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

Identified during Five Public Forums

July 22 – 26, 2002

Prepared by the
Governor's Commission on Disabilities

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Copies of this information are also available in Braille, large print, audiocassette and electronic file on computer disk. This document is also available on the Commission's website gcd.state.ri.us in Adobe pdf format.
Contact the Governor's Commission on Disabilities to arrange for a copy.

Executive Summary

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 to develop programs to improve the lives of people with disabilities.

The Public Forums

Five public forums were conducted the week of July 22 – 26, 2002:

Monday July 22, 2002 4:30 – 6:30 at Independence Square II Independence Way, Kingston, on 138, just west of the URI Campus
Tuesday July 23, 2002 4:30 – 6:30 at the Newport Public Library, Lower Level Program Room, 300 Spring Street, Newport
Wednesday July 24, 2002 4:30 – 6:30 at the Community College of RI, Flanagan Campus, Rear Faculty Dinning Room, 1762 Old Louisquisset Pike, Lincoln
Thursday July 25, 2002 4:30 – 6:30 at the Community College of RI, Liston Campus, Atrium, Staniford Street, Providence
Friday July 26, 2002 4:30 – 6:30 at the Warwick Public Library, 600 Sandy Lane, Warwick

Comments were mailed, faxed and emailed in.

Procedure following the public forums

During August and September representatives of the sponsoring organizations met to review the testimony and develop recommendations for action. Seven working groups were formed to review the testimony: assistive technology; education; employment; family and community supports; health care; housing and transportation.

The top three issues are:

(1) Better Coordination of Service to people with disabilities and their families that are provided by multiple state government departments and non profit agencies, under contract with the state;
(2) Expand Employment Opportunities for adults with disabilities through:
  (a.) Better preparation for employment (transition from school to career, vocational training);
  (b.) Elimination of the disincentives to employment (such as the loss of health care benefits and social services if working); and
  (c.) Creation of Work-Related Infrastructure (transportation, personal care services, job coaches, and other support services available for people with disabilities who are working);
(3) Affordable and accessible housing including
  (a.) Funding for modifications to homes/apartments owned or rented by families with disabled members and
  (b.) Expanding the public and private market of affordable/adaptable housing

Public Notice

Public Forums
State of Rhode Island

To identify the concerns of people with disabilities and their families

Monday July 22, 2002 4:30 – 6:30
Independence Square II Independence Way, Kingston
(on 138, just west of the URI Campus)

Tuesday July 23, 2002 4:30 – 6:30
Newport Public Library, Lower Level Program Room,300 Spring Str.

Wednesday July 24, 2002 4:30 – 6:30
CCRI, Flanagan Campus, Rear Faculty Dinning Room,
1762 Old Louisquisset Pike, Lincoln

Thursday July 25, 2002 4:30 – 6:30
CCRI Liston Campus, Atrium, Staniford Street, Providence

Friday July 26, 2002 4:30 – 6:30
Warwick Public Library, 600 Sandy Lane, Warwick

Comments may be made in person during the forum, or you can mail, fax or e-mail them by July 29th to:
Governor's Commission on Disabilities
John O. Pastore Center – 41 Cherry Dale Court, Cranston, RI 02920-3049
462-0106 (fax) or disabilities@gcd.state.ri.us (e-mail).

We ask that you use unscented personal care products - that you not wear perfumes or scents to an environmental illness accessible event. 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.

For more information or to request accommodation needed to ensure equal participation, please call: 462-0100 or 462-0101(tty) at least 3 business days before the hearing so arrangements can be made to provide such assistance at no cost to the person requesting it.

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

Interpreters for the Deaf will be at all the forums, except Providence, courtesy of OSCIL.

Spanish language interpreters will be available in Lincoln on July 24, Providence on July 25th and Warwick on July 26th, courtesy of the Office of Human Resources, Outreach & Diversity.

Request for other language interpreters, should be made to 462-2130 at least 3 business days in advance.

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

Lincoln Almond, Governor

These forums are co-sponsored by the organizations listed below:
Alzheimer's Association, RI Chapter, Elizabeth Morancy, Executive Director; **Arthritis Foundation-SNE,** Stephen Evangelista, President & CEO; **Assistive Techology Access Partnership,** Regina Connor, Project Director**;Council on Assistive Technology,** Marie Younkin-Waldman, Chairperson; **Department of Elementary & Secondary Education,** Peter McWalters, Commissioner; **Department of Health,** Dr. Patricia Nolan, Director; **Department of Human Services,** Jane Hayward, Director; **Developmental Disabilities Council,** Christine Singleton, Chairperson; **Governor's Commission on Disabilities,** Doreen McConaghy, Chairperson; **Harmony Hill School, Inc.,** Terrence J. Leary, President & CEO; **Disability and Health Program Advisory Committeee,** Aleatha Dickerson**; Long Term Care Coordinating Council,** Lt. Governor Fogarty, Chairperson; **Ocean State Association of Residential Resources,** Mary Madden, Executive Director; **Ocean State Center for Independent Living,** Lorna Ricci, Executive Director; **Office of Library & Information Services,** Anne Parent, Chief; **PAL,** Doreen McConaghy, Executive Director; **PARI Independent Living Center,** Leo Canuel, Executive Director; **Paul V. Sherlock Center on Disabilities,** A. Anthony Antosh, Director; **RI Council of Community Mental Health Organizations,** Elizabeth Earls, President/CEO; **RI Disability Law Center,** Raymond Bandusky, Executive Director; **RI Parent Information Network, Inc.,** Vivian Weisman, Executive Director; **RI Public Transit Authority,** Dr. Beverly Scott, General Manager; **RI Rehabilitation Association**, Jane Massa, President; **Special Education Advisory Committee,** Lillian Patterson, Chairperson; **State Rehabilitation Council,** Carol Krause-Ferraioli, Chairperson; **Statewide Independent Living Council,** Stephen J. Carr; **Training Thru Placement,** John J. Capobianco, Executive Director

Table of Contents

Part II. The Testimony

Part I. Findings and Recommendations

Below are the specific findings and recommendations based on the testimony at the 5 public forums. After each finding are the citations of the page(s) in the transcripts that this finding comes from and the name of the person(s) testifying.

I. Findings and Recommendations of the Assistive Technology Working Group

Chairperson: Jeanne Panarace of the RI Department of Health

Member: Regina Connor of the RI Department of Human Services, Office of Rehabilitation Services / Assistive Technology Access Partnership

A. Adaptive Housing

Need for increased funding for accessible housing and home modifications. Currently, the two IL centers have waiting lists for home modifications. pg. 8 L. Canuel & pg. 79 C. Pollock

Recommendation: More funding is needed to eliminate waiting list.

More resources for home modifications

B. Accessible Housing

Accessory apartments could enable people with disabilities to remain in their homes with the use of these modules. Communities may have zoning restriction prohibiting their use. pg. 25 J. Mason

Recommendation: Change in local community ordinances to allow for these units or modifications more readily.

C. Outdoor Recreation

Outdoor recreation facilities are not accessible to people with disabilities. Playgrounds are unsafe for children with disabilities. Need to survey locations throughout the State, and correct situation. pg. 32 S. Cooper

Recommendation: Improved services: GCD could evaluate and make recommendations.

D. Universal Design

Improved access to transportation and other Outdoor facilities have expanded benefit for all people. pg. 33

Recommendation: More funding is necessary to continue the process of making all public facilities accessible to people with disabilities and therefore improving access to everyone. Continued education of the need for universal design is also necessary.

E. Increased funding and public awareness for Assistive Technology

The public needs more information about AT. ATAP provides information, evaluation, training, etc., but need increased funding to continue the programs. pgs. 53 – 54 D. Sweet

Recommendation: More funding for AT related programs. (Federal, State, local)

F. Assistive technology information resource

The lack of information about assistive technology known by consumers. pgs. 71 – 72 K. Samways

G. Accessible mammography machines

Accessible exam tables, exam chairs, mechanical lifts in doctors' and dentists' offices. pg. 72 T. Ayers & pg. 110 E. Kinzie

Recommendation: Improved services: advocacy and education directed towards medical profession through Brown U. Medical School and continuing education programs of physicians.

H. Help with cost of hearing aids

Promotion and support of Assistive Technology
Increase in funding for Adaptive Telephone Loan program (ATEL) pg. 101 J. Panarace

General Recommendations

Increased funding for home modifications
Inspect/regulate playgrounds for safety and access
Increase Assistive Technology funding to continue and expand programs
Increase Adaptive Telephone Loan (ATEL) funding

II. Findings and Recommendations of the Education Working Group

Chairperson: Kimberly Bose of University of Rhode Island, Center for Public Policy
Members: Andy Egan of Office of Library and Information Services and
George Singleton of UCP Rhode Island

A. Findings

1. The issue of coordination of services among different departments

To often parents/guardians have to make the connection between resources when there should already be one established. pg. 9

2. The government is doing away with the three-year evaluations in schools and also the short-term objectives for students with disabilities. pg. 9
3. There needs to be social groups established for teenagers and young adults with disabilities. pg. 11
4. The issue pertains to making sure that the key people in the school systems, government, state, etc. know of the laws that pertain to people with disabilities. pg. 13
5. The need for Paraprofessionals in the state and the lack of education that is out there for them to gain. pg. 38
6. The issue of transitioning into the independent word and the lack of resources available to access to make that transition a smooth one. pg. 56
7. The shortage of special education teachers in the state. pg. 56
8. Because of that, the regular classroom teachers are forced to include the special needs students into their classroom without the proper environment or course of study for them.
9. The issue is that of the transition period that occurs from High School to young adulthood. pgs. 116 & 118

How do we prepare these young adults socially, educationally, and recreationally?

The issue is that different school systems offer different amounts of assistance to students with disabilities depending on what town that you live in.

B. Recommendations

1. Parents/guardians are spending too much time advocating and achieving the rights that their children are eligible for. There needs to be more education among Government agencies, schools, private organizations, etc., so that the employees of these agencies are informed and can assist the parents instead of the parents endlessly searching for information and services they are entitled to.
2. There should be more investigation into the three-year evaluation and short-term objectives geared towards children with disabilities that the government is doing away with.
3. Establish after school programs and other social events for children with disabilities. This population needs more opportunities to involve in social activities.

4. Many students with disabilities are unprepared for the future. Their needs to be in place a program to assist young adults who are transitioning into independent life.
5. There needs to be more education/trainings for paraprofessionals. There is a great shortage of this profession in the state.
6. There is a need for more Special Education teachers in the state. More teachers are necessary for students with special needs to get the education and attention that they require.
7. There needs to be a consistent and enforced standard of education for students with disabilities around the state.

III. Findings and Recommendations of the Employment Working Group

Chairperson: Regina Connor of the RI Department of Human Services, Office of Rehabilitation Services / Assistive Technology Access Partnership
Member: Jeanine Dionne of the RI Department of Human Services, Office of Rehabilitation Services

A. Medical benefits

Medicaid buy-in has not happened; people with significant disabilities need the range of coverage that Medicaid provides pgs. 7, 8 L. Canuel

Recommendation: Legislative change is necessary to allow for State to offer program.

B. Transition from school to career

Students with disabilities in Transition programs need social skills training as well as job training. Inappropriate behaviors can result in the loss of a job, rather than lack of work skills. pgs. 12, 13 B. Remington

Recommendations: Improved services to include training in social skills development.

C. Disincentives to employment

Social security and other programs have rules that seem to prevent people from going to work. (Changes in federal legislation may impact positively on this situation.) pgs. 14, 15 M. Pattison

Recommendation: Improve services. (Public awareness of changes in Federal legislation.)

D. Discrimination in employment

People with disabilities face discrimination on the job due to lack of awareness
Doesn’t appear that there are many effective means to address the problem. pgs. 39-43 N. Ciravo

Recommendation: Improved services through advocacy and education.

E. Existing barriers to employment

Inadequate transportation, employers need to be educated about disabilities, consumers need better job training and supports.
Private insurance offered by employers does not generally cover the cost of hearing aids. Riders are too expensive, so employers do not offer them. pg. 36 J. Panarace

Recommendation: Mandate parity in insurance coverage for prosthesis, including hearing aids.

F. Youth with mental illness

Need more programs to provide training in daily living skills, need supported employment opportunities. pg. 42

Recommendation: Improved services (see Transition)

G. CNA training

There is a shortage of trained certified nursing assistants (CNAs). Need to recruit people with

disabilities to be trained for such employment. pg. 60
Recommendation: Funding for specific training with targeted population.

IV. Findings and Recommendations of the Family and Community Supports Working Group

Chairperson Rosemary Carmody of Cranston Arc
Bill Inlow of the RI Public Transit Authority

A. There is a need for respite services to assist families of persons with severe impairment

Recommendation: Stabilize the respite services for families currently in the system and extend services to include families of all persons with severe disabilities regardless of age or type of impairment. Ensure a seamless transition for individuals moving from children services to adult services. The longer families are supported in maintaining children (including adult children) at home, the less expensive it is for the State, avoid more expensive residential care. pg. 49 M. Napolitano

B. There isn't a comprehensive Independent Living Services

Personal care attendants are not hired by an agency; individual consumers are responsible for hiring their own PCA. PARI provides [Medicaid, Rehabilitation Services Administration, or state (only)] funds for a consumer to hire and train their own PCA. Due to the waiting list, people often stay or more into nursing homes, or use home health aids. Although additional Medicaid dollars are available, there isn't the state match.

The waiting list for home modifications, so individuals who become disabled can return to their own home, is increasing. It's far more costly to maintain someone in a nursing home than modify his or her home or apartment. None of the state home modification funds may be used for apartments or rented homes.

There has been a large increase in the number of calls [to the accessible housing phone #] from consumers seeking affordable and accessible housing. People are being evicted, living in motels, and shelters, due to the increases in rents. People with Section 8 Vouchers can't find realtors who will rent to them.

RI Housing is concerned about budget cuts and reduction in-group homes. People with disabilities face many challenges finding stable supportive housing environments. There are waiting lists for Section 8 Developments for both elderly and people with disabilities. Without the option of group homes, families may face accommodating their disabled family member without adequate physical or financial resources. pgs. 5 - 8 L. Canuel, pgs. 114 – 115 S. Eleoff, & pgs. 100 - 101 S. Bodington

Recommendations:

Provide matching funds to increase the number of personal care attendant slots to the Medicaid authorized limit, provide for support services to consumers for training PCAs.

Continue and expand the home modification program to include rental property and reduce the waiting list for current homeowners

Greater effort in going after federal funds and grant for home modification with goal of keeping people in their homes for as long as possible.

Continue to fund the Neighborhood Opportunities Program to increase housing for people with disabilities and their families.

C. Financial Supports

[QUOTE] "I am allowed to make $780 a month over and above my Social Security Benefits. I'm sure you are all aware of the figures. My benefits are $514 a month. Because I raised two children by myself and wasn't ever really able to work a full time job, which made my benefits low. I have always worked. Now I am on the edge of being turned down for my benefits because for the last 10 years, probably three years out of the last 10 years I have made over the amount and they are telling me that I am gainfully employed. In order to stay within these parameters, and stay in the $718 a month, that is before taxes, my house is breaking out now. My children are going out on their own, the only place I can go is subsidized housing so that means although I can work approximately 20 hours a week, and I can earn approximately $1,200 a month, because my education and experience, I have to turn that down and I have to go to the Governor and ask for subsidized housing, food stamps, Medicaid, and whatever else the government has for you to ask for $1,200 a month, and my benefits, I can be self-sufficient." pg. 11 M. Patterson

Recommendations: Eliminate work disincentives, encourage not discourage work and establish parity in the earnings level regardless of type of disability.

V. Findings and Recommendations of the Health Care Working Group

Chairperson Ernie Savastano of Coalition for Consumer Justice
Dr. Victoria Wilcox of the Governor's Commission on Disabilities
Maureen Maigret of the Long Term Care Coordinating Council
Rebecca Martinque of the Arthritis Foundation

A. Medical benefits

Medicaid buy-in has not happened; people with significant disabilities need the range of coverage that Medicaid provides pgs. 7, 8 L. Canuel

Recommendation: Legislative change is necessary to allow for State to offer program.

B. Accessible mammography machines

Accessible exam tables, exam chairs, mechanical lifts in doctors' and dentists' offices. pg. 72 T. Ayers & pg. 110 E. Kinzie

Recommendation: Improved services: advocacy and education directed towards medical profession through Brown U. Medical School and continuing education programs of physicians.

C. Help with cost of hearing aids

According to the Behavior Risk Factor Surveillance System at least 1 in 4 Rhode Islanders, living in the community has a disability.

Hearing aids cost between $1,000 and $2,700 per aid. Private insurance offered by employers does not generally cover the cost of hearing aids. Riders are too expensive, so employers do not offer them. Health insurance companies most cover other assistive devices (wheelchairs, artificial limbs, etc.). The physical and psychosocial functioning of a person with a hearing impairment, who does not use hearing aids decreases as their hearing loss increases. A hearing aid could actually reduce medical and social service costs. pg. 101 J. Panarace

Recommendations:

Establish parity in prosthesis coverage by health insurance companies, treat hearing aids the same as other prosthesis.

Ensure providers are aware of assistive technology lemon law and subject to some type of standard/certification by Department of Human Services, as other providers.

D. Affordable Prescription Drugs for Younger Adults with disabilities

Some drug companies offer financial assistance through rebates to purchase medication. Even with these programs the co-payments can add up to thousands of dollars, and not just for seniors with disabilities, but also for younger people with chronic impairments. Four states do not honor these coupon rebate programs, Rhode Island being one of the four. pgs. 10-11 G. Reeve

Recommendations:

Allow the use of pharmaceutical company rebate coupons.

Direct state departments to aggressively go after federal grants programs to provide prescription drugs for younger adults with disabilities, not just seniors with disabilities.

E. Loss of Statewide Arthritis Program

About 24 % of Rhode Islanders have some kind of Arthritis, about 181,000. Most don’t know the type of Arthritis; there are well over 100 forms. For the next 2 years the federally funded Statewide Arthritis Program is assisting these people, but the program will need to continue. pg. 11 R. Martinique

Recommendation: To continue the Statewide Arthritis Program, beyond the current 2-year federal grant.

F. Mental Health Parity

It takes lots and lots of money for people with disabilities to lead productive, active, busy and fulfilling lives. With the state economy, the first thing taken away is money for these programs. There is a disparity between the supports for people with mental disabilities as opposed to people with mental illness. pg. 11 J. Fay

Recommendations: Establish parity in support services for all people with disabilities

G. Youth with mental illness

Need more programs to provide training in daily living skills, need supported employment opportunities. pg. 42 unidentified speaker

Recommendation: Improved services (see Transition)

H. CNA Training

There is a shortage of trained CNAs. Need to recruit people with disabilities to be trained for such employment. pg. 60 unidentified speaker

Recommendation: Funding for specific training with targeted population.

VI. Findings and Recommendations of the Housing Working Group

Chairperson Raymond Bandusky of the RI Disability Law Center
Paul Choquette of the PARI Independent Living Center

A. Home Accessibility Modifications:

There is an overall lack of funding for people with disabilities who wish to make their homes more accessible to them. There is also a lack funding for Section 8 Voucher landlords to provide accessibility modifications for tenants who have section 8 Vouchers. pg. 7 L. Canuel, pg. 79 C. Pollack, & pg. 115 S. Eleoff

Recommendation: Funding should be increased to provide these modifications for consumers. Also a mechanism should be put into place so that landlords who wish to rent to a person with a disability with a Section 8 voucher can make necessary modifications (low or no interest loans?).

B. People with Multiple Chemical Sensitivity:
Many people who have Multiple Chemical Sensitivity cannot live in multifamily rental housing due to the presence of chemicals in the environment. pg. 20 L. Naddermor
Recommendation: Provide Section 8 vouchers for individuals with MCS so that may live in single-family rentals where exposure can be controlled.

C. Handicapped Parking at Section 8 Complexes:
There are not enough Handicapped Parking Spaces designated at Section 8 housing complexes or they are being used inappropriately. pg. 24 S. Kimbriel
Recommendations: Outreach to Property Management companies regarding their responsibilities under Fair Housing Act and ADA to provide adequate spaces. Also outreach/information to tenants regarding the regulations.

D. Zoning:
Many towns have restrictive zoning that prevents certain types of accessibility modifications / adaptations. (i.e. in-law apts.). pg. 25-6 J. Mason
Recommendations: Legislation allowing in-law apts. Or other additions to homes to address the accessibility needs of people with disabilities.

E. Lack of Affordable Housing:
There is an overall lack of affordable/accessible housing for people with disabilities. Also those people holding Section 8 Vouchers cannot find housing that fits under the monthly rental cap. pg. 51 D. Sweet, & pg. 115 S. Eleoff
Recommendations: Provide incentives to develop additional affordable/accessible housing units. Raise the allowable rent for Section 8 Vouchers.

F. MHRH Group Homes:
Many people are upset over the potential closing of several group homes funded by MHRH. pg. 81 & 110 F. Trainor, pg. 83 P. Burgess, pg. 90 A. D'Antuono, pg. 92 Senator J. Sheehan, pg. 94 M. Martin, pg. 99 R. Jenkins, pg. 100-01 S. Bodington.
Recommendations: Provide advocacy support to existing efforts to stop the process of closing the Group Homes. Increase MHRH funding to prevent consolidation in the future.

VII. Findings and Recommendations of the Transportation Working Group

Chairperson: Anne LeClerc of the RI Public Transit Authority
Members: John Carroll of the Arthritis Foundation
Camille Pansa of the RI Statewide Independent Living Council

Findings are grouped into three categories:

The need to expand transportation options, especially public transportation services;
The need to improve RIPTA and RIde information available to the public;
The need to address environmental barriers to mobility and to develop accessibility guidelines that can be easily used by cities, towns, and private businesses.

The first two categories are divided into several issues, and separate recommendations are made for each issue. In some cases, more than one recommendation is given.

A. Expansion of Transportation Services

This testimony focused on the need for more transportation options or longer service hours. Transportation to and from work was also an issue. Some of the testimony is also cited in Finding 2 regarding the need for improved information.

1. ADA Paratransit Service

The lack of ADA paratransit availability during weekends when the bus route changes and when home is no longer in the ADA corridor.

The limitations of the ADA corridor. pg. 9 J. Behie & pgs. 113-114 James Spicola

Recommendation: Advocate for additional funding for expansion of the ADA Service.

2. Additional Transportation Services

The need for transportation and funding for some social groups for young adults. Speaker currently provides transportation and organizes program on an informal basis.

The need for more RIde buses.

Mother must drives her son or the staff from his group home drive him to her house.

The lack of transportation in the Westerly area. pg. 11 J. Behie, pg. 84 V. Qualiata, pg. 111 F. Trainer, & pg. 118 N. Warner

Recommendation Advocate for additional funding for expansion of RIde and RIPTA services.

3. Availability of Appropriate Transportation Options

[Quote] "We are…underrepresented in terms of transportation. We can't take public transportation because of gasoline fumes. Because of smokers on the bus, because of the scents and perfumes and detergents people wear on the bus." (regarding people with Multiple Chemical Sensitivity) pg. 20 L. Naddermor

Recommendation Determine and fund appropriate transportation options for people with Multiple Chemical Sensitivity.

Employment Transportation

[Quote] "…it's easier for me to work if I have a car rather than public transportation… It's very tiring to add another hour of commuting by public transportation to my day. I think a car is considered a work related expense."

That efficient transportation is a critical component for employment of people with disabilities. pg. 15 M. Pattison & pgs. 45 & 102 J. Panarace

Recommendation Advocate for consideration and funding of employment transportation within state programs aimed at improving the employment rates of people with disabilities.

Recommendation Exclude transportation expenses from earned income eligibility criteria when determining benefits.

B. RIPTA and RIde Information

This testimony had to do with lack of information about what services are available and what the requirements for service are, or about what RIPTA and RIde's procedures are and questions about the reasoning behind some procedures. Some testimony included is also included in Finding 1 regarding the need for more service.

1. ADA Corridor & ADA Information

Lack of ADA paratransit availability during weekends when the bus route changes and home is no longer in the ADA corridor.

The lack of information about the RIde Program. Speaker was not given information about ADA service, she had only known about RIde service for medical appointments through the Department of Elderly Affairs.

The distribution of free bus passes by RIPTA. Speaker questions whether RIPTA is following state law. The limitations of the ADA corridor. pg. J.Behie, pgs. 23-24 S.Kimbriel, pg. 67 C.Gibbs & pgs. 113-114 J.Spicola

Recommendation RIPTA and RIde should be asked to provide improved customer information about services available, including the bus pass program.

2. Disposal of RIde Vehicles

[Quote] "…the retired RIde vans and supervisory vehicles have been given to state agencies that have little or no association with the disability community. I understand that these vehicles have had wheelchair lifts removed and have been used to transport convicts by the Marshal Service. Regardless of their use vehicles purchased with funds earmarked to assist people with disabilities should remain in that realm. Subsequent use of these vehicles by organizations with disability related focus could and should be given top priority." pg. 9 S.Carr & pgs. 21-23 G.Levesque

The disposal of RIde vehicles.

Recommendation RIPTA should be asked to change their disposal procedures for RIde vehicles so that the vehicles continue to be used by the disability community.

3. RIde Hiring and Training Procedures

RIde procedures for hiring drivers and for communication between drivers and the dispatch office. Speaker states that RIde hires drivers who do not speak English well and that drivers do not know the area and should be trained for areas outside of Providence. Speaker also states that drivers use cell phones while driving. pgs. 65-66 P.Hopkins

Recommendation RIde should be asked to review the hiring and training procedures for drivers for all carriers under contract to RIde and recommend improvements where needed.

4. RIde Complaint Procedures

RIde procedures for complaints. Speaker states that drivers are told which passengers complain and that there are consequences to the passenger. Speaker asks that RIde not give out information about passengers or complaints and respect a passenger's right to privacy. pgs. 65-66 P.Hopkins

Recommendation RIde should be asked to review its complaint process and should stress the importance of privacy to its office staff and to the carriers and their drivers. RIde should implement procedures that protect passengers from retaliation for complaints.

C. Environmental Barriers and Accessibility Guidelines

This testimony centered around the accessibility of public rights-of-way and parking. More comments were made in this area than in any other.

1. Environmental Barriers

The lack of adequate number of accessible parking spaces in HUD housing despite the fact that the apartments are meant for elderly and disabled people. Only 3 out of 36 spaces are accessible. Another accessible space was taken away and given to the maintenance department.

Accessibility of sidewalks, crosswalks, and parking in Newport. Some attempts to improve accessibility have been ineffective. Speaker suggests that cities and towns consult with groups such as the Governor's Commission on Disabilities on design issues and accessibility of streets, buildings, and sidewalks.

The need to develop accessibility guidelines for cities and towns.

The lack of safe pedestrian access in Pawtucket.

[Quote] "When public buildings are identified, created, accessibility to transportation is not often considered… So my idea would be…that access to transportation be one of the criteria

that is looked at before a service is funded or a building or lease is signed for a public building."
The use of accessible parking spaces by non-disabled and the blocking of walkways by soda racks and planters.
The lack of accessible parking. Providence has given priority to a hot dog cart, and speaker was turned away from a lot at RI Hospital by an attendant who stated not enough spaces were available, though the speaker saw available accessible spaces. pgs. 24 S.Kimbriel, pgs. 27-28 A.Bourbonniere, pgs. 28-30 Senator J. Gibbs, pgs. 73-74 T.Carr, pg. 74 V.Ferrara, pg. 116 M.Belcher, pg. 115 unidentified speaker

Recommendation An accessibility guide should be developed to assist cities, towns, and private businesses in improving the accessibility of parking lots, crosswalks, sidewalks, and other walkways.

Recommendation Accessibility of buildings to pedestrian pathways and to public transportation should be promoted or required.

Part II. The Testimony

July 22, 2002 Independence Square, Kingston	
	Rebecca Martinque I think we are ready to begin. Welcome everybody. My name is Rebecca Martinque. I am the Program Director at the Arthritis Foundation for the first time the Arthritis Foundation is a cosponsoring agency for the series of hearings for the Commission on Disabilities. First I just want to make sure that Everybody has signed in before you leave we would love to have your name and address in the back of the room. I think we got all of you as you entered. There's also some literature in the back of the room, be sure to pick up before you go. And there are assistive listening devices. Try to also ask that when you entered that if you need one, I have some in the back of the room. A little housekeeping. If you need the rest rooms or telephones, you probably noticed that they are right outside the room. Rest rooms Will be on your immediate right and telephones are just across the Hall. Very easy. I just want you to be aware of the purpose of the program today. The purpose of the public hearings is to identify the concerns of people with disabilities and their families. In order to assist the State and developing programs to improve the quality of life of people with disabilities. The transcripts that are created from today's Meeting will be posted on the Governor's Commission on Disabilities Website. I'm sure it's probably on the handout somewhere. but www.gcd.state.rhodeisland.us. In about one week. Later this summer, The sponsoring agencies will review all the testimony and prepare recommendations which will also be posted on the website by the end of The summer. The recommendations and the transcripts will be printed And sent to the candidates for statewide and congressional office. And This will happen before the November election. And it will also be Sent to the newly elected officials of the general assembly in January. And finally, their commendations will be utilized to develop policy and Legislative initiatives for the next year or until they are Accomplished. Now I just want to take a minute to review the way we will do this with you. We want to give everybody an opportunity to speak, I think at this time we have four people signed up to testify and we will have people testify in the order in which they arrived. The panel member's role today is to listen. And they will try to gain an understanding of what your concerns are. They may ask you some clarifying questions. So, that will help us understand what your concerns are better. Because we

	have four people and we have about an hour and 45 Minutes, for our program tonight, we don't have any time limit this Time. But we - if we get a little crazier and more people show up we May have to have a time limit later on. But we will just ask you to be Brief, you know make your point as clearly as possible. And we will Just my role is to try to help keep things moving along today. Okay. I think now is a good time to take just a few minutes and Have the panel members briefly introduce themselves to you. So we could start at that end.
	Marie Younkin-Waldman: Okay I will try to be brief. Hello I am Marie Younkin Waldman, and I am the chair of the Rhode Island Council on Assistive Technology. Which is commonly referred to as RICAT. And it's an Advisory body to the assistive technology access partnership. Which Gets very confusing. But which is ATAP. And ATAP is federally funded Through the assistive technology act of 1998. The tech act and RICAT, Which is the council that abides this is actively involved in Legislative and other activities how to increase Rhode Islander's Awareness of and access to assistive technology. Many of the members Of RICAT use assistive technology, such as myself, I use hearing aids And assistive listening devices and cart. And RICAT works in partnership with ATAP, in removing barriers and improving access to assistive technology devices and services for individuals with disabilities of all ages. And I put a little literature on the back Table about the ATAP program if you are interested. just to name briefly the partners involved in this partnership, because they are all around Rhode Island. The office of rehabilitation service, tech access, east bay educational collaborative, ocean state center for Independent Living, the pole they are lack center at Rhode Island College and the Rhode Island Disability Law Center. And if you want to Find out more about ATAP, and assistive technology, you can contact our Information hot line. Which is 1-800-916-8324 or the voice tty number 401-463-0202. Thank you.
	Donald Churwick: I am Donald Churwick with the Rhode Island Department of Health Disability Health Program. Our disability health program is housed in the division of family health and we are federally funded With our program and we are accenting our activities this year on Communication impairment and we are partners are parry primarily OSCIL, And basically Brown University and Tech Access
	Ray Caroll: I am Ray Caroll from the Department of Human

	Services. I administer the Office of Rehabilitation Services, which has a number of programs, Vocational Rehabilitation Program. Assistive Technology Access partnership that Marie just talked about, provide services to The blind and visually impaired. And we also administer the disability determination services. Our purpose really is to assist people with disabilities to become gainfully employed and to be independent and to be fully integrated into our way of life.
	Anne Mulready: hi I am Anne Mulready I am an attorney at the Rhode Island Disability Law Center, and we are the federally funded law office that's been designated by the governor to protect and advocate for the rights of persons with disabilities in Rhode Island. And every year we are required by our federal funding sources to solicit information about what legal issues are most important to rough In Rhode Island. So this is a really helpful forum for us. Also Afterwards, we will be sending out a survey to anybody who has more information they would like to give us about their legal concerns. And I have a sign-up sheet that I will leave down the back, if people would like to get a copy of that survey. Thank you. People with disabilities
	Madeline O'Connell: excuse me. I am Madeline O'Connell a member of the Governors Arthritis Foundation, South Eastern New England we have our offices at the airport plaza in Warwick. Foundation primarily supports research, gives information and provides support groups, et cetera for anybody with arthritis. There are over 100 different kinds; a lots of People come to us for assistance.
	Andrew Egan: Good Afternoon I am Andrew Egan regional librarian talking about the bus program. We are part of the office of Information Services, our goal within the program is to provide reading material For K through 12 students to provide information and reading material For college students as well as to provide reading material for all adults in Rhode Island, that might benefit through our particular Program so we are always interested in getting feedback in terms of how to improve our services.
	Jane Hayward: My name is Jane Hayward Director of the Human Services in addition to the Office of Rehabilitation Services which Ray Carroll just talked about we also operate the Medicaid program here in Rhode Island, which provides services to those with disabilities, age 18 to 6 are 5 We provide a variety of services through that program and through Medicaid.
	Paul Choquette. Parry independent center also the Chairperson of

	the Legislative Committee of the Governors Commission on Disabilities. You are basically sort of both roles today. Wanting to Hear again from people about what's going on out in the community to Find out where we can look for in the next year to advocate Legislatively and policy wise to make things better for people with Disabilities in Rhode Island and look forward to hearing everything you Have to say.
	Kimberly Bose I am from the University of Rhode Island. I am working right now on the medication infrastructure grant which, is a four-year federal grant, purpose of the grant is to help people with disabilities live productive and independent lives. Thank you.
	Doris Duarte: I am Doris Duarte and I am on the Governors Commission on Disabilities as Commissioner and also on the legislative committee that Paul chairs.
	Mark Therrion: I am Mark Therrion from the Rhode Island Public transit, fix Route Transit Service in the state and also the manager administrator of the RIDE program, which provides a demand response services for disability and elderly throughout the state.
	Maureen Whelan Hi, I am Maureen Whelan and I spent most of my work life in the early intervention system, supporting families who have an infant Or toddler with delay or disability. Right now I am working at the Sherlock Center on Disabilities with Tony Antosh and my focus is really to look at how families transition from one system of service, early intervention, to life at three years of age which is often Preschool Special ed, but maybe community services or other early childhood programs. So my focus is really how to support families and give them the information they need. Thanks.
	Rebecca Martinque: Sandi Straus, Sandi Straus: Yes. Rebecca Martinque: this is Sandy Straus, what happens the name of the Organization. Sandi Straus: Vote for America it used to be called democracy compact but We just went national and changed the name. RebeccaMartinque: So Vote for America. And she's here to conduct Voter Registration for anybody who needs that service. And has her Literature set up in the back and I guess as people leave today you can Help people register to vote. So that's great. Welcome. Before we actually get started with our testimony, I just want to make sure that each speaker identifies themselves before he or she speaks and that will make the transcription much

	easier so that goes for the panel members when you are asking a clarifying question as well. As for those here to give testimony. So just state your name, and if You are representing a group, what group you represent that would be Very helpful. Any questions about how we are going to proceed?
HealthCare: Personal Care	Rebecca Martinque: Well our first person who would like to testify is Leo Canual. Leo Canuel: You almost got the spelling right. Canuel. Leo Canuel: I am the executive director of PARI Independent Living Center and I thank you for allowing me to come speak today. I Have a variety of issues that I want to bring to this hearing today. And some of them are more involved so please just stop me as I go along if there's something that I say that is a little bit confusing or you don't have if you have a question to it. The first issue I want to bring to your attention is the Personal Care Assistant Program here in Rhode Island, PARI administers the only Personal Care Assistant Program in Rhode Island. We have approximately 100 people now on the Personal Care Assistant Program and the program Is funded mostly in three ways. It is funded by Medicaid, the state is completely state funded program and also ORS has some slots that they right now are not using, but do have access to. And it is mostly a program to allow people with disabilities to live independently in the community and have their personal care needs taken care of by people they desire. Other programs you might be familiar with are home health aides the way this program is different The agency does not. There is no agency to provide an attendant to Come to your house. We provide funds and training for the consumer and The consumer hires who they wish to provide their personal care assistance. The particular program that I want to bring up today is the Medicaid funded PCA program. The medicated PCA program that we administer currently, currently has 80 slots therefore we can only allow 80 people on to the program. We have out grown that program, currently This is known as a waiver program of all the waiver programs in the State of Rhode Island, the Medicaid funded PCA program is the only one That has a waiting list. Even though that waiting list is small, we evenly have about five people on that program because we just started the waiting list a few months ago. It is important because what's been happening is we have been getting telephone calls from people. They Find out there's a waiting list and they go elsewhere. Or they are using home health aides people cannot go without services so they find Other ways of getting services. We have also been putting people on to the state PCA Program, the

state PCA program is 100 percent state Funded. We have a limited number of dollars on that program. If we Use them up, we have used them up and what that means is that the end of the year, people are going to go without services if we put too many people on to that program. Medicaid is willing to expand that program up to 150 slots. The problem that has happened is the governor has put a freeze on that and Has not allowed us to expand that and the state legislator has not allowed us to expand that. The whole point behind this and what we tried to explain to the state legislature this year is this is cost neutral. 48 percent of the Program is federally funded. Or federally reimbursed. And people Won't get services irregardless if they go to home health aides or we Put them on state PCA program. What's happening is it's actually Costing the state more money not to expand this particular program. So I'm coming to look for assistance at getting this particular program Expanded, up to 150 slots. I see two ways that this can happen. The First way is to get the governor to take off the freeze. And then Medicaid would be allowed to extend that. Medicaid is perfectly Willing to do that. However, we cannot do that. The other way is to get the state legislature next year to do it legislatively, to extend that. We tried to do that this year, and we Were not successful due to the budget cuts. So that's one issue related to the PCA Program. The second issue related to the PCA program is Rhode Island is one of the last states to Take their PCA program and move it into the modern era. We still say

Employment: Medicaid Buy In Housing: Modification	That current people that work, as PCA's are private consultants the IRS Does not look at it, as they were private consultants the IRS looks at It as these people are employees. And Rhode Island the Medicaid and State and ors PCA program right now do not look at these PCA's as employees. Therefore, no taxes are taken out of their pay. They do Not have workers' compensation or any other benefits that a normal Employee would have. We have been lucky so far that the IRS has not Come down on us as other states have had happen. And we also have been Lucky that no PCA has been injured in such a way that they have tried To sue the consumer or sue the state. I have heard of other horror Stories in other states where people who are on the PCA program have Lost their homes, have lost their businesses, have lost many things Because PCA’s have been injured and had no other recourse but to sue The homeowner for homeowners insurance or sue the consumer for what ever they can get. We really need to change that. We put in proposals now for three years into the state legislature to try to get this Changed. It means a little bit more money, but it can be done. We also PARI also needs an increase in our fee for services to Manage the PCA program. We receive $35 an hour to manage the PCA Program. We have been at this rate for a number of years now. We have Never gotten an increase. elderly services is receiving $65 an hour For the same service. But yet, we cannot get the increase of 45, which Is a what we are looking for so we really need assistance at trying to Get us up to a more marketable rate. We are basically operating our Program on 1995 or 96 rates. And as you know things have gone up. So those are my issues related to the PCA program. The other Issue is the Medicaid buy in program we really need to push this year To get a Medicaid buy in program and I know it's being worked on, I'm on the committee as well. But to get a program for all people with disabilities that are not eligible for Medicaid services at this time. Irregardless of what there benefits are even if they are working full Time. Other states have done it. Other states have gotten people with Disabilities on to Medicaid. People with disabilities cannot rely on Private health insurance. It doesn't work for most people with Disabilities. Medicaid is the best system and we need a rational Reasonable Medicaid buy in program for people with disabilities, either A supplemental plan to supplement their private insurance, and a full Program if they don't have private insurance. Last thing that I would like to bring up today is we need an Increase in dollars for home modifications. We now provide home modifications to people with disabilities so they can remain in the Community. Many

times people with disabilities or people with newly Acquired disabilities are still living in their current homes. And we Want to keep them in their homes. It's far more expensive to put People into nursing homes and just as -- just for human dignity Reasons, it's much better to keep people in their own homes. The home Modification program has allowed us to do that. The federal dollars That we get to do this has gone down incrementally every year, which Has been a problem. And the state dollars have been level funded for The past three years. We have not had an increase. We usually end up running out of dollars by February, March of the year. Combining the state and federal dollars. So we really do need Some type of an increase so that we don't have to tell people, I'm Sorry, but you have to wait two years before can use your bathroom, Before you can go in and out of your house without assistance. This is real human dignity issue that we need to bring to the forefront so People know that people are being carried and people are having to do Their bathroom routines in a kitchen or living room because they can't get into the bathroom. Those are my three issues I need to bring forward to the community today. I would like to entertain questions The committee might have.
Rebecca Martinque: Questions?
Rebecca Martinque: I guess I don't understand for the home modifications, Are you asking for -- is there proposal for a certain amount or different way of funding it?
Leo Canuel: We currently receive 200,000 from the state. We share that with the other independent living center. We do have a Proposal and have had a proposal in twice now to increase that to 400,000. By increasing it to 400,000 would put a good dent into the wait list where people would not have to wait more than 6 months in Order to get the services that they need. So far, I just want to remind panelists to state your name before you ask your question. You got me in trouble.
Gene Garvey: Yes hi State Representative Gene Garvey I am wearing two hats I am with my son John than. People know John than and Myself And my wife Mary Jane. You mentioned that during the year you went up to the General Assembly what procedure did you use, were you working with any special legislator, like Paul Sherlock or did you go directly to finance, I was wondering how
Leo Canuel: We went to we were working with Tony Pires as well as going right to the finance committee and testifying before the Finance committee of the senate and the house.
Gene Garvey: Did you come up with any legislation?

	LeoCanuel: There was no written legislation for most of this because it's all part of the budget Gene Garvey: Okay. I would like to work with you maybe, Leo Canuel: Sure. Gene Garvey: I would be glad to sit and talk with you. Leo Canuel: Okay Thank You. Rebeccca Martinque: Anything more? Leo Canuel Thank you very much. Rebecca Martinque: Thanks Leo.
Transportation: RIde	Lauren Rubins: My name is Lauren Rubins I am reading this for Steve Carr. I am reading this testimony for my boss Mr. Stephen J Carr who is very vocally compromised. He is chairperson of the Rhode Island Statewide Independent Living Council RISILC and a member of the Accessible Transportation Committee. Attack. He comes here today to offer testimony to this panel as a private citizen, however concerning Concerns with these issues. He says. Recently I wrote a letter on behalf of the membership of the Attack to Dr.. Beverly Scott General Manager of RIPTA, apparently the retired RIDE bans and supervisory vehicles have been given to state agencies that have little or no association with the disability community. I understand that these vehicles have had wheelchair lifts removed and have been used to transcript convicts by the Marshal Service. Regardless of their use vehicles purchased with funds earmarked to assist people with disabilities should remain in that realm. Subsequent use of these vehicles by organizations with disability related focus could and should be given top priority. Marla T.: Rhode Island Public Transit Authority is in receipt of this letter and we will be responding. Lauren Rubins (Speaking for Stephen J Carr) : Okay RM: Thank You, Stephen.
Education: Students	Jeanne Behie: I am here as a parent of a young adult with disabilities and I am also here representing Rhode Island Parent Information Network. Where I work as a Transition Coordinator in Southern Rhode Island. I have a few issues that I would like to bring up that I see a need for and these are issues that are brought to me by other parents and families that I work with and students. I think there's a need to really gather support for idea, reauthorization as many of you may know at this time the federal Government is looking to make some changes in idea and some of the recommendations include doing away with three-year evaluations in school, and doing away with short-term objectives. And that's all I Can mention right now because I haven't seen

	what the report is recommending. But it's quite concerning and we really need to I think as different agencies, as parents, as families, really write to our legislature to let them know that we do not want to do away with these laws. Another area of concern is I think their needs to be better enforcement of idea by the Department of Ed. There have been families that have had written complaints to the Department of Ed and they have not been acknowledged at all. So I think it's really Important that the Department of Ed enforces law because it's not right that families have the responsibility to get services that are promised Under the law.
Transportation	Transportation is an issue, paratransit a person may be eligible for paratransit during the week and in the weekend not be eligible because the bus route changes and it may be further than two miles away from the person's house then. So it makes it very difficult For people to get bus services on weekends if they are not quite in that area that's covered. Health insurance, and Medicaid has been brought up as a concern. And I want to reiterate that's very important.
Health Care:	Health Insurance for students who are in post secondary programs taking less than the required credits that may make them ineligible for the family's health Insurance. It's a very big issue for students. Also students or young adults or people with disabilities that are working part-time and therefore not eligible for health insurance from their employers. And Some of these people may not be eligible for Medicaid. I think it's very important to have that medicate buy in program. Also besides being a parent of a child with disability I happen To be a daughter of two parents who have disabilities now, as they have gotten older. In New York, there is Medicaid coverage for people who become disabled and require nursing homes. And in New York there's a law that spouses can transfer assets from the disabled person to the person to the spouse without the disability making the person with the disability eligible for Medicaid. And personally, my mother has paid for the last five and a half years for personal care assistance For my father 24 hours a day, 7 days a week, so that he could remain at Home and he could live a comfortable life. She's depleted many of her assets and it's not right that spouses should become indigent to take care of a spouse. This is done in New York. I would love to see it done here too. We talked about funding for home modifications. There's a program called Access to Independence, which is a way for families to keep family members with developmental disabilities in the house. There's very limited money that's funded

Employment Transition Socialization:	for this program. I don't even know If it's been funded for this year. I haven't heard that yet. But in My own case, my son would like to live at home. And he would require some modifications to the house. He would like a little apartment in Our house but there seems to be many demands for that limited funding. Okay. I don't know if any of you have ever applied for food Stamps. But it is quite an awesome task with page upon page upon page Of information that's required. When my son turned 18, and he applied For Medicaid, he was deemed eligible. And we thought he would have him Apply for food stamps and looking at the form I said there was no way I was going to subject myself or him to filling out that information. It's not right that it should be so involved. Okay. One thing in my work as transition coordinator and what transition is, is working with students and families of children that are 14 to 21 who have disabilities helping them access information and resources so they can plan for what they want to do after high school. And this can be post secondary training, it can be working, and it runs The gam us of giving them information of all of the agencies and Representatives that are out here. The one thing that's come to my mind, time and time again is questions about social groups for teenagers and young adults and there Is such a need to provide some sort of opportunity for young adults and I'm sure for anyone with disabilities but I'm here for young adults to get together for other young adult, RIPIN ran a mentoring program for young adults for a number of years and that grant ended. It was headed by Connie Sousa and the people that were involved in the program really enjoyed it. I have gotten so many inquiries about continuing it, that I do it on an informal basis in south county but I'm the one that transports these people. I'm the one that is the adult that goes to All the events and as much as I like it, I have a lot of other responsibilities. There's a real need and maybe with the Independent Living Centers, there could be a way of providing some sort of funding For that or some of the adult service providers providing more funding For some social groups for young adults. And I thank you very much. Rebecca Martinque: Any questions? Madeline O'Connell: Yes. I would like to know what they are proposing to change on the testing for the re-evaluation that you said. The three-year evaluation Jeanne Behie: I have heard that they want to do away with it completely three-year evaluation.

	Madeline O'Connell: So the child would be or the person would be evaluated at the beginning Jeanne Behie: I don't know. But I have a 70 page paper at work That I am going in to get tomorrow and I will be happy I also will have it on e-mail and I will be happy to e-mail a copy of the proposed draft for the reauthorization of idea to anyone who would like a copy of it. And if you wants I can pass around a piece of paper and people Can write their addresses or their e-mails on it, if I have a spear piece of paper.
Healthcare: Medicaid	Marie Younkin-Waldman: I am Marie Younkin. The question was about the Medicaid and the long-term disability insurance. And you said that in New York Medicaid paid the nursing home. Doesn't Medicaid pay for Nursing homes everywhere? Jeanne Behie: Yes, but in New York there's a law that a couple, when one has a disability and requires nursing home care they can transfer assets from the disabled person, person with the disability to the spouse without a disability, making the spouse with the disability eligible for Medicaid and then providing for the spouse without a disability, with some assets to live his or her life – Marie Younkin-Waldman: Okay because I ask that question because I know a lot of people are being persuaded to get long-term disability insurance Today because of that gap. So if you have the care, custodial care When you are at home as opposed to having Medicaid put you in a nursing home Jeanne Behie: Right. But a lot of those long-term disability plans provide up to 100 a day for nursing homes and nursing homes Cost much more than that right now. MarieYounkin-Waldman: Well I don't want to get into all that. The other thing I want to make a comment on, your thing about the youth groups. Young adults I think having been a former worker in the employment supported employment program, at Easter Seals, I can very definitely see a need for that. Maybe ORS has some groups like that because many times after placing people with disabilities in jobs, and so forth they do very well at the particular skill, but the behavioral skills need a little bit of help there and sometimes that causes them to lose jobs. So I think with the groups where they are learning about group behavior and different things and how to relate to people would be very important. Speaker: ray carol, I just want to acknowledge that something came in the office today on idea, which I just scanned basically, but I am going to send to you, Jean, kind of an edited version of some of the themes that are being discussed relative to the reauthorization of idea, which it appears will be

	reauthorized maybe in 2003 now, I don't believe anything is going to happen this year. And also in Rhode Island, next month will be the first youth leadership forum. There are A number of agencies and I know you are shaking your head because you are very much involved too, with this effort to mentor youth, particularly high school youth in terms of being a catalyst to organize social groups and so on and so forth. And of course, I want to acknowledge too that jean represents the RIPAN on the state Rehabilitation Council as well. A lot of good issues you brought up. Rebecca Martinque: Thank You. The next batch of sign in sheets, are there any other people Signed up? Thank you.
Education/Healthcare: Support Services	Rebecca Martinque: Okay. Barbara Remington. Barbara Remington: Hi. My question to the group is, as a parent of a child with a disability, who happens to be here with me today, and for a struggling with the state of Rhode Island, not only as far as an adequate and appropriate education for my son, but most recently also for adequate and appropriate healthcare. I my concern is how are we going to make that easier for parents. How is the state of Rhode Island going to best start meeting the needs not only of the child, but also of the entire family? I think sometimes people aren't aware of the enormous strain that the energy one needs to devote to advocacy takes not only on a personal level, I know for myself what it has taken away my role as a mother, as a worker. What it's taken away for my ability to be a contributing member of my community and of my career of choice. Because of the amount of energy I need to advocate for the things that my child justly deserves. As a parent in the town of South Kingstown, we have been through an enormous amount of turnover in administration. So from the age of three when we started dealing with IEP's is now the age of 14, we have been through so many administrators that with every new wave of the administration that comes in, it's go get them and then have you to reeducate everyone. We tried that. We are not going to do that again. It's been an exuberant amount of energy and I really hope on a going forward basis that we can address the needs that legally these children and these families are entitled to these services, please, please don't make parents and siblings advocate and bear the brunt of what the Law requires the state and the local districts to do. So, that would be my concern and also health wise. I was so disillusioned in this state by trying to get proper mental healthcare. We waited two months for in patient services. We were actually turned away by Hasbro, by Bradley, showed up at their door and they said sorry, we can't meet your

	needs Go home. I asked what my services are I could sign over. Then it would be seen as an emergency. I felt like I was in a catch-22 I was parent who was concerned. I was working so I had private health Insurance. Silly me. That really became a problem that I was doing what I thought was the responsible thing to do. I didn't want DCYF involved. I am a foster parent. I have adopted a foster child. I didn't want that involvement in my life with my own biological child. Luckily I was able to wear -- to weather this out at home with incredible services through perspectives cooperation they were servicing my son at the time because the town of Kingstown could not and had not been able to. They had really caused irrevocable damage to my son. So it was only through the help of perspectives we were able To maintain my child at home for two months until there was an opening. I find myself to be a rather educated woman and I worry about those parents who don't know how to advocate, don't know what they are legally entitled to, don't know their voices will be heard if they persevere. So I ask, desperately, that you think about the terrible, terrible burden this puts -- I don't like that word burden -- I think you take what a situation that is already challenging and the state and local levels are putting even more obstacles in our way and I find that just appalling I think it's disgraceful I really do. We want to help you oh, but jump over this hurdle. Jump over that hurdle and I find that to be a really sad commentary for the State of Rhode Island. Rebecca Martinque: Questions? Thanks Barbara.
Healthcare: Medicaid Employment:	Rebecca Martinque: I think we have gone through our list of people who were here to testify. I did mention that I had a question. Okay, I'm sorry I must have -- could you Melanie Pattison: Introduce myself Melanie Pattinson I'm not sure if this is the right place For me to be for this issue but I'm here to address the people who are disabled who want to work and become self-sufficient. Rebecca Martinque: Could you speak a little louder Melanie Pattison: I lost my glasses so I'm not sure I can read my notes but as it stands right now, I am disabled. I have always worked. I am allowed to make 780 a month over and above my social security benefits. I'm sure you are all aware of the figures. My benefits are 518 a month. Because I raised two children by myself and wasn't ever really able to work a full-time job, which made my benefits low. I have always worked. Now I am on the edge of being turned down for my benefits because for the last ten years, probably three years Out of the last ten years I have made over the amount and they are telling me that I am gainfully

employed. In order to stay within these parameters, and stay in the 718 a Month, that is before taxes, my house is breaking out now. My children are going out on their own the only place I can go is subsidized housings so that means although I can work approximately 20 hours a week, and I can earn approximately 1200 a month because my education and my experience, I have to turn that down and I have to go to the governor and ask for subsidized housing, food stamps, Medicaid, and whatever else the government has for you to ask for. 1200 a month, and my benefits, I can be self-sufficient. There are many, many parameters in this system that are wrong. They are telling me work related expenses. I tried to get my medical prescriptions as an expense. Well they said do you need it to work? I said well, yes. I need it to live. And I need to work so -- whether it's to live or to work, they fall into the same categories but they said no because there's one medication I can take, that I do take to make me able to work but the rest of them are not covered. It just goes on and on down the line. Expenses because I'm disabled, it's easier for me to be able to work if I have a car rather than public transportation. Run to go bus stops, running, in the cold after working a five, six-hour day it's very tire to go add another hour of commuting by public transportation to my day. I think a car is considered a work related expense. All these things need to be addressed in the system. I have been trying to talk to people and I have been trying to find out where I can go. I mean, I will go to Washington I will sit in Congress. And I will address this. I need someone to get me there.

Ray Carroll. Can I try to drop in. a couple things I would like to get your name and how we can reach you. But there's a couple of things happening in 1999, there was a law passed called ticket to work, and work incentives improvement act. And it will be implemented in Rhode Island next year. But it provides individuals an Opportunity and choice to try to work without jeopardizing their health Insurance benefits, and their payment. Also we have a benefits planning and outreach resource in the state that right now can sit down with you and take a look at some of these expenses that you are talking about, to see whether or not they can impact on your payment. and so forth. So the congress has acknowledged and recognized that there are many, many disincentives, work disincentives that will not allow individuals on social security disability or SSI to assertively seek work, for the obvious reasons that you talked about. So there are some efforts under way, and we can talk afterwards.

Melanie Pattinson: I would appreciate that.

Rebecca Martinque: Thank You.

I guess we can take a little break. We will be here. We are going to wait. We are here until 6:30 And if there's anybody has something they would like to raise, that hasn't been raised already. Well I think we need to take a little break. If anybody would like -- Sandy about voter registration she is in the back of the room.

Audience member: Reauthorization sheet, anyone know where it went so I Can take it with me?

Rebecca Martinque: we are just going to kind of officially wrap up our get together and we have more commissioners than participate -- panelists than participants at this point but does anybody have any other Concern, question, any last final words before we officially adjourn Our meeting?

Speaker: I guess I'm not really clear on the interaction between what was said, the role of panelists, and then the commission. Where -- besides just sitting and listening, it seems a fairly passive activity, what's the point of the panel.

Rebecca Martinque: Do you want to answer that Paul?

Paul Choquette: I can answer that. By having a panel, it is really an opportunity for people -- more than anything else it's an opportunity for the sponsoring agencies to be all together so that we can hear what everyone's hearing at the same time and also perhaps really network for lack of a better term so we really know what each of us is doing in here and I think also to maybe help out the people who are in the audience like Ray did earlier with that lady and by having a diverse group of people up here, maybe we have an answer for somebody right away. I think what we then do ongoing forward is sponsoring organizations, yours being one of them as well, will get together at the Commission after these are all done, we will meet to go over this, all the transcripts, from all five hearings and really what we will do is we will allow your group to have full benefit of the whole state and then whatever information that you think will be useful for you and your group and the people you represent, that you will have that to them -- really do with it what you want to do but also we think sometimes we found that a lot of the commonalities we found from last year to this year, the groups that were somewhat diverse worked together to advocate together or in a local level it gave an opportunity to gather more strength that way. What the Commission does is we listen to all the concerns. We try to shrink them down to say several key areas and then looking at -- like say transportation or access to healthcare, Medicaid whatever it might be -- and then we look at based on the testimony, what -- based on the testimony should the priorities be for the next year legislatively, policy wise and we try to prioritize things so we then look at basically my job as the chair of the legislative committee is to come up with a list of priorities and then tell Bob Cooper say okay Bob, you go do these and that's what he works only. What we do sometimes if we find something that needs legislation we will see if we get sponsor and advocate and support that Bill and we will try to keep people, our partners involves with this, if we need to have additional help, that's how we do it. So I think doing it this way, previously up until two years ago it was just the Commission, it was just a couple Commissioners sitting up here listening and we just found that there -- we needed to work together. One of the things we are all working independently. The commission was working independently, Arthritis Foundation all working on our own thing but we found so many commonalities it was better to understand what everyone was doing. It seems to work pretty well. That's in a nutshell why we do it this way as opposed, does that answer your Question.

Speaker: Thanks I felt like I was taking away more than I was contributing

Paul Choquette: We are here to listen. Sometimes again, sometimes one of us may have the answer for somebody. That's why I think it's important for all of us to be up here. Even if it is a hot night.

Speaker: And we are on the nighttime air-conditioning schedule.

Speaker: The building's owned by a nonprofit they have to save money where they can.

Toby Ayers: I am Toby Ayers Director of the Commission on Women I want to thank you. It's been very helpful to listen to what I have heard so far. And I'm actually coming tomorrow night as well. I have been listening with an ear to the issues and how they may affect women differently from men. And – I mean clearly there are some issues that might be specific to women, while it didn't come up in the testimony, with one of the panelists I talked a little bit about the lack of Mammography. A scan for women who are wheelchair bound there's no such thing in Rhode Island. I am thinking more of the issues I heard that on the surface sound non-gender but when you look at them in more depth, again the issue that one woman raised about a spouse becoming indigent in paying for nursing home care and at the same time when you look at elderly people in this state, women's incomes are significantly less than men's and women are more likely to be indigent so, I guess I, I guess I would encourage maybe as you ask questions, if those kinds of differences could be pulled out of some of the testimony that's given, that would be very helpful to me to hear. Because I'm having to imply a lot of that. And so part of my question is, as an audience member, if I have a question like that, can I jump in and ask that question to clarify as well?

Rebecca Martinque: Sure. I think we try to set this up as a forum, you know not really just -- try make it as informal as possible. I think it's important to again work together to try to figure out what's going to be the best way, how to meet the needs of everyone we are working with. we are here because we want to help people and we all could have our individual and group of people we work with but on a broader scale, what helps people you work with will help the people I am working with. I think it's important and actually, if I can also -- keep in touch can the commission because one of the things when we have to get together when these hearings are done an actually go through all the testimony, we need people to do that because it's a very daunting task, as you are talking pages, pages. My fingers are about an inch apart for the real-time person, so -- it is a lot and it's a lot to go through and we need people who are willing to do that, actually pour through the stuff. A lot of times we don't have people who want to do that.

Toby Ayers: I would be very happy. I think what you are doing Is very impressive. And I will be very interested to see some of the file of testimony that you get. So thank you.

Rebecca Martinque: I think 30 seconds I think we can adjourn.

Thank you so much everybody, and to the participants who are still here. And my mother in the back who helped me as a greeter tonight.
Speaker: Bring her out to dinner.
Quantros.

July 23, 2002 Newport Public Library, Newport

Doreen McConaghy Hi guys. For those of us who arrived on time, I would like to honor that and begin this process. My name is Doreen MConaghy. I am the Chairperson for the Governors Commission on Disabilities. I would like to start out by thanking everybody for coming. This is the second in the series of five public hearings that will be having this week, every single night from 4:30 to 6:30 from northern Rhode Island down to westerly. We have a panel of people here that are going to be earnestly listening to your concerns. We will be recording here. We will be taking notes. The process will be at the end of all of the hearings a transcript is created And then a group of volunteers who have helped sponsor these five hearings will then go through all of this information, and come out with a document -- (laughing) -- which will be available hopefully sometime in September. That document, as far as the Governors Commission on Disabilities is concerned will represent our legislative agenda for the upcoming general assembly here, beginning in January. So, I would like to thank everybody again. And if the panel could Introduce themselves, it would be very helpful.
Bill Inlow I am Bill Inlow I work for RIPTA and I am on the Governors Commission on Disabilities, Legislative Committee. And I can tell you last year I did participate in four of the five hearings and I was incredibly impressed by the comments made by persons with disabilities and by families of persons who had disabilities and that information was very important to the Governors Commission on Disabilities and to other organizations, other cosponsor organizations from the state of Rhode Island in developing priorities for services for people with disabilities during this past legislative session. So, these were important meetings and the words you say tonight don't get lost, they have an impact in very important ways. I hope that was all right?
Doreen McConaghy: Perfect.
Bill Inlow: I ran a little long.

Joyce Matthews: I am Joyce Matthews I work with the office of services talking plus which is the region I work for the blind we service the Public library for blind, visually impaired people.

	Annette Bourbonniere: I am Annette Bourbonniere. I am with the State Rehabilitation Council and that's the organization that works with the office of Rehabilitation Services. And I am also going to have my own comments, Which I will save to the end of this.
	Doreen McConaghy: what we are going to do is we would like to -- sorry Camille Pansa : I will introduce myself Doreen McConaghy: Absolutely, I'm very sorry (laughter) Camille Pansa: I sort of squeezed in at the end here. I am Camille Executive Director of statewide independent council. Frank Spinelli: I am also a panelist, but I am going to sit back here.
	Doreen McConaghy: Can you squeeze around? Frank Spinelli: Is there room? Doreen McConaghy: Squeeze right up. Frank Spinelli I am from the Rhode island department of human services I work in the sister for bell -- I would like to do what Bill said we participate a lot last year, a lot of very good comments and information. Not only use with legislative package by also used in terms of our programs design and policy, so we welcome any comments, thank you for joining us Tonight.
	Doreen McConaghy: In the back of the room is my cohort, Chris Lambert who works for the organization that employees me, PAL, and PAL is one of hosts for this afternoon. Our goal is to save the last 15 minutes for Any other questions and comments and wrap up. If people have come in and they intend to speak and haven't signed up, please do so. And People will be called in the order in which they signed up. Any questions? Chris, can you -- can you call up the first name because I don't have the list up here.
HealthCare: Housing	Linda Naddermor: It's okay for me to speak. I am Linda Naddermor and do you want me to face the audience or just address the panel or Doreen McConaghy: Address the panel I think. Linda Naddermor: I have what is called multiple chemical sensitivities anyone heard this before. It's very hard for me to be here today. So Take it easy on me if I have trouble speaking I am here to represent both myself and anyone else who has Multiple Chemical Sensitivities, other patients in the state have asked Me to represent them here. We have -- if anyone understands multiple Chemical Sensitivities to a great degree, you may realize that we -- we Feel that we are very under represented in

the state in terms of our needs. One of our primary needs is safe housing. And I think the housing people just simply don't understand that we can't be in regular housing, it's very hard for us to be. Right now I had to move through a force move and I am in a building where everybody smokes I had to put certain things in the building I am sick a great deal of time. Even the building materials everything else can affect us. So we feel that one of our first priorities is safe housing, for Multiple Chemical Sensitivity patients in Rhode island. Our second concern is the Consideration for medical care because when we go for regular medical care in any regular medical facilities although MCS is recognized by The ADA it's recognized by a number of federal agencies, doctors in Rhode Island are not educated to this. We have to have a regular type Of medical procedure, we are often ridiculed, they don't understand the illness, they don't understand the seriousness of it. We don't have any advocacy of hospitals oftentimes we are verbally verbalized I went into Newport Hospital with severe, severe Pancreatis and was told I had to be either -- I had to be an alcoholic because they didn't see anything of all their tests and they didn't understand in the medical literature it shows we can have these very serious life threatening reactions so not only was I seriously ill in a hospital that didn't have the facilities to deal with me because they were -- it was also chemically latent I had to be verbally abused by the doctors as well. Even advocacy for my own medical care and that kind of situation was very hard on me. I had to file complaint afterwards. I didn't know I was going to get out of that alive. So we feel the state doesn't -- we are under represented in terms of housing, under represented in terms of medical care, under represented in terms of transportation we can't take public transportation because of the gasoline fumes. Because of smokers on the bus, because of the scents and the perfumes and the detergents people wear on the bus. No one is addressing those needs for us as well. I am trying to -- you know put all of this in, in one -- in a short time so I don't take up all the time, but that's what I am here to say, we need some sort of advocacy at the Governors Office and we need these problems desperately addressed.

Doreeen McConaghy Any of the panelists have any questions?

Speaker: In terms of smoking on public transportation, we are -- are you referring to the fact that there are people who do smoke, not on the bus but the smoke is --

Linda Naddermor: Exactly, yes.

Speaker: Clothes, Hair.

Linda Naddermor: Right they are not allowed to smoke in public

	places but it does mean it is on their clothes, perfumes, scents, hair sprays Else. Speaker: Thank you.
	Speaker: Hi. Doreen McConaghy: If people have difficulties hearing any of the comments, I Would like to know that because what we can do is ask people who may have comments to kind of stand and face -- okay. Robert good. Francis good. Doreen McConaghy: Blair Baldwin. Blair Baldwin: I am going to pass. Doreen McConaghy: Robert Perrello. Robert Perrello: I don't care to speak.
Transportation RIde	Doreen McConaghy: George Levesque George Levesque: Let's see how I can put this. For the past year and a half, I have been trying to get RIPTA to recognize the fact that the RIde buses that were bought with federal funds, 80 percent federal funds, 20 percent contributed by the ride carriers, when they come off-line, should be given to non-profits that deal with people who need that form of bus. They have -- since they taken over the program, they decided that the buses are their private property to be dealt with as --as they see fit. And they haven't seen to see fit to do it in the proper manner. Now up until 1994, when this program was basically in the Department of Transportation, a lot of the arcs received vehicles and when the lease time of five years was up, basically they were allowed to keep the vehicles. They had to maintain them and pay for all the gas and things like that. And then after ten years, they were basically turned over to the ops, a lot of people haven't realize that had problem because of that because they have some of those -- it would be up until 93 vehicles on the road. Okay. Starting in 94, all that money was put into buying ride buses. And RIde took over basically the program of giving rides to the elderly, ADA, and the ops and other Groups. Which is fine and I think it has some problems but I think it's a pretty good program. The problem is that when those buses come off-line, and now we had two years of those buses coming off-line, the 94s and the 95s, actually I think the 96s too have come off. So we had three years and those vehicles, which are better, suited to the conveyance of people with disabilities, and better than the 15 passenger vans that are used a lot, should be put back into the community. And they are not. And I have been literally for 18 months banging my head against the wall telling them I have

promises from RIPTA promises from the Governors Office. And I just don't know where to go next. It's -- seems to me in tight budgetary times that such an easy thing to do, it's not -- it will not cost them one penny to do this. We will be responsible for all the maintenance and fixing it up. But to take a ride bus and put maybe 10,000 into it to build the engine or something like that. But if it's in good condition, is a lot better than going out and spending 30,000 for a 15-passenger bus that doesn't necessarily meet the needs. Okay. And to take these buses with their wheelchair lifts on them, and give them to other government departments, like the department of corrections and things like that, where they just rip them up. They don't want it for the wheelchair lift. It's just -- an obscenity. Really. And a lot of groups just having realized up until this time that they won't get replacements for their 93 buses. They are not going to get replacements for what they bought in 94. And I know for a fact that people have been calling up community organizations that used to get vans through the caps for the seniors and things like that are calling up and saying, well it's time for me to get a new bus and they say, no, you are not going to get it. And there should be a system in place to allow this to happen. And in fact, there is a system in place to allow for it to happen. I did all the legwork and contacted people and Mr. Inlow who has been very helpful by the way, it's not his problem but I sent him -- when I was turning in my buses I sent him a sheet from the governors office that they could have just signed it over to me. They refused to do it. He gave the sheet to his superiors and the superiors said no, you have to bring the bus back here if you want to get the new bus for the thing. And I said that's not the way it has happened up until now and they said, well that's the way it's going to happen now. And I got promises from plot green when I was ahead of the transit task force and he said this should be very simple to handle and I said yes, it should. And that was close to -- well that was probably about eight months ago, and now I am told that there are some people at RIPTA saying that we never even requested this. And I have written to numerous people, all the way from the head of the department of administration, right on down to all the people at RIPTA asking that these buses be put back into the community, which they are serving now, and allow to continue their useful life for the reason that they were built. And with the tax dollars that people paid. I mean the buses were paid for with 80 percent federal funds. The rest of the money comes from the carriers RIPTA did not put any money into the purchase of these buses. And I think the fact that

	they claim that they are theirs and they are treating them like they are other buses, is wrong, and I would like to see something done about that as soon as Possible. Thank You. Doreen McConaghy: Thank You. Questions? Speaker: I have a question. The lifts and everything still work after that period of time? George Levesque: The three buses that I turned in were in excellent condition. We have a very strong maintenance program that may change now that RIPTA is taking over the maintenance program but we had a very strong maintenance program for the buses and we had uses for the buses, and the fact was that we also act as a server for ride and when the new 2001 buses came they said you are not getting one until you give us one back in return, and that's the only reason why I mean I tried to hold off. Actually I did hold off for about a month (laughing) but when push came to shove I needed the new buses for the vehicles and so I brought them up there and they sat in the lot basically doing absolutely nothing, for six months. And now I find -- they moved them to another lot where they sat there. And that's irritating when you go up there and you know you have uses for these buses and you see them sitting there. And so no, they might not be as good condition as when we brought them there. But if I had the buses that I had turned in to service my clientele yes they were in good shape and they were in better shape then the buses I have. Speaker: Thank You.
	Dorreen McConaghy: Chris. Chris Lambert: That's all the people who have checked off who wanted to speak.
Health Care:	Sharon Kimbriel: Yes, I will. Doreen McConaghy: Sharon and then -- Sharon Kimbriel: I am Sharon Kimbriel a new resident of Rhode Island. I don't represent anyone, but myself and possibly disabled new residents to Rhode Island. And what I found in moving here, I came from Arizona in April. I thought I had done my homework through the Department of Elderly Affairs. I thought I had everything in order for the move here. And when I got here, I found out that what I really could have used was some advocacy program that didn't seem to be offered through the Department of Elderly Affairs. It's been very difficult since I moved here to get all my medical things in place. To get -- as an example, getting into the ride program, that could take my to my medical appointments and registering and finding out that I had to give

Housing	them from two weeks up to six weeks advance notice of doctor appointments, which I didn't have. And therefore, although I still am able to drive myself, that also is difficult because the facility that I live in has -- is subsidized housing apartments under HUD, they cater to elderly and handicapped people. There are -- I don't know how many people, five or six that I know of in the 36 units with handicap Stickers and vehicles. There are three handicap spaces. There were 4; one was taken away for the maintenance man. The management has their parking spaces and other people have to park around behind, walk a long way with canes and walkers. If there was some advocacy group or people that could help with things like that, also I just now learned after almost three months of muddling through all of this, that there is an American Disabilities Act I could join and that would have helped me with the RIde program. But until a resident where I lived told me that, I had no idea. Nobody in RIde told me that. They just told me I wasn't giving them enough notice for my medical appointments. And so I just want to say it's very difficult. I thought I had handled all the questions that I would have. If you don't know what questions to ask, you can't ask them. So had there been some -- had I been aware of some program or person that could have helped me with learning what some of the questions were, when I moved here I believe that my three months so far here could have spent -- been spent with much less stress and difficulty. Thank you.
Heath Care/Housing	Jeff Mason: Good afternoon I am Jeff Mason. I want to thank you for being as accessible as you are being by going around the state and listening to people from every part of the state. I have been involved in watching a start up in healthcare for the last 21 months that is a mission driven to try to ensure that people remain at home and out of institutions for as long as possible, and my approach is sort of multidimensional. A whole listing approach if you look at issues related to housing, issues related to socialization, to spiritually up lifting, et cetera. And I am hopefully only about two or three months away from actually producing the first housing aspects of my effort. My company is called Healing Homes. One of the issues that -- one of the many issues that I dealt with over the last 20 months and expect continue to do once I am actually up and running is the whole level of resensitivity that is really going to run the continuum relative to local zoning boards and their willingness to embrace -- I have one of the products -- university design master bedroom suite that can be leased or purchased and can be attached to a main reps dense or to the home of a child, et cetera. I know

having been the staff to the state house appeals board at one time, that there re certain communities in Rhode Island, as there are in any state in this country, that simply have a total nimby mind set and it doesn't matter architecturally what you do. It doesn't matter in terms of how -- the housing. It simply a need jerk response saying not in our community. And in looking at the success that the legislation has created back in the early 90s, relative to opening the doors to all communities for affordable housing, and also realizing that actually the disability community has been beneficiary of that particular legislation, homes that wouldn't be built today working from that piece of legislation. And what I would like you to entertain is the idea that there be another statute created essentially runs parallel to that. That speaks directly to people with disabilities who are trying to maintain their sense of place and remain at home and when a local zoning board acts in a totally arbitrary and capricious fashion when someone comes in requesting a special permit there be some level of recourse available to that individual at the state level that says we are prepared to give you a fair injury and that doesn't mean that's simply an express lane that opens the door to every situation but there's at least a sounding board and a legitimate medically appropriate well documented disability gets consideration than someone simply wanting to expand their house or something to that nature. Thank You very much.
Speaker: Could I ask sir, what special permits for what kind are you talking about?
Jeff Mason An example, A person wants to either lease or purchase one of my units and they want to attach it to the side of their house, and in a given community, there's a certain setback requirement. That if the local zoning board chooses, it's in their set of regulations, they can simply interpret that per the letter of that regulation. The -- a special permitting process would request a variance upon that particular issue where there isn't significant potential encroachment to the neighbors plot, et cetera. But taken this basically on a one by one situation, and making a determination where it's appropriate that this is not either harmful to a neighbor or to the neighborhood or the sense of community, but in fact is supporting that by providing for the needs of people with disability who will function much more fully at home Yes.
Speaker: Are you talking about like a module unit that you would bring in that I would have a master bedroom and a bath perhaps and stick it on the side or the back of the house.
Jeff Mason: Exactly.
Speaker: in England they have this program, the term is not very

	good Butts called a granny flat (laughter) sorry. But in the United States they are called echo housing, echo, anyway. Little units that can Stick -- they are an in-law apartment type thing. But then they can be moved as well. Right. You can take it off? At some day in the future if you wanted. Jeff Mason: echo, Excuse the pun but I am echoing their experience. HUD funded a pilot program back in the mid90s say can echo housing is something that particularly senior but certainly many people with disabilities can benefit by. They went into -- they had 100 allocations for 100 units, 20 were built. And I spoke to the consultants down in Maryland who spearhead that had effort and they said, largely it was a function of exactly what I am describing, local zoning boards simply saying, we just don't want it. I hope to -- as phase two, include an echo type of unit in the Total mix of my products and services. I have the entire AARP file on Echo housing. So I am pretty well equipped Speaker: so it allows the older person or person with a disability to still live in close proximity to their family but to have their own independent space. Jeff Mason: Exactly. I mean, the issues of independence and -- the other major issue of control that -- both the universal design and contextual component but I also have teleconferencing that allows people to stay in touch with their loved once if they are in work they can have a teleconference with them two or three times a day and allow their loved one to be a productive employee or worker in the scenario, not give up their jobs to provide the care for the person living at home. There's also a telemedical component that would provide monitoring to the hospital. Speaker: I see. So someone who might in appropriately be place in the a nursing home could be able to live as much more independence and. Jeff Mason: In their own like Rhode Island in the rest of the Country has to come to grips with this very quickly. This is a very compelling issue that is being recognized. Many people being overly institutionalized and this is -- it's not a panacea but it's one of the set of solutions that will be available to transition people out of institutions and into homes. Speaker: Thank You. Jeff Mason: Thank You.
	Doreen McConaghy: That's all for people who signed up to speak. I think there was panelist who wanted to say something. Did you want to say something? Annette Bourbonniere: I do. Okay. I am aware that a n

Transportation	Doreen McConaghy: Name Annette Bourbonniere: I am with a lot of cities and towns have committees to help in issues related to disabilities and I know Newport does not. and that's been -- as fond as I am of this city, I find that quite a problem. I have tried to sensitize them to some issues. And they are not terribly responsive. They did this nice thing on Broadway, where they put in this raised crosswalk, across from the City Hall, and that made it easy to cross -- it made it level with the sidewalks and that's great and then they actually even put a handicapped parking space next to it, on the wrong side. Nobody with a wheelchair can use that handicapped parking space because most people with wheelchairs get out of their cars on the passenger side, either they use a van and those all open on passenger side or they need to pull their chairs in and out. And you can't take the risk somebody is going to park right next to you. So I called them and asked them, could you just move that parking space to the other side of the crosswalk, where it would be perfect. and of course, it's still not done. And won't be. They have done other things like this. Your handicapped parking space in front of the post office. You know it's great to have one, of course it is the furthest parking space from the ramp which is not terribly logical but also, if you open your car door, it's right into a trash barrel. So you can't get out of your car there. So, it's ineffective. There's another one down on – I believe it's on Long Warf, and it's great. There's a nice handicapped parking space and right next to it is the curb cut to go up. The problem with it is if somebody's using that handicapped parking space, nobody else can use that curb cut. So, I mean, you know, on one hand I want to say, gee I'm glad they finally are trying -- there's actually one place you can cross America's Cup in a wheelchair. One. That's all. But that's one more than we have had for a long time, but if they would just seek consultation from, you know, individuals or have a committee designed to pay attention to this, you know they would be much more effective. And that's what I would like to see happen, is that it be mandatory that these cities and towns have some form of consultation or committee to deal with those issues, so that when they are making a good hearted attempt, that it's actually effective. Speaker: I hate to keep requesting questions Annett Bourbonniere: Go right ahead Speaker: Annette One of these sponsors of these hearings is the Governors Commission on Disabilities and they have full time professional staff who know a lot about design issues and accessibility in terms of streets and buildings and sidewalks. It

seems to me one thought might be to ask through the municipal organizations of the state that when they intend to make changes to assist people with disabilities, their citizens that first they get some advice on those changes from the Governors Commission on Disabilities. It seems to me that might make sense
Anette Bourbonniere: I agree.
Speaker: Or if they don't know someone local, I guess in every town, at least they could do that.
Annett Bourbonniere: Yes.
Speaker: wouldn't you agree
Annette Bourbonniere: That would be ideal. And I -- you know, tried to be very sensitive in the way I have dealt with it. I haven't called and said, hey dummies, or anything like that. But I really tried to be very sensitive and I believe that was one of the avenues I suggested. But -- it should be necessary for them to consult on things like that so that they are truly accessible.
Doreen McConaghy: We have -- Do we have --
Chris Lambert : There's just -- Teresa,
Audience member: I imagine Senator Gibbs does to, to thank you for coming down. While I only caught the ending, Annette, I see that parking space every day and it never occurred to me it's on the wrong side of the sidewalk if you are getting out of the passenger side. So I think your thought is well taken. Maybe even the Governors Council on Disabilities putting out some guidelines or suggestions. There must be something that we can coordinate to get the information to the cities and towns because as you said that's certainly a very good hearted attempt, well intentioned, to put a handicap spot intentionally on the wrong side. But just, we need to have more input from -- ahead of time. That seems advisory is always the best way. But thanks to awful you for traveling to Newport we appreciate it. It's always nice when The state officials come to the community, rather than the community Going to them. So thank you.
Audience Member: Well I just would say that I am here particularly as a representative of the long-term care coordinating committee which has over the years worked very hard on the connection of services as you mentioned, to try and get a whole continuum of services, and I think what you are looking for apparently is some kind of statewide legislation which would either empower or hopefully require the towns to consider this.
Audience member: as they have done with the home care housing over the last decade but they haven't come to that level of enlightenment by themselves. It required --
Audience member I understand exactly what you are saying

(laughter)

And I think when the legislature reconvenes too, this is a very Appropriate time for you to call one of us and suggest –

Speaker: this is sort of step one right here.

Audience member: Yes.

Audience member: I would be happy any other forum address it again.

Audience member: Yeah. I think that's very important and I personally can't see why they can't just move that handicapped parking space. That ought to be the simplest thing in the world.

Speaker: Just take up the sign.

Audience member: Are they not getting the message?

Speaker: I guess not.

Audience member: I don't think they understand because they are not In a wheelchair and you have to be in a wheelchair to understand what’s going on. I think you are talking about the parking space that's right Down in Warf, right next to that big hotel in Newport harbor front Hotel is that the parking space you are referring to?

Speaker: No. I was referring to the one on Broadway.

Audience member: By the town hall.

Speaker: across from city hall there's one across from Bowen's Warf It's kind inform bad shape too. I don't think there's enough room for you to open your van and get out on a wheelchair.

Audience member: is there any press here today? You might want to make note of that in the paper. It might reach somebody's attention.

Speaker: There are similar issues for the curb cuts. The telephone Company will come by and stick a pole in the middle of a curb cut Because it's a convenient place to put it. And so you come up to the Curb cut in your wheelchair and you have to go around the telephone pole, interesting. They also have bus shelters over which I do not believe the Department of Transportation has any authority because it's a privately owned company if I understand it correctly. And they -- Plop them where they want. Sometimes they are in an area that is very difficult for someone to come from a curb cut and go around. lots of issues.

Speaker: The person who just spoke didn't get introduced and I'm Produced to introduce her because I'm one of her constituents, Senator June Gibbs and I would like to take the opportunity to tell you I was talking to a woman today who's running for the state senate for the First time and I said, well I hope you can use as a role model, my State senator June Gibbs. I mean that. Very sincerely. And Senator Teresa PaivaWeed have been good friends with people with disabilities and elders in this state and that really needs to be said. But I would like to say something to respond to Senator Pivaweed's Comment you know I never notice that. In response to your point as Well. Those of us who don't have official disabilities, we all have abilities and disabilities, but those of us who can walk around freely, We need to be reminded periodically that other people don't move so freely. And we need to listen carefully. That's what these hearings Are all about? At sincere effort to listen to people with disabilities and family members and others affected by disabilities, and I think

That's very important that we listen and hear, and then respond.

Doreen McConaghy: Anybody that came in late that wants to make a comment? Okay. From the panel?

Jim Engstrand Thank you. I am Jim Engstrand a staff attorney at Rhode Island Disability Law Center. And sorry to be late, first of all. I got tied up on the streets of Newport. (laughter). Maybe redundant. And we are the federally funded agency to help provide some legal assistance on certain disability related legal topics, and we hope to provide advocacy that is often needed for a number of the issues that you encounter. Having said that, we are in the process right now of annually reviewing and revising types of cases that we have to limit ourselves to. Priorities for cases, and they are in a written document that's a public document every year. You can -- I brought a few of these years if you would like. Or contact us if you would like to pursue it further. Also I have a survey, if you would like to sign up, this year we are going to try to do a survey form and mail to a big mailing list to try to facilitate responses Coming back and get feedback on what people think are the important problems they would like to see us work on. Own a legal means, so I have a survey here I will put on the front of the table here, and you can help yourself to the mailing list. Thank you.

Doreen McConaghy: Yes.

Audience member: Hi, you are from the disability law center. I would like to suggest that you return people's phone calls.

Jim Engstrand: Oops.

(laughter).

Audience member I think when someone calls up and asks for help, and they are in immediate need you sometimes don't get a phone call back until two or three weeks after that even then they say we will have a meeting -- they ask you what's wrong and

	they will have a meeting to ascertain whether or not they will take your case and then they never call you back. So, I would like to make a suggestion that even if you can't take someone else's case that you call them back and let them know that and not make them wait and it might be a wise idea to call people back before three weeks, because sometimes people are in very Severe emergencies. Thank you. Doreen McConaghy: Yes. Audience member: Just like to apologize for being late and to say that I will be reading your report so that those who testify before I got here, I will get your testimony. DoreenMcConaghy We had let people know that it's going to be several weeks before all of the information from the five hearings are compiled Audience member: I understand. Doreen McConaghy: You can keep checking the Governors Commission on Disabilities website and that the document that is created, a group of volunteers who represent groups that sponsored the five hearings will be going through all of it and creating the legislative agenda for the Governors Commission on Disabilities for the out coming year. Audience member: And it will come to us. Doreen McConaghy: Yes. Audience member: I can assure you. Doreen McConaghy: I will be happy to let you know when it's available on the Web site too, June.
Recreation	Susan Cooper: I am Susan Cooper Director of Parks and Recreation here in Newport I know that the State Department environmental management has a comprehensive out door recreation plan. Are members of your commission involved in the planning of that? Because it addresses out door parks, beaches, state parks, municipal parks, and inventories all the sites around the state. I would think that, you know, two state agencies would probably give each other an opportunity for information and that is required by law every ten years to get the federal monies to improve out door recreation. Doreen McConaghy: The Governors Commission on Disabilities is supposed to get plans from any of the state offices and governors that are going to be either renovated or built and they should get the plans before the grand opening of the building Susan Cooper: This is an inventory. Doreen McConaghy: An inventory? Susan Cooper: It's the -- What it is is like their long-term plan for out door recreation space first they inventory what's in every

community and then they look ahead to see if it addresses the needs of the state. It's not particularly plans or any site, specifically.
Doreen McConaghy: The only thing that I can speak to right this minute, because I'm not Bob Cooper who has every fact at his finger tip is we have been involved in the last couple of years in legislation for safe --
Susan Cooper: Playgrounds.
Doreen McConaghy: Which I don't believe has passed yet, but every year it ends up on the agenda because there are playgrounds that certainly are not safe for any children and actually cause disabilities, and I believe that 2003, if they have not met the compliance, technically, many of our playgrounds could close. We are hoping that would be impetus to pass the legislation that will be coming forth.
Susan Cooper: I believe that Director Cooper has actually -- Newport is in very good shape because of her efforts I think we started off with four programs on bob coopers list now we are down to two. She had a quick vision of somebody in the playground and the right to work. But I think that document --I think that's actually overly Document I'm not sure it's the over all inventory that Director Cooper is referring to and that might be a good document for this commission to look at, to start taking a look at access to parks because if that's their bible that they are going by. It makes sense to me that that would be the point of which the coordination could take place makes a lot of sense.
Doreen McConaghy: Other comments? Thoughts. Yes, sir.
Audience member: I am going to wear my other that this time as a former Representative, hopefully a future Representative. There has been legislation introduced in the past. I know the house side, by relative -- that address what is the gentleman was talking about, in terms of -- I think you were basically talking about accessory apartments, and you run into a lot of stone walls with local zoning boards and things like that. I think that middle town has the ability - I think there's somebody that -- there's one person that has an official accessory apartment in middle town I think now. Maybe more than one.
Audience member: There have been individual cases
Audience member: Yeah. But that was just a naked legislation. I Think it would be very good for this commission to get behind -- just the neighborly legislation for local communities.
Speaker: one of the things that the commission historically talks About is universal design. This isn't just for a person who is in a wheelchair or who uses crutches, it's for someone who has

	arthritis, whether they are young or old. It's a young family pushing a baby carriage every time somebody uses a curb cut it's a wonderful thing, and it isn't necessarily just a person with a disability. So it isn't really a disability issue, as much as it is a global community universal issue. We are not there yet, collectively in our thinking. That's where we are trying to motivate people to go, and in the meantime, people are still putting their disability hats on because they are trying to push forward the agenda of people with disabilities but in the year 3,000, I won't be here I don't think. It's going to be universal thought, what is comfortable for everybody. Personal comment. Speaker: I wonder if I could ask a question from RIPTA. In Newport, Is that okay? Speaker: yes.
Transportation	Speaker: figure I get permission. Tough woman, I know this woman. Laughter. In Newport, lately you might have seen some strange looking new RIPTA buses. They are powered by compressed natural gas, which is more friendly to the environment. And they -- so they look a little strange. They are also called low floor transit buses. The floor of the bus is literally lower to the ground than a regular RIPTA bus. You only have to step one step up, and then you are into the bus. That’s good for everyone. Frail elders, persons with disabilities, women, or men carrying babies and groceries and baby carriages. Another interesting thing about them -- and I want to ask you a question if anyone has had experience with them -- the wheelchair -- There's a ramp and it's in the front of the bus, everybody gets on this bus the same way. Persons in wheel cares get on the same way through a ramp, not a lift, just the same way everybody else right where everybody else walks on to the bus. The wheelchair secure positions are straps that holed the wheelchair secure in place are in the front of the bus rather than as they have always been in Rhode Island, in the back of the bus and ways wondering if anyone here had any experience with those new buses yet. Speaker: Are those the trolley type buses Speaker: They are not trolleys. They are just strange looking -- (laughter) They look like turtles. With this big hump type thing, compressed natural gas is actually on top. But at any rate, has anyone ridden on any of those buses yet? Speaker: I guess not. I thought it was the trolley type. Speaker: they are only in Newport, but it is an example of RIPTA trying to listen. RIPTA does a lot wrong every day. We do a lot right every day too. One thing we heard from the disability community was we don't like riding in the back of the

bus. We don't like wheelchair lift that is don't work very well.
Speaker: Yeah, that's a problem
Speaker: And these buses are an example of us trying to listen. They have a ramp that folds out, fewer moving parts. No hydraulics, no electricity that works. It's in the front of the bus, and people with wheelchairs ride in the front of the bus.
Speaker: An example of Universal Design, bill.
Speaker: It is an example. It's better for everyone.
Speaker: But the trolleys you ride in the front of the bus
Speaker: That's true too. But trolleys are only mostly, there aren't too many of them. These new ones are the new type of transit bus that we hope to have more of in the future. But no one has had any Experience with them, okay. Well if you have experience with them, please call me at RIPTA. Bill Inlow and I would be most pleased to Hear from you. Thank you.
Doreen McConaghy: no other comments? Questions? Don't forget to visit our website www.gcd.ri.us
Audience member: State.
Doreen McConaghy: State --
Audience member: Just put www and you got the website?
Doreen McConaghy: Yes.

Sandi Strauss: I am Sandi Strauss I am from Vote for America. I don't know If everyone here is registered to vote.
Doreen McConaghy: You want to do a change of address.
Sandi Straus: Anything. I would very much -- Senator PivaWeed and Senator Gibbs. It was a Warm day, which weren't sure, what if thunderstorms come. (laughter).
Thank you.

July 24, 2002 Community College of RI, Flanagan Campus, Lincoln

Regina Connor: Hello everyone. I would like to welcome you this afternoon to This public hearing. I am Regina Connor, I am the project director for The Assistive Technology Access Partnership, or ATAP as most people know us. We are within the Department of Human Services, Office of Rehabilitation Services. ATAP is hosting this public hearing this afternoon. Okay. Before we really get into the substance of the hearings, I just want to review a few items so that we kind of all know What the process will be. We will first have the panelists introduce Themselves, giving their name and the organizations they represent. Then We will -- let's see here -- also I should mention that assistive listening devices are available for anyone who may need them. We have -- as you can see -- deaf interpreters and cart reporters for anyone who needs these accommodations. Okay. So

	why don't we begin first of all by having our panelists introduce themselves. Some are up here and some have joined you around the room. We think it's probably a much more comfortable situation for all of us. So
	Roberta Green: Okay. My name is Roberta Green I work at the Rhode Island Disability Law Center; legal advocate there and I also work as a funding and policy specialist for the assistant technology project.
	Chris TanboyAuto I am Chris Tanboy advocate for the Arthritis Foundation
	Dianne Kayala, Department of Human Services in the medical assistance office.
	Ann Leclere:I am Ann Leclere, planning with RIPTA
	Carol Ferraiole:I am Carol Ferraiole, chair of the State Rehabilitation Council
	Victoria Wilcox:I am Victoria Wilcox on the Governors Commission on Disabilities an serve on the legislative committee
	Susan Silva:I am Susan Silva have an I work with the Office of Rehabilitation Services and I am on the board for the Rhode Island
	Joyce Matthews: I am Joyce Matthews and I am with the offers of library and Information services. I work in talking heads plus Rehabilitation Association
	Jeanne Panarce: I probably should produce myself as a sponsor, although Bob suggested I sit in the audience because I am going to testify. My name is Jeanne Panarce and I guess my primary hat to wear is manager of the Disability and Health program. I am representing the Department of Health As a sponsor of these hearings.
	Arthur Plitt: Well I am Arthur Plitt, chair of the Disability Enterprise Committee, of the Governors Commission of Disabilities and also a Commissioner.
	Rod McMinn I am a Commissioner on the Governors Commission on Disabilities am also Co-chair of the Parking Committee and soon to co-chair the Accessibility Committee.
	Regina Connor: Are there any other panelists here that we missed? Okay. Thank you. Beverly Andrade: The purpose of these public hearings is to identify the concerns of People with disabilities and their families in order to assist the state, develop programs to improve the quality of life for people with disabilities. Now what will happen after we have completed the series of five public forums around the state, the transcript of the hearings will be posted on

	the governors commission with disabilities website, which is www.gcd.state.ri.us and that should happen within about a week. After That, later in the summer all the representatives of the sponsoring Agencies will meet to review the testimony and prepare recommendations. These recommendations will also appear on the GCD website. That will probably be by the end of the summer. Once that has been completed, the transcript, and the recommendations will be printed up and will be sent to all the statewide candidates for public office as well as the congressional candidates. In addition, the Newly elected members of the general assembly will also receive this material in January. And from these recommendations, program and legislative initiatives will be initiated over this next year. And really until they have been accomplished. So that issues that are brought up over the series of these forums will be considered very seriously and whether or not we are able to achieve the kinds of changes that need to take place this year, we will continue working until those accomplishments have been completed. What we will do -- hopefully everyone has signed in. And those of you who wish to speak have indicated so on the sign-up sheet. We will allow -- ten minutes for each speaker to present their concerns. We will also allow for panelists to ask clarifying questions of the speakers in order to better understand the issues at hand. And I would also ask that when the panelists ask their questions, if they identify themselves for the benefit of the cart reporter so that we will have an accurate transcript of today's activities. Okay. Do you have the sign-up sheet? Roberta Regina Connor: My understanding is we have four people that have signed up to Beverly Andrade: Let me just go in order. I know that one person on the list passed a concern about time would it be okay to have that person? Regina Connor: Yes.
HealthCare	Beverly Andrade: We have four people. The first one will is Paula Parker Paula Parker: Thank you very much. Thank you for inviting me to speak. I was intending to. My name is Paula Parker I am the Executive Director of The Rhode Island Partnership for Home Care. I represent the home healthcare providers in the state of Rhode Island, several of the visiting Nurse associations as well as hospital based home care and other home care providers. Frankly I came here today to hear from the Disability Community. But this lady asked me if I might offer some comments about

The situation in home healthcare. My job basically is to promote and strengthen home care services in the state of Rhode Island and the disability community is a large part of the population that we serve, as well as very disabled pediatrics and very frail elders. We have a very, very serious problem that I'm sure everyone here is aware of, and that is a lack of capacity. We work very hard with the state to build programs and to increase reimbursement rates for providers, but we are running up against a lack of available work force. And while we have programs that are available, we have funding sources that are available, and we have willing agencies that would like to provide more service, we are having a very difficult time recruiting and retaining home care staff. Unfortunately, it's a problem that cuts across all segments of the healthcare industry. And we certainly don't want to draw staff from the hospitals or the nursing homes, but unfortunately it's a very limited pool and we are all competing for the same work force. So, it's a problem that I think everyone in this room is very aware of. It's something that I don't see getting better in the immediate future and we are very open to any support or suggestions or help in terms of expanding community options for care. Thank you.

Carol Krause-Ferraioli: I have a question. I am Carol Krause-Ferraiole from the State Rehabilitation Council. The question I had -- the question I had is that you mentioned that you had funding sources. Do those funding sources also include available funds for scholarships for training of CNA's and a Licensing program?

Paula Parker: We have gotten a couple of interesting opportunities in The past couple of years. One was through the Department of Human Services; we actually got a small grant to train nurses and CNA's in pediatric home care. And that did result in a slight expansion of the work force to work with those cases. We are also currently working with the Department of Elderly Affairs and a grant that came through of the Administration on aging, to provide work force development and we have – We trained 50 CNA's last year who were already in the field, and we plan to do another 50. There are opportunities. What we really need to do is expand the pool of candidates, unfortunately. I think certainly the larger economy has played a very large role in people who want to do the type of very, very critical and very, very difficult work that's required of home care workers. When they have opportunities for perhaps a similar salary, including benefits and other compensation, to work at something that might be a little more appealing in terms of, you

	know, working at a retail setting or that type of thing. It takes a very special person to be committed to home healthcare; a very unique and committed individual and we really are committed to finding the very best folks. So, we just have not had a large pool of candidates from which to draw. Even if funding is available, we are just not getting the response. I hope that answers your question Carol Krause-Ferraioli: Yes, Thank you. Regina Connor: Any other questions from the panelists? Victoria Wilcox: I am Victoria Wilcox with Governors Commission on Disabilities, I am just curious since you know a lot about the problem, do you have any changes you would like to see made? Audience member: there are a couple of things that we think are very, very important. I have been on very many committees that have looked at, For example, the certified nursing assistant role which we think is, for many people, the hub of a successful home care plan. And one of the problems is we feel that it's not just a question of money and pay; it's a question of status and prestige and value. I think there are people who don't go into the work because they don't see an opportunity for advancement.
	I think in the past, they have felt disenfranchised from the Healthcare team. They didn't really know that their input was valued. I think they are under valued in general in our society, the status of that job. I think there are a lot of things that go into making a career attractive to people. And I'm not sure that all of those factors are in place for some of these home care staff people. It's something we are very, very committed to. We have worked with CCRI, we worked with the New England Geratology Academy, both train CNA's. We really think that a very Significant value in terms of salary and prestige and inclusion as well as opportunities for advancement need to be factored in. It needs to be seen as a career. And we have a lot of ideas about how to do it, so. Beverly Andrade: Thank You. Regina Connor: Other questions? Well, thank you. For your comments. Beverly Andrade: Thank You Paula.
	Regina Connor: Okay the next person was Noelle Siravo Noelle Siravo: Thank You. Please excuse my back. I am here basically to represent myself and my son Joseph Siravo who is 30 years old. Joseph is a victim of 22 que deletion and I don't know -- it's the letter q -- I Don't know if any of you are familiar

Employment	with 22q deletion but it is a genetic disorder it involved the 22nd chromosome which a portion is missing at birth. And this can result in a number of physical anomalies, as well as developmental anomalies and mental retardation. Joseph has had all his physical anomalies corrected, from the time he was born until age 12 he had 18 major surgeries done. Both if Rhode Island and at children's hospital in Boston. His IQ falls between 65 and 74, and he functions higher than that in some areas, it's pretty remarkable. Joseph was 8 through my prodding he was put into an early intervention program, 28 Years ago. That was really unheard of at that time in the Pawtucket School Department. He attended Curtis school and continued through the education system and graduated from Davy's high school both mainstreaming in some of their classes for special ed he was not able to speak until he was 7 and had to attend speech pathology classes three times a week until that age and then on a lesser basis afterwards. Joseph drives. He did not succeed with the drivers ed program at first but I found a Special Ed teacher that was willing to take him on and they worked with him and he is able to drive. He was employed by the Stop and Shop and shop markets for 12 years, recently resigned because he was in a position as a custodian that warranted his working six to 12 at Stop and shop and then two to ten as a custodian, it was a little too much. He was weeks away from the end of his third probationary period that they gave him, and this is why I am presenting his case today. Because I'm kind of at a loss. I think I spoken with people from nearly every agency here except perhaps from Arthritis foundation and Alzheimer's If they are represented, which I don't think they were. But I have contacted the Governors Commission on Disabilities. I contacted the ADA. I contacted the Human Rights Commission. I contacted the Disability Law Office. I will give you just a brief summary of Joseph's interview process. We had trained him for interviews before he applied for this position as custodian and he walked into the head of the department, who was to interview him on this particular day and the gentleman looked up from his desk did not even introduce himself and said oh, I just wanted to see if you have two arms and two legs. You can leave now. This is what his interview consisted of. That was a year and a half ago. They never told him that he needed to pick up any paperwork from the beginning of his job nor did they provide him with a job description. And I asked specifically for a job description because I know that his area of difficulty lies in abstract versus concrete needs. If he has some reminders or guidelines that he

can use in the workplace, he does much better. And I was not -- I was told there was no job description for a custodian. I have to give a great deal of credit to ORS. I was desperate One day. I work in the neonatal intensive unit in Women and Infants Hospital as the end of Joseph's first probation period they told him he could go home. They didn't need him any more that his work wasn't satisfactory at this place that he works at and I was absolutely beside myself. I stopped in at 40 fountain street sand spoke to Barbara Ridings who happened to be in the hallway and could he see how distraught I was. So she put me in contact with the correct people. And Ms. Leandy had an evaluation done and found he was in fact eligible for services through their agency, and has -- went through this whole big process an arrange for a job coach for Joseph so that this type of discrimination he is facing in the workplace would not continue. I want to just mention one extremely upsetting incident that he has experienced. And that was that on one particular occasion when he was alone in the building as a custodian, a maintenance -- this was an absolute horror -- a maintenance worker was sent in to fix a broken pipe and Joseph said to him, it's on the second floor in the lavatory, I just finished cleaning so the man said well I have to use the bathroom anyway so I will go up and fix the pipe. After he left, when Joseph went up to the second floor, this was one of his superiors; the man had defecated in the urinal. And left in a for Joseph to clean up. So we have situations that are -- things that would not -- people wouldn't do to their animals let alone to fellow human beings. The real sad part about this is that the place that he has been working is the Pawtucket school department and this is with the superintendent of schools in Pawtucket who's well aware of what has taken place. In addition, Dr. Deleth has ignored the request of ORS to work with Joseph and to provide a job coach for him, and to provide a job description, which I have since found out is readily available. They do have job descriptions for custodians it's just that they didn't want him to have one, I guess. The other thing is that he was injured on the job on a day when he was cents out to cut three foot tall grass with a lawn mower that was broken and he doesn't understand mechanics so he kept trying to push it, and it result in the an injury on May 30th. The school department has neglected to file a first report of Injury to workman's comp therefore Joseph has not been able to collect unemployment, TDI, workers' comp. He is currently not employed by the School Department they told him he doesn't have his job any more and he is in depression at this point. He has seen a psychiatrist because everything that we have worked so hard to instill in him about living independently and functioning independently and having pride in himself And in his work has been taken away from him. And so, when I did contact The disability law office they told me that they only handle people who are on SSI and Joseph didn't fall in because he's not on SSI so he didn't fall into that category. We have applied for SSI with him because he was making almost $13 an hour this is something my husband and I thought was a great job for him because he can do the work, and he would be able to function independently when we are not here anymore. On our next goal was to get him into independent living they said because he makes too much money he doesn't qualify for SSI so the human rights commission, however said that just the interview process alone was enough for me to file a complaint on Joseph's behalf. And when I contacted the Governors Office On dis -- the Commission of Disabilities, they told me that it would probably be in my best interest to hire a private attorney. The Disability Law Office also told me they would send me a list of lawyers that did handle situations like this but I have yet not received that. So I wanted to raise public awareness about this. About 22 q deletion, that people are able to function very well when they are afflicted with this, but they need to be given an opportunity. And I'm extremely grateful to the people from ORS for the work that they have done with Joseph and they have followed up with me on a weekly basis, to be sure that we are continuing the process of seeing that he gets treated fairly. So if anyone has any questions or they would like to know any more about it I would be more than happy to answer them for you.

Regina Connor: Questions from the panelists?

Speaker: I do have a question. You spoke so articulately and so thoroughly that, I think that's why there are were not a lot of questions. The only question I have is what exactly is it that you want. Do you want to file a discrimination --

Noelle Siravo: Absolutely.

Speaker: Okay. And you are having difficulty --

Noelle Siravo: I just don't seem to get any answers anywhere other than to hire an attorney privately and I find it hard to believe that this kind of a situation can exist in a municipality in a school department and not come to the attention of some of the government agencies that would oversee the education of these people, and yet not want to encourage them to succeed in the workplace. So, I'm just looking for someone to tell me what direction to go to with this because it's difficult to understand the ignorance of the public in a situation like this.

Beverly Andrade: Jeanne, did you have a question.

Jeanne Panarace: I just wanted to ask you, the Human Rights Commission said they would not handle –

Noelle Siravo: Oh, they would. They sent me the form; you know to fill out to file a complaint. Which, that's being done through the private attorney, actually it's Julius Michaelson representing Joseph, he's very familiar with employment law and disability discrimination law, but it's not, you know, I'm extremely frustrated that this type of thing can—just the worrying, the workman's comp filing a first claim and ignoring the work that Miss Landy put in from ors just is amazing to me that that can go on, and that it can be just blatantly ignored.

Speaker: as an Employee of the Pawtucket School Department, was he a member of any union?

Noelle Siravo: Yes he was. However because he was still under probationary period, the union will represent him but they really don't have any rights. They have filed a grievance. That grievance was supposed to be answered by Dr. Deleth within a week it has been almost two weeks now he hasn't answered the grievance. The next step is to take it before the school committee then it would go to arbitration. But Dr. Delethe is saying he doesn't have any union rights even though he pays union dues.

Speaker: And the union agrees with that?

Noelle Siravo: the union is fighting it just the same because they have seen some of the actions that have taken place, and they are fighting it as fairly labor practices, so they definitely will proceed with this. It's just that the actual superintendent of school has the final say as to whether or not they can represent him. He's not protected by the union rules.

Speaker: I think it's very important that you brought that to the attention of this panel because certainly our municipalities receive federal funds cannot be in violation of any federal statutes, and they certainly have.

Noelle Siravo: Well,

Speaker: Appear they have

Noelle Siravo: The Workman's comp thing they had ten days in which to file the report of first injury, and it hasn't been done. We have a doctor's note, everything. He was able to return to work on July 1, and he went down to the superintendent's office, the week before to find out which school he was to report to, and they said you don't have a job so don't report anywhere. So that was the end of that

Speaker: thank you.

	Noelle Siravo: Thank You for listening I appreciate that. Regina Connor: Thank you.
Health Care	Our next -- Jeanne Panarace. Jeanne Panarace I think probably I should mention at the outset that I wear a lot of hats but because I am also here as a consumer, we thought I should speak from the audience. Very a severe hearing loss. I sit on the Rehab Council, I manage the disability and health program at the Department of Health, I sit on a number of other committees and, I have been involved in the disability community for many years. At least one in four community adults in Rhode Island has a disability. One of the things that the disability and health program has done over the last several years is sort of take a leadership role and developing statistical information that can then be used by policymakers On programs, service providers. The -- these statistics, they are based on the results of what we call the BRFSS, the behavior risks factor surveillance system which is a major national survey that is done in each state, and over the last few years, the disability and health program has provided the funds for an expanded sample of the number of people who have called during the survey, and has also provided for funding of some additional questions related to disability, because this survey though does not reach people in institutions and does not reach people who use text telephones, we theorize that the numbers may actually be higher than one in four. The first item I would like to suggest for consideration for policy program development is effective legislation that assists with the cost of hearing aids. And by effective, I mean something that really works. My impression of the current legislation is that it allows the various insurers in the state to offer employers a rider (insurers) now what happens is the employer decides that the rider is too expensive and nobody ever sees that option. Now, I’m not talking about folks who, you know, might have a good income like myself and can afford to purchase the hearing aid. Right now, the costs run from 1,000 to 2500 even more, per hearing aid because of improvements in technology. That's a big chunk for someone who's not covered by any other health plan or might be living marginally. Most of the time people in my field are not going to buy a hearing aid if it is going to cost too much. That's one of the issues that I wanted to bring o your attention. The national council on aging conducted a major study of 4,000 individuals recently. And it showed that elders who do not have a use of hearing said suffer social affects decrease ability to

Assistive Technology Employment	function independently and have corresponding decrease in their functional level. The physical and psychosocial functioning decreases as the hearing loss increases. Many do not have or use hearing aids because of the cost. A Hearing Aid could actually be an effective way to reduce medical and social service costs and increase economic and social participation. The second item that I wanted to mention is the need to promote Assistive Technology and support it in the community. Health and social service providers need to learn about the benefits of Assistive Technology. Several studies have shown that at can increase functioning in independence of its users. One study in fact showed that over an 18-month period, 15,000 in healthcare costs were saved for those patients or consumers who used assistive technology. A third item of interest to me, the adaptive telephone equipment loan program needs a funding increase. I chair the Advisory Committee for that particular program, and for the last several years, there have been waiting lists of several months, up to six months, for a person to receive an adapted telephone. Now, in many cases that might be the lifeline for the person, and I do not feel that people should have to wait that length of time for a simple piece of equipment. We actually have two problems. One is the funding level. And the other is the slowness of the state purchasing system. And I think there are some ways that that can be modified to speed up the purchasing process. Last item that I wanted to call to your attention is the need to increase employment of persons with disabilities in all settings. Only 58 percent of working age Rhode Islanders with disabilities are employed. We need to increase that significantly through removal of disincentives, employer education, appropriate consumer preparation and support, and efficient transportation is also a critical component. Not just for obtaining a position, but for maintaining one's employment. At one of last year's forums a request was made for census data on disabilities that is now available in the census bureau and the statewide planning program at the disability -- the department of administration. In Rhode island, according to the census, 20.2 percent of the civilian Non-institutionalized population over age 5 has a disability. And is Mentioned only 58 percent of those of working age are employed. Now the reason, there is a difference in the definition of disability used between the BRFSS and the census, but I think that, you know, those figures are fairly consistent. One in four to one in five people have a disability. And finally, if you are interested in more disability data, I would like to mention

that the disability and health program plans a major data forum in the fall of next year. We will provide a comprehensive portrait of disability based on four major surveillance tools. The BRFSS, the Health Interview survey the census and another major survey, which will determine How many children in the state have Special healthcare needs. I know I covered a lot of territory, but I also wanted to mention, as I conclude that the disability and health program has partnered with many of the agencies in this room. And one of our major goals is to promote health and wellness of folks with disabilities. Thanks for the opportunity to speak.

Regina Connor: Thank you, Jeanne. I do have a question. You mentioned assistive technology. Do you know what the range of assistive technology was that people were using that enabled them to be more functional?

Jeanne Panarace: I would have to look back at these article specifically

Regina Connor. But I think -- I know that a number of items had to do with mobility, assisting people who had mobility impairments. One of the problems I encountered in doing research for the current grant that we receive is that there really isn't a lot of studies focusing on Assistive Technology and it's effectiveness. But I will say that, you know, next three years, the disability and health program is going to be engaged in a health intervention, which will have measurements before and after the use of Assistive Technology, that will provide some of the data that's needed on specific types of devices.

Regina Connor: other questions for Jeanne?

Anne LeClere: I have one.

Regina Connor: And --

Anne LeClere From RIPTA also the chair of the State Planning Monitor Committee for the state wide Independent Living Council, and is I related to my work on the council, you said with the data forum you are going to come up with additional data on disability. Will that include institutionalized people? One of the things we had very difficulty with last year trying to do a needs assessment with people in institutions was that we couldn't get into the institutions.

Audience member: I am aware of the difficulties you had because somebody approached me about going to the folks at facilities regulation to see if you could. These studies are not normally conducted in institutionalized settings, but that doesn't mean that the disability and health program couldn't at some future point conduct a special study. We can think about that. But

I know that most major studies, even with substantial government funding don't go into institutions.

Speaker: Just curious, Thank you.

Audience member: but I have heard though, I mean with obviously in the nursing home setting but also the correctional setting that disability rates are much higher. We will look at that.

Regina Connor: Any other questions for Jeanne from our panel.

Kristen Bole: Yes. Kristen Bole, Arthritis Foundation. Would you mind just reviewing the -- you spoke about $15,000 saved in healthcare costs. Where did that information come from, what was it related to? What's the sample of people was that taken from? Or was that just an overall –

Jeanne Panarace: I guess I should have brought that study with me. But I can provide it after -- it was a highly controlled, you know, professionally published research study that was done, I think the author's name was Mann, Dr. Mann. But if you would like I would be glad to -- it was done over an 18-month period they had two groups of folks. One group received assistive technology to help them function more independently in both at home and maybe outside the home. The other didn't. And they saw a significant savings in health costs for those that received the equipment

Kristen Bole: This was just a one-month study?

Jeanne Panarace: An 18-month study.

Kristen Bole: Sorry. Thank you.

Dianne Kayak I have a question. It's Dianne Kayak. Department of Human Services, you mentioned that the ATEL program needs more money. I was wondering if you have a sense of how much in funding would perhaps eliminate the waiting list for the adaptive telephone equipment loan program.

Jeanne Panarace: Yes. We have a little bit of a difference of opinion Between ORS and myself, but I think probably 100,000. It's currently funded up to 75,000 level. But I think one of the problems I have about funding is that it's kind of dependent on the appropriation process, whereas the original program was to be funded through a surcharge and well that money kind of got used up in other expenses. So I would almost like to see maybe a return to the original type of funding scenario. But I Think 100,000 would probably be sufficient.

Dianne Kayak: Thank you.

Regina Connor: Any other panelists

Roberta Green: I have a question Roberta Green just a follow-up to yours Dianne, is that 100,000 additional or 25,000 --

Dianne Kayak: 25,000 in addition to the 75. So a total.

	Roberta Green: Thank you. Regina Connor: Thank you, Jeanne. JeannePanarace: Okay, you are welcome.
	Regina Connor: Our next panel Beverly Andrade: Our next speaker, Michael Napolitano Michael Napolitano: I am Michael Napolitano I am really here in two capacities I am a parent of a ten-year old autistic boy and I am also on The board of directors for FEAT, families for early autism treatment. One of the first FEAT families in the state of Rhode Island to have a home program in my house through the use of the Katie Beckett Program through the Grownen Center. I went to see Dr. Evar Lovar speak in Boston several years ago and was impressed what he had to offer as far as home programs and actually hired one of his under studies to come out to Rhode Island to train a group of therapists to start a program. A couple of the reasons why I am here today. First one is I would like to talk about respite services. My son for the last two and a half years has received respite services, the first half year we received 50 hours. And the last two years we received 100 hours. There is a process of telephone call, I called Judi Hard graves, department of human services, I follow up with a written letter. When I receive a letter by July 1, authorizing the hours that we use for the entire year. When this July first came and I received no letter, I immediately got on the telephone. She did return my call within a week. And it was explained to me that basically everything was on hold. I spoke with Donna Hodges at the Grownen center in charge of 60 families that receive respite services, also spoke with several families that are members of feat that had the same problem. No one seemed to have any answers. Here we are on July 24th, still don't have any answers. My last telephone conversation with Judy pretty much said that these services were not originally intended for children that they were only intended for adults and I should be lucky that I was receiving them and they don't have to provide them, and I don't think she was taking it on me personally but I think she heard from so many parents she had just really been fed up at that point. So, to date I have heard three or four different stories. One story from another parent stating that we are supposed to get some of the hours and they are supposed to be sending letters. Then another story they are sending out a letter saying there would be no hours until they further looked into it. To date I have no answer and I don't know what is going on and no one can give me an answer. So that's one of the reasons why I'm here. The second reason why I'm here is I have been attending a series of meetings run by the state under

john young, in regards to the funding of the home programs that is done through Katie Beckett and they have been using it as a guise to obtain information, but as these informational meetings have been going along, they have been cutting hours. And many of our FEAT families home programs, they have been cutting super advisory hours, they have been cutting meeting hours, they have been cutting treatment hours, and they say it's under the guise of restructuring and coming up with better programs. Which makes absolutely no sense to me. So those are really the two reasons why I'm here today. I really -- more addressing the first situation because I can't get any answer.
Regina Connor: Questions of the panelists?
Dianne Kayak: I have one question I guess and that would be on the respite. You said you still vice president received any kind of letter at all.
Michael Napolitano : Nothing.
Dianne Kayak: Okay, Thank You.
Michael Napolitano: And my last phone call was a week ago. And I was told the same thing, everything is on hold. We are still looking into it but meanwhile, we are 24 days into the month and we should have known before July first. And I was basically told there's no money. And my response a to that was, well I understand that, but perhaps you might look into cutting the amount of hours down or doing something and she didn't have an answer for that either.
Regina Connor: I have a question
Roberta Green, I have a question. Michael, when was the last time your child actually received services under that program?
Michael Napolitano: Mid June. You see you have so many hours you have to use it in your 12-month year, which ends June 30th. If you don't use them, you lose them. And everything starts up -- they don't accumulate. You can't use them the following period. So when July 1 comes we have to wait for the letter, and start all over again. Generally the letter is there before July 1. Nothing this year. No phone call, nothing. No answers.
Speaker: did you receive a letter saying services were going to end or
Michael Napolitano: No. We know they end June 23. When they send you a letter approving (30n (your hours they tell you you must use these hours between July 1 of this year and June 30. So we already knew that ahead of time they were going to end June 30. Donna Hodges from the Grownen center makes a phone call to the families a month ahead of time if you require services for next year make sure you call, get your letters in. so Everybody

	does that. And I did that. I guess what happens the most irritating is we weren't even told there weren't going to be any services or weren't told anything, and couldn't Get any answers. Speaker: I can clarify a little bit about that. This isn't really the Place to do it. But I will wait and talk to you afterward. I can clarify I can't tell what you is going to happen. It isn't DHS at all we don't Have anything to do with it. Audience member: what department does Judi hard graves work for. Speaker: I believe it's mental health retardation hospitals Audience member: Okay. Speaker: Thank you.
	Beverly Andrade: Regina, are there any other people in the audience who would like to speak who hadn't indicated that in the sign-up sheet? Maybe now have comments that they would like to make. Jeanne Panarace: I have a question. I am wondering this federal fund fortress pit services that your son is using. Michael Napolitano: I believe it's state funds. Jeanne Panarace: it's all state funds
Assistive Technology	Beverly Andrade: Regina: Any other speakers? Among our audience? Regina Connor: We have one coming up -- walking slowly. The lovely blue shirt on and its Donna Lee Sweet. Donna Lee Sweet: I wasn't going to speak today and I am just talking off my top of my head. So, please bear with me. My name is Donna Lee Sweet and I work for a human service agency in Warwick. I go out to people's homes all over the community. So I get to see a lot of problems with services in the state And with the availability of supports for people of all ages. I do work under a grant relating to assistive technology so my first concern is the continuation of funding for programs to bring information out to people about the availability of Assistive Technology, because I -- no matter how much information I am aware of, it appears that very few people know what is available that can help them maintain their independence and do things for themselves and really -- their reliance on their families relieve another concern I have, relating to the Assistive Technology is support some comment that is Jeanne already made about the ATEL program, the adapt ever telephone equipment loan program. Quite a Few of people -- since most of the people I work with are elders, and are people who are visually impaired and hard of hearing, and have physical impairments, most --

many people I have assisted in filling out applications for the ATEL program and it's very discouraging to find months later that they haven't received any kind of word on the telephone. So, on the availability of an adapted telephone. So I did call ATEL myself in late may, early June and learned that the first 100 people on the waiting list might get a telephone sometime in the fall of this year. All of the people that I had assisted and was calling to check on had applied within the last two to four months. And their numbers were more -- they were down on the list around 140 to 185. So their chances of Getting a telephone would have to wait until the next purchasing cycle and possibly sometime after Christmas. So that's an awfully long wait to expect people to have to be patient for, and to have to go without being able to use a telephone. So I do support Jeanne's request for more funding for the ATEL program. It's really -- and it's becoming more and more essential as we age, more and more people are having problems and statistically can be expected to have problems with hearing and being able to use the telephone Another issue that comes up all the time is the lack of affordable housing in this state. It's becoming a terrible crisis situation. We at our agency receive phone calls several phone calls every day from people who's houses have been sold, and they can no longer afford the rent and they can't find affordable housing, even if they have a section 8 certificate they can't find a landlord that will accept the certificate because they can get double the rent that the certificate will allow. Their needs to be increases in what people are allowed to spend on -- if they have a certificate, and their needs to be an increase in the availability of subsidized housing. The waiting list for most subsidized apartments is quite long; if it's in a desirable neighborhood it can be five or six years. And that would be for a single bedroom. If you have a family who is looking for several bedrooms, that's impossible for them to Find a place that they can afford to live in. And this is something that's just escalating on a daily basis. Housing is a big issue that our legislature needs to look at. And there are many creative ways they can look at it. I myself notice all of the empty office buildings and industrial buildings which could be converted into housing complexes, but that's my own opinion. Another issue that comes up that has been coming up recently is a lack of services to support young people who have chronic significant mental illness they don't seem to fall under the department of developmental disabilities for services. Yet they need support for being able to live on there own in the home. In their own apartment or even to be left alone in their homes when their families aren't home. And these are just daily living supports that people who have fall under developmental disabilities criteria are able to get home care help and recreational help, as well as assistance with supported employment. But that doesn't seem to be available for young people, young adults who are -- have a significant mental disability and that -- I recently saw someone who has schizophrenia and it's been an absolutely impossible to find any kind of support services for that young man. So off the top of my head, those are just some of the things that I had to complain about.

Regina Connor: Thank you, Donna lee. Any questions from the panelists for Donna lee?

Kristen Bole: I do. Am I a panelist now Kristen Bole with the Arthritis Foundation

Carol Krause-Ferraioli Ihave one question, Carol Krause-Ferraioli

Beverly Andrade: Kristen first

Kristen Bole: You mentioned about the assistive technology and the lack of Information for people. What types of information do you feel would be most helpful to educate people in selecting, I guess, assistive devices?

Donna Lee Sweet: Well, I really don't know how we can -- I think we need to do more of what we already are doing, going out and doing public presentations, as well as training more professionals, other professionals that go into the homes, nursing staff and home making staff and even volunteer programs. There needs to be -- just more awareness of the general public. Continued -- the programs that are in existence now need to continue and be expanded. And it's – I think we are doing a lot on a shoestring right now.

Kristen Bole: Can you name one particular program?

Donna Lee Sweet: The ATAP project is really -- is really being spread thin in getting the information out. We are succeeding in getting the information out in some ways. But still every where I go when I do a presentation, I am still kind of pulling teeth and coming up -- and then at the end people say gee, I wish I had known what this was about because so-and-so should have been here. But in the beginning, you know, it's hard to get people to stay in the room because they say I don't need this. So I really don't know how to -- I don't have the answers. But I feel their needs to be more funding for continuing the program and expanding the program.

Carol Krause-Ferraioli: A couple of questions, a follow-up to the comment you just made. When you said that you felt you were getting the information out. Do you provide information on funding sources, because that usually is a stumbling block to Assistive Technology?

Donna Lee Sweet: Yes. We -- when I go out and do presentations and I'm sure when other people in the project go out to their various target populations, we do share information about funding that we are aware of and the funding is shrinking. Programs -- all the programs are shrinking and funding is shrinking and becoming more difficult to come by. So here are people who fall through the cracks. It would be ideal if insurers would see the value of Assistive Technology and saving dollars down the road. And would cover more at and most of the at that I deal with is low tech, inexpensive devices, mostly under 150, mostly under $20 per item, but if it is technical, it's pretty inexpensive for an insurer. In some cases it might be something in the case of a reading machine, it might be a couple of thousand dollars but again to be able to -- for a person to be able to maintain independence and avoid making mistakes that could end them in the hospital or a nursing home, it's a big savings.

Speaker: is there a comprehensive resource of funding sources or

Carol Krause-Ferraioli: No.

Donna Lee Sweet: Or is it catch as catch can. Would it be helpful if there were a comprehensive resource of those funding sources available to all, crossing disabilities, crossing providers

Audience member: I would be happy to see one.

Audience member: Carol.

Speaker: Go ahead.

Jeanne Panarace: I already approached the Disability Law Center. For lack of a better term, position paper on funding of Assistive Technology and we do also have information that we compiled so that we could distribute it to physicians. We have done several trainings with physicians and residents. My hope is that we can do training -- not only on disabilities but on the use of Assistive Technology and the social workers program, somehow incorporate that into the curriculum and into the Brown Medical School curriculum because these are two major professions that come in contact with -- not just the general public, but people who have disabilities. So we are hoping that maybe over the next year we will be developing some kind of comprehensive guide and physician paper that can be presented to the legislature and public agencies for their support.

Speaker: as a follow-up to your question about affordable housing, which is a major problem. There is a disincentive for

	developers to convert the types of buildings that you see empty in that HUD no longer funds disability on the same -- disability housing on the same ratio that it did. It is easier to build housing for the elderly than it is to get any kind of grants or supports to build housing for the disabled so that we are working against a governmental disincentive in that area. Regina Connor: Other questions of the panel?
Health Care	Siravo Noelle Siravo: I am not a panelist but I wanted to address the issue that our first speaker brought up regarding CNA's, care for elderly and pediatric patients in the home setting. I just wonder Female student: It had ever been thought of to approach the people who are in shelters or through Travelers Aid and see if HARI Hospital Association of Rhode Island would provide CNA training for these people so that they would begin to realize the importance of self-esteem and that they may be able to find employment that is gainful and meaningful to t hem, since many of the people who live in this type of situation have experienced tremendous hardship, and show a level of compassion for both pediatric and elderly frail patients would probably be there, and I wonder -- I know Harry offers programs that are -- eight week courses for CNA I wonder if perhaps collectively they would take on groups of people who may be interested. That's just a thought. Audience member: Yeah. And actually, HARI has discontinued their CAN program. They are no longer offering it unfortunately. One of the things that we do find, I represent home care agencies that are licensed by the Department of Health. And there are very strict regulatory requirements for people to be licensed to provide care in the home. And I think -- yes we are always looking for populations where we might recruit good workers. But again the standards are very high in terms of professional expectations. Home care is a little unique as opposed to institutional care, or facility care in that our workers need to be able to get themselves to the home to provide the service, they need to be able to work independently without supervision, so as I said, we strive to recruit and retain the very highest quality of folks. And we look at every option in terms of populations for recruitment. People do things creatively. They put value pack coupons, notices about CNA trainings. Supermarkets wherever they think people may be interest in the entering the profession They do. Thank you very much. We are always looking for populations to approach.
	Regina Connor: Are there --

Health Care	Jennifer Hanley: I came in late. I don't know if I would be able to speak for a couple of minutes. Regina Connor: Excuse me, I can't hear -- yes. Jennifer Hanley: Sorry I came in late I wanted to know if I could say a Couple of things. Regina Connor: Yes you may. Can you identify yourself Jennifer Hanley: I am Jennifer Hanley on the Governors Interagency Coordinating Council for addressing the issues with children 0 to five as well as the Autism Society of Rhode Island. I wrote down a couple of things. I want to make sure this is where I should be. Of course, mental health is a big issue with pediatrics right now, with the exploding amount of PDD and Autistic children. And we just don't have enough resources out there to Help rain professionals on these areas. And right now I am taking it upon myself as one person to educate a lot of pediatricians, who are reluctant or not, sending out pamphlets to the offices to educate the parents to educate the doctors in reverse action. I would like to know if maybe we can find some professional development programs to incorporate more of a state level of training professionals in these areas of autism. It is a very complicated type of mental health issue that many people, even being a mother of an autistic child and I am still learn ago lot of new things, but there is not only physical issues that are going on. There’s also mental issues. So that was something that I would like to see the Governors Council on Disabilities address as far as pediatrics goes and as adolescents with Autism. We are having some problems with specialty clinics and with the privatization of so many of them. And best practices, a lot of specialty clinics we are finding -- a lot of issues coming out of them with just the treatment of children with disabilities in there as far as mental health goes and autistic. Specifically phlebotomy area it's very difficult to find an phlebotomist trained out of a three to eight week course bringing from outside state training facilities and automatically drawing blood on pediatric children, with a disabled autistic child that's not exactly easy and a lot of the criteria’s that fall in the phlebotomy don't specify how many people are in the actual facility to be able to draw the blood, there's a lot of specifics in that area that are not covered. So it's very general as far as how best practices are in the specialty clinics as well as in the EG labs, MRI labs a lot of these specialty clinician that have gone private we kind of lost track of how their best practices and how they are treating people in the facility and kids are actually coming out of it with more problems they go in there. Especially a lot of stress and I say that as a mother, as well

Education	as for many other parents that are having an issue with this. I would like to see this addressed on a state level as far as going in to find out how we will deal with so much privatization of all of these specialty clinics as well as adolescent transition supports. We have a lot of children that are in High School or just in junior part of their high school and they are having a hard time with guidance to their transition into the independent world as far as finding more supports out there in the realm of commercial enterprises enabling them to become apprentice or working with them as far as that issue goes and I heard that CCRI is somewhat looking into a kind of pilot program to address that issue. But there are many pilot programs out there and they are very small. So we are not really grasping the whole concept of what's going at us so fast in this state right now with these amounts of children that are being identified with mental health issues. Also I would like to address something that's going on in the school systems right now because I am also a President of the Cumberland Special Education Advisory Committee in Cumberland and I know I am emphasizing Cumberland, but we have general education teachers that are refusing to teach children with disabilities in their classroom. And when it's addressed there is no disciplinary action, follow through on this particular area. And maybe sponsors -- it's not within my contract (response is) So I think the Governors Council -- Commission on Disabilities needs to look at the teachers union's contracts and how -- whether they are conflicting with the law of idea, individuals with disabilities education act, as well as section 504 and calm other areas because we are finding that for some reason, these contracts are coming into conflict with the federal and state laws and we would like that addressed as well. So I think -- I agree with the CNA issue. I have CNA at home because I am a disabled veteran from Persian Gulf so I have issues of my own and I needed the assistance with taking care of my son. So the CNA's that had come in, had not only helped my therapist with my own issues, relieved a lot of stress in my own therapy they also helped my son keep schedule at home and I said autism is very hard to understand and you know, I couldn't -- I wouldn't have enough time to go into explaining how important it is to keep structure, not only carrying it from school but also into the home. And to have people in your home to help you do that is very important and many parents out there are willing to just advertise, we will train if you can provide us somebody that's willing to come in here and help, just have a mentor or someone to work with my children, and I thank you for calling a public

Education	meeting and I hope that you can get something together for people that are disabled like myself. It's such a hard area. Thank you. Regina Connor: Thank you. Any questions? From the Panel. Victoria Wilcox. The Governors Commission on Disabilities I am just wondering if could you tell me a little bit more about what kind of transition programs you would like to see for adolescents. Jennifer Hanley: Right now, we are having a lot of parents call about the whole area of self-esteem, number one. And the transition from taking on so many things, including the fact that they are going through adolescents, now they are also taking on challenges of independency. So that's probably the primary area, the transition area. Victoria Wilcox: Thank you. Regina McMinn, Commissioner on the Governors Commission. Have you brought this to the Cumberland school board about the teachers contract? Jennifer Hanley: We did. And right now it's in -- right now it's being said is that we really need the staff. It's pretty much a staffing issue right now. We really need the staff so we are trying to adapt to the best way we can possibly do this. And because they don't actually have the teacher directly coming out, Superintendent saying I refuse to do this. This is where it's becoming an issue because it's not concrete. But they schedule the curriculums where the child is not in that particular classroom. Where if you have an advance math class where the child is in a resource class right now, but has come to a level where they can be mainstreamed into a general classroom and that's the only classroom that they are able to go in, there are different situations that come up here There is not enough room in the classroom all of a sudden. And there's a lot of kind of red tape and excuses to why that child is not in the classroom, without the back room always says other things. But when it comes down to the table. So what we have done in the special education advisory board is we submitted a letter to the superintendent to address the issues that are going on and to hope that that can be addressed. But being in the position I am, also Autism Society I am finding that this is not just in Cumberland, it's happening across the state. And one of my points that I made to our advisory committee was that prior to children being diagnosed they are in a general education classroom. A majority of these children that are coming up with add and a lot of or learning disabilities have already been in a

general education classroom. So my -- the way I presented to a lot of the parents is look at it this way. The general education teacher has already been teaching that child. Why is it ditch now that they have been labeled with an IEP or you know having a disability they have been already teaching all this time they were able to identify the issue. Why is it now all of a sudden quoted, as a disability and I can't handle that in my classroom now you need to put them in a separate classroom. It's a real big issue. It's a little bit of discrimination going on because now they are labeled. So we are having a big problem with that as far as inclusion goes across the state and the word inclusion is really hard because it can be taken either way.

Ron McMinn: Okay, Thank you.

Regina Connor: Jeanne, you had a question.

Jeanne Panarace: Not a question, more of a comment. I represent the Disability and Health Program at the Department of Health. The division that I am in also encompasses the early intervention program, and the maternal and child health program, which in its coming year must devote a lot more energy than it has in the past to addressing the needs of youngsters with disabilities. And you mentioned the need for professional education. That may be something that we can look at, especially with pediatricians who have -- need to be trained in working with youngster who is have serious disabilities I just wanted to offer it as a possibility for the future. We are developing a plan so certainly include the need of youngster who is suffer from autism as well as a health issue

Regina Connor: Thank you, Jeanne. Any --

Audience member: Question. Arthur Plitt. Has the transition academy proposal is that of any value?

Arthur Plitt: with the CCRI that's going on right now? We have had The director at the autism society that's connecting with the person with That -- sort of in the stage of development as far as with autism specifically going on right now. She hasn't gotten back to me on the specific details. But this just came up last week. So it's fairly new as far as that portion goes.

Regina Connor: Other questions or any other speakers at this time?

Jenine Dion: Regina if I can just comment on this last lady's dilemma I am Janine Dion, supervisor Office of Rehab Services. Have you been in contact with RIPIN because they can help advocate for that.

Audience member: Yes. Well there's a lot.

Jenine Dion: You are aware -- that's all I needed to know. The other thing is if your child is getting to be a junior or senior in

	high school they should be in contact with the Office of Rehab Services for continued service once they terminate high school. I just wanted to put that in. Regina Connor: Any other speakers?
	Monica Paten: My name is Monica Paten I am here from Vote for America I just wanted to let you all know one way you can definitely influence all these issues you are discussing is through voting an encouraging your friends and family and your children and their friends and family to vote and I brought registration, voter registration forms in the back if you would like to register or take some registration forms home with you to your friends and family. Thank you. Regina Connor: Thank you.
	Regina Connor: If there are no additional speakers, I would like to thank everyone who has taken time from their busy schedules to come here this afternoon and give testimony. We will certainly review all of this information that we gathered here today. And hope to be able to respond effectively to all the important issues that have been raised. Also I do thank all our Panelists for attending for listening to the comments from our audience. Thank you all.
Public Forum 7/25/02, Community College of RI, Liston Campus, Providence	
	Paul Choquette: I think we're all here. We're going to start our hearing today, I'll start by introducing myself, I'm Paul Choquette, the Director of PARI and also a member of the Governor's Commission on Disabilities. I would like to welcome everyone here today to this public hearing. This is going to last until 6:30, and we'll be sharing issues. Briefly what I'll talk about how we're going to run this tonight. Everyone who's here who wishes to speak will have an opportunity to speak. We have a sign-up sheet here in the front and some people indicated they wished to testify. If you didn't sign up on the sheet and wish to testify, you still may. Can you hear me now? All Right. Okay, I don't want to be too loud now. Now, I feel self-conscious holding this thing. Okay, should I start from the beginning again? I'm Paul Choquette, the Program Director of PARI and the Governor's Commission on Disabilities, and the State Rehabilitation house. We're going to have the next two hours available for people to present testimony to help improve things for the people with disabilities and their families in the state of Rhode Island, and what I'll start by doing is laying out a couple of rules and we'll move on to people who wish to present testimony, and at any time if you did not sign up on the sign-up

	sheet and wish to testify, you still can, just raise your hand. The only thing we ask is that you identify yourself when we speak is because we have a real-time caption person here taking a transcript of these hearings so that we can then use this information in the future to help plan programs and policies for people with disabilities. Let me just read this. The purpose of these public hearings is to identify the concerns of people with disabilities and their families in order to assist the state in developing Programs to improve the quality of lives of people with disabilities. We want to make share everyone can take part in the proceedings. Okay, again I'll read this one more time, the purpose of these public hearings is to identify the concerns of people with disabilities and their families in order to assist the state in developing programs to improve the quality of lives of people with disabilities. Bathrooms are back there around the corner. That's off to your left, my right around the corner and there's also a pay phone there if you need it. We have interpreters here if people need Spanish language interpretation, we have those available. Please indicate if you wish to have interpretation, and I think what I'll do right now is allow the Panelists to introduce themselves and tell what agency or group they're from and then we will move on to testimony.
	Dennis Costa: I'm Dennis Costa. I work for the Rhode Island Department of Elderly Affairs, I'm on the legislative committee and the Administrator of the Rhode Island pharmaceutical to the elderly program. Mark Therrien: I am Mark Therrien from RIPTA. We are the operators of the fixed route bus system in the state and also the managers of The RIde transportation services. Carol Ferraioli: I'm Carol Ferraioli. I'm the chair for the State Rehabilitation Council. Beth Perry: I'm Beth Perry from the Library of Office Information Services. We're in charge of the reaching the library for the blind. Don Deignan: I am Don Deignan. I am a member of the Governor's Commission on Disabilities. I'm the chairperson of the Governor's Advisory Council for the blind. I am the Vice President of the Board of Directors of the PARI independent living center, and I am also the Statutory Representative for patrons with disabilities on the library board of Rhode Island. Andre Mayer: ORS Victoria Ferrara: Hello, My name is Victoria Ferrara, I'm with the Sherlock Center on Disabilities and also a Commissioner.

	George Singleton: I'm George Singleton. I serve on the legislative committee. Ray Bandusky:My name is Ray Bandusky, and I'm the director of the Rhode Island Disability Law Center and a member of the legislation committee of the Governor's Commission On Disability and both developmental disabilities consult and the statewide living consult.
	Paul Choquette: Thank you. What the panel is here to do today is to listen to your concerns, listen to your Issues whatever they may be, and some people may take Notes. What we're going to be doing is to give people an idea of what's going to happen after this hearing is over. We've had a series of five throughout the state, we started in Kingstown, and we were in Newport, Lincoln, and we will be in Warwick tomorrow. We will then take the information and testimony that was presented at the hearings and use that to help us Decide or help decide which areas need attention in the next year for people with disabilities in Rhode Island. So, again, anything that you feel is important, that is the problem or whatever it might be, that we urge you to let us know so that we can take this information and use it. Many times what happens is individual agencies who are represented up here can actually solve some problems pretty quickly with information which is why we have this wonderfully large group of people here that have a great deal of experience working with people with disabilities in Rhode island. What may happen is if you do present some testimony, one of the panelists may ask a question to clarify what it is you're looking for. So we may ask you a question just to clarify things. So does does anyone have any questions on how this is going to run? If not, I'm going to grab the sign-up sheet and get to the first person who did offer to testify. Since we have plenty of time, we're not limiting the time, but if you feel there is something that needs to be talked about, we will give you some time to do that. The first person on my list is Mary Braun.
Financial Support	Mary K. Braun: My name is Mary K. Braun, and what I came to speak about was the way we have to live on the money that we get. There really has to be something done about the amount that we get because we're below poverty level. I made a little over $7,000 from the United States Government -- 10,000 and it's like most people that I know, they can't make it to the third week, the money is all spent. No matter what we do, and I think that people should be aware that we're not lazy. We want to work, but if we get a job, they take 50% off the top. Our rent goes up 30% and

Education	the government takes for every two dollars we make, they take a dollar after we go over $85. And uhm, I'd just like to know if there's something that the state could do to help us out. I personally am an advocate and get paid by stipends, which see me through the month. I get like 20, 25 dollars a month when I advocate and it's -- I have to live on that, and it's really tough. and I am on SSI, but I don't know about SSDI and people think we're lazy or stupid. We're really not. Some people can't live on what we get, and I just was hoping that maybe the state could help us out. I'm applying to ORS to go to school. I had wanted to go to Katherine Gibbs, but I think I'll get a better future if I went to RISD. I had taken a course at CCRI at the Knight campus in Warwick, in art. I want to do Claymation. They said at Katherine Gibbs, I could go, but I had to wait two years before I could take the course at CCRI, and I got a b out of that course and hopefully, I can go back to CCRI and get some more courses under my belt, because when I did apply to Rhode Island school of design, they said if I had courses under my belt, then it wouldn't cost as much when I applied. So I was just -- I'm lucky because I have ability and I know I do. Some people don't function on the same level as I do. They have more difficulty. They don't have the ability to talk up and speak up, which I'm doing a terrible job. I'm talking in circles. I think we all should have a good decent level of life, and all my money this month, I Bought an air conditioner secondhand for $145, then I had to get my food and pay my rent, which took $60 out of my rent, because I had to pay for 3 months of electricity and I just got the air conditioner in July, which was $145 because there was a $25 installment fee. All my money was gone by the 5th. If it wasn't for the stipends, I wouldn't have anything at all. I'm lucky because I can talk, but some people aren't into that. I don't know how they're going to do or get along. I have no family; I have to take care of myself. I have no family, I was an only child, and I just don't see how we can live like that. How people can expect to us live like that. Everyone I know and in PAC, we all want to work. We can't. Some people can't because they just are afraid of losing their benefits and I think it's up to the government to help us out because I learned that the government is here to help the people and we're not stupid, we're not lazy. We just need a little break so maybe they don't take 50% off the top. So they don't raise our rent 30% and take 20% from the SSI check. Something can be done; I know there can because we have smart people in the senate and the state, but we need help. Thank you.

	Paul Choquette: Thank you.
	Paul Choquette: Next person, Kathy Samways. Declining. Okay, the next person is Reverend Carlton Gibbs.
Health Care Diversity	Reverend Carlton Gibbs: My name is Reverend Carlton Gibbs. I'm the former pastor of Saint Paul's Community Church here in Providence. I'm a founder of the South Providence community concerned citizens and residents. I'm an African American, born in the United States of America. We see that there is a problem and we've attempted to address this particular problem with the governor and with the mayor and with the state attorney general's office. That problem is in the city of providence, the second largest city of New England and the capital of Rhode Island. There is not one black African American born primary care entrepreneur. Not one black doctor in their own office, their own facility, with their own staff. We have women doctors. we have Cambodian doctors, Spanish doctors, nonminority doctors, Jewish doctors, catholic doctors, not one black African American born primary care physician in the city of Providence and haven't had one since the 1920s. According to the Anthology By Mr. Andrew Bell who was our funeral director and if anyone should know it would be our funeral director, we've advocated that to those powers to be what I've just mentioned. That moneys be set aside for at least three Black American primary care physicians, staff, facilities, medications and they will reside here in South Providence, they would see whoever could get an appointment. They wouldn't necessarily see just African American people. We feel that from our experiences, that there is a subliminal euthanasia, or genocide, or final solution, or a doctor's plot. For those who follow the medical history, You Know What I'm talking about. Too many of our people are being over medicated, under medicated, over operated On, misdiagnosed or in some other ways not medically treated or given proper medical care. For some reason, it seems that the powers to be in the medical profession feel that African American people don't desire to have African American physicians. We do just as much as as oriental people desire to have a physician that knows about their culture and not have a doctor from South Africa who happens to be Black. And you can do that across the geographical. We need black American primary care physicians so we can question physicians with impunity and that doesn't happen as much as it ought to happen recently, when we say we have a pain in our rib area on our right side, we are often told that what you need is some narcotics for your pain. 100 pills for $6. But not x-rays, not

	MRI’s and not examinations that would verify one way or the other what the medical prognosis in some cases are talking about life and death. We have spoken with physicians that have graduated out of Brown University Medical School and they say that we can't stay here because the system Medicaid and Medicare and private insurers won't pay us. So we have to move out of the second largest city in New England and the capital of Rhode Island. Something should be done about it. I think that if you care, it would be easy for this group of people to do something about that. If you care. But only if you care.
	Paul Choquette: Thank you. Anyone have any questions for either of our two people who have spoken.
	Speaker: I have a question for Mary. Mary, have you made that application MB I had a course through ors paid through January and April, but I want to go back, I want to go to school because -- I'm sorry, Mary K. Braun: -- What was the question again, please? Speaker: The question was, are you a client of ORS? You said that you had been approved for services. Mary K. Braun: Yes, I took the course this past July. Speaker: Do you have a counselor? Mary K. Braun: Yes, Yes. Speaker: Thank you. Mary K. Braun Thank you.
	Paul Choquette: That is all I have for people who were signed to wish to speak. Is there anyone who is here who wishes to speak that did not sign up? Going Once? What we're going to do is we will be here until 6:30. So you don't need to necessarily if you feel you want to speak later, you certainly can. I think what we'll do is take a short break for a bit so people can chat if they wish to and we can come back together again in 20 or 30 minutes. We will be here and if anyone wishes to speak, look for the guy running around in the wheelchair at the speed of light. Thanks. (break) Paul Choquette: I think we're going to come back together again because I believe I have heard that there are a couple of people who wish to testify and Actually, I was given some testimony from Sharon Lane who asked that I read it for her. I'll do that and we'll go to the other person who wanted to testify.
Interpreter for the Deaf	Paul Choquette This is testimony from Sharon Lane. One agency -- excuse me -- one agency did I was selected as the agency that the state should contract for interpreter for the deaf. This agency also fills positions for other languages. Certified interpreters

	hesitate to offer themselves to the agency because the agency doesn't always use qualified interpreters for the assignment or the right interpreter as an ASL or signed English for different assignments. There's qualified certified interpreters are not able to be called on assignments and the state loses out on not having the best. What can be done to insure that agencies that bid for state jobs are qualified and have qualifications to do the job right? Thank you Sharon.
	Paul Choquette: Can you identify yourself?
Transportation	Paul Hopkins: Good evening everyone. My name is Paul Hopkins, and I am thankful that we have the opportunity here to speak up and speak out if necessary. I'm thankful that we have the opportunity to address and get acquainted with one another sharing our concerns. I want to mention the RIde program which is incidentally doing an excellent job overall as far as providing services to a few thousand people, elderly and disabled in the state of Rhode Island. They're limited with some of the staffing that they have, they're Limited with the reservationists, but they're basically doing well. There are three things I would like to mention where there are some problems and we hope and pray that they would be resolved. One is RIPTA, they send -- they hire Drivers that don't speak English very well and a few cases they barely speak English. I happen to travel with ride every day and I traveled with RIPTA most of the time. For the most part the Scheduling is good. They pick us up on time; get Us to where we're going basically on time, unless There's a driver who's out. What happens is the Run that I am on, there are several blind people and we travel, we commute to the insight center in this general area daily from the Warwick area. One particular time we got a driver who spoke very poor English, and had no idea where he was going In the Warwick area. And any driver, who speaks English well or not, should be trained to the Urban areas outside the city of providence. They Should know Route 2, Route 117, Route 5, Route 1, Post road area, West shore road area. They should have some basic knowledge. Some of these drivers do not and they're sent out on a route. This Particular day, this driver, I was the first pick-up, and when he looked on his manifest I was going to providence and there were several other people to pick up. He said oh, you go to providence? How far you go? And being totally blind I was taken in a little bit, figuring how am I going to direct this gentleman to the next pick up when he doesn't speak English very well. I was able to get to two or three of them, and fortunately when we picked up another person who

had vision, she was able to direct the driver with his limited English to pick everyone else up. So we hope that the training in other areas for drivers who are not familiar is necessary. Number 2, drivers who are driving on weekends in particular even during the week sometimes, they're using cell phones. There were several of us picked up going to Providence for a meeting, in the Chestnut Street area. He picked us up and used the cell phone the whole way and dropping people off. Very nice driver but was on the cell phone the whole trip. So, we ask that you know some of this should be resolved as well. The drivers have to concentrate on the routes, especially if they're not familiar with them, and concentrate on the passenger safety. This is what RIde is all about. Number 3, if there is a complaint that is turned into the RIde program because of either a misunderstanding with a driver or an actual offense, such as speeding, or even harassment, which sometimes happens, twice I had two different drivers two different carriers, one because of harassment, one because of speeding. And what I found out was, information was leaked out to the driver, and he knew who the complainer was in both situations. That's not good. The girls at ride should be trained to not give out information about people to either other drivers or to even other clients. As far as I know, the right to privacy act still holds in the state of Rhode island and in the united states. So, we ask that mark, who is here from RIPTA, guess I would be more aware of that in working with the staff and when there are complaints or if other RIde consumers are calling about other passengers that information not be given out unless they have permission to do so. But again, I thank everyone that is here that they have the opportunity to speak, and I thank the people from the different agencies, from rehab, from RIPTA, and from the Other services that they can be here to listen and to be familiar with the problems that do occur and the good that these services are doing and again, I thank RIde and RIPTA for doing, as a whole, to serve us and that we can serve RIPTA back by being patient and being honest and when a driver does need help, that we can help one another, which many times is the case. But thank you everyone for listening. We just pray that the services will continue to grow and the funding is there to help as long as possible. Thanks again.

Paul Choquette: Thank you, Mr. Hopkins. Anyone else who wishes to present some testimony?

Speaker: I've got a question. Reverend Gibbs when you were discussing the primary care physician, my question is what was

	the issue with Medicare and Medicaid as far as African American doctors being accepted through the payment process, or what was the issue?
Health Care	
Transportation	

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Reverend Gibbs: Thank you for your question. From what I've been told with respect to the physicians, is that the physicians are saying that they were not being paid, and that was the reason why they had to, after they graduate, relocate and go to other places and when one considers the fact that there hasn't been a black African American born primary care physician since the 1920s, you have to say there's something wrong. What I didn't say when I testified earlier and I want to testify now is I didn't identify myself as a disabled person, I have a spinal cord disorder, diabetes and pain from my toes to my navel with respect to diabetes, crushed right clavicle. I've been told I probably have liver disease or Pengertitis as well. I have pain almost every waking hour.

What I also wanted to say with respect to when someone raised the issue about RIPTA a moment ago, what I want to say about RIPTA is under the state of Rhode Island general laws, RIPTA has a free bus fare program for anyone who is a recipient of Medicaid, but that's not being implemented by RIPTA. They have decided to take it upon themselves to make a new law without going through the legislators and so they are not passing out the free bus passes to individuals who are disabled. Individuals who are disabled, I'm not talking about people who have children, that's on Medicaid, but individuals who have been on Medicaid. I presently do not receive Medicaid, Medicare, disability of any kind financial. I receive no social security disability, and I've been disabled since 1990. When on my wedding night, my bride and I were involved in an automobile accident because of a drunk driver. With respect to my attempt to get social security disability, I ran into some problems when medical records I discovered had been altered. I have two sets of medical records. The first set I received in January about 7 years ago and the second set of medical records I received five months later and they gave me an entire set as they had the first time only to find that those medical records had been altered. Why? I don't think it was a godly reason. It's often said that we don't have money to help bring in African American doctors, we don't have no money for that, but we've got money to give away to political cronies to pay for buildings, a 1.2 million for buildings that are empty and the building is worth $325,000, but we ain't got no money for life and death issues. Somebody needs to get serious. Somebody needs to get locked up. Somebody needs to go to jail for altering medical records and lying about there's no money for people who are disabled, people who are in pain. People who are

	hurting every day. $6 for a hundred pills won't do it. And if there's another, question I'll be happy to try to answer it for you.
	Paul Choquette: Thank you. Questions? Any other people who wish to speak at the moment? Okay, I just ask that you identify yourself for the record.
Health Care	Jeanne Fay: My name is Jeanne Fay and I'm the mother of a very beautiful lovely 17 year-old girl who happens to have both developmental disability and a mental illness and I used to grieve very much about my daughter's future. I used to wonder what would happen to her after she finished high school how I would make sure that she had a good quality of life. Then I began to work for PAL and I had the pleasure of meeting many adults with disabilities through my work and I realized that due to lots of good people like many of the people here in this room today, people with disabilities have productive, active, busy and fulfilling lives and I was really relieved about that. However, that takes money lots of money. And my concern is that with the State of the economy now, that the first thing that will be taken away is money for programs for people who have disabilities and that once my daughter leaves school in a few years, she won't have the kinds of supports that people are receiving now. So I just hope that when our legislators go to make the new laws or make change in the laws that they think about people with disabilities and they continue to provide the same level of services or even maybe an increased level of services, especially for people with mental health disabilities because I see that there is a little disparity sometimes between the kinds of supports from people with mental disabilities as opposed to people with mental illnesses. They seem to have much less support. So I just hope the funds are there a few years from now. Thank You.
	Paul Choquette: Thank You. Anyone Else?
	Norman Lincoln: My name is Norman Lincoln I used to live close to this building here on the South Side. We had the opportunity to move to Warwick. This gentleman here said some things and I was wondering if there were people who had the expertise, I was under the impression that the ADA Law which I felt was a dynamite law and I also might say that the ADA law if the civil -- one of the things I'm concerned about is when I hear of someone having difficulties and he comes to a meeting like this and there's no one here who can address this individual. That's some of the problems that happens because when we get sick and I talk about folks that look like me, or him when we get sick, there doesn't seem to be any help anywhere. You have to go

Health Care Transportation	to a doctor who's not in your community because like he said, we're short of everything we need, and I think we're going to come to a session like this, there should be some folks here who have the answers and the solutions. Sometimes we all don't have the answers. There are some people who work in this field. When he talks about not having any doctors of color in a community, that's a valid situation. Now, I live in the city of Warwick and I moved from South Providence to Warwick and it was like a different world altogether, because there are people here in the providence Rhode Island that teach other people different. I'm a retired military. I have two children and one is disabled and the thing that burned me up is when you serve your country for many years and your family is dependent on that military person, I could not take care of my daughter who has the disability. I had to emancipate her because the state had a better program than the military has. That was kind of upsetting to me as an individual because I Wanted her to have all the benefits I had as a military person because I think my family deserved that. It didn't go that way. When you look into the system, you find out that there are certain people being treated differently. I just came from a meeting -- if you treat me different than the rest of the crowd that's discrimination and if it's discrimination and you treat me unequal, I have to fight you because of it. So whenever you give to someone else and you make me fight for it, You're wrong and if I have to sue or do things like that. This gentleman here was pretty nice. A long time ago, if I was a person like this, I would go to a lawyer and sue. The ADA was going to help all folks that were disabled. They made buildings and buses accessible. But what is it if you're of color and you don't have these advantages. He mentioned something also about RIPTA But I don't hear any feedback. If he said that RIPTA is doing something wrong, then the Person at RIPTA should acknowledge or not acknowledge it. If you know that there are no doctors of colors or caregivers then there should be a way of getting some caregivers. There's no sense of coming with all your qualifications if nothing is said. I would like you to address this individual and address it in any way that you can. Privately, in a letter. I'm sure he will give you his name. Why should he leave here at 6 o'clock with the same problem he's had for 12 years. I want some answers. If I can't get the answers now, then give it to me later on, but at least get to some solutions. I thank you very much.
	Paul Choquette: Thank you, I can address your concerns -- the reason that we're here is to hear this information because I know for myself, this is the very first time I've heard this as an issue.

	So I think one of the reasons we're here is to gather information from people. And if people that are here on this panel do have a solution or can help with that, we can do the best we can to do that today. There are some things that can't be solved right now, maybe can't be solved tomorrow or a month from now but by having the courage to speak up and bring up the problems is how we can begin to get solutions. I'm not trying to put you off, but we need to know them and this is the opportunity to do that which is why we have these get togethers around the state. I applaud you for bringing this issue up. And if there is a member of this panel or someone here today that can start the process with you, I'm absolutely positive that we can do that. Be assured that we are here to do that and listen to this. We offered a sign-up sheet for people to speak. If you wish to sign up later, I'll get the sheet back to you. Anyone else? Let me ask you, the people who came in late, let me refresh why we're here today. We're here to do a public hearing to hear the issues that people with disabilities and their families have that will help us and help the state become a better place to live for people with disabilities. Again, we're looking for things to help people with disabilities and problems for the people with disabilities. Identify yourself.
Health Care	Stacy Peck: My name is Stacy. I found out within the past three years, that early intervention in the state of Rhode Island is a free service and I was very thankful for that. I have a son who is three years old and he has trouble with speech and language, and I had him tested and found that he was delayed. So I went and from that point sought early intervention and it was great. They tested him, they made sure that he would get the services that he needed and I was very pleased at that point. At some point, I got a language therapist to work with him and she was excellent. She did everything that she needed to do to engage him in language and I saw small developments along the way. Midway through, that speech therapist left and I wound up having to have another speech therapist come in and work with him. It was very difficult to see but instead of speech therapy, I was watching play therapy. She would place toys in front of him and expect him to speak and nothing was happening. He wasn't progressing. When I brought this to the attention of the speech therapist, she basically told me the philosophy of the program that he's in is for them to learn through play. To me it makes a bit of sense if you're taking whatever it is that he's playing with and engaging him to speak and creating a vocabulary and building on his language, but I didn't see that and my question goes towards, is there some form of formal way to bring this issue so that the therapist is doing her

	job. I just felt like I brought it to her attention, and nothing was done personally, and I was just wondering if there was some formal way and if so, what can I do to make sure that my son gets services that meets his needs?
	Paul Choquette: Thank you, Stacy. Do you want to address that right now?
	Vickie Ferrara: I'm Vickie Ferrara, and I personally don't have the answer for you, but within the Sherlock Center, one of the staff addresses early intervention issues and helps with advocacy and I would be happy to give her your name or I can give you her information and you can call her. Her name is Maureen Wayland and our number is 456-8702. And I would be happy to speak with you further after the session today. Paul Choquette: Thank you, Vickie. Anyone else who wishes to speak at the moment. Actually, I would -- I recognize someone who entered the room representative Antonio Pires is here. I would like to welcome him here. We're here until 6:30. We'll do another little break and see if anyone else comes or if anyone else thinks of something else they wanted to say.
	Kathleen Samways: My name is Kathleen Samways and I'm here not with a problem but with a resource an information resource for people. I'm representing the Rhode Island Council for Assistive Technology. The council for RICAT because we are state advisory, we have to have an acronym, so we're RICAT, we're the supportive and advisory body to the assistive technology project and the Assistive Technology project helps people get access to Assistive Technology. Assistive Technology is defined as any kind of an item or device a piece of equipment or a product system that increases, maintains, or improves functional capacity for an individual. Many of the RICAT members use that technology or have family members that use it. We advocate for access to Assistive Technology because it facilitates -- such as voting or attending meetings. It reduces the risk for injuries such as falls, it minimizes the occurrence of secondary conditions such as circulatory and inactivity, and improves quality of life for bottom line people. It also has been shown to decrease health care costs. Our partners are the office of rehab services, the Tech Access, which is the central resource center in the community and will do demonstrations for people in the community. We partner with the east bay collaborative that addresses the needs of the children in schools up to the age of 21. The ocean state center for independent living that provides information to elders and with sensory impairments to increase

	their capacity in their lives. The Sherlock Center at Rhode Island college which helps us assess the effectiveness of our programs but also obviously runs other programs that can be of help to folks in the community and the disability law center where the funding specialist works who assists people with other barriers to assistive technology and I just want to give folks a number to call if they're interested in more information about the council for assistive technology and the access partnership. I could say our operators or standing by but probably not right now. There is an 800 number, 916-8324 or a tty number 463-0202.thanks for letting us talk here today and we hope we can help people with their access to technology.
	Paul Choquette: Thank you, Kathy. Anyone else? Questions?
Health Care	Toby Ayers: Thank you. I'm Toby Ayers. People have talked about technology and there are some really Assistive Technology, it seems to be Money for technology out there. I just wanted to raise one specific question in terms of women who are seeking mammograms in Rhode Island who are disabled and wheelchair bound for example, what I've been told by women who are disabled is that there is no mammography machine in Rhode Island so For their testing they need to go to Boston. Is Anyone aware of that, or what is preventing Rhode Island from getting those machines and having that t Technology accessible? It doesn't seem like it ought to be a big problem to me, but maybe there is a piece of it that I don't understand? Thank You.
	Paul Choquette: Anyone have an answer to that? I know I don't have one. I'm glad you're raising that. Again, that's why we're here. When we hear the results of these hearings and we have these recurring themes that come up, those are the areas we'll be addressing, to make the changes that need to happen, make changes that are needed in the community either through health care providers or from the technology to provide screening for people with disabilities so that's why we're here and that's why we want to listen to these things. We are here to listen to these things, listen to these issues and do the best we can to solve them today. Many of them can't be solved today, but because they're raised, they can be solved soon. We've been very successful in the past and as a result of these hearings making some good changes for people with disabilities, we've been able to expand programs, make prescription drugs available for people of ages 55 and older, and that's as a result of these hearings. The problem of affording prescription drugs. The issues that everyone is raising here, we're listening and working with you to try to make

	these changes. So anyone else? Thank you. Carol just reminded me, this transcript that our cart person is so diligently taking is going to be printed up and bound and sent to all of the candidates for statewide office and also federal office. We'll also be doing a summary of this testimony. This group of people here and other representatives from these agencies will be getting together to come up with a summary of what was brought up and that summary will be sent to all the candidates for office so that they know what the issues you are bringing up are. I would also like to mention that this transcript will be on the Governor's Commission on Disabilities website, we hope to have it up in three weeks and I thought we had some handouts with information from all of the sponsoring organizations, contact information, telephone numbers et cetera, and I believe I have them, I just have to find them. Again, I think we will, if I don't see anyone who has a burning desire to speak at the moment, we'll take another quick break and get back together in 20 minutes just before we close at 6:30 so that way if anyone does feel they want to speak, they'll have an opportunity to. Thank you. Paul Choquette: I think we will do one more opportunity before we adjourn for the evening, and I believe we had one other person who had stated they wished to say something. Then we'll wrap it up.
Transportation	Terry Carr: Good Evening. My name is Terry Carr and yes, I was not going to speak tonight. I did speak last year about the sidewalks in the city of Pawtucket. When I was a fully sighted person and driving, I thought nothing of the sidewalks. I thought who uses sidewalks? We all drive. But now as a legally blind person, believe me, if I was alone, I wouldn't go out. But, since I very often have the opportunity and the pleasure to leave with Mr. Hopkins here so that we can go to a restaurant or various places around the city and can't, we can't get the RIPTA bus for that all the time, but so, very often we walk and find out that there are some places that we -- it's just too dangerous. Fortunately in my own neighborhood, we can walk in the road. There are a few places, the sidewalks are either unlevel or grassy or turf. It's very very difficult, even with a cane and I have fallen on two occasions On the sidewalk, that seemed to be okay, but just because it just changed you know, levels, but more than that is such things as cars being parked on the sidewalk so that when we reach it, there's no way around it. I have to take a totally blind person and get out into the road to get her to maneuver around and of course, that's dangerous. My vision is about five to ten

	feet, so we have to go by hearing. When I say vision, I have vision for around me, but not at a distance. So I find this very scary. The other thing is the obstacle in the way, cans, poles, fire hydrants right in the center of the sidewalk unbelievable. Newport avenue, and I did mention this before, at the intersection of beverage hill and Newport avenue where they extended the intersection beautifully, but the signal lights, the red lights, the poles that hold the red lights are planted right dead in the center of the sidewalk and there is less than two feet on each side of that pole. Coming up to that area, I have to stop, and have Paul walk behind me or separate, just say we're coming to a pole, I'm going on this side of it, you go on that side. There is that little space. And this is a big you know, big intersection. Extremely dangerous. So I just would like to see something happen to evaluate this, widening the sidewalks. They've already done that and that's probably why the fire hydrants are in the middle of the sidewalk. I don't know what the answer is, but for persons who are blind or impaired, children, mothers with baby carriages, all of this is a terribly, terribly dangerous situation. So, uhm, thank you. I just wish something could be done. Thank you.
	Paul Choquette: Thank you, Terry. Any questions for Terry from our panel? Okay. We have someone who is now stepping up, removing one hat and putting on another one.
Transportation	Vickie Ferrara: Hello, my name is Vickie Ferrara My concern is related to the access to public buildings. When public buildings are identified, created, accessibility to transportation is not often considered. For instance, the network Rhode Island office in Warren, which is supposed to be a place where anyone can go look for a job, does not have access to public transportation. In many of the vendors that state agencies or federal dollars support who provide services to people with disabilities and for people who are in low income, are not accessed by public transportation. So my idea would be for future contracts for public buildings or if they're being developed for funding for public services that access to transportation be one of the criteria that is looked at before a service is funded or a building or a lease is signed for a public building. That's a low cost solution for a time when the budget seems to be quite tight these days.
	Paul Choquette: Thank you. Okay. I think it's about that time. I would like to thank the people who came to testify. Your testimony is very valuable to us and we appreciate your courage and candor in speaking what's on your mind. I would like to thank all the panelists and for listening to everyone I appreciate

your efforts, and again, I would like people to take a handout, we have handouts listing the agencies who have signed up and are taking part in this and also information about how to contact us with information and questions about what we're attempting to do. I think with that, we'll close this hearing. Thank you very much. Drive safe everyone.

Friday July 26 2002, Warwick Public Library, Warwick

Lorna Ricci: this is purely just to hear what you have to say. A number of people are here. I would like to share who's here. We have Paul Choquette from the Governor's Commission on Disabilities and from PARI, wearing two hats tonight, Dianne Kayala from the Department of Human Services. Andy Egan from State Library Services and Information, Talking Books plus. Did everyone hear that? Charlie Kettlebere (phonetic) from Mental Health Association, and Kate Sherlock from the Governor's Commission on Disabilities and the Rhode Island Disability law center. Are you also on the governor's commission on disabilities?

Kate Sherlock: Our Director is but I’m not.

Lorna Ricci: I'd like to turn your attention to the printout that I hope you all received at the back. This is listing all of the sponsoring agencies; many state agencies and human service agencies came together to put this on. I'd like to add the Mental Health Association. We've received some funds from them as of today, so please add them to your list. You'll notice on here the different dates it was held. You'll also notice a date for written testimony. If you should come today and hear something, maybe an additional issue sparks your interest, something else you wouldn't have time to testify to today, but there's something definitely on your mind, you can put that in writing and send it to the governor's commission on disabilities, the address is on here. Please send it postmarked by June 29th.

Speaker: July

Lorna Ricci: I'm sorry July 29th. We're in July. We'd like to start, and the first person is Richard Moorehead. If you would like to come up Richard, and after Richard will be Faye Trainer.

Richard Moorehead: I'm just here to see if I can learn anything else about disability. I just recently applied for disability, and I'm just here trying to learn and see if there's anything else I can find out about my particular situation, and I suppose this lovely lady over here, I can't remember her name, she answered most of the questions I had. Thank you very much.

Lorna Ricci: Is that all?

	Richard Moorehead: That's It.
	Lorna Ricci: Fay Trainor
	Fay Trainor: I don't know what I'm getting in for, so maybe we should wait until we know what's going on.
	Lorna Ricci: We'll come back to you. Next is Max Cohen.
Health Care	Max Cohen: Right here. My name is Max Cohen. I'm 79 years old, and I'm a volunteer at the Elderly Arthritis Foundation. I'm here basically to see what we can do about prescriptions. I can tell you a short history. I've had appendix; hernia twice; I've had Arthroscopic surgery on my left knee; replacement left knee; upper spinal surgery. They replaced my right knee. I had gallbladder and carpal tunnel and lower spine surgery. And because of that, I take a mess of medications. I do have Blue Chip, but invariably I run over my limit. I take Hyprin, Prilosec, Vioxx, Amphetamine, and Ambien. My biggest thing is hopefully we can figure out some way to get more help with prescriptions.
	Rebecca Martinique: I'm Rebecca Martinique from the Arthritis Foundation. Lorna Ricci: Thank you. We're not really addressing things right now. Rebecca Martinique: I'll talk to him after.
	Lorna Ricci: Okay. Next we have Stephen Bowers. Could Stephen possibly come up here?
Financial Support	Stephen Bowers: Yes, one of the things that I'd like the Commission to perhaps address is the cost of living increases for long-term disability Pensions. Right now, in congress, it's still in committee for long-term disability pensions to be able to have cost of living increases attached to them. But if the federal government hasn't been able to get them on the committee, I was wondering if it was possible either through regulatory mandates by insisting that pension plans over 50 plans or if there's a state law that's passed that mandates that long-term disability policies do include cost of living increases because otherwise people are being forced to live in poverty. Number 2, for your consideration there's a program for the elderly that's called senior health insurance program, and it offers free information consulting and assistance for health care insurance. If a structure statewide was made for people with disabilities that would be of great aide. The third thing is that it's a wonderful thing that recently RIBAY has extended the program to include disabled people, but the age of 55 I feel is too high. Someone with disabilities like myself will probably be disabled for a long period f time with very extensive

	drug costs and they would need more support than for someone that's older than a longer period of time. It's unfortunate finally, I have a letter, which I could submit, and the amount of difficulties I've had with my own private insurance. They cut me off bogusly for 6 months, and it took me over 6 months to get my coverage back, the day-to-day grind of making sure that everything was in order so that my benefits would continue going not only for social security but them as well. I am bipolar and I have MS. So I'm affected every day. It's not easy to be writing letters making phone calls and keeping every I dotted and T crossed. It's very difficult. I would help that an organization of some type would be able to intercede because lawyers are very expensive, and I think all it takes is for someone on the other side that's willing to push. Senator Reed's office helped me a great deal. Thank you for listening to me.
Housing	Lorna Ricci: Thank you. Nancy Burgess: I'm here on behalf of the Blueberry Lane Group home in North Kingstown. My brother-in-law, Peter Burgess, along with Jeffrey, Brad, and Walter all live together at Blueberry Lane. Those three men have been living there for a very long time. The staff that works with them, it's not a job for them, they love these men. We were told two weeks ago that the home is going to be closed. I understand the state has budget cuts in many areas and the group homes are one of them. We received a letter that there's been a process for a year trying to decide what to do and how to reallocate funds and move people around. Two weeks ago we were told this has been happening for a year. All four families for these men will do everything to stop the closing of this home. I spoke to one man's sister who tells me her husband is a construction worker in North Caroline, and he will load his truck with materials and drive to Rhode Island to increase the size of the house so more people can be put in the house. The staff is willing to work harder so they don't have to separate these four men. The staff and the men are a family. And we want to do anything and everything we can to stop the closing of this house. Moving these men will totally disrupt their lives, and we find it unacceptable. So anything the state can do to work with us, we're willing to work with the state.
	Lorna Ricci: Thank you very much for your testimony. We had some more panelists join us. I would like them to take a minute and introduce themselves. Hold on one minute.
	Nicole Rossi: My name is Nicole Rossi and I'm with Rhode Island Statewide Independent living council.

	Maureen Maigret: and I'm the Director of the State Long-Term Care Coordinating Council. Lorna Ricci: I apologize for the microphone problems this year. Anne LeClere: I'm Ann LeClere with the Public Transit Authority and a member of the Statewide Independent Living Council.
	Lorna Ricci: next, I'd like to ask Patricia Robishaw and Walter Robishaw. Are you coming up as a team?
Housing	Patricia Robishaw: Yes Walter. And the other three boys at the blueberry have been living together and three of them have been together 41 years and this is their home. This is their home. we have done everything possible to save this home. We've talked to politicians and they still are trying to close our home. And personally, I can't see how the government can separate a group of boys who are actually brothers. Actually brothers. I mean, 41 years that's a long time. Voice). My Jeffrey, can you hear, Pat? Okay. These boys have been together for approximately 41 years, 3 of them. And he's been with the group home for six years I believe. They spent 18 years down at the group home and they have love and care from all the staff and the neighbors, and they are all for keeping this group home open for these guys. They are great neighbors. Absolutely fabulous neighbors. And we want blueberry group home to stay open. There has to be another way there has to be another way. Jeffrey's sister spoke, Peter's sister spoke on behalf of blueberry group home staying opened and we have done everything possible. We have contacted Senator Reed, Aram Garabedian who is supposed to be here tonight, but he didn't show up. We're just doing anything. We're open for suggestions. If they're willing to convert the garage over to fit in two more clients, this would save this group home, especially when the work is being done by a construction company in North Carolina. Do you have anything to say?
	Speaker: I do like to watch all the time. I'm interested in construction companies too.
	Lorna Ricci: Thank you very much. (applause) Lorna Ricci: Next will be Charles Pollock, and after Charles will be Tim Gregson. Charles.
	Charles Pollack: Hello, I've never done this before it's kind of new to me. My name is Charles Pollock, and I'm a member of the Rhode Island Council on Assistive Technology, RICAT. I'm on the Legislative Committee, plus I'm disabled. Four years ago, I

Health Care	was on the side of the road giving directions in south county, and a motorist came by and came off the road and struck me. I sustained severe damage and injuries. I was taken to Rhode Island hospital and remained in the trauma intensive care unit for 3 months. When it was time to move to a rehabilitation facility, my wife and children couldn't find any assistance to help them select the right facility to help me. Now, I don't know if this is good or bad for you guys, but this is true. My wife and son designed a questionnaire based on research gathered on the internet, believe it or not. They then visited five rehab centers in Rhode Island and Massachusetts, and made a selection. Vanderbilt in Newport, Rhode Island was their choice and after spending 3 months at the rehab center, I was released to go home in a wheelchair. Again my wife and family did not have any assistance with getting my home handicap accessible showers needed to be installed. Doors needed to be widened, ramps needed to be installed. She again turned to the internet. I would hope that RICAT and the state of Rhode Island will increase information to assist accident or stroke victims in their rehab. The public as a whole are unaware of what assistance exists and what agencies are there to assist. I wasn't and my wife wasn't and I would suggest you give me any suggestions you have. I would appreciate it and if anyone would like to question me or give me any information, I would be happy to hear it. Thank you very much.
	Lorna Ricci: Thank you very much. Tim Gregson is next.
Financial Support	Tim Gregson: Good Afternoon. Five years ago, I lost the sight in my right eye, completely blind in the right eye. I've got pressure clouding the left. At the time I was a CDL. They took my licenses at the time. I'll never be able to do it again. I've got very limited peripheral vision and no depth perception whatsoever. I went for a field test and passed and the doctor said you're all right. I said why am I not declared visually impaired? He said that's because you have one good eye. I said I want my license back, and was told I couldn't because of my bad eye. My question is, when is the state going to start looking at people with just half a disability? I'm not declared legally blind or visually impaired. I've called the association for the blind and can't get anywhere with them either. Thank you.
	Lorna Ricci: I was so taken with his testimony I forgot my pad. Next is Joseph Farrell.
	Joe Farrell: Thank you very much. My name is Joe Farrell, I serve on the Board of Directors in what's known as the Kent

Health Care Housing	Center, been on it for 8 years. I'm a consumer. Since I was a teenager, I've had a mental illness called depression and now at the age of 58, I've been through the system, in the system, I serve on the Rhode Island Council Mental Health Organizations, that's the eight CEO's of the Community Mental Health centers. I've helped the Rhode Island Disability Law Center write a bill of rights for people with disabilities that passed through the state legislature. We have a program called Hillsgrove House, and it was started by people with mental illness in New York City. What it was is people in New York used to be let out of institutions and they had no place to go, they would be left with one or two days medication. When they were let out of the institutions, they would be placed down at the bus stops or train stations, and within a couple of days, they would be out of money, no place to go, so these individuals gathered together. And as a result, relied on each other. I'm moved by the save our group home sign. In fact, today I just received information regarding that from Katherine Power. And I'm broken hearted. About 47 group homes being reduced to 41 in the state. What I ask is where are the priorities in this state? When you're in a situation like I've been in, the consumer movement inside the integrated mental health system what I found is the system was built by and for the Bureaucrats. It is not about the people who are ill. And that's the shame and the damn shame of it all. I noticed recently that a bunch of money was given to dog kennel owners out at Lincoln downs and to me; this startles me when I see the cutbacks in group homes and mental health. Where are the priorities in this state? I actually could sit and stand and talk for a couple of hours because there's so many things to say but because there's only five minutes I just want to tell you about some of our programs at the Hillsgrove House. Recently, we had the legislative meeting and we had a surprise for Paul Sherlock. Mr. Sherlock has done so many wonderful things over the years for people with disabilities and with mental health also. So we had a legislative meeting where politicians came and whatever, and we surprised him with an award. Family members got up and spoke that night. People with mental illness, but we too have a home called Hillsgrove House and many of our members, have no families, or have families that mistreated them, sexually abused them so Hillsgrove House is our home and I'm appalled by what I'm seeing. Lately, staffs are being cut back, yet, all I ever read about is 4.5% raises for state workers, more raises for the bureaucrats and yet, what is happening in the state for people with disabilities? They're being cut back. That's all I have to say

	for now, but will much more to say in future months. (applause)
	Lorna Ricci: Thank you for your Testimony, Joe. Marie Perna is next and after that, would Faye Trainor like to come forward?
	Marie Perna: Yes.
Health Care Accessibility	Marie Perna: I'm here to bring a message Of hope and excitement because I have MS and as a support group leader and a volunteer for the MS. Society, my group is undertaking a project to put together a mobility brochure for the physically handicapped for Rhode Island for all residents With physical disabilities. I've been in touch With many of the commissions here today. We have Some 30 people who are out now assessing doctor's Offices, medical centers and restaurants as to ADA Compliance from the parking lot into the bathroom. So that we hope to have at least a small brochure by the end of the year, hopefully a much larger one as time goes on so that those of us with physical disabilities can look at a list and see a particular doctor's office or a particular restaurant is there to meet our needs and what we're looking for is people like yourselves who have disabilities to help us assess these different sites so that we can put them together in some kind of an order and have a brochure available to us that will make sense and won't intimidate us or embarrass us when we go to a doctor's office or restaurant. That's what I'm here for, and I hope that we can continue to get The response we had from the state offices. Thank You.
	Lorna Ricci: Thank you for your testimony. (applause)
	Lorna Ricci: Faye Trainer. And next up will be Amelia Whitford.
Housing	Faye Trainer: I'm Faye Trainer and Brad is the fourth member of the Blueberry Group Home and they are indeed, brothers there. Most of the people here are represented by brothers and sisters, but Bradley has a mother and Bradley was born in North Kingstown. He has spent his life in North Kingstown. I don't get around very well so this Blueberry Lane thing is not only good for Bradley, but also good for me. I can get Bradley and he puts his arm out and gets me to the car and he helps me with the shopping and helps me with the laundry and while I am still living, I would like to be a part of Bradley's life because I am very much aware of all the residents who are in homes, and they don't even know where the parents are or the parents have died. So I would like to continue to be in brad's life and I would like brad to continue to be with his other family in North Kingstown and at the Blueberry. Thank you.
	(Applause) Lorna Ricci: Thank, You Faye and Bradley. Amelia Whitford.

	(applause) Lorna Ricci: Next is Norma Lovegreen.
Health Care	Amelia Whitford: Good evening, everybody. I'm Amelia, and I'm a five-year member of Hillsgrove House. I would like to address the over 40% of our members are on mobile treatment team, which means they come to Hillsgrove House basically free. They're on Medicaid, but they're MTT, which is for poor members that need more help or need some kind of assistance more often than those of us who are, I hate to say, higher functioning but not as needy. And this date has been promising or put through a law for certified mental health clubhouses that they would be able to bill Medicaid for mobile treatment team and we really need this because we are terribly under funded and our agency has been carrying us for a long, long time and they may not be able to carry us much longer. So we would appreciate anything that the state could do for us. Thank you. Great job, Joe. (applause)
	Lorna Ricci: Norma Lovegreen, and after her will be John Burgess.
Health Care	Norma Lovegreen: I just can't stand here and have people behind me because my mother wouldn't like it. Basically, I've been going to Hillsgrove House. I've been working for MHRH in personnel for about two years as a TE program. Hillsgrove house transports me to MHRH, picks me up at MHRH, takes me to Hillsgrove. I have lunch and then I interact with the members there, my friends. Today they took me and had my haircut and I feel really good. Two weeks ago, I had lobster for the first time and that may not seem important, but I just haven't had the opportunity to be involved enough to be able to have it all the time, and oh, it was delicious. I am also on the board of Kent County Center, and I'm really concerned about the cuts that are coming down. We don't know if people are leaving. Everybody seems to be a little tense about what's happening. My mother has Dementia, the rest of my family is sick. I am diagnosed with major mental illness and until two years ago, I was in bed calling Kent County from my bed and saying I'm depressed, and will you please come down. And they say get up; take a shower, go down to the community room. Well, I go to Hillsgrove House and that's my family now because my family expects me to be something different and I can't be what they want. They love me there anyways. They appreciate the positive things and they take me at my positive side. The negative stuff just has to go away and sometimes I'm negative and I can't really help it but I'll tell

	you, there's many, many people at the Hillsgrove House that have major mental illness and one thing I've learned is that I finally have a place where I belong. I never belonged anywhere. I've been homeless two times, I've had a stroke, actually I had two, I didn't know it, and I'm a survivor. And one thing I know is I've always had Hillsgrove on my side. And they tell me the things I need to know that are positive and when I'm being negative and without Hillsgrove, I wouldn't have a life. I'm really concerned about the funds that go to Hillsgrove. I've had more opportunities going to Hillsgrove. We have the weekend; we go out to different places and do things. Holidays we do things and it's just a wonderful place, and I would be very concerned if I couldn't go there. It would get me back in my bed and I don't ever want to get back in there. Thank you very much for listening. (applause)
	LornaRicci: John and Pat Burgess and Peter wish to come up together.
Housing	Pat Burgess: Hi. My name is Pat Burgess and this is my husband, John, and his brother, Peter, lives at the Blueberry and we're here to support the effort to stop the closing of this home. I have a couple of statements and then I have one request. The first statement is in trying to figure out who is on the panel of decision making with regard to closing this home, I keep coming up against a lot of people telling me their hands are tied and it's not their decision and it's very confusing. I have no idea where the buck stops. I would like someone to tell me who is making the decision to close blueberry, and after that, my request is can't we slow down? I don't know what's driving the move to close this home in September. Maybe fiscal year end is really what's driving it since we're talking about money. But I asked maybe even though the people who have been involved in the decision about closing this home have had over a year to think about it and to think about how to rearrange it, the family members and the people who live there and the workers, have not had that luxury. We've only had a couple of weeks and there's been no preparation for us to help our family members adjust to such a huge change in their life, a traumatic change and the last statement that I have is this is really just the beginning of our effort. That we're not going away. Whoever is involved in this, we are here to stay. We are going to make a lot of noise. So get us in touch with the right people because we've got a lot to say and you're going to hear about it. (applause)
	Lorna Ricci: Valerie Qualiata, and after Valerie will be Maureen

	Whelan.
	Valerie Qualiata: I would like to say who's doing all these cutbacks. Is our Governor, and we need to get him out of the office. (applause)
Transportation	Lorna Ricci: Is that all you wanted to say? Valarie Qualiata: That's a lot. We need more transportation increased, the RIde buses.
	Maureen Whelan: I'm Maureen Whelan, and I'm here because I'm Valerie's friend. We used to work together and we no longer do, but we found but we grew up -- Valerie is a year older than I am, as you can tell -- we grew up about a mile apart when we were younger, but obviously there was no way that we were going to bump up against each other, be in the same crowd. I'm not saying I was smart enough or confident enough at the time to have been friends with Valerie because I didn't see what she had, but I'm smart enough now and I guess my point is saying that sense of humor and social skills are overlooked. We weren't attracted to be friends because of any cognitive skills that we have, but we have the same sick sense of humor together. And I guess that sounds like it's a soft side that it's not really looked at for outcomes for people with disabilities, but social skills gives you the biggest bang for your buck, and it's a missed opportunity if you don't look at that. So that is the story of Valerie and me. (applause)
	Lorna Ricci: Thank you, Valerie. Gwen Reeve.
Health Care	Gwen Reeve: My name is Gwen Reeve and I'm the The Director at the National MS Society. Even I would like to say that I am very new to the world of disability. I started working for the ms society 6 months ago and my eyes have been really opened to the problems and issues that people have and I can say with real honesty that I wasn't aware of that all prior to being in this position, but there are numerous things that I get calls about every day in terms of transportation issues and accessibility and affordable housing issues. But one of the things that directly affect MS is the availability of prescription drugs. People that have ms take multiple drugs for not only symptom treatment, but to slow the progression of this disease and these drugs are exorbitant when you look at the cost of the drugs, they're 13 or 14 thousand a year. Most of our people are on disability, Medicare and it doesn't cover most of the drugs. Recently one has been passed and there are four different drugs. There are some financial instant programs and they still don't cover the drugs. We still need to work on drug coverage. The other thing

	that's been brought to my attention, is that some of the drug companies offer some financial assistance through rebates and one of the drug companies that's quite helpfully used is a coupon program to the folks that are taking these drugs and have medical coverage, have medical insurance, but they're still looking for some assistance because their co-pays are so high and when you add them up for the whole year they're thousands of dollars. There are four states in the united states that do not honor the coupon rebate program, and Rhode Island is one of them and we've been trying to find out why Rhode Island doesn't honor the coupon rebate program. So we would like to find out who enforced that law? What's it about and how we can change that among other things? So that's one of our goals in general and just better coverage for prescription drugs. (applause)
	Speaker: Thank you, Gwen. Sharon Brinkworth.
Health Care Housing	As she said, my name is Sharon Brinkworth, and I'm the Director of theBrain Injury Association of Rhode Island and I'm here today for two things. First of all to bring a message of progress and hope for people with brain injuries. The lead agency in Rhode island for Traumatic Brain Injury is the Rhode Island Department of Human Services. They were the lead agency for the funding grant that was completed in 2001, and this grant developed a plan for TBI to begin to have services for people with brain injury in Rhode Island. And I'm pleased also to announce that the department of human services was recently awarded a three year h-e-r-s-a funded TBI grant and we would like to thank Director Jane Hayworth for that grant and also for our request for services and programs for people with brain injuries and their families. There have been more than 8,000 hospitalizations as a result of TBI in Rhode Island over the past ten years and this doesn't include the thousands who incurred a mild traumatic brain injury which it's called mild but it's not mild to the person it has affected. Just a few of the programs that this grant is going to cover is that we will be increasing the competence of providers within the existing system. We know that the department of MHRH serves hundreds of people with TBI through their developmental and behavior programs and the hospital. This new grant project will educate the existing providers and service coordinators. As to the unique needs of people with traumatic brain injury and also increase public awareness of the causes of brain injury is critical. So another significant activity will be to establish a resource center and an information line that will be available not only to people with

	traumatic brain injuries, their families, but to service providers and to professionals and we believe that we have to strengthen and facilitate the access to the existing system for continuing to build new capacity where none currently exists. This is a three-year project though, so we need to start thinking now about sustainability for a project like this. And one mechanism for sustaining this would be funding is to create a traumatic brain injury trust fund, that is used by 20 states and trust funds are generally levied by adding a small surcharge on moving vehicle. According to the half of all traumatic brain injuries are the result of transportation injuries or motor vehicle crashes. So this would provide the state with a means without using general funds. This legislation for a traumatic brain injury trust fund was introduced into the general assembly last year. But unfortunately we didn't have a hearing on that bill. But the Brain Injury Association intends to keep working on this issue because we feel this is a great way to provide some extra money. Because those people who are most likely to cause the accidents need to start to contribute to them. And I also wanted to thank the Governor's Commission on Disabilities. They did support this legislation this past year. There are still two areas though that we need and there's a tremendous need for case management for persons with Traumatic Brain Injury. It's a critical component or individuals and families to sufficiently access negotiate the complex health care and support systems and also developing the capacity for residential day services is still a goal for the Brain Injury Association. Those who sustain a Traumatic Brain Injury after the age of 22 often have no alternatives in our state. They either go to nursing facilities or many times they have to go out of state if they're unable to live alone in the community. So in closing, those two issues, the targeting case management and the day services do continue to be important services still needed by people with traumatic brain injuries, but we are pleased that we're moving forward with the implementation grant. So I just wanted to let you all know that. (applause)
	Lorna Ricci: Rebecca Martinique, and after her will be Pam Goes, and I would like to if Tim Gregson could provide the lady at the round desk in back with your phone number before you

	leave. I think a human service person would like to call you.
	Rebecca Martinique: Max Cohen and I are going to do this together. First of all, I am the Program Director at the Arthritis Foundation and I represent about 24% of Rhode islanders. We estimate based on some surveys done by our Department of Health that 24% of our population does have some kind of arthritis diagnosed by a doctor and that number is going to increase over the next 20 years because of the baby boom generation coming into the prime time of life for the development of osteoarthritis, which is the most common type of Arthritis. First, I want to give you a couple of points that be be a little bit of background for why we think the two issues we want to raise are important. In addition to just the sheer number of people with Arthritis, the 24% works out to be a little more than I think 181,000 people in Rhode Island. 55% of those people don't know the type of Arthritis they have and there are well over a hundred forms of Arthritis. People need to know the type of arthritis they have in order to advocate for themselves, for the best treatments possible. It's the second leading cause of disability in Rhode Island behind back and neck problems. In 1996, the survey that was done by the Department of Health showed that Rhode Island had the second highest rate of chronic joint problems among the seven states that did this particular survey and 38% experienced chronic joint systems but had no Arthritis diagnosed yet and that number represents 113,000 additional people in addition to the number already diagnosed. We know from research that early treatment is really important to try to delay or even prevent some of the disability that Arthritis can cause. Arthritis limits daily activities for more than 7 million Americans and in Rhode Island that turns out to be about 88,000 people and that's a significant impact on the quality of life for people in our state. It's an expensive disease. In the country, we estimate about 65 billion dollars annually is spent on treatment so all kinds of medical experience, as well as social expense, missed days of work et cetera. There are a lot of myths out there regarding arthritis, like it's only a disease of

Health Care	the elderly. That is it's just a few minor aches and pains. It's not serious, there's nothing that can be done for it. These are all myths that the Arthritis Foundation tries to fight. There is good news and we like to let people know that some kinds of Arthritis can be prevented. For example, osteoarthritis can be reduced for people if they watch their weight and watch out for sports and occupational injuries. Appropriate management which would include medications weight control, physical and occupational therapy and joint replacement surgery and the Arthritis foundation considers itself a part of that because we offer a lot of programs throughout the state that can help people with all forms of arthritis, including support groups and several types of exercise programs. So with that as some background, Max and I are here today, and I'm going to ditto what Max said earlier and that is the Arthritis Foundation firmly supports the increase in access to medications and also as some of our sister organizations have already brought up earlier. It's a complicated issue we know that. The Arthritis Foundation appreciates how complicated this issue is but we want to make sure there is an increase in access to the most effective and safest medications possible for all people with arthritis. We firmly oppose measures that prevent people from the best treatments out there. The second thing that we wanted to address is something called the National Arthritis Action Plan and essentially, I would like to ask for some state funding of a Rhode Island version of the National Arthritis Action plan. Again, just a tiny bit of background. Currently we are able to reach somewhere between five and six thousand people annually with our programs that's out of 181,000 people. That's a drop in the bucket. The goal is to guide the use and the organization of our nation's health resources to combat the single greatest cause of chronic pain and disability in our country and it will also help the arthritis foundation do its job better by opening up so many doors for us to reach more people. Beginning in 2000, the Rhode Island Department of Health spear headed the development of the draft state of Rhode Island Arthritis Action Plan, and they applied and received CDC funding which is available to all health departments throughout the country for a competitive grant process in order to develop and hopefully start implementing a state plan. It addresses increasing awareness, preventing Arthritis when possible, early diagnosis and management, minimizing people, it will help to minimize pain and disability when possible, and we hope to support people with arthritis to access resources they need to cope with their disease. The plan emphasizes prevention uses and

	expanding the science base, building partnerships for an interdisciplinary approach. CDC funding for health departments averages about $120,000 per year. These grants are renewable for three years. Since their inception they have been considered start up moneys for state arthritis programs. And it is awarded through a competitive process. This process will occur for two more years and then federal money may run out for this program. And at that point, states will need to be able to pick up the expense of a statewide arthritis program. So what we are requesting is that we would like the average CDC grant amount which is $120,000 at least to be considered to insure the continuation of an arthritis program in Rhode Island. Other states have been successful in this cause, New York, Michigan and Pennsylvania have all received statewide funding for their programs and so we just appeal to the state and to the governor's commission on disabilities to advocate for these two items on behalf of people with arthritis. Thank you.(applause)
	Lorna Ricci: Thank You, Pam goes. And after Pam, Cassandra Vecchia.
Health Care	Pam Goes: My name is Pam goes. This is my son, Paul. Thank you for the opportunity. I haven't heard too much said about children in Rhode Island. I am the mother of a child with a developmental disability, and services and funding for those services are slim and getting slimmer. Right now, there is a six-month to two-year wait for home base treatment for children, which is a critical need. Services that children receive in the school obviously end at 2 o'clock. There's a long time for the rest of the day and services are usually given to children in their home and community and in the lives that they live with their families. Families have also been told this year that there is no respite for families who are new to the system; families who have not yet received respite are not getting it this year. Those who have had it in the past were getting half of what we got last year. The state does not know at this time if there will be any further funding for the respite. My son is an adolescent, so I’m also looking ahead to the future. I'm looking for when he finishes school. I'm told by the state that residential services for my child will not be available as long as my husband and I are still married and in reasonable health. The only residential placement will be for those in critical need of a home. Parents must be elderly or dead and the child facing homelessness in order to be eligible. That news on top of hearing that the state is closing

	group homes is very, very frightening for a family. We're looking at many, many years of services being needed to support our family and our son. Obviously, we don't have a disability that's going to go away or get better, and we feel it's a real critical need and we appreciate as many people as possible being aware of it and looking into it. Thank you. (applause)
	Lorna Ricci: Thank you, Cassandra.
Health Care	Cassandra Vecchia: Hi. I'm a member of Hillsgrove House and MTTP. People are coming there for free and they really shouldn't be. And group homes are closing down, shouldn't be. I was at the state hospital and I was placed in a group home, thank god, or I would still be there. People are being kicked out of the state hospital and they're not ready to be. It might be unsafe for them or they don't know anything else. It's really not a good idea. They should be ready and willing to be out in the community. They shouldn't be pushed out. Thank you. (applause)
	Lorna Ricci: Ann D'Antuono
Housing	Ann D'Antuono: I don't know who I'm supposed to speak to because I want everyone to listen to this story. My brother, Jeffrey, is a resident at Blueberry Lane. Unfortunately, growing up my siblings and I weren't aware of Jeffrey. He was institutionalized as a toddler. We found out about him in January and what we found out was for the last 18 years he was living a group home. This was very new to us. Our parents are deceased. We went in search of him and were a little bit afraid of what we would find. I'll tell you what we found. We found him living in a beautiful family atmosphere with the kindest, sweetest, family members, staff members that I've ever met in our life. The boys Peter and Walter and Bradley have become -- they're like brothers to us, and I really feel strongly that closing Blueberry Lane and sending these boys elsewhere where they've been 18 years together is detrimental to their emotional and physical well being. We can go on about their physical handicaps and their emotional problems, but it would be a harmful situation to them. I would like to read a letter from my sister. Allen Construction Company hereby proposes to initiate the planning of improvements to the Blueberry Group home. These improvements shall meet or exceed present standards to include --. Necessary sewer and septic improvements. The said improvements is for the soul purpose for the state of Rhode Island to accommodate two additional clients to share the

	financial burden and allow current residents to remain together at the current address. These materials will be furnished in part by this company. We ask the department mental health to consider, accept, and respond to this proposal. I just have a question for all of you, being a single person with no children; I pay my share of taxes. I want to know where the money is going if you can't take care of my brother? (applause).
	Lorna Ricci: Thank you for your testimony. Thank you for everyone's testimony. This is the end of people who have signed up. I Don't have anymore who have signed up to speak, but that doesn't mean you can't now. If you would like to after hearing some of the things mentioned today, if you feel so indulged and wish to express your own opinion, maybe agree with something that's been said, feel free. We'll probably stick around until 6:30.
	Dianne Kayak:I'm Dianne Kayak with the Department of Human Services. On the Hillsgrove people who spoke. Is Hillsgrove funding cut or are you just concerned because the MTT's not -- I just wondered what the issue what is.
	Speaker: in 1996 the state cut our budget 33 1/3%. I had asked a member to write a letter to the governor. Previous to that, I could see where the state was going. I received a letter saying; don't worry about being cut, nothing will happen. Of course we were cut 33 1/3%. We fought and fought and fought and got the cutback to 20%. But as a result, the state what they were trying to do was force people out by getting them out to work even if they weren't ready, that way they wouldn't have to pay for them. I personally witnessed as a member of -- I was sent to Newport Rhode Island, to see about when these job development programs, and I was sent with another man. We were on the board of Mental Health Consumer Advocates and one of the things I saw was a picture showing a picture of a gun pointed at person with mental illness, because you want to pressure them, get them up to work. The people, who do this, claim you're mistaken. But this is what it's about. And what my fear was that all these wonderful people being let out of the institutions, all these wonderful people, what was going to happen to them. Because what I saw in one center was, the idea of the state was get rid of the day programs, therefore, people would go back into their section 8 houses or back into their apartment and then, Thank God, if they didn't get sick, they would get bored and would have to go out and get work. That is just a part of what I saw and a part of what is going on in this state and for us, we've

	been fighting and fighting and fighting we've been everywhere for years. I myself I travel around the world for the clubhouse model, because it's the only program, 95% consumer run, and we're the only program around this world that now we have developed programs in 30 countries around the world. Recently, in Moscow, where they opened up a clubhouse, which was the first mental health program ever, which was called the human soul. We've opened up places in Kosovo and other countries. Those for hillsgrove house and for our staff who continually are told they're getting raises, but basically it means 3% raises, so you lose good staff. And the staff you get from out of college they're taking jobs for peanuts, a year later, they take jobs elsewhere, they use the mental health system as a pit stop. And who is suffering? The people who are suffering are the people with the illness. Because when you have a mental illness, it takes a long time to trust people and after you develop a trust with a staff person, they're gone and that's what the system has become, and as I said earlier, please understand, you need to tare down the system. You have to build the system not around the bureaucrats so they can keep patting themselves on their back; you have to build the system around the people who are real. Not the providers and not the bureaucrats. Lorna Ricci: Senator James Sheehan. (applause)
Housing	Senator James Sheehan: Thank you. Senator James Sheehan, North Kingstown, and I thank you for the opportunity, coming out and hearing our concerns. And I'm going to speak today specifically off the top of my head about the concern of the closing of the facility at 45 Blueberry Lane in North Kingstown. Some are aware of the issue have read it in the newspaper. And it may appear to some that this is kind of a he said-she said issue of budget cuts were mandatorily made and something had to give between a rock and a hard place and that type of effect, and in effect someone is getting hurt. That's not the case. In fact, I want to make it very plainly clear what the case is I'm calling into question, and I do request the judgment or the wisdom of closing what I consider to be a model facility in this group home system. I will just speak briefly about some of the improvements I've seen. I've been a resident and next-door neighbor of this group home. I purchased the home from my father who passed away. I've seen from the very beginning the promise of the group home system. It was a promise at that time. LADD school was closed and people were put out in the communities. But I have to tell you that to my pleasant surprise, the group home next-door not

	only exceeded expectations in the neighborhood, but turned out to be quite the diamond in the rough, 17, 18 years later, I consider them good neighbors, and I want you to know I'm not here as a senator first and foremost. I am here as a neighbor. I'm concerned about them, their mental state, their well being has been jeopardized recently, and I don't know if you heard, I think it more confidential not to disclose some of the things, but I can tell you I'm very, very concerned for the welfare of some of these residents who, in their environment in that home, really constitute a family and that was the ideal and the goal that the department strove for to reach and they actually attained it, and we all know and we kind of throw up our hands here in frustration at times when the state is saying one thing and making a claim and not always making that expectation. I think here it was met and exceeded with flying colors. I certainly care about the clients who have made tremendous progress over the years. Walter Robishaw, in particular, I see him all the time and he's made tremendous progress and others in the home make tremendous progress. The staff at this particular group home, I have to say they deserve a citation because they are excellent, top-notch staff members. (applause)
Housing	Speaker: They go above and beyond the call of duty. One staff member even taking home a client, not seeing him as a client or place where he works, but seeing him as a family member, brings him home for Christmas, that was of course before he discovered his family, or his family discovered him. The home is wonderfully situated at the end of a cul-de-sac, suburban type of community in North Kingstown that I call home, nice situation, no crime to speak of, just a wonderful situation. So to the point. My question is, is there another way that we can approach the obvious budget cut and I understand that's a reality, but yet to make a more prudent cut, a more humane cut, a more prudent cut again, because the way I see it, this is a model home. I've heard anecdotal stories, perhaps other homes have not or are not quite as successful, cannot boast the same kind of track record over the last 18 years that this home has achieved and earned with flying colors. Maybe a home that there may be some type of hazard there in the home, environmental hazard, some type of leak in the home that can't be remedied or there's a problem with the structure. I've got to believe that the clients in those facilities, or let me go one step further and say how about a situation in the home where the staff isn't exactly what we would hope it would be and the clients don't benefit from a stable, loving environment where they can make tremendous progress in their personal lives

	as human beings like the rest of us. Why not take some of those clients, and invite them to this home, which I know can expand to at least one more person, we've had that already. This is not an extraordinarily small facility, based on the entire system and we've also, I was told you heard tonight that one of the newly found members of the family, of Jeffrey Dunne has offered generously to expand and pay out-of-pocket to expand this home to accommodate up to two new residents. So what I'm asking is if we're looking for the best interest of the members of this family that was created and I think done wonderfully, why not take members from another home that's not doing quite as what we would like it to do and give this same gift of a wonderful home to them by inviting them to come to 45 Blueberry Lane. I just think that makes more sense to me, and that's all I'm asking. I understand, I've been on that side of the table and hearing remarks and criticism, critiques, but I think it is a good choice and given the fact that the funding to expand and renovate the facility will be privately funded at no expense to the taxpayer, I think it's a wonderful opportunity. I beseech you to take advantage of this opportunity. These are great people. They've made tremendous strides. This is the shining star in my eyes. There are other facilities that I'm not aware of. If we want to keep pointing to a model facility take them to blueberry lane. I thank you for your time. (applause)
Housing	Lorna Ricci: Maureen Martin. Maureen Martin: Good Evening. My name is Maureen martin and I am the Union President that represents the employees, who work at Blueberry Group Home, and I hadn't expected to speak but I think that so many good questions got off that I might be a small help. We are, needless to say, appalled at the idea of closing any of the facilities where people work that we represent and we are pursuing the issues of what's going on with the state. But in this particular case, I think that one of the I things I wanted to do was support the whole notion of looking at how to better satisfy the budget problems without having to I think bring to harm a lot of folks who have been living and working together for a long time. So to that end, we will be meeting with the management of RI class who is the governing organization for this group home on Tuesday, the local union and management will be meeting. We will be presenting a lot of what we think are very viable options for RI class to save some money short of closing at least this particular group home. We agree with the director of MHRH that it would be nothing short of -- I don't want to misquote her, she said it would be a miracle to come up

	with something to resolve this issue. It certainly would be a miracle to stop the closing of all four facilities, but I think anyone who's aware of all the stuff that's going on, blueberry group home is one of the human problems. We will be talking about the possibility of making renovations through this generous offer that apparently a family member has made. In addition to that, the staff at the group home have volunteered their own time to help out in that endeavor. And I'm sure we can recruit some other folks in the local to help out on that. I guess I would like to say to this board or this commission, if you can do anything within your power to get the powers that are, to really look into this situation a little deeper. There are people who are making decisions on this, and I'm quite confident that they think they're making a good decision, but I think what happens often times you see people make a decision and then they're kind of stuck with it. So I think that you guys are really an important part of getting people to think a little bit differently about this as a human situation rather than a financial situation that they find themselves to be in. Thank You. (applause)
Housing	Stephen Bowers: You know, I think in the long run, a society's going to be judged not necessarily divinely but by its survival in how it treats its elderly or weakest members. In Conjunction with that especially with Blueberry, It came to mind that a lot us here because of handicaps are in some very unusual home Situations, you know? There are group homes, but their homes are families. There are people like myself who are disabled caregivers with their fathers and mothers. There are a lot of people out there taking care of people with disabilities. These are families, and you don't get recognized On taxes. You don't get recognized as a family unit by any of the services provided. You are an individual with -- you know -- and I think that's part of the problem, we're not looked on as a family. So all the things that happen with Regards to my benefits being cut and any social services I could have applied for, my father was separate. Our family is gone. You know? And just to go in terms of details with regard to some Of the things that happened. Three or four separate occasions my human resources department switched my primary insurance coverage. It got to the point that mid-June of last year, my medical Claims were not being paid and every time it was resolved my human resources department would tell the other one that they were primary. And it took Senator Reed's office to get involved in order to straighten out that situation. Another thing that happened was in terms of dealing with Medicare, the coordination of benefits. They've been Privatized

	and they haven't received proper training. So you get whatever kind of an answer the other person on the other end of the line wants to give. Someone I had contacted in the insurance business, Department of Business Regulation, finally gave me an answer that was different from what I actually got from the private insurance company and finally from the Medicare individual that was a big muck-a-muck and Even to the point of with social security, the very doctor that was going to review for my three Year review for neurology he was the one who Misdiagnosed me. I almost had to plead, don't send me to him, he messed me over. He said you Have Post-Traumatic Syndrome, go have some fruit juice and have good thoughts, and I had MS. And finally when it comes to people determining their status of disability, the doctors are not helpful. They're afraid of lawyers. So when they see a Letter that comes from a lawyer for files, they're Thinking malpractice. They're not thinking I'm helping my patient. I had to have my lawyer pressure my neurologist, to write a letter reinstating my disability. She didn't want to do It. And also my psychiatrist. I'm bipolar too, He's treated me for over 14 years, he said let me Know how it works out in the end. I'm not getting involved. Two things, the work they have to do in Managed care, so every time they're releasing Medical notes they're afraid someone is look for a lawsuit. I had a horrible time just being able to reinstate my benefits. I couldn't do it again. If they asked me to do it again, I couldn't afford To. I'll go bankrupt. There are a lot of things being passed today to help people. Someone is standing in the gap. A lot of times you can't afford the resources and there's nobody else to Turn to. Thank you very much for listening. (applause)
	Lorna Ricci: What was your name? Stephen Bowers. Lorna Ricci: I think we're going to take a short break where I think we've heard everyone who wishes to testify. Has anyone else decided?
Health Care	Norma Lovegreen: Recently, I went to my doctor I've been going to the Kent Center since I was 19 and had the case manager for five years, I trust her, and recently I had to go to the doctor by myself because of the blood clots I fell apart. And I didn't get a good visit. I just don't like going to the doctor by myself because of my trauma and I'm really sad to hear that they're not thinking about people with trauma because there are a lot of people at the Hillsgrove that have trauma in their background and trust is a big issue. And I really wish you would look into that because it's not

	a very good thing. I'm Norma Lovegreen.
Health Care	Joe Farrell: Can I say one quick thing? Joe Farrell. And what Norma was talking about is because of what's going on in the centers and shrinkage of the money coming in, what we're seeing more and more of is micromanagement and what that's doing is taking away what mental health is about. What mental health is about is not the physical bruises, it's about the emotional bruises and those emotional bruises that continue throughout your lifetime. This is also what's happening to these young people. They're going to suffer not physical abuses, but it's the emotional situation. That's why say the system needs to be changed, broken down, begun again, 1961, they started the administration, 1963 they started the mental health system. It needs to be broken down. It’s about the bureaucrats and the providers. (applause)
	Lorna Ricci: Do the panelists have any comments?
	Kate Sherlock: I don't really have a comment but I have a sign-up sheet up here for anyone who wants to receive a survey from our office. Every year we have to select what kinds of cases. I'm from the disability law center for those of you I was introduced hours ago now and every year we have to pick what kinds of cases we're going to pick. And this year we're sending a survey to the public to get the public input, so anyone who would like to receive a survey, please let us know. We do take in the input from these public hearings too, but I'll put that on the table during the breaks. Thanks.

	(applause) Lorna Ricci: Okay, we're going to take a ten-minute break and we'll resume in just about 10 past 6.
	Lorna Ricci: May I have your attention. We have just a few more minutes. Peter would like to speak.
Housing	Peter Burgess: I'm going to wait for all The guys. I want to say to all the family. Okay, Sit up. You know what? It's going to be opened it's not going to be closed. We're going to win fair and square you know why? Speaker: Why? Peter Burgess: I said something. You know why? Speaker: why? Peter Burgess: Because we're the winner. We're blueberry group home forever.
	(Applause) Lorna Ricci: Anyone else have anything to say? Did I see a hand in the back?
Criminal	Kathy Brourllard: I wasn't going to speak. I came here tonight my name is Kathy Brourllard and I'm young, but I have a son in a group home. And he got there not because that's where I wanted him, but he's there when he doesn't want to be there and I don't want him to be there. It's a 24-hour hour group home through an agency. This was a boy that was high functioning. I took advantage of the CSLA plan, but along with that plan came the responsibility to find housing for him. I did that. We went through a year and-a-half of training with him for self-help skills. He was doing excellent. He worked a full-time job for three years. Yes, he's moderately retarded, but he knows he doesn't belong in a 24-hour hour group home and I know that. But situations have occurred that put him there. He had a violation of caregiver. I was the one that had to go to court. No agency went with me. No social worker went with me. I had to go to the supreme court. My son went into crisis because of the way the psychologist handled it not because of the situation but the way he was handled. He was put into another placement another agency took him. Put him into a program of apartments. Well, he played his music too loud, he was a little too boisterous with the other tenants he was removed from this placement because he was going to jeopardize their placement. It was supposed to be 24-hour hours, now it's been four years and he has declined and gone into crisis after crisis after crisis because of medical issues that were not looked at and I have not to this day, I have worked with the state, I have gone to the state people, gone in front of

Housing Health Care	Linda Kahn with things that have happened. I showed documentation of money things, issues, physical issues, and nothing has really been done to my satisfaction. I had other incident just this week. He's seizure; he has seizures they're controlled with his medication. They put him on another medication for his nerves, whether it was drug interaction or whatever. His dilantin went way down. They wanted to upgrade his dilantin. Neither one of us wanted that. I got involved again. But this boy originally didn't belong in a 24-hour hour program. You're talking about taking away from these poor people because you can't afford it and you've got a child not a child but a 32 year-old man living in a 24-hour hour care situation that doesn't need to be there. But the problem is number 1, they're not getting him out of the crisis he started in. They're just getting him in deeper and deeper. He has regressed 100%. He was social minded, he did all kinds of sports, he worked a full-time job, put him into the system, he didn't get any better care and now I'm still trying to get better care for him. What I would like to see the state do is check on the funds they're already distributing and getting more bang for their dollar because I'm not seeing that from where I am. I'm not seeing that dollar being utilized to the best ability and I hate to see these poor people in a home that's working with providers that want to help them work survive and be happy, but I've got a 32 year-old son that got put into the system, was a happy young man and the system let him down. Because I had to go to work full-time, I can't be there with him all day. They weren't offering any other assistance after he went into crisis and lost his full-time job so they put him in a 24-hour hour group home. Where is that cost effective where when he was in an apartment setting I had to ask for 25 hours care and they refused it? Well, now the state is paying 24-hour hour instead of 25 hours a week. Where is that cost effective? these are the things I would like to see taken care of. We need the dollars that we're already spending being utilized to their best ability. Especially in the times that we're in right now and I don't foresee things getting better for a long time and we're going to have more and more kids, we're spending more and more money in the school systems educating the kids to go out in the community and after they get out of that education world they're dropped into the adult world with no services. We have some services around the state, but in all, there are a lack of services. They've taken these people out of Ladd School, and I said at one time, if you're going to worry about money, you might as well open up LADD school again because some of these people are

	not being cared for. You talk about choices, you talk, you know, the quality of life, my son has no quality of life. I'm sorry, I can't afford to quit my job and stay home and take care of him every day and that's what he needs. He either needs a job to go to, a life to have or he needs somebody just to guide him through his life. And it wouldn't have been that hard if they would have just helped him stay where he was. But that's what's happening. You're getting all these people even out of the school systems, they're saying go out here, go to work, have a life, go into the community, but the support system is not there to help them succeed and you're having these people like my son go backward in time and spending more money on them which isn't warranted. That's what I have to say. (applause)
	Lorna Ricci: Thank you. I think that about wraps it up. Thank you for your testimony. I'd like to thank our interpreters.
Housing	Ron Jinkens: I would like to make a few comments. If possible. I'll make it brief. Good evening panel. Thanks for listening to us tonight. I'm a direct care staff member at the Blueberry Care Home, Ron Jinkens. In sticking up for the guys that live there. The management has not approached us on any of the on goings of what's going to happen with our clients at Blueberry Lane. They've made their decision and threw it at us and myself and my peers my fellow workers in the back of the room they all worked there with these guys for 20 years plus and we've known them most of our lives and no one knows them better than we do. Just to have them draft up a plan and present it to us and tell us how it's going to be, I think it's ludicrous to deal with human lives like that. I'm speaking for all the staff, all the class in the community group home because it may happen to them as well, as well the clients. I hope you guys can take into consideration those thoughts. Thank you. (applause)
	Lorna Ricci: Can I ask you how you spell your name? Ron Jinkens: J-I-N-K-E-N-S, Ronnie. Lorna Ricci: I think that finishes our testimony. That was wonderful testimony. I would like to thank our interpreters, Paul Giard and Mary Earls, and our court reporter, Sherri. Thank you all very much.
Letters, E-mails and Faxes	
	Rhode Island Housing And Mortgage Finance Corporation Susan E. Bodington, Director of Policy Rhode Island Housing is responding to your invitation to identify the concerns of people with disabilities and their families.

Housing	Rhode Island Housing is concerned about the closing of six group homes that the Governor recently announced as part of the FY2003 budget reductions. Persons with disabilities face many challenges; however, finding and maintaining a stable, supportive housing environment should not be one of them. Although the current residents may be placed in other group homes, the closing of these facilities represents a significant loss of housing opportunities for disabled individuals who may need a supportive housing environment sometime in the future. Waiting lists in Section 8 developments that house both the elderly and persons with disabilities are often years long. Disabled persons who finally are given a Section 8 voucher often cannot find a unit in the private market that can accommodate their needs. The supply of affordable housing is very limited in Rhode Island, and every housing opportunity should be preserved. Without the option to live in a group home, families may be asked to accommodate their disabled family member without adequate physical or financial resources and/or services or the disabled individual may be left on their own to find a place to live that might not be affordable or suitable for their needs. While the state-funded Neighborhood Opportunities Program targets some of its resources to create rental housing for persons with disabilities, the demands for service-enriched affordable housing for this population far out-strips the supply. Rhode Island Housing urges the Governor's Commission on Disabilities to support the preservation of existing affordable supportive housing for persons with disabilities, including group homes.
	This testimony is given from several perspectives, as Manager of the **Disability & Health Program, RI Department of Health**; Chairperson, **Adaptive Telephone Equipment Loan Program;** member, **State Rehabilitation Council**; member **RI Transition Council**, and the **RI Council on Assistive Technology**; collaborator with the **Office of Human Resources, Outreach & Diversity/DOA**; and as a consumer with a severe hearing loss. At least one in four community residing adults in Rhode Island has a disability. This is based on the results of the Behavior Risk Factor Surveillance System, an annual telephone survey conducted by the Department of Health. (Because this survey does not reach those in institutions, those without phones, and those who use text phones, the number may be higher.)

Health Care	1) Effective legislation assisting with the cost of hearing aids is needed. NCOA and many other studies have shown that that elders who do not have/use hearing aids suffer psychological and social effects, and decreased ability to function independently. Their physical and psychosocial functioning decreases as hearing loss increases. Many do not have/use hearing aids because of the cost ($1 ,000 $2,700/aid). A hearing aid could actually be an effective way to reduce medical and social service costs, and increase economic and social participation...
Assistive Technology	2) Assistive Technology needs to be promoted and supported Health and social service providers need to learn about the benefits of AT. Again, several studies have shown that AT can increase the functioning and independence of its users. One study showed a savings of approximately $15,000 in health care costs over an 18 month period for consumers using AT, certainly a strong argument for insurers to cover assistive devices. 3) The Adaptive Telephone Equipment Loan Program needs an increase in funding. Applicants for an adapted telephone often have to wait several months to receive the equipment, because funds are not sufficient nor readily available, and because of state purchasing regulations.
Employment	4) Employment must be increased in all settings. Only 58% of working age Rhode Islanders with disabilities are employed. We need to increase that significantly through removal of disincentives, employer education, appropriate consumer preparation and support. And efficient transportation is a critical issue for both obtaining and maintaining employment. At one of last year's forums, a request was made for census data on disabilities. That is now available on the websites of the Census Bureau, and the statewide planning program at the Department of Administration. In RI, 20.2% of the civilian, non-institutionalized population over age 5 has a disability, and as mentioned, only 58% of those 21 to 64 is employed. If you are interested in disability data, I'd like to mention that the DHP plans another major data forum about a year from now which will provide a comprehensive portrait of disability in RI, based on four major surveillance tools, the BRFSS, the RI Health Interview Survey, the census, and another major survey to

	identify children with special health care needs. Jeanne Panarace
Health Care	**Brain Injury Association of Rhode Island, Inc.** The lead agency in Rhode Island for Traumatic Brain Injury (TB!) is the Rhode Island Department of Human Services (RIDHS). They were the lead agency for the HRSA funded TBI Planning Grant which was completed in April 2001. This grant developed the RI Plan for TB! through a collaboration with hundreds of individuals, families, service providers, state agencies and advocacy groups. We are pleased that RIDHS was recently awarded a three-year HRSA funded TB! Implementation Grant. We would like to thank Director Jane Hayward for her support of this Grant and our quest for services and programs for people with Traumatic Brain Injury and their families. There have been more than 8,000 hospitalizations as the result of TBI in RI over the past ten years. This number does not include the many thousands who incurred mild TBI without an overnight hospital stay. Yet, as our Needs and Resource Assessment discovered, there is still a giant lack of knowledge, services and supports by qualified providers for this large segment of our population. This project prioritizes actions based on recipient identified need and the results of the Needs and Resources Assessment. The long term goals developed by the Planning Grant are: A. Brain Injury awareness and service competency will be improved and expanded through information and education. B. A coordinated and linked system of services and supports will be readily accessed and used by people with TB! and their families. C. A full array of services will exist in RI for people with TB! regardless of their functional capacity or ability to pay. A significant grant activity will be to increase the competency of providers within the existing system. The RI MI-IRH serves hundreds of people with TBI through Developmental Disability programs, Behavioral Health programs and the state hospital. This new grant project will educate existing providers and service coordinators as to the unique needs of persons with

traumatic brain injury. Increased public awareness of the causes and consequences of brain injury is critical to the development of a comprehensive system of services and supports for Rhode Islanders with brain injuries. Another significant activity will be to establish a resource center and information line that will be available to not only people with brain injuries and their families but to professionals and providers.

We believe that we have to strengthen and facilitate access to the existing system while continually striving to build new capacity where none currently exists. This is a three year project and hopefully we will be able to provide substantial progress toward an ideal system. But we must look for sustainability for this project after the three year period is up.

One mechanism for funding is the creation of a Traumatic Brain Injury Trust Fund. Used by at least 18 states to fund services for TBI survivors, Trust Funds are generally levied by adding a small surcharge on moving vehicle infractions of approximately *$5*. According to Centers for Disease Control statistics, *45%* of all TBI's are the result of transportation injuries. This provides states with the means to provide services needed without using General Treasury Funds, directly from those most likely to cause the injuries. The monies levied can be used as the state share for Medicaid and Vocational Rehabilitation programs, and for limited state-only services for those ineligible for other funding within certain income guidelines.

This legislation was introduced in the RI General Assembly last year. Unfortunately there was no hearing on the bill, but the BIARI intends to keep working on this issue again next year.

There is still a tremendous need for targeted case management for persons with traumatic brain injury. It is a critical component for individuals and families to successfully access and negotiate complex health care and support systems.

Developing the capacity for residential and day services is still a goal for the BIARI. Those who sustain a traumatic brain injury after the age of 22 often have no alternatives in our state. They have to either go to nursing facilities or out of state if they are unable to live alone in the community.

In closing, the targeted case management and residential and day services are still two very important services still needed for people with traumatic brain injury.

Sharon Brinkworth, Executive Director

Health Care	Dear Members of the Commission: Thank you for allowing me the opportunity to testify at the public hearing held by you at the Warwick Public Library on Friday, July 26, 2002. I would like to summarize my comments here and add some additional information, if I may. One of my recommendations was that the insurance companies, who provide long- term disability polices to employers in the State of Rhode Island, be required by either state insurance regulation or law to have cost of living adjustments (COLA) clauses in their policies. Too often, the structure of the coverage forces those who may never be able to work again into poverty. Second, that the RIPAE change to include disabled individuals extend the age range lower. From an actuary basis, those with chronic disabilities, more likely, will be on medications longer for their conditions than the elderly A arid, and these medications may even be more expensive. For example, my Multiple Sclerosis medication, Betaseron which slows the progression of the disease, retails for over 1,000 a month. The co pays For my other medications alone are well over $150 a month. The Dept of Elderly Affairs has an organization know as SHIP, that provides help and advice for the elderly on how to make the best of their heath care options. The same would help for the disabled as well. I am attaching a letter, with personal information as to my former employer and insurance company deleted, that describes some the things that have happened to me since being disabled. To summarize, the Long Term Disability insurance companies can be hostile. Due to the fact of the size of my former employer, they fell under ERISA and nothing could be done to aid me in some cases. From the very beginning, 1 have been lied to and hassled. My claims manager has been changed at least three times. My benefits were stopped on a false basis in Sept of 2001 and it took over $5,000 to get my benefits back. The claims manager who stopped my benefits in Sept of 2001, which were restored in April of 2002, is blocked from receiving my calls. I found this out when I tried to obtain information about my reinstatement. It is not only rough with the private insurance people. The state neurologist who was going to make an evaluation for my 3 year review on Social Security was not only a doctor who had originally misdiagnosed me 1 3 years ago, but when 1 saw him on the basis of a second opinion when I had been approved for disability in 1 1998 (not in his capacity for

the state) did not consider me disabled! One of the things you might wish to check into is the patient questionnaires given to people received testing at the Butler campus, or for that matter, any information obtained from people whose benefits hinge on the results of such testing. In my experience at Butler, the process was extremely intimidating. At the risk of losing all of part of your income, you are asked a very extensive set of questions which may have nothing to do with your illness and be very damaging to you or to your family, independent of your Illness. For example. I was going to an independent assessment of my psycho neurological problems that have developed since I have been diagnosed with Multiple Sclerosis. Whether my siblings have had **a** criminal record or venereal disease has nothing to do with my problem. For that matter, If I become a spend thrift or become hyper sexual and act on those impulses when and if when I become manic being bipolar, in **no** way has any relationship to me able to have certain for perceptual processes. This information can be gleamed and used against the client in a practiced know as "brinksmanship" in the insurance Industry and it is not very ethical at all.

Another thing that may not be apparent from someone who is not In the situation in fighting for your benefits with the legal system is that your own doctors may not be helpful at all. When they see the requests from the lawyers for your files and for written reports and the like, they fear being exposed to a situation where they can be sued as well as just extra paper work and other concerns that have been foisted upon the medical profession with managed care. At one point in the process of reclaiming my benefits, a key doctor, my neurologist, was too tired and too busy to write a summary to help me get my benefits back. And the psychiatrist who has prescribed my psych meds for 1 2 ears told me to let him know how the situation turn5 out, he did not want to be involved. I cannot tell you how stressed my Father and I were at that point. I think that this contributed to having to break up our household and my Father arid I am now apart, he is in an retirement community. It is only my faith and a good psychologist who kept me on course through this. The final result for me is that I had to divest myself of my assets, I have filed for bankruptcy and I am applying for state aid with Section 8 and food stamps. There are many unconventional family units in out state, that touch heavily up the disabled. A major political and religious concern of late has been for the family and family values, But it has been so myopic. Help from **state agencies** for

	the most part did not see my Dad and I as a family. Also, hearing about the Blueberry home in Warwick, that too has not been seen as a family. One thing that might eliminate some of the problems I have touched upon in the latter part of this letter is an advocate in the government or in the agencies that may aid the disabled person when these situations arise. I know **I am** not alone. We often have no where to turn and limited resources. I believe that a society will be judged, it terms of It's continued survival, by how it treats it's most defenseless And, the aiding of a life into the world, Sustaining a life damaged or aiding someone into the next, to the degree in which we can be involved, are the most Profound of human experiences. Thank you for your time and consideration. Sincerely, Stephen Bowers Middletown
Health Care	September 4, 2001 I am writing this letter in response to the difficulties I have encountered with Unum Provident, the insurance provider for Long Term Disability program and the Human Resources Department's handling of my health insurance coverage. I left on a medical leave of absence in July of 1998. I was diagnosed with Multiple Sclerosis in August of 1998, A definitive diagnosis was made and it was clear, because of the symptoms I was experiencing, I was not able to return to work. In Feb. of 1999, when my TDI insurance benefits were running out and I was awaiting the beginning of my payments from I was told, by the claim specialist, on a taped line, he had lied and that my records had not been cent for medical review. He could not say when my monies would be forthcoming. This shocking statement was after repeated requests for my medical and other information needed to process my case I intervined and was able to resolve these issues, The specialist denied the story, but, you can imagine, with monetary resources getting low for my Father and me, it left a definite impression on both of us. To this date, even as then, I am his caregiver, due to his disabilities I have bad further problems as well. My illness is not the type to suddenly disappear at this stage. They wore requesting monthly, then bimonthly statements from my neurologist, who treats me for MS, on my disability status. Unless I have a crisis, I am only

scheduled for visits every six months. After I sent in a request to get extend the time between disability statements it was "lost" and I had to start the process all over again. I wish I could afford to have been as careless with my work at It had gotten to the point I could tell when my checks were going to be late In addition to that, even though my checks showed up in this, irregular fashion, when I first asked to have them match the date of my Social Security Disability checks., I was told that is was not possible. A new claims specialist stated it had stay with the date of the original claim. The original claim date centered on the 6th of the month. I may get my check on the first, sixth, eighth. Or, I would call and my check had to be sent by Federal Express This would be duo to the fact that it had not been cleared or forgotten Recently, I finally went to the manager of the claim specialist who is in charge of my account and he stated this would change. I brought in a neuropsychological report to the Human Resource department, one for my file and One for I considered this a courtesy I wanted to assure my ex-boss that problems I had been having were due to a disease process and not an inability to perform my job end for my records with It May be a coincidence, but, within a short period of time I had a request from for another exam of this type. I had no problem with that, except, the questions that the independent Medical examiner goes into are extremely unnecessary and invasive, Whether a family member or I have a criminal record does not have a thing to-do with my cognitive problems with MS, trust me. Anyway, I had this test in July and as of August 9, has had the report. A release for the information has been sent in so that the export could be given to my doctors To date, after 3 telephone conversations and messages left (even just a request to have the report sent by inter-office mail from their doctor to mine, they are in the same medical center!) I have gotten no response

As far as the Human Resources department is concerned, I called in November last year to check on bow the Medicare/United Healthcare coordination of benefits would work. At the time, did not know When I bad been informed, at first United Healthcare in this case would remain primary, my claims wore processing smoothly until around March. After this, I could not get any of my medical bills paid by either Medicare or United healthcare To make a long story very short, every time I called Medicare Human Resources or United Healthcare nobody could help and everyone was pointed the finger at someone else - Finally in

June/July, I contacted Senator Reed’ a office and they got in contact with everyone including the compliance Officer for United Healthcare Maria Lamberto who stated that United Healthcare was primary and Medicare secondary. On August 24th, to be exact the situation was flip flopped again and now my providers are getting double payments and confusing messages from both Medicare and United Healthcare. IF the investigation follows though like the one in July, the source of the messages in from Human Resources at It is causing confusion and frustration for my providers. I have never been told when these changes are to happen, and besides, from what I have been told, to be blunt, it is not legal The worst part of my disabilities has boon these snafus not the illness. I can deal with the fatigue, the muscle spasm cognitive problems etc. The things I have described are unnecessary and would be stressful to anyone, even more so a disabled person. In closing something that may help all disabled people covered under this policy. It was inherited from Paul Revere, a company we-held in the. past. The policy does not allow for direct deposit of funds but rather it has a check out every month. Perhaps an amendment can be added to allow direct deposit. Also, the policy has. no cost of living adjustments with the cap over Social security one is forced slowly into poverty, if you cannot go back to work. Actually, it is of interest to not. how the coverage is set up. Younger, lower paid disabled employees got pushed into 58 disability fully if they cannot get back to work and older disability workers will retire before they burden the insurance company too much for payments.

Neat.

Anyway, I enjoyed working for and I thought you should know what happens when you have to leave disabled. I thought I was going to be treated the same way as when I was a valued employee. I guess I was in error.

Stephen LeRoy Bowers
Middletown

July 20, 2002

Dear Sir:

I regret that I cannot attend one of the Public Hearings but I would like to submit the following statement in behalf of my wife Judith D. Kinzie

My wife has Multiple Sclerosis and has lost the use of her legs and has limited use of her arms and hands. This restricted

Health Care: Accessibility	mobility is especially a problem when she visits her doctors and dentist. She cannot be put on an examination table, in an examination chair, or on an X-ray table because there isn't a means or staff available to help transfer her. My wife weighs approximately 200 pounds and it would take three strong men to manage her if there was adequate space. She is in need of dental work at this time, but obviously cannot be treated until some sort of a method is provided to transfer her to the examination chair. I have installed a mechanical lift in my house to manage my wife. It is a battery powered unit with tracks installed in the ceiling. It is made by the Barrier Free Lift Company. The unit *is* battery operated and can be moved from one room to another where ceiling tracks are installed to lift and lower her as needed. I wouldn't doubt that the medical and dental fields consider the totally disabled of such a small minority that an investment into such a lifting devise wouldn't be profitable, but what does the totally disabled do to obtain need treatment? Thank you for your time. Ernest A. Kinzie Barrington
Housing	RE: Blueberry Lane Group Home Dear I am the mother of Bradley Trainer, a resident of the Blueberry Lane Group Home in North Kingstown. On July 12, I received a letter from the Rhode Island Community Living and Supports, which informed me that Blueberry Lane will be closing in the near future. Since then, I have had the opportunity to speak my concerns in a variety of forums. There have been several meetings at the group home, articles in the Providence Journal, and a piece on the Channel 10 news. The neighbors, including Senator Sheehan and Representative Mel Benson, and other members of the community have rallied in support of the group home. After expressing my opinion to a number of people, I have been asked to voice my concerns on paper. Bradley has been diagnosed with autism. He was originally sent to Bradley Hospital, from which he was sent home. Due to his severe behavioral problems, he became unmanageable and was intensely medicated. Bradley was then bounced for the next few years between several buildings at Ladd School and then to a

group home. His behavior was out of control, and even with medication, could not be treated. Finally, Bradley was sent to live at Blueberry Lane. The environment there is quiet and made Bradley feel comfortable. After some time, he calmed down and became much easier to manage. Bradley is no longer recognizable as the difficult person he used to be. When he goes out, people often remark on how calm, well-behaved, well-mannered, pleasant, friendly, and helpful he is. He is now stable, not requiring any medication. The group home on Blueberry Lane is in a quiet neighborhood on a semi-circle. Bradley was born in North Kingstown. His home is a half mile away from his residence. His brother, nieces, and nephew live a few miles away. Bradley is familiar with the local establishments, and frequents McDonalds, Carter’s 19th Hole, and Fleet Bank. He has a family within his church at the First Baptist Church of North Kingstown. He has friends in the neighborhood who take him for walks and rides in the car. He loves attending concerts at the town beach and taking his dog for a walk. As Brad’s mother, I have made a commitment to be a part of his life. While visiting him at Ladd School, I was aware that most of the residents were abandoned by family members. With Bradley living so close at Blueberrry Lane, I can see him on Sunday and spend holidays with him. At 71, I am not always in the best of health and able to get out of the house. The staff at Blueberry Lane have been very helpful and supportive, often dropping Bradley off and picking him up if I am not able to transport him. It is very important for me to see my son on a regular basis, but even more important for him to see me. He is excited when I come to pick him up on Sunday mornings. If he is moved, I would be deprived of the access to him that I have enjoyed for the last fifteen years. Being disabled myself, I am not able to make such a long drive, so I would be incapable of bringing him back and forth on a regular basis.

Bradley is nonverbal, making it difficult for him to express himself. He isn’t capable of defending himself when someone picks on him. During his time at Ladd School, the other residents bullied him, sometimes stealing his food and belongings. When he is sick or hurt, Bradley does not express his pain to anyone. In the past, when Bradley has had an infected tooth, ear infection, foot ache, or stomach problems, I was the one who found out, knowing from his mannerisms that there was a problem.

Bradley has made a home for himself at Blueberry Lane. He is able to participate in the work program at LaPlante Workshop,

	where he has learned many new skills. It has been a wonderful experience for him, as he is working with a very adequate, capable staff. He has been able to participate in the Special Olympics. The staff at Blueberry Lane has been teaching Bradley living skills, and I see improvements in his demeanor every time I spend an afternoon with him. In my opinion, uprooting Bradley from his home would be detrimental to his physical, mental, psychological, and social well—being. I fear that all of the progress that he has made in recent years will be reversed if he is taken away from his friends, his home, and the routine, quiet lifestyle to which he is accustomed. Sincerely, Faye Trainer North Kingstown
Employment Health Care	Dear Bob Cooper, I see in the Providence Journal where there will be some public hearings concerning disabilities that will be open for suggestions or concern. Since I really became hard of hearing I find intimidation harassment and discrimination can be done very openly in the workplace which is very degrading and pathetic, especially when you are over 60 years old. I find when you try to complain about it, you get a very big run-around. Even Human Rights figure you have to show harassment and discrimination in caused by you hearing loss, so as long as they do not call you a deaf bastard, (sick bastard is o.k.) they can get away with very open harassment and discrimination in the work place when they want you to leave a long time job which really speaks for itself. Also affirmative action told me they can only recommend action that should which leaves the victim at the mercy of management where I see very little effort if any to stop the very open bias attitude while injustice march's on when you have a biased supervisor who isolates, intimidates and discriminates. We need true protection by law without double talk for such biased treatment. I also find buying hearings aides more like buying a used automobile, if you do not have the experience or knowledge you can be mislead or fooled by clever sales talk, so it would be nice for especially senior citizens to have a support group or someone they can discuss hearing aides of the why or why not without profit in the way for such expensive equipment. I can show my own case of bait and switch by a well known hearing aide

	provider which shows how clever they can be, but I did not let them get away with it and was lucky to get my money (just under $1800.00) back. You learn to live with intimidation, harassment, or discrimination, so I hope to get a sensible reply. Yours Truly, George F. Mumford Carolina
Transportation: Ride	Dear Mr. Cooper, Thank you for speaking to my mother, Josephine Spicola, earlier today. She said that you suggested that I contact you through e-mail. My name is James Spicola. I recently applied for the RIPTA RIde program, as I am a legally blind individual. I was initially approved with unrestricted access for this program. However, when I contacted ride, for my initial pickup, I was informed from the staff at that office, that I have since been “red flagged” for curb-to-curb service, for everyday use. I will only be allowed to receive curb-to-curb service from my home, for medical appointments, not for everyday use. The problem that I am having is that the law of the ADA states that I must live within three quarters of a mile from a regularly scheduled RIPTA bus stop, in order for me to be picked up at my home, by ride. I live in the Town of Scituate and although I live close to a regularly scheduled RIPTA stop, unfortunately, I do not live within the allowable distance, for home pickup. I am unable to read street signs, due to my disability and it will be very difficult for me to get transportation to another bus stop that is located within the allowable distance. After being informed of RIde’s decision, from a ride staff member, I was told that they could pick me up at Scituate high school, located on Trimtown road, providing I can get my own transportation to the high school. This would be great, but again I would have to count on someone else to give me a ride to the high school every day, which is difficult, because both of my parents are working full time jobs. My parents are the primary drivers for me, as I have to depend on them, to drive me places. I was really depending on being approved for the everyday curb-to-curb service offered by ride, because I will be attending CCRI, in the fall. I had planned on using ride to travel from home to CCRI, Monday-Friday, but I realize that is not possible for me, from my home. Is there any suggestion that you could offer to me, that would help me to find transportation, in my area? I would really appreciate any assistance you could offer to me. I am also willing to receive

	other names or web addresses that you could recommend to me, that may help my situation. I wish there was something else that I could do, that would help to get the three quarters of mile situation changed in the future. Thank you for your time and effort! James Spicola Scituate
Housing	Ocean State Center for Independent Living Affordable and Accessible Housing I work as an information and referral specialist at the ocean state center for independent living (OSCIL). During the past year, our agency has seen a large increase in the number of requests for assistance from consumers seeking affordable, accessible housing. Many of these callers are desperate – some have eviction notices, some have moved in with relatives because they have lost their apartments, some are living in motels and some are homeless. Most of these persons are living on disability income and some are working at low-paying jobs. I have worked at OSCIL for almost ten years and have never received as many calls from people in such desperate situations as I have had this year. About half of the calls are from renters who have lived in the same apartments for many years and their houses have been sold to new owners who want to renovate them and double or even triple the rents. Another scenario: people have portable section 8 vouchers and cannot find landlords who will accept these vouchers, especially if they have any children. People tell me they have called all the area realtors, searched in the papers and have even gone door to door in neighborhoods looking for apartments with no success. I have also had calls from two people who have been lucky enough to find landlords who will accept section 8, but the apartments are in old homes that are not accessible and the landlords says they cannot afford to put in ramps or modify bathrooms, and the tenants themselves cannot afford to do this. The P*rovidence Journal* has written articles about the escalation of property values and rents and how difficult it is to find affordable housing. Add to that the need to find affordable, accessible housing, and it becomes an almost insurmountable task. Subsidized apartments for low-income seniors and persons with disabilities have long waiting lists for apartments and only a small Percentage of these are handicapped accessible home modifications OSCIL's home modification program has also seen an increase in the number of requests for

	ramps, stair lifts, bathroom, and other home modifications. Here we are looking at homeowners who may be forced to sell their homes because they are on fixed incomes and cannot afford to make their homes accessible. Most of these callers cannot afford to take loans to pay for the needed modifications. Both OSCIL and PARI independent living centers have some limited funding for persons with disabilities who meet the eligibility criteria to receive home modifications. However, the demand far exceeds the funding and we currently have a waiting list of over one year. I hope funding will be increased to the independent living centers for home modifications. Compared with subsidizing a person to live in a nursing home or assisted living facility, a grant for a home modification to keep someone in his or her own home is a cost savings measure for our state. Susan Eleoff
Transportation	Hello I have had a complaint for several years that has been ignored. Why does a hotdog cart take priority over a handicapped parking spot in front of the Garrahy complex (family court)??????? Also, the parking lot at 2 Dudley Street (RI hospital). I have a valid handicapped license plate. They had several open handicapped parking spaces. They would not allow me in the lot until there were 25 openings!!!!! I complained to the manager and he said they are within their rights to do this despite the fact that it takes me longer to get into the building than someone not disabled! Thank you
Accessibility	I am a person with a disability. There are many places that are not handicap accessible. I shall list some of them. 1.Gas stations with flower planters placed directly in the way of restroom facility. Doorways not wide enough for wheelchairs to pass through. Once you enter you do not have room to pivot to exit. Many places do not have doors that close and lock for privacy. Most locks are broken, and doors are sprung (restrooms). 2. Most do not have rails to hang on to for balance. 3.Walkways blocked with soda racks, flower pots, etc., to main doors,(service stations) .4. Handicap parking spaces being used by non-handicap employees.5. Restaurants, obstructions pathway to restrooms. Sincerely, Muriel P. Belcher Sat 7/27/02 1:49 pm

Recreation	I read about the forums going on this week, but am unable to attend. My daughter, who will be twenty in January, sustained traumatic brain injury in June of 2000. She is attending Sargent rehabilitation in Warwick, and they expect to do vocational training with her in the near future. I have a couple of concerns about what is available through the state for her future. I have applied for benefits through the division of developmental disabilities and am waiting to hear from them. Another concern is the lack of social and recreational activities for these young adults. They no longer "fit in" with their friends from school, and they do not qualify for the benefits that may exist under the Dept of Mental Retardation. I've also contacted the brain injury association of RI, and they claim that many parents have expressed the same concerns I do about recreational services. If there isn't anything in place, I feel that something should be implemented for them. Sincerely, Pat Felisberto Wed 7/24/02 8:36 am
Health Care	To whom it may concern: My brother, who had two strokes and a brain hemorrhage a number of years ago, is only 50 years old. He does not qualify for assistance with his medications because he is not considered "elderly", as yet. He is collecting a monthly disability check from social security, but it cannot cover all of his bills, partly because of the costs of his medications. Please consider assistance for those persons who are diagnosed as "disabled", regardless of their age. Thank you for your attention to this matter. Sincerely, Judie Smith Tues 7/23/02 11:37 am
Health Care	Subject: concerning public forum in Prov. Journal 07/17/02 To whom it may concern: As a disabled Rhode Islander I would like my voice heard in the upcoming "public forum". I feel the RIPAE program should be changed to include Disabled people as well as the elderly. Also, I would like to see Medicaid changed so it would apply to a higher income limit. I am disabled from two strokes + a brain hemorrhage. I have been seeing a psychiatrist for 6 years for problems related to my brain insults. Less than a month ago, I spent a week at butler hospital in an intensive treatment unit. This one trip to the hospital will

	cost me over $800. For a deductible from Medicare. Medicare, when you get right down to it covers very little compared to Medicaid, which covers everything there is. Try comparing the two programs and you will understand why it is quite obvious which is the much better plan... I hope something can be done to help individuals like myself who can not buy prescriptions under RIPAE, or be covered by Medicaid. The other very important issue that should be covered is the fact that if we opt to buy prescriptions through the internet like canadameds.com which saves us as much as 60% in cost; the fact is, Rhode Island is the only state which will not allow prescriptions from other countries to be shipped here. I found this out when buying through canadameds.com, I was told we are the only state objecting to their mailing of drugs here, so I shipped them to my sister's in Wallingford, CT. Where I drove to get them. Thanks for allowing me to voice my concerns, From: Peter Leonard Wed. July 17, 2002 2:27 pm
Health Care Transportation	I am unable to attend the public hearings so I am writing my concerns. They are as follows: attention is needed for persons with a mental illness as well as a developmental disability. I have a 29-year-old daughter who has a developmental disability as well as a bipolar affective disorder and attention deficit disorder. There is no one working with her who has a "clue" in terms of her mental illness. They do not have enough knowledge of the illness, the medications, and the treatments. Her male companion has a traumatic brain injury, epilepsy, ADHD, and a substance abuse problem. I have tried for three years to find help for him and I don't believe it is available in Rhode Island. He needs a Neuropsychiatrist. He is now homeless! Transportation is a major problem in the Westerly area. I would like to have a family oriented residential and vocational program for both of them but that is not feasible. I see an incredible waste of resources and money; problems are never solved. I have been to meeting after meeting and they are a waste of everyone's time. There is no knowledge of guardianship among the staff that work with my daughter. I am available for more discussion on these matters. Thanks for allowing this opportunity. Sincerely, Nancy Warner Charlestown Tues 7/23/02 8:12 am

Health Care	Dear Sirs, I want to thank you for offering this avenue to allow families to communicate with you. I am the mother of a child with Asperger's Syndrome. As any parent of a child with disabilities, my concerns Are numerous. The CEDAR center has been a godsend in attempting to access services and information. I am very frustrated by the lack of co-ordination between agencies within the state. When my son was deemed Medicaid Eligible, they told me there was no "booklet" that listed providers that took the card, or what services The card applied to. It has been a difficult time Attempting to access what he needs strictly through Trial and error. I am sure that you are well aware of the lack of providers for needed services within the state. The waiting lists are long for home based, as well as outpatient services, but the needs are great. I have been unable to find anything in services south of Warwick, and living in Westerly, this makes for quite a time consuming commute to my son's services, three days a week. I have been searching for sibling support services {to no avail} for my typical children...they are affected greatly by their brother's disability. The need is so great in the psychology end of services in general...it's truly staggering! I was also amazed to learn that within our state, every school district stands independently in as far as mandating what is provided within the classroom based services. Some towns have special ed teachers within the rooms, some one to a building. Your zip code truly determines the level of services your child will receive within this state...and that is sad. I am saddened to report, that when we filed a due process suit in Feb. 2001, I received a letter stating That I could be assured of the matter being settled in 45 school days...the final papers may be signed by Aug.1, 2002...18 months after filing...obviously, no one followed up to see that the case is still open. As the autism diagnosis rate has reached epidemic proportions nationwide, many states and towns are responding with specialized programs to ensure that these kids have the support they need to succeed in life. I am especially referring to the Stonington, CT. program founded by Delores Olean, that supports these kids through college. It's truly a win-win situation for all involved as the supports being given are reducing the need for in-home and supplemental services. Their Staff is trained to teach autistic kids in the way they learn, and it's working. Shouldn't we look at successes and model them, much as we want our kids to? I realize that the state is re-looking at the

	Medicaid issue, and rightly so due to the misuse of funds. Please remember that the services of speech, occupational therapy, and physical therapy alone are staggering, not to mention psychotherapy at $140+ a session. Most insurance doesn't cover any of these costs, since idea was written that the brunt of it falls on the schools. It's hard to work to pay for the services, but have to take time out of work to go to the services, as they are only offered m-f 9-5{ps...the child's in school at those times too!} I appreciate this opportunity to express some concerns, and thank you for taking the time to read them, and hopefully consider them in your decision Making process. Sincerely, Kate Barnas Mon. 7/22/02 11:52 am