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

Part I. Executive Summary And Recommendations

Identified during Public Comments submitted at the Eight Public Hearings
August 20 – 24, 2001

Prepared by the
Governor's Commission on Disabilities
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Report on the Concerns of People with Disabilities and their Families

A. *Table of Contents*

B. *Public Notice*[i]

Public Hearings
State of Rhode Island

To identify the concerns of people with disabilities and their families

Monday, August 20th

2-4 PM Zambarano Hospital, Auditorium, Wallum Lake, on Rte.100, Pascoag

5-7 PM - Rehabilitation Hospital of RI (Fogarty), McAvinn Conference Rm.
116 Eddie Dowling Highway, North Smithfield

Tuesday, August 21st 5-7 PM

Providence Regional Family Center, 206 Elmwood Avenue, Providence

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

Wednesday, August 22nd 5-7 PM

Warwick Public Library, Large Conference Room, 600 Sandy Lane, Warwick

Thursday, August 23rd

5-7 PM - Independence Square I, Conference Room
500 Prospect Street, Pawtucket

5:30-7:30 PM - Newport Hospital, Community Conference Room
11 Friendship Street, Newport (parking off Powell Avenue)

Friday, August 24th 2-4 PM

Arnold Conference Center, Regan Building # 60
John O. Pastore (formerly Howard) Center, Cranston

Comments may be made in person during the hearing, or you can mail, fax or e-mail them by August 28th 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) will be available at all sites.

Interpreters for the Deaf will be available at the Warwick, Newport and Pawtucket Forums and have been requested for the other locations.

Spanish Interpreters will be available at theNorth Smithfield, Providence and Pawtucket Forums.

Lincoln Almond, Governor

C. *August 14, 2001 Providence Journal disABILITY Column*

The Providence Journal

Tuesday, August 14, 2001

Forums key time for people with disabilities to pipe up

DISABILITY
KATE McCARTHY-BARNETT

I went to Washington, D.C., at the beginning of the summer to participate in a rally and joined more than 700 breast cancer advocates chanting into megaphones to raise awareness of issues to members of Congress. It was exciting to travel to our nation's Capitol, but a trip to Washington is not always required to get your message across. During the week of Aug. 20-24, eight public forums will be held in Rhode Island to hear the needs and concerns of people with disabilities and their families.

For the past decade, the Governor's Commission on Disabilities has sponsored a yearly public hearing to identify barriers that prevent people with disabilities from participating fully in our society. This year, the commission is collaborating with 23 state departments, commissions and community organizations to sponsor a week of hearings across the state. Recognizing that people with disabilities and their families who receive services from many different organizations and agencies often have the same desires and needs, these forums will provide the opportunity for increasing knowledge and understanding of many critical issues.

"Problems can never be solved until an awareness of the issues has been created," says Bob Cooper, executive secretary for the Governor's Commission on Disabilities. "These forums will provide the opportunity to start creating that awareness."

He believes people may have suggestions to improve the lives of individuals with disabilities and their families, whether it be providing access to technology for people who are blind, offering employment and training for workers with developmental disabilities, or ending workplace discrimination for workers with mental illness. You might have comments on substance-abuse treatment for expectant mothers, early intervention services for infants with HIV or AIDS, community-based, long-term care for elders with Alzheimer's, or barriers to recreation.

"The state policymakers and planners want to hear about what is affecting individuals with disabilities and their families because their opinions guide the state's efforts to improve services and expand opportunities," Cooper said.

The public forums will be held at locations throughout the state and will have captioning services that project everyone's words onto a screen so people who are hard of hearing will know what is being said. Interpreters for the deaf and Spanish interpreters will also be available at some sites (below).

Following the hearings, transcripts from each forum will be provided to all sponsors for review. They will determine what government and private organizations are doing about a concern presented and what is not being done. Then, with input from many different sources, solutions will begin to be developed. In some cases, the solution may be to work with legislators, policy advisers, advocates and administrators to enact into law programs to address the concern. If a law is enacted, then the work begins to establish new programs. Regina Connor, project director of the Assistive Technology Access Partnership at the Office of Rehabilitation Services, one of the 23 sponsors of the hearings, says, "The forums will provide a broad perspective of what the needs are within the community and any commonalities identified from the comments will lead to greater strength of the importance of critical issues."

At the forums, Connor plans to address the issues of funding sources for assistive technology and program changes. "This is an opportunity for consumers and organizations who have similar goals to network and together increase their influence on policymakers."

Almost all of the commission's legislative priorities over the past decade started with a comment at one of the public hearings, such as concerns about discrimination in the workplace, personal care attendant pay and equal access to mental health services. A resident from Cranston expressed her concern at a previous forum about leaving doughnut shops where the only curb leads people using wheelchairs into the direct path of cars exiting from the drive-through window. This year, the General Assembly enacted laws setting procedures for local zoning boards to review pedestrian safety before granting permits.

Transportation to work for people with disabilities who do not have an automobile and don't live near a bus route is another topic that was addressed at previous forums. As a result, RIPTA has worked with the Commission to design a pilot project ordering vans and determining areas to be served and will continue to develop this project until all areas of the state have transit services.

If you have an issue, concern or suggestion, I encourage you to attend one of the public hearings. Far too often people assume that their issue is not important or that someone else will eventually address it. The reality is, your message is critical and you can be part of the solution.

Here is a schedule:

Monday, Aug. 20: From 2 to 4 p.m. in the auditorium of Zambarano Hospital, Wallum Lake, Pascoag, and from 5 to 7 p.m. at the Rehabilitation Hospital of R.I. (Fogarty), McAvinn Conference Room, 116 Eddie Dowling Highway, North Smithfield.

Tuesday, Aug. 21: From 5 to 7 p.m. at the Providence Regional Family Center, 206 Elmwood Ave., Providence, and from 5 to 7 p.m. at Independence Square II, Conference Room, Independence Way, Kingston.

Wednesday, Aug. 22: From 5 to 7 p.m. at the Warwick Public Library, 600 Sandy Lane.

Thursday, Aug. 23: From 5 to 7 p.m. at Independence Square I, Conference Room, 500 Prospect St., Pawtucket, and from 5:30 to 7 p.m. at the Newport Hospital, Community Conference Room, 11 Friendship St., Newport.

Friday, Aug. 24: From 2 to 4 p.m. at the Arnold Conference Center, Regan Building Number 60, in the John O. Pastore Center, Cranston.

CART Recorders (real-time captioning) will be available at all sites. Interpreters for the deaf will be available at the Warwick, Pawtucket and Newport forums. Spanish interpreters will be available at the Providence and Pawtucket forums.

Comments may also be faxed to 462-0106 or e-mailed to disabilities@ged.state.ri.us by Aug. 28.

For more information or to request an accommodation call 462-0100 or 462-0101 (tty).

Kate McCarthy-Barnett, Ed.D. can be reached at kmccarthybarnett@aol.com or by mail c/o Features Department, The Providence Journal, 75 Fountain St., Providence, R.I. 02902.

D. *Sponsoring Agencies*

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

Commission on the Deaf & Hard of Hearing, Jan Luby, Chairperson;

Council on Assistive Technology, Marie Younkin-Waldman, Chairperson;

Human Resoruces/Outreach & Diversity Office, Department of Administration, Dr. Robert Carl, Director;

Department of Elderly Affairs, Barbara Rayner, Director**;**

Department of Health, Dr. Patricia Nolan, Director;

Department of Human Services, Christine C. Ferguson, Director;

Department of Mental Health, Retardation & Hospitals, A. Kathryn Power, Director;

Developmental Disability Council, Kathleen P. Leonard, Chairperson;

Governor's Advisory Council for the Blind & Visually Impaired, Donald Deignan, Chairperson;

Governor's Commission on Disabilities, Doreen McConaghy, Chairperson;

Governor's Paratransit Taskforce, Clark Greene, Chairperson;

Long Term Care Coordinating Council, Lt. Governor Charles J. Fogarty, Chairperson;

Mental Health Association of RI, Cynthia O'Neil, Executive Director;

National Alliance for the Mentally Ill of RI, Nicki Salin, PhD., Executive Director;

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, Barbara Weaver, Chief Information Officer;

P.A.R.I. Independent Living Center, Leo Canuel, Executive Director;

RI Arc, James Healey, Executive Director;

RI Rehabilitation Association, Jane Massa, President;

RI Disability Law Center, Raymond Bandusky, Executive Director;

State Rehabilitation Council, Carol Krause-Ferraioli, Chairperson;

Statewide Independent Living Council, Robert Bryan, Chairperson;

TechACCESS Center of RI, Paula Olivieri, Operations Director

University Affiliated Program of RI/ RI College, A. Anthony Antosh, Director

E. *Support Services*

Real-Time Captioning & Transcription Services provided by: Allied Court Reporters

Interpreters for the Deaf – Arranged by the OSCIL – Interpreter Referral Service, under contract with the Commission on the Deaf and Hard of Hearing

Spanish Interpreting provided by the Departments of Administration and Human Services

Vietnamese & Cambodian Interpreting arranged by the Language Bank - Socio-Economic Development Corporation for Southeast Asians

Compiliation of Preliminary Draft Testimony by Meghan Kelly O'Brien of U.R.I.

1. Executive Summary

A. *Purpose of the Public Hearings*

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

B. *The Public Hearings*

Eight public forums (hearings) were held during the week of August 20-24, 2001 in: Burriville; North Smithfield; Providence; South Kingstown; Warwick; Pawtucket; Newport; and Cranston. Over 300 people attended the hearings and more than 100 testified. An additional 57 people submitted correspondence, e-mails or faxes before the end of August

C. *Procedures following the public hearings*

During September and October representatives of the sponsoring organizations and the Governor's Commission on Disabilities' Legislation Committee met to review the testimony and develop recommendations for action. At the first meeting six (6) working groups were formed to review the testimony focusing on specific reoccurring topics: accessibility, assistive technology, barriers to employment, education, health care, and transportation. The working groups met, each prepared a summary of their findings that were distributed to all the sponsoring organizations. The Governor's Commission on Disabilities staff compiled the working groups' summaries into a listing by topics that required legislative action and non-legislative action.

D. *Top Issues of Concern to People with Disabilities and Their Families*

After reviewing all the testimony the sponsors identified the top five (5) issues from the public forums:

- **Statewide access to:**
  - ***Health care,***
  - ***Transportation,***
  - ***Employment, and***
  - ***Housing and***
- **Stabilization of the direct-care and supportive services workforce.**

2. Recommendations

A. *Topics Requiring Legislative Action*

I. Health Care

a) Requires Funding

(1) Medicaid/Medical

(a) Expansion and/or maintenance of Existing Services

(i) Increase income eligibility levels for Medicaid; home care, assisted living, and community support services *see pages 67, 68*

(ii) Expand mental health preventive services *see page 104*

(iii) Increase nursing staff at Zambarano Hospital *see pages 3*, 11, 11, 12

(iv) Increase personal "needs" allowance for the residents of institutions *see page 118*

(v) Expand personal care services to include – budgeting, paying bills; personal hygiene, housekeeping and cooking, & transportation *see pages 3, 50, 84, 109, 109, 110, 111, 111, 112, 112, 112, 112, 113, 114*

(vi) Provider Reimbursement [see V. Stabilizing Direct Care and Supportive Services Workforce]

(vii) Expand substance abuse treatment services *see pages 47, 71, 95, 100*

(b) Creation of New Services

(i) Prescription coverage for people with disabilities who are ineligible for existing programs *see pages 19, 28, 31, 33, 38, 48, 49, 62, 106, 125*

(ii) Universal access to health care for people with disabilities and their families *see pages 29, 31, 32, 33, 34, 73, 75*

(iii) Orthopedics services *see page 90*

(iv) Foreign language interpreters when Medicaid services are provided *see page 52* [also see VI. Accessibility – Emergency Sign Language Interpreters]

(v) State matching funds for Department of Human Services' federal Multiple Sclerosis grant (already awarded) *see page 47*

(vi) Establish in-state residential center for people with traumatic brain injury *see pages 82, 85, 91, 107, 108, 119*

(vii) Establish day habilitation/rehabilitation services for people with traumatic brain injury *see pages 82, 85, 107, 119*

(viii) Establish in-state residential facility for individuals who are deaf, mentally retarded, with behavior disorders *see page 105*

(ix) Establish support services for women substance abusers/prisoners *see pages 86, 87, 122*

(c) Medicaid Recommendations Needing Further Study

(i) Adequacy of existing:

(a) Respite and home based care services see pages 20, 48, 51, 69

(b) RIte Care and Medicaid providers see page 90

(c) Assisted Living Supported "Slots" see page 48

(d) Nursing care for children with disabilities see page 51

(e) Transition medical/health services see page 52

(f) System of service and support for families see pages 54, 97, 126

(g) Family support for childhood disability see page 53

(h) Medical support services: stair lifts, orthopedic shoes see page 20

(i) Personal care attendant hours see pages 60, 118

(j) Medical services for homebound see page 119

(ii) Creating of long-term care services and facility for persons who are deaf and use sign language *see pages 122, 128*

(iii) Confidentiality and family members *see page 79*

b) Legislative Mandates

(1) *Health Care Insurance coverage of:*

- **(a) Eyeglasses** *see pages 33, 75*
- **(b) Glucose testing supplies** *see page 125*
- **(c) Prosthetic follow-up services** *see page 75*
- **(d) Hearing aids** *see page 42*

(2) *Licensing of Prosthetics by the Department of Health* *see page 75*

(3) *Labels/distinctions between developmental disabilities and other neurological impairments; should not distinguish between types of disability, esp. for eligibility* *see page 34*

II. Transportation

a) Requires Funding

(1) *Medicaid/Medical*

(a) Transportation is critical to getting the therapy and continuing mobility:

- **(i)** RIde vans should provide trips to detox centers at all hours *see page 47*
- **(ii)** Provide transportation for medical trips for families on Medicaid, but not on RIte Care *see page 52*
- (iii) Transportation to medical care is also critical for people with disabilities who are not eligible for Medicaid funded RIde services *see page 96*

(2) *Other Transportation*

(a) Transportation to and from schooling, jobs and other destinations is an integral part of achieving and maintaining a quality life for all persons, including those with disabilities: *see pages 29, 30, 74, 104, 110*

- (i) Expand statewide 3/4-mile RIde/RIPTA ADA service corridor; *see pages 15, 17, 80, 124*
- (ii) Expand RIde/RIPTA routes especially in rural communities, and add more bus stops and increase the number of accessible buses; and *see pages 4, 68, 89, 90, 90, 92, 106, 115, 121*
- (iii) Create a sliding fee, based on income for RIde ADA trips *see pages 96, 124*
- (iv) Weekend service *see page 30*

III. Employment

a) Requires Funding

(1) *Medicaid/Medical*

(a) Two major barriers to employment are transportation and health insurance:

- (i) General lack of health insurance on jobs *see page 32*
- (ii) Offset the loss of Medicaid, due to increased income from working, by adopting the Medicaid Buy-In Options *see pages 19, 38*
- (iii) State Match the Department of Human Services' "Rhodes to Maintain Independence" grant. [See I. b) (v) Health Care.]
- (iv) The Federal work incentives are meaningless when combined with the state "disincentives":

(a) *The Medicaid eligibility criteria place the income limit at $625 a month - After that there is a dollar for dollar spend down of income to obtain Medicaid. Medicaid covers prescriptions, attendant care services and durable goods supports. Without these services or products the ability to work is compromised by reduced functioning* see pages 66, 116

(b) *Other economic disincentives such as increased rent in subsidized housing, increased taxes, which combined with the Medicaid spend downs result in negative earnings* see page 96

(v) *Transportation to work* [see II.a)(2)(a) Transportation]

b) General Revenue Funding

(a) Obtaining reasonable public transportation as a problem specifically related to work [see II. 2) Transportation]

(b) Fully fund the assistive technology loan program [see VII. Assistive Technology]

(c) Hillsgrove House is a clubhouse associated with Kent County Mental Health that works on an employment model - Members are helped to find and keep work with job coaching and other supports. In January 2001, new restrictions placed on Medicaid recipients have affected the ability of this facility to provide services *see pages 90, 90, 97, 101, 102, 102, 102, 102, 105, 123, 124, 124*

IV. Housing

a) Requires Funding

(1) Increase the number of accessible, subsidized apartments for single adults, adults with live-in personal care attendant, and families *see pages 41, 67, 81, 110, 113*

(2) Federal and or State Funding *see pages 35, 53*

Accessible Housing need to find an equitable way to help families who have children with disabilities”; that is, to defray some of the costs related to child disability….i.e. families have to purchase lift vans and make adaptations to their homes

b) Legislative Mandates

(1) Priority for people with disabilities in occupying accessible units in public housing *see pages 66, 73*

(2) Promote mixing of disabilities in community based residential facilities *see page 93*

V. Stabilizing the Direct Care and Supportive Services Workforce[1]

a) Requires Funding

(1) Improve compensation for direct care staffs, including pay, health care and other benefits *see pages, 49, 51, 53, 55, 55, 59, 59, 60, 61, 61, 71, 92, 95, 96, 110, 110, 110, 111, 111, 111, 111, 111, 111, 112, 112, 113, 113, 113*

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[1] Direct care and supportive services include: employment and training, health care, personal / independent living, rehabilitation, and residential service professionals and paraprofessionals.

(2) Establish career development and continuing education programs to improve the quantity and quality of direct care and supportive services professionals and paraprofessionals *see pages 51, 95*

(3) Improve compensation for job coaches, rehabilitation counselors, and other employment services *see pages 111, 112, 112*

VI. Accessibility

a) Requires Funding

(1) Medicaid/Medical

(a) **Expand transitional evaluation and services to assist persons move from nursing home settings to less restrictive environment** *see page 81*

(b) **Create accessible mental health services for people who are deaf [see I. b) (viii) Health Care]**

(c) **Establish a Rhode Island Assistive Living Facility for persons who are deaf [see I. c) (ii) Health Care]**

(d) **Create accessible substance abuse services and prevention programs for persons who are deaf** *see pages 46, 99*

(2) State Funding

(a) **Establish a 24 hour emergency (sign language) interpreter service** *see pages 39, 123*

(b) **Expand the home modifications program to assist people with significant disabilities to remain in the community:** *see page 81*

(i) $400,000 a year will reduce the year or more waiting list *see pages 51, 114*

(ii) Establish a program for modifications installed in private (not subsidized) rental housing *see pages 38, 114*

b) Legislative Mandates

(1) Improve communications accessibility through:

(a) **Business telephones using recorded messages and voice mail are not accessible to Deaf and hearing impaired. Need to speak with live person** *see page 39*

(b) **Captioned movies in RI** *see page 39*

(c) **Cable TV programming should include closed-captioning and** *see page 42*

(d) **By utilizing assistive technology [see VII. Assistive Technology]**

(2) All public facilities should have automatic doors *see pages 75, 81*

VII. Assistive Technology

a) Requires Funding

(1) Medicaid/Medical

(a) **Medicaid should pay for stair lifts, not just external elevator/lifts** *see page 20*

(2) State/Federal Funding

(a) **Expand the talking book program** *see pages 29, 39, 80*

(b) **Expand the state assistive technology loan program to:** *see page 81*

(i) Include loaning technology on “trial” so people with disabilities could try it before they have to purchase it; and *see page 38*

(ii) Purchase assistive technology for people with disabilities who cannot afford assistive technology *see page 83*

(c) **Install audible warning signals at traffic signals at pedestrian crossings** *see pages 38, 57*

VIII. Education

a) Requires Funding

(1) ***Assist in the establishment of the RI Youth Leadership Forum*** *see pages 38, 43*

(2) **Establish after school programs to include children with disabilities** *see page 102*

(3) **Allocate additional funds for Special Education programs to fulfill IEP directives** *see page 119*

b) Legislative Mandates

(1) ***Greater control of confidential disability related information in the schools. Too many people have access and there are breeches of confidentiality.*** *See pages 31, 32*

IX. Financial Support

a) Requires Funding

(1) ***Increase Social Security Disability Benefit, and allow some earnings*** *see pages 50, 103*

(2) ***Without the state reducing the SSI benefits for every federal increase*** *see page 50*

(3) ***Increase Food Stamp assistance program*** *see page 104*

B. *Topics Requiring a Public Information / Awareness Solution*

Establish a central clearinghouse/information service on all disability related issues:

I. Health Care

a) **Substance abuse/disability awareness** *see pages 3, 46, 63, 88, 95*

b) **Mental health: awareness and provider training** *see page 88*

c) **Domestic violence education** *see page 87*

d) **Physical and "attitudinal" access awareness, including information about assistive technology support, for employees in health care facilities** *see pages 29, 34*

e) **An Inventory of substance abuse services** *see page 46*

f) **Disseminate census data, related to people with disabilities** *see page 100*

g) **Information and outreach targeted at Minority persons with disabilities** *see page 126*

h) **Physician's attitude, training on how to work with person having disability** *see pages 68, 83*

i) **Information pertaining to available health care providers and services** *see pages 23, 28, 67, 72*

j) **Information regarding health care benefits for young adults** *see page 25*

II. Transportation

a) **Make information available to families about transportation opportunities to visit their relatives in Zambarano and other facilities for persons with disabilities** *see page 6*

b) **Education family members and staff on how to use public transportation and encourage persons with disabilities to maximize their independence by using it whenever possible** *see pages 43, 92*

c) **Sensitive, all public groups, to the fact that transportation is needed for persons with disabilities to be able to participate in hearings and otherwise make input to policy development** *see page 58*

d) **Information regarding modified vehicles and tax credits** *see page 37*

III. Employment

a) **The employment prospects for minorities people with disabilities is very poor, create an outreach program for minorities with disabilities** *see page 126*

b) **Address the perception that people with disabilities would not be hired by employers with health insurance, because of the high cost of insuring them** *see page 31*

c) **People with disabilities have many employment problems related to the Americans with Disabilities Act (ADA) compliance - The issues varied widely, from:**

  (1) ***No compliance, or slow compliance;*** *see pages, 14, 40*

  (2) ***Not knowing how to get help with an ADA issue*** *see page 14*

  (3) ***The lack of ADA awareness among school guidance counselors*** *see page 32*

  (4) ***Training government employees on ADA issues*** *see page 98*

d) **Creating an awareness of the range of education and vocational training services that are available:**

  (1) ***Many adults with disabilities are not familiar with services such as ORS*** *see pages 32, 74*

  (2) ***Network Rhode Island was mentioned as being very helpful, but the speaker noted that not many people know about it*** *see page 32*

e) **Improve employer and public attitudes towards disabled workers** *see pages 83, 90*

f) **Create an awareness that assistive technology will help people with disabilities, work** *see page 84*

g) **Social Security Administration offices do not answer their phones- it is difficult to get information on work incentive rules** *see page 29*

h) **Information about disabilities due to chemical exposure at work** *see page 40*

IV. Assistive Technology

- a) **Increase awareness of the range of assistive technology that is available in the community:**
  - *(1)* ***Need "to have better communication…going down to the agency level"*** *see page 7*
  - *(2)* ***"Private agencies…there's a lot of competition and competition hurts the consumer…get private agencies to work together in a more complimentary and cooperative way."*** *See page 7*
  - *(3)* ***Create public service announcements - "There needs to be an effort to get the word out about what is available to make peoples' lives easier"*** *see page 35*
  - *(4)* ***Centralized place to get information about state agencies and funding sources for Assistive Technology*** *see page 26*
- b) **Create awareness of the adapted driver's education - people do not know about and all you have to do is request it through the registry of motor vehicles and a course taught in your community** *see page 35*

V. Education

- a) **Higher education and training** *see pages 25, 73, 74*
- b) **Special education** *see pages 31, 63, 105*

VI. Financial

- a) **Information on impact on other support services** *see page 26*
- b) **Social Security information** *see page 29*
- *c)* **Information on financial benefits** *see page 40*

VII. Housing

- a) **Information on available housing** *see page 81*

C. *Topics Requiring Improvement of the Delivery of (Existing) Services*

I. Health Care

- a) **Improve the coordination of multiple services to the same individual (i.e. persons with disabilities who are substance abusers, and need accessible treatment, a transition center, and assisted living accommodations)** *see page 6*
- b) **Improve security at state residential facilities** *see pages 4, 75*
- c) **Less restrictive environments in institutions** *see page 88*
- d) **De-institutionalize more persons with disabilities to less restrictive environment** *see pages 10, 10*
- e) **Faster provision of equipment to critically/terminally ill children** *see pages 79, 86*
- f) **Timely assistance – home modifications, reduce waiting period** *see pages 81, 115*

g) **Cultivate more providers willing to serve transitioning kids with disabilities** *see page 52*

h) **Improve the process of determining eligibility** *see pages 69, 79, 115, 116*

i) **Improve transition from in-patient services to community based services** *see page 80*

j) **Consumer directed services** *see page 94*

k) **Improve in-patient discharge planning** *see page 101*

II. Transportation

a) RIPTA/RIde

- *(1)* ***Add three more wheelchair positions in RIPTA buses and RIde vans*** *see page 5*
- ***(2) Reconsider the current RIPTA ID cards for customers with disabilities that "marks people as disabled"*** *see pages 25, 26**,** 27*
- ***(3) Improve coordination of transportation service with the state of Massachusetts and RIPTA, including taking passengers over the state line to a bus stop or paratransit van*** *see pages 57, 57*
- ***(4) Improve scheduling and communication with riders*** *see page 98*

b) Disability Parking

- ***(1) Revise the process for applying for parking permits and to be more "customer friendly" without lowing the eligibility standards - "had to wait three months" to get the permit*** *see pages 66, 68, 71*
- ***(2) Incorporate disability parking spaces at public accommodations into local building and zoning code enforcement*** *see page 72*
- ***(3) Coordinate Department of Transportation and municipal public works installation of curb cuts and RIPTA bus stops*** *see page 45*
- ***(4) Locate disability parking in front/next to entrance doors rather than at the end of buildings*** *see page 66*
- ***(5) Include on disability parking Signs "NO STANDING" sign, which would keep people from parking in disability parking spaces while they wait for someone in the building*** *see page 125*

c) **Warning Signs**

- ***(1) Establish uniform procedures for requesting road signs about deaf children, amongst the cities and towns*** *see page 71*

d) **Zambarano Hospital**

- ***(1) Replace the aging vans at Zambarano Hospital with safe, well-equipped vans*** *see pages 5, 8, 9, 10, 11*

III. Employment

a) **Improve the transitional planning between childhood and adult services, related to preparing for employment** *see page 105*

b) **Place in management positions in state agencies more employees with**

disabilities *see page 116*

- c) **Establish public housing near the places of employment** *see page 93*
- d) **Provide adequate training for upward mobility** *see page 58*

IV. Stabilizing the Direct Care and Supportive Services Workforce

- a) **Treat direct care and supportive services employees with dignity** *see page 60*
- b) **Develop student nursing and career exploration options at long term facilities such as Zambarano** *see page 5*

V. Assistive Technology

- a) **Recognize that Assistive Technology purchases are a very time sensitive [see I. e) Health Care]**
- b) **Clarify Medicaid standards for assistive technology:**
  - ***(1) "Wheelchair is from MA and I assume other states cannot be fixed in RI…people should be able to have wheelchairs and other pertinent equipment fixed anywhere in the country."*** *See page 101*
- c) **Purchase and install coin-operated washing machine and dryer at Zambarano for use by the residents, to learn/test independent living skills** *see page 9*
- d) **Expand computer on-line access for residents in institutions** *see pages 9, 9*

VI. Education

- a) **Focus secondary education transition period (age 14 and beyond) to prepare students with disabilities for the "real world":** *see page 32*
  - ***(1) Many students do not have the skills necessary to find and keep employment, pay bills, etc.*** *see page 30*
  - ***(2) Many students are being shortchanged in needed services and are unprepared for the needs of the future*** *see pages 30, 52*
- b) **Establish in-home support services for families of students diagnosed with Attention Deficit Hyperactivity Disorder (ADHD)** *see page 44*
- c) **Modify Special Education programs to meet specific health issues of young children** *see page 52*
- d) **Continuing education for independent living skills** *see pages 58, 104, 104*

VII. Legal Services

- a) **RI Disability Law Center**
  - ***(1) Improve services to deaf people, and add a deaf members to their board*** *see page 122*
  - ***(2) Provide legal assistance on employment discrimination cases*** *see pages 14, 16*
  - ***(3) Improve the range of legal services*** *see page 67*

D. *Topics Requiring Regulatory Changes*

I. Health Care

a) **Eliminate "homebound" rule** *see page 69*

b) **Flexible home modification rules** *see pages 38, 115*

E. *Topics Requiring Enforcement of (Existing) Regulations*

I. Health Care

a) **Inadequate care, dirty conditions, rights violations of those in long term care** *see pages 63, 64*

II. Accessibility

a) **Communications Accessibility**

(1) ***Small Claims Courts - change the existing Notice of Suit form & Processing forms to mention of availability of assistive listening devices or any other forms of accessibility*** *see page 24*

(2) ***Narragansett Town Hall – post procedures for requesting assistive listening devices*** *see page 24*

b) **Disability Parking/Curb Cuts/Sidewalk Obstructions**

(1) ***In Bristol***

(a) **CVS Handicap parking spot is located at the end of the building in a dangerous area** *see page 64*

(2) ***In Narragansett***

(a) **"Summer visitors take the handicap spots"** *see page 68*

(3) ***In Newport:***

(a) **Cumberland Farms** *see page 66*

(b) **Washington Square** *see page 66*

(c) **Broadway (across from city hall)** *see page 78*

(4) ***In Pawtucket:***

(a) **Overgrown shrubs** *see page 54*

(b) **Unpaved and hilly sidewalks, forcing you to walk in the street** *see page 54*

(c) **New Port Ave and Beverage Hill have polls in the center of the sidewalk** *see page 54*

(d) **"Sidewalks are dangerous, curb stones that are too high or broken"** *see page 54*

(e) **Need for cross walks** *see page 57*

(f) **No curb cuts on Pawtucket Ave. across from high school** *see page 45*

(5) ***In Providence:***

(a) **Curb cuts, parking and access to the Providence Place Mall** *see page 23*

(b) **Problems with sidewalk and handicap parking access "the corner of the State House is a like a death trap."** *see page 23*

(6) ***In Warren***

(a) **Physical access in the Warren School Department** *see page 63*

c) **Physical Accessibility**

(1) ***General concerns***

- (a) **Store access is not very good - heavy electric wheelchairs can not be lifted over a couple of steps** *see page 37*
- (b) **Building Inspectors overlook accessibility issues** *see page 69*
- (c) **Accessibility to public and private buildings is an issue, especially for those in wheelchairs. (People will say to the person having disability; *"we will come out and get you"* but you can not get in there to get them to tell them to come out!)** *See pages 78, 105*
- (d) **Health Survey Results Indicate Persons with Disability Desire Additional Access - into building/Physician's office** *see page 83*

(2) Specific Complaints

- (a) **Narragansett Town Hall Elevator does not work** *see page 36*
- (b) **George's Restaurant - "Handicap restroom is on the second floor"** *see page 45*
- (c) **Lake front at Zambarano Hospital** *see page 4*

III. Assistive Technology

a) State Courts:

- ***(1) Court notices - No mention of availability of assistive listening devices or any other forms of accessibility*** *see page 24*
- ***(2) Washington County district court…proved to me as a hearing impaired person, dealing with this court is not an easy hurdle."*** *See page 24*
- ***(3) The judge did not attempt to use a microphone*** *see page 24*
- ***(4) Changes to the existing district court-small claims*** *see page 24*

b) Town of Narragansett:

- ***(1) There's no captioning, there's not even an interpreter*** *see page 36*
- *(2)* ***If they are required to provide sign language interpreters, as an accommodation why can't they be required to provide one of the cart systems*** *see page 36*

3. Selected Demographics

A. *Excerpts for the October 2001 Update of the "Rhode Island Disability Chartbook" with the 2000 Rhode Island BRFSS data, by the RI Department of Health*

Approximately 25% of the RI non-institutionalized adults (an estimated 183,000 adults) reported that they had experienced some kinds of limitations because of any impairment or health problem.

Most frequently reported impairments or health problems were: back/neck problems (16.2%), arthritis/rheumatism (14.3%), heart problems (9.7%), depression/anxiety (6.9%), and fractures (6.9%).

People with disabilities were much more likely than people without disabilities to report poor general health (33.2% vs. 8.1%), poor physical health (27.0% vs. 3.2%), and poor mental health (23.6% vs.6.3%).

While people with disabilities were less likely than people without disabilities not to have routine checkup in the past year (14.8% vs. 20.1%), they were more likely not to have dentist visit in the past year (31.4% vs. 23.0%).

People with disabilities were more likely than people without disabilities to report that there was a time during the past year they could not see a doctor because of the cost (14.6% vs. 5.3%).

People with disabilities were more likely than people without disabilities to report that they got insufficient social/emotional support (35.6% vs. 23.9%) and were dissatisfied with life (17.4% vs. 3.5%).

Working-age adults with disabilities were much less likely to be employed for wages or self-employed (59% vs. 82%) than adults without disabilities in the same ages.

B. *Excerpts from the Employment Transportation for People with Disabilities: Work Link Survey Results, RIPTA June 2001*

Employment status and transportation need by number of respondents

The following table gives the total number of respondents for each town. The total number of respondents for each town is sorted into those who are employed and those who are unemployed. The number and percentage of each group who cited transportation as an issue in accepting employment is a so given.

TOWN	TOTAL # OF RESPONDENTS	EMPLOYED			UNEMPLOYED		
		YES	ISSUE	% WITH ISSUE	YES	ISSUE	% WITH ISSUE
Warwick	112	68	53	78%	44	41	93%
Pawtucket	85	49	43	88%	36	28	78%
Cranston	70	44	36	82%	26	23	88%
East Providence	62	33	28	85%	29	28	97%
Westerly	60	30	19	63%	30	29	97%
Providence	45	35	30	86%	10	9	90%
Woonsocket	44	32	21	66%	12	12	100%
Coventry	41	24	18	75%	17	15	88%
Bristol	26	22	17	77%	4	4	100%
South Kingstown	25	16	16	100%	9	9	100%
Central Falls	23	10	9	90%	13	7	54%
Newport	23	20	15	75%	3	3	100%
North Kingstown	23	16	12	75%	7	7	100%
North Providence	20	15	12	80%	5	3	60%
West Warwick	18	13	12	92%	5	5	100%
Lincoln	17	10	10	100%	7	6	86%
Johnston	16	9	8	89%	7	7	100%
Tiverton	15	12	10	83%	3	2	67%
Middletown	14	10	8	80%	4	3	75%
Warren	14	10	10	100%	4	3	75%
Burrillville	13	10	10	100%	3	2	67%
Cumberland	13	8	8	100%	5	3	60%
Narragansett	13	9	7	78%	4	4	100%
East Greenwich	12	7	7	100%	5	4	80%
North Smithfield	12	7	5	71%	5	4	80%
Portsmouth	10	8	8	100%	2	2	100%
Scituate	10	7	6	86%	3	3	100%
Glocester	8	8	7	88%	--	--	--

TOWN	TOTAL # OF RESPONDENTS	EMPLOYED			UNEMPLOYED		
		YES	ISSUE	% WITH ISSUE	YES	ISSUE	% WITH ISSUE
Smithfield	7	6	5	83%	1	--	--
West Greenwich	6	2	2	100%	4	4	100%
Charlestown	4	1	1	100%	3	3	100%
Jamestown	4	4	4	100%	--	--	--
Barrington	3	1	1	100%	2	2	100%
Exeter	3	3	3	100%	--	--	--
Richmond	3	2	1	50%	1	1	100%
Foster	2	2	2	100%	--	--	--
Little Compton	2	1	1	100%	1	1	100%

C. *Excerpts from the Social Security Administration, SSI Disabled Recipients Who Work Report, December 2000 by state (Rhode Island)*

Total # of Supplemental Security Income Disabled Recipients
18 – 64 years old 17,364

Total # of Supplemental Security Income Disabled Recipients Working 1,846

% Of Supplemental Security Income Disabled Recipients Working 7.8%

The Social Security Disability Income and Supplemental Security Income work incentives:

Impairment Related Work Expenses (IRWE) 16

Subsides and Special Conditions 0

Unincurred Business Expenses 0

Unsuccessful Work Attempts 0

Continued Payments under a Vocational Rehabilitation Program 0

The Social Security Disability Work Incentive programs:

Trial Work Period (TWP) 0

Extended Period of Eligibility (EPE) 0

Continuation of Medicare Coverage 0

Medicare for People with Disabilities who Work 0

The Supplemental Security Income Work Incentive programs:

Earned Income Exclusion 0

Student Earned Income Exclusion 0

Plan for Achieving Self-Support (PASS) 3

Property Essential to Self-Support 0

Special SSI Payments for People who Work – Section 1619 (a) 110

Continued Medicaid Eligibility – Section 1619 (b) 441

Special Benefits for People Eligibility Under Section 1619 (a) or (b) Who enter a Medical Treatment Facility 0

Reinstating Eligibility without a new application 0

Other Supplemental Security Income Disabled Recipients Working 1,270

The special work incentive programs for people who are blind:

Substantial Gainful Activity (SGA) applied under SSDI to people who are blind 0

Substantial Gainful Activity (SGA) not applied under SSI to people who are blind 0

Blind Work Expenses Under SSI	16

The Medicaid work incentives programs:

Medicaid Protections for Working People with Disabilities	0
Help with Medicare Part 'A' Premiums	0

D. *Excerpts from the Governor's Advisory Council on Health, Annual Report 1999 – 2000: Medicaid: Population*

Population Group	Average Individuals Eligible Each Month	Percentage Average Eligible
Elderly Adults (including MR/DD & SPMI)	18,708	11.6%
Adults with Mental Retardation / Developmental Disabilities (MR/DD)	2,320	1.4%
Adults with Serious and Persistent Mental Illness (SPMI)	3,072	1.9%
Adults with Physical Disabilities and Chronic Illness	15,088	9.3%
Children with Disabilities and in DCYF Custody	9,391	7.1%

E. *Excerpts from Information Works! 2001 by the RI Department of Elementary and Secondary Education*

Student Population		156,454
Total Special Education Students	20% or	31,291
In Resource	12% or	18,774
Self Contained Classroom	5% or	7,823
Other Programs	3% or	4,694

F. *Excerpts from FY 2002 Budget: Actual FY 2000*

Department of Health

Percentage of RI Children Receiving Early Intervention Services	6.0%
Percentage of Children with Blood Lead Levels	10.0%

Department of Mental Health, Retardation and Hospitals

Percentage of Mentally Disabled Adults in need of services who are receiving services from the public mental health system 73.3%

4. The Panelists

Sponsoring Agency	Represented by
Monday - 8/20 2-4 pm Zambarano Hospital - Auditorium	

Sponsoring Agency	Represented by
Department of Mental Health, Retardation & Hospitals (MHRH)	Paul Despres (moderator), Dick Freeman
Office of Library & Information Services (OLIS)	Joyce Mathews (Talking Books Plus)
Governor’s Commission on Disabilities (GCD)	Paul Choquette, Bob Cooper, James Pitassi
Council on Assistive Technology (ATAP)	Ed Zuromski
Commission on the Deaf & Hard of Hearing (CDHH)	Jan Luby
Department of Human Services	Susan Silva
Disability Law Center	Martha McVicker
State Independent Living Council	Judith Kapuscinski
State Rehabilitation Council	Carol Ferraioli
Monday - 8/20 5-7 pm Rehabilitation Hospital of RI	
Department of Human Services	Susan Silva (Office of Rehabilitation Services - ORS)(moderator), Ray Carroll (ORS)
Department of Mental Health, Retardation & Hospitals (MHRH)	Linda Kahn
Office of Library & Information Services (OLIS)	Beth Perry (Library Programs)
Governor’s Commission on Disabilities (GCD)	Paul Choquette, Bob Cooper, Victoria Wilcox, Jeannine Dion
Disability Law Center	Anne Mulready
State Rehabilitation Council	Carol Ferraioli
Tuesday - 8/21 5-7 pm Providence Regional Family Center	
Department of Mental Health, Retardation & Hospitals (MHRH)	John Young, DHS – Health (moderator), Dan McCarthy
Office of Library & Information Services (OLIS)	Joyce Mathews (Talking Books Plus)
Governor’s Commission on Disabilities (GCD)	Bob Cooper, Arthur Plitt
Department of Human Services	Susan Silva (ORS), Susan Olson (ORS)
Disability Law Center	Kate Sherlock
RI Rehabilitation Association	Jane Massa
Tuesday - 8/21 5-7 pm Independence Sq. II, Kingston	
Governor’s Commission on Disabilities (GCD)	Paul Choquette (moderator), Doris Duarte, Bill Inlow

Sponsoring Agency	Represented by
Department of Mental Health, Retardation & Hospitals (MHRH)	Kathleen Spangler
Office of Library & Information Services (OLIS)	Andy Egan (Talking Books Plus)
Council on Assistive Technology (ATAP)	Emily Lennon, Paula Olivieri, Marie Younkin-Waldman
Department of Human Services	Ray Carroll (ORS), Dianne Kayala (Medicaid)
Disability Law Center	Ed Stapins
Wednesday - 8/22 5-7 pm Warwick Public Library	
Ocean State Center for Independent Living (OSCIL)	Lorna Ricci (moderator)
Department of Mental Health, Retardation & Hospitals (MHRH)	Lynda Kahn
Office of Library & Information Services (OLIS)	Andy Egan, Beth Perry
Governor's Commission on Disabilities (GCD)	Paul Choquette, Bob Cooper, Ann Porto, Vicki Ferrara, Arthur Plitt, James Pitassi, Ernie Savastano
Commission on the Deaf & Hard of Hearing (CDHH)	Mary Katherine Hess
Mental Health Association of RI (MHA of RI)	Charlie Kettlety
Department of Human Services	Frank Spinnelli (Medicaid)
Disability Law Center	Kate Sherlock
State Rehabilitation Council	Margaret Hoye
Thursday - 8/23 5-7 pm Independence Sq. I, Pawtucket	
Governor's Commission on Disabilities (GCD)	Paul Choquette (moderator), Bob Cooper, Paul Caranci
Office of Library & Information Services (OLIS)	Beth Perry
Department of Human Services	Dianne Kayala
Disability Law Center	Anne Mulready
Thursday - 8/23 5:30-7:30 pm Newport Hospital	
Commission on the Deaf & Hard of Hearing (CDHH)	Mary Katherine Hess (moderator), Gavin Fitzgerald
Office of /Library & Information Services (OLIS)	Andy Egan
Governor's Commission on Disabilities (GCD)	Bill Inlow

Sponsoring Agency	Represented by
Council on Assistive Technology (ATAP)	Bob Perrillo
Long Term Care Coordinating Council (LTCCC)	Sen. June Gibbs
Disability Law Center	Craig Enos
Friday - 8/24 2-4 pm Arnold Conf. Center, Cranston	
Department of Mental Health, Retardation & Hospitals (MHRH)	Craig Stenning (moderator)
Governor’s Commission on Disabilities (GCD)	Rory Carmody, Bob Cooper, Bill Inlow
Long Term Care Coordinating Council (LTCCC)	Maureen Maigret, Roberta Hawkins
Mental Health Association of RI (MHA of RI)	Cynthia O'Neil
Department of Human Services	Elaina Goldstein
Disability Law Center	Ray Bandusky, Kate Sherlock

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

Part II. The Testimony

Identified during Public Comments
submitted at the Eight Public Hearings
August 20 – 24, 2001

Prepared by the
Governor's Commission on Disabilities
e-mail disabilities@gcd.state.ri.us or
fax 401-462-0106

5. The Testimony

This report contains a “rough draft” transcript of the testimony at the public hearings and testimony faxed, mailed, or e-mailed during the hearing period. The transcript attempts to identify the speakers and attach their names to the statements, but it is possible that some statements have been identified with someone else’s name.

A. *Public Hearing – Monday August 20, 2001, 2-4 PM Zambarano Hospital*

Lucien Vilandre: Like I said I have been a resident of Zambarano for 8 years and when I first came here I said "how am I ever going to live in this place" and now I would not trade it for any other place. And when I first came here I would not get involved in anything, any meetings, now I'm very involved with family council. I was elected vice president of patient's for progress about two months ago and I think it is the best thing you can get and anybody that has anybody with a disability. This is the place to come. And they'll do a lot for you. The nursing staff is great. And also being vice president of the patient progress I would like to see the backside of the hospital -- look just as nice as the front side and I don't think I can go on ten minutes.

Bob Cooper: You mentioned that you wanted the backside of the hospital fixed up. Can you tell us a little bit more about your ideas for what we should do?

Lucien Vilandre: I had an idea of having the American flag put in the back of the hospital, I spoke to a couple of people about it and I think we should be proud to fly an American flag in the back as well as in the front we need a pole and more flowers and bush and shrubbery in the back. I also go to occupational therapy, which I find very interesting and I'm willing to help plant the flowers and stuff in the back.

Martha McVicker: I was going to ask him, is there something here at Zambarano when a new patient comes in. I would imagine that it is a difficult transition, is there something that goes on with the staff and the patients to welcome the person?

Lucien Vilandre: Yes, whenever a new patient comes into the hospital, there's somebody from TR that comes up and introduces themselves, they have the best TR department and also we have a computer room, it is great. We have a teacher, we have UCP, and we also have the YMCA that comes in and there's plenty of volunteers.

Martha McVicker: Thank you.

Bill Feole: My name is Bill Foley (Feole). I injured my spinal cord in an automobile accident. After a year in the hospital I moved into my home, where my parents moved in also to take care of me for 3 and a half years, I found it very difficult living at home, needing 24 hour care. It was very taxing on my family, both emotionally, physically and financially and after 3 and a half years it came to the point that I had to make other arrangements and I came here in April of 1988 and at first I did not want to be here. I don't think anybody in their right mind would want to leave the comforts of home to come to an institution. After a year and a half I finally adjusted and decided to give Zambarano a chance and also to give life another chance. And what led me to pursue that desire were the staff and the residents that always offer us immeasurable amount of support and compassion. The first two residents I met were Frank and Terry and they were a great help in helping me get use to the place and figure out where I fit in and where I did not fit in. I feel very safe and secure here. I have made some very, very good friends and the care we receive is outstanding. There's not a day that goes by that I'm not thankful for being here, not only for the care that I receive, but my quality of life has improved tenfold. I would need a lot more than 10 or 15 minutes to tell you everything that has happened in 18 years, a few things is that I went back to school in 1990 and I got my associates degree in social work, I started writing poetry and I published a small volume a few years ago and have probably written about 500 or 600 poems since then. My hope is pursuing the possibility of self-publishing all of my stuff. I'm not sure how I'll accomplish that living here. I'm active as an advocate on the patients for progress committee. Our human resource committee, the developmental disability council, and the patient's advocacy council. Being an advocate has been rewarding not only speaking up for my needs but for those who cannot speak up for themselves, as you probably know there are quite a few people that are unable to communicate. I feel it is my sense of responsibility to speak for others. Some of the concerns I have here, probably the first one is there's not enough nursing staff to provide us with the care we need and deserve. The nursing staff and the others work very hard at making us feel comfortable and at home. And the reason I say that is this place feels like a home. It is a community type atmosphere that I have not known to be any other place. That's why we like it here. Everything is pretty much contained under one roof as far as physical therapy, social services and recreation, we have our own chapel we have a lot of things going on, we have a lot of activities, I know that there are some of us that would like to move beyond Zambarano into the community and I've been thinking about that during the last year or so. My main concern, of course, is feeling safe and secure and always having somebody there to take care of me, I'm not sure how I could actually afford such a move considering the high cost of rent and having nursing care 24 hours a day. I'm a big guy, sometimes it takes two people to take care of me, to get me in and out of bed in the shower and things of that nature. I know it is not an impossible thing to do, but I'm not sure if it will be possible for me at this time and for others. Another area that I would like to see some improvements made is in the area of teaching family, residents, employees more specific information about various disabilities. There are a lot of in-services on policies and procedures and not enough on the daily life of people with disabilities, the things we experience, the difficulties we face, our ambitions and aspirations and everything else in between and it would help the staff to know more why someone is behaving the way they do or how an illness or injury affects that behavior, rather than just knowing the basics of care needed to

- A. I a)(1)(a)(iii) Health Care: Nursing Services
- A. I a)(1)(a)(v) Personal Care Attendants
- B. I a) Disability Awareness

	get us by day-by-day. Even though they are in wheelchairs and we have all kinds of infirmities we are still people on the inside, i want to stress a lot of importance on that. We have the same feelings and dreams and values and beliefs as anybody in a physically healthy body and those things should -- we should be able to express them and fulfill them and go after our goals and, of course, a lot of times we are hampered by our physical disabilities, but in a lot of cases we are hampered by the system that does not allow us to move forward. I'm very happy here, I'm glad I came here and if I had to recommend a place, Zambarano would be the place. Thank you.
	Paul Despres: Okay, let's move to the next speaker, Frank.
➢ C. I. b) Health Care: Security ➢ E.II.c)(2)(c) Physical Accessibility ➢ A.II.a)(2)(a)(ii) Transportation: RIPTA	Francis Beazley: I don't think Bill could have said enough of what he did say, my name is Frank and I've been here 36 years and I have to say that they've been good years. It is a funny thing. When I first came here I was in bed for six years and I was dead for 6 years, without Zambarano Hospital I would not be sitting here talking to you. There are a lot of things that come to me from patients that they would like to do this and that. And I'm here to try to speak to those patients that cannot talk for themselves. For one thing, there's something that I think we should have here. Maybe another security on the gates because right now we are getting patients that are more flexible, they are walking around more and ourselves we are in wheelchairs which cannot protect if something were to happen. A doctor told me one time that you hate to do it but sometimes you have to do it, you have a weapon it is your chair. At one time I was cornered and I will never forget it as long as I live. That gentleman beat me twice across the face and cornered me and every time I see people coming in that are walking around that should be here, but still we are in wheelchairs and we would love to see a little more security around the grounds when people are out there riding around enjoying themselves. I don't think it is fair and I think something should be done about it. Another thing is the smoking is getting very bad up here. I assure you that there's an area on the south side that they would love to smoke. There is right now in the making of a smoking place for them to smoke and everything else. Really we cannot tell them not to smoke where they are not supposed to smoke. Even if there are signs, I do not want to see a parent or somebody getting on the person saying "who are you". Another thing is that I would love to see down by the water, I would love to see the road raised so when patients go down there to ride around, that they are not going to be tipping over because there's an awful hill right there and the terrain there is kind of out of the way for them. Like I always say is that I'm a very, very heavy advocate. I'm a Nova Scotian. I took it upon myself to really get my --I see a gentleman over there from RIPTA I want to thank him and everybody that was involved in saving our bus. I had told them we are in wheelchairs but it would be the same way if you were blind, if you had no legs, like we have a gentleman and if you were deaf and you could not ride you have to depend on these buses to get you it is just like the nurses, if the nurses have to work and they are frozen in and nobody can take them home, RIPTA is there to take them home. This place really thrives a lot and it thrives on people, like we have sitting over here

➢ C.IV.b) Support Services	like Jim Benedict, a man who came here and I'll always say "here is a man that opened our eyes" he was the man that made us live again. When we used to be put to bed at 2:30 in the afternoon and that's where we would stay for the rest of the day. The recreation, wonderful. The horticulture, wonderful, the computer, the ceramics, wonderful, get a hair cut when you need it. Where in the name of heavens would you like to go and not enjoy what you get here, where? I'm a poet, I do art work, but it is people that come up here that open our hearts and minds to you and to us. Even though we are the way we are. The doctors, 24 hours a day, wonderful, wonderful people. Fundraisers, we are always raising money for recreation, always, we have vehicles we go out on trips, if you want to go out on a trip you go out on a trip. We have the people that understand us, that listen to us, and that's the name of the game. Listen. There is another thing that I would really love that we used to have, student nurses, wouldn't this be wonderful. Years ago when I was here, we used to have student nurses that used to stay here from Monday to Friday and they would work with us and take us wherever we wanted, downstairs, upstairs, another thing I would love is I would love volunteers to come in and write letters for patients that cannot use their hands. This is my goal and this is my dream, thank you.
	Bill Inlow: I have one comment. I'm on the -- I'm privileged to be on the Governor's Commission, I do work for RIPTA and I will convey your comments to our general manager, RIPTA service is far from perfect but we are glad it is still going to come up here for the staff and we are also glad to some of the folks here at Zambarano that make use of the RIde program. I did want to ask a question of each of the people that have spoken so far: how do you get out of this area once in a while and go on trips or go to meetings of the committees that you serve on, sir? How do you do that?
➢ C.II.d)(1) Transportation: Vans	Audience member: Zambarano has two big buses and a smaller van and they are very accommodating getting us to meetings and field trips to where we want to go. Not where someone else wants to take us, for the most part that works out very well. It has for many years every once in a while the buses get tired and we need a new one and the ride program has certainly helped. They also make arrangements for family visits into the community and other special occasions that might not happen somewhere else. And the only other thing I want to say is that I think God is definitely in this place, there's really a lot of good people here and I would just like to hope that everyone will continue to support us.
➢ C.II.a)(1) Transportation:RIPTA	Francis Beazley: I did -- when I was at the meeting down in Warwick, I ran this by Beverly Scott and asked her "wouldn't it be nice if RIPTA had an area for 1, 2, 3, wheelchairs and they could go in," at least they would have a little more security to go with one or two chairs like they say if this one has a friend or a wife, they would feel better that if there was 2 or 3 wheelchairs in the bus, they had written that down because I think it would be a wonderful, wonderful thing, because one person going into the bus, I think twice before going downtown alone. But if they had a friend, it might be more security for them.
	Bill Inlow: I'll make note of that.

➢ B.II.a) Transportation: Family visits	Panel Member: I was wondering, let's say someone has a family and the family lives in Bristol and the family does not have a way or transportation to get up there is the staff pretty flexible of finding a way for a family member to visit? Does it work out?
	Francis Beazley: We have a wonderful recreation department here and if there's any way that they could accommodate them to go home I assure you that Steve Westerman, who is the head of recreation, he would be the one that would try to accommodate and they would send a chaperon.
	Paul Despres: Next one on the list.
➢ C.I.a) Health Care: Smoking	Ed Zuromski: I don't think I need the microphone, but if I do. Okay, my name is Ed Zuramski (Zuromski) and I'm a psychologist and I teach at CCRI in the faculty of the psychology department, I've been a consultant here at Zambarano hospital and the Eleanor Slater hospital for many years, in fact, I've been coming up here for 24 years and I have to say that I agree with Bill of the changes that have occurred at Zambarano and I would like to think that all of us played a part in that who are in this room, who were there 20 years ago and so on. A couple of other comments and just reacting to some of the things that was said. One regarding smoking, the hospital did support us in acquiring materials to enable patients to quit. As a matter of fact, I was a certified quit smoking trainer through the Rhode Island psychology association and we have attempted to get patients to stop smoking, I cannot say it is anymore successful than it is outside of the hospital with anyone else. So some people have fallen back, some have cut back, but the offer still stands that we are here to serve our patients and try to help them to stop smoking, then we would not need another smoking area and would not have to worry about people arguing over cigarettes as does happen in an institutional setting. I actually came here to give kind of a testimony to some of the work done by a number of us through the Rhode Island council on assistive technology. I'm going to tell you a little bit about that. I would like to say a little bit about Zambarano hospital first. Back in 1976 when patients were -- there were some interesting things going on. Patients were allowed to eat in the cafeteria down stairs from the pediatric units, we were beginning to implement technology for the patients betterment here at Zambarano hospital, some of the first work we were doing is enabling people to communicate, enabling children who were here at the hospital in the old days to play and to have satisfying relationships with other people through technology, a lot of the technology that you see at Zambarano hospital or around the world today was pioneered here at Zambarano hospital, although we would probably not get credit, not that we are looking for it. We have a tremendous computer department and a tremendous adult special education department, who are providing some wonderful services to the patients to help them get their GED's so to enable them to go to college, mostly the Community College of Rhode Island as far as I know and that sort of thing. There are some great things going on with technology. The horticultural therapy program, it could probably use a little bit more design, but it is designed to enable people with severe physical disabilities to do their own gardening and benefit from the peace of

a garden that's necessary to better themselves. Over the years I've been involved in the technology and got hookup with the Rhode Island council on assistive technology, maybe about 6 or 7 years ago. I would like to just tell you a little bit about that. Just as a general information so that people, if they require assistance, could contact us. Perhaps to link them up with technological resources. I'm a participating member of the Rhode Island council on assistive technology, we are basically a consumer advisory council for a program that was funded to provide assistive technology to Rhode Islanders, some of you probably hear of the assistive tech access -- tech access being one and there are 3 others, one used to be RIPAS. It is a wonderful program, one of the programs that I see as a practicing professional in the field it is a lack of communication as to what is available in the community. I have a neighbor who is about 72 years old, they were good friends of ours, they are good friends, she has a daughter with down's syndrome who is about 42 years old she as dual hearing aids and the run around they got with dealers and the state was a horror show until a couple of years ago, there have been some strides there. The mission of RICAT -- Rhode Island council on assistive technology is to involve individuals with disabilities, it includes the elderly in a significant way in the development of technology related assistive programs and to assure -- incidentally they do not necessarily have to be certified disabilities, growing up in this field the way I have since the late 60s and early 70s, you could only participate if you were a point 002 or a point 003. The fact is that there are probably thousands of people who require services who are out there in the community and even here at Zambarano hospital, often times, we don't just fit the letter of the law and that becomes problematic. One of the things we need to do and how it would be done I'm not sure is to kind of relax some of the really strict guidelines that we see with programs that prevent or act as a barrier to people who may not satisfy all of the needs of a specific rubric or a specific type of disabilities. Some of the accomplishments of RIcat Rhode Island council on assistive technology, we have a working partnership with the assistive tech access partnership and we helped pass the Rhode Island lemon law, it allows those who purchase assistive technology to bring it back and get their money back. We helped pass the amendment to the hearing aid and dealers and fitters and described a consumer protection brochure and expand the Rhode Island re-use equipment network in our state. I'm proud to have been a member of this group for a number of years but a lot more work need to be done. One of the primary things in Rhode Island is as small as we are, is to have better communication as to what is available. Going down to the agency level. I have to say, that my observation among private agencies is that there's a lot of competition, and competition hurts the consumer, I don't think it helps, I think we need to look at that competition and maybe try and get private agencies to work together in a more complementary and cooperative way that they do. So thank you very much and the next speaker.

- B.IV.a)(1) Assistive Technology: Communications
- B.IV.a)(2) Assistive Technology: Agencies

<u>Steve Onchelet</u>: I'm a horticulturist, who has been doing work with the -- I'm from Cranston even though I'm from there, I was the consultant horticulturist for them. I was also the consultant for the garden club at the senior center and also for the city of Cranston. Now, the horticultural club

that we have here is not the same that I had at the senior center. You have to remember that those people are able to walk and do things at home. They are very easy, the only problem is here they are mostly in wheelchairs, even though they are in wheelchairs, what they have to remember is this: you can learn horticulture, it is not just gardening, it is the study the flowers, also the study of the actual meaning of the flower, the whole thing on horticulture that a lot of people do not realize is that it is not a science it is an art. The science is botany that's the science, if you know that, you will know your horticulture, if you want to learn that, very simple, I can teach you that, I can teach you a little bit about the botany, once you know what you are doing, there's no way in god's green earth anybody can take that away from you. I'm going to talk about this hospital, I've only been here 6 months, I have a lot to learn. There are a lot of things I would like to do, unfortunately, they interfere with a lot of programs that I have to have and I've been told what they are and I'm going to learn. Slowly, but surely I'm going to go through them. But I do like a lot of the things that go on here, people have told me about the practicality of being able to visit the home or visit the senior center that I would like to do because I would like to get up to the garden club there at the senior center again, just because I'm here does not mean isolated from my own world. My own world is my own making. There I have found September 10, all of a sudden we'll have a bus load of people here from the senior center and they all belong to the garden club and I know that they will be here to pick my brain. They always do. And I'm grateful for it. Thank you.

Paul Despres: Thank you.

- C.II.d)(1) Transportation: Vans

Kelly Regan: My name is Kelly, I've been here for two years this place has been very good to me, I met -- when I first came here I met Kenny Almedia and then Lori, they were the first two people that I met before I met anybody that's up on my unit, south two, the only person I recognized up there was Elaine Pullnan because I met her when I lived with her in may previous placement. When I came here I had a lot of problems, a seizure disorder that I've had my whole life and this place has helped me tremendously, I have to give credit to a lot of people one of them is Steve Westerman and the social service and everybody has been wonderful. I have a couple of things that I would like to see hopefully change and Bill mentioned one of them. We do need more buses for transportation for when we go out because it is true, we do have problems with the buses and when we have to take trips for just regular trips with Steve or if people need to go to the doctors, there goes one bus, then we have one bus or a van or we are only left with one bus, there are times when dawn, with social services has to take people out, too. What are the patients to do? How do we get around if we need to get around the outside we have no transportation we need another good bus. Because there is a bus that we have that has seating where you go and you sit in one of the seats on that particular bus, I do not remember which bus number it is. It is where you sit down and the seat automatically collapses into the springs we do need that desperately and Bill is right on the staffing. For the most part the staffing is good and for the most part we have a lot of freedoms, this place is great and I have to

	give it credit. Just keep doing what you are doing and try to help us as much as you can. Thank you. Irene: The last person I have recorded to speak is Lori Almedia (Almeida).
➢ C.II.d)(1) Transportation: Vans ➢ C.V.c) Assistive Technology: Laundry ➢ C.V.d) Assistive Technology: Computer	Lori Almeida: Basically, what I wanted to say is probably a back up for everything that everyone else has said. We do need the buses and we do need help. The help that we have here is probably some of the best help in Rhode Island, but they sometimes are overworked and I feel for them extremely. I know what it is like to be frozen into a job that although it is your main source of income, and you really do love it, it can get tiring. As far as the buses are concerned Zambarano does need new buses they are doing the best with what they have. The mechanics are doing a great job keeping them running, but we do need something more and I would not say "safer" just more into 2001. Some of the tie downs need to be looked at since they all must be front facing and not side to side. The poles are not working, the one van that we do have pulls in to secure the chairs should also be replaced. Zambarano, as I have said many times to people, is what you make it. I've been here two years. Within the first three days of being here I remember calling one of my brothers "come and get me I do not want to be here" fortunately, he unexpectedly visited me today and could not believe that I have come to accept this as home. And I mentioned to him "it is a big difference from two years ago calling you with tears in my eyes to come and get me" I found a new life here, I found a wonderful man, who is now my husband, Kenneth Almedia he's sitting directly in front of me. He cannot see me, but as far as bringing Zambarano further into the 21st century as it begins, there are many things that I would like to see available to them. One of which would be actually a coin-operated washing machine and dryer, it would generate money for the patients for the different activity funds and help the patients that can do their own laundry and are going on to independent living getting used to doing things on their own. I, for one, would love to do laundry. I thought I would never say I want to do laundry but I would love to do it. I think the fact that if it is coin-operated we can access it for the patients for TR to continue with their activities and just general all around fund. I thank Steve Westerman and the TR department who I've been very close to and the computer room is very adequate, I spend a lot of time in it. I've been doing computers for 19 years, it is helping me to just relieve stress and go down and check out different things regarding ms, which I have. Spinal cord injuries, which my husband has, and any kind of new research that's coming up. I thank you all for listening to me, have a good day. Thank you.
	Martha McVicker: I have a question. Do I take it from all of the comments about the computers that we now have internet access up here? Great, excellent.
➢ C.V.d) Assistive Technology: On-line	Lori Almeida: We need more, we only have one phone line.
	Martha McVicker: So that would be a need for more --

	Lori Almeida: A dedicated line not a phone line. More than one.
➢ C.II.d)(1) Tranportation: Van Safety	Kelly Regan: The other thing that we do need -- I wanted to mention one thing when I was speaking earlier, there is one thing that we are missing on the chairs for when we go on trips, not that many people or some I should say, for the most part, people do not have seat belts on their chairs. What if and I say that because what if the driver ends up stopping short and the person does not have a seat belt on, they could get hurt on the bus and then the driver ends up feeling bad for the patient. The patients need to be protected on the buses everybody who has wheelchairs needs a seat belt I hope and pray we can get that done, I know that certain staff that works with Steve Westerman with the TR department has said that before and nothing has been done. I stress to you people get seat belts on the chairs. Thank you.
	Irene: one more speaker.
➢ C.I.d) Health Care: Community Based Options	Pat Raymond: Hi my name is Pat Raymond and I'm in the psychology department here at Zambarano. I wanted to make a comment about one of the short falls that I see in the community for us as a hospital for discharge and that's group home settings for people who are not having mental health problems or developmental disabilities but fall out of that group that maybe people with traumatic brain injury where they may live in a less restrictive environment. We have a lot of divide identifying that resource that would be a helpful piece of advocacy that the commission might take on and work on that for us, it would give us a chance to get more people out there living independently or at least semi-independently.
	Panel member: You said traumatic brain injury, what other kinds of people fall through the cracks as far as that goes?
	Pat Raymond: I wanted to be broad and say other neurological problems, one of the problems that we have is that when we start defining the .categories so distinctly then we cannot use the group homes if someone shows up who has something different so it would be traumatic brain injury or perhaps someone with Huntington's disease or MS but then if someone comes up with a different diagnoses, maybe more flexible diagnostic category, that issue of having them tagged as developmental disabilities homes and mental health group homes limits the ability to get some people back out into the community. I know there have been advocacy groups working on this before.
➢ C.I.d) Health Care: Community Based Options	Lori Almeida: As Dr. Raymond was saying about the group homes, one of the things that I've been not really concerned but it has been on my mind since I have been here is that there are buildings that are empty on this property, if it is funding to get some funding or outside help through the community or through the state itself please do not tear these buildings down, they have been up and withstood many years of the New England weather and I seriously think that not expanding the hospital per se but having a group home on the property where someone can get the taste of being independent but still having the capability to come to the hospital if they needed to. I understand it is an asbestos problem as far as cleaning out

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	the buildings it would cost less to clean them out as it would to tear it down and build up a new one, any consideration on this matter would be greatly appreciated and I'm sure that making space within the main hospital itself. And putting people into a Zambarano group home -- on the grounds, it would be a lot better than sending them out anywhere else first. Thank you. Paul Despres: Thank you. Is that the final speaker? Okay. Is there anyone else who is interested in speaking?
	Frank Beasley: I want to make a rebuttal, Paul.
	Paul Despres: Just one minute Frank. Ken?
➢ A.I.a)(1)(a)(iii) Health Care: Community Based Options	Ken Almeida: Hi, my name is Ken and I got hurt in 1998 I jumped off the Mount Hope bridge. I can remember coming here and coming through the doors and thinking I was in that movie the One Flew Over the Cuckoos Nest. I was never so scared in my life. I came up here and I always had -- I suffered from panic attacks and did not know it. And I came up here and Pat Raymond took me under her wing and got my medication and I can say this if it meant being normal again, or my life or being in the chair, I would be in the chair. First you hate the place, then you get used to it, and then you depend on it. And I think I depend on it, I can go out on the bus whenever I choose to, I just cannot say enough for what they did for me as a person, thank you.
	Paul Despres: Thank you. Frank.
➢ C.II.d)(1) Transportation: Van Safety	Frank Beasley: I would like to make a rebuttal on the seat belts. It is one thing that we have here that we have not mentioned. We have a wonderful, wonderful adaptive equipment and they are two men that are very, very concerned about how comfortable patients are in the chairs, when we go out, seat belts are, honest, they are to be around us they do not put them in buses, when they do not put them on chairs unless the seat belts are on. But the patient has their rights and I assure you that recreation will not go down the road until every patient has their seat belts on. Thank you.
	Paul Despres: Thank you, Frank.
	Audience member: I wanted to tell that you we also have drama class run by David Francis and we put on a play, I was in this and it was Midnight Summer's Dream, we had a lot of fun. We studied and worked hard for a year. We put the play on at the auditorium. Thank you.
➢ A.I.a)(1)(a)(iii) Health Care: Community Based Options	Audience member: I learned everything by heart. We had a wonderful fashion show which was great and this is what goes on. I tell you about Zambarano. Zambarano, as soon as patients get up in the morning their first job is downstairs in the kitchen we have a kitchen, we all gather there and we all love to take and love to say "well, how are you today" this is the beauty of Zambarano hospital. If somebody came and said to me "good morning how are you" and say "good god I feel like this" I would say, what is wrong with you, there's nothing wrong with you, look around at some of the patients that cannot talk or some of the patients that cannot -- or some of the patients that cannot get out that would love to get out. I say "please" another half hour he comes back and apologizes, and he says "I thank you

	very much" this is what we thrive on at Zambarano. I assure you that I would love to here a couple of the families say something about Zambarano hospital. I think they have their loved ones here and I think we would love to here from some of the families.
	Paul Despres: I think the list, I believe that's the end of the list but there are some individuals that want to comment, in light of the fact that it is only 10 minutes past 3:00 we can allow that.
	Ed Zuromski: I failed to mention that the Rhode Island Tech Access Council is looking for new members and especially looking for membership from diverse cultures. So if anyone is interested in participating in the Rhode Island Tech Access Council, they can contact me or they can call 1-800-916-8324. We would be very happy to have you visit our council meeting. Thank you very much.
	Martha McVicker: I wanted to also tell you people that I've seen you many times when you go down to the house finances committee and I've seen from you television, I'll be at home and see your group you always make such a good presentation when you go to the State House.
	Frank Beasley: Thank you.
	Audience member: I would like to thank the TR for helping me go to my family functions. It is very nice. Thank you.
	Paul Despres: Anyone else that wants to make a comment?
➢ A.I.a)(1)(a)(iii) Health Care: Community Based Options	Mary Theroux: I'm Mary and my son is sitting over there and it has been 6 years that he's going to be here. The first night that I left him here I was not sure I would sleep sound and in 6 years, there's not a day that I went home unhappy about the fact that he's here. In fact, he comes home nearly every weekend and I ask him "do you want to stay another day" and he says "no I want to go back to Zambarano" I cannot say enough about the people. You will not find 100%, but that's anywhere you go. It has got every other place beat by far. I'm just happy that he's here.

Paul Despres: Anyone else that wants to make comments or speak at this time? Hold on one second.

Audience member: Talking about the question of seat belts on the bus. I had a particular thing that I used to say to the bus drivers in Cranston at one time "you don't put a belt around me soon, I'm going to tell you, you stop short and the wheelchair and me are going right through that window" well, I tell you, we do have belts, we have belts here, too. If you want them they'll put them on and they'll get them on you as fast as possible. Now, one of the things I wanted to tell you, this is not a hospital per se for a person who comes to spend the rest of his life. It depends on their goal, really of how he wants to do it, where he wants to go. The care that you have outside the hospital, group homes and things of that nature. There's a lot of people that Zambarano, when I first heard about Zambarano years ago, when I came here, and they told me "that's a place you go to die" and I could not believe it. I have never believed that. Because I'll tell you I don't believe in dying. I don't believe that even though I'm handicapped, the fact that I have no legs, I can still practice my profession and I do, every single day. Do I pray to god? I believe he's in my garden and I pray to him every time I'm there, thank you.

Paul Despres: Thank you.

Bill Feole: As you have heard, everybody here that has said their peace, they are very happy with the place and the reason for that is like I said earlier, it is a very home-like, family oriented, community-oriented and whatever barrier that is may separate us from living a fulfilling life have been torn down both internally, within ourselves, because of the people that take care of us and encourage us and support us in so many different ways and, of course, the services we receive from the state and the community and everybody else in between, but it has been a good home to me as I said and a good home to everybody else and there's always room for improvement and as long as you are open to our suggestions and ideas, although they may not be very balanced at times or seem possible, but anything is possible and I just thank the employees and I thank god and my family and everybody else who has helped me to become the person that I am today, thank you.

Frank Beasley: As you know, like I say, I come from Nova Scotia and when I broke my neck I was up here but I met a lot of friends up here at Zambarano and I've met so many friends, that there's a woman at the Journal Bulletin and she used to come and see me and she practically adopted me because I was born an orphan and she has asked me "did you have a dream" and I say there was always one to put my feet or the chair on the soil of Nova Scotia and with her and Marcia Smith the columnist they wrote a big write up in the paper and I'll tell you it was wonderful, wonderful. "Let’s send him to Nova Scotia" let's give him his dream there was more money that came through and he went there and I had a wonderful time and I took a nurse with me, it was very, very wonderful and I told her "I need care" and she says "I'll take care of you" and I said don't worry about the money it is there, paid her way and everything and it was great. But this is the people; they trusted her as I trusted her to take me there. This place has tried to be closed about five times when it was for tuberculosis, it was one thing, then when it was a rehabilitation center and I have to tell you about the gratitude for what they did for me and it was one of the great things that everybody that came here and god bless them, Terry, Mike, Louie and everybody at Zambarano, they would never, ever say a bad word about Zambarano. It is because it is the kind of people; it is the kind of place and the nurses that give all of this TLC, the tender loving care to us. I, myself, I have become a heavy advocate when I became an American citizen at Zambarano hospital in 1984 I said that was my time to give my outpouring on what Zambarano is all about. I was awarded the victory award of Rhode Island, I had the honor of going to Washington DC and representing Rhode Island and Zambarano hospital. And I tell you it has been a very, very wonderful thing that people out there, because you see I always said "it does not matter what the building looks like, it is what is inside the building" that's the most important thing, you can look at a building and say "oh my god this is beautiful" but it is the kind of people that are on the inside that give us everything that we do here, and we can't thank them enough, no more than they can give Zambarano what we have. But you just can't stop today or tomorrow, it has to be a continuous effort. I thank you very very much.

Bill Feole: Can I recite a poem for you? It is called "my disability" people sometimes ask what it is like for me to be so severely paralyzed from a spinal cord injury, I say it is a lot of things each day is not the same, I try to keep myself busy to help myself and on occasions their sensation I pray it will not cease, always feels that are not really there, they drive me crazier and are hard to bear, from being independent and very active physically to mostly an observer is devastating as can be, refreshing reminiscing about the things I use to do as a kid, wanting to be well again to have a friend who truly cares to do something very simple, be accepted as I am, for inside this paralyzed body lives an ordinary man, with the hopes, dreams and desires as anyone who is well with a heart and soul like you who wants to be treated equally and wants to be happy and peaceful as any one can be. Yes, it is not so easy, but I try with all of my might to do the best I can to put up a good tough fight for there's more to life that be I may know or see that god may have plans in the future for me, my disability.

Paul Despres: I believe that that's the end of the testimony, and I would like to thank everyone for their comments and their testimony and if there are no further questions this is the end of this public hearing.

B. *Public Hearing – Monday August 20, 2001 5-7 PM Rehabilitation Hospital of Rhode Island, North Smithfield*

- B.III.c)(1) Employment: Discrimination
- B.III.c)(2) Employment: ADA
- C.VII.a)(2) Legal Services

Richard Horrent: I have glasses on because I just had eye surgery. I would take it off but it's not the prettiest picture. The reason I am here is because for over a year now I have been dealing with this -- herniated disk in my neck with arthritis. And from repetitive work, working at the housing authority in Woonsocket. There's another employee beginning to show the same symptoms. And my problem is since September, I have been trying to get back to work. To get off of workers' comp, but I find the court systems, and all the agencies involved seem to foot drag. And most people want to stay on workers' comp. I do not. I am sick of being on workers' comp. I would like to return back to work. And I am being discriminated against because the housing authority has allowed at least 7 to 8 people to return back to work with disabilities or health conditions. And I could outline them if you want me to. Everything from narcalepsy to a pacemaker. Another person has two heart attacks, weighs 300 pounds, is allowed to come back to work with limitations on his job. Another employee has a herniated disk on his back and was allowed to return back to work. The list just goes on and on. My problem is trying to get an agency involved. I have contacted the governor's office. I did file a complaint with them in January and December. And what happens the housing did not wish to mediate at that time. I find it very disheartening because so many different people tell you so many different things. I want to get back to work. I am sick of being on workers' comp. I am losing pension money. I am forced to stay home. I have limitations in my job. But I am able to work. There is a union. I am trying to get the union involved. They are also dragging their feet. It just seems that this whole process, nobody really wants to take a bull by the horn. Contact the housing and say look, this man who was employee of the year in 1995, contributed to the children of the housing, who lived there, the residents. Worked so many years for you and wants to come back to work. I don't want to be placed on permanent disability. I don't want to get and stay on workers' comp. I want to get off. But the reason I am here today is hopefully someone from the governor’s office, I have written to the human rights. I filed a complaint with the human rights. I mean I don't know where to turn. My attorney, he's just, you know, doing his thing with workman’s comp. He collects his little check from them. But there's no resolution. I have seen other people when I'm in court they have been going the same process for four years. It's so disheartening to have a person 47 years old, diagnosed with a neck of the 70 year old who is trying to get better, wants to be made accommodated and maybe in time I can go and do my full job. But presently, I am not even allowed to walk in the door and go to work. The housing is discriminating. And it's very disheartening. It's a situation I do not want to be in. And I am hoping today that, one of you people can step forward and call the housing, do something to allow me to return back to work. I mean, I am told that after a year they don't

	have to take me back. Whether this is true or not, I do not know. I have also been told after a year and they do not take me back, I can be pensioned off as 66 and two-thirds percent. What is true and what isn't? I wish someone would sit down with me and explain to me the whole process, or is it just going to be a whole foot dragging process? And that's basically what I have to say this evening. It's disheartening. I have been employed for 12 years and I want to return back to work. I have done my job. I have done all the over time. Done all the hard labor. Certain jobs I cannot do. My doctor has spelled it out. Dr. Maloany of the medical board has spelled it out. I have spoken to vocational counselors, Carberlla. I want to return back to work. I don't know why it's so difficult that an employee that has been with the housing for 12 years and had received numerous accommodations, employee of the year, accommodations for my contributions to the children of the project and I just wish I could go back to work. And that's basically what I have to say this evening. And thank you for hearing me out.
	<u>Susan Silva</u>: Thank you for coming. Our next speaker would be Lynda Adler. Hi Linda.
➢ A.II.a)(2)(a)(i) Transportation: RIde	<u>Linda Adler</u>: Hi. I have a question about the ADA paratransit service. I used to receive the RIde program bus when I lived in Lincoln. I recently moved to Cumberland, well, a few years ago. And I tried to get that RIde bus to work. And I have been unable to get that because I do not live within three quarters of a mile of the RIPTA bus corridor. I have had conversations with Bill Inlow, who is the RIde paratransit person, I don't know what his title is exactly. And he advised me of that three quarters of a mile rule. It was suggested to me – I live on Nate Whipple Highway in Cumberland and it was suggested to me that it was a reasonable walk for me it walk from my house to the coffee and cream restaurant on Providence street in North Smithfield. I would like to see him do it on a really good day. Then I got back to him and said that was not possible. I know that there must be a bus that goes to Woonsocket Hospital, which is on Cast Avenue, which is down Mendon Road and they scoped it out. They said at the top of Cast Avenue there is a school and that could be a bus pick up point and that was a reasonable walk for me. My brother clocked it from my house. That's three miles. Now if you do not have any disability, a three-mile walk might be pretty refreshing. But I am a professional. I carry a briefcase back and forth to work. I use a cane. I don't know if you tried to use a cane, but when you use a cane, it's a wonderful thing. But if you hit a crack in the sidewalk, it's like shoveling snow in a driveway and you hit, hit a crack or something. It just throws it right back into you. And it's just not practical for me to walk three miles each way just to get a ride bus to get back and forth to work. I have addressed that and I don't seem to be getting anywhere. I wrote to Beverly Scott, and her response to me came in march of 99 once again quoting me the rule that it must be within three quarters of a mile of a bus route. And although I certainly understand those words, I don't think the law makes any sense. I don't know how to challenge that law. I have written to Senator Kennedy, I have represent -- Representative Kennedy and Senator Reed. Senator Reed recently responded to me in August 10 of this year saying that he's going to contact Ms. Scott and look into it. And I can already tell you what she's going to say. That I need to live within three quarters of a mile of the bus

	route. I would like one of the folks who designed that law to be me or someone like me and walk three miles a day, back and forth to work. Use a cane. Don't say oh, well. Cross streets. I would like them to do it. Never mind every day. Think about the winter. And that's what I'm here to address. I'm hoping someone can look at that law. Please don't quote me the law again. I hear it. I speak English. I am a social worker. I graduated with a Masters from Boston University. I get it. I just don't understand why. Thank you.
	Susan Silva: Thank you very much. Do we have any other speakers tonight or anyone else who would like to say something. This is our Spanish interpreter I understand. I don't think anyone needs any interpretering done.
	Victor Mendosa: I am ready.
	Susan Silva: Anyone want any of that in Spanish now? Okay. Well basically that's the reason we were here this evening was just to get your comments. To find out what you thought might need to be changed and what problems you were encountering in your lives. And I think the panel members here will take that information and consolidate it along with the other public hearings we are having and try to make some differences and some changes. Any comments from any other panelists?
	Bob Cooper: Richard, you said your workers' compensation attorney -- has he ever posed to the court any proposal for the court to order, your lawyer to make accommodation?
	Richard Horent: He has filed a motion to make reasonable accommodations. They refuse to do so. They tried to -- not pension me but pay me off with a settlement, which I refuse to do so.
	Bob Cooper: He filed a motion with the court to order it, or did he make a request.
	Richard Horent: It was a request to have me reinstated. A request for reinstatement to employee, to be back to work.
	Bob Cooper: Because there is a section in the workers' comp law, which does require you reinstate. Does authorize the workers' comp court, to order it.
➢ C.VII.a)(2) Legal Services: Employment	Richard Horent: They refuse to make any rulings. We are seeing Judge McConical, and you go into court, and nothing really happens. You go back two months later, nothing really happens. And two months later, and nothing really happens. And I was there one day and a gentleman was telling me, get rid of your lawyer. And I said why. He said he's not going to do nothing for you. He said I have been going through this for four years. So I wrote to my attorney and I said listen I don't want to be man. I can go back to work. There's 20 or so odd jobs I can do and it's for 6 weeks period. So my doctor can kind of evaluate how I'm progressing. And I just wrote to him and said look, let's not drag this thing out. I don't want to be on workers' comp. And I have even approached one of the commissioners for the housing. And she said well it's a workers' comp issue. And I have called workers' comp and they don't want to talk to me because I have an attorney. The reason I hired an attorney was so that he could handle aspects of this whole situation that I don't understand. I mean, I don't want to flop $8 an hour. I work at the housing and make $16. When I started I

was making $9 an hour. I don't think I should have to look for a job. I have a job. All I'm asking is to be accommodated. They have accommodated the fat man. The narcolepsy man. The pacemaker man. The herniated disk in the back man. But they refuse to accommodate the skinny man with the herniated disk in his neck. Now if that's not discrimination, I don't know what is. I have called the law center. I believe I spoke to maybe this young lady right here. She said well right now we are evaluating and in October we are hoping to get federal funds. But I'm not back to work. It's depressing. It's sad. Because you have an employee that wants to go back to work. What do I do? Stay home? Wait for the cameras to come around and see what you are doing. This is not where I want to be. Oh, well you were doing this. Or you were doing that. I want to work. I have two hands. I have two eyes. I have two feet. But I also have the neck of a 70 year-old man and most 70 year old men in my condition would probably be unemployed or retired. I am not asking for any of that. I just want to go back to work.

Susan Silva: Oh, go ahead.

Bob Cooper: How long have you filed?

Richard Horent: I just filed that maybe a week or two ago. I finally, you know, I called Washington. I called Boston. I called Virginia. I have gotten packets in the mail. And I have called all these agencies. And everybody says well that's not our division. Oh, we don't handle that. Call this person. Nobody is willing to take the bull by the horn. So you pass it off to the next guy. This one passes it off to the next guy. Everybody passes it off. Nobody's willing to take the bull, make the phone call and say look, get this man back to work. He doesn't want to be home. He wants to punch in the clock at 8 he wants to leave at 4:30. And I don't think it's too much to ask. I really don't. I mean, the tenants want to know where I am. All the children like me. I'm not a criminal. And I just want to go back dealing with these people. A lot of people that work for the housing call the tenants pigs and slobs. I don't look at these people like that. I look at them as individuals with rights. They have issues, whatever they are and I'm not one to judge them. That's probably why I'm a little different from most of the employees that work there. They want their check and they don't care about the tenants. Myself I have always cared about the tenants. From the little boy that has no father, I built him a bike because he didn't have one. And that's why I was employee of the year. Because for two years I would take my own funds, pick up bikes on the street and fix them and give them to children that did not have a father. Didn't have the finances. To give back to the community. And I want to go back to them. I don't think it's too much to ask.

Susan Silva: Well, if no one else has any comments that they would like to make I would like to thank everyone for coming this evening. And you are free to go. It's an early night. You want to connect with anyone individually and talk with them that's fine. But thank you for coming. We really appreciate it.

- A.II.a)(2)(a)(i) Transportation: RIde

Linda Adler: Can I say one quick thing about reasonable accommodations? When you brought it up, it suggested to me. I want to make a comment about my employer's reasonable accommodation to me. I am a social worker. I am on the road all day long even though I don't drive. My employer is Meeting

Street Center. And they actually cab me all over the state the home visits. And I think that's really fabulous of them to do that. And they also bought me a large screen for my computer. I brought my computer in when my own monitor died because I have large screen monitor they put in a $3500 monitor. They made tremendous accommodations for me. Now if I can only get back and forth to work it would be really nice. That's the part I'm having trouble with. And if you are wondering how I managed to get back and forth to work for the last two and a half years, I will tell you. I am part of a dry cleaning route. I get picked up like laundry in the morning I get dropped off like laundry in the evening. I thank God for that ride. No, I don't ride in the back of the truck. The front. But now my brother who provided that for me, his dry-cleaning plant closed last week. Friday was his last day there because the plant closed. And now, I am on vacation this week. Now what? What happens Monday? Mr. Cooper, I wrote a letter to you. I would like to speak with you afterwards. Thank you.

C. *Public Hearing – Tuesday August 21, 2001 5-7 PM, Providence Regional Family Center, Providence*

Speaker: I am "Ms X" I have a question. Where is this information going because I will be saying some personal things.

Bob Cooper: There will be a transcript of what's being said.

Speaker: Is it for public distribution?

Bob Cooper: It will be used internally. The comments, recommendations will be filtered into a report. So if there are issues you don't want to appear, let us know and we will make sure we have those.

Speaker: Okay thank you. I am "Ms X" as I said. I am 48 years old and I have had some kind of disabilities basically since I was an infant but my health has deteriorated at the wonder of catching new disabilities throughout my life. And some of the things I have, have gotten worse. Apparently there's something the matter with my immune system. I have chronic fatigue and I have chemical sensitivity, which is not very well understood. And even as a very small child I already -- at the time no one knew what was going on. Now I know it was the beginning of that. I have other stress related illnesses. And I was in a massive car accident and was in a wheelchair for two years and still have mobility impairments. So I have a number of things going on. So I am speaking from lot of different angles. There were five points I just wanted to make. I guess part of what I said also is that I have been disabled in a lot of ways for a long time. And I have had some experience with trying a lot of methods of coping and also applying for and receiving or not receiving just about every form of government assistance there is. I really have to thank god if I had to be disabled I am disabled in the right era because I know the services now are much better than they ever were before. But there are still some spaces that would be very helpful. I also really want to say I don't want to sound greedy. I appreciate that society gets to decide

- A.I.a)(1)(b)(i) Health Care: Prescription Medication
- A.I.a)(1)(a)(i) Health Care: Medicaid/Income Levels
- A.III.a)(1)(a)(ii) Employment: Medicaid/Medical

whether it wants to help me or not. But in another time or another world, it would be just my tough luck that I couldn't take care of myself. But given that we purport in a society to care about people with disabilities and to help them. There are Uneven-nesses I wanted to mention. To not take a long time here I just want to say the first one which, I'm sure you hear about from seniors, also is that medicine is not covered if you don't have Medicaid. And the theory is that if you don't have Medicaid it's because you are not really poor. But that's not entirely true. And also if you are seriously disabled and have a number of problems, the fact that you might have some income doesn't match. The math doesn't work out very equitably. When I was living by myself I had Medicaid. I had social security. And I had SSI so I was eligible for Medicaid. That was a big help, although some of what I need is not covered by either of those. But I had the incredible blessing to find a wonderful husband and get married five years ago. And while he's not a rich man, he makes a decent living. And I lost my SSI and I lost my Medicaid. And people talk about the IRS trying to get rid of the marriage penalty. Well, I really feel disability has a marriage penalty. I cry sometimes. It upsets me. My husband accepted me with my physical limitations as a partner. And on top of it he gets zapped with a bill. And he doesn't make enough money to absorb that. And the first year we were married because of the system I still had my coverage. And then the next year it cost us about $3,000 because I did not have that coverage. I have to pay for all of my medications. I lost my SSI, which was a certain amount of money. And I have to pay $45 a month for my Medicare out of my other benefits also. At this point I actually keep a separate checking account, which my Medicaid check goes into and nothing else. And all of that money goes to take care of my health. That's the level of medical bills I have. Work also has the same problem. You know if you earn a certain amount of money then you -- there's a certain amount of grace period. But if you go above, boom. You are out of your insurance. If I wanted to try to leave disability, I probably can't. I have tried very hard to work because feel bad about this. I cannot maintain 15 hours a week even with back sliding on my problems. But if I could, I could certainly see where that would be very difficult because if I lost my Medicare, if I had to give up my disability, I would lose my Medicare. And I know there's a grace period of like a year. If you try to get on your own feet, a year is not solving your problems. Who's going to insure me? I am not at risk. I am a walking guarantee. I have huge medical bills. That's how it's always going to be. In terms of getting myself a better life -- and I do work some. I try to contribute as much as I can both to our household income, and to society I pay taxes. And to my community I do volunteer work. I can manage. There are things that would help me be more able to do that. There are medicines I don't take because they are too much money. There are medicines I pay for, but I am penalized in other ways because my money only goes so far.

(Break in transcription) (Next witness began before transcription started again)

Maria Garcia: My mom has progressed to the point we have to carry her up and down the stairs because Medicaid does not pay for stair lifts. Okay. I believe almost -- Bob Cooper, hi. He referred me to the Rhode Island

Disability. And I met a wonderful gentleman who is trying to help me.

- A.VII.a)(1)(a) Assistive Tech: Medicaid

I have an agency, which I don't want to mention. They promised me I would get on their list. They saw my mother's condition. My mom is 65, a U.S. Citizen, worked 45 years of her life, has paid taxes, lived in Rhode Island. She is 65. I have been taking care of her for six years. She is in diapers. She no longer speaks. She is going blind. And now she is losing her ability to walk. The agency that came and promised me, practically promised me, then denied me on the basis saying it is a convenience for me to have the stair lift. I've already fell two times down the stairs. My unemployment just finished. And I just recently hope that I will get employed. Okay. I have here a copy of what Medicaid covers and does not cover. I do not want an elevator. They say they don't cover elevators. They say they do not cover stair glides. They do not cover stairway elevators. That's not what I want.

- A.I.a)(1)(c)(i)(h) Health Care: Medicaid

However, they do say that they cover a seat lift chair, motorized mechanism. I am trying to buy it. And I can't because I don't have the money. It costs almost $3200. A place will install it, but I have to come up with $1,000. I can't. So I would -- and I ask them who made up this list for Medicaid. Nobody can account for it. How can I live in a state that they cannot -- how they adapted this list. Supposedly -- this is the same exact list that Medicaid has. I can't get the stair lift for my mother. I have been to every state agency. I have been PARI. Department of Elderly has been wonderful to me, assisted me, sending me to different places. Nobody can help me. When I called this one agency, they said if you were employed for two years consistency -- I said I was. Since January I have been unemployed. In January they told me, well, you are unemployed. Now you can't help me. You can't help me with my mother's issue because I am unemployed and I need help. It is cheaper to keep my mother at home. If you see my mother when the nurses come in to see her, they say if every person had Alzheimer's was taking care of her the way she was, the world would be wonderful. I could be a nurse, but I just need a degree. I have help from the state. I have a wonderful woman who comes in. I go through CNA's. Because they don't make enough money, they make too little money for what they do. They are wonderful. The women speak Spanish. My mother came to this country. She graduated high school here. And she did a lot of stuff here. My mother worked, doing a lot of jobs, always paid taxes. My mother does not even know how to speak English any more. She can't verbally say anything. All she said is, la la. You have to look and figure out what she's trying to say. The aide is wonderful. God bless her is all I can tell you. All she complains is I don't know how long I can stay because she doesn't got Medicare coverage paid, vacation pay. I am glad I have her. On days she doesn't get paid, she does come and stay with me. She stays with me, and my mother. Respite, I can't get respite because I can't pay the part of respite that is supposed to be paid because I am not working.

- A.I.a)(1)(c)(i)(a) Health Care: Community Based Options

When I was working, it was hard to get someone to come in the evenings. I don't have a chance -- I don't have a life. The family members I have -- I have a brother who is a fireman, a co, correction officers. A sister unemployed. Got employed. I don't get help from anyone except this woman. I have been able to go on interviews. And I haven't gotten a job. I can't get a stair lift. That's all I want. A little chair that goes up and down the stairs. I can't get it. The last answer I got was from the -- from my mother's social worker. She says go straight to the top. See what you can do. My next chance is to see Mr. James Langevin. That is who I have to see because I don't know what else to do. I am at a loss. I can't get a stair lift. And I don't understand how can they cover everything else. But they cover a seat lift chair motorized. Why can that not constitute as a stair lift? Why do they have to specifically exclude stair glide and stairway elevators? I wish somebody could give me an answer to that. That's all I need to keep her at home. I already -- like I said, I fell two times. And my husband -- and right now he's unemployed. He is trying to get a job because he doesn't speak English. That's not the issue here. The thing is my mom worked. We paid taxes. I pay taxes. I lived all my life in this state. And I cannot get a simple stair lift for my mother because they word it different here. And nobody can tell me who made up this list and why Medicaid won't pay for it. I am at a loss. The agency that came to my house said, sorry it's a convenience for you. We can't help you. I tried everything. There's nothing I can do. And I am telling you right now I am Latino. I grew up in this country. I have been here 35 years. I refuse to put my mom in the home, even if I have to work at night and get help during the day. I can't do that like her. She raised me all my life. Gave birth to me. I went through 18 years of drug addiction. I have been sober for 15 years. My father died in my arms and my mom had Alzheimer's. Unless I medically have to, it is cheaper for the state and for everybody else. So I don't know what to do. I hope to get some answers. And that's all I am asking her for. The only last thing they told me to do was do fund-raising to get it on my own because nobody will cover. Medicaid they think it's a convenience to keep her at home. Does anybody have any questions for me. I know I speak fast. I'm sorry. But I guess that's part of my culture. Anybody have any questions. I just want to say thank you to Mr. Cooper because he sent me to a wonderful place. And they are doing great. One more thing. I believe that this is like a discrimination against people who are suffering from Alzheimer's and who are mentally challenged. I really really do. Because they don't have to be put in homes. They don't have to be put anywhere. All they need is love, and care. That's all they need for you to give them attention. And I believe that just that simple thing that I can't get they discriminated against my mother. It has nothing to do with race. It has to do with the disability that she has. And I really think something has to be done. Thank you.

<u>John Young</u>: Is there anybody else we haven't listened to that would like to speak? Yes, sir.

<u>Audience Member</u>: I want to add something especially to -- (inaudible) disability. Like sometimes after they were like 15 year, 20-year, apply for Social Security benefit though deny it and they get a letter to appeal. They don't know. And I just would like to let them know how the community especially the letter, the public -- I would like to understand that more. Thank you.

<u>John Young</u>: Anyone else?

<u>Jan Lube</u>: I understand as far as the alternative care that you brought up. That Rhode Island just recently passed -- I might be wrong. But my understanding

is just in the past year Rhode Island; some health insurance will pay for like acupuncture and that kind of thing. It depends on if you are not working. I'm not sure how it works. But this is very recent. So perhaps because we have gone -- what it is, like the agency that you work for that you are purchasing your healthcare benefits through, if they okay acupuncture, as something that the insurance will cover then it will --

Audience Member: It's a rider on the policy.

Jan Lube: it's a step in the right direction, but perhaps it's moving in that direction. I would hope so because it's the only -- I have a stress related illness. It's the only thing that helped me. I have a job. But I can't afford to pay $50 and go.

John Young: Anyone else? Well, if not, the speakers and listeners, thank you for coming. The closing will be assembled and distributed. I'm not exactly sure how. But I imagine to keep in touch and we will follow how that happens. If you are interested in getting the materials, in your case you specifically want to see those. So, if there's nothing else, thank you for coming. Have a good evening.

Audience Member: What kind of time frame are you looking at for us to--

Bob Cooper: Well, we will finish the series of hearings by the end of this week. This is our third hearing. We had two yesterday. And simultaneously there's a hearing going on in Kingstown. We will be in Warwick tomorrow. Newport and Pawtucket on Thursday. And Cranston on Friday. And many of the 23 agencies that are on the handout at the front from sponsoring will be getting back together, looking at the transcripts, looking at the notes people took, preparing findings and recommendations. They will go to the governor, the general assembly, back to all of the agencies. Some of the agencies provide service. Some of them who are advocacy oriented and we will -- one thing I can promise is what you commented on and any suggestions you may send in afterwards will be acted on and will be trying to work on solutions. The commission has every year had a hearing. This is the first year we have added -- gotten 22 other organizations to join us, listening to it. Each year we worked on issues. We have Dan McCarthy on mental health. We are not there yet. We are getting better. Transportation, we are working with public transit authority to expand the paratransit services. Eventually I think our goal is, wherever you live in the state, wherever you want to go in the state, you can use the private vehicle, have access to a private vehicle. Somehow we are going to create a public transit service before all of us retire that is truly a Rhode Island public transit system. 20 years to go. Well. We get one neighborhood, one town at a time. There are only 39 cities and towns in Rhode Island. We already get many of them. So we will be working on these issues. Whether it's chronic fatigue, whether it's family support to keep families in tact. We know. I know the folks from healthcare quality, like John know that keeping the family in tact helps maintain the level of healthcare of an individual, much better than having to separate out from one's loved ones and the cost of an institution. It's finding creative ways around -- and finding the money to match up. We may be calling on some of you to help us, which is why we wanted your names and addresses. So if you

	managed to get something before the general assembly maybe you could be able to help us make a change in the system. A better Rhode Island. Okay. There is someone else coming through the door. Hold on a minute.
➢ E.II.b)(5)(a) Accessibility: Physical ➢ B.I.i) Health Care: Information/ Availability	Louise Kafflin: I am Louise. I recently moved here two years ago from Seattle, Washington. So I am somewhat new. And one of the things that I was sort of surprised about was how they almost made it wheelchair accessible but not quite. Such as Thayer Street having just one step up. And they would be happy to help me in, but I can't seem to get there on my own. And all of the many places that even Lord and Taylor who -- brand new mall -- they have made a little platform. And they have cut out a little section. But it's blocked off by other cars. So it's pretty much of no use. And little elements like this that just happen day after day in my life that make it so that I don't want to quite participate as much as, and give companies my money. They don't make it easier for me to spend it. Healthcare wise, I -- I found it really, really difficult because of the fact that everybody with a healthcare provider and basically nobody is taking new patients. So you have a hell of a time trying to find somebody that will even take you in your times of need. You pretty much end up months after you have any concerns of actually being able to say hi to a doctor. And I realize that this is part of the HMO crisis that Clinton helped create. But that's another one of my concerns is that nobody's really getting as good as healthcare as they can because nobody's taking any patients because everybody is overbooked. That's my -- those are just off the top of my head.
	Audience Member: There's no breaks, they installed new ones, and several have the lamp posts right in the middle of it.
➢ E.II.b)(5)(b) Accessibility: Physical	Louise Kafflin: The one I like the most is the State House, and then there's one space for wheelchair that's handicapped. It's always filled by non-handicap people. But if I get out, at the bottom there's these bricks that are all messed up. So that if I actually get to park there, and then get on the sidewalk, I will have a catastrophe if someone is not there to help me because the bottom, the very corner of the state house, it's like a death trap. Anyone else want to take over?
	Jan Lube: We just got you through the door here because we were wrapping up.
	Louise Kafflin: Sorry. I work in Marlboro, I took off and drove as much as I could.
	Elianna Breeler: I was in a chair for two years. Is there any kind of group that is like making some efforts in making the streets accessible who knows what they are doing?
	Bob Cooper: The federal government has required cities and towns to have a plan. People can look at it. It identifies every intersection where there's a crosswalk. They date for when those changes take place. Comment about the capital city providence. They do have a mayor's commission on disabilities. The chair of that is a Fitzgerald Himmelsbach who you can call at city hall. The Mayor's office. And part of what they are struggling with is where you live. The sidewalk around the State House is probably state property. So we

will make sure the Department of Administration know tomorrow that issue was raised. The -- problem with the new mall. The curb cut that was blocked at the new mall ?

Louise Kafflin: Yeah.

Bob Cooper: Again the City of Providence, police department is responsible for ticketing.

Louise Kafflin: There is a curb, but you can't get to it because it's nice for that one person who gets that one space. But then a car is blocking it. So it's somewhat -- It is cars blocking it.

Kate Sherlock: In the parking lot.

Louise Kafflin: In the parking garage. They need to make sure people can't park close to it.

Bob Cooper: One of the problems is the access aisles. The least respective of everyone else.

Elianna Breeler: In Boston it's $100. Boston needed the revenue. There's no more problems for the most part. Someone in a chair, when they made it $100 it started forcing it. It made a difference. Providence needs money. Any would really help.

Bob Cooper: Questions?

John Young: Speakers, thank you. And have a good evening.

D. *Public Hearing – Tuesday August 21, 2001 5-7 PM, Independence Square II, Kingston*

- E.III.a)(1) Assis. Tech.: Assistive Listening Systems
- E.II.a)(2) Accessibility: Communications
- E.III.a)(2) Assis. Tech: Access Communications
- E.III.a)(3) Assis. Tech: Access Communications
- E.II.a)(1) Accessibility: Communications
- E.III.a)(4) Assis. Tech: Access Communications

Myron Waldman: I wrote this up to make it nice for everybody. My name is Myron, I reside in Narragansett, I live with a hearing disability and would like to use a recent experience as an example for recommending an action on the part of the Governor's Commission On Disabilities or other groups for improving accessibility to Rhode Islanders. One of the most used vehicles for remedy of small civil issues is the Rhode Island small claims court. That court hears thousands of cases each year, yet processing forms make no mention of availability of assistive listening devices or any other forms of accessibility. Typically, neither party uses a lawyer for advice or representation because claims are limited to $1,500, hearings are held in various courtrooms around the state. My recent experience with the Washington County District Court located in South Kingstown proved to me as a hearing impaired person, dealing with this court is not an easy hurdle. Without a lawyer at my side, I had no one to ask about what was happening during the course of the day. I asked one of the marshals to help me. By letting me know when the judge was calling my case. When the case was called to be heard, the marshal was considerate enough to tell the judge that I had difficulty hearing. That judge tried his best to communicate in a spirit of toleration, he promised to yell. Yet the barriers were there. The judge did not attempt to use a microphone, sitting right on the bench. It may or may not have been connected. There was a great physical distance making lip reading difficult. The court room acoustics were poor, I would like to see the governor's commission on disability or any other group recommend changes to the existing district court -- small claims. Notice of suit form, I'll repeat that. District Court Small Claims notice of suit form. It was last revised in April 1989. We would like to see that revised to include all personal accessibility rights under state statutes and how to go about getting what is needed. Thank you. Do you

	have any questions?
	Paul Choquette: Any questions?
	Audience member: Do you have a hearing aid?
	Myron Waldman: Right here.
	Panel member: Is it working okay?
	Myron Waldman: It never restores hearing. Right now it is working fine.
	Panel member: I have a question. Do you think this problem is limited to this one specific type of court or is it endemic of a problem that's throughout the court system in Rhode Island?
	Myron Waldman: Good question. For several years, the court system was aware of this. They are still aware of it in general. They tried to institute on a global basis in the state, something, to do things here or there. Things never move very quickly. What I would prefer to do is to focus in on one court that hears so many cases dealing with people that have so little support and maybe something can be done because that court only uses one form. And that form affects a lot of people.
	Panel member: They are individuals that do not have representation by a lawyer, usually. The individuals who are dealing with that form and in that court do not have representation by a lawyer.
	Myron Waldman: Correct because the claims are up to $1,500 and that's not enough to pay for a lawyer's lunch. (Laughing)
	Paul Choquette: Thank you Myron. The next person who asked to testify. Virginia (O'Hayer).
➢ B.V.a) Education: Higher education ➢ B.I.j) Health Care: Information/ Young Adults ➢ C.II.a)(2) Transportation: RIPTA	Virginia O'Hayer: I'm an educator and I'm a parent. I'm very nervous. I have a list. I would like to see in the state a place and entity where people can go to get higher education, no matter what level or multi-intelligence plan they are in. I'm on a transition council and I know that there are efforts to work towards different areas, but I would like to see people who are seeking adult education services now to find places where they can get them. Maybe the department of education needs to take over some of that role, which would include: financial aid services, transition services, adult education opportunities, resources rather than it being organizational or agency based. Also, this entity might address ADA issues. Which are very hard for individuals and family and parents to seek college-by-college or university-by-university. That would be an area of guidance. That's the big one. That's a big one. Another big one is health care. I think people need health care and I think they all need good health care. And I think that 18 year olds need to be informed in some way that they can understand that their services will be cut and what it means to attend a hearing if that's what they have to do in order to get permission to get health care. Even with a disability. Also, in that ADA entity I think that scholarships and grants should be addressed as well as financial aid. I think that RIPTA is the only organization that I've seen in many years of changes that marks a person as disabled. And it is shameful. And I think that after somebody works as hard as I've seen people do I think they deserve a bus pass that says it is simply a bus pass and after getting a driver's

➢ B.VI.a)(4) Assistive Technology: Information	license and getting services to do that and all of the things that they've done I think it is horrendous after paying for the bus and after they take a class and travel to providence that they finally get this bus pass thankfully and it is marked "disabled" what a shame. Somehow, I do not know how, I do not have the answers, I think people need to be educated about marketing and budgeting and somehow it is all of our responsibilities to do that. And when grants are offered or given from agencies, somehow families need to be involved and guidelines that need to be set as to what that grant might mean to the family and what it might mean to the individual if they are suddenly out of the family. Counselors need to be very aware of evaluations that may have been done so that those tech-access agencies they can be revisited and the issues can be addressed some of the updated -- and important grants that are being offered.
	Panel member: Could you explain about the grants I do not quite understand about grants from agencies?
➢ B.VI.a) Financial: Impact of Services	Virginia O'Hayer: I mean resources, in general resource. I do mean a computer may be or assistive technology may be given for different reasons and I'm not familiar with all of the areas. I do think that there are things that people need to recognize that they cannot just be given. I think, I guess that family waivers are important. I don't really know about them, I've heard about them. I do think that there are adults whose support systems and ways of living are outright threatened. Their housing is threatened, their medical benefits are threatened and serious aspects of their lives are threatened in order to obtain and get services for their children, adult children as well as for their non-disabled children. I think everybody sitting at this table as well has to realize that.
	Paul Choquette: Any questions for Virginia?
	Panel member: Could I ask her to elaborate a bit on the disabled bus pass/card? Just to hear more.
➢ C.II.a)(2) Transportation: RIPTA	Virginia O'Hayer: My question is: if an individual applied to DHS for a bus pass there could be some financial guidelines is that right?
	Audience member: Could the Department of Human Services? I would assume.
	Panel member: Why not refer someone to DHS to apply for a bus pass instead of having the individual fill out a form for your agency stating he's disabled so that your agency can pump him out a card titling him as disabled. I have every attention of going to DHS. It was my advocacy for him to get a bus pass and we could have gone to DHS and would have, but as a client of ours I thought, "gee, maybe that's what these services can help us with" and the only thing they helped us with was to really degrade some very hard work.
	Virginia O'Hayer: I'm really trying to understand this and I respect very much your opinion I'm trying very much to hear it. The fact that it says "disabled" on the card.
	Audience member: It just really bothers me.
	Virginia O'Hayer: It is like this.

Audience member: That's not what it looks like. It is a different one from that. What is on the front of that? It is not that.

Virginia O’Hayer: Here is mine. The new ones --

Audience member: Big it takes almost half of the card.

Virginia O’Hayer: And it says the word disabled.

Audience member: Disabled I believe.

Audience member: That's a person who has a disability. I'm not disputing it, I’m really -- I ride the bus very frequently, regular RIPTA bus, when people get on board and I have to do it too, some people show a monthly bus pass and they sort of show it to the driver and some people show a senior bus pass and some people show a student bus pass, the point is the concern you have is that it says disabled on it.

Audience member: This is a person who has never chosen to disclose a disability. And to this day, has to decide which agency and what part of his life he will disclose a disability.

Audience member: I understand that, I’m trying to understand -- many people who get on the bus show a card. They only show it to the driver.

Audience member: Do adolescent parents get on -- does that bus pass say they are poor or pregnant. The senior says it is senior.

Audience member: That's correct.

Audience member: The employee says employee.

Audience member: Maybe all this means is compare the size of the letters; it may be saying that your agency recommends that people have to say that.

Audience member: Absolutely I’m not saying that at all.

Audience member: Obviously, he has to disclose if he wants some services and that's acceptable to me, but I need you to know that this person has a driver's license. The department of motor vehicles never said anything about whether or not he was a disabled person and I sought out help so he could get services.

- C.II.a)(2) Transportation: RIPTA/RIde

Audience member: If your point is that a person who has a bus pass for persons who has disabilities should be more discrete in identifying that pass, then certainly that's a very important issue that I will convey to the individuals to design those bus passes.

Audience member: Let me be very clear it is not only discrete, it is that may be an agency like ORS with a counselor who is working for an individual can be very clear that this kid needs a bus pass after we've given disclosure of many other areas of our life. As long as we are required to go through your agency, maybe you can realize that it is on a list of possible things that this kid might need. And incorporate it into a plan that recognizes: budget, transportation, and that recognizes how he's going to survive a semester of school as long as we are pioneering roads here.

Audience member: I certainly will convey the points you made about the RIde

	card.
	Audience member: That's a very good point as she said, are bus passes identified if the person is poor? I do not know how they are given out but are they identified in those manners?
	Audience member: If someone gets a bus pass it is a RIte care if a person knows you have to be low income to get that, the person would know that.
	Audience member: It does not say, "This is a low income person" it is a participant in a RIte care.
	Audience member: Would it be better.
	Audience member: What about revisiting, does it need to identify the reason why they got the bus pass?
	Audience member: It might be just a generic bus pass for people.

Paul Choquette: I would like to ask that we -- I think the issue is important and I think the members of the panel have taken down the information I do not want to stifle this give and take but it is really not appropriate for this particular forum right now. Once we adjourn if we want to discuss this more in full you are more than welcome to. We have the one person who is here to bring the issue back up to the higher-ups at RIPTA, I understand people's concerns but I want to move on.

Speaker: Do I have to identify myself?

Paul Choquette: If you are going to provide testimony.

Audience member: I wanted to ask a question, not on the bus pass.

Paul Choquette: The questions, when we talk about asking questions not that people who are in the audience cannot ask questions but it is for more the people on the panel to get clarification for us to know what we are going to be doing with this information later. The reason why I mentioned questions is again for people, because we are going to be taking this information and trying to craft either policy, law, legislation or whatever, so that helps us, for your own information I would like to limit it for now. If you have a question for her after we are done, that's fine. Is that fair enough for everyone? I probably should have explained that earlier.

Audience member: How about at the end.

Paul Choquette: Certainly, okay. Any other panelists have questions for her? Thank you. Barbara Gilligan.

➢ B.I.i) Health Care: Information Access ➢ A.I.a)(1)(b)(i) Health Care: Prescription Medication	Barbara Gilligan: First of all, I'm glad that we have all come together because most of your offices I've never heard of and I'm sure it is just the usual, but it is encouraging to know that people care enough to come to a public hearing. I have had wonderful service since I've lived in Rhode Island. Not much negative. In 1993 I was diagnosed with bipolar and posttraumatic stress syndrome and since that time, I was hospitalized. Since then I have nine more diseases or disorders with diabetes and all of this stuff. I take 20 medications, which is obviously, an awful lot of medications to keep up with. I recently had a heart attack and they added four more. I don't like taking medicine and I don't like that -- it bothers me that it is being paid for by the state. Before we got approval for Medicaid there was no other way. We just did not get the medicine. It was either have supper or take a pill. My husband did not make a lot of progress without. I've since, since November we've been granted

➢ B.I.d) Health Care: Awareness	section 8 housing in an Indian run village in Wakefield. Nice facility. Nice people and we kind of fit right in. I'm there 20 years too soon, I'm very grateful for the help that I've gotten. I read the questions on the back of the form and I would love to work. In fact, I went back to college at 46 and graduated. So I was greatly disappointed that I was not able to continue my work and all. At the same time I'm finding my self-esteem to be helping other people listening to people on occasion and that's about all I can do for work. And I feel good about that. Because some people have me come so they can tell me stories. As far as the mental health, I'm served through South Shore Mental Health and I'm on the committee health team and they've taken very, very good care of me. When I've been in crises, which I have been occasionally, they have been right on the ball and known what to do. It is difficult to -- as you talk about being disabled. It took me ten years to be able to say the "I'm disabled" once I did I realized I'm facing this truth and my kids don't like it. They are grown, of course, they say "mom you are fine" my husband doesn't like it, you know, I wish things were like before. I wish you were like you were when you were 30.
	Panel member: Don't we all.
➢ A.I.a)(1)(b)(ii) Health Care: Medicaid	Audience member: Unfortunately, he still does. All in all, there's a gentleman named Jim McNulty he was the president of the manic-depressive group in the state. You may be hearing more of him because he's becoming a national representative. He's a very personable man and he has helped us a lot, so all in all, who knows how many of them my name passes by. I just want to say thank you. If I've had to go through human services because it always started with the social security girls, I was there visiting with another friend and she says "come in and we'll see if we can do anything for you" and that was the main office in Connecticut. Within a very short period of time, there was major action taken and it changed my life. Because of Rhode Island has the Medicaid I was able to start living a normal life so I would like to thank you.
	Paul Choquette: Thank you any questions.
	Marie Younkin-Waldman: We appreciate you thanking us. That's very nice.
	Paul Choquette: I'm going to apologize ahead of time because I'm not sure how to pronounce this name. Jeanne Behie.
➢ A.II.a)(2)(a) Transportation ➢ A.VII.a)(2)(a) Assistive Technology: Talking Books ➢ B.III.g) Employment: SSA ➢ B.VI.b) Access: Information	Jeanne Behie: I think I would like to expand what she said about thanking, I have a son with a disability who is 18. He's just beginning adult services, I work for Rhode Island parent information services. I have found, too, that there's been some wonderful people to deal with in the state and one comes to mind is the motor vehicle bureau with the disabled license plate. The most cooperative and friendly people in the world I've dealt with there. Talking books are terrific we get them so soon it is a wonderful opportunity for my son. The Social Security Administration, which is a new experience for us, the people that have worked there have been very helpful. Talking about The Social Security Administration it is absolutely impossible to get hold of them by phone. That's not right. There needs to be a better system where people can call up and have questions answered and deal with things over the phone. I'll tell you, instead of dealing with things over the phone the only way I was

able to get a response is writing letters and stopping by the office and that's not very convenient but we were able to be seen right away and that was faster than trying to call and call and continuously getting a busy signal. There's a problem. There needs to be better cooperation between agencies and departments. For instance, this week we just acquired, for my son, an ID card and we got that through the Department of Elderly Affairs and after we got it, which is a pretty time consuming event and that was surprising because we were the only ones there. But it took an hour to get the card and we had gotten the Paratransit card that took about 15 minutes, afterwards, in talking with some people I was told that we can get that at the Motor Vehicle Bureau and that information needs to be shared if it is correct. That you can get these things at different places, there needs to be better understanding of services that are out there so when I talk to Department of Elderly Affairs and I was able to get them on the phone it would have been nice if they said "you can stop by the department in Wakefield instead of going to Providence" that's an issue. There needs to be better understanding with doctors about available services and that underlines the importance of the cedars project and initiative to get it moving so there's one place that people can go and get wrap-around services. Ginny brought up a few really important issues, concerning transition planning. Concerning students who have gone through school and they have been in a least restrictive environment, mainstreamed and now they are coming out the school and some of them are ill prepared for the real world.

- C.VI.a)(2) Education: Transition

There needs to be greater efforts by the school departments to prepare students with disabilities for whatever they are going to do once they graduate, whether it be going on to college or some sort of post secondary education or going on to the world of work. Ginny was alluding to the need for some sort of academy or transition program, some sort of post-secondary program for students because they are not prepared for what the real world is like. They don't have the skills they need for budgeting, getting around transportation, that's a real issues, especially down here and in many parts of the state for people with disabilities.

- C.VI.a)(1) Education: Transition

How are they going to get to CCRI if they are going there for classes? How are they going to get to work? How are they going to get a job if they are not prepared by the school departments? We need to look into what sort of training and support we can give to students and better prepare them for life and as Ginny also mentioned there's a transition council that I remember, too.

- A.II.a)(2)(a)(iv) Transportation: RIde

We need support from all agencies, from all departments, this is the way to go. We need to support kids with disabilities and give them that extra push to get what they need to be successful. Talking about transportation, there needs to be transportation for people, there's a paratransit but if you want to take it on weekends the bus schedule changes so you may be eligible during the week, because the bus schedule changes on weekends you may be further away from a bus stop and all of a sudden be ineligible to participate on the weekends for the service. So that's a problem.

- A.II.a)(2)(a) Transportation: Employment

I've also heard about young people that have jobs and it just takes forever to get to work. They may be working with a community agency, and they provide transportation if they are giving them job support, but still it can be quite a time consuming trip. So we really need better public transportation, we need better job opportunities and I think possibly looking at tax incentives to companies for hiring people with disabilities.

	Paul Choquette: Thank you, questions? Okay, the final person we have signed up to testify. Karen.
➢ A.I.a)(1)(b)(ii) Health Care: Access ➢ A.I.a)(1)(b)(i) Health Care: Prescription Medication ➢ B.III.b) Employment: Discrimination ➢ A.VIII.b)(1) Education: Privacy ➢ B.V.b) Education: Special Ed	Karen Shabshelavitz: I'm Karen I apologize for being late. I'm a staff assistant to the state rehab council, I'm three weeks young in a brand new job, which I'm just delighted about. I now work for the Rhode Island children's crusade as a family engagement coordinator; it is an initiative to get kids from low-income areas to go on to higher education. I mention that because in the course of the crusade you come into a lot of families that have a lot of different difficulties including disabilities, as I've already found I also serve on the state special education committee. I'm very concerned about the lack of health care benefits for a lot of individuals with disabilities. Some individuals qualify on the basis of SSI, some individuals qualify if they're economically eligible for rite care but what happens to a lot of students with disabilities is when they graduate from high school unless they are becoming a full-time student they are often not eligible for health care under their family's plan. This could include the cost of medication which many of them need in order to lead successful lives, it can include dental care, good health care, there are many part time jobs in Rhode Island that do not offer health benefits and unless you've been without health benefits, I think people don't really realize how scary and how awful it is. Unless you've walked in peoples' shoes who have been without it, there's the catastrophic possibility that if you ever developed an acute health problem you would not have the money to pay for good medical care that's very, very scary. I think there is discrimination against people with disabilities in hiring, particularly if they would know in many cases that this person might cause their health plan to go up as far as having a lot of medical bills that would be covered by their group, I think they do something like when insurance companies look, they look at the average cost of the health care and what happens. I think in Rhode Island, we have a particularly unique experience in that it is a very small state and I, as a very vocal advocate, have been concerned about protecting my own children's privacy, when you advocate when they are young, people learn very quickly about your family, that's a lot of private information and a lot of private information about the individual. When that individual is going out and seeking other kinds of things, like employment, I think it can serve as a barrier to that individual. I don't know how you solve this, but I do know that it has been a big concern of myself and other people I have spoken to. People fear retaliation in a small state because of some times, it is like Rhode Island is one big small family in many ways because there's a lot of crossover. I do think families a lot of times fear retaliation when they do speak up or complain about something that they don't feel is right. I'm concerned now that my youngest of the six children has graduated from high school. I can say, unequivocally, there was certainly a lot of difficulties going through the educational system that we experienced. Because once a child got labeled as "special ed" often times you are looked at by other members of the community as taking money away from their children because money had to be spent on "special education" often you would hear in the public dialogue, I live in the town of Narragansett, often you would hear about special education students and the special education budget which makes it very uncomfortable for

- A.I.a)(1)(b)(ii) Health Care: Medicaid
- B.III.d)(2) Employment: Network R.I.
- B.III.d)(1) Employment: Awareness
- A.III.a)(1)(a)(i) Employment: Health Care Access
- C.VI.a) Education: Transition
- B..III.c)(3) Employment: ADA Awareness
- A.VIII.b)(1) Education: Privacy

families residing in that community and I'm sure the same is otherwise. I would like to see more being done about eliminating the distinction between a "special ed" student and a "regular ed student" this is partly public relations partly educating the community and educating the school committee members and partly educating educators. Often times, my sons were told that they did not qualify for services because their disability was not severe enough. I was even told at one point that I should apply for SSI for them because it might be their only way of getting any kind of health care, I certainly did not want to tell my sons that I felt that they were so disabled that they could not work and this is the only option was to apply for SSI. I think network Rhode Island is a wonderful, wonderful thing. I think it needs a little bit of tweaking as far as the publicity about it. I had a family come into my office that ended up having a high school dropout, the family, this child was nearly 20, he was a minority member. He had dropped out of high school in the 10th grade and he's not working and he has not really -- he did not really know about what kinds of things he could do to go back to school or to get employment. The mother had heard about network Rhode Island, but she had just gone in and looked on the computers and had not known that you can talk to somebody there. I know that the state now has a grant about having a benefit specialist in all of the network Rhode Islands, but I do not know how soon that will come to be and my concern is that it is not soon enough and my concern is: how will people know that what network Rhode Island has to offer, if they are really not familiar with that or not in that circle of information. I do agree with Ginny about having tax incentives for businesses that hire people with disabilities, we should have some sort of legislation that mandates that people have access to health care when they are employed because there are a lot of jobs available, but if you cannot get health benefits, how helpful is the job? As far as that goes. I do agree with agencies having to work more closely together. I don't think that can be stressed enough. I think transition for students with disabilities that are in high school has to start very early on, it is the one-to-one contact that really makes the difference. My son -- one of my sons had the benefit of a wonderful ORS counselor, who became, it was almost like he was his mentor and he had a wonderful relationship with the ORS counselor, but I don't know that all students can have that because of the pure numbers that we have for each case manager. My younger son was told his disability was not severe enough that he would qualify for ORS services. So we didn't have the same benefit of having an ORS counselor, but I think you cannot say enough about having a one-to-one relationship. When that person is there as an advocate looking at employment issues or at IEP meetings, there are a lot of things that might need to be-- like when a student is in high school he's not thinking of his health benefits in most cases, particularly a student -- that may have learning differences or whatever. As soon as this student became 18 and once the family member is the guardian, that student member was in control of his program. And that was another difficulty because at 18 students are asked to sign off on their records. Those records can go out to employers, go out to colleges, the schools were telling my son that he was old enough to make his own decision and in other words once they turn 18 it is the magic number where they are not a minor anymore. I think it leaves students with disabilities at a particular risk because they might be signing off information that they are

	not cognizant about the information in the long-term record that should not be in there. I'm concerned that some guidance counselors do not know that they cannot release information about students with disabilities. That information becomes part of their employment reference or their college reference or scholarship reference, I'm concerned that people do not know enough about the ADA and laws that impact students beyond special Ed. So I guess those are most of my concerns.
	Paul Choquette: Thank you. Questions? Okay. That's the end of the people who had signed up originally to speak, is there anyone else here who wishes to testify or add anything? If so this is the time to do it.
	Diane Kayala: Can I ask a question for clarification, the question I had I'm Diane at the Medicare and Medicaid office. A couple of people mentioned medication, can anybody who testified be a little more specific about what you think health care benefits should look like for people with disabilities.
	Paul Choquette: Go ahead.
➢ A.I.a)(1)(b)(i) Health Care: Prescription Medication	Audience member: I was on RITE care, I did not know about it until my son had a medical crisis needing an acne medication that was very expensive. The school did not tell me that we were eligible. We were on a free lunch, how could the school not even inform you that there's this rite care program. Initially, we had not been eligible because you needed a child 6 or under or be pregnant and then there were changes that I was not aware of. I know my son ended up telling other students he knew that did not have health benefits about rite care that were eligible because their families did not know about it either. If you are not in the loop or the circle or do not have a social worker. When he became 18, I no longer had any kind of health benefits. People said: "you can get rite care and pay for part of it" that was not the case, there were only four companies that had it and they had very limited positions. That's one example of there are not enough. There's not even sliding scale, there's just medication or if you need -- you avoid going to a doctor because it is just too expensive. Some of the doctors, I think there was very limited selection in certain areas of rite care about which doctors you could actually go to because which ones would take premiums from rite care. I think it is very hard to get a job with benefits. And I think there are a lot of people that are going to be without health care or the "working poor" who are working but cannot afford good health care, I do not know if that's what you meant.
	Diane Kayala Thank you.
➢ A.I.b)(1)(a) Health Care: Coverage ➢ A.I.a)(1)(b)(ii) Health Care: Access	Audience member: I have a question, my husband is working. He cannot afford the insurance where he is. That's a minor problem but it is major to me. I had glasses about a year ago or a year and a half ago and they have been wonderful, except now because of the diabetes I've had a significant change in my vision so to pay for the exam, but they will not pay for lenses, it will take time for us to save money. I'll go with these as long as I can, but it is really tough.

	Audience member: I can bring that back, that's an issue I've heard about, I can bring that back because you are right there are many people in your situation, your benefits for eye glasses and things like that there should not be a rigid cut off like two years before you get more.
➢ A.I.a)(1)(b)(ii) Health Care: Access ➢ A.I.b)(3) Health Care: Eligibility ➢ B.I.d) Health Care: Awareness	Audience member: I think the anxiety of not having health coverage is strong. We all go through these mid life crises and we can get a lot of medicines to treat that, but not knowing that it is going to end is enough to put you in a tizzy. The medicine, for me there's a real misunderstanding the protocol of not only getting the appointments but then if there are medicines that are not covered and calling either your insurance company or the pharmacy or the doctor and who does what if it costs what? It is really confusing and two and three weeks go by. There was something that I did want to add in my communication or understanding of disability issues recently, I do see a lot -- I do see a differentiation between physical and mental disabilities or developmentally delayed disabilities and physical disabilities, I think that there ought to be some kind of medical understanding of what even people with developmental disabilities go through or their medical histories in order to get to where they are. I mean, I don't think there needs to be such a distinction. Maybe it is more of the same special Ed criteria. Appointments, if appointments are missed or made, what are the rules? What are the regulations? People should be informed of what happens to their benefits if they miss an appointment. What are the rules? And I think we need to be sensitive and aware that there are definite levels of care and your work force is affected by those levels of care, and it is not the same care as other people get. We are all getting different kinds of care it seems to me.
	Paul Choquette: Thank you.
	Audience member: I think this was a wonderful opportunity for the dialogue to start to occur, however, I would like to see more hearings in the fall because I know I called a lot of the members of rehab council to get them to come and a lot of them were on vacation this week. And I really appreciate you coming down to Kingstown because many people think that South County ceded from the union a long time ago, I think it helps the communication and interest. And I'm sure you would get more feedback if you did it again just because of the timing and thank you again.
	Ray Carroll: Just a comment. Three of the speakers, Karen, Virginia and Jeanne from RIPEN mentioned transition services and we are well aware that this is a great need and we have in the vocational rehabilitation program joined forces with the office of special needs at the Rhode Island department of ed and working with the educational collaborative to really improve transition services and I think we are doing a quality job with very few individuals and the issue for us is increased resources to expand these services in a rather dramatic way, so perhaps as an outcome of these public meetings this may be a priority item for the legislative calendar for the governor's commission. There are many needs and the resources are restrained and the frustration we have is listening to these kinds of family situations and knowing that we can do a better job with increased resources, all I'm saying is basically, improving transition services is a very high priority for our program.

	Audience member: Good.
	Paul Choquette: Any other people who would like to present any testimony?
➢ B.VI.b) Assistive Technology: Awareness ➢ B.IV.a)(3) Assistive Technology: Access to information ➢ A.IV.a)(2) Housing	Audience member: I would really like to emphasize and I would like you all to take note about the importance of publicizing programs throughout the state, such as rite care, network Rhode Island, the cedars, there's an adapted driving -- driver's ed that people do not know about and all you have to do is request it through the department of motor vehicle and they can have a course taught in your community. These are all things available to the people but it is like the biggest secrets in the world. There needs to be public service announcements. I never heard of RIte care until I started working at RIPIN and I still have not seen as public service announcements about rite care. There needs to be an effort to get the word out about what is available to make peoples' lives easier. There needs to be housing issues available. They have a misconception that once the kids reach 18 or graduate from high school that they can move into a group home, that's not the case, there needs to be more opportunities for anyone with disabilities to find housing, affordable housing, there was a grant, I believe it was through the department of mental retardation, a grant for families to make accommodations in their house to put additions on for family members with developmental disabilities to stay in the house, I've been told that there's no money available for that. That would be a legislative issue. There needs to be more opportunities for people with disabilities to be a part of their community with public housing, affordable housing and grants.
	Paul Choquette: Thank you.
	Audience member: I think this was a wonderful opportunity for the dialogue to start to occur, however, I would like to see more hearings in the fall because I know I called a lot of the members of rehab council to get them to come and a lot of them were on vacation this week. And I really appreciate you coming down to Kingstown because many people think that South County ceded from the union a long time ago, I think it helps the communication and interest. And I'm sure you would get more feedback if you did it again just because of the timing and thank you again.
	Paul Choquette: The reason that we have them during this month is that I know for our purposes at the governor's commission we use this feedback to develop our legislation package for the year, what we are going to be asking for in legislation we need to do that by -- we have a deadline of the first of October. What will happen, let me segway into what we'll be doing at the commission, we'll take this information from this meeting and the other six that occur during the state this week and try to basically combine it and come up with some themes and some things that we feel are the most important that you say were the most important. I was at two hearings yesterday and heard transition and transportation. So those are going to be -- if that holds true for the rest of the state those are the issues we'll be working on in the year. Doing them again in the fall or later. It is unfortunate that -- it does cost money to do these hearings and we are very fortunate that this year for the first time we partner with all of the organizations that you see here that allowed us to do 7

	hearings, usually we do one in Cranston we are excited about the response we got and we are hoping to do it again every year and plan it a little bit sooner so the word gets out sooner so people can make plans to be here. I did want to say that. I'm not saying that to wrap up but rather to segway from what you said. Anything else?
	Marie Younkin-Waldman: I signed up but I did not check to speak but I thought of something. Is it possible for me to make a statement, very brief?
	Paul Choquette: I don't see why not.
	Marie Younkin-Waldman: As a consumer.
	Paul Choquette: Certainly, you are a consumer.
➢ E.III.b)(1) Assitive Technology: Access/ Communication	Marie Younkin-Waldman: Should I take the mike, is it working? Can everybody hear me? Can you hear me is this working? Never mind, it is not working. Okay, can everybody hear me? I'm Marie and I'm hard of hearing, severe to profoundly hard of hearing and my husband, Myron, who just testified is also hard of hearing. The thing that I was thinking about was that if you want to get involved in your town government or you want to go to a meeting at your town hall or you can't hear when you go to the town hall because recently we had someone in our family that wanted to get involved in the town government and hear about an issue that was going on but it does not do any good to go to the town hall because we cannot hear anything there, so we stay home and try to watch it on television and guess what? There's no captioning, there's not even an interpreter I'm talking about Narragansett right now, I happen to live in Narragansett; it is focused here in south county. Once again they have a reason, I forget my husband explained it to me, Myron what was the reason that they cannot have captioning?
	Myron Waldman: They are not required to do by law by hiring a company.
	Marie Younkin-Waldman: I do not understand that reasoning because of the ADA and so forth. There's the captioning thing we've no captioning on capitol television. It has not happened yet and for people who take an interest in their local government as my husband and I do, we are just limited, like other people like us, to participate, so that's my little issue.
	Paul Choquette: Thank you.
➢ E.II.c)(2)(a) Accessibility: Physical ➢ E.III.b)(2) Assistive Technology: Access/Physical	Audience member: I'm not a lawyer, but I've been aware that there have been problems in Narragansett, for over a year the elevator did not work and somebody could not get into the town council because of the elevator, and my thought is. If they are required to provide interpreters, sign language interpreters, as an accommodation why can't they be required to provide one of the cart systems under the ADA I'm not a lawyer but I would wonder if you requested a reasonable accommodation, and they denied you that, whether a complaint could not be made to the attorney general I'm not a lawyer but it seems to me if that's the kind of accommodation you need. Here I am a resident of Narragansett.

Paul Choquette: Anyone care to address that? I'm assuming that if you make that request they would have to do it, again I'm not a lawyer either.

Ed Stapins: I might think you might pose that question to the Disability Law Center as a general issue about the responsibility of local municipalities to comply with the ADA in terms of appropriate accommodations to citizens of their municipalities with disabilities. But I would suggest that's a good question. We have a member on the legislative committee who is, in fact, the executive director of the disability law center and we'll make sure that he hears that comment.

Paul Choquette: Thank you. Someone just came in. Do you wish to testify? Or have something to say, just here to listen.

Audience member: She just got out of work.

Gail Johnston: I do have some concerns about -- I'm Gail Johnston and I'm here with my daughter.

- B.II.d) Transportation: Awareness: Mod. Vehicles
- E.II.c)(1)(a) Accessibility: Physical

Audience member: One of the things, real specific to her is any kind of breaks for people that get vans from the town from their taxes on the automobiles, we got a van that is registered to her and she's going to be driving -- it is modified and if she were on her own she would not be able to come up with the money to pay the taxes on the new van. And I understand that's dropping though, every year. Also I find that accessibility getting into stores is not very good. We noticed more with the electric wheelchair versus the manual chairs and you can get them up a couple of steps. The electric wheelchairs are too heavy to be flexible with. That was it. Do you have any other things?

Audience member: No. You spoke for me.

Audience member: As usual, sorry.

Paul Choquette: Anyone else have anything else? Okay, then I would like to thank everyone for their attendance and their input. I appreciate the numbers we have many people here and I'm heartened to hear that apathy does not exist in south county that's great or Washington county, more specifically, as a north Kingstown native. I would like to thank everybody, this information will be taken by the governor's commission and all of these agencies will be using it to develop legislation or policy or whatever it may be, and I invite anyone who would like to state involved to, there's a sheet of information about each agency represented and I believe some contact information, if you wish to stay in contact with us please do, with that I will close this public hearing.

E. *Public Hearing – Wednesday August 22, 2001 5-7 PM, Warwick Public Library, Warwick*

Harold Jackson: I'm intimidated by all of these wires but they do not seem to be working. I do not know if I'm in the right place or the right time or what. I've never been to one of these, I have a complaint that I feel something

➢ A.VII.a)(2)(c) Assistive Technology: Audible Warnings	should be taken care of and that's audible sounds at traffic signals, I brought it up at the city of Warwick and I do not know what has been happening and I've been told it is going up to the state, but I have no idea if something is being done. It is of concern to me and a lot of people that I know who are not seeing well, I only see from the side. I've been trained to cross streets, I have been up in the state of Connecticut and in Attleboro and you cannot rely on it totally but it does help. That's all I wanted to say, I hope I'm at the right place. I did my best and I want to thank everybody for listening to me.
	Beth Perry: We are trying to get the sign-in sheets straight. Our next speaker would be Stephen J. Card.
	Steven Card: I'm coming. The next person will be Susan Shapiro and then Wayne Cook after that.
➢ A.VI.a)(2)(b)(ii) Accessibility: Housing ➢ D.I.b) Health Care: Home Modification	Steven Card: Good evening. My name is Stephen Jeffrey Card and before I got in the Greenwood Village Apartments I was living in the Warwick Oakland Beach area, but it was not set up for the handicapped. I had to have the church put a ramp in so I could get up the stairs. Where I am now is a lot better. I've been in a number of places that I liked. Indian Run Village in Wakefield, Rhode Island. Kings Grant in North Kingstown and there's not too much more I can say, thanks. (applause)
	Beth Perry: Susan Shapiro.
➢ A.VII.a)(2)(b)(i) Assistive Technology: Loans ➢ A.III.a)(1)(a)(ii) Employment: Medicaid ➢ A.I.a)(1)(b)(i) Health Care: Prescription Medication ➢ A.VIII.a)(1) Education: Youth Leadership	Susan Shapiro: Good evening, many of you know me as an employee of Services For The Blind And Visually Impaired, I'm not here in that role today I'm here as a family member of people with disabilities. I grew up with a mother who was disabled but I did not know she was disabled using those words I knew she was bedridden and in chronic pain and I knew she could not participate in a lot of things that other mothers did. I have a son with a learning disability and a husband with a physical disability. There are a couple of issues that I wish to bring attention to tonight and one is what I see as a need to establish a loan program for folks to try technology before they have to purchase it. I know that there is the tech access center where people can look at things, but you need to bring it home and try it and see if it works for you and a loan program would help in that area. I also wish to speak for the need for a Medicaid buy-in, people cannot go to work because they have to sacrifice their medical insurance, their Medicaid and the cost of medication and personal care services are prohibitive, even some of the co-pays and some of the medications that people use cost $1,000 or more for a single medication and having to pay 20% of that means the difference from surviving or not. Also, I'm a volunteer in a number of capacities, one is the youth leadership forum. A group of us have gotten together and are planning a youth leadership forum for high school students with disabilities. This is a completely volunteer undertaking and we need funding for this, the purpose for this is to help you understand their strengths and to begin to build on their strengths so they become the leaders of tomorrow. I would ask folks to consider developing funding sources for that program. It will be the building block for future leaders for the state and for the country. Thank you. (applause)

	Beth Perry: Wayne Cook, please. Monica Dizalo is on deck.
➢ A.VI.b)(1)(a) Accessibility: Communications ➢ A.VI.a)(2)(a) Accessibility: Emergency interpreter service ➢ A.VI.b)(1)(a) Accessibility: Captioned movies	Wayne Cook: My name is Wayne Cook and I'm president of the Self Help For Hard Of Hearing and I'm the state coordinator for national. We have three concerns that we feel are important to the hard of hearing and also the deaf community. Telephone systems that businesses use where they have the recorded messages "please press one" if you want this and please press two for this. We feel you automatically should be able to reach an operator where you can talk to a person over the phone and have a rational conversation instead of trying to figure out what button to push at the right time. Some of us cannot hear these messages very well, and also I think older senior citizens have the problem with the ability to react fast enough and we feel that the business community in the state of Rhode Island should have operators that the people can talk to relay their concerns about whatever questions they have. The next area that feel is very important is that the commission for the deaf and hard of hearing should receive funds to start their emergency interpreter service. We feel this also benefit not only the deaf community but also the hard of hearing community where a number of us do sign. We feel the funds for this have been long overdue, year after year the bill is being killed and we feel it is an important area for both the deaf and hard of hearing community. The next area that we feel we would like to see captioned movies in the state of Rhode Island. Instead of having to drive to Massachusetts to see one, especially businesses in the entertainment industry should have and be mandated to have captioned movies in theaters. Not only the cost factor of traveling to Massachusetts, but in Rhode Island we feel we should have the right to have captioned movies in our theaters, these are the three areas that the sergent chapter of the self help for the hard of hearing would like to see some movement in the near future.
	Beth Perry: Monica and Frank will be the next speaker and then Donna Owens. I assume if any of you have any questions you will speak up.
➢ A.VII.a)(2)(a) Assistive Technology: Talking Books	Monica Dizalo: I don't want to be talking to the wall. Even though I do work for the state, I'm here as a consumer, there are many issues that are very important to those of us who have disabilities, my disability is visual. The two important concerns I have, have to do with the talking book program and technology where if you are sighted you can go into any library and get a book, go home, sit down and read it, those of us with visual disabilities we have to depend on the Talking Book program. It is outstanding. The books are as current as they possibly can be. But there are more and more people here in Rhode Island who are sustaining visual disabilities so there's now becoming more of a financial need to continue this program in order so that those of us who have visual disabilities can continue to read, no ifs ands or buts technology is very important. As you can see adaptive equipment, that takes a lot of time to learn how to use adaptive equipment to interface with the computers and there's so much involved and to me as a child I learned to read, as an adult, I read to learn. I think it is so important that the talking book program keeps going and the technology be available to individuals even though it is a very visual world many of us have the skills and the equipment and we want to continue to be as self-sufficient and enhance our life quality as

	anybody else. Thank you.
➢ B.III.h) Employment: Chemical Exposure ➢ B.VI.c) Financial: Information	Frank Muenzel: Hello I'm glad to be here. My name is Frank, I was born and raised in Warwick, Rhode Island and when I was five years old I lost sight in one eye. I have had a cane all of these years, now I have more complications because I have had chemical exposure and nerve damage. So all of my life I never complained about the disability, now I'm up in the years and I hope that I could get some help, if I can, for being disabled. As far as working is concerned, I worked in Spidels for five years, 35 years -- and the last years I worked for Monet and I've done pretty good in the jewelry business and I've gotten five awards and I made cuff links for the former President Richard Nixon when he went over to China. I believe that being handicapped we can do anything we want. When I was working I knew I was handicapped but the people I was working with, I figured I had to compete with them and I figured that I was just as good as them with the people who had two eyes and I mean, sure, the jewelry went out of business but now I'm wondering, I need help I'm 71 years old and I need help and any help I can get will be appreciated, thank you.
	Bob Cooper: Could you give us a little bit of more information about the kind of help are you looking for --?
	Frank Muenzel: Right now I have chemical exposure and my lungs are closing up from the chemicals, I can't breathe too well. If I can have any help I would appreciate it.
	Bob Cooper: Are you looking for help to pay medical bills?
	Frank Muenzel: No, my medical doctors don't think it is from work, but I know it is from work and what is happening is that I'm losing oxygen to the brain because of the chemicals at work. I worked with any chemical you can think of, I worked with it for at least 45 years. Any help I can get I really would appreciate it.
	Beth Perry: Thank you. Donna Owens, then Kim Kardoz -- I would like to welcome Representative Tony Pires.
➢ B.III.c)(1) Employment: Compliance	Donna Owens: I have coped. Which makes it hard to be here, I'm not able to breathe freely. If I have an opportunity to make a case, it would probably be that when you ask for accommodations so that we can continue to work. That there is some way can expedite the accommodation, because in my case a delay of two months makes me just that much sicker. And I could not work. I work for the department of corrections. I was in a basement office for ten years with mold and mildew exposure and I don't want to plead my case but if there's a way to expedite because now I'm in the position that I cannot make my rent or utility payments because the department does not want to acknowledge the fact that it is a sick building. We need help. When we have CLPD -- quite naturally when you cannot breathe you are isolated. It is hard to socialize because you cannot keep pace. There are no local rehabilitation services. I signed myself up at South County Hospital at the pulmonary rehab and it has helped me but I cannot complete the program, I have to get back to work to pay rent. The process takes far too long. I don't have anything else to

	say.
	Ann Porto: Has anything been done for the work environment?
	Donna Owens: They found a place for me to go to, but it was too late I was too sick. I was almost 200 hours into sick leave. Because I tried, you know, I would go in and I would work a couple of hours and have to leave and I was taken out of work in a rescue a couple of times. So by the time they came up with something for me, my boss did not want to lose me, I cannot speculate and I do not want to do that. It was just too late, I was too sick.
	Paul Choquette: When you say expedite I'm hearing that we should have a process.
	Donna Owens: It took a long time for rehab services, they concurred that I cannot be accommodated in that building, from the time they got the letter from my doctor, to the time the letter from rehab services came in confirming that I needed accommodation, it was almost three months. Three months can be too late. Thank you. Kim Kardosz --
	Kim Kardosz: Hi, I've had a learning disability since I was a little girl. I'm here for a reason because -- I went through vocation rehabilitation, I've had this disability since I was a little girl. I went through special education from grammar school through high school and now I have picked up services again.
	Ann Porto: Can you talk louder?
➢ A.VI.a)(1) Housing: Subsidized	Kim Kardosz: I picked them up through vocation rehab and vocation resources and I'm currently working full-time at Main Stays hotel. I have two little girls that have learning disabilities, too. My top priority is finding housing. My thing that brings me here is I need help finding housing. There's not enough subsidized housing out there for people like me.
	Bob Cooper: Have you been in touch with any agency to try and assist you whether it be the public housing agency?
	Kim Kardosz: I've tried that and the Warwick housing authority and they will not even touch me, the reason being is apparently right at the present time I have two little girls with learning disabilities, they are not with me in my care they are in state care, but they are due to come home September 13. When they do come home they are in special education in the Warwick schools, my top priority right now is me, taking care of myself before I bring them home and getting housing.
	Panel member: Where have you applied?
	Kim Kardosz: Last week I applied for section 8, which just opened up here in Warwick last week.
	Panel member: Anywhere else?
	Kim Kardosz: I tried Greenwood village but they tell me there's a waiting list and they will not even touch me.
	Panel member: Outside of Warwick is there another place?
	Kim Kardosz: No, I want to stay and reside in Warwick, my job is in

	Warwick and I have family here in Warwick, too. I right now live at home with my mom and dad but I want to be out on my own with my two daughters and my own place. That's all I have.
	Beth Perry: John Tolento.
➢ A.VI.b)(1)(c) Accessibility: Communications	John Tolento: Thank you, I just want you to know that I lost my hearing a couple of years ago and I happened to be very fortunate because I was the first one in Rhode Island to have a cochlear implant, the reason I'm here and I'm glad to see we have some legislative people is that my biggest problem is representing the hard of hearing and the deaf with closed captions, not so much the movies but legislature, what good is it for me as a voter with this disability to turn in on channel whatever it is because I just flip by it because all I see is moving lips but nothing comes to me, why can't the state of Rhode Island give us closed captioning. I know you had better bow your head. That's an important factor, secondly, Cox television, they have all of these beautiful service programs, recently they had a woman, who had hard of hearing and she was interviewing about deaf people, but Cox does not provide closed captioning TV. Number three, the only station in Rhode Island that has real closed caption TV is channel 10. And unless you are deaf and hard of hearing you really appreciate that in the sense of if I'm watching channel 6 which has a good onsite report, fine, we now bring you john doe from middle village, then we go to middle village, no more closed caption. The only reason I know he's talking about it is there's a fire in the background so I say "he must be attending a fire" that's the kind of thing. Also channel 6 has an excellent sports program, better than most. Let's go down to the patriots' training center, dead air as far as I'm concerned, those are the things that you can work on. I'm concerned about the legislature because they can do that. Closed captioned movies excellent idea, but I'm more concerned about the other things. The more humorous things about the relay telephone. I want to thank the people of Warwick to help me. When you call to make a telephone call and they say "please press 1, 2," by the time it says record, the beeping is gone because the whole recording so now you make a second telephone because you know you want to use number 3 or number 4, I'm not complaining about how it works it is humorous how we have come to this business that everything has to be press the buttons but it does not address about having a live person. I thank you very much for the privilege and I'll be looking for September for closed caption TV. (laughing) (applause)
	Beth Perry: Mr. Degregorio then Connie and Mark Sousa.
➢ A.I.b)(1)(d) Health Care: Hearing Aids	Richard DiGregorio: First of all I want to thank you for taking time out for this forum, I'm a councilman in the city of Warwick, I'm a little partial to everybody who has some kind of disability. I passed an ordinance in the city of Warwick that has a handicapped patrol of cars that are parked in handicapped signs in parking spots and the police automatically send them a ticket it has been working out very well. Also, I'm here to I'm partially deaf myself which came about in 1988. I'm on my 4th pair of hearing aids, so I'm wearing my retirement. I feel for those that don't have the money, we have no coverage, Blue Cross does glasses. The prices are outrageous on the hearing aids. The markup is great. At my last check up the best one would be digital

	where I can focus on two not pay, it is not cosmetic, it is something that we all need, we need to start lobbying to get blue cross to cover it like eye people or 180 degrees, I had to settle for a $1,600 pair because I could not go to $5,000 for it. We do need help. Also we have programs in the state about getting -- about drunk driving getting kids off smoking and drugs, do you know boom boxes are going to do to these kids with hearing? They are going to be wearing hearing aids a lot younger and we need to educate adults about what noise can do to their health. We need to put together a program together so start educating, I want to thank you very much for having this forum, tonight. (applause)
	Beth Perry: Connie Susa. Mark Susa.
➢ B.II.b) Employment: Transportation	Mark Susa: Hi, my name is Mark Sousa and I live at 51 Puritan Drive and I would also like to thank you for having this forum. I am here to talk about the different people of special needs with developmental disabilities. This is a real topic that is important. What I would like to ask you is that I could use extra additional money because I need that because I'm traveling to people in Rhode Island with disabilities and also that's good because I am getting numerous staff reports on people both in the afternoon and morning and if you know this, we are now in the 21 century, which means we have medium buses, we have the older buses, we have the 2000 RIPTA buses and news channel 10 that reported -- they will purchase 60 more buses, so if we divide that in half, plus the number of travel time between that -- that's a good amount of what I'm doing, now, while I'm on the same issue of developmental disabilities I recommend that I see close to somewhere between 200-4,000 dollars for my savings account. I know that's a lot of money, but I appreciate if you take time to think about this. Me and RIPTA and you guys can all work this out because this is part of my business -- access and community transportation. Does anybody have any questions?
	Vicki Ferrara: I sometimes have difficulty following numbers, you had a lot of numbers to share and I'm wondering if may be you could submit something in writing that would outline your analysis for us. So that we would have a better understanding of your concepts and your ideas.
	Mark: Okay, who would I write that letter to?
	Vicki Ferrara: That would be helpful. I was trying to write down and I was having trouble keeping up, so thank you.
	Beth Perry: Now, we have Connie Susa.
➢ A.VIII.a)(1) Education: Youth Leadership	Connie Susa: One of the most important jobs in family is separation and individuation and as I grow up I hope that I'm doing things separately and more individually so that Mark has his issues and I have mine, I'm here just to add my voice to Susan Shapiro's about the Rhode Island leadership youth forum, a broad-based coalition of people in this state. Those interested in the transition of youth with disabilities from school to adult life have been working very hard for the last six months to make this program a reality in Rhode Island. I distributed some materials about it when Susan was speaking and I hope that using Vicki's strategy of providing print materials I will be able to supplement the little bit of time that I have. I just came back from

	serving as a counselor to the Vermont youth leadership forum and saw firsthand the potential that this program has to help young people develop their advocacy and self-determination skills and prepare to better serve the community. I know that as we've talked about self-determination over the years that's about people serving their own needs. What we are talking about is leadership, so that they can serve the community as well. We hope that the division will consider that a priority as they -- and the commission will consider that a priority as they plan for the future. Thank you very much. (applause)
	Lorna Ricci: Thanks we need to take a short interpreter break, 5 to 10 minutes, please help yourself to coffee, I want to recognize Paula Brady from congressman Kennedy's office.
	Paula Bradley: It is Bradley.
	Lorna Ricci: I'm sorry, changed your name. Sorry, glad you are here. Five minutes and we'll start again.
	Lorna Ricci: Excuse me, could we continue the hearing. Beth?
	Beth Perry: Our next person is Jean Cannery and then Gordon Hunter.
➢ C.VI.b) Education: ADHD Support Services	Jean Cannery: I'm a parent of a child with a disability. A hidden disability called Attention Deficit Hyperactivity Disorder, I'm an adult with this disorder who was not diagnosed until 45. I'm the co-coordinator for the children and adults with attention deficit. I've been running that group for three years, using my time, energy and my money, we've created a good service base, but we have no support, no support. I'm talking now for all parents who have started support groups and run support groups and use their time and energy and money especially when they are stay-at-home moms. We need support, we need financial support and help to be able to continue to do the jobs that we are doing. We have members across the state, unfortunately by the time they get to the meeting they are stressed out, they are dealing with the school department, the physicians, dealing with the child with attention deficit hyperactivity disorder can be very stressful. Parents come to us and they are stressed. We don't have a lot of volunteers because they are stressed. Those of us who feel that it is just so important and so crucial that we go one step above. With the support, we'll be able to maintain these groups around the state and find help with people being able to coordinate more. We deal with pre-schoolers to adults with attention deficit, there's a wide variety. Early intervention is crucial and coexisting morbidities and ADHD has a 40% co-morbidity percentage, we have parents calling us constantly in tears they do not know what to do, how to handle themselves, they do not know how to get through to the school department, to the particular teacher that does not believe in ADHD, I'm not sure where to go for this help. It is clearly needed and I can only talk about myself, but many parents running support groups that are just, you burn out because if -- I'm going back to work, I've been home for five years and now I have to find a job, I don't want to find a job, I'm working 60 hours a week on Chad because it is so important to myself, my daughter to educate everybody around us and also help all of the other parents and kids get the services, help the children

	reach their potential and that's what is so important. I know myself I'm on the verge of not being able to do it because I do not have the support services that will make my group keep going.
	Ann Porto: The support services that you are looking for is it financial? Professional assistance in the form of people running these supports groups? Information to the parents?
	Jean Cannery: I have a very good network. I work with other people. I would imagine it would be in the form of grants, how to find grants, how to write them, have somebody write them for us, we are already doing 1500 jobs, we maintain a hot line, an e-mail hot line, if a grant were available somewhere it would enable me to keep on going and doing this job. People tell me "there are grants out there" but when you are doing everything from soup to nuts you do not have time to look for grants or you have already called too many people. The parents need support back up. The parents who are coming are not getting the support services from the city, or the state or the schools, they are picking up the slack, in order to continue to do that we need help. It is a disability that people do not understand, that causes a lot of pain and heartache. These kids need to reach their potential. My daughter will not go through what I went through as a child and an adult being undiagnosed because she has me on her side but I'm on the side of all of the other parents, too and I need help. (applause)
	Beth Perry: Gordon Hunter, then Christine Hawkins and Doris.
➢ E.II.b)(4)(f) Accessibility: Curb Cuts ➢ C.II.b)(3) Transportation ➢ E.II.c)(2)(b) Accessibility: Physical	Gordon Hunter: I live in Riverside. On Pleasant View Avenue. The bus stop, they moved it down to the right and left further away. It is perfect when you get a wheelchair they stop and let you off. And over at the -- on the Pawtucket Avenue across from the high school that bus stop is up on the curbing but there's no ramp to get up to it, you have to go out in the street to get the bus. I went to (George's Restaurant) they have a handicapped bathroom but it is on the second floor, they don't have it on the first floor, but you can't get to it on the second floor.
	Panel member: It is easy to keep it clean.
	Gordon Hunter: That's all I have to say, thank you.
	Bob Cooper: You are looking for us to clarify the question regarding the buses. From what you've said it looks like there's a need to coordinate where they have the curb cuts and the bus stops so they are close to each other.
	Gordon Hunter: if you have to get in the middle of the street. The cars will run you over getting into the Ames parking lot.
	Beth Perry: Christine Harkins and Doris Duarte after him and Linda Kanuton after her.
	Christine Harkins: I am here representing the Drug And Alcohol Treatment Association of Rhode Island. This is what celebrities must have to deal with. I'm delighted to be here, because I feel it is an excellent way to get people behind issues that need support in order to help Rhode Islanders get the access and the assistance that they need. The drug and alcohol treatment center is a

- B.I.a) Health Care: Information about disabilities
- B.I.e) Health Care: Information about services
- A.VI.a)(1)(d) Accessibility: Communications

professional trade association that consists of over 22 treatment agencies that assist Rhode Islanders with addiction problems and other comorbidity problems that attend this disease. First and foremost I need to say that we would like in some way and in many ways to raise the consciousness of people in Rhode Island regarding addictions indeed being a disease and a disability. Often folks do not categorize it that way in our consciousness and if we don't then the other things that we need to assist don't follow. The laws, the compliance, the support, et cetera. So first and foremost that would be number one. Another is this: experts in the field tell us that individuals with disabilities are far greater to experience addiction problems and yet, the population of individuals with disabilities is greatly under represented in those persons coming into treatment centers for assistance. Now, that disparity is something that greatly concerns the treatment centers and I think indeed should greatly concern the rest of us. Where are these people? Now, we have a sense that those -- because addiction is one of the disabilities that tells you that you don't have it. We feel as though those people are out there and would indeed accept some information and assistance and support towards better health. If we were to have more accessibility and greater outreach. So we are also asking you to think about ways in which we can outreach to people in Rhode Island that have disabilities and may also be suffering from the disease of addiction and do not know where to get assistance that will match their needs. The treatment centers are ready, willing and somewhat able to help with this by the way. But I don't think we can do it alone. For example, if a deaf person wanted to come to the treatment center that I serve as executive director at, we are very proud to have a counselor who is pending licensure to counsel and we are proud of the fact that we have interpreter as well as a staff member who is an interpreter. However, if someone comes into our residential treatment center and wants to participate from 9:00 until 10:00 we will be outstripped of professionals that could help us, the attraction, the retention of professional sign language interpreters in a functional system that refers them and assists them is quite important to us. Although we feel that money is not the only solution, we know that money has a lot to do with this. My line item at Kent House Treatment Center for professional sign language interpreters which does not count by the way the on-staff person because that's separate. Was in excess of $25,000, that was equal to what it costs me to give 3 meals a day to 42 men in residence, 365 days a year, therefore I was in the unenviable position of deciding whether people get food or people get treatment. Having 42 residential beds makes Kent House no longer the small and humble center that started in west shore road in Warwick but rather one of the larger treatment centers in Rhode Island. That outstrips one of the largest treatment centers to serve this one person. It is not an unwillingness on the part of Kent House, that calls for a partnership, if it is a priority with you folks, then when you make up your legislative slate you can look to our leaders and say "this is imperative" these are not people digging their heels in and saying "we are only servicing this portion of our citizens" we need to see this as a state problem, not as a contract problem or a willingness problem, but as a statewide community problem. We believe that everyone should be able to go to their local community center and have both physical and programmatic access to treatment. However, we also feel that perhaps there

➢ A.II.a)(1)(b) Transportation: RIde ➢ A.I.a)(1)(a)(vii) Health Care: Substance Abuse	should be deep conversation around the idea and the concept and support of centers of excellence can a treatment center perhaps really perfect its service to a group of individuals and would that be a more efficient use of dollars, while still following the law, the spirit and the letter of the law regarding access. Would that be possible? For example, if someone were excellent at Braille, excellent in serving the visually impaired and this staff member would be a find, a star, would we want for example, equipment for copy books and voice activated systems to be located at another treatment center, is there some way we can make centers of excellence, that's a conversation we would like to have and have some support behind. Another issue that's very important is transportation. If someone decides that they want to start getting help for their addiction today and they are in Warwick, and they need to go to detox we'll somehow have to make it to Roger Williams hospital or North Kingstown Rhode Island, I do not think RIPTA runs to the middle of route 1 in North Kingstown at 11:00 at night when that maybe the moment we can help that person. When the detox was located in the medical complex it was just – it served in one way, local police were on the team sometimes to help somebody get there safely and sound, the detox center has a lot more to offer now, but geographically, we have a problem. We really need to be able to get people to detox. We also need in order to serve these individuals in Rhode Island with a disability of addictions more treatment beds. It breaks my heart to say to someone “you're going to have to wait four to six weeks in order to get help" it would be odd for us to say that somebody with a heart attack has the ambulance come and they are wondering whether to take them to Kent County or Rhode Island Hospital and the answer is: you are going to have to wait four to six weeks in order for a doctor to see you for your heart attack. You are going to have to wait four months someone to see you for your stroke. What will happen to that person? We know what will happen that person will be dead. People are dying every day or having more progression of an incredibly insidious disease with its stigma, when we cannot have that access immediately it is an emergency situation. Therefore, I have given you enough to chew on for this time and I’m hoping that you star all of these items because we truly, honestly need you as a support team behind those of us in the trenches, we need you sending us supplies. Thank you so very much.
	Beth Perry: any questions? Doris Duarte is our next speaker.
➢ A.I.a)(1)(b)(v) Health Care: Employment	Doris Duarte: well, I’m changing my role. Last night I was on that side and tonight I have a different hat. I'm representing the National Multiple Sclerosis Society. Two issues, one is that The Department Of Human Services last year was very pro-active in writing a grant to get money for a pilot program that was called "road to maintain independence" and that program was funded by the federal government, by the Department Of Health And Human Services so we got the funding for the federal portion and then what we needed was to get funding for a matching state money to do this program, what this program does. It is a pilot program, it is trying to show that if people with multiple sclerosis who are presently working are given support services in what they need to help continue working, that they will be able to remain in the work force and be productive people. So I want to really put in a plug for this again, because we still have the federal money or we will get the federal

➢ A.I.a)(1)(b)(i) Health Care: Prescription Medication ➢ A.I.a)(1)(c)(i)(a) Health Care: Community based options	money, but we need the state match in order to make this a reality and we could be the first people in the united states to have a program like this that could actually make a difference in peoples' lives. As many of you probably know, multiple sclerosis is a chronic disease hitting people between 20-40 and it hits people in the prime of their life, people are starting and raising families, how can we help them maintain their independence and be productive workers and be a benefit to the state in being productive. The second part that I would like to bring up tonight is the need for prescription coverage for home health care and respite care for people with disabilities. I struggle because I know that older people have some of these benefits through the state, through the department of elderly affairs, if you are age 60 or 65 you may qualify but people who are younger and disabled have the same needs but do not have the programs that they are assisted with and currently there are 3 medications for multiple sclerosis that can help slow the progress of the disease and they cost $10,000 a year. If they do not have prescription coverage or if they are on SSDI with Medicare coverage and they have their other supplemental coverage it has a limited prescription benefit plan it would be impossible for them to cover that cost. In terms of home health care, often times, a person may be at home and their spouse is unable to care for them because they are working and they need that kind of care and there's no way of having any financial assistance for that home care, also respite care service. I've had calls from parents who are now aging and are caring for a child who is in their 40s or 50s and they say "how are we going to be able to get away to enjoy some of the time that we are retired" I would like to just say that that's an issue that I think not only for people with MS but for people with disabilities to have those kinds of programs would be very helpful.
	Beth Perry: Linda, this is our last speaker who has signed up to speak, if anyone else is interested in speaking, let the ladies in the back know and we'll sign you in.
➢ A.I.a)(1)(c)(i)(c) Health Care: Housing	Linda Knutton: Good evening, like Doris I have a couple of hats that I wear. I'm going to have to talk to Doris afterward because she led right into what I had hoped to talk about. The first hat that I wear is I'm a geriatric social worker in Warwick and the second one that I wear and that I came here tonight to talk about is I'm on the board of directors of a brand new non-profit organization called the Warwick Interfaith Association For Affordable Assisted Living. The affordable is in quotes because that's the biggest problem. I realized many years ago when I began to work for the City of Warwick as a geriatric social worker. There were changes in our society. No longer do we have the luxury of having women at home taking care of their children and being available to lend a hand to the senior members of the family. The women are all out working. So as a result we have many seniors who are left to their own independence and in later years are not able to manage independently, when I began this project, I called resident service coordinators throughout the city of Warwick and talked to them about the population that's residing in section 8 housing. They were able to tell me simply that there was 20-25% of seniors who are aging in place, who are no longer really able to function independently. There are a lot of seniors who are able to get home care in place so they can remain in their apartments, but

- A.V.a)(1) Direct Care: Workforce
- A.I.a)(1)(c)(i)(c) Health Care: Housing
- A.I.a)(1)(b)(i) Health Care: Prescription Medication

there are many others who cannot. There are a couple of major issues, one of them has recently been addressed and that is to raise the minimum for the CNA's. So that we can get the kind of staffing that we need to keep people independent. The other thing that has been introduced and worked on between the state legislature and the Department Of Elderly Affairs and Department Of Human Services and the federal government is the various assistance programs that can get people into assisted living at an affordable level. We are talking not only about seniors but younger disabled folks who are really not able to cope with total independence. The programs are SSI, for assisted living. Medicaid waiver programs and a nursing home waiver program, there are a total of 630 slots between the 3 programs, needless to say they are all taken. We need those slots to be expanded, we need to have the kind of support from the state that is going to allow more low-income seniors and disabled folks to access assisted living. Our association is only allowed 5% of our time and monies to lobby for improvements that's one of the definitions, so I probably used up my 5 minutes tonight. I felt it was important to talk to you about it because it is a vital concern for 14 of us, there are 14 people from various walks of life and various ages that have come together with this interfaith association to try and pull this off. What we really would like to do is build a new facility in Warwick to accommodate some of these folks. I don't think that we could ever accommodate all of them and Doris implied that MS is one of those diseases that does hit later on in life. I have clients that come through the senior center who are not seniors yet but they are disabled by multiple sclerosis or a number of other diseases who can no longer cope at home and there's not a whole lot we can do for them. So we need your support across the board. The other piece is the prescription issue as a senior advocate, I can say that the department of elderly affairs has done a remarkable job to this point I hope that the federal government can come as close, I doubt if they will. We do need to address the younger disabled folks who are caught in a black hole, they don't have the same advantages that the senior citizens do have with the prescription health and the bill introduced to lower the age for the RI-pay program, we are inundated. Every time that RI-pay is in the newspaper we get call after call from younger disabled people that I cannot help. Anything you can do to help Doris and I would really be appreciated. If anyone is interested in hearing more about our little association we would be glad to forward more information about it.

Beth Perry: Anyone else who did not sign up to speak or would like to speak? Then I thank you very much, would any of the commissioners like to address the audience? Thank you all for coming, we really appreciate all of the comments and efforts to be

F. *Public Hearing – Thursdays August 23, 2001 5-7 PM, Independence Square I, Pawtucket*

John Martinelli: Good evening. Thank you for taking the time to hear my concerns and the concerns of others that are in similar situations as I am. I spent the whole afternoon on the computer trying to get fancy. A whole

- A.IX.a)(1) Financial Support
- A.IX.a)(2) Financial Support
- A.I.a)(1)(a)(v) Health Care: Personal Care Attendants

bunch of quotations from different government organizations. Basically what it comes down to is a commitment from the federal level for people with disabilities. From employment to assistive -- transportation, and President Clinton stated if not now, when? I say a great movement in this country to support people with disabilities and make opportunities for them equal. The problem is, from a state level, the state does not support what the federal is trying to do. What I mean by that, under the social security laws, a person with a disability is qualified to come up to $700 a month, and still keep their Social Security SSDI income. This is fine. But when you get down to the state level, under the house -- federal finance administration, it gives the power to the states to regulate Medicaid. And Medicaid is and always has been a program that is based on earned income. You still have to spend down to welfare guidelines or you have to be indigent to be qualified for the services of the personal care attendance or home care. So, the monies that you are allowed from the federal level, you are penalized because either the Department Of Human Services or our legislators do not exercise the full potential of the law under the federal poverty level guidelines, which stipulates that the legislators or the Department Of Human Services could set these guidelines at a more realistic financial level of 300 percent. It is hundred percent which is set now I believe 706 a month. My out-of-pocket expenses -- I am only working part-time, added to independent living which I am proud to say now -- $200 a month. But that $200 a month, that whole bunch of $200 a month is figured at my out-of-pocket expenses. So not only does it go for dollar for dollar that I have to make, that $200 a month I earned is paid toward my PCA services. But on top of that, that is regulated at gross earnings. So I have to pay taxes on top of that $200 a month. And to continue, I am paying $665 a month and I only earn $1200. So I am paying over 33 percent towards my PCA services. I could earn more. They won't allow me to in the state level. The federal gives the power to the state. But the power should be given to the state, fine. But not to circumvent the existing federal laws that apply. Under the reconciliation act, people on social security, disability income, have to pay taxes on their disability check if they earn up to x amount of dollars. So I am paying taxes. A few thousands dollars a year on my Social Security Income checks that I paid into FICA. My employer paid into FICA for over 84 years. 80 years for my wife and I based on joint income. So if you earn over 40,000 gross level, a family for 80 years that's 30,000 after taxes. So two adult people in their 60s are earning 15,000 a year, that's what it comes down to. I think it's outrageous. We want people with disabilities to work. But we do not set up the incentives for grown-up people who want to compete in the real world like you are, to raise families, not to live in subsidized housing but to pay fair market rents, to take care of their children. Who don't take into consideration rents, food that people have to buy to eat, insurance. I cannot stay on a program. And I don't know if I am not in danger of being institutionalized because of the programs new -- I suppose are to protect me and people like me. Thank you for your time. Any questions?

Paul Choquette: Thank you, John. Next person is Beth Pinkham.

Beth Pinkham: Hi. I am Beth Pinkham. I am the Coordinator at the Ocean

- A.VI.a)(2)(b)(i) Accessibility: Home Modifications
- A.V.a)(1) Direct Care Workforce

State Center for Independent Living. And we just had a couple of budget items that we want to call people's attention to and seek their support on. We do have written testimony up there that you can look at. Obviously get back to us with any questions. But the first basically resolves around the state modifications. And I am speaking tonight on behalf of PARI and the Ocean State Center for Independent Living. Both centers right now have 48 individuals on their waiting list and seeking full modifications. For the past three years they have modified the program at $200,000 split between both centers. The 48 people on the waiting list, we see it's not getting the job done. Both centers are sharing that money. We would like to see the area of $400,000 a year so that we can put down the waiting list and get people the modifications they need to stay independent in their homes, in the community, not only because -- in a more timely fashion. They are not waiting a year for those modifications. The second one involves around personal care that we coordinate at PARI. Right now this year we were successful in getting the 8.15 subsidy to 8.74 which is great and we appreciate that. What we need to do at this point however is bring that up to $11.22 an hour to meet the employer portion of the pay roll deductions for social security, other taxes that people are responsible for. So we will be -- looking for the process to seek 8.72 up to 11.22. That's about it for me. Thank you.

Paul Choquette: Thank you, Beth. Next person is Robert Burke.

- A.V.a)(2) Direct Care Workforce
- A.I.a)(1)(c)(i)(d) Health Care: Nursing Care
- A.I.a)(1)(c)(i)(a) Health Care: Respite

Robert Burke: I have printed copies. I am Robert Burke from Memorial Hospital. The Chairperson of the Disability Youth Rhode Island Chapter of the American Pediatrics. My practice of 20 years I have specialization to care for children with disabilities, complex medical needs. At the present time at Memorial there are 200 children with any from relative mild to profound complex disabilities. I am here today to discuss several of my personal concerns, but more important, to relay those of parents of children that I take care of. So this is somewhat of a potpourri of concerns. I limit myself to ten. At any point I get too deep or too lengthy, stop me at any number. The first is nursing service. For those families who benefit -- kids, children who require constant or frequent nursing care in home nursing coverage essentially. The need for -- it costs two feedings and other services are essential to the child's well-being and survival. The lack of adequate nursing is stressful for families. And though there are many dedicated nurses who are interested in caring for children with complex medical needs, however the shortage, there always seems to be a shortage that slips the need. The need for programs to increase the number of trainers, nursing care and the number of nurses is essential. Sufficient funding should be provided to encourage nurses to participate in home care and to continue providing in home care. And also to provide training for nurses so that they can better provide care to children with complex medical needs. The second point of concern is Respite care. That is supervised care of children with disabilities are in relatively short supply in Rhode Island. And though parents may have an entitlement to Respite care, it is often difficult or impossible for parents to identify sources of in home care for the disabled children. Center based care for children who are medically fragile or who have complex medical needs is

- A.I.(a)(1)(b)(iv) Health Care: Interpreters
- A.II.a)(1)(c) Transportation: Health Care
- C.VI.c) Education: Special Education
- C.VI.a)(2) Education: Transition
- A.I.a)(1)(c)(i)(e) Health Care: Transition
- C.I.g) Health Care: Transition

essentially nonexistent in the state. This type of program needs to be developed, as they are going to be more children surviving with complex medical conditions that will need essential services. Interpreter services. At the present time, neighborhood health plan provides interpreters for families whom English is not a useful language to understand serious and complex medical information. This is an enormous help to families and the healthcare providers. It -- as important, it is a significant factor to improve the quality of care by increasing the understanding and allowing clear communication of complex issues. This service is available to families covered by neighborhood healthcare plan. However, no such entitlement exists under Medicaid funding programs. We are often faced with using family members, sometimes children who are -- who are Spanish speakers but may have no medical familiarity. Spanish or other language speaker, who have no medical understanding of complex medical issues and use that as interpreters. All Medicaid funded, funded programs should apply the service as an essential service to the families and children. Similarly transportation is not -- is number four on the list. Transportation is an issue for families who are covered under Medicaid programs. Under the rite care program, under neighborhood healthcare, transportation is provided. However for those children who are funded under Medicaid there is no similar type. A fifth area of concern -- special education services. Special education service needs in the state, needs to be fine-tuned to meet the needs of children with specific health issues. We recognize the need for specialized education programs for severely profoundly hearing impaired children. However, even with IDEA and individualized educational plan programs in place, there are essentially no specialized programs for children who need particular needs. Most children receive a somewhat generic program that consists of classroom teaching, speech, language and occupational therapy. However this is not for teaching children in early intervention age, early preschool age and early school age populations. Some programs, similar to teach, teachers' aides, South Carolina -- North Carolina program that focuses on language development and socialization, a very intense program. Some programs such as this should be developed for children in the state of Rhode Island. I point out the state of New York has recently proved to be use of a somewhat more rigid program but still of the advance behavioral analysis, either program could be adequate and certainly benefit the generic program that most children receive today. Number 6 is transition services. The transition of children in adolescence to the adult service care system is a complex journey. It is a lengthy process that really begins in childhood extending into adulthood. It must include issues related to education, training, employment, housing, transportation, finance, support, mental health services, as well as healthcare and medical services. Let me focus on healthcare services for a moment. Almost every pediatrician whom I know, who cares for children with complex medical needs, continues to provide services for these children into adulthood. One of the factors that cause patients to continue with pediatricians is hopefully their satisfaction in the service. But another factor is the inability of families to find adult health care providers interested in caring for individuals with complex physical disabilities that occur in childhood who have developed behavioral disorders arising in childhood.

- A.IV.a)(2) Housing: Accessibility

The -- the present time, the state of Rhode Island, the Department of Health in the state of Rhode Island, are jointly looking into transition programs for children. However, we must keep this issue on the front burner in order for it to rest. Accessibility, accessible housing, and I will use an example. One single family, one single parent family for which I have been taking care of until recently when they had to move out of the state to receive better services. Have two children with severe developmental physical disabilities. Both six-year-old children use wheelchairs. The mother lives in a third floor apartment. In order to get the children into the upstairs apartment, she has to take -- carry one child upstairs. Leave the child upstairs. Go down and get the other child. Bring that child upstairs. Go down and get the wheelchair of one chimed, bring that upstairs. Get the wheelchair of the other, bring that upstairs. And then get the groceries. She has a thriving back injury and a back problem. However, the housing, her housing entitlement is met according to state regulations because she has two children. Their need goes unrecognized. Uncovered -- resources for uncovered losses disability. Rhode island served by itself having one of the best insurance programs for covering the needs of children and children with special needs in the country. However, there are many unrecognized and uncovered losses that are related to childhood disabilities. The cost for specialized clothing. Adaptive modifications in the family home go unrecognized. Families have to purchase vans rather than cars and have lifts placed in. Parents who may be unable to work outside the home in order to care for a child with a disability. While in another family, the parent may have a second or third job to pay for unmet needs. We need to look into these costs and find some equitable way to help families meet their children's needs and defray some of the covered expenses related to child disability. Excuse me; I will take care of medical services now. Get them all on my list. Fee for service coverage for patients with complex medical needs is an important issue. One of the -- the academy of pediatrics and the state department has looked at barriers to care for children with special healthcare needs. One of the barriers in that reported previous studies is the financial cost to providers for providing care to children with disabilities. One of the barriers faced by families is getting healthcare when there is not appropriate compensation, primary healthcare providers to provide services to care for children with disabilities. Some children with severe disabilities are covered by a decapitated system, which I might receive $2.50 a month for providing care for this child with a severe degenerative neurological condition, whom I see at least twice a month. And who requires many hours of professional service. Almost every pediatric provider, family physician whom I know provides care to patients such as I described. However, it might be understandable that they might accept other patients if -- in my own case, I am paid salary by the hospital. However, in a primary -- in a provider practice said having 100 patients for whom you receive $2.50 a month, and the cost of the practice is several thousand, is not likely to receive support, either from a doctor or from his office manager, especially from the office manager. Support services to families. Of all of those involved in the care of children and adults with disabilities the most important and the hardest for care providers. The stresses and strains of caring for children who are medically fragile or depend on medical

- A.V.a)(1) Direct Care: Reimbursement
- A.I.a)(1)(c)(i)(g) Health Care: Support Services

➢ A.I.a)(1)(c)(i)(f) Health Care: Support Services	technology to remain healthy or even alive. With an autistic child with behavioral learning problems. In my own practice 7 children, brothers and sisters of children with disability who suffer -- who's brothers suffer severe -- in my own practice, I have several children, brothers and sisters of children with disabilities who suffer from severe depression and behavior problems because of the stress put on them by being a sibling of an autistic child. There is an issue of the threat on disability on the entire family. The system -- a system of service and support to all family members must be developed. The Rhode Island chapter of Academy of Pediatrics and the state chapter of the Academy of Family Physicians, family voices and other organizations, the governors agencies, all working on all parts of the system. There are many initiatives and programs which -- for which we can be proud of. Among these are the early intervention special education programs and the newly developed secures program and the RITE care. But there are many challenges for caring, and caring for children with disabilities. And each -- when we find a solution for each problem, it highlights another chapter. Thank you very much.
	<u>Paul Choquette</u>: Any questions? Thank you, sir. Teresa Carr. And after Teresa is Mary Wierzbicki.
➢ E.II.b)(4)(b) Accessibility: Physical ➢ E.II.b)(4)(a) Accessibility: Physical ➢ E.II.b)(4)(c) Accessibility: Physical	<u>Teresa Carr</u>: I do not have a prepared statement. But I am concerned about a few problems within the city of Pawtucket. Basically being legally blind and walking the streets as a blind person, as -- I have found many problems. To name a few, especially York Avenue, the sidewalks are almost impossible from say Vineyard Street to Beverage Hill. At least the sidewalks with no room, they are unpaved, hilly. Sometimes forcing us into the street. And York Avenue is highly traveled, so it's very dangerous. So we try to avoid it. There are a few other places in the city where there are overgrown shrubs from fences, et cetera, that make it almost impossible to travel and you have to step-off the curb. But one of my main concerns is Newport Avenue and Beverage Hill, which I believe is state run. They enlarged that intersection and made it very good, at least it -- I did appreciate that. But the signal lights, the poles to the signal lights have been placed directly in the center of the sidewalks at the corners. Which makes it -- for two people to get around, especially both of us with canes, we have to be very, very cautious just to get around the pole. And I think every time I do this, that what if it was a wheelchair. I don't know how a wheelchair would get through that particular corner. So I think these are some of the measures that should be addressed for the safety of those of us who have to travel the sidewalks. Thank you.
	<u>Paul Choquette</u>: Any questions? Thank you. Mary. And then Nancy.
➢ E.II.b)(4)(d) Accessibility: Physical	<u>Mary Wierzbicki</u>: My name is Mary Wierzbicki. Regarding curbstones. As I have to walk everywhere. I have found sidewalks that are dangerous, curbstones that are too high or broken. I have had an injury due to a curbstone. I think it should be taken care of. Also because I also think of people, like my mother, handicapped and blind people, and I really think the city should get together and straighten these curbstones out. Some are too high. And -- that's my most concern is the curbstones. I have seen a lot of them. Thank you.

Paul Choquette: Nancy Tetreault. After Nancy, Joe Simoes.

- A.V.a)(1) Direct Care: Reimbursement

Nancy Tetreault: Good afternoon. I am Nancy Tetreault. I work at Black Stone Valley. I have been there 21 years. Over the years, the services have decreased. The aging population is aging. It takes more time to get services than needed. There are a lot of people with Down Syndrome who are starting with Alzheimer's. They are confused. They need more time for explanation and care. The bathroom duties. They take about an hour and a half, four times a day. There are people who are being forced to come to work that don't want to come to work. I couldn't force someone to do something. But yet the people who run the group homes or the apartment programs. We have a person that comes in. She doesn't want to be at work. She has self-injured so she does not have to be there. Or if she doesn't do that, she injures someone else. There's no funding for those individuals who want to stay home. Why isn't there? Why should their rights be violated? And there are not enough professional people. There are not enough professional psychologists. We have been without one. We used a consultant who used to work for us. There's not enough pt, physical therapist people. And no physical therapy assistants. Staff has to be taught every one's programs on top of many responsibilities. People are being shortchanged. And it's not fair to them. They are not getting every service that they deserve and need. What we do need also, the state feels that we have enough staffing. Well, I would like to see them come in and keep up with us. I really would. Because of the many, many things that we encounter during the day, we wear many hats doing our job. We all love our jobs. But it can be very, very tiring. But it's also very rewarding. And one of the things is, we don't have enough staff because we don't get paid enough. We don't get paid what the state workers get paid, nowhere near what they get. And we do the same exact jobs. Most of all, the people that are suffering are the people that we are servicing, forcing folks we are servicing. Thank you.

Paul Choquette: Thank you. Joe Simoes. Then Bernadette and Vincent Chapman.

- A.V.a)(1) Direct Care: Reimbursement

Joe Simoes: Hi. I am an organizer with 1199, New England Healthcare Employees Union. I represent 4,000 members in the state of Rhode Island, represent a total of 22,000 healthcare workers in Rhode Island and southeast Mass. With about 6,000 workers working with people with disabilities. I am here to speak on behalf of Black Stone Valley Chapter, the newest organization that has joined our union. And I am sure all of you have heard of what happened not too long ago. I am here to speak on behalf of what I feel is a growing crisis. Not just BVC but also throughout this industry. Over the past few months, a lot of people have come forward and said; you know we have a crisis in this institution. We have a crisis because we can't get people to come in and work in these agencies. And it's true. We can't get them to come in. I have asked staff. As a union organizer, I have asked them please, don't go. Give it some time. Because people are just leaving. They can't afford to stay and do this kind of work and support their families unless they work 60 to 80 hours a week and have many, many members in the agency that do that. The effect of the crisis is that consumers are going without services. The state of Rhode Island many years ago did a wonderful thing. They closed the institutions. They brought the consumers into the community where they should be, with the understanding that they would continue to support these people. These people need support. But we can't do that. We can't continue to provide the kinds of services that some of our consumers need with the staff that we have. Every day I get calls from people. We don't have enough staffing in the workshop. Nancy talked about people not coming to work. I can tell you why they come into workshops. There's nobody at the group homes to take care of them if they are home sick. At least in a workshop they will be minded. In the group home there is not enough staff. It's a shame that we have to send people into work when they should be out. But that's the only option we have. I am not here to blame management. I am not here to blame anybody. I am here to let you know that the effect that this is having is going to continue to increase. Not until I go, I would like to see -- additional funding for CNA's and nursing homes which we represent a lot of. We have a lot of members that do that kind of work. It was not even nearly enough what they passed on to the workers and these agencies. You know, basically what's happening is that people are leaving, going to McDonald’s and Burger King. Some of them, believe it or not, are making exactly the same thing at a McDonald’s or Burger King makes. You can leave black stone valley chapter RIARC and go work at Burger King and make the same. And you don't have to deal with all the stress and all the work that people that deal -- that do this kind of work have to deal with. People understand. Most people at BVC didn't come here to make a lot of money. They know. These people are not asking for a lot of money. They are asking for a live-able wage. The bottom-line is that if the state of Rhode Island at some point doesn't do something about it, we are going to have no choice. And you are going to see some of these agencies closing down and some of these Programs. It's, you know, staffing is dangerously low. And I mean dangerously. You have one support staff per 15 consumers. How do you do -- how do you do it? You don't. You cut corners. You do the best you can. And that's what you get. I don't think that's what the state of Rhode Island had in mind when they closed the institutions and decided to move people where they should have been all along, into the communities. They weren't -- what they said is they made a commitment to continue to provide the supports these people needed. I don't think they were saying -- we are going to send you out into the community, and then you do the best you can. I am pretty sure the commitment was made when people went into the community, they would continue to get the kinds of services they need. I have an example. Our independent living -- our what we call our department program, state of Rhode Island has set a rate of 18.45 per hour. It's not even enough to take care -- to get a support staff. For 18.45, BVC is to hire support staff, nursing if needed. Site assistance if needed. Speech assistance if needed. Physical therapy, if it's needed. It is supposed to provide everything. You tell me in this day and age when you can find a psychologist or physical therapist or speech therapist for 18.45. You can't. Never mind nursing. We have an extreme shortage of nursing everywhere in the state. Our members are tired, frustrated. Tired because they work hard. They are frustrated because they love to give the kind of

	services that our consumers deserve. Unfortunately they can't -- please help us. The state of Rhode Island can fund RICLAS to pay their workers more, $3 more an hour, which they deserve. Why can't they do the same for us? Thank you.
	Paul Choquette: Thank you. Any questions? Bernadette?
➢ A.VII.a)(2)(c) Assistive Technology: Audible Signals ➢ E.II.b)(4)(e) Accessibility: Crosswalks ➢ C.II.a)(3) Transportation: RIPTA/RIde	Bernadette Chapman: Good evening. There are a few issues I would like to address. The first one is the follow up that the lady spoke earlier regarding Newport Avenue and that particular road. I live right near cottage Newport. I cannot cross my street. It is impossible. I was -- it is impossible for me to cross the street because people want to run the red lights. They don't stop. One thing I would like to see would be audio lights. I often travel in audio because they do have it there. And I do know the city was able to put it in and fit it into the budget. I would like to see possibly a way of safe travel for people like me and other people that are vision impaired and blind in the state of Rhode Island. I can sympathize with her about the crosswalks. I have no crosswalks on my street. I have to walk in the street. There are no lights that are very visible I am worried at nighttime if I am going to get hit by a car that is going 50, 60 miles in a 25-mile speed limit. That is an issue I also can sympathize with. It is a scary place out there. A few other issues I would like to address. The first is paratransit. Being on a state line, I have across the street is Massachusetts. I have trouble using the paratransit because with small children I cannot take them to a doctor. I have to rely on someone that can drive me to there. I have trouble accessing, going to certain doctors because you can only go on a bus route. And that makes it kind of hard because not every doctor is covered through -- and I have to walk a good distance, which is not a good idea with no audible lights. Another issue I do have is why -- I cannot because I am a resident in the state of Rhode Island in Pawtucket. I do take the train. The train does run into providence, but it runs into Mass. Now because I'm a resident -- being a resident of Rhode Island, I am not able to get a disabled car for the train. And which then I have to pay fare when I do business in the state of Massachusetts. I can't even go into Attleboro without paying .75. Another issue with that is the -- I am being close to GATRA and RIPTA; it's a beautiful service. I have to walk about a half mile to get to one or the other. And I live right near a main road. These are the issues I have. And Vincent has a few too.
➢ C.II.a)(3) Transportation: RIPTA/RIde	Vincent Chapman: I am concerned with the RIPTA. Most case the RIPTA will drop them off on the state line, 1500 feet from the state line. They have to walk down, across the bridge or something in the middle of a parking lot. And I don't know what's involved in trying to get connectivity so the bus will bring you to the bus shelter rather than the state line on the side of the road. Usually the bus shuttle I am familiar with. Seekonk Central Avenue the bus shuttle is across the state line. But the RIPTA bus drops you across the bridge. And you are forced to walk on the bridge to get the bus. And the other ones I know of are Broadway and Washington. You have to walk across that bridge and across the street to get to the bus shelter. It just doesn't make sense to me why the bus can't go another thousand feet and turn around and take you into the parking lot rather than turn in the street. The -- with the

NPA, operating in providence, expanding services to Warwick, it baffled me to operate in the state of Rhode Island yet the state of Rhode Island is nonresident when they pass stuff of that nature. Thank you.

<u>Paul Choquette</u>: Okay. Karen Ema and then Robert.

<u>Karen Lema</u>: Hi. I am Karen. I am speaking on behalf of the International, which is an organization that for people with disabilities. And I would like to present to you a video that talks about our concerns. Thank you.

<u>Paul Choquette</u>: What we will do is make copies of this and we can distribute to everyone. I don't know about the video, but -- is there any particular agency that you would like this video[ii] to go to? Then if it's okay with you, the Governor's Commission will take possession and we will look at it.

<u>Karen Ema</u>: Thank you.

<u>Paul Choquette</u>: I am sorry the last -- I am having trouble reading it is Robert Geale?

<u>Robert Geale</u>: Good evening. I am Robert Geale. I am grateful you are setting up these hearings. I have to tell you I am dismayed and I am sure that people here are also somewhat dismayed that a lot of what you are hearing tonight was said months ago in the hearing. And it's one thing for me to kind of feel like I have been -- my piece being ignored. I had e-mailed those politicians that ignored my pleas. I have protested and had a sign in front of the Statehouse. Any number of things that people who also take to that hearing, people with disabilities may not have access to a computer to e-mail these politicians. They may not have access to transportation to protest when their views are ignored. And that's really a shame. It's a shame in this state to treat that way. I have been in a hearing with the entire afternoon, and -- I don't want to dismiss their views or needs for services. My focus here tonight -- I don't have a prepared statement -- is continuing education. While the federal and the passage of the budget issue in the state has continued to pour money into education and special education for our public schools, people that the state and federal government are ignoring are those people with disabilities who need continuing education. Here we have, I would say of the 500 consumers roughly that we service, I would say the vast majority of them have not received an adequate education from the high schools where they attended. This leads to our trying to teach people to fill out job applications, to fill out forms necessary for services, to fill out banking forms on their behalf, and things like this. If people came with the indication we would see a dramatic increase of the people getting jobs because they could fill out a job application. And they would have confidence. They would be able to go to that job and read instructions about that job, and they would be able to talk to people on that job and feel as though they were a team member in a retail store or a McDonald's or Shaw's, what have you. Our people who are finding jobs in the community are finding that the jobs available to them are very limited. If I take an individual to Shaw's and ask someone to give that person a chance for a job, the first job that they are going to get is to be putting carriages in the parking lot and that is where they will stay. We have an individual who has been doing that job for about 12 years. So there's no

- B.II.c) Transportation
- C.VI.d) Education: Continuing Ed.
- C.III.d) Employment:

Training ➢ A.Va)(1) Direct Care: Reimbursement	opening of the mind as far as management is concerned to see that possibly this individual has more of a capability to do a better job. Maybe they could work in the deli department. Maybe they could work in the produce department. But the mind-set of people in the community is still that our individuals are very limited. And yes they will give them the opportunity for employment, but that employment is very limited. And I can tell you from teaching these individuals myself; their aspirations are far greater than collecting carriages. And they deserve that opportunity if they have that capability. When we do classes here at the BVC -- by the way our services for the federal government putting in services -- rather funding -- to people at a higher level, we are now reduced to having almost nothing if anything at all to continue education with people with disabilities. We have approximately 50 individuals in the resource center where I work. And about I would say two-thirds of those have been in classes of one kind or another. We have a reading class. And we have a Spanish class. The majority of people coming into our state are Spanish speaking. We hope that this will enable them, to help them get a job market in the future. But we have no funding. Our funding is reliant on our own agency saying; yes this is a worthwhile project to do. These classes are a worthwhile endeavor, which thankfully they have. And also finding grant monies to do special projects. And we have gotten some grants through brown university square center and through the Rhode Island department of education projects. But again, we are not getting enough services. We are not getting enough classes. We need money for teachers. We need money so that we can provide those individuals who need one-on-one education. We need money to provide individuals with job training. Because again the staff is training to do that to a certain extent. But staff also, as many other people have told you, have many, many other responsibilities. And my experience unfortunately if there is a crisis going on a certain day or the staff shortages or such, education is the last thing people think about. Just having enough people to work with those people that are impaired and disabled, who need the services, one-on-one services. I would ask to go back to the governor and press the urgent need to continue or to give funding for continuing education for people with disabilities. It is something that all of us have the opportunity and many of us have taken that opportunity to go to college and have courses under our belt that we may have not gotten when we were younger. And certainly education should be a lifelong endeavor. And this is true for people, whether it's individuals with disabilities as well as ordinary citizen. Thank you.
	Paul Choquette: Thank you. Any questions? Okay. Louis Luongo.
➢ A.V.a)(1) Direct Care: Reimbursement	Louis Luongo: I don't have much staff right now -- we need more staff persons. We are short on staff persons. We need more. We don't have enough workers. We do need them bad. We can't get them. What can we do? We can't be doing everything. We need some help. Thank you.
	Paul Choquette: Thank you.
	Dianne Kayala: Where is it you need more staff?
	Louis Luongo: We are short on staff persons.

	Dianne Kayala: Where is that?
	Louis Luongo: BVC
	Paul Choquette: That was the last person I have that has indicated they wish to testify. Is there anyone else present who would like to?
	Audience member: -- Yes.
	Paul Choquette: Can you identify yourself?
➢ A.V.a)(1) Direct Care: Reimbursement ➢ A.I.a)(1)(c)(i)(i) Health Care: Personal Care Attendants ➢ C.IV.a) Direct Care: Support	Karen Winer: Yes. Hello I am Karen Winer. I am a support staff person at Black Stone Valley. I have many things to say. I guess the first thing I will start off with is right now we are so short staffed. We can't get people to come work for us because of the starting wage. The people that do come in would be starting off at $8.50 an hour for the work we do. I have been here for almost 8 years and that's what I make, same as a new person coming in. And I don't think people realize what a crisis this is. We have many programs here. We keep accepting more people into our programs. And as I said, we do not have enough staff to cover the hours. I will give you a for instance. On any certain day, I work ten hours, and what I am responsible for is -- I pass meds out to individuals in the morning. If we happen to be short on that day, I might have to see two people in that one-hour span, where the person is allowed one hour. And this is how it goes throughout the day. Right now what we are doing, we are doing things that are really important, as far as people's food shopping, their laundry. Other hours are being lost because we don't have staff to fill it. You know, the state approves the plan for individuals. They receive a certain amount of hours. And they are not getting it. I really don't know how. I wish I had an answer how to get staff people. I have said to different people, we have been to the state talking to politicians, letting them know that we need more money. People really need to listen to this because right now it's affecting the whole agency. And who's suffering? The consumers are suffering. And what's happening? I hear a lot of people say that they are leaving because they just can't do this any more. For many of us have worked, you know, with low pay. But there comes a point where things start getting shut off. I have had my electric shut off. I have had my gas shut off. I am a single parent with five children. This isn't something I am proud of. But what am I going to do? Here I am. I don't want to lose the guys I work with. A lot of people here are working two jobs. You come to work. And you see that people aren't getting the things that are really important. We just started a program with two other ladies that it's 24 hours. Well, we didn't have a staff person. And the other night there was no one with them. Is that right? When the woman said it to me the next morning, she has to be mistaken. I called my director up and said, she told me no one came here last night. Is this what we are going to do? Just keep letting the people that are working -- lose out. Someone has to listen and someone has to help. You know we have -- for years we have been here at Black Stone Valley. The people who work here, people on the outside have no idea what we do. We don't. A lot of us just give our time. And we are not complaining. Yes. We have a shortage right now. Hopefully things will get better. But the people who work there they care. They really, really care. I am -- I also have a daughter who has a disability.

	And my daughter just turned 21. She graduated. And I don't have her in the program. I don't have her involved in anything with the state. And people think I am terrible, but I see what's going on here. And I don't want my daughter involved in this. I really don't. You know, if she received hours, what's going to happen? We don't have it. So her hours would be taken away to be given to someone else. And it's going on all over the place. And I think people have to listen. And there has to be more money given. The years -- I was always proud to live in Rhode Island and anything that came up, when there were bond issues. All of us know that the people of Rhode Island, they always approved bond issues for the people that we work for. People have heard the state employees make so much more money than us. Why? We do exactly the same. The people we work for become like family members to us. And we are here to speak for them. You know and people have to listen. If there's anything you can do, please. I am begging you, listen. Help us. That's all we want to continue. I
	Heard yesterday different people in my program saying, I can't do this any more. I can't. Some people haven't had days off for months.
	They're directors, and they haven't had time off. Yes, when we are out on strike, they worked real hard. But people need to be able to get time off. On my team, my director just cancelled her vacation. Why? Because we are so short staffed. Thank you.
	Paul Choquette: Thank you. Next? Is there anyone else who wishes to testify that has not -- okay. Well -- yes.
	Audience Member: Me.
	Paul Choquette: Give us your name.
➢ A.V.a)(1) Direct Care:Reimbursement	Pat Gormer: I am Pat Gormer. Most people, the short staff people. They help us. More staff people. Thank you.
	Paul Choquette: Anyone else?
➢ A.V.a)(1) Direct Care: Reimbursement	Christine Gagnon: Hi I am Christine Gagnon. I work for BVC. I will be very brief. I just wanted to mention I am a recent college graduate with two degrees, one under my belt. And I came to work at BVC close to graduation in the speech department with a very good Speech Pathologist. It is very difficult to be sure consumers are getting appropriate amount of therapy when I find myself needed out on the floor with the consumers to do basic care. I find myself working through the workshops every day and I notice short staffing and the need is so great. I enjoy my job very much and find it very rewarding. I didn't expect to get paid thousands of dollars for the first job out of college. And I have gained so much valuable experience in this job already. It's just been wonderful. However, it really truly is a need for more staffing. There is no way to ensure that our consumers are getting adequate amount of therapy when there's no one to carry through. Thanks.

Paul Choquette: Anyone else? Well, I think that -- we will wrap this up then. I would like to thank everyone who provided testimony. Everyone who came tonight. This is extremely valuable. This is something that, to hear from as many people as we did, it really helps us to prioritize things. And I think for myself, I know what one of our major priorities will be this year. And I would like to thank the people who provided their testimony. That will at least make that a priority for myself. And again, I invite people to stay involved. At the sign in table was a sheet, an info sheet of all of the agencies, state agencies and private, non-profit agencies that have sponsored these forums and the contact information. I urge you to keep in touch with us. Find out how we are doing on this. I know that -- what we are doing at the Governor's Commission will be taking this testimony, finding out not only from this site but the other sites across the state, and seeing what things are coming up as the most important things. We will be using those to address in the legislature as well as with the individual state agencies if it's something that we have done through policy. And again I would like to invite people to call us on that. Make sure we are following through on things. And again, just keep in contact with us. I would like to thank everyone for being here tonight and providing this testimony. And with that, we will close this hearing for this evening. Thank you very much.

G. *Public Hearing – Thursday August 23, 2001 5:30-7:30 PM, Newport Hospital, Newport*

- A.I.a)(1)(b)(i) Health Care: Prescription Medication

<u>Audience member</u>: Good evening, I'm please to meet you here at Newport hospital. When I became mentally ill it was after the Vietnam war and my best buddy got killed there and since then, I've haven't been doing the same I have was drinking and driving and one of the party I went to we hit a pole at 11 o'clock at night and we were trapped in a car and not found until the next morning and since then I came to the Newport hospital and I asked for help and they've helped me. I've kept a job I've had a half a business and the disability problem I have is the problem I have to keep a little job on myself just to keep myself on medication, anyway for me to get more insurance, so I can keep my medication and my dad died a year and a half ago, things have been going downhill since, I have to pay 500 a month for medication, that's one check right there and everything is working out well, but I have CHAPUS insurance and Medicaid and Medicare and I'm a -- they've helped. I did not now if I was going to live another day, but from that I've become really good friends with a lot of people and there's a lot of guys I see now that I have not seen in 10 years, we shake hands and go out and have coffee and the phoenix one club is one of the better ones that I've gone to. So I've really appreciated the employment job. We were playing cards; there were three of us, two workers and me we keep a can aside we could not spend on nothing but us. We used to play poker and whoever won would put a dollar in and then we would treat the whole floor to pizza. Dr. Quafame is my psychologist he sees me every 6 months every time he gives me such a feeling. I have not drank since 1978 or 1979 and if I ask me for marijuana I tell them "get out of here that rots your brain" from that I would like to thank this hospital, I thank all of you in the mental health field and that bus is excellent sir, RIPTA they come in handy. I take a bus four times a week, four days a week. I have no complaints, the insurance is good I would like a little more, I'll work for it, no RIPTA complaints, no hospital complaints at all, I thank god I'm still here. Every day I wake up I say "thank god my feet are on earth," all I have to say is thank you and keep up the good work.

	Mary Catherine Hess: Thank you very much. My apologies in my technical jitters, a couple of basic rules, we have around 15 witnesses tonight, so you'll get about five minutes each to speak. This is your opportunity to speak about your issues you have it is not an open discussion or debate it is your opportunity to for us to listen and take down your issues, the panelists may ask a clarifying question, but it is not an attempt to have a debate with anyone here, just be aware of that, okay.
	Mary Catherine Hess: The next person is Carol-Leigh Vaness.
➢ E.I.a) Health Care: Quality Care ➢ B.I.a) Health Care: Information re: Disabilities ➢ E.II.b)(6)(a) Accessibility: Physical ➢ B.V.b) Education: Special Education	Carol-Leigh Vaness: I'm pleased to meet you all. I never attended a public hearing for people with disabilities and their families. I'm from Connecticut I did sit on a board to advocate for people with disabilities. I'm here tonight because there have been a few things that I've noticed in my life and in other people's lives with disabilities from elderly to children. I just have a few things that I really want to bring out. Before I bring out my own issue I want to point out a couple of things that I've noticed that I'm very appalled at. I've been a state certificated CNA for 13 years. And I came up June 1 to Rhode Island. One of the things that I want to point out that I was very upset with. I tried to take a position as a CNA in two facilities in Rhode Island. I was very upset at the care that these people were getting. Some of them elderly, some of them people with disabilities and the response that I was getting back. I was very disgusted and appalled by this. The other thing that I wanted to bring up is that I have a child that has Asperger's syndrome. He has a neurological impairment. Neuropsych impairment that's undetected at this point. On June 5, I swept into the Warren school department to let them know that I was here and my son needed services. We went through a lot with these people they did not acknowledge my child's rights or disabilities. On State Street it is not wheelchair or handicapped accessible. My son could not come up those stairs because he has had a lot of problems with his legs. I did go to get some advocacy for him and I don't want to get too much into this, but I want to point out that we were basically; I was basically told that I was to put him in a certain school period. His needs were not addressed at the fact what his diagnosis were that I had brought with me from doctors and I'm very upset and disgusted by it. I've had a lot of this -- I'm ready to contact the governor at this point. He's extremely talented in art and music. It is just the fact that it feels like nobody wanted to deal with it and that it was a cost issue. I was willing to work with these people. It just makes me feel good to be able to come here and have people understand me, then on the other side of it, after 13 years back to the other thing that I just wanted to cover, I quit working in facilities quite recently because I do not agree with the way things are happening in these facilities. I probably will further -- I work in a group home right now and it is wonderful. I still can't help feeling compelled to do something for these people in facilities. I've taken an interested in disability law and hopefully when I am able to take care of my child I'm going to look into that disability law.
	Panel member: Can you tell me what the problems are in the facilities? What kind of care problem?

➢ E.I.a) Health Care: Quality Care	Carol-Leigh Vaness: Dirt the filth. We had a man with both legs amputated and we had EMT workers come in and they said "did you put the lift sheet under his body properly" and he said, "You had better. And I looked at him and I said "you had better treat him right. I was appalled. And the fact of an elderly person wanting to go out of their room at 2:30 and it was 2:15 and they stopped here. And said "that activity has not started yet and I said to that person "but she wants to come out of her room" and the first thing out of her room is "it is so nice to see people out here in the hallway" it is degrading and their rights are being violated. There needs to be some things done about this. I also understand that there are a lot of good things in Rhode Island and wonderful things but there are some issues that really need to come out and I felt that I needed to come here and say this as someone that worked as a CNA for 13 years and I know there are funding and money issues and CNA's not getting paid enough, but there are a lot of different levels that need to be worked on. I'm very disgusted, very upset. After 13 years of saying -- I even had the person from the facility call me this week "are you coming in Saturday" and I told them I will not be back I told them that I cannot work in these conditions. It is horrible. I still feel like something else needs to be done. I will be calling the state on them. On both of the facilities. And I will give the state the names of both facilities. I'm trying to balance and handle two things at once. A caregiver and a parent with a disabled child. It makes it difficult at balancing that out. I'm good at that I'm good at advocacy. Coming into Rhode Island and seeing this right in the face it was pretty hard. As far as my child on his behalf, I've filed a complaint with the state board of education; they failed to at first give me a meeting. After I filed the complaint. They formed a team very quickly, but I noticed what happened today I have documents that have been tampered with, I'm used to that happening. So I have to further my complaint with the state on that. I felt that I needed to come out here and say something. And get the governor's number and thing like that and get out there and make sure things get done it takes more than one person to get started. I've noticed there's a lot of places that are not wheelchair accessible to people. I mentioned it at this one building that I went to and the answer was "oh" thanks.
	Mary Catherine Hess: Thank you very much, the next person I have on this sheet unfortunately no one checked off who wanted to speak. Craig Enos. At the end we'll ask the panelists if they have anything. Caramel La Russo would you like to speak? I'll bring this microphone back to you.
➢ E.II.b)(1)(a) Accessibility: Physical	Caramel La Russo: My problem is the handicapped parking at the newly built or recently built, a few years ago at the CVS parking lot in Bristol Rhode Island. Ten months ago I wrote to Mr. Ryan the CEO of CVS. He referred my letter to a Mr. Boyce and there is the reply this was in November. "Dear Mrs. Russo, thank you for your letter, Tom Ryan has asked me to address your comments about the handicapped parking. We appreciate the time you took to -- as CVS customer input plays an important role in our decision-making, therefore I will make sure that the construction department is made aware of your comments regarding the

comments. We'll take your questions into question. Thank you for your input we value your patronage and value you. " I waited a few weeks and I never got a reply from them. So I wrote to her again and asked her "what the construction department did about my suggestions? " until today I never received a reply. I wrote to Mr. Ryan again and until today I never heard from him. I contacted the Governor's Commission on Handicapped and I was put into charge with Harvey Salvas. His remark is: the first time I called him he said nothing was wrong. I conveyed the problems to him and he said he would look into it. The second time he told me the manager was not in. I called him many times I always had to call him he never called me with any results. This is very frustrating but I was beginning to feel like a pest. I told him I would meet him at CVS to show him the problem a handicapped person has. It should be at the entrance of the building. Especially with the design of this building. Not at the end the building. Also it is built in a shopping area it has an island in the center. And if you try to go down the ramp, which at the end the building with purchases in the carriage, you almost run into the island, where cars are entering and exiting. It is a very dangerous situation. He said he brought someone else with him to evaluate the condition and nothing can be done. He suggested that I go to the Warren CVS to shop. In this world nothing is impossible. This condition must be corrected even though minor repair construction has to be done. You can put two handicapped parking spaces in front of that door. Make the curbing and a handicapped person can go right in. I'm not criticizing CVS but they give millions of dollars for charitable organizations and that's great but they should take care of the handicapped-parking situation at the store. Now I know that the governor's commission for the handicapped, where can I go next? He said "to the department of justice" now if I have to go there I will, there's no reason why something cannot be done, why should they cannot get away with this? People like us cannot go in there to shop. Thank you.

Mary Catherine Hess: Thank you very much. Representative Bruce Long? Would you like to speak this evening?

Bruce Long: My name is Bruce Long and I’m a state representative in Middletown, I represent district 95 I’m here tonight because I’m interested in what you folks have to say. I've served in the legislature for over 20 years as I hear the complaint from the lady from Bristol, there should be something that government ought to be able to do to correct that situation. If it cannot be done administratively then it should be done legislatively. Senator Gibbs is here as well. When we leave here is there going to be a transcript.

Mary Catherine Hess: There will be -- there's a transcript where they will compile all of the information and putting together and figure out what the different common threads are.

Audience member: I’m not taking notes I’m listening and I intend to review the comments that are made here and take some take of action on behalf of your folks. Anybody can become handicapped at any time at all. It is up to the private sector to do their share and up to government to make sure that that happens. So I’m here to listen and I’m going to be here at the end if you have any questions of me. I will be available to work any of you folks afterwards. Thank you.

Mary Catherine Hess: Thank you very much. The last person I have, I have a question mark next to whether or not they want to speak. Nini -- would you like to speak?

Nini: yes. This is weird having my back to the crowd here this is strange. Sorry folks. I want to speak because I just came from Connecticut, too like the other lady and moved here in April and I’m disabled I’m on Social Security Disability which is my only source of income and right now I’m sleeping on my parent's couch, basically, it is not a good situation it is not healthy and it is overcrowded and I love my folks but taking over someone's living room is not a great thing. I'm basically homeless. The housing situation. There does not seem to be any priority for disabled people or for people that are homeless to get into appropriate housing. Newport Housing Authority I’m told has a two-year waiting list because they also have regular low-income people, elderly and they have disabled people. There's no priority for anybody with special circumstances. I have not been able to locate any legal help. I was making all sorts of phone calls to try and find somebody that can help me. They do not want to allow me to on the waiting list because of something that happened and I explain why I felt it was not justified and they want to have this hearing and I have to try and find people to come and support me but I’m trying to get legal help to I know exactly what the rules are and maybe I can walk in with a lawyer at least a paralegal to have somebody speak for me better than I could speak for myself. Another problem, I took three months to get a parking permit, in Connecticut I had to get a letter from my doctor and walked up to the counter with five dollars in my hand. Here it took my three months they questioned my doctor they did not believe him and they wanted all of my MRI reports for the last year or two years and I had to get them all from out of state and send them up to them and then they only meet once or twice a week and then they sent me a one year permanent. So for 3 months not be able to park in any of these handicapped spots that are at the end of the buildings and most frequently they are filled up with people who are not handicapped. That happened to me at Cumberland Farms. I have seen with the handicapped spots are not there. I have to go down by century parking lot. You know where that's is at the bottom of Washington Square I have to go to a building down there every day and there's no place to park it is jam packed full of people and there's no handicap parking around that there. There's only place is lower Broadway and that's too far away from me. I live on Anadale road and today I got my very own handicapped parking space on my street because the people from New Jersey or New York were all parking on my street and I had to walk blocks to get to my own home. At least I was able to find someone to help me do that in all of the other places I have the same problem that the lady has. Taking 3 months to get a permit is ridiculous. Medical is another problem. The guidelines for income are totally unrealistic with today's cost of living. You have to make less than $625 a month in order to get Rhode

- ➢ A.IV.b)(1) Housing
- ➢ C.II.b)(1) Transportation: Disability Parking
- ➢ C.II.b)(4) Transportation: Disability Parking
- ➢ E.II.b)(3)(a) Accessibility: Parking
- ➢ E.II.b)(3)(b) Accessibility: Parking
- ➢ A.III.a)(1)(a)(iv)(a) Employment: Medicaid

➢ A.I.a)(1)(a)(i) Health Care: Medicaid	Island Medicaid state assistance and that covers prescriptions I have a few hundred dollars in prescriptions. After next month I will only have Medicaid or Medicare. The first two years I had no insurance and they want me to make a $1,500 spend down every 6 months, people who are working do not have to pay that I'm disabled and I get $935 a month. On top of that they take $50 out more Medicaid, 100 deductible to boot and 20% of everything. Disabled people have much higher medical bills and prescription needs and there's no way to get those needs met. Connecticut has a comp pay. There's no program here I've been able to find. Human services I found out that I'm entitled to get part of that $50 back, but 3 bucks is a lot of money to me at this stage. The lady who works there did not even bother to tell me I was eligible I found out from somebody else I've had to hunt, peck and find. People make me feel like dirt, less than a human being and it is terrible the way that they treat you and look down on you. I need help for medication, medical help, I need legal help, and I need help with housing. I'm not eligible for any kind of assistance or food; I do not make enough money to live on. Even if I get the housing I calculate expenses and with my expenses I'm 2 or 3 hundred dollars in the hole and that's eating peanut butter and crackers and I've car that's worth about $300. I would like to find out if there are issues. Am I suppose to be homeless for two years, sleep on a couch for two years, I do not think it is fair. And I don't think it is fair that we don't have the medical help that we need and the parking issues. That's most of the things that I can think of right now. I appreciate your listening and I hope that there's somebody out there that can do something to lower the wage standard that the state of Rhode Island and many other associations use in order to get help. There are a lot of people out there if you make less than $625 a month that's well below poverty. I think people who make what little bit we are able to get back from what we paid into working, at who I became disabled, I worked all of life since I was 15 and now I'm being treated like dirt and I don't like it.
	Panel member: Thank you.
	Mary Catherine Hess: thank you very much. The next person we have listed to speak is Georgette Swan.
➢ B.I.i) Health Care: Information on Services ➢ C.VII.a)(3) Legal Services ➢ A.IV.a)(1) Housing: Community Based Options	Georgette Swan: Hi, I've been a teacher and worked with handicapped children and been a social worker but that was a long time ago, due to my disabilities I would like to just list some issues that I have jotted down. One is the lack of help advocacy, when you call agencies. I have been through so much trying to get help. Like you need a full-time secretary who knows all of the secrets to do this. I learned a little bit before at work. Legal help was another one. I heard people mention. There's not a lot of help for people with low income. It is not like we asked to be disabled. I think it is great that they are doing a lot for the elderly, but every time they mention things they do for the elderly I'm glad but wish they would do for more the handicapped. One is handicapped housing, another one is support groups and not for just the different diseases but all of the muscular diseases such that I have and maybe something where handicap people can meet together as a whole, anyone who has a handicap, more information on resources, so

➢ A.I.a)(1)(a)(i) Health Care: Income Eligibility ➢ A.II.a)(2)(a)(ii) Transportation: RIPTA/RIde ➢ E.II.b)(2)(a) Accessibility: Disability Parking ➢ B.I.h) Health Care: Quality of Care	we don't have to spend days and days on the phone trying to resolve issues and get help. More help with medical, with doctors, dentists, medical supplies, the income is just too low for handicap people. We have needs that are much greater than people who receive other kinds of help and I know the elderly have a lot of expenses too, but we have a lot of medical and doctor bills, Social Security does not cover enough and when I did not work for a number of years, I'm only able to get Social Security Insurance not Social Security Disability so that you would only get $100 a week. In my situation my husband makes just enough where I cannot get that. Transportation is a big problem. When you can't really stand and wait at a bus stop. Where we live, we live in Narragansett; they make it so you have to call two days ahead to get to the regular bus stop because they've moved them so much. It is hard to get to doctor's appointments, if you cannot get a ride. We have a big problem with handicapped parking in the summer and I imagine you would have the same problem here on the island. A lot of people come from other places and we cannot get handicapped parking if we live in the area and want to go shopping. Our family has a rare muscular. We've gone through years of going through the system of doctors an have doctors discriminate against us saying it is psychological and actually been turned, one of my children, well they are all 18 and over, they were turned away from an MRI when they had an appointment because one doctor talked to another and said "get out of here there's nothing wrong with you" I went to doctors in Boston and I have multiple problems with my nerves, we all have problems to some extent. I have a lot of problems my whole spinal cord is not working properly, I have multiple problems, to have to deal with doctors that don't want to deal with you because you have a lot of problems or they do not know what is wrong so they say it is psychological and go through the pain and suffering and have to wait so long until your symptoms get so bad that either things show up in tests or that you get so bad physically that's just not fair. I think there's a lot of thing especially muscular diseases. There are a lot of cracks in the system. I don't know what the answers are, but I know what the problems are. I think a lot of the answers that people need to people together and advocate for each other and people need to be more aware of handicap problems and needs. It is really frustrating, I was always an advocate for handicap people but I never thought I would be so handicap also. Thank you.
	<u>Mary Catherine Hess</u>: I'm looking at the time and I'm going to do two-minute witnesses then a five or ten minute break and then come back and regroup. The next person I have is Joseph Guay.
➢ C.II.b)(1) Transportation: Disability Parking	<u>Joseph Guay:</u> Hi Annette, I know her. I also now Ernie from sailing. He's one of my sailing partners. Anyways, I've been paralyzed over 21 years from a spinal cord injury from an accident. When I first got hurt I used to park in handicapped spaces, I used to get yelled at. I guess because I was much younger they thought I was not disabled until they saw me unloading the wheelchair from the car. Then they would calm down. Since then, I've notice the requirements have loosened up, I see a lot more people who are ambulatory and they do qualify and there's nothing wrong with that but I'm

	here to ask the panel to request that they require doctors to tighten up because I feel that too many people are getting these handicapped placards I've seen people park in the city and sprint across the street when they got out of their car with a placard. I know a guy personally, who has one, and he does not have a disability. He has urinary problems but nothing related to the spinal cord, he asked his doctor and they gave him one. I've seen people walk into Wal-Mart and shop around and these stores are over 100,000 square feet and they are walking around the whole store I do not know what their limitations are, apparently they qualify for placards. I know of one person that got it because he was depressed, the doctor gave him one. I hope you guys can do something to tighten up on that.
	Audience member: It has already been done.
	Audience member: If it were I would not be here.
➢ E.II.c)(1)(b) Accessibility: Physical	Joseph Guay: Also, another issue, getting back to the stores and the places that people have mentioned that are not accessible. Part of the reason is because I was just informed of this and my friend is an architect. He told me that the building inspectors they are not required, they overlook these accessibility issues because they are not required by law to enforce them so maybe we could have that looked into or tightened up as well. That's all I have to say, thank you.
	Audience member: I'm not on the list to speak but I'm from the Rhode Island Council on the Handicapped.
	Mary Catherine Hess: The next person I have is Betty Harrison. Is that someone who wanted to speak this evening? After Betty we'll go ahead and take a break.
➢ C.I.h) Health Care: Community Based Options ➢ D.I.a) Health Care: Homebound ➢ A.I.a)(1)(c)(i)(a) Health Care: Respite/Home Care Services	Betty Harrison: I'm a single mother of three children and my youngest son has multiple disabilities. He now gets services, support services and I mainly just want to express the need for these support services to continue for him, but also to be -- you pretty much have to jump through hoops to get these support services. He has autism. He has this mind that works really well and he has a body that works really well, but whatever it is that connects the two there's a total breakdown. He's so -- he does not even know that if he's cold he should pull the covers up. He has a lot of eating restrictions. It takes him 45 minutes to eat 12 ounces of food and he needs constant reminders to take another bite. He has no concept of what his body needs in order to survive. He needs constant reminders to go to the bathroom, to eat, he can't go out of the house on his own. He can't be left alone for any amount of time. The support services that he has received are what have enabled Eric to remain living at home because he would not be able to stay at home with just me taking care of him it is physically impossible for somebody without support to take care of somebody with this many needs. So I basically just wanted to let you know how important these services are and how important it is to keep them going. The respite services the hbs, every 6 months we have to go through a process and a new proposal has to be written.
	Bill Inlow: Could you tell us what that means?

Betty Harrison: Home-based treatment services. He gets 35 hours a week of house-based treatment services. He's 17 years old now. He has been getting these services for three years and it has taken three years to teach him with probably 3 or 4 people every week working on this to learn how to pick up a spoon and actually bring it to his own mouth. Physically he's able, but the connection is not there. To actually go into the bathroom on his own and do everything he's suppose to do. You still have to stand at the door and give the verbal prompts. Every single skill that it takes to live he needs reminders. So I just want you to know how important these support services are in order to keep people in their own homes, thank you.

Mary Catherine Hess: Hello. Okay, if we can ask people to go ahead and come back in and go ahead and regroup. If you see anybody out there can you wave them on in.

Audience member: Can I ask you a question? Is this meeting -- this is a meeting place?

Mary Catherine Hess: This is an event for individuals with disabilities and their families to discuss any issues or concerns that they may have. Do you have any issues or concerns that you would like to raise?

Audience member: yes, I would. I feel like --

Mary Catherine Hess: Dora Bliss. Just so everybody is aware we have about 5 to 7 minutes for each person henceforth. Just speak into the microphone whatever issues you would like to raise.

Audience member: The issue is Social Security. The average person gets what 4 or 5 for social security.

Mary Catherine Hess: Actually we are asking people just to voice their concerns it is not a question and answer session.

Audience member: See that's had and I want to find out.

Mary Catherine Hess: The purpose of this evening is for you to just tell us what issues you have and we are going to actually -- we are taking this information in, it is not a question and answer it is not a dialogue.

Audience member: I'll let them speak if there's time at the end maybe I'll understand it better and come back.

Mary Catherine Hess: You might at the end if somebody is around for a few minutes that can answer questions for you that might be a possibility as well.

Audience member: Can I keep this until the end?

Mary Catherine Hess: Yes. Thank you very much. Okay, Bill we'll save you until the end. It is another name that I'm not going to pronounce correctly. Annette -- we are going to hold you off until the end. How about George Levesque --

Audience member: he left.

Mary Catherine Hess: Judith M. Wardell. Would you like to come up and

	speak? Thank you.
➢ C.II.c)(1) Transportation: Warning Signs	Judith M. Wardell: Yes, I wrote a letter. I saw Nancy at a meeting and I was telling her about the trouble we are having trying to get signs -- deaf signs being put up. We live on a terrible hill that you can only see what is coming from your right side, what is coming from the left you cannot see. Two busses have almost gotten hit to get to our house to pick him up because they pick him up right at the house. We have been to the town council and the Little Compton. The town council did not do much of anything at all. We went to the police and they've been no help. We've contacted Senator Enos from Tiverton. We were told that half of the town wants it and half the town does not want it. Yet wherever you go you see signs up for people who are deaf. Children or whatever. So Nancy suggested that I come here and see what you could do in order to get us some signs, I do not see what harm they will do. It is right on a bad hill. We've been trying for the last three years to put signs up. We were thinking about doing it ourselves but I do not know if it would be legal or not. It is a very bad place. We would like to see or eventually try and get signs. They've put up school bus stop signs and they are still going up to 70 miles an hour or more. The cops have promised us that they would be monitored but we've seen nothing. We would like to see some signs put up for the little boy.
	Gavin Fitzgerald: Would you remain at the end of the meeting and I'll talk to you. I'll get some more information.
	Judith M. Wardell: Okay, thanks.
	Mary Catherine Hess: Margaret Brigno, would you like to speak?
➢ C.II.b)(1) Transportation: Disability Parking ➢ A.I.a)(1)(a)(vii) Health Care: Substance Abuse	Margaret Brigno: I really came here with no issues and was not planning to speak. I just wanted to commend you for all of the things that are available. The handicapped parking, although it is not perfect it is still available. Many of the stores have motorized carts, which allows me to be somewhat independent. The services that are available. I have a son who is a drug addict and he has gotten very good help and has been able to go into rehab because of the state's ability to help him. I've been very pleased with the independence that all of your work has allowed me to have. Thank you.
	Mary Catherine Hess: George Levesque.
➢ A.V.a)(1) Direct Care: Reimbursement Rate	George Levesque: I'm glad I'm back, too. I don't know if when you introduced me if you said I was from the Mahar Center, I'm here to listen for the Mahar Center, what my testimony is my own, and it involves just a number of things that I've witnessed in and would like to testify. I used to be part of the problem because I was a state representative for a number of years. And a lot of these problems I personally feel can be solved with money. It is a small piece of pie. And everybody has got their hand out, and everybody has to balance their budgets, and I think that in some instances this community gets left high and dry. Not necessarily on the services provided, but if we are not willing to pay a decent living wage to the people who service this community then it is hard to get good people

and keep good people in the area. I lived through four budgets and I know the pressures that are on at various times. We increase the reimbursement rates this year by 3.8% for people in the developmental disabled area. Which is basically what people got for pay raises. I never did like percentage pay raises because mainly I was always been at the low epidemic of a salary structure so 3% of $10,000 is a lot less than 3% of $100,000. I think we should be looking at in terms of raising it on the lower end and modifying it at the higher end. To the woman who was looking for legal counsel at 50 Washington Square in Newport there is a Legal Services office I would think that she can go down there and qualify for legal services in dealing with the housing authority. I serve on the housing authority with Gavin in Jamestown and I understand some of the problems that arise from some of those situations, too. A number of years ago, when the head of the Department of Administration, Robert Carl, was then at MHRH, I'm going to give Rhode Island a slight pat on the back. We instituted the move to close down Ladd School in the state. Which was probably the most foresighted program for the developmentally disabled and what we have done since then in that field in terms of people and putting people into the community allowing them to be productive members of society is nothing short of a miracle. We set up a two-tiered system when we did that. Basically, we have the state on one side and private, non-profit agencies on the other side and the state takes care of its own fairly well and the private non-profit agencies not as well. There has been a change in the world. There is not as much volunteer work as there used to be. People especially women; want to be paid for their work. Understandably, there was a time when people would do a lot of volunteer work and sometimes I think in these agencies even though they are getting paid it is basically volunteer work. It is love of the job. And love of working with the people. We have a great problem and maybe this will address it somewhat. We have a problem with communication and we have a problem with redundancies and loopholes. If I could suggest any one thing to someone is to have a centralized location, possibly a number of them throughout the state even if they were only open one day a week where a person could go with any form of disability, they could go and get a clear understanding of what is available within that community to help them so that they can get help and have people knowledgeable manning these positions. I cannot tell you the number of times that dealing with state government that I've called someone that's suppose to know what they are talking about and I have to go do the research and go back and tell them what their job should be. And that should not happen. I'm a person who spent a lot of time with the law and dealing with the law and creating legislation and I do not know that the average citizen is going to have the temerity have and the obnoxiousness that I have to go out and basically tell someone in the state what they should be doing. We should have people trained that know what they are doing and we should have an open-line of communication for this. I would just like to address rather quickly, the woman with the handicapped-parking situation. Just very quickly. It is a local issue and people have to get to their zoning boards and tell them "it has become convenient to save a couple of thousand dollars to put the

- B.I.i) Health Care: Information on Services

- C.II.b)(2) Transportation: Disability Parking

	handicapped access at the end the buildings" those plans get approved by the zoning board. If a zoning board in a town puts an ordinance that says "we want them in front of the doors" then all new construction will put them in front of doors. As long as zoning boards are approving the construction and the handicapped parking spaces are at the end the buildings, it will not happen. Thank you very much for your time.
	Mary Catherine Hess: Thank you. Thank you very much. The next person I have listed is a Michael Swan. Forgive me for saying this again. I have 7 more people; I want to keep it to that.
➢ A.IV.b)(1) Housing ➢ B.V.b) Education: Higher Education	Michael Swan: First I wanted, this is the first time I've been here so I do not really know all about this, but it sounds pretty neat I thank you all for being here. My concerns are: like a lot of other people's concerns. Transportation is one that came to my mind. RIPTA goes here and there and everything but it seems that that is a difficult thing to stand and wait and call. I should have written down what I came up here for, my real concerns are the housing and the medical. First of all, I don't know why they do not put handicap or disabled people at the list on housing when they are the ones having all of these problems it is much more difficult for them to live in other peoples homes or live in shelters, people who are healthy but don't make a lot of money but they deal with it better physically and mentally. Also, I don't know why but I have been back and forth from the state of Connecticut. I do not know why Rhode Island does not cover some things that Connecticut does. There are budget concerns and that brings me to other concerns about why does the Rhode Island government already have in their budget take out plans to renovate things or spent millions dollars up in Providence or do this to URI, instead of paying that debt off and rather help somebody who is disabled they get into more debt so there's going to be less money for these people. It does not make sense. It seems like there's a clear way out of it and it does not seem like they care. Education also, that goes right into that point the education is very important. Myself and I'm 26 years old. Ed I've had health problems my whole life. I'm wondering how if I'm not able to get an education, I will not be able to pay the loans off. I will have to deal with that. That does affect me. I know the solutions around that, but those are the concerns that I have. I don't know if I should talk specifically on the concerns.
	Mary Catherine Hess: Anybody have any questions to clarify?
	Michael Swan: I think that anyone on the panel that are helping disabled people, for that matter anyone that's not disabled and cannot afford it, they need help with housing, education and transportation. There was something else I wanted to say. If I don't think of it I will go.
	Panel member: You mentioned medical.
➢ A.I.a)(1)(b)(ii) HealthCare:Access	Michael Swan: Medical concerns I have a problem where because of my health problems my back slips out a lot. My joints like to move around and I have to go to physical therapist and chiropractor, someone like me who absolutely needs it, does not get it in Rhode Island. I was just in a

	shelter not too long ago; I've been back and forth between my parents, friends and shelters. -- I forgot what I was saying. That's part of my neurological problem I forget what I'm saying. They do not cover as much in Rhode Island I wonder why. When all of this money that they are spending on all of these other things and they keep getting raises themselves, why do they not want to help people. I know of a situation, there's one story. This woman had a problem with her back for a long time. She had a minor problem it was very minor, so they just adjusted her back and she never had headaches after that, for someone who really needs that, 3 times a week if I do not get it I'm in bed, I'm pretty much entirely bed ridden because I have so many pinched nerves and muscle spasms that I cannot move. I'm concerned about myself and other people. I hope I have not taken up too much time. Those are my concerns I hope you guys can do something with that. Hopefully I'll be back and be able to help out in some way.
	Mary Catherine Hess: Thank you. For all of the money in the world that you spend on technology it is the basic things that fall apart. Okay, the next person I have on the list and I think I covered this person earlier and they were not going to speak but Beth, okay, Patty -- okay, and I have a name that I cannot read very clearly. LaVonn -- Would you like to speak?
➢ B.V.a) Education: Higher Education ➢ B.III.d)(1) Employment: Awareness	LaVonn: Yes. All right, I'm supposed to be in college. I was at one time a volunteer nurse's aide when I was a teenager; I wanted to become a doctor. I got into engineering and art and many, many other things and I would like to get on the right track again where I can start learning to help people instead of being dependent. And I've had doctors tell me I have a ruptured disc, I do not believe it. Then they pulled all of my teeth out and I have had several embarrassing moments with this incontinence, since I've had my teeth pulled out. I want to get back on the right track again; I was a pin striper probably in this hospital.
	Mary Catherine Hess: is there a particular issue that they need to look into? Something that they can take back with them. Anything specifically that you want them to look into. Is it an education issue?
➢ A.II.a)(2)(a) Transportation	LaVonn: money for education and transportation. Basically, that's the two things that I'm interested in.
	Craig Enos: If I can talk to you when we are through I would like to talk to you more. Thank you.
	LaVonn: okay.
	Mary Catherine Hess: the next person is Robert Perrillo.
	Bob Perrillo: I do not have anything to say I would like to respond to some of what these other people.
	Mary Catherine Hess: let me get to the last people to testify and if we can ask -v that discussion at the end the John Racofsky.
	John Racofsky: okay, I should probably clarify that I did not really come to testify so much as to listen. I'm going to take a brief amount of time, just

	mention the fact that I'm here from the Eleanor Slater Hospital. It is the state's long-term care facility. Certainly, I have heard a lot of the things that have been said so far relative to needs and sensitivity from the individuals in nursing homes or hospitals, I will take that information back to the hospital. Essentially, I'm a listener rather than someone who is here to make a lot of comments. I was in Slater hospital for three years.
	Mary Catherine Hess: Thank you very much. The next person I have on my list is Ernie Savastano. Do you want to speak this evening, sir?
➢ A.I.b)(1)(c) Health Care: Prosthetics ➢ A.I.b)(2) Health Care: Licensing of Prosthetics ➢ A.I.a)(1)(b)(ii) Health Care: Access	Ernie Savastano: Yes. Hi folks. I'll be brief. My issue is with people who make prosthetics for amputees. Sometimes it takes years and years to find a person who makes a good fit and to keep that relationship with the person that makes the prosthesis can be a difficult thing for an amputee because of insurance purposes. I would like to see legislation making insurance companies actually follow the person or actually allow the person who makes the good fit for them. The second issue is I found out that people who make prosthetics are not licensed and I believe that the department of health should have a qualification for certification. That brings me to my third issue. Health insurance should be for everybody in the state not just for the certain few who have to qualify for it. People with disabilities have to jump through hoops to get health insurance, so I would like the commission to work towards a universal health insurance in the state.
	Gavin Fitzgerald: Are you familiar with any other states having licensing procedure?
	Ernie Savastano: There are and I'm sure we can find that out and form legislation.
	Mary Catherine Hess: Thank you. Are there any more names that have been added? We are down to our last page. We have three people left that are listed and if any of the panelists would like to come up and then close out and we have about 17 minutes left. Let's see here. Georgette Swan.
➢ A.VI.b)(2) Accessibility: Physical ➢ A.I.b)(1)(a) Health Care: Eyeglasses	Georgette Swan: I want to mention the heavy doors; it is hard for us to open. It would be nice if more places had those buttons to push. And the other thing is agencies that will not help you if you do not have insurance, like for eyeglasses I have 5% coverage and they will not help me to pay the rest.
	Mary Catherine Hess: The next person I have here is Kathleen Collins. I see you are on the carbon copy.
➢ C.I. Health Care: Security/Housing	Kathleen Collins: I live in a disability apartment building and some of the concerns for the people in the building are security for one. We have a security building, the locks on the doors, such a visitors going out because their hold lives they've been told to hold a door for a lady they let anybody in. They hold the door for anyone. We do not have the finances to get the recorded camera to help with incidences in the building. Security is a big issue help with that would be wonderful. Another issue is helping the managers of building. Tenants in my building had a number of meetings begging the managers to evict certain people that have drug problems that

are tenants that are pains in the -- they are a problem. Managers are unable to do it because of the ways that the laws are set up. In other words, we end up having to put up with a lot of whether it be police, rescue, whatever. It interrupts your living, your nights, your days, managers don't -- they can't do anything. There were three things I cannot remember the third because I’m nervous. I know what it was. I had a neighbor for a long time that we had a lot of problems with if you get a person that's violent, it takes a lot to get that person -- another thing with the management, you are not living safely because your neighbor is a -- I don't want to say a mental health patient but a person with big violent tendencies. I actually have a question as to how they get into the buildings they pass checks even though they went after a manager in other building with a knife and was court ordered out of the building we get them as neighbors even though they pass the VCI checks, I would like to see people safe and secure in their units and able to walk the halls whether it be day or night and not have people who -- and also not to have neighbors that are unsafe to them, make sure living unsafe.

Gavin Fitzgerald: Who is your landlord?

Kathleen Collins: I man in Boston. Shockette, the management cooperation -- he has two jobs. It is done through HUD but Shockette has to do with it. For two years we've been asking our manager for the recording equipment.

Gavin Fitzgerald: Recording equipment by law is required in places for the elderly. The Department of Elderly Affairs.

Kathleen Collins: What it is both handicapped and elderly.

Bill Inlow: I’m going to follow that up. We'll follow that up.

Mary Catherine Hess: okay, any of the panelists would you like to provide any testimony to go on record tonight. Anyone? Takers?

Bill Inlow: Anyone else from the audience be interested in testifying this evening.

Audience member: all right.

Mary Catherine Hess: This will be the last person I believe then we'll wrap up.

Dora Bliss: The situation is better than when I went there. The problem is something that I know nothing about. I'm trying to find out. When I first went there it was kind of hard. I went from Green Lane, sometimes I forget deep down, sometimes I cannot remember all the way up. We have solved our problems if we talk. You know, Rhode Island and Newport still Rhode Island and our sister city is Providence, I think Governor Cianci is one of the greatest men, he gave up -- I should not say that, he made a city. How many can do that? We look around, if we do our work god gives us something, sometimes we can go to sleep and forget it. We always have some. I always liked Newport. I come from providence. I used to come here when I was 17 with my boyfriend. I would like somebody to give me some information. Where was Hurley's at? Anybody know?

Mary Catherine Hess: I don't know, but I think is there a specific issue that you want to raise that's concern.

Dora Bliss: I'm raising it because I'm the guilty partner. I learn to take the news while I have dreams. You can't jump out of a cab into an elevator unless you get an automatic shotgun and go down to the water front. People do not believe what they see. Some people see too much. If they are going to fry me like they fried my mother they are not going to fry me. I don't care, I shouldn't say that, see that, but we all are. Do you see, (singing) I don't know answer my door after dark not even for my family, but I will once in a while to break up the monotony and the buzzer business and these new things grabbing us for the money. I got so I don't even want to go to the store to do grocery shopping. I know I -- we'll take one day at a time. We all get plenty of time. Where else can you go get your supper, breakfast and dinner god blesses a child.

Mary Catherine Hess: Was there anyone else in the audience that wanted to say anything before we wrap up here?

Audience member: I would like to see people get together more and discuss these issues and not just drop this and get a lot of things done.

Doreen McConaghy: My name is Doreen and I'm here representing the Governor's Commission on Disabilities. Part of our job on the commission is to on an annual basis go out and listen to John Q. Public and find out what your concerns are. Put that camera away! (Laughing)

We have a commission of 20 and 30 people present a package that we want to support and work toward in the legislature. All of these comments here and the comments that we are getting from the other seven hearings that have been happening this week will all be recorded. They are all going to end up in a public document. We are somehow going to go through it and identify significant issues that people have raised and work on that throughout the legislative upcoming session. So this was not to get everybody else, so you would have no dinner or a late dinner. We are listening and recording the information and everybody is going to know what happened. Okay.

Audience member: Can we write to you if we want to give you more details?

Doreen McConaghy: Yes, you can write to us and you can go on our website. A lot of you are here because you got notification from other agencies and organizations, this is an enormous collaborative effort on the part of many, many organizations who donate thousands of dollars to provide this kind of support at every single public hearing. Do you have a pen? You know what. We have this. The website if you want it.

Mary Catherine Hess: Okay, we have one of the panelists who would like to say a couple of things.

- E.II.c)(1)(c) Accessibility: Physical
- E.II.b)(3)(c) Accessibility: Disability Parking

Annette: Hi, I want to echo some of the problems that some have brought up. Accessibility to buildings both public and private is often an issue and you know somebody will say, we'll come out and get you, but you cannot get in there to tell them to come out. So that's a problem. Parking, handicap parking is a major issue. Both with its enforcement and with placement. I know I've talked with the city of Newport about their new handicapped parking places over on Broadway across from the city hall where most people who use a wheelchair use a van or otherwise get out of their car on the passenger side where the handicapped parking place is. That's impossible. So people have to understand that just placing the sign there is not adequate. I think our biggest barrier is the attitude one, where when you try to get things done. You are looked at like you have two heads and that's the biggest barrier that we all have and hopefully thing like this. Events like this will start changing that. Those are my comments.

Mary Catherine Hess: We have one more person and that will be our last comment. Just speak up.

Audience member: I'm young I'm 26, on a better day I might not be using my cane and you might think I'm healthy and fine I have serious health problems, my doctors say "you are so young, why do you have these problems" and I say babies are young to have cancer, it does not matter what age. And there's something else that I forgot.

Bill Inlow: Keep thinking if you remember jump up. I want to tell you how much I admire each and every one that came up to testify. It is not easy to come up and talk in front of a microphone especially if your words are up here, too. I want to assure you we listen very sincerely and we'll respond to the issues you retzius and I want to express my personal appreciation to you.

Audience member: Is there a mailing list or way we can get numbers or addresses for someone to get back to us by mail or phone.

Mary Catherine Hess: I think it is going to be a public record and analyzed, I do not know if they will be addressing individual concerns, they will not contact people individually.

Audience member: I was not sure whether you were asking for a phone number where you can ask questions. Audience member: where, if I -- I'm just curious about the outcome of a lot of this. Could I get a flyer or something?

Doreen McConaghy: What will happen with all of this information, once we have gotten it all down, we are going to pool together all of the partners who helped this happen. And then collectively all of the organizations are going to help us how to disseminate. It is not just something that the Governor's Commission on Disabilities is going to do. We are going to meet all of the partner that is helped us. If you have questions when this may happen, I do not recommend tomorrow, but you can call the general governor's commission on disabilities number. It is 462-0100.

Mary Catherine Hess: Okay, I think we need to wrap up because we are only booked in the room until 7:30, we are going to wrap up and we thank each and every one for your testimony we are very grateful for it. If you want to address some of the panel members directly. Thank you so much for coming. Thank you.

H. *Public Hearing – Friday August 24, 2001 2-4 PM, Arnold Conference Center, Cranston*

- C.I.e) Health Care: Medicaid

Michelle Calesi: I'm Michelle Calesi and I'm representing my daughter and myself. I have a child who has a terminal neuronal disease, through my experiences, equip. Is a big issue? Not just commitment like swings, safety equipment, bath chairs, we have a time sensitive issue because we were not given beyond a year and a half or two years of my daughter's life, it takes 6 months, so months, I've had other moms contact us, what is the hold up? I meant with the DME commitment Vanguard, I'm also a nurse and a nurse case manager with Blue Cross. I have background and I know where thing get tied up. It is when authorizations end up on the desk at the state of Rhode Island department of health. We are trying to come through this system and it is difficult. We have a very time sensitive issue. I have moms out there with Tay-Sachs. I'm very fortunate my daughter has done very well and the equipment has helped us but we are waiting a long time. We need some help with this.

Maureen Maigret: Thank you. Next Roberta Hawkins.

- C.I.h) Health Care: Eligibility
- A.I.a)(1)(c)(iii) Health Care: Confidentiality

Roberta Hawkins: I'm a member of the Long-Term Care Coordinating Council. I'm here today to do testimony for a family member, a mother who is going through difficult times along the mental health system. I'm also the mother of a deceased person with mental at disabilities. As the parent of a young woman diagnosed with major depression I've spent years in sadness, frustration and rage, these emotions are not probably unique to me and reflect many parents, my story focuses on the mental health system or lack of. At the age of 19 my daughter was hospitalized following a suicide attempt. There was an episode dying 911 and having her seen at the local hospital. At that time there was alcohol in her system and her behavior was difficult and uncooperative. The physician indicated that perhaps this was just an intoxication issue, despite the continued expression by her of suicide ideation, imagine my surprise that a police officer told me she was being transported to the police station where she will be held for her own safety until she could be evaluated. The explanation was that the hospital did not have a safe room and this was a practice worked out by the mental health center, hospital and local police departments, my daughter spent the night locked in jail. There were no changes. The evaluation process should have given me a hint as to what was to come. The staff came to my house and handed her back to me. She did not meet the criteria for involuntary hospitalization; she was hospitalized two days later at Butler Hospital where she remained and an additional 13 days for out-day hospital. In all of that time not one staff member spoke to me or my husband about our perceptions about what was going on, our ability to be helpful to our daughter and simply hand her back to us again, with no plan. Since that time, she continues to have major problems and episodes, we can continue to try and support good decisions on her part. She has been evaluated a number of times and again, no one speak to us. We understand that the laws regarding confidentiality prevent the information being given to us. But it does not prevent the practitioners from receiving information, despite that no one still talks to us. They operate from information provided by our daughter, who frequently does not represent the facts of situation, and then the

➢ C.I.i) Health Care: Community Based Options	exploitation is that the parents will take her home. Operate from the basis of ignorance and it will start over again. We've reached a level of frustration, we have a mental health system that has focused its limited resources on those seriously mental ill. For those not reaching that level are minimal and it is only crisis oriented. Having further good health insurance does not mean that the treatment is easily accessed. We fully understand that our daughter as an adult as such she is in a position to make decisions, both about treatment and other life issues, except that she really can't. We continue to try and support her emotionally without enabling her financially to continue in self-destructive ways it is a terrible place for any parent. I do not look forward to the next episode which I know will help, but I have -- to appalled at had your decision to no longer cooperate. We'll refuse to participate in a plan that we have no input into. We must work harder in Rhode Island to see that individuals with disabilities do not end up in jail cells. It seems a return to the practices of the 19th century. In addition, we must have a system that has entry doors clearly marked that does not require crises as the criteria for entry, finally we must create a system that makes the best use of family support as part of that solution. It is the families that have to carry out and on the plan, give us the help that we need to do so. After all we are the ones who deal with it every minute, pick up the pieces and not just within the medical coverage period. I'll tell you that's the end of this lady's testimony. I wept through similar things with my daughter from the age of 18 or 19 until she died in self-inflicted at the age of 36. We had to take grandchildren away from her, we had to do what we could to protect all of us and at times it was a distance and could not be there. We did not have the training as the mental health people; we did not know where to turn to. When we did, we did not get the help we should have gotten. As I was telling Maureen. My granddaughter has a friend his name is Leo, he's one of the nicest young men I have ever known. Last week he signed himself into the hospital into the psych unit saying he was suicidal. He stayed until Monday, he was released with no medication, no plan of care, no one to assist him, when he went to the mental health community center they said he could have an appointment in 3 weeks. Does that tell you that we have a good system? I don't think so.
	Maureen Maigret: I would like to announce that Dennis Costa representing the Department of Elderly Affairs has joined us, another cosponsor. Lorna Ricci.
➢ A.VII.a)(2)(a) Assistive Technology: Talking Books ➢ A.II.a)(2)(a)(i) Transportation: RIde	Lorna Ricci: I'm the Director of the Ocean State Center for Independent Living. I'm here as a consumer I'm visually impaired. I have six things I would like to mention. First of all the importance of the continuance of talking books. Personally I benefit tremendously from this program. I know it is always in jeopardy, for it's continuance and I would support whole heartily it's continuance to consumers, the paratransit services, it is a service available for people with disabilities to practically go anywhere in the state right now. Though it is limited to ribbon areas following bus lines, I would ask for an expansion not only of the routes, but also of the geography and the services, I'm asking for time. I'm asking for it all

➢ A.VI.a)(1)(a) Accessibility: Community Based Options ➢ A.VI.b)(2) Accessibility: Physical ➢ B.VII.a) Housing: Information ➢ C.I.f) Health Care: Home Modification ➢ A.VI.a)(2)(b) Accessibility: Home Modification	hoping to get some of it. It is so needed. Particularly the working disabled program. It is allowing people with disabilities get back to work. A wonderful program but I encourage its support. Not all of us have handsome chauffeurs. My husband takes me places. I would like to mention the nursing home transition services. Two independent living centers are working on look the inappropriate placed into nursing homes for those people who have no community supports, the family did not know of any other options, were put into nursing homes and now they wish to get out. The two centers are helping people to connect with the support services that are necessary to make a safe transition. Lots and lots of things have to be in place. I would ask for your support should we ask for funding in the near future to help with this, we are both applying for some significant grants. I would like to make mention that it is an important program that needs to continue. At our center we have people that come in every day with disabilities. There's one thing we hear nearly daily. One person asked me this morning that all public places. This is number four -- all public places please have automated doors. I think this is something that could be easily done for all new buildings, please put them in. Number 5 is OSCIL is under way to institute a housing registry to go to the OSCIL site. It is being developed; it will be an interactive site where landlords will put their rental properties on this site. You, as consumers can go in and peruse and see if there's something available. There may be a request for a minimal amount of money to keep the operating costs. Lastly home modifications, this is something that the centers are providing to people who wish to maintain independence in their homes. It comes in the forms of ramps, elevators, modifications to their bathrooms, it is now state funded. Thank you to people here who had anything to do with that. However, we've already spent just on projects that have started. This year's money and all of next year's money. It is a tremendous need and it is a wonderful, wonderful program it keeps people independent in their own homes. That's it and I thank you for this opportunity.
	Maureen Maigret: Beverly Andrade.
➢ A.VII.a)(2)(b) Assistive Technology: Funding	Beverly Andrade: One of the big concerns we have is that currently ATAP is funded through federal funds and they will shortly go away. Our concern is that the state should have some type of plan in place if these funds do terminate that there is a plan in place to continue the partnership. A lot of the work that we do at Tech Access is with school-aged children and a lot of problems that people are having is transitioning students interest schools into college or the workplace. There are poor plans in place now. It is something that needs to be addressed. As a central information site for the access partnership. We receive a lot of calls from people who are confused about state agencies and funding sources. People really need to know where they need to turn and where they need to go for these things. That's something else that we feel that needs to be addressed.
	Maureen Maigret: Cathy Donovan.
➢ A.IV.a)(1) Housing	Cathy Donovan: I need to find a place to live that's more accessible. Where I am now is accessible, but they don't have good help. So, I would

	like to be able to find a better place to be able to live. They don't seem to provide any nice places to live. For anyone that's disabled, that's about it. Thank you.
	Maureen Maigret: Thank you, Cathy.
➢ A.I.a)(1)(b)(vi) Health Care: Community Based Options	Paul Bohac: I'm a member of the Rhode Island Head Injury Foundation and I heard that there is money through a grant available for a home for people who suffer traumatic brain injury, unfortunately when I was injured there was nothing available I had to leave the state. When you become brain injured your life is completely different. In aspects of your mental ability. Your cognitive skills suffer tremendous setbacks, you cannot remember things, planning and organizational skills are affected. I broke both of my legs and I had to do a lot of physical work in getting stuff to where I am now. Just your daily living skills need to be planned and organized. I was able to get that through -- I won a scholarship to attend a head injury rehab center in Hyannis and they helped me schedule my daily event and help me organize my day. Basically, after my initial stay in the hospital, when I got back I was put back at my parent's house and it was good because at my parent's home, but as far as growing individually, there was nothing. I wish there was a group home where I could have learned as other people who are head injured how to grow as an individual.
	Maureen Maigret: Thank you Paul. Pam Doucette.
➢ A.I.a)(1)(b)(vii) Health Care: Community Based Options	Pam Doucette: I had a brain aneurysm at work. Around 6 years ago. I had a good job and excellent benefits that's gone forever. I often wonder why I'm here. The Brain Injury Association in Rhode Island opened my eyes in so many ways; I was deeply impressed meeting people trying to help the brain injured. To find an association that is on our side is very important to me. I want to do whatever I can to help strengthen our ability to let people know in Rhode Island that we are here. And their support and understanding will be greatly appreciated. There are so many survivors in Rhode Island with nothing to do and nowhere to go. Depression and sadness and uselessness become a big part of their lives. What we need is a similar situation to a senior center. And call it "clubhouse" where we can go, see people, play games, watch TV, read books and learn different things and feel useful. My other problem is not on here I just remembered. I was at Butler, a few years ago I felt very depressed and I did not care whether or not I was here or not. I was at Butler and totally disgusted because I saw a psychiatrist and what he gave me was medication, he did not talk to me. Medication, come back in two weeks, to sit down and talk to me it would have been a lot better. I got rid of the medication and I decided to get a counselor. I have one now for 2 and a half years, they are seeing me and she's part of the brain injury association and I see her to talk to someone. And another thing I had a question, actually is a gentleman from the department of elderly affairs. Where I live is in a complex and you buzz the door to let people in and out. From 9:00 until 6:00 in morning your doorbell is rung, you have to go to the door yourself. Handicapped, disabled elderly, I received a letter back anonymously that of more or less says to the senator like the person telling this and the other

anonymously. Is lying --

Maureen Maigret: Could can you to speak with Mr. Costa after the meeting or during the meeting about that. We are not here to really talk about individual specific problems, but rather problems that affect a lot of people. If you have a specific question like that I’m sure Mr. Costa could help you on that particular one.

Pam Doucette: I imagine it would affect a lot of people that are disabled.

Maureen Maigret: I’m talking about the doorbell issue at your housing. If you have a question about the particular question relating to the doorbell I’m sure Mr. Costa would be able to help you on that.

Pam Doucette: Can I say one more thing? I don't know if -- if you become brain injured in Rhode Island and cannot get any kind of help they put you in a nursing home no matter what age. Rhode island is so far back compared to Massachusetts. It does get me going. Why, I say just move to Massachusetts. Thank you.

Maureen Maigret: Thank you. Jean Panarace.

Jean Panarace: Good afternoon, I’m a consumer who has a very severe hearing loss, I’m also manager of the disability and health program at the Rhode Island Department Of Health and I’m on loan interchange to the department of administration for the governor's diversity initiative. I'm speaking from a lot of perspectives. The health department's activities have included a number of surveys of consumers, who have communication impairments as well as surveys as primary care physicians to serve folks with disabilities. Some of the major findings we've had are folks with disabilities need and desire additional access, whether it be to the physician's office, perhaps his attitude or perhaps the physician needs training about how to work with the person with the disability. Equipment, doors, physical barriers are also mentioned as really big issues when people go to their doctors for basic health care. Personals who have severe hearing loss have for many years been in great need for mental health services that are accessible. This includes interpreters for the deaf. They are in short supply admittedly. It really makes access to care so much better if the interpreter is present. We've also partnered with agencies in the community. Such as Ocean State and Tech Access, to bring information about assistive technology and find out what the person's need is in terms of their daily functioning and health care. These findings will be published, but one of the most signature things that have come out of two big surveys we did was the need for more information about assistive technology, so I can support the tech access hope that there will be some funding. Also, actual dollars available for those people who cannot afford assistive technology. Hearing aids today can run as high as $2,500 even the most basic piece of equipment could be hard for someone on a restricted income. The last thing I would like to mention is the need to increase employment among folks with disabilities. Folks with disabilities may be unemployed at a rate as high as 70%. We need employers who are understanding that will provide the supports that people need so they can

- E.II.c)(1)(d) Accessibility: Physical
- B.I.h) Health Care: Quality of Care
- A.VII.a)(2)(b)(ii) Assistive Technology
- B.III.e) Employment: Awareness

➢ B.III.f) Employment: Assistive Tech.	function in the workplace and that, in turn, improves your psychological outlook on life, your physical health improves that's one of the aims of the disability and health programs to try and improve the health and wellness of people with disabilities. The CDC has recognized this. Employment is very critical and all of the supports such as transportation, assistive technology, changing employer attitudes and changing the attitudes of the general public. I'll be providing some written material. I thank you for the opportunity to speak today.
	Maureen Maigret: If anybody does not wish to speak can certainly submit written testimony. Do you have a time frame for that?
	Bob Cooper: We would like to have it by the end of next week. We are going to take the testimony from the eight hearings. We'll be forming a working group to review that, put it altogether, and try to combine similar testimony and then prepare a report back through the legislature, back to the governor and to all of the sponsors, if you get it to us by the end of next week I would appreciate it. The address is e-mail or postal address right on the front.
	Maureen Maigret: Lisa Marotto.
➢ A.I.a)(1)(a)(v) Health Care: Personal Care Services	Lisa Marotto: I'm Lisa Marotto, I live on my own and I wanted to get more hours. It is a program I'm on Gateway To Change. And they will not let me have anymore hours. The reason why the hours, I have appointments and a lot of meetings and a lot of I need help with my housework. I need physical therapy and I need to have somebody to help me when I have a problem I need somebody to be there because I can fall and I live on my own and I'm afraid to get hurt and if I get hurt I do not know who to talk to. That's why I need more hours. I even need more food shopping that I need to do and meal shopping; I need somebody to help me do that. I cannot be alone to do that by myself. I can write a list and help me with the money and I tell them what to buy and what I can and cannot have. I have bad problem with my stomach and I have not done a lot because I've been dizzy a lot and falling a lot. And I have been losing my balance and that's another reason why I need more hours but nobody believes me that I need more hours and I work every day but in the workshop. Nobody is believing me and I'm having physical problems and I'm complaining to people and nobody understands what I'm saying and I went to the state health and everything and they did not do thing for me. And I'm mad and upset and depressed and I do not know what to do. I only have 12 hours and that's not enough for me week. Especially when I live on my home and I'm going a group home! And I'm not going home to live mother.
	Maureen Maigret: Could you clarify and I said more hours, you need more hours of personal care.
	Lisa Marotto: staff support, homemaker. Person to help personal care. PCA and stuff like that and help me to make sure all right. And I went to all of the -- please help out.
	Maureen Maigret: Sharon Brinkworth.

➢ A.I.a)(1)(b)(vi) Health Care: Community Based Options ➢ A.I.a)(1)(b)(vii) Health Care: Community Based Options	Sharon Brinkworth: Good afternoon I'm the executive director of the Brain Injury Association of Rhode Island. And I just wanted to tell you that traumatic brain injury is an epidemic that has become a major health problem for many of Americans. The CDC reports that there's 1.5 and 2 million incidents of brain injury that works out to be 5.3 million Americans currently living with a disability. In Rhode Island alone there are at least 600 hospital discharges and one hundred deaths associated with traumatic brain injury, in addition to that there are hundreds of mild brain injuries that go untreated and later result in cognitive difficult that are often bewildering to surviving alike. They can be serious and affect almost every aspect of one's life. It has only been in the past 10 to 15 years for individuals with traumatic brain injury that's why the population is growing. Modern technical advancements have allowed many more people to survive. The challenge is that the many of these people will live for the rest of their lives with physical limitations and disabilities in communication, learning and the ability to perform routine daily lives task that is could require long-term treatments and supports. I also brought a packet of information that I'm going to leave, too. In 1999 the health resources and services administration awarded a TBI planning grant to the department of human services to the Rhode Island department of human services and the purpose was to establish a collaboration of state agencies, community providers and their families to plan a system of service delivery, for survivors of brain injury of all ages and needs. That has been done and we do have that plan. And it is right here and I'm going to give that to the commission also. The next step for us is an implementation grant. Eligibility for an implementation grant is going to be contingent on matching funds. The person will provide 2 dollars for every one dollar that the state contributes up to a maximum of $200,000. Right now we are looking for funding for that to start with our implementation grant. And a few of those would be as Pam mentioned we need to develop capacity for residential and for day services. We also need funding for targeted case management. And funding for an annual conference and so these are a few things that we need to get started to provide some services for people with brain injuries and essentially, we identified that children with brain injuries there are services covering them. Sometimes if they qualify for elderly services. But the age group from 22-64 that fall between the cracks that do not qualify or are not eligible for the services that we are going to try and target for the next couple of years, we want the governor's commission to help us with that.
	Maureen Maigret: What is the time frame for that grant that you mentioned? You said there needs to be state matching money?
	Sharon Brinkworth: it is December 1, 2001. What we looked for from the legislature this past year is we needed a 75,000 match, that's what we need of to be assured of by December 1. We are going to be looking at a lot of places for that. I have my plan and testimony in more detail and I may have a videotape of the testimony that our people did before the house finance committee. Where should I leave this?

Bill Inlow: another point, you said that's a federal agency.

Sharon Brinkworth: Health Resources Services Administration. From the federal Department of Health and Human Services.

Maureen Maigret: Thank you Sharon. Cynthia Holmes.

- C.I.e) Health Care: DME

Cynthia J. Holmes: I work with children and their families with disabilities ranging from the age of birth to three. It is an early intervention program and it is statewide and it is under the umbrella of the department of health. I've been in this service for 22 years and I specialize in terminally ill and very medically involved children. I'm here today to hope that I can explain well and maybe help some of the medical fragile and their families, they need special equipment, chairs, bath chairs, to maintain a quality of life for the infant and for their families. As it stands now, some children wait 3 months to 7, 8, 9, months for equipment. I would hope to think that there was a possibility that we could find a fast track that we could identify children that are terminally ill that do no have this kind of time to wait, provide some specialized workers that could expedite the approval of the equipment. Most of these children are on medical assistance. If it is not actually the application has not begun at the hospital. Sometimes that in itself will take 3 or 4 months. For these families, when I go into their homes and I see them and they don't think that their child has 3 or 4 months. To find those answers or help them come up with reasons and answers and equipment has been very, very frustrating. I would like the Department of Health and the Governor's Commission to please look at this and possibly help these families and these infants. Thank you.

Maureen Maigret: Thank you. Elizabeth Trimmers.

- A.I.a)(1)(b)(ix) Health Care: Community Based Options

Elizabeth Trimmer: I'm the coordinator for Rhode Island -- there are a few of us here today and we'll be forwarding a written testimony next week. We are also known as Rhode Island Cares. That's the acronym for our organization. We are a grass-roots organization, dedicated a voice of empowerment for those in alcohol and other drug dependents and reducing stigma attached to addiction. We are here to stand up for the beliefs -- I am in recovery from my own addiction for 14 years, I was 17 when I entered a treatment facility and I was lucky enough to have a bed available for me. Luck should not have anything to do with it. As a coordinator for an advocacy group for people in recovery and their friends and family members, I get many calls from people, especially women seeking treatment. Often times they are women with children and they are looking for a facility that can accept them and their children? A. There's only a couple in the state of Rhode Island and they usually have lengthy waiting list. These barriers really prevent women from entering treatment. I also receive calls from treatment providers. They have women ready to graduate and complete their program but they have no place for them to go, that's no safe place. There are many more sober houses for men than women. I feel our state is doing a good job but we could do much better. Please help our women and family receive the support and treatment that

	they need. They are our future.
	Maureen Maigret: Susan Kent.
➢ B.I.c) Health Care: Education ➢ A.I.a)(1)(b)(ix) Health Care: Community Based Options	Susan Kent: I have copies of my testimony. My name is Susan. I was incarcerated in the ACI for a little over two years, what I saw there changed my life. Before living within the prison walls I had thought America's prisons were full of bad people. I learned through my own experience and subsequent research that that is not the case. The majority of prison inmates are sick not evil. They suffer from the disease of addiction to alcohol and other drugs. Many have major mental illnesses; most have little education and no job skills. The majority of women who end up in prison have been victims of abuse at some point in their lives. Education about domestic violence is a required class for women who are receiving substance abuse treatment. Because using substances to self-medicate. Before I was sent to prison I had an education, nice house, and good job. Things most incarcerated women never had. I competed the program offered in the prison and I celebrated five years of freedom from alcohol this past July (applause) thank you. But I have found is easy to stay sober since my release because my nice home and my good job were waiting for me when I got out. Unlike so many other women I did not have to return to living in a drug infested neighborhood. I did not have to return to living with an abusive husband or boyfriend because I could not support myself otherwise. I watched heart broken as women left the prison after their time was served because I knew what kind of a life they were going back to. No matter how good their intentions were to stay clean and sober. The odds from against them because of the environments they were returning to. Some of the lucky ones made it back inside the walls. Others, like my friends Linda and Lori, died before they could get another chance. There is a desperate need for safe, sober housing for women, there is a need, a desperate need for residential treatment programs. There are women in prison after their time has been served because they are waiting for a bed in a treatment facility. They are safer waiting in prison than out on the streets. Some treatment centers will not admit new clients on weekends; others will not accept people with mental health problems. Some refuse clients who require medications, we need to make it easier for people to access the programs and services that they need to help them save their lives. The prison offers many programs and services that can begin the process of turning a woman's life around. Substance abuse treatment, psychological counseling, mentoring program, women in transition, but the prison cannot do it all. We need to provide ways to help women before their lives become so desperate before they land in jail and we need to provide ways to support women after they are released from prison. It is not just a substance abuse issue, not just a mental health issue it is not a housing issue we need a comprehensive integrated approach and continuum of care that includes following through with help and support until a woman is ready to stand on her own. I've put my name and phone number here because there is a real lot more stuff if anybody is interested in these issues, that's me and that's my number you know where to find me, thank you. (applause)

	Maureen Maigret: I do want to recognize I see in the back another member from my organization who is the vice chair, Neil Corkery. Jeremy Gravell.
➢ B.I.a) Health Care: Awareness ➢ B.I.b) Health Care: Awareness	Jeremy Gravell: Good afternoon. I'm here representing RI Cares I'm a recovering addict. I would like to share briefly about my past would led to my addictions and mental health. As a child I was physically, emotionally and sexually abused by my father that led to mental health problems. At age 16, a severe bout of depression I felt completely excavated. After spending four days in a hospital and two days in a coma I was transferred tie meant at institution I spent 60 days, at that time I never dealt with the real issues that haunted me but my subconscious mind was at war and I had self destructive behaviors, I began using drugs. I had no hesitation about using any and all drugs I could get my hands-on. I was going strong for two years and after overdosing many times, I finally ended up being clinically pronounced dead, after coming to I felt I was given a second chance. From that on I stayed clean for four years, following hard work and determination I was able to recognize and deal with many issues with regard to my psychological state. I thought I would never give my myself destructive behavior again and I did and I became very out of control and self destructive by being involved in an abusive relationship, I ended up using drugs, but this time I destroyed, everything I had and hit a bottom I never thought possible. During this time I learned an awful lot about myself, but I got a pretty good taste about how I was perceived by others particularly in the medical field. Consumed by depression and constantly suicidal, I ended up in many different hospitals. One time in particular that I had intentionally overdosed in my apartment. The paramedics have to give me an IV to bring me back, I was treated as if I was not a human being. When I arrived in the hospital I was put into a dark corner, I was told to leave the premises immediately after I stopped vomiting. It was December with snow on the ground and sleeting. Not only was I without a ride but I was wearing only a pair of boxer shorts I was not even given a blanket. Had my fiancée not been there, I would have only had that. Basically, every time anything like this has happened and if I had a parent with me, I was treated with respect and held for observation, for things much less serious, I'm very grateful and I've been clean now for a year, I've work at a couple of 12 step programs and I'm involved in RI Cares. Unfortunately the stigma of mental illness and addiction present themselves in my life still. I got pancreatitis, it is an experience, while in intensive care in the hospital I told my nurse that I got myself into that state and I needed to get my head screwed on straight. Luckily RI cares member was present to advocate for me. I feel very strongly for anybody who helps to deal with the public to be informed. Our fathers, mothers, sisters and brothers, hopefully some day the situation will improve it is only through education and awareness that we can do it and I believe we can. Thank you.
	Maureen Maigret: Thank you Jeremy. Linda McGovern.
➢ C.I.c) Health Care: Quality of Care	Lynda McGoverey: I apologize I did not know I was able to speak. I'm going to start out with a few issues that are really on my mind. I have

	Multiple Sclerosis; I worked at Blue Cross for 8 years. I was an assistive supervisor there, now I find myself in a state facility being told what to do. I have chronic pain along with my MS. This facility is accredited by the joint commission, and these are the pain standard guidelines that this facility is not following. Also, I worked with multiple sclerosis, -- I had a choice, I could have gone on disability but I wanted to work. Now because I'm in a state facility I lose all of my benefits. I have no benefits anymore. My Medicare benefits are gone, my Medicaid benefits are gone, I don't understand how the state can do this to a human being. I'm on a locked ward at Eleanor Slater hospital because -- I don't even know why because I have VRE of the intestinal tract I can live at home with that for 8 years, I'm sure everybody knows that VRE is not a death sentence and it is unconstitutional to keep me locked up here on a locked floor to boot. I have no access to a computer, can I not get a computer line, I am a thinking human being and I'm forced to sit in front of a TV day after day, 24 hours a day. That's all I can do. Or I can go out of my room if I want to stare at people who are basically cognitively impaired, sitting in a wheelchair like vegetables, this is what I have to look at if I leave my room in the state hospital. I'm totally disgusted, I feel like I deserve more for that because I worked in a system that I chose to work and not be dependent on the government or the state. I did that for 25 years with multiple sclerosis, now I have a case of chronic pain that can I not even get taken care of here because it is unknown etiology. I'm forced to sit in front of a TV all day long without a computer.
	Maureen Maigret: Thank you. Ann Marie McKenna.
➢ A.II.a)(2)(a)(ii) Transportation: RIPTA	Ann Marie McKenna: Basically, I work with disabled individuals and my main concern is transportation for them. A lot of them work within the community and transportation, some of the bus routes are being changed and cancelled.
	Maureen Maigret: Are you with an agency?
	Ann Marie McKenna: Yes. John E. Fogarty Center. They are stopping routes altogether. One of the routes they plan on taking there are five or six complexes on the route. Mineral Spring Avenue. There's Mineral Spring Manors there are a lot of people there who need that transportation. Tom would like to say something about the transportation.
	Tom: I like to work. I work at Stop And Shop and I like to work and I want to get the bus.
	Panel member: What days can't you work?
	Ann Marie McKenna: On holidays. My bus does not run.
	Panel member: So he's not entitled to work because the bus does not run he uses the transportation independently. That is it, thank you.
	Maureen Maigret: Laura Rebello.
	Laura Rebello: Hi, I'm here to talk about a few issues that are important to me. First about Medicaid. I went for orthopedic shoes to help with my

➢ A.I.a)(1)(b)(iii) Health Care: Medicaid ➢ A.I.a)(1)(c)(i)(b) Health Care: Medicaid Providers ➢ A.II.a)(2)(a)(i) Transportation: RIde/RIPTA ➢ B.III.e) Employment: Employer Awareness	walks, Medicaid would only allow me with this type of shoe, but I need the ankle support and I was told I could not have that type of shoes because of Medicaid allowances, I have turned down by doctors and I saying that they do not accept Medicaid anymore. My doctor stopped accepting Medicaid patients but he's keeping me on. I would also like to mention the RIde program. When I'm waiting for the RIde van to show up, I think there should be more routes, more drivers and more buses because at times I've had to wait over 45 minutes to -- late, to get to go home. My supervisors had to wait for me for the bus to show up. I think that more allowances should be made for more drivers and buses. There are many routes on RIPTA where there's no accessible bus line. I had attempted to go to someplace on Bald Hill Road. For someone with a disability like myself it was very difficult to manipulate myself. They dropped me off on Tollgate Road and I had to cross Bald Hill Road and that was not easy and I think more routes should be given and more places for the bus to stop. The last thing I would like to mention is for employment for those with disabilities I'm working myself. I would wish that more employers would be willing to help people like me who want to be in the work environment because working for me has given me major increased self-esteem and I would like to have that for others.
	Maureen Maigret: Amelia Whitford.
➢ A.III.b)(c) Employment: Community Based Options	Amelia K. Whitford: I'm here representing Hillsgrove House and a little bit for myself. The lady had talked about running a clubhouse, Hillsgrove is a clubhouse based on the working day. A lot of us are physically disabled too; if we want to work they'll teach us work skills. Right now I'm going to college and I was lucky enough to get funded by ORS. It is not easy to fund yourself when you have 500 dollars a month. I'm also in section 8 but it is still money.
	Panel member: Where is it located?
	Amelia K. Whitford: In Warwick on 70 Minnesota Avenue. Hillsgrove House. They'll help you with work skills. They'll help you get into schools. I decided that five days before the school opened. I started working here at MHRH the hazard building the same day I started class and I would not have been able to do any of that without Hillsgrove house.
	Maureen Maigret: Norma Lovegreen.
➢ A.III.b)(c) Employment: Community Based Options ➢ A.II.a)(2)(a)(ii) Transportation: RIde	Norma Lovegreen: I'm also a member of Hillsgrove House. I'm currently working at MHRH in personnel. I've been homeless this year. I have not been hospitalized. I could have been hospitalized at least 3 or more times. Because of the support with Hillsgrove house, with vans to take me to work. Recreation and for the first time in my life, I like myself. It has taken 51 years and at this point in my life I have no family support but I have the family at Hillsgrove house and I have a lot of friends.
	Maureen Maigret: The van that takes you to work is it one of the RIde vans. Paula O'Connor.

- A.I.a)(1)(b)(vi) Health Care: Community Based Options

Paula O’Connor: I’m president of the Brain Injury Association of Rhode Island. I would like to share with you how and why I became a member of the board of directors. In June of 1987 at the age of 12, my son, sustained a traumatic brain injury as the result of an accident. He came home and entered the day school rehabilitation program. After 3 years he was ready to transition back into public school. Prior to his accident he was a five year veteran of hockey, participated in soccer and was a great downhill skier, it was not an easy transition for him to return to school and face old friends as a special needs student in a wheelchair, Jason’s friends and classmates had grown and had experienced life as it should be. Jason had not he was still stuck in many ways at 12 year olds, meanwhile my 10 year old daughters care free life was turned up side down. She went from neighbor to neighbor and relative to relative until we got a grip on ourselves. During Jason’s school years I spent hours searching for appropriate social and recreational programs for a traumatic brain injury survivor, there were none and there are still none. Still with the help and cooperation of teachers and a supportive family in June 1995 Jason graduated from high school at the age of 216789 amp his graduation there was nothing for a TBI survivor, nothing available to continue his cognitive and emotional growth. As his caregiver and advocate and mother, I’ve watched my son struggle to return to the classroom to pass into manhood and struggle for independence as an adult with a brain injury. After an exhaustive search, we reluctantly expanded our search out of state. He has been living 235 miles away from us in the state of Vermont. It was a difficult decision to make and a heart wrenching separation, since my son's departure I have had to question the well being of other TBI survivors, I was surprised to two others in Rhode Island at the same facility as my son. Not forgetting the great personal expense. I began to wonder how other TBI survivors and their families were coping. Without services or programs available. How and what were other families doing to keep their beloved ones growing and advancing. Are nursing homes the answer? Or in some cases they are institutionalized and forgotten about. That's when I became an active member of TBI. After 14 years of an emotional roller coaster ride, which has brought my family through pain, grief, anger, isolation and frustration, I’m proud to say that we, as a family, remain together. In Rhode Island there will be approximately 1500 new cases of infants, children and adults sustaining traumatic brain injury alone. Whether from vehicular accidents for falls, or injury, we need Rhode Island support to help us to put an end to this epidemic of traumatic brain injuries and establish appropriate services and provide services to those already afflicted. Thank you very much.

Maureen Maigret: Thank you. Paula, would you tell us. You said you had -- or I don't know if as a group home. And that's in Vermont.

Paula O’Connor: It is strictly for traumatic brain injury.

Maureen Maigret: We have nothing like that here in Rhode Island. How many residents are in the home that your son is in?

Paula O’Connor: they have several different facilities, some are living in duplexes, some are in a group home setting with 24-hour staff, and they have some homes just for women, and so forth. Some have their own apartments, yes.

Maureen Maigret: Thank you. Joseph Farrell.

- A.V.a)(1) Direct Care: Reimbursement

Joseph Farrell: Excuse my appearance today I had a sloppy joe. I'm a member of the board of directors of the Kent County Health Center. I'm on the faculty at clubhouse and that's out of New York. We travel around, people with mental illnesses such as myself also travel around with staff to different places where we do certification of clubhouses that way the family members know and everybody knows that the place is quality. You can get either a 0 where you are not receiving a good accreditation, you can get a one-year or 3 years, at Hillsgrove we have a three-year accreditation. In 1995, I sent a letter to Governor Almond telling him of our needs and he sent the letter, unfortunately six years and two months later. We not only, we are not at the money we had and now are 20% less than we had. They have 40 people out working but our staff can no longer get paid for taking people out and job coaching them. Those are just a couple of the things that are hurting us. As a member of the board of directors, I have to spend a couple of minutes each month, explaining to the board why we are losing thousands of dollars on our program, I have not been very happy, at Hillsgrove House, we had Tony Pires and after meeting with us, as a result of the meeting, Medicaid’s benefits have been pushed up and that was just through what Hillsgrove House had presented and Kent County Mental Health Center. I find is very frustrating that we are the only program in the state. I've been watching more and more people being hospitalized and they've been closing down the day programs, down to almost nothing. In 1996 I had come to these grounds and predicted that that is what would happen. Yet, I do not see the programs around for people where they have a place to go to during the day, where they can have peer support. Be able to do work or go out and work outside and so I’m here today letting people know that I’m going to hang in and fight. I don't care if it takes ten years as long as we can stay open and I believe we have the best mental health care facility in the state.

- A.II.a)(2)(a)(ii) Transportation: RIPTA
- B.II.b) Transportation: Public Awareness

John Susa: I’m here to talk from the perspective of a parent and the first part is I understand my son was here a couple of days ago before another meeting and I think he unabashedly started asking for money from you and the state. I'm very proud of him because he's not afraid to say what is on his mind. I want to follow-up on some of the comments that have been made. If he were here he would have said, "our public transportation has to be beefed up" he probably would have also said that more people with disabilities need to be supported in learning how to use public transportation. Certainly one of the reasons why RIPTA and other organizations stop providing some kind of bus service is because it is not used enough. So there's a need to increase utilization of fix-route bus systems, our experience is that there's a barrier to that because there's a lack of training at three different levels. First of all it is at the level of the user. There are many, many people who have not been given the chance to learn how to use public transportation. At another level are the people who support them. Both their parents and the professional support people who help them are also very unfamiliar with the use of public transportation. They are afraid of it because they are not users of it. They need training at some level those who are supporters of people with disabilities need to be trained and prepared to encourage the independence of people in using of the public transportation. At a third level there's another need of training and that's with the people who are the policy-makers and the people who influence programs that support people with disabilities. That is that I'm amazed at how many times when I talk to people I find that they are being found and placed in employment and housing situations that are not in places where public transportation is available. It is a counter productive process of find the job first and then hope that there's public transportation available. I think we need to change that thinking. It is a little bit of training that needs to happen. We need to look where the public transportation networks are and then find employment and housing opportunities for people with disabilities. Along those corridors, I'm very passionate about this because we as a family we are vested in the need for Marc to be part of his community and transportation is the key to his success as an individual with a disability. Aside from the fact that some day I'm hoping he will become a millionaire with his bus to help people learn how to take transportation, before he becomes a millionaire my wife and I will probably have to find some way to help him live the kind of lifestyle that he's been accustom to at home. Support is provided by a variety of different state and federally funded agencies and services and with all of that he's very active in his community. He has the opportunity to interact with people with and without disabilities and take advantage of all of the great things we have in the state of Rhode Island. I'm afraid because he is he has a physical disability, cognitive disability and hearing problems. When it is time for him to move out the options he'll have available to himself where he can live will be limited. He'll have options of living in section 8 that's either a mixture of people who are elderly or people with disabilities or ending up living in a place where everyone has a disability. We want him to continue to be able to live like he is now. Having a mixture of friends, a mixture of opportunities. We think that there's a need in Rhode Island for the development of housing that provides better opportunities for people of all different abilities to live together. Of all different social economic levels to be living together and all different ages, it is an integrated, multi generational, multi-income kinds of opportunities. We do not have any of those in this state. I would like to suggest that we start to look at creating some kind of experimental initiatives to look at how that might be supported. I'm not saying that everyone will want to live in that kind of environment. But there will be some who want to and may benefit from that. Maybe if the Governor's Commission how, through initiatives from RIHMFC and others that those options can become available. There are these ideas of communities and other ideas of supporting inclusive community living; we do not have, I don't think, enough of those options in Rhode Island. I would like to see the Commission work on that. The last point. I cannot help but very affected by hearing the stories of so many people here today and the

- C.III.c) Employment: Housing
- A.IV.b)(2) Housing: Community Based

- C.I.j) Health Care: Consumer Directed Services

amount of work and energy that they have to expend to try to survive and live happily in Rhode Island. I really think that my wife and I and my son are very lucky. We have been able with the support of a variety of different organizations and individuals, we've been really able to try and explore and experiment with very individualized solutions to our problems. I think other people should be as lucky as we are. I think at a state level we need to promote more individualization and more flexibility and more personal control over funding. I would like to see frankly more of the funds that are used in the state to support people with disabilities come under their personal control. I would like to give them the opportunity for them to decide how they want to use it. I want to see them be able to not just have to use it on certified vendors and approved providers, I would like them to be allowed to use them any way they think they need it to make their life better. We are trying to experiment with that kind of approach. I'm very lucky and I want to see other people be that lucky. Some of the people who have been mentors to my wife and myself is a couple in the state of Kansas. Mr. And Mrs. Turnball. A couple of months ago they wrote an important article in Tash. The title. Article was self-determination for individuals with significant cognitive disabilities and their families. It is important to read it and recognize it. This couple between them has 6 college degrees, college and graduate degrees and they write about the challenge it is to struggle with a state system that does not allow them the kind of flexibility I'm asking for.

Maureen Maigret: I think your time is up, but we would love to get that article.

John Susa: I thank you very much for this chance to talk about it.

Maureen Maigret: Thank you. Kenny.

Kenny Melia: Good afternoon. I'm a recovering alcoholic. I lost everything. I lost the jobs, the relationships, I lost my family, I lost it all. I did not care about anything. All I wanted to do was drink. I was isolating in my apartment. Not answering the phone, not paying the bills not even staying in touch with family and friends, I was not feeling too good. One Sunday morning I started to read the papers and could not see. My doctor told me I had diabetes, he asked about my drinking abilities and I have lied. I just did not get it. I was alone. My eyesight was getting worse. I burned myself badly. The hospital and residue personnel were getting upset because I was getting picked up at my house. I had no self-esteem I decided to take my own life. I woke up in the hospital they asked me if I wanted to go to a residential treatment facility for men. I said yes, I had to surrender completely to the disease of addictions. I talk about my problems every day and all of the problems I thought were mine alone were not. They understand our needs and us. They are there when there's a problem. The house has 24 men and we all work together. All ages and all walks of life. It is a safe place to get your life back together. I stayed in that treatment center for 16 months. I feel that my life is full again. I have a little over 26 months clean and sober now. I have a higher power that I called god. I'm involved in a 12-step recovery program. I attend meetings

➢ A.I.a)(1)(a)(vii) Health Care: Community Based Options	regularly. I help people who are sick and suffering, I help to spread the word of recovery, I have true friends now. I have myself confidence back, my family back and it feels good. My health is better. I like myself today. I'm now a productive member of society. I now work in a homeless shelter helping me in a positive way. I have a long-term relationship that's healthy today because of recovery. I even have my cat back who waited for me. I have my own apartment. I vote today. I pay taxes today. I pay my bills today. We need to look into more sober housing in the state. People like me need a place to live and a second chance to live. There's a long waiting list for beds. From the time a person is discharged from detox until they reach sober housing it could take weeks or months. We have to make it easier for treatment not harder. Thank you and good day.
	<u>Maureen Maigret</u>: Joseph Hyde.
➢ A.V.a)(1) Health Care: Reimbursement ➢ A.V.a)(2) Direct Care: Training ➢ B.I.a) Health Care: Awareness	<u>Joseph Hyde</u>: I work for the Drug and Alcoholic Drug Treatment Center of Rhode Island as its training director. I want to talk about issues related to work force development. I'm also part of a six state that is looking at issues of work force development. Last evening I was facilitating a focus group from around the 6 states it is something important to talk about. The mission of this is to look at some of the broader and sweeping issues; one of the things that are increasing of great concern to providers is that people are getting out of the business. Not only getting out of the business of substance abuse counseling and social work and all of the allied helping professions. The human services, that's a real concern it is harder and harder to recruit people and it is harder and harder to retain people because the work is more challenging people are having to do more with less and wages have not kept competitive. And some of the paperwork. I spent prior to my current work as a training director; I was 20 years as a clinic supervisor. Paperwork is a regrettable thing in life. I tell people you get paid to do your paperwork. There are increasingly fewer people coming into the procession and more people with leaving the profession. I think the issues are -- some that I just mentioned, I would also think and hope that perhaps some outreach or some initiatives can be hatched with our educational institutions perhaps to provide incentives to bring people into the professions. Whether that is through scholarship or other kinds of supports because the needs of the social service population are not changing. If anything I think people are becoming sort of more acute. If our qualified work force dwindling, we have problems. And then I want to deal with co-occurring disorders, people in substance abuse they are talking about mental disorders in listening to people talk of all of the kinds of disabilities and I've heard people reference here today it is important to recognize that substance abuse frequently is an issue in traumatic brain injury, in folks who are hearing impaired, some of those things predated and some have lives of their own. Some of those came in the aftermath it is important in terms of the training for all professions that they have some fundamental awareness. Some fundamental skills and capacities to screen for those and have available to them appropriate services so if somebody in rehabilitation and recovery they can get the appropriate helping resources to address all of the difficult and challenges that they are having so they

	can effect a full recovery. Thank you.
	Maureen Maigret: Rolf Gjertsen and Chris Craddy.
	Chris Craddy: this is Rolf and Ken Renauda. We are from Advocates in Action.
	Maureen Maigret: It is good to see you.
➢ A.V.a)(1) Direct Care: Reimbursement	Rolf Gjertsen: I have testimony from many people that we collected for the budget hearings[iii] [see **J. Written Testimony** beginning page 109]. We would like to speak to you about this. The staff needs more money. We need your help in getting more money for our staff. Because they are very important to us. We cannot do it without staff we cannot live independently without staff. I need staff help; I need people for 9 hours a day. And they help me do everything. Thank you. (applause)
	Maureen Maigret: We are doing very well. We should finish up a little after 4:00. The next person is Mary Brown.
➢ A.III.a)(1)(a)(iv)(b) Employment: Financial Barriers	Mary K. Brown: Hello, I'm a mentor or pal and the information peer information network and I'm here to say that what we do is go out and tell people with special needs that they should go back to work, but the way that the system is, their rent goes up 30% and the government takes for every $2 they make they take a dollar out and that's 50% off of the top. We cannot live on that. I made a little over $6,800 and poverty starts at $10,000. We need help with the money to live on because everybody I know and I have some friends from Hillsgrove house. We cannot live on the way the system is right now. We want to work. We want to work. Almost everyone has said that they want to work, but we cannot work under these conditions, because we are shot down before we even really take off because of -- it is like we are being punished because we have a disability. It is not fair. Because we want to work. And we are not lazy. We don't want to be shackled but some bureaucracy that says, "You cannot do anything" we know we can. I just wanted to let you know. Thank you.
	Maureen Maigret: Jill Prescott.
➢ A.II.a)(2)(a)(iii) Transportation: RIde ➢ A.II.a)(1)(d) Transportation: RIde	Jill Prescott: I'm having problems with transportation. For four years I was under a doctor's care, I was in a rehab and therapy or water therapy program. Recently I was told by RIde I would have to pay, it is $2.50 one day. I do not have that kind of money to go for water therapy. Right now I am all crippled up I've been -- I have over 3 pounds of fluid in my on my legs my shoes are 9 and a half I'm using the use of my legs arms, what I'm frightened about is how am I going to get back to the water? Because I'm losing the use of my legs, I'm going to be in a wheelchair, I see how people are treated out here in wheelchair with the bus and everything and it scares me because a lot of busses do not have the facilities to put you on the bus. So they sit out there in the freezing cold in the rain, I would love to have one of you people take place in a wheelchair and sit out there in that heat there's not a lot of shelters out there to provide people with shelter from the rain or the snow or the cold. And it really scares me I'm trying to keep myself together. I need help with transportation and I do not know

	why the money was taken away.
	Maureen Maigret: You did a good job, thank you.
	Jill Prescott: I'm an incest, child abuse victim survivor and I'm doing the best I can.
	Maureen Maigret: You did a good job and we appreciate you coming.
	Jill Prescott: I need to get back into the water and I want my dependence back.
	Maureen Maigret: Thank you Jill. Jean Callaway.
➢ A.III.b)(c) Employment: Community Based Options	Jean C. Callaway: I'm a manic-depressive. I have been displaced. I lived in Florida in the process of a divorce and I'm here in Rhode Island. My family took me back up to Rhode Island. What I want to share with you right now is what Hillsgrove House means to me. I was isolating really bad in my dad's apartment. Luckily a nurse at Kent County Mental Health noticed it and said "I have a program for you to get into" when I first got there I cried. I was in a lot of pain emotionally. The family was there to pick me up. They were there to support me. Every single one of them whether it is staff, another consumer, they were there to help me. I have -- I left my life in Florida and I'm here now and I'm starting my life all over again. I love Hillsgrove house and I really hope that you still support it and don't take it away. Thank you.
	Maureen Maigret: Thank you very much. Norris Nichols.
➢ A.I.a)(1)(c)(i)(f) Health Care: Support Services	Norris C. Nichols: My wife had depression anxiety, posttraumatic stress disorder; I would say around 8 years. Then because of her mental state her depression, her health really went downhill and she had a stroke. She's been paralyzed partially on her right side for about four years now and she needs 24 hour a day care. I know I'm not the only one in this situation, I know there are a lot of people that want to take care of their loved ones, but the state does nothing to help. I need -- I have two children, I have a son 17, he will be leaving home pretty soon. He graduated from high school and I have a daughter that's 12. She'll be leaving home in 6 years, that's my only income right now. I cannot go to work because I have to stay with my wife. I know in California they have in-home support services. The state pays for somebody to stay with his or her loved one, whoever it is. Mother, father or whatever for a certain amount of hours a social worker comes in and assesses what goes on. My daughter told me about it she's a social worker in California. How many people are in this state having a problem with people in nursing homes and I've been told by several different organizations that the state is going to put in people in institutions instead of keeping them at home. I could go back to work and make good money. Instead I would rather stay home and take care of my wife. Once my children are gone, I will have no income, just my wife's social security. That's basically why I'm here. I would like to read what it says in the draft for the state for independent living. Now, this is what the people that are on the council it says "in conjunction with DHS that SILC will prepare a resource plan attachment to the SILC budget for the

provision of resources cash in kind including staff and persona, telephone, expenses, travel and other expenses, child care, personal assistance, compensation to the member of the SILC if the member is not employed or must for forfeit wages, for each day at that time member is engaged in performing SILC services, that will be necessary to carry out the functions of the SILC during the term. All I'm asking for is the same thing. If they get compensated I think I should be. I think everybody in this state that wants to take care of somebody in his or her family should be compensated. Thank you very much.

Maureen Maigret: Thank you. That is the last person that had signed the sign in sheet is there anyone else here who would like to add anything at this point? Then I would like to on behalf of all of the co-sponsors and Bob Cooper from the Governor's Commission to thank.

Larry: I'm Larry. I would just hope so very much that people, that other people out there realize for themselves things are -- I'm hoping so very much that things get a whole lot better. That everybody is treated real fair on things and that things go real well and that poor woman. What I saw her going through. I hope very much that the world becomes a better place. Things get a little better. That people, that other people out there start to help those people out there are in desperate need and stuff. I try to -- I have short-term memory loss I think and I get rusty in my conversations, I pray to the lord very much hoping very much that the world will eventually become more like his place and that things are more than fair enough and so on.

Maureen Maigret: Thank you Larry.

Bill Inlow: As a panelists I would like to express my gratitude to all of you who spoke today and came here, I was very inspired by your words and by your courage and your commitment to quality of life for yourself and everybody else in the state of Rhode Island so thank you for coming here today. (Applause)

Maureen Maigret: Larry, I think you concluded the hearing on a wonderful note that we all want this to be a better place. I think your courage in coming here today is remarkable. These are not easy stories to share, your comments will be taken to all of the sponsors to the series of public hearing and help formulate policies on the coming year, thank you so very much.

I. *Faxed Testimony*

- C.II.a)(4) Transportation: RIde

Barbara Walsh: The Customer Service Rep. and Doug Woods, be urged to be more customer-oriented. Not telling people, for example, that their pickup times have been changed, leads to disruption, waste of time, and sometimes, unsafe conditions. If people are waiting outside, in dark places, etc., and don't even know their times have been purposely changed. Barbara Walsh

- B.III.c)(4) Employment: Training

I would recommend funding for a training position, in the Office of Training and Development, DOA, which would be available to all state departments plus others, to conduct or coordinate training programs on ADA; staff trainings to enhance skills when working with the disabled; helping prepare them for employment; tech. needs, etc.; hiring and interview techniques; sensitivity training; benefits available, etc. Thank you. Barbara Walsh, Department of Administration, Office of Training and Development

Michael S. Nordstrom: Thank you for taking the time to discuss the Written Testimony that the Johnston Substance Abuse Prevention Task Force would like to offer in the Commission's effort to collect information to help it - and other State Boards, Commissions and Departments - develop a Legislative Package that will have a positive impact on the Quality of Life of Individuals with Disabilities. It is our specific intent that this communication - in its entirety - become part of the Record of the Hearings your Commission is now facilitating.

- A.VI.a)(1)(d) Accessibility: Services

As you are aware, from our inception in 1987, a primary Mission of this Task Force has been to develop successful and cost efficient Substance Abuse Prevention Programming that is designed to include Individuals with Disabilities in the Mainstream of Community Based Prevention.

Our approach has been to develop, enhance and improve Prevention Programs that are Responsive to Local Community Need; Innovative in Design; and, Flexible in implementation to enable us to constantly monitor and improve the Quality of this Programming.

The Local Effort of this Task Force has resulted in our helping to Facilitate School Based Prevention Programming at the Rhode Island School for the Deaf in Providence; developing the Sister School Program with St. Rocco School in our Community, Introduction of Sign Language - with a focus on Deaf Culture Classes for both children and adults; developed and implemented what has become known as the Camp Hemlocks Residential Experience in Prevention - bringing Individuals with Disabilities together with their non-Disabled Peers in a Learning, Living, and Prevention focused Program.

In addition, we have had opportunity to Employ Individuals with Disabilities in our Total Prevention Programming Effort; Decimated Information throughout the Country on our Effort to Include Individuals with Disabilities in the Mainstream of Community Based Prevention to others who wanted to explore how to replicate our success; served as Consultants to National Agencies who wanted to incorporate the Disabled Community in their own Programs; and participated as Presenters in Mandated Training by our own Funding Sources.

Our Prevention Effort has been Recognized by Gallaudet University, in Washington, D.C. and Stamford University in Palo Alto California. Regrettably, our Effort has received little or no Recognition from the Authorities in the Field of Prevention within out, own State of Rhode Island.

The Experience of the Johnston Substance Abuse Prevention Task Force has helped us understand that Substance Abuse - just as Disability - while having a National and State-wide impact - occur at the Local Community Level. Our work in School Based Prevention at the School for the Deaf falls short of involving Parents as Partners In Prevention because Students - unlike most schools - come from every Community throughout the State. When this Task Force wanted to see what other Communities were doing in their own Effort with I could not identify an Inventory of such Individuals with Disabilities, we Services by Community.

It is against this background that we welcomed the letter from Mr. Craig S. Stenning - Executive Director of the Behavioral Health Services Unit of the Rhode Island Department of Mental Health, Retardation & Hospitals - encouraging us to give input to the Hearings now underway to explore how the Service Deliver), System might be improved through the Legislative Process. The following are areas of concern to the Johnston Substance Abuse Prevention Task Force:

- A.I.a)(1)(a)(vii) Health Care: Substance Abuse

AN INVENTORY OF EXISTING SERVICES in the Fields of Substance Abuse Prevention, Intervention, Treatment and Aftercare designed to meet the needs and concerns of individuals with Disabilities in Each Community in the State of Rhode Island - by Community.

- B.I.f) Health Care: Census Data

UTILIZATION AND DISSEMINATION OF FEDERAL CENSUS DATA to assist EVERY Leader in EVERY Community understand every Community has an estimated 20% of its Total Population comprised of Individuals with Disabilities.

MAY A BEING SUPERIOR TO OURRSELVES SAVE US FROM AN EXEMPLERARY PROGRAM IDEAL By its very nature such an Ideal implies that an Authority has judged a specific, Program or Event to be Worthy of Note and to be considered for possible Replication. If one views Failure of Effort to be part of the Learning Process - as this Task Force does - then one is open to giving Recognition of Effort to work to Include Individuals with Disabilities in the Mainstream of the Community. Meaningful Recognition given for Effort - can be the catalyst that keeps the Ideal alive beyond the failure of the moment.

Many ask this Task Force what we attribute our success to? The answer is simple. From our Origin - by Vote of the Task Force – Sign Language Interpreters were engaged for all Meetings and events of the Task Force. From the perspective of many Authorities, this was a failure to utilize meager Financial Resources wisely - thus, In their judgment a failure. Yet, from the perspective of this Task Force, no single action or event has contributed more to the success of our Prevention Programming than to have the Sign Language Interpreters present to deliver a non-verbal message of our Effort to include Individuals with Disabilities in the Mainstream of community Based Prevention. It is from this small and insignificant beginning that all of our Prevention Programming has been successful.

Should that early Effort have been Recognized? No, but, certainly the success our Prevention Effort has achieved that resulted from that initial insignificant step should have received at least a means to be decimated in the State of Rhode Island. Meaningful Recognition in our early days would have given an opportunity to help others understand the Effort can be simple and easy to Include Individuals with Disabilities in the Mainstream of Community Based Prevention.

Mr. Cooper, I do hope that the thoughts expressed in this commentary are helpful to you and to those who are working hard to improve the Quality of Life of Individuals with Disabilities.

If you should have any questions, or if you should need more information,

	please do not hesitate to call me at 942-6649. Thank you - in advance for the time and consideration I know you and others will give the content of this communication. Cordially, Michael S. Nordstrom – Chairman, Johnston Substance Abuse Prevention Task Force
➢ C.I.k) Health Care: Discharge Planning ➢ C.V.b)(2) Assistive Technology	"X": Hospitals release people before they are really able to fend for themselves. Then when they do need help at home, visiting nurses visits are limited to once a day (too bad if you need an IV more than once a day). Also, health aides' visits a length of stay are limited. It should go by the needs of the patient. The patient is also told he or she cannot go out while needing their services. Making people prisoners in their own homes. I think this law is illegal and if challenged would be overturned. A while back the newspaper had an article stating more money was needed for psychiatrists to go into senior housing to help these people. If they were allowed to go out when able and live as normal a life as possible, this type of doctor would not be needed. Assessments should be made by the doctor and nurses on the case. Wheelchairs from Mass. and I assume other states cannot be fixed in Rhode Island. They do not recognize Mass. Health People should be able to have wheelchairs and other pertinent equipment fixed anywhere in the country. I would like to see more physical therapy for the severely physically disabled. Science has proven that exercise helps the heart, circulation and skin and bones. Would help prevent skin breakdowns, and reduce infections and nursing care to help heal them. Also, important, helps prevent blood clots.
➢ A.III.b)(c) Employment: Community Based Options	Ann Lavigne: Dear: I am a fairly new member of Hillsgrove House. I came somewhat reluctantly (okay, very reluctantly!) but from the moment I walked in the door, the staff and members have been amazingly friendly and welcoming. A result of my illness has been the tendency to – myself-fearful and anxious to leave my apartment. Unfortunately, while tremendous progress has been made in reducing the negative effects of the stigma attached to mental illness, there is still a pervasive fear among a significant portion of the population of interacting with a mentally ill person. Fear, --wariness, disdain, mistrust-these are just a few of the ways people respond. It makes withdrawal an even more attractive alternative to trying to deal with the hurt and humiliation. The absolute absence of this attitude is the magic that rests at Hillsgrove House. Staff are knowledgeable, supportive, patient and to an almost unbelievable extent, cheerful. They create an atmosphere of acceptance and safety. There is also a continuous focus on the future-a future that is potentially filled with positive change, exciting new goals, a real promise of possibilities. In addition to the staff, fellow members add another amazing dynamic to this clubhouse. The members of Hillsgrove House, as diverse a population as seems possible, offer an endless amount of opportunities to re-enter the world of social interaction. Giving and receiving encouragement, providing inspiration, sharing excitement over another's small or large triumph, just having companionship at a meal-all this and more happens each day here. Sincerely, Ann Lavigne
	Joan Call: When I Joined Hillsgrove House Clubhouse. When I was in my apartment in the Hartford Ave. Projects; the first half of the day; I went for

➢ A.III.b)(c) Employment: Community Based Options	breakfast at the Community Senior Center, or even for walks to the Manton Ave. Olneyville fast-food or Material Possession shops like Burger King on Broadway and Hartford interchanging or Manton Ave and Hartford Star Market and Jewelry etc. stores; Afternoons I cooked my supper around noon to 3:00, or slept on a one box spring mattress bed all afternoon then cooked for two hours, ate, then back to sleep. Here, I do 2 lunch census pks. Or sit half asleep but <u>not</u> asleep, just foggy but I know the names of my many, many friends who try to keep me conversing. I have till lately, been talking to others in the club. Now I, today etc. talk to them and myself. I am in an assisted living unit of an assisted living nursing home. I now don't sleep as long as Hillsgrove gives me a reason to be up and shower, breakfast and out of my room for the whole day into the Hillsgrove House Clubhouse. I used to be at Providence Psychiatric Counseling and Rehabilitation Center. There's a giant office work unit where Providence Center had a cramped cubicle taking and sharing space with 12-16 other people. And modern computers to learn up to date typing, word processing, and internet work. I am in the bare basics of computer typing lessons and practice. Member Joan Call.
➢ A.III.b)(c) Employment: Community Based Options	<u>Nancy Oliver:</u> I am so glad I could come to Hillsgrove House. I was getting depressed at home. I had to come so I would not get depressed. I like to come to Hillsgrove House. It's good for me to around other people. I have learned a lot of paper work. I'm doing the lunch reservation list. I keep busy. It's good for me. Thank God for Hillsgrove House. –
➢ A.III.b)(c) Employment: Community Based Options	<u>Greg Nugar</u>: Dear Sir- I am Greg Nugar and I go to a day program called Hillsgrove House. I have recently learned that you are cutting funds for many, many day programs across the state. I think cutting funds for Hillsgrove House is not a good idea because we need our day program to help us rehabilitate us into society. Our program builds character and helps us --. Without Hillsgrove House we would have a hard adjusting to work and daily living. Our program helps us make friends and other relationships. So in final please don't cut our funds. Sincerely-Greg Nugar
➢ A.III.b)(c) Employment: Community Based Options	<u>Carol Coker:</u> Hillsgrove House means a lot to me. If I didn't go to the clubhouse, then I would be isolated in my apartment all week. At least I see my friends at Hillsgrove House and always have someone to talk to. Member Carol Coker
➢ A.VIII.a)(2) Education: After School Programs	<u>Gloria Perry:</u> Dear Members of the Governor's Commission on Disabilities: Looking Upwards provides Home Based Therapeutic Services (HBTS) for children with disabilities. In our work with children and their families as well as in the course of discussions with parents who are currently on our intake list, one issue repeatedly arises; the compelling need for an after school program that can meet the needs of all children, including those with disabilities. Often children with disabilities have difficulty in finding a peer group with whom to associate after school. Parents of children with disabilities must be creative in developing ways to assist their children to integrate into the community socially. This usually required some form of one-on-one support in well-chosen activities. Many families, due to employment or the needs of

	their other children, are unable to provide their special needs child with the individualized supports necessary for successful participation in after school activities. For parents who need the income provided by their employment, finding productive after school provisions for a child with disabilities is a daunting challenge. These parents often have no choice but to rely on after school programs to provide childcare and to facilitate their children's social development. Yet, many children, due to their disabilities, are unable to successfully participate in after school programs. The stress of raising a child with disabilities is then compounded by work-related stressors as parents risk their employment trying to fill in the after school gaps as their child is dismissed for multiple after school programs. In some cases where a child has extensive home and community based needs, or the child is able to participate in a wide range of after school activities, support for social development can be provided by Medicaid funded HBTS. However, even for the children who meet these criteria, support is not in sight. Due to the rapid growth of the HBTS program, wait lists for services throughout the state are a minimum of one to two years. Looking Upwards is in the process of seeking solutions to the issue of after school care and social inclusion for children with disabilities. We welcome any suggestions, or dialogue that your committee may provide as we work towards developing an after school program where children with and without disabilities can learn, have fun and develop friendships together. I can be reached at www.lookingupwards.org or by phone at 847-0960 ext. 24. Sincerely, Gloria Perry; Executive Director.
➢ A.IX.a)(1) Financial Support	Al Hagenberg: To whom it may concern: I am a retired disabled police officer. I was forced to retire because of injuries that I received in the line of duty. Since my retirement I have always worked a part time job to try and supplement my pension as much as possible. When I was laid off from my job in 1998, I was always allowed to collect benefits until I was able to find more work. Every time I filled out an application I always made it quite clear that I had a disability and that my disability met all the reason given was that I could not work full time. It did not seem to matter to the people in the unemployment office that the only reason I could not work what they considered full time, 35 hours a week, was because of my disability. R.I. anti-discrimination laws (42-87-1) (42-87-2) (42-87-3) also state that people with disabilities cannot be denied benefits or programs based on the fact that they have a disability, the RI Laws virtually mimic the ADA. Every time I have talked to anyone from the Department of Labor and Training I have asked for a copy of the law, regulation or memorandum which says that a person with a certified disability can be denied unemployment benefits when that disability alone prevents them from working what the department considers full time employment especially when that person has worked long enough to have more than the minimum required in their count to collect unemployment benefits had he or she not been disabled. The policy of the Department of Labor, as it now stands, would deny benefits to a disabled person even though they may have worked 20 years in a part time job simply

	because their disability, as mine did, prevented them from working full time. I have copies of all my unemployment records including all the applications that I have submitted. I also have all the replies from the Department of Labor none of which mention the fact that I have a disability and that disability prevented me from working full time. Respectfully yours, Al Hagenberg.
➢ A.II.a)(2)(a) Transportation ➢ C.VI.d) Education: Adult ➢ A.IX.a)(3) Financial Support ➢ C.VI.d) Education: Adult	Sharon Parker: Please include this written testimony. * Transportation-more monies are needed for transportation to places other then doctor's visits, i.e. shopping, swimming, groceries, exercise. * Financial assistance for people with disabilities to take classes such as art, sewing, music, etc. * More food stamp assistance. The amount I receive does not get me through the month. *I would like to see a reward program. This program would reward people financially who were honest when applying for various services. *I feel there is a great need for classes, funded by the state, to teach coping skills for people with disabilities.
➢ A.I.a)(1)(a)(ii) Health Care: Mental Health	Jan Lorensen: National Perspective On December 13, the Surgeon General released a report on mental illness in which Dr. David Satcher asserts that "Through much of this era of great challenge and greater achievement, concerns regarding mental illness and mental health too often were relegated to the rear of our national consciousness." "My message to Americans is this," said the Surgeon General, "If you, or a loved one are experiencing what you believe might be the symptoms of a mental disorder, do not hesitate to seek effective treatment now. Insist on the kinds of services that this report makes clear which can and should be available. While there is no single solution to any mental disorder, most people with mental disorders have treatment options-including medications and short term psychotherapy, and community-based supportive services." The report proposed broad courses of action to improve the quality of mental health in the nation including: continuing to build the science base, overcoming stigma, improving public awareness of effective treatment, ensuring the supply of mental services and providers, ensuring delivery of state-of-the-art treatments, tailoring treatment to age gender, race and culture, facilitating entry into treatment, and reducing financial barriers to treatment. **State Perspective** In June 1999, the Governor's Council on Mental Health presented its Rhode Island State Mental Health Plan, Into the Millennium – Recovery. This plan points to new directions for mental care in Rhode Island. "It focuses on the way in which services should be provided in order to achieve client recovery and empowerment, and as a result, community membership." Hillsgrove House is pleased that the State of Rhode Island is moving in the direction of recovery. We support Into the Millennium – Recovery and we concur with the statement "Recovery is a process, not a one time end stage goal which is attained once and for all, but a work constantly in progress." We believe that as a clubhouse, Hillsgrove House is a vital step for many individuals who voice a need for assistance with the process. At Hillsgrove House members

➢ A.III.b)(c) Employment: Community Based Options	find assistance from others, both members and staff. The support extends to a job site, at school, or in social settings within the community. At Hillsgrove House members have one goal, “I take responsibility for my recovery process.” At Hillsgrove House Our program provides: *A proven environment and best practice, which continues to expand throughout the world due to tits success in assisting individuals with mental illness reach goals of recovery over a 40 year period of operation. *Consistent employment for active members exceeding the national average of 20% for persons with serious mental illness. *Ongoing hospital diversion with a minimum number of hospital days for active members. *A place to be needed and wanted in a work-ordered setting with additional activities provided on weekends and holidays *The opportunity to be empowered within and accepting, rehabilitative community, which supports goal attainment and recovery for consumers. As of January of 2001, restrictions were placed on many Medicaid recipients, which prevented funding of their extensive services within the Hillsgrove House Program**.** In addition, all members who have private insurance attend the program unfunded. Approximately 50% of the members involved on a daily basis are now in these categories. As an agency, Kent County Mental Health Center has continued to support these individuals, regardless of the lack of reimbursement. The financial implication of continued service provision without adequate funding places all participants of the program in jeopardy of losing this necessary resource. – Jan Lorensen, M.A. Hillsgrove House Director.
➢ A.I.a)(1)(b)(viii) Health Care: Community Based Options	Robin Duquette: My son, Michael Duquette is a Rhode Island resident. He is deaf and is ready to come back to his home state. He needs 24 hour care (behavioral care) in the state of Rhode Island. Can you please help him? He signed papers wishing to live near his family. He is deaf, 19years old, post traumatic stress, pervasive developmental disorder, mental retardation, oppositional defiant disorder, obsessive compulsive disorder, attention deficit disorder, and on occasion aggressive and sexualized behavior, but…he is the greatest kid you’ll ever meet. Please help him come back to R.I. Sincerely, Robin Duquette

J. *Written Testimony*

➢ E.II.c)(1)(c) Access: Physical ➢ B.V.b) Education ➢ C.III.a) Employment: Training	Brenda Behie; Meghan O’Leary; Scott Driggers; Adriane Resmini; Anne Bisikirski: Dear Governor’s Commission on Disabilities: We feel that there are many things needed for people with disabilities. There should be greater accessibility to different places for people in wheelchairs, better education in the schools for students with disabilities, better preparation and training for jobs, more job opportunities, better public transportation, especially in rural communities, low cost medication and health insurance for all. We are young

- A.II.a)(2)(a)(ii) Transportation
- A.I.a)(1)(b)(i) Health Care: Medication

adults with disabilities who are in high school, or have recently graduated. We would like to see programs for students after high school to help prepare us for the Real World. Sincerely, Brenda Behie; Meghan O'Leary; Scott Driggers; Adriane Resmini; Anne Bisikirski.

Margaret P. Lacouture: I am enclosing a copy of my testimony from March 2001 before the Subcommittee on Human Services of the House Committee on Finance. Although the funding was not approved in this year's budget process, there is a critical need in Rhode Island for funding for Traumatic Brain Injury (TBI) programs. I urge you to support it next year. Please include my statement in your deliberations. Thank-you. Sincerely, Margaret P. Lacouture

Statement of Margaret P. Lacouture
Before Subcommittee on Human Services
House Committee on Finance
March 26, 2001

My name is Marnie Lacouture and I live in Exeter. I am speaking before you today to urge you to appropriate funds for day and residential programs for traumatic brain injury survivors.

I am the primary caregiver for our son Andy, who sustained a traumatic brain injury (TBI) in a car accident in 1987 at the age of seventeen. Before his accident, he was a popular high school senior who planned to attend college. He could juggle, ride a unicycle, windsurf and play soccer.

Because Andy's accident happened while he was still in school, after seven months of hospitalization and rehabilitation he was sent to the brain injury program at the Sargent Center by the Exeter West Greenwich School Department. He attended this program until he turned twenty-one, at which point we felt as though we'd been abandoned. We floundered over the next few years until partly by chance and partly by searching, we learned that he was eligible for funding from the Department of Developmental Disabilities. He now receives day services from Perspectives Corporation and the Blackstone Valley Arc.

TBI affects each individual differently. Today Andy, who recently turned thirty-one, is personable, good humored, and patient. However he has practically no short-term memory, so the learning of new information is very hard for him. He is forever in danger of falling because of problems with balance, reflexes, and attention. We have lost track of the number of times he has had to go to the emergency room for stitches. Although he is fairly independent walking around the house, we never leave him alone for fear he may fall or even set the house on fire. He has turned the teakettle on with very little water in it and tried to put wood in our woodstoves. His judgment is poor, and because he lacks awareness of his disabilities, he thinks that he can do the things he did before his accident. The organization and completion of basic tasks is almost impossible for Andy. Decision-making is very difficult.

Because we do not leave him alone, we are like parents of a first-grader. I must be home every afternoon, and my husband Pete and I never go out without either taking Andy along or making arrangements for someone else to stay with him. We no longer have other children at home to help us, or family in Rhode Island to support us. When we go on vacation, Andy goes with us. I have an eighty-seven year old father in Minnesota who is unable to travel, so I rarely see him.

Because Andy doesn't remember what day it is or where he is going or what he is doing each morning, and because he doesn't initiate activities (at least the ones he should be doing), it is up to me to get him going. He is very slow and easily distracted, so it is a constant push to have him ready on time. He needs to be reminded daily, sometimes several times, to shave and to shampoo. Pete is very helpful and patient with Andy, however he works long hours and is always under a lot of pressure at his office. Last fall he had a couple of episodes of chest pains and was taken to the hospital early one morning by rescue. I cannot describe the isolation I felt at not being able to go with him. I did not have anyone to call who did not have a job to go to or who knew Andy well enough to help him get ready for his day. I was able to go to the hospital once Andy's staff person for the day arrived, however I had to return home in the afternoon and then make arrangements for someone to come stay with him (a friend who does not know Andy's routine) so that I could go back to the hospital. The next day presented similar problems. Fortunately someone from Perspectives was willing to meet Andy's RIDE bus so that I could take Pete home when he was released.

- A.I.a)(1)(b)(vi) Health Care: Community Based Options

- A.I.a)(1)(b)(vii) Health Care: Community Based Options

From the time of Andy's accident until now Pete and 1, with whatever help we could find, have been creating a path, albeit crooked, of rehab, activities and supports for Andy to follow. Other families and survivors of TBI have been doing the same thing. Pete and I are now at a point where we realize the importance and urgency of finding a way for Andy to live independently so that he can adjust to new surroundings and settle into a life of his own while he is still young and we are still alive to help him. It would have been beneficial for him to have done this years ago. He is a sociable young man who enjoys the company of others, and I am sure that he would make strides toward a more independent life without two parents directing his every move. At this time there are no group homes appropriate for the brain injured population, although we know many people who would benefit from them.

My husband and I have devoted most of our time and energy to Andy's care and recovery over the past thirteen years, perhaps to the detriment of our other children. We love him dearly, but we are worn out. We cope with day-to-day life like we are treading water, although at times it seems more like we are sinking fast. I urge you to take the first step towards meeting the serious needs of the brain-injured population.

Thank-you, Marnie Lacouture

Shelley G. Green: To Whom It May Concern:

Every year in the United States, two million people sustain a traumatic brain injury. Here is one woman's story:

It's every parent's nightmare. The police come knocking on your door at 5:00 in the morning to tell you to get to the hospital right away. The fear begins and the horror starts.

My only son Todd fell asleep driving. He was not wearing a seat belt when he hit a telephone pole on Smith Street, and he suffered a traumatic brain injury.

At that moment, I could not believe it was real, this could not be true. He just got home from serving during the Gulf War, he was healthy and strong. I just saw him hours ago. He was fine. But as I kept saying no, I knew how horribly real it was and I could not stop it. I wasn't going to wake up from this nightmare. It had only just begun.

When the doctor walked around the dark comer of the hall at Rhode Island Hospital with the priest to tell me my son had a traumatic brain injury and would not live the night. If he did, he would be brain dead. She said she was sorry and turned to walk away. And I died.

Please God, not my only 21-year-old smart, handsome and healthy baby boy. Please God no. I asked God so many times ... why? As I asked God for every second he'd laid in his broken body, in a coma alive. Praying that one-day he'd come back to life, to me, for him. I no longer ask God why. I know why this has impacted my life. I am a sister of a brother who died at seven at Zambarano Hospital from a TBI he suffered at birth. I named my son Todd in honor of my brother Todd. I am also an ex-wife of a victim of a motorcycle accident where he was not wearing a helmet and suffered a TBI the summer of 2000.

I will lobby to my death if that's what it takes to educate and prevent traumatic brain injuries. To work for programs in Rhode Island to get the supports for the victims and families faced with this crisis.

- A.I.a)(1)(b)(vi) Health Care: Community Based Options

I thank God every day for the miracle I have been given. My son Todd after many years can now live independently. The process has been an unbearable journey, from hospital to hospital, from rehabilitation center to rehabilitation center, from mental health to mental health facilities, from organization to organization, from state to state. Because he was over 21 and this was not an organic injury, he fell through almost every crack. It was with the help and support of the Veteran's Hospital we found a program in Connecticut working with TBI adults.

In efforts to gain a greater quality of life I had to take this child who at the age of 26 was like at most a 13 year old mind with lots of dysfunction and move him from his only life line, me. In need to support him I would drive 2 hours each way as often as I could each week. That continued for more than a year. He continues to make improvements but the program we moved him to has been closed for months.

So now I'm trying to find housing for him back home in Rhode Island where he belongs. We are on the waiting list with 1 00 others who also need supported housing.

Traumatic Brain Injuries impact every area of your life, your world and your spirit. As you fight endlessly for the life and needs of your unable child, you watch your own life as you know it quickly disappear. Family, friends, supports, jobs, money, pleasure, freedom, peace and dreams fade away.

As a parent you will never want for anything greater than for the life of your child. As you read this story, you may imagine what this is like to experience. As I would have before my son's accident. Trust me, you cannot even get close to how this feels and impacts your world. The pain and lack of support devastates your life at a time when you need all the strength and the hope just to face another day. In your efforts to get help, you're most often dismissed.

Please do not close your hearts or minds to the needs of those suffering from traumatic brain injuries. We must educate and fund programs to help prevent, or care for the traumatically brain injured.

If saving lives is not enough of a reason for increased funding, saving the taxpayers' money should be. The cost to the state for one survivor can be multiplied many times over the amount of the grant. It cost over a million dollars to save my son Todd.

Please let's put our healthy brains together to advocate for the prevention and the rights of those who are already injured and unable to advocate for themselves or for the families who are too overwhelmed to face one more battle.

If you have any questions or continents, please contact me. Thank you for your time and attention, and I hope support for a most needed increase in funding. Sincerely, Shelley G. Green

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- A.I.a)(1)(a)(v) Health Care: Community Based Options

My name is Marilyn Lima. I live at 30 Rowland Street in Pawtucket. I have my own apartment and have lived on my own for seven years. I can do this with help from my staff at the Blackstone Valley RI Arc. If I am not able to get staff I won't do my shopping or get to work, or be safe and healthy. I like living on my own and not relying on my parents because they are getting older. My parents visit me. I even cook Thanksgiving dinner at my apartment and my whole family comes!

I am the Self-Advocacy Coordinator for the BV RIArc. My job is very important to me. I help people speak up for their rights. I helped a lot of people write letters to the Finance Committee so you know about us and what we need. I am a registered voter and so are most of my friends. We know how important it is to be good citizens and to speak up. I am also a member of the Advocates in Action Board. I think it is important for all self-advocates around the state to be organized because we have a lot of the same concerns, like transportation, housing, good jobs, and good staff.

When you are voting on the budget, please think of me and my friends and the things we need as citizens with developmental disabilities. We want the same things that everyone else wants, but we need some extra help to have a good life. Please make sure that we can get and keep good, caring, helpful staff.

- A.I.a)(1)(a)(v) Health Care: Community Based Options

My name is Karen Lema. I live at 50 Tim Healy Way. I work at the Blackstone Valley Chapter RI Arc as a Peer Advisor for the Advocacy Office. My job is to teach people with disabilities like me how to speak up. We need to let you know what we want in life. I want to be able to do more on my own.

I want to know that my house will always be there for me and there

- A.II.a)(2)(a) Transportation
- A.V.a)(1) Direct Care Workforce

will be staff to help me. I need help with bathing, hygiene, household jobs, and transportation. I use a lift van to get around. There are times when the vans break down or there are no vans available. Then I am stuck in my apartment.

I am very upset about the staff at BV RI Arc going on strike. I am afraid we are going to lose good staff. It is too bad that this is happening to us.

Please make sure that there is enough money to pay for the support I need and the transportation I need. I could not continue my life the way it is without support. I hope you can help us.

- A.V.a)(1) Direct Care Workforce

My name is Lorraine Beaudoin. I live at 85B Ashton Street in Pawtucket. I have testified before the House Finance three or four times before. I liked speaking up. Representative Sherlock always listens to us because he knows we try to do the best we can.

This year I am writing a letter to tell you how things are going for me and my roommate, Heidi Luescher. This year will be nine years that we have lived together in our own apartment. We share the expenses together. We have staff from the Blackstone Valley RI Arc. We have staff every day and we like having them. I don't know what we would do without them! Some of our staff leaves because they want a different job and need to make more money. They would probably stay if they made more money. It's hard when staff leave because we have to get used to new ones but we are getting used to this now because it happens so much.

I work at the BV RI Arc's resale shop, New to You, in Pawtucket. I do the cash register, give the customers change, fold clothes, bring in donations, put prices on the clothes, there are lots of jobs that I do. I love my job!

I am also a member of the BV RI Arc's Board of Directors. I listen, ask questions, and vote on motions. The Board makes important decisions. It is our job to make sure we can find and keep good staff. We need to have enough money to pay the staff so they will stay. Please make sure we get enough money in our budget to do this.

- A.IV.a)(1) Housing
- A.I.a)(1)(a)(v) Health Care: Community Based Options
- A.V.a)(1) Direct Care Workforce

My name is Betty Henman. I live in Lincoln at 681 Great Road. I have lived there with my parents all of my life. I am 60 years old and I have a developmental disability. My mother is 89. My father passed away a long time ago. My mother is in a nursing home now and I have been staying with respite providers and sometimes with my neighbor. I need to find an apartment and people to support me with running my own household. I will need to learn a lot about living on my own. I would like to have a roommate.

I get a lot of support from the Blackstone Valley of RI Arc where I work in the cafeteria at Independence Square.

It is very hard for me right now with my mom being sick. She had four heart attacks and I had to call 911. I blacked out at work and they had to call 911 for me three times.

Please make sure there is money to pay for my supports. I don't know what I would do without people to help me.

From: Bethany Indeglia

My name is Bethany. I live at home with my parents. I'm a registered

➢ A.V.a)(1) Direct Care Workforce ➢ A.V.a)(3) Support Services	voter. I had a job coach who helped me get and keep a job at Rojacks. They taught me how to bag groceries, get to work on time and meet my co-workers. Now I work all by myself Staff just helps me get to and from work. My staff is always nice to me. I wish they could get paid more money because I like to keep my staff and not have to get used to new staff. Thank You!
➢ A.I.a)(1)(a)(v) Health Care: Community Based Options ➢ A.V.a)(1) Direct Care Workforce	From: Sherrie Tibbetts I live in a group home in West Kingston managed by RICLAS. My staff helps me with a lot of stuff like bathing, dressing, cooking, shopping, budgeting and medical needs. I need their help. I can't do it by myself I have Cerebral Palsy. Staff helps me with my speech. Sometimes I have good days and sometimes I have bad days. If I have a problem, I talk about it. It's important for me to keep the staff I have because they understand my speech. The staff is my voice to other people. It is really sad to me when I loose staff. It is very difficult to find new staff. I like the services and staff I have right now. I just wish there was enough money to help other people like me. Thank You!
➢ A.V.a)(1) Direct Care Workforce	My name is Chris Vecchia. I live in an apartment in Providence and I'm a registered voter. I receive services from the Division of Developmental Disabilities by an agency called Refocus. I like my services but I don't like when my staff leave for a better paying job. After they leave, I get very depressed and it is difficult for me to trust new staff. My services would be a lot better if we could pay staff enough money so they wouldn’t leave us. Thank You!
➢ A.V.a)(1) Direct Care Workforce	Hi, my name is Billy Kwiatkoski, people call me Billy K. I'm 34 years old and I live in my own apartment in Providence. I am a registered voter and voted in the last presidential election. I think staff should get more money because they don't get paid enough and they are too good! They take me where I want to go and where I have to go, like doctor appointments. They help me set up my calendar be as independent as I can be. Someday I want to get married and have kids. I know I will need more staff support to help me with the responsibilities that go along with being a good dad and husband. Thank You!
➢ A.I.a)(1)(a)(v) Health Care: Community Based Options ➢ A.V.a)(1) Direct Care Workforce	My name is Melissa Armstrong. I live in Richmond with my parents and I'm a registered voter. I have support staff two times a week to do fun stuff. We go to the movies, out to eat, shopping and other activities. I would like to live in my own apartment someday. I can do a lot of things independently like food shopping, budgeting cooking and laundry. I know I can do it with the right amount of staff support. Self-Advocacy has changed my life. Since I've joined a self-advocacy group I get along better with other people and I have more friends. I’m learning a lot about my rights. I want you to know that I like my services from the Division of Developmental Disabilities. I hope that when I'm ready to start living on my own that funding will be available so I can live more independently and not rely on my parents to take care of me. Thank You!
➢ A.V.a)(1) Direct Care Workforce	My name is Ed White and I live in a group home in Exeter, RI and I'm a registered voter. My staff helps me out when I have problems. They teach me to talk about my problems and to be good to others and myself. I like my staff and I want them to be happy so they won't leave me for

	a better paying job. You can help by approving a budget that would give them a pay increase. Thank You!
➢ A.I.a)(1)(a)(v) Health Care: Community Based Options	My name is Gary Shurtleff and I am a registered voter. I live at home with my parents in West Kingstown. I get a lot of services. My support staff helps me do my food shopping, laundry, and cooking. My services have helped me to do things by myself. I don't need to rely on my parents anymore to take care of myself. Someday I would like to get married to my girlfriend. I know we will need a lot of support to live independently. I am very pleased with the support I get from the Division of Developmental Disabilities. I hope you continue to make good decisions about their budget so they can help me and others lead more independent lives.
➢ A.I.a)(1)(a)(v) Health Care: Community Based Options ➢ A.V.a)(1) Direct Care Workforce ➢ A.V.a)(3) Support Services	My name is Bobby Deritta. I live with my mom in Middlebridge and I am a registered voter. I get recreation and job support from the Division of Developmental Disabilities. My staff helps me be more independent. Some day I would like to move out of my mom's house and get an apartment of my own. I know I will need staff to help me with food shopping, paying bills, laundry and transportation. Self-Advocacy helps people out with their problems. People get involved, support each other and form friendships. I think staff needs to make good money and get raises. Job coaches work hard and deserve to make enough money so they don't have to work two jobs. Thank You
➢ A.V.a)(1) Direct Care Workforce ➢ A.V.a)(3) Support Services	My name is Jenna Brachenbury. I live at home with my parents in North Kingstown. I am a registered voter. I work at the LaPlante Center on piecework and I also work at the coffee shop at URI. My support staff helps with transportation to and from work. When I first started to work at URI I had a job coach who taught me how to do my job duties. They taught me how to clean the tables, make cookies, set-up the coffee -shop and run the cash register. Now I can do everything by myself! I think it is difficult to find support staff and to keep them. I hope you increase the budget so staff can make decent money for all their hard work. Thank you!
➢ A.I.a)(1)(a)(v) Health Care: Community Based Options	My name is Mark Susa. I live at home with my parents in Warwick. I'm a registered voter. I knew whom I wanted to vote for president because my mom helped me fill out a form from the RI Polling Center. I'm glad my candidate won! I own my own business. I help other people with disabilities learn how to use the RI Public Transit Authority, RIPTA. My staff help me with travel training and learning how to be more independent. They're great! I don't know what I would do without my staff. I talk to my staff if they don't do something right and they listen to me. Someday I would like to get married and move to an apartment or house. I will definitely need more staff support to continue to lead the life I choose. Thank You!
➢ A.V.a)(1) Direct Care Workforce	My name is Joyce Kasnanek. I live in an apartment in Narragansett. I'm a registered voter. I like the new machines! My sister has Cerebral Palsy. She needs a lot of staff support to get around. I want to make sure she continues to get good services. I have support staff too. I'd go stir crazy without my staff. I want to be more independent so I don't have to rely on staff. I like my services in Rhode Island from the Division of Developmental

Disabilities.

It makes me sad to lose my staff. About a year ago, I lost the best staff I ever had I still miss her! I wish she didn't have to leave me so she could make more money to take care of her family. Thank You!

- A.V.a)(1) Direct Care Workforce

My name is David Vaughn. I live in a group home in Richmond and I'm a registered voter. I have support staff 24 hours a day 7 days a week. The staff helps me work towards being more independent. Someday I'd like to move to an apartment.

Good support staff and teamwork is important. I really need my staff to help me with problems and to be a good listener. It's upsetting to me when my staff leaves because I loose a member of my team. It takes me a while to get a new team player.

Self-Advocacy has taught me to help other people. Advocates in Action help us speak up for ourselves. Sometimes we write letters when things are important. That is why I'm writing to you. Lots of people need the same services I get and don't get help because there is not enough money. Let's get people off the streets. People are graduating from High School and want to move out of their parents home to live on their own. They will need a lot of support. We need your help to fund the services they will need. Thank You!

- A.I.a)(1)(a)(v) Health Care: Community Based Options
- A.IV.a)(1) Housing
- A.V.a)(1) Direct Care Workforce

My name is Jessica Rohdin and I am 20 years old. I live at home with my parents and I am a registered voter. I voted in the last presidential election. I learned a lot about the candidates from watching T.V. and reading the newspaper.

I work together with my staff. We work as a team. It's been about one year that my staff helps me for 15 hours a week. I did not get any services from the time I was 3 to 19. I wish my parents and I knew about services, that were available to me, sooner. I feel like I have missed out. Maybe I'd be more independent today if we had known about support services.

I am graduating from high school this year. I will be 21 in May. I will need a place to live and staff to help me with my needs. It's important to me to be part of my Self-Advocacy Group and to learn about my rights and responsibilities. I want the same opportunities that my friends in the group have. Please make sure there is enough money in the budget for new people like me. Thank you!

- A.V.a)(1) Direct Care Workforce

My name is Melinda Taylor. I live in a group home in Narragansett and I'm a registered voter. My support staff is important to me. I have no family since my mother passed away. My support staff has become my family. It is very sad and hurts me when my staff leaves for a better paying job. I need them to help me. They teach me new skills and help me gain independence.

Self-Advocacy is part of my life. I've made new friends, helped other people and learned to speak up about my rights. Could you please help me keep my staff by making sure they get a good paycheck? Thank You!

My name is Lisa Caetano and I live in East Providence and am a registered voter. I am very interested in the MHRH budget hearings coming up as I get supports from the Division of Developmental Disabilities. I would like to learn more about the budget.

I live in an apartment and get services such as clothes and food and home.

- A.I.a)(1)(a)(v) Health Care: Community Based Options

My staff helps me to be more independent. I feel services are good. I would like to go out more for activities. We need more staff help. A good staff person is someone who makes me laugh and talks and listens to me. I am involved in self-advocacy, which helps me to think about positive things. It helps me to communicate and speak out more. The name of our group is "All Advocates Together ".

Thank you for your attention to this matter.

Ellen and Philip O'Hara:

We recently learned that the State of Rhode Island conducted hearings to "identify the concerns of people with disabilities and their families" during August. We were unaware of these hearings as we were out of state on vacation. We would like to take the opportunity now to provide you with a description of a situation encountered by our son that we believe illustrates a gap in services that should be addressed.

Our son, Peter A. O'Hara, age 32, was born with Spina Bifida and uses a wheelchair for mobility. Up until one year ago, Peter lived in our home, which was made wheelchair accessible over 25 years ago through a low-interest loan from the Community Development Block Grant program. Peter graduated from high school, CCRI and URI. It took him ten years to complete his college education, and it was quite an accomplishment for him. He worked as an Americorps Volunteer for two years, gaining important job skills, and subsequently was hired for his first job in October of 1999 with MetLife. With job and income stability a reality, Peter was anxious to become more independent in his living situation.

- A.VI.a)(2)(b)(ii) Accessiblity: Housing

In the Spring of 2000, after surveying available and affordable apartments, in areas served by the Ride Program, it became quite apparent that modifying a rental apartment for accessibility was going to be, either a major undertaking, or not possible at all. In June of 2000, he turned to Rhode Island Housing and purchased a home under their First Time Homebuyers Program, which gave him access to low-interest and deferred mortgages. He found a small ranch-style home, ideally constructed to allow handicapped accessible modifications.

We would like to provide the Commission with a description of our son's unsuccessful attempts to obtain some financial assistance to make his house accessible.

ACCESS INDEPENDENCE II

- A.VI.a)(2)(b)(i) Accessiblity: Home Modifications

The staff at RI Housing referred us to the home accessibility program offered through the Department of Mental Health, Retardation and Hospitals (MHRH). In June of 2000, I first discussed with Mr. Paul Grenon Peter's potential to be eligible for this program. I described his disability and diagnosis, and his income status. Mr. Grenon encouraged Peter to apply and sent an application in the mail. He did warn us, however, that the program had run out of money at that point in time, and that it was not clear when future funding might be made available. Immediately after closing on the house, (ownership was a pre-requisite for eligibility) Peter submitted the completed application. We heard nothing, not even an acknowledgement of our application. When we called, we were told there were no funds available.

In the meantime, we began searching for other sources of funding, the results of which are as follows:

PARI

- C.I.f) Health Care: Timely Modifications
- D.I.b) Health Care: Flexible Rules

It would appear that Peter would have been eligible for this program, based on his disability and income. However, the waiting period before funds would become available, we were told, was nine months to one year, with an emphasis put on "one year" by the person providing the information to us. In order to be considered for the program, the house (or the apartment) to be made accessible would have to be in the applicant's name. In other words, Peter would have to buy the house, then apply to the program, then wait at least a year to receive the funds and then make the necessary construction changes. *<u>This would be a financial challenge for most applicants.</u>* We were told that no funds would be available retroactively. In other words, Peter could not submit his application, borrow money to finance the construction, move in to his home in a timely manner, and then receive funds to pay for the renovations made. We spent considerable time with the program staff person, discussing several hypothetical situations, trying to determine if there was any flexibility in this program to meet Peter's needs - all to no avail.

VOCATIONAL RERABELITATIVE SERVICES

- C.I.h) Health Care: Eligibility
- A.II.a)(2)(a)(i) Transportation: RIde

Based on information provided by the Department of Vocational Rehabilitation, Peter was not eligible for any assistance from this program because he was employed. He was told, as an alternative, that he could *quit his job*, which would allow VRS to place him in another status category, thereby making him eligible for housing rehab assistance! (Additional information in this situation, which is relevant, is that Peter's place of employment, MetLife on Division Road in West Warwick, was just beyond the boundaries of the RIDE program. In order to get to work Peter had to use a combination of the RIDE Transportation and paying for a private taxi. VRS assisted Peter for several months to defray the cost of the taxi. Since June of 2000, however, Peter has been able to access additional West Warwick subsidized transportation and no longer needs the VRS financial assistance.) It is extremely ironic, that now, at the time that he had actually achieved his goal and had gained fulltime employment, this agency was telling him he should become unemployed!

Ocean State Center for Independent Living

Peter was not eligible for any assistance from this program. We were told that they do not provide funds to *working people* or to help people to *get to work*. Rather their funds assist people to remain in their homes, or in an independent living situation-people who might otherwise be headed for group care or nursing home. However, the staff of this agency *<u>advocated strongly</u>* on

Peter's behalf with VRS, as it was their belief that VRS was the proper agency to provide assistance to Peter.

Access Independence II

- C.I.h) Health Care: Eligibility

During this past summer Peter was re-contacted by Access Independence II and evaluated by them for eligibility for their program. They denied him assistance, as he did not meet the developmentally disabled criteria. He met two of the three categories required - *diagnosis* and *mobility* - but not the third one in the *learning* category, despite the fact that Peter has received Special Education services throughout his entire academic experience, including college. (We are in the process of appealing this ruling.)

In summary, there were not any funds available to this young man, wheelchair bound since three years old, who, after 32 years, had reached his goal of independent living, to assist him to make his new home accessible. It really surprised us, after so many decades of major accomplishments for people with disabilities, that there were not any resources to respond to this relatively uncomplicated request. As a result, we borrowed $26,000 to assist Peter to move into his own home.

We would strongly recommend that the Commission review all programs that provide housing accessibility funds and identify those bureaucratic and programmatic *barriers to access* that prevent applicants like Peter from receiving assistance to which they are entitled.
Sincerely, Ellen Crosby O’Hara, Philip J. O’Hara

K. *E-mailed Testimony*

- C.III.a) Employment: Barriers

“Mr. X”: The State of R.I. should be an extemporary employer to the public and private sectors by having people with disabilities visual at management levels (not just entry levels or token positions here and there) and especially with programs who work with people with disabilities such as DHS and the Office of Rehabilitation. By doing this it will inspire the general public, the private sector as well as people with disabilities.

This state is now making some advances in Public Transportation for people with disabilities to work, shop and keep appointments more funding is needed. The author’s name is confidential.

- A.III.a)(1)(a)(iv)(a) Employment: Barriers

John Martinelli: Dear Ms. McConaghy, (Doreen) With Public Hearings scheduled for the week of August 20th regarding "Concerns of People with Disabilities and Their Families." I would at least for the record like to explain serious issues that continue to undermine the very foundation of the Disabled to Work Programs. First and most dangerous to the national effort to have equal employment opportunities available to person's with disabilities wishing to compete in the workforce is this mind set that one must meet Welfare Guidelines to become eligible for any Personal Care Services pertaining to Medicaid Waiver Programs? The cornerstone for the success of this

program is not to make more and more restrictions but to remove all barriers, obstacles and disincentives, but that is not the case; It reminds me of the joke that asks: Why are services from The Department of Human Services exactly like a Tampon?
Because no matter how many times you use them there's always a string attached. PCA Services under the Medicaid Waiver Programs or (PARI WAIVER) are controlled, regulated and financed totally by State government. In my opinion DHS have worked for so many years as leaders in the field of Mental Health & Hospitalization they don't know what Independent Living or Self Determination means. It means to me, a person with a disability can do the exact same things as the able bodied community just by knocking down all the economic guidelines such as, spend downs, Welfare Federal Poverty Level guidelines, that are set and totally controlled by DHS, The Federal Government gives the power to the State to set these economic guidelines regarding Medicaid. That doesn't mean that state government should undermine laws already implemented by the federal government, but should use the federal laws to build upon. Although the Director of the Department of Human Services could set the FPL Guidelines at 250% + the guidelines are set to the weakest link possible. To be eligible for any medical care, Attendant Care, or Homecare, the prerequisite for any of these services one must be indigent. All federal efforts are in vain.
How could East Berlin be a Democracy if the Berlin Wall was still standing, yet you talk Independent Living but the walls that control Attendant Care are as strong as ever. When are all the walls based on Welfare guidelines going to be torn down? Attendant Care is a necessity not a privilege that is dolled out to the chosen few. Many persons with disabilities who could work, pay taxes, and earn large profits for their employer's, sit at home.
I believe there is a philosophy that believes one must take care of the disabled they are not suppose to take care of themselves. Tell me what is the difference if a person is living independently at home and every day they watch television while receiving Attendant Care or Homecare, or if they get up every morning go to a 4 -10 hour job every day? That same person needs the exact same care?
The difference is you Keeper-of-the-Keys are afraid that this same disabled person might earn enough money to go to the Capital Grill. You want the disabled to work and earn money , but not too much money, you wouldn't object if they dined at the 99, but how dare they eat at the Capital Grill when those disabled people are receiving free Health Care. I mean they are receiving taxpayers Welfare money for their medical, so let them work, earn money, but not too much money other wise we will need to add tariffs, penalties , spend -downs, anything to regulate income earnings just so they can earn a few crumbs, but not enough for the loaf. SOCIAL SECURITY ADMINISTRATION: The SSA has set guidelines regarding the working disabled that are somewhat more realistic and based on fairness and even compassion, but they only go so far. They do allow

	the Working Disabled to maintain their SSDI monthly disability benefits and still earn wages from Home Employment or Part Time Employment up to $700.00 a month based on Gross Earnings. Other incentives apply such as out-of-pocket medical expenses and work related expenses. Programs such as TRIAL WORK PROGRAM, PASS PROGRAMS, and many other excellent starter programs are available . They still tax the disabled and elderly SSDI checks at 85% of ones annual income. None-the-less, they do open the doors to many wonderful opportunities. So for that Thank You Very Much. DEPARTMENT of HUMAN SERVICES: To receive Medicaid one must have income below the Federal Poverty Level Guideline, (based at 100% of FPL) which for the Working Disabled in Rhode Island is $706.00 a month, Income over this monthly Welfare allowance is a disincentive to the wage earner, or SSDI recipient. Personal Care or Homecare is totally based on Welfare Economic Guidelines. Out-of-Pocket Medical l Expenses must be your total responsibility until your assets are brought down to this Poverty Level Income Standard. EXAMPLE: If your SSDI earnings are $990.00 monthly and your allowable earned wages based on SSA guidelines are $600.00 a month based on Gross Earnings. Your portion for PCA Services for Attendant Care or Homecare Services are $884.00 a month. That's correct $884.00 for Medicaid Services Your deductions must be for Medical expenses. Rent, food, heat, electric, etc .are not deductibles for Attendant Care or Homecare. So if your monthly income is $1,590.00 = $884.00 a month is deducted for Medical or 53% . So all that the SSA, HCFA, HHS, etc. are trying to do to improve services for the Working Disable are all undermined by DHS WELFARE ECONOMIC GUIDELINES. - John Martinelli
➢ A.I.a)(1)(a)(iv) Health Care: Financial Allowance	Samuel Williams: I attended the hearing at Zambarano but stepped out of the room before making my statement. I would like to ask the Commission to look at the amount of money (monthly living allowance) given to those people who reside in nursing homes or hospitals. We get $50 a month right now, but find it hard to spread the money over the 30 days. If we want to go out on a trip once a month and buy something new to wear such as a pair of sneakers, we have to save for several months. I think that the living allowance is too small. In my case I also smoke which makes it impossible to save for much of anything. But even if I didn't smoke it would be hard to take care of my personal needs with so little money each month. I hope you can help with this problem. - Sam Williams
➢ A.I.a)(1)(c)(i)(i) Health Care: Community Based Options	J. Bowden: My primary concern is getting home health care on the weekends for my disabled husband. Nine years ago, he had a stroke, which paralyzed his left side; previous to that he had both his legs amputated due to insufficient circulation. When he came home from the hospital, I was advised that I would have help with his care seven days a week. We do have assistance during the week, but often go Saturday and Sunday without any. Our home health care agency does a commendable job in providing skilled CNA's from Monday through Friday, but apparently have difficulty

	in getting anyone to work weekends. They have tried to insist that their aides work at least one weekend a month, but it seems when they try to enforce the rule, the aides quit that agency and go to other agencies where they do not have to. It is a major problem, as my husband is very heavy and also requires skilled help. J. Bowden
➢ A.I.a)(1)(c)(i)(j) Health Care: Community Based Options	"BoMomsBack": My concern is for proper medical attention for homebound people. My father died July 23, 2000 and I had taken care of him for 4 and 1/2 years. He was diagnosed with multiple sclerosis in 1960 and during the years I took care of him he was bedridden and tube fed. He also had a catheter the last year or two. His mind and eyesight was very good. My main problem was getting him proper medical attention. I had an eye doctor who provided excellent care. I was able to get a foot doctor who would see him at home but she would not see new patients in their home. Other than those two individuals, it was very frustrating to get him proper medical attention. Getting medical attention involved hiring an ambulance to take him to a facility. This was costly and was very uncomfortable for him. He had a special mattress at home as he couldn't move his body. To be on a stretcher for long periods of time was very uncomfortable. I certainly don't have the answers and I realize that it is more efficient to have people come to doctor's offices, but if family members are going to take care of the elderly at home, they need to have services available. You shouldn't have to put them in nursing homes in order to have doctors come to them. We would have been willing to pay double or triple the regular amount but I guess doctors aren't allowed to charge extra for services. I hope this problem will be addressed. I did find a company that rents vans, etc. for wheelchairs and a company that took x-rays in the home.
➢ A.VIII.a)(3) Education: Special Education	Pamela K Weiger: Attention Disabilities Commission: Money is not being received for Special Education. Please designate funds for Special Education to avoid needless spending outside of the Special Education Department. ESY Special Education Students needs to receive qualified appropriate services. An ESY student needs to have services provided in a qualified facility with qualified staff to fulfill IEP directives. Sincerely Yours - Chairperson Pamela Weiger, North Kingstown Local Advisory Committee
➢ A.I.a)(1)(b)(vi) Health Care: Community Based Options ➢ A.I.a)(1)(b)(vii) Health Care: Community Based Options	Frank R. Sparadeo: I am unable to attend the public hearings because I am presently out of town; however I wanted you to be aware of some of the issues related to TBI in Rhode Island. I have attached a statement. I am Chairman of the Governor's Permanent Advisory Commission on TBI Frank R. Sparadeo, Ph.D.

Traumatic Brain Injury - Presented to the Governor's Council on Disabilities

August 22, 2001

In 1986, in response to a groundswell of concern regarding the incidence and prevalence of traumatic brain injury in Rhode Island, a legislative committee was formed to study this issue. After approximately one year of study that legislative committee submitted a “white paper” to the legislature and to the Governor with its findings and recommendations. As a result of that report legislation was submitted and passed that provided a small level of seed funding to the Department of Human Services, Office of Rehabilitation Services. That legislation also established the Governor’s Permanent Commission on Traumatic Brain Injury. The monies that were provided at that time allowed for the development of a special program of vocational rehabilitation called Project Reentry for survivors. Additionally, the funding also provided funding for a special assessment project for traumatic brain injury (TBI) survivors who had visual impairment and also a small legislative grant was established which was awarded to the Brain Injury Association of Rhode Island (BIARI) to assist them in their important work of running support groups and providing information and referral for survivors of TBI and their families.

In 1987 a bond issue was passed that appropriated money for the development of a group home for survivors of TBI. That bond issue was never implemented because programmatic funding was never established. The loss of that money was devastating to the R.I. community of brain injury survivors, their families and the professionals that are involved in their care. Over the years the legislative grant to the BIARI has been reduced significantly, several programs for brain injury rehabilitation have lost funding and closed, including Project Re-entry, which lasted 12 years despite receiving funds for only 3 years. The loss of programming for a population that is growing is prevalence has been devastating. Many TBI survivors are either being treated out of state, participate in programs that are not designed for them (e.g. developmental disabilities programs, programs for the elderly, or programs for the mentally ill), live lives that are unnecessarily limited or unfortunately develop secondary psychosocial problems (e.g. substance abuse, mental illness or criminal activity). The facts are quite revealing. The severity of TBI ranges from mild to severe. The greatest numbers of TBI survivors are those with mild TBI. It is estimated that over the course of a one-year period over 1,000 people experience mild TBI, which results in ongoing impairment (usually cognitive disability). The incidence of moderate to severe TBI has dropped since 1987 due to improved safety of motor vehicles and increased use of seatbelts and motorcycle helmets. It was estimated in 1987 that there were over 1,500 moderate to severe TBI survivors in R.I. Presently, it is estimated that there are approximately 600 survivors of moderate to severe TBI in R.I. per year. The cost of treating these survivors is enormous. An individual with a moderate to severe TBI is seen initially in the trauma center, surgery is often needed, and then there is a long acute hospitalization followed by hospitalization in a rehabilitation hospital, which is followed by long-term outpatient rehabilitation. Once formal rehabilitation interventions have concluded there are problems related to housing and long-term independence, life-long disability issues, and issues related to taking care of secondary problems that may emerge. The statistics and facts above primarily relate to the adult population, there is also a population of children that experience TBI as a result of bicycle accidents, motor vehicle accidents and falls. TBI in children in R.I. has not been well studied, however the consequences of TBI in children are dramatic. TBI in children can arrest the developmental process and it creates problems in education and social development. The impact on the family is very dramatic when children experience TBI. Understanding the incidence and prevalence of TBI results in only a partial understanding of the problem. It is important that anyone interested in the plight of a TBI survivor understand the needs they have and the availability of services for those needs. Rhode Island is one of the few states that does not fund a state office dedicated to the ongoing study of TBI. Although the Department of Health has been very helpful in collecting hospital data and the Department of Human Services has also been helpful in implementing an important planning grant for TBI, there is no single state authority on this important health problem. Our closest neighbor, the

State of Massachusetts, implemented a model statewide office, many years ago, through the Massachusetts Rehabilitation Commission. That office is highly visible and called the Statewide Head Injury Program (SHIP). The R.I. Department of Human Services has implemented a statewide planning initiative through a grant from the U.S. Health Resources & Services Administration in which the Governor's Permanent Advisory Commission on TBI serves in an advisory capacity. The results of the DHS planning grant are quite revealing and indicate the existence of huge gaps in service delivery in R.I. The gaps in service range from post acute rehabilitation, residential community reintegration, day and evening programming, long-term care, housing, social programming, family programs including respite, and education and training for professionals as well as families and survivors. In essence, the continuum of care for TBI survivors in R.I. is very poor. The lack of programming in R.I. is due in part to the failure of insurance programs to be flexible in their funding and to understand the complexity and long-term implications of TBI. It is also due in part to a lack of conviction in the legislature that results in continually overlooking this very costly problem. The legislature will have many difficult decisions to make this year. Within the numerous legislative actions requested and bills submitted will be requests for some attention to be directed toward individuals who have survived the devastating impact of Traumatic Brain Injury. The TBI survivors in our state do not have a fancy well-funded and highly experienced lobbing effort. The TBI survivors of R.I. can only rely on a poorly funded association (BIARI), a few dedicated people in the Department of Health and the Department of Human Services and the non-funded Governor's Commission and a few dedicated professionals who volunteer countless hours of time to spread the word of their needs. As the Chairman of the Governor's Permanent Advisory Commission on TBI, as a Clinical Neuropsychologist that must clinically evaluate and treat hundreds of TBI survivors each year and as a citizen of this great state I request that you seriously consider the needs of the TBI survivor and his/her family when developing your budget proposals and plan. Please read the DHS planning grant results and please implement its recommendations. Respectfully submitted, Frank R. Sparadeo, Ph.D. Chairman, Governor's Permanent Advisory Commission on TBI, Clinical Neuropsychologist, Clinical Assistant Professor Brown University School of Medicine

➢ A.II.a)(2)(a)(ii) Transportation: RIPTA/RIde	Cora Banerjee: I am a counselor at ORS and unable to attend the Hearing scheduled for today. I am very frustrated with transportation issues. I just called RIPTA and tried to get a young man from South County to MetLife in Warwick for an interview and possible employment but he would have to take 2 busses and then the Flex service. It could be reduced to one bus and Flex if Bus 66 would always stop at the Mall coming and going to Providence. It only makes this stop in the middle of the day and evening. This also cuts out any South County clients I have who want to attend CCRI. For another client near Snug Harbor I asked if the Westerly Flex service could pick him up just off Rt. 1 and take him to the Wakefield Mall so he could go to Providence but they won't stop outside the Westerly zone even though it's on the way. I had the same problem when I worked for the FIP program in No. Kingstown. I had clients getting employment exemptions because there is no bus service along Rt. 1. I've also just found out there's no Flex service planned for the Richmond- Hopkinton. I thought I heard at a RIPTA meeting last year that this was going to happen down the road. I could go on and on but I have other work to do - which is hampered by the lack of transportation. - Cora Banerjee
	Sandra Mahoney: Dear Ladies and Gentleman - I am writing as the Child of Deaf adults (CODA) to address one of the concerns of the Deaf community.

➢ A.I.a)(1)(c)(ii) Health Care: Community Based Options	Currently, my mother resides in the New England Home for the Deaf, which is housed in Danvers, Massachusetts and my father died in a local nursing home without any communication access. This is true because Rhode Island lacks any facility for Assisted Living or skilled nursing which is designed to provide communication access for Deaf people. The Home in Danvers is located one and a half hours away from Providence and forces spouses and children of incapacitated Deaf adults to "send" their loved ones away from Home in order to assure a safe, accessible environment. My mother loves the fact that the entire staff speaks in sign language with a large number of Deaf staff and the fact that all the residents are Deaf. She hates being so far away from her family and her home. We hate the fact that she is such a distance and we are only able to visit her weekly. If she were in RI she would have her family visit daily. Deaf people should not be forced to choose between living in an accessible environment and being with their families. As an interpreter at the RI Deaf Seniors, I see a large number of Deaf seniors who would greatly benefit from a facility here at home. These same Deaf seniors were RI taxpayers for all of their adult lives and are simply asking for a basic need to be met-the right to live and be cared for close to home in a place which allows them to socialize with each other and to live in an environment which respects the fact that their primary language is American Sign Language. Please help it become a reality. Place the mandate for an accessible Assisted Living facility for Deaf people on the Legislative agenda for the coming year! Bring our parents back home! Thank you. Sincerely, Sandra Mahoney
➢ C.VII.a)(1) Legal Services	<u>Earnest Okwara</u>: Dear Colleagues in the Disabilities Community- I am writing as an advocate for Deaf people in Rhode Island, to express my concerns about the lack of legal representation for Deaf people in Rhode Island and also about the activities of the Rhode Island Disabilities Law Center. This organization from my understanding receives funding from the government to defend the rights of people with disabilities. Unfortunately, it has failed to adequately represent the interests of Deaf people. I have received several complaints from Deaf people who went to this organization for legal assistance on issues related to discrimination in the work place and other services that falls under its auspice. In most these cases, these Deaf people were turned away or told that the Center was unable to meet their needs. In addition, this Center is violating the law by not having a Deaf person on its Board of Directors. I honestly believe that this lack of Deaf representative on the Board of this Center has made it become ignorant of the legal needs of this group. I am hoping that you will sincerely remember this very serious issue in your attempt to make RI a great place for people with disabilities to live in. Legal representation is one of the most important needs of members of the RI Deaf community and I hope you will find ways to address this. Thank you very much for your consideration. - Earnest Okwara, MS., M.Ed. Former President, RI Association of the Deaf
➢ A.I.a)(1)(b)(ix) Health Care: Community Based Options	<u>Elizabeth Trimmer:</u> My name is Elizabeth Trimmer and I am the Coordinator for RI Communities for Addiction Recovery Efforts. RICARE is a grass roots alliance dedicated to developing a voice of empowerment for, and decreasing stigma about those in alcohol and other drug dependence recovery. We are here today to stand up for our beliefs and the rights of those individuals still

	negotiating the treatment recovery system. I am have been in personal recovery from my addiction for almost fourteen years. I was seventeen years old when I entered a treatment facility. I was lucky to have a bed available when I needed it but luck should not have anything to do with it! As the coordinator of our advocacy group for people in recovery and their friends and family members as well I get many phone calls from people seeking treatment. Often these are women with children trying to find an opening in a facility where they can bring their children with them into treatment. There are not many places for them to go. There are only a couple of programs in our state that can accommodate them and they have long waiting list! This is appalling! These barriers are preventing our women from getting the help they need! I also receive phone calls from the staff that work in treatment facilities. These treatment providers are trying to find safe and sober housing beds for these women so to set them up for success instead of failure. They have women ready to graduate from their programs and leave to begin their lives a new but there is no place for them to go! If these women go back into the environment they came from most often it will hinder their recovery process. Currently there are far more sober houses, transitional houses, detox programs and treatment facilities for men then there are for women. We need to see equal amounts of beds for both genders. These women need to have an opportunity for successful recovery! I feel our state has been doing a good job but could be doing better! Please help our women and families receive the support and treatment that they need! They are our future! - Elizabeth Trimmer This is the last of the three testimonies am sending for our August 24, 2001 public hearing. Susan, another RICAREs member, handed her testimony in on Friday. I will also fax these to you tomorrow morning just in case you do not receiver the emails. Thanks. - Elizabeth Trimmer, RICAREs Coordinator
➢ A.VI.a)(2)(a) Accessibility: Communications	Anne McDonald: I attended one of your public hearings, but preferred to just listen to others rather than speak up. What concerns me the most is the emergency interpreter system or the lack of it.. I have yet to have a need to use it. When I do God help me as from what I heard this so called ":emergency referral service" is next to useless due to lack of funding. I would be probably get better results waking up familiar interpreter at 3 AM than waiting for a call back from the system. I urge the Commission to make every effort to secure funding for an emergency referral system. Thanks for hearing me out. Also, will there be a summary or transcript of the testimonies present at a later date, such as at the GCD website? Let me know. Thanks. Anne McDonald
➢ A.III.b)(c) Employment: Community Based Options	Norma Lovegreen: Recently, I went to the Public Hearing for Disabilities to state that my mental illness has been in check for some time now. I have a temporary job from Hillsgrove House which gives me something to look forward to every morning when I wake up. Now that they transport me to and from my job, My anxiety towards my job has decreased. The staff at Hillsgrove House provide excellent hands on projects that gives the area a warm feeling. I can grow in this environment and be successful for the first time in my life. My self esteem has improved tremendously since joining the clubhouse. Your attention and continued support to this matter will give me and my friends a reason to get out of bed and face the day. I will look forward

	to a reply. My address is 14 Lake St. Warwick, RI, 02886, Sincerely, Norma Lovegreen
➢ A.III.b)(c) Employment: Community Based Options	Melissa Fundakowski: To whom it may concern, I had never been introduced to a clubhouse setting before, so the very idea intrigued me tenfold. I have made many connections that I hold dear to my heart that I wouldn't give up for anything. This clubhouse has molded and shaped me in many splendid ways. I am now computer literate, I am more sociable, and I now have a better understanding of who I am and how I can make a difference in this world regardless of my illness. All I can say is Thank You Hillsgrove House. I hope it has made a difference in my friends, lives too.
➢ A.III.b)(c) Employment: Community Based Options	Gregory Dugan: Dear Sirs: I am Gregory Dugan and I go to a day program called Hillsgrove House. I have recently heard that you are cutting funds for many day programs across the state. I think cutting funds for Hillsgrove House is not a good idea, because we need the day program to help us rehabilitate us into society. Our program builds character and helps us relate. Without Hillsgrove House we would have a hard time adjusting to work and daily living. Our program helps us make friends and other relationships. So, in final, please do cut our funds.
➢ A.II.a)(2)(a)(i) Transportation: RIde ➢ A.II.a)(2)(a)(iii) Transportation: Cost	Linda Adler: (via Kate McCarthy-Barnett, EdD, Providence Journal Columnist "Forums key time for people with disabilities to pipe up" RIDE Transportation - ADA Paratransit Service Dear Dr. McCarthy-Barnett - I attended the forum held on Monday, 8/20 at Rehabilitation Hospital of RI (Fogarty). In response to your article and information gathered on transportation, my particular issue of concern, I would like to share with you my comments. I am legally blind and qualify for the RIDE program through the ADA. Mr. Bob Cooper, Executive Secretary on the Governor's Commission on Disabilities, advised me that as budgets are being developed I would be wise to contact state and federal legislators. I took his advice and have written to them with the following information. It is my understanding that the RIDE program will only provide transportation within ¾ of a mile of a bus stop. Since moving to Cumberland, I am unable to receive transportation to/from work unless I go to a pick-up point that is about a 3 ½ mile walk each way from my home. As cab fare is $2/mile, it would cost me at least $70/week, without gratuity, to take a cab to a RIDE pick-up point. When $70 is added to the cost of the RIDE, approximately $25/week, I would spend about $100/week for transportation. On 8/20/01, I attended a public hearing to identify concerns of people with disabilities at the Rehabilitation Hospital of RI (Fogarty). I found it very interesting and validating. I am most certainly not the only person facing transportation challenges. Various panel members presented their views. Ms. Susan Silvia, the facilitator of the hearing, said that she knows several individuals with disabilities living in Woonsocket with viable employment opportunities in Lincoln who, because of lack of transportation, are unable to accept these jobs. Another panel member said that some individuals with disabilities spend from 1/3 to1/2 of their weekly income on transportation between taking a cab to a RIDE stop and the RIDE fare. Our society encourages individuals with disabilities to work and provides vocational rehabilitation to promote

	economic independence. Further, the law provides disincentives to employers through the Equal Employment Opportunity Act for not hiring qualified individuals. To have transportation as a barrier to employment does not make sense. Mr. Cooper very much aware of paratransit issues. He is working on a gradual remedy through expansion of paratransit services. Due to limited funding, program expansion will be quite slow and tentative. As you are considering budget issues, I am hoping that you will provide funding to make access to paratransit services available by eliminating the ¾ mile corridor and making the service door-to-door. Thank you for your time and consideration. Sincerely, Linda Adler
➢ C.II.b)(5) Transportation: Disability Parking	Jane Berman: I would like to see parking spaces for the disabled labeled "No Standing." Very often these spaces are occupied by automobiles that include the driver, behind the wheel, while the passenger, who may or may not be disabled, goes into a building. This is very frustrating for the lone, disabled driver who must then find another parking spot, which is often a much greater distance from the destination. Even if the parked driver is disabled, he or she could easily park a short distance from the building and drive over to pick up the passenger when he exits. These "standing" cars are especially troublesome when the weather is icy or snowy. --Jane Berman
➢ A.I.a)(1)(b)(i) Health Care: Prescription Medication ➢ A.I.b)(1)(b) Health Care: Glucose Supplies	Karen Ksen: I am sorry I was not able to attend the hearings last week on the needs of persons with disabilities. I am a 59-year-old single woman with multiple chronic illnesses including kidney disease, stroke, diabetes and high blood pressure. Although I worked all my life, my many health issues caused me to become permanently disabled two years ago and require me to take 12 different medications each day to keep my conditions as stable as possible. My yearly income is less than $ 10,000 and consists of SSDI and a very small pension. However, it is slightly too much money for me to get Medicaid. I do have Blue Chip for Medicare, which I pay $ 119.00 every month for. However, I use all of my quarterly prescription drug allowance in one month, leaving me in a very difficult situation to pay for my medication bills of over $ 550.00 per month from my very limited income. The stress of worrying about how I am going to pay for my medications is making me very anxious. Also, because of my diabetes, I have other expenses for supplies for glucose testing that is not covered. I do the best I can to follow my diet and treatment program, but it is very hard when I have to live on such a limited budget. On my behalf and all the other persons I know who are having such problems paying for prescriptions, please ask the Governor and the legislature to either let persons under age 65 use the RIPAE program as many of my older friends do, or let us have Medicaid pay for our needed medications. Thank you very much for whatever you can do to help. Karen Ksen
	Sandra H. Jolly I hope it is not too late to make a contribution to the Commission's public hearings. I just found out that the study is taking place.

- A.I.a)(1)(c)(i)(f) Health Care: Family Support

I would like to bring one point to the attention of the Commission. Please consider the plight of the families of the disabled, especially the under 65-year-old care giving spouse (usually wife) of a disabled husband (family breadwinner) who is not eligible for health insurance for her own needs. While the husband will (usually) become eligible for Medicare as a result of his disability (and sometimes Medicaid), his care giving spouse will not. She cannot go out to work if he needs in-home care, so she is not covered by health insurance from an employer.

If the disabled spouse is in a nursing home or other residential care program, most likely Medicaid is helping to pay for that care, and, again, the spouse cannot go to work at a substantial job (which will earn her health care coverage in her own right) because then her income will be above the allowed limit and she will become liable for the cost of the nursing home care, which will (usually) far exceed her earning capacity.

If there are children under 18 in the family, they might be covered by RIte Care, but once they are over 18, there is no program to fill the gap for the spouse/caregiver until (s)he reaches the age of 65. (The care-giving spouse is also not earning credits toward her own Social Security for later years, and depending on the age of her husband when he became disabled, she might be in dire straits in her older years, especially if he should predecease her.)

In a very real sense, if one family member is disabled, especially the breadwinning spouse, the entire family is "disabled" and needs assistance. This problem might affect only a small number of Rhode Islanders, but the ones who are affected can often find themselves in very dire circumstances, losing their home, their health and their dignity, through no fault of their own. Disabling sickness such as stroke and heart disease, and disabling accidents, are extremely equalitarian, striking all levels of society with equal force. Thank you for your kind attention. Sincerely, Sandra H. Jolly

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- B.I.g) Health Care: Information on Services
- B.III.a) Employment: Minorities with Disabilities

<u>Aleatha Dickerson:</u> As a Rhode Island resident of minority heritage with a disability, I would like to bring to the attention of our State government an important issue recognized by the Federal government. Many eligible individuals of minority heritage with disabilities are not aware of and are not receiving rehabilitation services. In addition, minority individuals who have participated in rehabilitation services have had a statistically lower rate of successful outcome. I have attached an article, which documents the pertinence of this issue. There is an immediate need for the appropriation of resources to support the development and implementation of a concrete program to reach minorities with disabilities living in RI. The program is needed to facilitate the development of relationships between the minority communities and service providers. The goal of the program would be to enable eligible individuals with disabilities of minority heritage to receive available rehabilitation services, which result in successful outcomes. Currently, resources are only available to put a "band-aid" on this problem. Staff volunteers to advise rehabilitation administration to improve this situation. Future appropriation of resources could allow for a staff person to be responsible to work under the direction of an advisory committee and administration to effectively carry out duties necessary to facilitate ongoing

outreach and to collaborate with organizations serving individuals of ethnic minority heritage. Respectfully, Aleatha M. Dickerson

President's Committee on Employment of People With Disabilities

The Disability Messenger

Section One A guide to disability coverage Dual discrimination: Disability rates among minorities add to job barriers

By PAUL M. IGASAKI Insufficient attention has been paid to the fact that minorities have a higher prevalence of disabilities than the white population. Compounding the problems minority members of the disability community face are higher poverty rates, prejudice, discrimination and lower levels of educational attainment. Additionally, attitudes within some minority communities may make them less willing to challenge what may be discrimination by employers. The overall rate of disability in the U.S. was 20.6 percent in 1995. Significant gender and ethnic differences exist, however. Native Americans have the highest rate of disability for any ethnic or racial group, 23.9 percent. The rate of Native Americans with severe disabilities is 10.5 percent. If we look at adolescents and working-age adults (those 15 to 64), the disability rate among Native Americans is 27.1 percent, while the rate for all ethnic and racial groups is 18.7 percent. African-Americans have the second highest rate of disability for any ethnic or racial group in this country (21.6 percent). However, blacks have the highest rate of severe disability (12.7 percent versus 9.9 percent for all ethnic or racial groups). People of Hispanic origin have a disability rate significantly lower than the national average (16.2 percent versus 20.6 percent). Among this group, however, women have a higher rate of disability than men (22.6 percent versus 18.6 percent). Adolescents and working-age adults of Hispanic origin have a slightly lower rate of disability (17.4 percent) than the combined figure for all ethnic and racial groups (18.7 percent). The disability rate for Asians and Pacific Islanders is 12.1 percent, 11.4 percent for adolescent and working-age adults. The overall disability rate for male and female Asian-Americans is about the same, with women having a slightly higher rate of severe disability (8.1 percent) than men (6.1 percent). These figures, do not show substantial differences between Asian ethnic groups, however, though significantly higher rates are reported among refugees and immigrants. One of the major obstacles facing people with disabilities is finding a job. While the labor force participation rate for people 18 to 64 years old who do not have disabilities is nearly 83 percent, it is only about 52 percent for those with disabilities. The rate drops to 38.6 percent for non-whites with disabilities, and is even worse for people with severe disabilities (21.2 percent among Hispanics, 17.8 percent among blacks). Statistics were not readily available on the unemployment rates for Asian-Pacific Americans with disabilities. The generally higher rate of disability among racial and ethnic minorities is associated with a number of factors: Minorities are more likely to have a lower income, and people with lower incomes are more likely to have disabilities; Minorities are more likely to hold physically demanding and higher risk jobs which make them more vulnerable to higher disability rates; Non-whites are less likely to have health insurance; African-Americans, Hispanics and Native Americans have completed fewer years of school than the general U.S. population, and our educational system creates barriers for minority children with disabilities. Employment and advancement opportunities for minorities with disabilities are limited because they are likely to experience dual discrimination because of disability and minority status. When one compares the labor participation rate of racial and ethnic groups with the rate of discrimination charges with the Equal Employment Opportunity Commission, we see that African-Americans file at a substantially higher rate than their portion of the work force, while Hispanics and Asian-Pacific Americans file at a significantly lower rate. While these differences may involve a greater rate of discrimination experienced by African-Americans, other factors are at work. The 1964 Civil Rights Act, which created the EEOC, was motivated by the African American civil rights movement, so African-Americans have been less reluctant than some other groups to utilize the EEOC. Lack of fluency in English can pose a problem for accessing services available to people with disabilities, including discrimination protection. Certain cultural or ethnic groups, particularly among recent immigrants, may distrust government agencies, especially federal law enforcement agencies. This attitude may make individual members of these groups hesitant to call attention to themselves by filing charges of discrimination. Historic attitudes about disabilities within cultures may have an effect, too. Many Asian-Pacific Americans, for example, consider disability a private matter, or even a reason for shame or embarrassment. This has led, even more than in society at large, to sharp limits on the opportunities available to those with disabilities. These attitudes, in turn, may make Asian-Pacific Americans less likely to seek services for their particular needs. - Paul M. Igasaki is vice chairman of the U.S. Equal Employment Opportunity Commission

➢ A.I.a)(1)(c)(ii) Health Care: Community Based Options	Sandra Mahoney: Please read the enclosed story about a new facility being built. It relates to my previous letter discussing the need for a Home for Deaf people. Thank you, Sandra Mahoney

The Oregonian The Oregonian

Elderly, deaf and at home

08/05/01

ERIC MORTENSON

GRESHAM Conversations fly quickly at Mae Johnson's foster care home, as fast as two hands can talk. Asides and quips flash from the fingers. Remarks and responses flit back and forth like song-less birds.

Four women -- the youngest 75, the oldest 90 -- gather around a crafts table, attaching decorative notepads to garden gloves, which are shaped into the American sign language symbol for "I love you."

The residents have been deaf since birth. They've all lost their husbands.

Johnson laughs, as she obliges one of the residents by scratching her back. The woman smiles with relief, raises her right hand to her chin and extends it forward, repeating the gesture three times. "Thank you, thank you, thank you."

Johnson's foster care home is the only one in Oregon for older deaf people. Nestled along a fairway of Gresham Golf Course, it is a haven for people who have few other options.

For Johnson, it represents a reconciliation with her past as well as a dream for her future.

At Johnson's foster home, each of the residents has a private room; every television set is locked on "mute." In the living room is an upright piano. Sometimes Johnson's husband comes to play, and the residents lean against the piano to feel the music's vibrations.

Johnson, 49, is a registered nurse and knows sign language. She opened the home three years ago after encountering an elderly deaf woman dying of cancer. The woman told Johnson that she would rather die in her apartment than go to a nursing home where no one could sign.

"When she was in the nursing home, she felt more isolated than she did with her cat," Johnson says. "At least her cat was company, even when she was sick."

The woman's story touched Johnson deeply, even more so when she learned that the woman worked at the Oregon State School for the Deaf and remembered when Johnson's mother boarded there.

That started Johnson thinking about her own parents, both deaf and in their 70s. Checking with other children of deaf parents, she discovered no one had a plan for their parents' care.

She opened the foster home and soon had a waiting list 15 people deep. Out of that emerged Johnson's bigger dream: to build a four-story, 70-unit assisted living facility for elderly deaf and deaf-blind people -- the first of its kind in the Northwest.

The $7 million project has cleared the planning process and has attracted $100 room deposits from 15 people throughout Oregon and Washington. With luck, Johnson could break ground this fall on 2 acres within walking distance of the MAX light-rail line.

Advisers say Johnson's project makes sense from a business perspective. A market study showed there are approximately 1,900 deaf people older than 65 in the Portland-Vancouver area alone. Nearly 300 have health problems that would make them eligible for an assisted living facility, according to the study.

On a more personal level, completing the project will bring to a close an internal journey that's taken Johnson from childhood embarrassment and anger at her parents to understanding and reconciliation.

"It's a full circle," she says softly. "For 20 years, you couldn't pay me to go visit my folks."

Now she wants to build them a home.

Better being together Johnson's mother, Jeanne Jordan, often drives to Gresham and joins the residents in their crafts.

Jordan and her husband, Ray, are enthusiastic about the assisted living facility their daughter wants to build.

"I think it's the best I've ever heard of," Jeanne Jordan signs. "Because we are lonesome and isolated in our homes. Other deaf have told me they are frustrated in apartments, they would rather be in a place like this."

Jordan is an energetic woman of 74, and her sense of humor is apparent as she tells stories about Johnson as a young girl. Johnson interprets for her mother, laughing along as she talks.

There was a time, of course, when Johnson didn't understand her mother.

As a child growing up in Prineville, the second of five children, she was embarrassed by her mother's strained attempts at speech. She was afraid to play outside, because her mother might call for her and the other children would hear.

Her mother spoke to her children as best she could but often signed to them. She did not lip read well.

"Mom always wished us kids were more in tune to learning the language and understanding that it was her best language," says Polly Brooks, Johnson's older sister.

Johnson's father, Ray Jordan, was hard of hearing. The sawmill worker could read lips and got by with hearing aids for many years before losing his hearing all together.

"I felt like I didn't belong there," Johnson says. "I felt like I was stuck in the 'Twilight Zone.' "

Brooks felt the same. The stigma of having parents who were different was so strong that she wouldn't tell them when school functions were held.

The five children distanced themselves from their parents, dealing with bullies or other childhood problems by themselves.

As Johnson entered adulthood, associating with the deaf would have been the last thing on her list.

It would take her years to understand the isolation her parents had endured. Her mother's story was particularly sad.

The country doctor who pulled Jeanne Jordan from the birth canal used forceps and broke both her eardrums. Her parents didn't realize she was deaf, at first simply thinking her language development was delayed, because she seemed to respond to them.

The responses were misleading. When her father came into the house from outside, for example, he stomped his boots at the entrance to knock off mud. Jeanne could feel the vibrations in the wooden floor, and she would go to greet her father.

They lived on a farm in Idaho. Even as a tiny girl, Jeanne sometimes climbed on a horse and rode off, frightening her parents because she could not hear them calling. The family moved to Oregon and boarded her at the Oregon State School for the Deaf in Salem. She was 5 and had no communication skills.

Jeanne cried bitterly when her parents left her. She'd never seen people sign before, and the rapid movements frightened her.

Pushing for a dream Meeting the elderly woman who had worked in the school dormitory helped Mae Johnson appreciate her mother's story.

A class she attended on healing childhood trauma also helped. Even though she knew, intellectually, what her parents had faced, she began to understand it for the first time.

"All of a sudden it just clicked," Johnson says. "It was never their intention to be strange parents or different."

It's become her intention that they won't ever feel that way. Although she has never built a thing in her life, never dealt with buying property, construction loans, investment tax credits and the politics of Medicaid reimbursements, Johnson so far has pushed the assisted living facility through every hoop.

"The drive she has to push that forward is incredible," says Brooks, who is a free-lance sign language interpreter.

Gresham approved using $170,000 in federal grants to help build the facility.

"At this point, with a cold eye, I believe it's going to get built," says Sharon Nielson, a Portland consultant who is helping Johnson arrange funding. "It just works, it's a project that just wants to happen."

Nielson says she's had to educate prospective backers about why the deaf need a special facility.

"That's what's so intriguing about this population: They are isolated by being mainstreamed," Nielson says. "It's the reverse, absolutely."

The Oregon Association of the Deaf, based in Salem, fully supports the project, says Dot Johnson, the group's past president. She is not related to Mae Johnson.

"The issue of caregivers' inability to communicate with deaf patients in a regular nursing home is considered a very, very serious issue," Dot Johnson says by e-mail.

Isolation can cause deaf residents' health to fail, Dot Johnson says.

Mae Johnson is grateful for the support.

"I'm not the only one with the dream anymore," she says. "When you're holding the dream all by yourself, you get weary."

Her family has rallied to the idea and drawn closer in the process. It was only at a relative's recent wedding that, for the first time, the children saw their parents dance.

Meanwhile, Johnson plugs away with the forms, meetings and details required to pull off the project. Steely resolve hides behind her modesty. Sometimes it surfaces, such as last winter when she signed a bulky grant application form, attesting that the information supplied by her nonprofit organization was true.

She filled in her title, "President."

And she added, "Dream Keeper."

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6. Footnotes

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[i] ***Newspaper advertisement published in the:***
Providence Journal
Newport Daily News, South County Independent & North East Independent
Woonsocket Call
Pawtucket Times
Providence American
Warwick Beacon and Cranston Herald - Donated Ad Space as a public service
Westerly Sun
Kent County Daily Times
Providence en Espanol
Southern RI Newspapers: The Narragansett Times; The Standard Times; The East Greenwich Pendulum; The Chariho Times; & The Coventry Courier
East Bay Newspapers: Barrington Times; Bristol Phoenix; Sakonnet Times; & Warren Times-Gazette
Observer, Sunrise & North Star
Block Island Times
Saturday August 18, 2001 morning Spanish Language Radio interview on: WPMZ Poder 1110 AM

[ii] **Video of Advocates in Action members testimony**

[iii] **Advocates in Action, written testimony dated August 24, 2001**