCS is needed and accommodations to find adequate affordable housing is needed like higher amounts of rent allowed.

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. Medical expenses and other accommodations are not taken into consideration that is mandatory for our health conditions and how much money is actually available to live on and pay for rent. 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- \$700 that will meet my specific needs. 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

Community Support

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 online 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. The printer arrived in May 2006, three years later. 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 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. 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 plus 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 autoimmune 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

MCS Housing Accessibility and Accommodation Suggestions

Susan Hurd

Housing for those with MCS is a very serious issue

MCS impacts every aspect of one's life who is disabled with this condition

Affordable housing is crucial. HUD and sec 08 programs need to better understand the need of those with MCS.

Separate housing dwellings work best for those with MCS then fumes from neighbors won't affect the MCS individual as happens in apartment buildings and attached condo townhouses,

Wood floors or tile floors work best, sometimes older out gassed carpets or no VOC carpets can be tolerated

Windows that open are crucial

Air filters/purifiers and air conditioners that filter air to cool a home are crucial, and systems that can filter out VOC's

Filtered water systems especially for chemically treated city water must take place

NO to Low VOC (volatile organic compounds which include things like formaldehyde, benzene, toluene, acetone, etc) paints, stains, carpets, glues must be used

Pressed board has formaldehyde and VOC's, so no formaldehyde cupboards and building materials must be used

Chemical lawn treatments can't be used and organic or non-toxic lawn treatments must be used

Organic and non-toxic pesticide treatments must be used, toxic sprays must be avoided

Less toxic maintenance measures must be used and a person with MCS must leave the premises while possible toxic treatments and maintenance projects going on must take place

If one is able to have HUD/ sec 08, rental exceptions for higher rents must be allowed so that one can rent a small cottage or small home that has no new materials no chemical treatments, and a private washer/dryer available that uses non-treated water and no scented laundry products. Also, at least one spare room or clean basement must be available in order to outgas new products, tools, appliances, books, furniture, clothing etc, can take place.

Those with MCS need clean fresh air away from factories and heavy pollution and car exhaust fumes. Country settings work best. Many city neighborhoods can be hard due to neighbors spraying yards and scented laundry fumes waft in the air from washers and dryers, and other maintenance projects taking place that can waft in the air.

Those with MCS can't be living in neighborhoods with heavy lawn sprays or pesticide sprays used.

Those with MCS can't have their home and property sprayed for mosquitoes or other insects or reasons. The general area neighboring persons with MCS can't be sprayed due to possible being exposed to spray drift. Notification must take place by cities/towns of possible spraying.

Insecticides can not be used in a home occupied with MCS, nor can it previously be sprayed because sprays can contaminate for months to years thereafter.

Many with MCS can't use gas stoves or heating or some can but can't use oil heating due to chemical fumes make them very sick. One must be given the freedom to find a home that suits their personal needs and sensitivities.

HUD and other low income housing developments need to provide individual dwellings to accommodate one with MCS or RI needs to build a separate complex to accommodate those with full blown MCS to live in where building materials will meet needs and medical regulations of those with MCS. Marin County, California has a MCS HUD housing complex to accommodate low income persons disabled with MCS. This shouldn't be the exception but the norm, especially where MCS is on the rise.

Apartments don't work well because they need to be maintained in the hallways, and common area with things like carpeting, wall paper, paint, stains, lawns etc. It becomes impossible for one with MCS to pass through these areas and will affect the air quality in their apartment. Pest sprays are lethal for many with MCS. Many with MCS also have many allergies including to foods and therefore food fumes wafting from apartments can cause severe allergic reactions and other adverse reactions such as seizures and asthma attacks. Individual dwellings work best.

MCS and Allergy Suggestions for Better Accessibility

Susan B. Hurd

Fragrance-free public buildings including: hospitals, ER's, schools, libraries
Fragrance-free means refraining from perfumes and strongly chemical scented products like strongly scented laundry soaps and dryer sheets, scented deodorant soaps and personal products, and scented lotions, as well as lingering cigarette smoke, scented oils, and other fragrances that can pick up in clothing. It also means removing air fresheners and pot pouris. Cigarette smoke must not take place.

Keep certain areas fragrance-free and more Green so that areas and rooms would be safe, similar to smoke-free areas and rooms. This means using zero to low VOC building materials, paints, glues, carpets, formaldehyde free walls, cupboards and furniture, all found in common hardware stores. It also means installing air purification filters that pull out toxic fumes and reactive offensive odors. People using these public safe areas would have to comply to using chemical free, scent-free/ low scent organic/natural products nonreactive products.

Remove all air fresheners from public bathrooms. They are neurotoxic and carcinogenic and do not sanitize the air but only mask odors and trigger neurological reaction, asthma attacks, and migraines and other adverse reactions. Instead install better air ventilation or use air purifiers/filters that can also remove toxins from the air.

Have diesel free ambulances and buses since diesel is reactive for those with MCS and asthma.

Enforce workers in public medical settings including hospitals, ER's, doctors' offices to refrain from fragrances including scented deodorants and laundry products. And to remove scented candies, incense and air fresheners from bathrooms and waiting rooms.

Offer Fragrance-free/food free/Green waiting areas, and exam rooms, hospital rooms especially in medical buildings, ER's, hospitals.

Schools need to be kept fragrances-free and Green. Safe rooms need to be built to accommodate those with full blown MCS. Libraries need to do the same. Fragrances and chemical contributes to ADHD, learning disabilities, poor concentration, behavioral problems and emotional problems because these products are neuro-toxic and affects the brain and blood/oxygen brain barrier, especially in growing children that do not have fully developed systems. These chemicals also weaken the immune, respiratory, and neurological systems contributing to more infections, asthma attacks, and other health related problems.

Because many people with MCS have severe allergies including food allergies and adverse reactions to strong fumes, mandate safe food free areas. For example, I have a severe peanut/nut allergy as do 2% of the population and peanut butter is served in ER's, and workers will eat peanuts as they go from room to room. A trace of peanut fumes and/or trace amount of peanut oil touching me could trigger a life threatening reaction as it can for 2% of the population who has peanut/nut allergies. Peanuts don't belong in Medical buildings nor are necessary to allow food snacks in other public buildings like libraries and schools etc.

Latex is another common allergy and for those with MCS so it needs to be removed from hospitals. When I was in the hospital, workers delivering towels, cleaning, delivering food trays used latex gloves which would contaminate things which could trigger a serious allergic reaction. The workers did not read signs saying latex free, and perhaps some couldn't read well enough to understand.

Please look at these websites to better find how to accommodate those with MCS:

The Sustainable Hospital Project University of Massachusetts-Lowell. It is a supply and information resource warehouse offering non-toxic and more Green cleaning products and medical supplies to hospitals.

www.sustainablehospitals .or Health Care Without Harm: www.noharm .or Hospitals for a Healthy Environment: www.H2E-online or Canadian coalition for Green Health Care: www.Greenhelathcare:HElathy Building Network: www.healthybuilding.net

Clean Med Conference: www.cleanmedconference.org Physicians for Social Responsibility: www.psr.org Healthy Schools Network: www.healthyschools.org For more info on health related issues on fragrances and MCS see: www.fpinva.org

Also see magazine, UTNE issue Nov-Dee 2002 11 "The Greening of Health Care" by Karen Olson
MCS Facts

2% of the population is disabled with full blown MCS

30% of the US population has chemical sensitivities to various degrees and it is predicted that within 10 years 60% of the US population will be affected, with disabling MCS on the increase. It is becoming an epidemic due to the increase of chemicals we are bombarded with. Currently major

hospitals and medical schools are preparing for this epidemic and are going fragrance free and more Green in their buildings.

72% of all asthmatics are triggered by fragrances and common cleaners used.

Many people with migraines and headaches are triggered by fragrances and cleaners, high Voc Paints, carpeting, and other offenders that also trigger those with MCS.

The Fragrance and chemical industries have powerful lobbies and are poorly regulated.

Senator Ted Kennedy addressed Congress in 1997: (see: "Townsend Letter for Doctors and Patients", January 2001 pages 42-45, "Making a Stink") by Lily G. Causra. Note: this issue was devoted to chemical sensitivities and MCS, it is a medical journal.)

Cosmetics are broadly used by Americans, more so than prescription drugs, medical devices, or biological products and Americans routinely assume that these products are safe.

The cosmetic industry is a \$20 billion dollar 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 carcinogens.

Ingredients in cosmetics can cause severe allergic reactions, severe asthma reactions, central nervous system damage, potentially birth defects

The FDA bears the burden of demonstrating by its own testing that a product is hazardous to consumer's health, which is unlikely prohibitive.

Fewer than two FDA employees work full time on labeling and testing cosmetics.

In the absence of federal regulations, various states have attempted to require manufacturers to properly label cosmetics, and warn of hazards—as of example, California has done with industrial products. The cosmetics industry spends 70% of its lobbying dollar fighting the 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 protection.

In the Federal food and Drug and Cosmetic Act there are 126 pages devoted to regulations to drugs and devices; 55 pages to food regulations; eight pages devoted to definitions; and a mere two pages devoted to regulation of the cosmetic industry

Other countries Canada, The European Union, Denmark, Sweden, and Malaysia lead the way in consumer safety in cosmetics and proper labeling of hazardous substances.

(A footnote regarding labeling. Cosmetic activist, Linda Chae, remarks that the word "fragrance" can indicate the presence of up to 4,000 separate ingredients, most synthetic. (Linda has since died of cancer and had MCS.)

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,... 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, requiring transporters to suit themselves up and the products put in hazardous waste marked containers.

60% of what touches your skin is absorbed into the blood stream. This is why patch medications are effective.

The olfactory system in the body's oldest system and directly wired to the brain. The sense of smell is very primitive which helped humans survive.

Neurotoxic fragrances as used in car fresheners and other products are deadening the sense of smell and people are smelling less and needing stronger, more pungent fragrances to be smelled and detected.

People with MCs have a heightened sense of smell and can detect smaller traces of scent than the average person and are more quickly affected by small traces of fragrances, leaking gas, cleaners, out gassing materials. A person with MCS may still be adversely by products out gassing that don't affect the average person. Many people with MCS can't ride in a new car for example and it still smells new

and affects them adversely even after 3 plus years old! The same can happen with new carpets and other building materials. MCS persons must outgas new products for weeks, months or years before easily using.

The blood oxygen/brain barrier is somehow affected more easily for those with MCS. It is thought to get damaged. MRI's and PET scan of the brain show that a person with MCS's brain doesn't function properly upon chemical exposures even to minute traces of substances causing very real neuro-cognitive adverse reactions which may seem crazy and made up to the average person. However tests of the brain confirm what MCS sufferers claim with the reactions they experience. The reactions cause disabling weakness, fatigue, pain, vertigo, inflammation and can also cause temporary personality changes of moods since it is affecting the brain and can cause a person to more easily get upset, cry, become confused, hysterical or irrational. Which can easily be dismissed as one being simply crazy and not recognized as physiological reactions occurring in the brain. The result is many with MCS get easily dismissed and don't receive the respect or support and accommodations they desperately need. When a person with MCS avoids toxins they are able to function in a fairly normal way and are often rational, calm, pleasant persons. They simply need accommodations and safe housing and work places. Toxic exposures to chemicals like chem. Lawn, carpets, paints, cleaners, pesticides can debilitate them for days, weeks, months years or indefinitely, taking a very long time recover from a exposure.

Fatigue, achiness, spaciness, confusion, insomnia, hyper- reactivity, or hypo- reactivity, rashes, seizures, vertigo, dizziness, loss of balance, blurring of vision, difficulty learning and concentrating upon exposure, digestive problems, blood pressure changes, heart rate changes and other symptoms can occur, including potential death and anaphylaxis shock.

In Canada the city of Fairfax Nova Scotia has made their city Fragrance free and has also banned chemical lawn treatments. Quebec, Canada just banned chemical lawn treatments. Marin County California has cities that banned chemical lawn treatments and mandate fragrance free public areas. Massachusetts now has a bill presenting to pass to ban chemical lawn treatments. New Mexico has a strong support for MCS and many cities including Sante Fe enforce fragrance-free buildings and green products to be used. Many places are going more Green and fragrance-free and the time is for RI to do the same.

San Francisco now uses non-toxic Green products in all their public city buildings. They find it is cost effective and feasible and better for health.

RI is the smallest state in the union and it could feasibly go more Green and make more places fragrance-free.

Note: I counsel patients with fibromyalgia, chemical sensitivities and auto immune health conditions in the Healing Choices Fibromyalgia Clinic at the Rehabilitation Hospital of RI. It is an older building with tile floors, cinder block walls and older furniture. I can easily be in my office to counsel and do my clinical intern training for an eight hour day without problems. It had good air ventilation too. I believe since I can be in this hospital that it should be proposed that it be made accessible to treat people with chemical sensitivities and MCS. If one hospital in the state was made accessible and had a team of doctors and staff that understood how to accommodate and treat MCS and keep people safe it would be beneficial. Simple measures like fragrance-free, smoke free, non-toxic cleaners used, and removing air fresheners in all the bathrooms could make this hospital accessible. Currently since waiting rooms are not kept fragrance free and toxic cleaners are used and air fresheners are in some but not all bathrooms in the hospital it makes it not conducive for the severely disabled but

it could be accessible with these small changes, I keep an air purifier in my office and all patients come fragrance free.

I am happy to discuss how to help better to accommodate persons with MCS in RI. Feel free to call me. I am a success story in adapting to living with MCS. I now have my MA degree in Holistic Mental Health Counseling due to accommodations made in keeping classes fragrance free and peanut free. Also my classes are held in older buildings in the mansion classrooms at Salve Regina University. Newer buildings wouldn't have permitted me to pursue my degree.

Thank You,

RESOURCES

Less Toxic Alternatives, Carolyn Gorman, 2001

Better Basics for the Home, Annie Berthold-Bond, 1999 Creating a Healthy Household, Lynn Bower, 2000

Home Sweet Home.- Protecting Yourself and Your Family from Everyday Toxics and Harmful Household Products, Debra Lynn Dadd, 1997

Secondhand Scent: Accommodating People with MCS; Video from Boston Self-Help Center, 617-277-0080 Environmental Health Network, www.chnca.org Fragranced Products information Network, www.fpmva.org Chemical Injury Information Network, 406-547-2255, www.ciin.org

FDA Petition letter by biochemist: <http://users.imi.net/-witworks/FDApctition/Irconrad.htm> Other websites: www.ourlittleplace.com www.chemicalbodyburclen.org www.skinabuse.com

The Hidden Dangers of Fragrances References "Acute Toxic Effects of Fragrance Products," Rosalind C. Anderson, Julius H. Anderson-, Archives of Environmental Health, 1998, 53(2):138-146.

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"Respiratory Toxicology of Fabric Softener Emissions," Rosalind C. Anderson, Julius H. Anderson-, journal of Toxicology & Environmental Health, 2000 Part A bO:121-136.

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Did you know?

-Scents have not been proven safe. -The fragrance industry is unregulated. -Fragrances make it difficult for some people to be in public.

-"Sensitive" people are not the only ones at risk.

If you use soap, shampoo, perfumes, cleaners or scented products of any kind, this brochure is for you.

Produced by

THE ENVIRONMENTAL HEALTH COALITION OF WESTERN MASSACHUSETTS
a grassroots organization dedicated to environmental health issues and serving the needs of chemically injured people

FRAGRANCE FACTS

One in five people experience health problems when exposed to fragrance.

Chemical and fragrance manufacturers, protected by special laws, don't have to disclose ingredients or testing data to the public, the government, or any regulating body

Several hundred chemicals can make up a single fragrance.

The majority of fragrance chemicals, either singly or in combination, have not been adequately tested for human safety

We inhale fragrances whether or not we use them, just like secondhand tobacco smoke.

72% of asthmatics have adverse reactions to perfume, and asthma attacks can be fatal.

Asthma rates have gone up 40% in the past 15 years and cost \$13 billion in U.S. health care annually

Substances applied to the skin are absorbed into the bloodstream (which is how "the patch" delivers a drug like nicotine).

Infants are especially vulnerable to fragrance chemicals due to an undeveloped defense called the blood brain barrier.

Fragrances deny many people access to public places and events.

Terrell frequently visits the emergency room, and can no longer attend high school, due to severe asthma attacks triggered by fragrances.

WHAT'S IN A SMELL?

Fragrances today are not just simple odors. Scents originally came from plants, but most are now made in laboratories by the multi-billion dollar fragrance and chemical industries. Manufacturers mix many chemicals together to make fragrance, as well as to control color, shelf-life, time-release properties and adhesiveness (fabric softener is so sticky it is almost impossible to remove from clothing). Fragrance chemicals which have been tested are known to be harmful to the brain and nervous system.

95% of the chemicals used in fragrances are derived from petroleum and are neurotoxic. They include benzene derivatives, aldehydes and many other known toxins and sensitizers capable of causing cancer, birth defects, central nervous system disorders and allergic reactions. Certain chemicals, such as formaldehyde, can make a person permanently allergic or sensitive to other chemicals.

Once sensitization has occurred, even tiny amounts of a substance can cause symptoms.

In 1991, the Environmental Protection Agency (EPA) studied 31 fragrance products and found toxic chemicals such as acetone, benzaldehyde, benzyl acetate, ethanol ethyl acetate, linalool, methylene chloride, and a-terpineol. Each and every fragrance sample tested contained toluene, which is neurotoxic, carcinogenic and designated as hazardous waste. Synthetic musk's are used in fragrance and can have hormonal effects as well as cause cancer. They are long-lasting environmental contaminants which have been found by scientists in human fat tissue, blood, breast milk, water supplies, fish, wildlife, and elsewhere. Hormone disrupting industrial chemicals called phthalates, associated with thyroid and reproductive disorders, are also in many fragrances. According to sources such as www.riottoopretty.org, this includes products by Calgon, Calvin Klein, Jovan, Lancome, Christian Dior, and Elizabeth Taylor, as well as hairsprays by Pantene and Aqua Net; deodorants by Arid and Degree-, and nail polishes by Cover Girl, Sally Hansen and Maybelline. It is not surprising that women of child-bearing age tend to have the highest levels of phthalates in their bodies.

Although synthetic chemical fragrances tend to be the most toxic, "natural" fragrances can also be problematic. Essential oils are not always free of contaminants, and some people can react severely to even pure, organic oils. Also, a very large percentage of "natural" products are scented with unnatural fragrances.

Maria, a 53 year-old nurse, experiences impaired motor functioning, slurred speech, and mental confusion when exposed to Fragrance chemicals.

SYMPTOMS & HEALTH EFFECTS

Our lungs and skin allow scent chemicals to get into our bodies and bloodstreams, while our nasal passages provide access to our brain, the most important and delicate organ in the human body Those especially vulnerable include infants and children, people of reproductive-age, asthmatics, the chemically-injured, and those with allergies.

The EPA found the following health problems to be associated with fragrance exposure:

- Asthma, Reactive Airway Disease (RADs), difficulty breathing, coughing
- Eye irritation

* Sinusitis, rhinitis, inflammation of mucous membranes

- Skin problems, dermatitis

- Kidney and liver damage

- Immune system damage, chronic illness

* Nausea, vomiting, abdominal pain

- Blood pressure changes (drop or rise)

- Effects on brain and nervous system: coma, convulsions, headaches/migraines, depression, dizziness, irritability, confusion, panic attacks, anxiety, memory loss, impaired concentration, drowsiness, insomnia, impaired vision, ataxia, stupor, spaciness, giddiness, slurred speech, twitching muscles, tingling in the limbs, loss of muscular coordination. Constant low level exposure to neurotoxins can lead to progressive and permanent brain damage.

- Cancer

- Death due to respiratory failure (severe cases) Symptoms and illnesses like these cost billions of dollars each year in medical expenses and lost work productivity

Chris is a computer technician who gets a migraine whenever exposed to even mildly fragranced products.

PRODUCTS TO WATCH OUT FOR

Chemicals permeate all aspects of our AS lives, from personal care products and clothing, to the materials used in building, furnishing and maintaining our homes. We are increasingly surrounded by fragrance chemicals, and many people are developing reactivity from this constant onslaught. Fabric softener and dryer sheet fumes pollute whole neighborhoods by escaping through dryer vents.

The following products usually contain fragrance chemicals that are designed to linger:

Personal care and beauty products such as soap, deodorant, lotion, makeup, nail polish & remover, shaving cream, hair products.

Household products including glass cleaner, laundry detergent, fabric softener, dryer sheets, bleach, dishwashing detergent, disinfectant & deodorizer, kitty litter, toilet paper & tissue, trash bags. Miscellaneous items such as advertising materials, magazine perfume strips, markers, candles, and scented paper. (Watch out for hidden sources like lamp rings.)

Air "fresheners" are used regularly in bathrooms, automobiles, hotels and many other places, coating nasal passages with nerve-deadening agents and impairing our sense of smell.

Donna a chemically-injured laboratory technologist gets respiratory distress, severe migraines, disorientation and vertigo when exposed to synthetic fragrances.

ACCESSIBILITY ISSUES

Sensitivity to fragrance is an invisible disability. Health effects from exposures to fragranced products make it impossible for some people to work, socialize or participate in their communities. Fragrance-free policies are becoming more common as businesses, organizations, towns, and public events organizers respond to the growing number of scent-related problems.

The Canadian town of Halifax, Nova Scotia is one of the first places to have established a large-scale fragrance-free policy Halifax considers fragrances to be a form of pollution, just like pesticides and cigarette smoke, and has banned them from most public offices and some private businesses. Another example is the town of Shutesbury, Massachusetts, which now holds fragrance-free town meetings.

Health and medical professionals should avoid wearing fragrance to work. Many medical offices also now request that patients not wear fragrance to appointments.

These are very important steps, as even small exposures to fragrance can be debilitating or life-threatening for some people. Experts estimate that the percentage of people allergic to chemicals will increase to 60% by the year 2020, and that 20-30% of the U.S. population already reacts to one or more synthetic chemical substances.

Adam, a mild-mannered 45 year-old mechanic, experiences extreme irritability, moodiness, headaches, and a sore throat any time he breathes perfume.

SAFER PRODUCTS

Fragrance use is a matter of personal choice, but it has consequences for everyone. If you wear a fragrance that is difficult for someone else to tolerate, they may not tell you. If you are unsure whether fragrance causes you trouble, one way to experiment is by eliminating fragrant products for a while, then trying one at a time to see how you feel.

A range of safer products is available. Please read labels carefully. Check for terms like "Fragrance-free" and "No perfumes, dyes, or additives." Be aware that "100% natural" or "unscented" do not necessarily mean safe. "Natural" is an unregulated term, and an "unscented" product may contain masking fragrances (usually listed in the ingredients) which disguise odor but make the product more toxic. "100% fragrance-free" is usually a better bet.

To be entirely scent-free, stop using perfume, cologne, after-shave lotion, scented or essential oils, fabric softener and dryer sheets, and consider replacing the following scented items with safer, unscented alternatives: shampoo, conditioner, soap, lotion, deodorant, powder, cosmetics, hairspray/gel/mousse, sanitary napkins, tampons, laundry detergent, and sun block. Order from companies that specialize in products for the allergic or chemically sensitive (see "Resources"), or buy products generally considered fragrance-free and safer than commercial alternatives (examples below). Most can be found at natural/whole foods stores and food co-ops. Some are available at almost any pharmacy or market. Useful multipurpose substitutes include baking soda and vinegar. Shampoo: Lagona Free- Dr. Bronner's unscented Magick Botanicals Oil-Free, Fragrance Free- Granny's Pure Essentials Fragrance Free; Heritage Products Olive Oil Shampoo; Stonybrook Botanicals Unscented.

Soap: Neutrogena, Original Unscented bar; Dr. Brenner's Baby Castille unscented; Kiss My Face Fragrance Free Pure Olive Oil Soap Clearly Natural glycerin bar; Tom's of Maine Fragrance Free/Unscented-1 Shaklee Basic H.

Shaving Lotion: Kiss My Face Unscented Shaving Gel, also see soap section.

Deodorant: Baking sodas Tom's of Maine Unscented-, Almay unscented; Le Crystal.

Powder: Baking soda, cornstarch, arrowroot powder, Magick Botanicals White Clay Baby Powder.

Moisturizer/Lotion: Eucerin creine-1 food-, rade vegetable oils (almond, apricot kernel, coconut, olive); Allercrème unscented.

Hair Spray and Gel: Magick Botanicals FragranceFree Hairspray & Unscented/Chem-Free Gel-, Beauty Without Cruelty spray gel, Aubrey Organi(s B-5 fragrance free styling gel-, Living Source spray (see resource section); for homemade get dissolve one teaspoon plain gelatin such as Knox (vegetarians can use agar) in a cup of warm water and --, hill. Cosmetics: Aubrey Organics, Almay, Paul Penders, Real Purity, Organic Excellence.

Sunblock: Zinc oxide, Banana Boat Kids, Z,ubrey Organics, Alba Botanica, Zia, Shaklee Enfuselle. Laundry Detergent: Baking soda & vinegar, Arm & Hammer Super Washing Soda, Allens Naturally, Shaklee Basic L Free, Shaklee Nature Bright.

Other options: White vinegar and water for cleaning windows, white vinegar or hydrogen peroxide for disinfecting, baking soda for deodorizing, explore alternatives to all scented and/or toxic home and personal care products (see "Resources" for more details).

Note: Any product (conventional, unscented, natural or "safer") could be problematic for any person. SOURCES

N.E.E.D.S., 800-634-1380, www.needs.com -Chemically Sensitive Living, 888-891-7293, www.chemsenlvng.com

Magick Botanicals, 800-237-0674, www.magickbotanicals.com

0The Living Source, 800-662-8787, 254-7"6-4878, www.livingsource.com

Lifekind Products, 800-284-4983, www.lifekind.com -Shaklee Products, 413-369-0124 or 877-327-6931, www.shaklec.net/solutionfinders -Terressentials 301-371-7333

- Health by Design 877-862-5417

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Brochures are printed using soy-based ink on environmentally- responsible paper

The Fragrance Brochure: FRAGRANCES: Fragrance facts.

Health problems associated with fragrances.

Listing of products containing fragrance.

Fragrance-free alternatives. Resources for alternatives, books, articles and websites.

Also Available- The Healthy Homes Brochure: Why you should live in a healthy home?

Basic principles for creating a healthy home. Checklist for choosing healthy housing. Resource listing of books, videos, websites, newsletters, magazines, consultants, testing and products.