# Public Forums to Identify the Concerns of People with Disabilities and Their Families

## July 27th – July 31st 2015

Prepared by

## The Governor's Commission on Disabilities

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Adopted November 30, 2015

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

## The Commission

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**Rosemary Carmody of Coventry**
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## Public Notice

**7State of Rhode Island and Providence Plantations**

### Public Forums to Identify the Concerns of People with Disabilities and their Families

During the week of the 25th anniversary of the Americans with Disabilities Act, the Governor's Commission on Disabilities and many other state and non-profit agencies conduct a weeklong series of open forums to hear concerns of people with disabilities and their families.

The forums are open for all to come and speak; representatives of the sponsoring agencies will be there to listen. Policy makers and planners want to hear your concerns about current services, unmet needs, and suggestions for improving services and expanding opportunities.

**Monday, July 27, 2015, from 3:45 – 5:45 PM**
S. Providence Library, 441 Prairie Ave, Providence
Hosted by Perspectives Corporation (Spanish translator avail.)

**Tuesday, July 28, 2015, 2 – 4 PM**
Warwick Public Library, 600 Sandy Lane, Warwick
Hosted by the Ocean State Center for Independent Living

**Wednesday, July 29, 2015, 4 – 6 PM**
Peace Dale Library, 1057 Kingstown Rd, Peace Dale
Hosted by National Multiple Sclerosis Society RI Chapter

**Wednesday, July 29, 2015, from 4 – 6 PM**
Middletown Library, 700 W. Main Rd, Middletown
Hosted by Opportunities Unlimited

**Thursday, July 30, 2015, from 1:30 – 3:30 PM**
Zambarano Unit, Eleanor Slater Hospital, 2090 Wallum Lake Rd, Pascoag
Hosted by Zambarano Unit, Eleanor Slater Hospital

**Thursday, July 30, 2015, from 4 – 6 PM**
Woonsocket Library, 303 Clinton St, Woonsocket
Hosted by RI Department of Health

**Friday, July 31, 2015, from 2:45 – 4:45 PM**
E. Providence Library, 41 Grove Ave, E. Providence
Hosted by RI Statewide Independent Living Council and National Federation of the Blind of RI

**Thursday, August 20, 2015, from 4– 6 PM Wireless Free/Scent Free Forum**[1]
Cold Spring Community Center, 36 Beach Street, North Kingstown

Remarks can be made in person during the forums, faxed to 462-0106, e-mailed to GCD.Disabilities@gcd.ri.gov, or mailed by August 8th to Governor's Commission on Disabilities, John O. Pastore Center - 41 Cherry Dale Court, Cranston, RI 02920. CART Recorders (real-time captioning) and assistive listening devices will be at all sites, courtesy of the Office of Rehabilitation Services / Assistive Technology Access Partnership. The RI Commission on the Deaf and Hard of Hearing will provide sign language interpreters for each forum.

To request information or accommodation, call 462-0100 or 462-0101(tty) in advance; arrangements will be provided at no cost. Language interpreting is available with the Deptartment of Human Serivces and requests can be made to 462-2130 in advance.

When making the ADA reservation with RIde to get to and from the public forum, tell the RIde reservationist (1-800-479-6902) that this trip is for the Governor's Commission's Public Forums in order to guarantee your return trip, after normal RIde hours of operation. ADA fare is still applicable.

When attending the forum, please use unscented personal care products. Mild fragrances can constitute a toxic exposure for a person with an environmental illness.

**Gina Raimondo, Governor**

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[1] When attending this forum, please turn off any wireless devices (including cell phones, internet connected tablets, and FM assistive listening devices). Only use unscented personal care products. Mild fragrances can constitute a toxic exposure for a person with an environmental illness.

## Public Forum Sponsors

AccessPoint RI;

Brain Injury Association of RI;

Bridgemark Addictive Recovery Services;

Fogarty Center;

Goodwill Industries of Rhode Island;

Governor's Commission on Disabilities;

In-Sight;

Living in Fulfilling Environments, Inc.;

Meeting Street;

Mental Health Association of RI;

National Federation of the Blind of RI;

National Multiple Sclerosis Society, RI Chapter;

Newport County Community Mental Health Center;

Ocean State Center for Independent Living;

Office of Rehabilitation Services / Assistive Technology Access Partnership;

Opportunities Unlimited;

Perspectives Corporation;

ReFocus, Inc.;

RI Commission on the Deaf and Hard of Hearing;

RI Department of Administration/Office of Diversity, Equity and Opportunity (ODEO);

RI Department of Health - Office of Special Needs;

RI Developmental Disabilities Council;

RI Disability Law Center;

RI Parent Information Network/RI Department of Health;

RI Relay (Hamilton Relay);

RI Statewide Independent Living Council;

Seven Hills Foundation; and

Sherlock Center at Rhode Island College

## Table of Contents

# 1. Executive Summary

This year, thirty agencies hosted or were a party to seven forums across the State of Rhode Island to hear the concerns of the people and families of those with disabilities from 27 July, 2015 to 20 August 2015. The forums were hosted in a variety of locations and by different agencies: 27 July in South Providence hosted by Perspective Corporation; 28 July in Warwick hosted by the Ocean State Center for Independent Living; 29 July in Peace Dale hosted by the National Multiple Sclerosis Society R.I. Chapter; 29 July in Middletown hosted by Opportunities Unlimited; 30 July in the Zambarano Unit, Eleanor Slate Hospital; 30 July in Woonsocket Library hosted by the R.I. Department of Health; 31 July in East Providence hosted by the R.I. Statewide Independent Living Council and the National Federation of the Blind of RI; and the 20 August forum at the Cold Spring Community Center in North Kingstown.

A wide variety of concerns were expressed across the forums with the main themes being transportation, health care, accessibility, and education.

The most prominent concern is transportation with multiple persons voicing their concerns at each forum on the state of, access to, and cost of state provided transportation. Namely RIPTA and RIde programs respectively. The primary cause of concern is the fluctuating fare rates as well as the lack of access in certain parts of state. Persons are concerned the fare rates for individuals who are elderly and /or disabled who use state provided services as an essential mode of transportation will no longer be able to afford the service. Also RIPTA/RIde dropping routes which they deem underused without an announcement or notice.

RIde services were widely criticized for making individuals wait for prolonged times, wake early hours of the morning just to receive transportation, then enduring lengthy and untimely trips. Some reported to be over two hours long then repeating the process on the trip back.

On the topic of health care the most prominent concern voiced was the navigation of the system itself with the paperwork being often times confusing, and agents of the system being either unavailable or difficult to get through to in order to solve the problems.

Another concern voiced was the lack of access due to individuals with sensitivities to electro-magnetic fields, for example Wi-Fi, which are widely used throughout public and private businesses, hospitals, schools, and so forth. Individuals with sensitivities to chemical substances are lacking access to various government services and schools.

Concerns were raised for the state education services, namely that students with disabilities are not being properly accommodated for success in schools, and college. Transitioning services and the ease of access for youths moving to adult services was expressed as a concern. The process is difficult to understand and navigate and as mentioned above agents and personnel are difficult to access.

# 2. Community Concerns and Recommendations

## Accessibility Concerns and Recommendations:

### Business

Concerns: Retail and grocery store and other businesses' aisles are blocked by displays, stacks of items on sale, narrow entrance double doors (try holding two doors open, while pushing your wheelchair). Pages: 5-56, 5-63
Recommendations: The GCD conduct training for managers of retail and grocery store and other businesses.

Concern: There is little to no access for individuals with electro-magnetic field sensitivities retail or grocery stores and other businesses. Pages: 5-68, 5-80, 5-81, 5-82
Recommendations: The GCD advocate for the US Department of Justice to adopt a Wi-Fi free accommodation standard on what steps retail or grocery stores and other private businesses should take to serve customers with electro-magnetic field sensitivity.

Concern: There is little to no access for individuals with multiple chemical sensitivities to retail or grocery stores and other businesses. Pages: 5-64, 5-72, 5-82, 5-104
Recommendation: The GCD advocate for the US Department of Justice to adopt an accommodation standard on what steps retail or grocery stores and other private businesses should take to serve customers with multiple chemical sensitivity.

### Elections

Concern: Outdated voting machines are used at polling places in Rhode Island, some polling places still have barriers to voting, and financial town meetings do not use accessible voting machines. Pages: 5-18, 5-22
Recommendations: Ensure replacement voting machines are fully accessible at all polling places and for all elections, including financial town meetings.

### Healthcare

Concern: Hospitals lack Video Reporting Interpreting (VRI) services, when there is a lengthy (several hours) delay before an on-call interpreter for the deaf is available. Page: 5-10
Recommendations: The Department of Health, in consultation with the RI Commission on the Deaf and Hard of Hearing should require all hospitals and urgent/emergency healthcare facilities to have: on-call sign language interpreters readily available; staff trained and American Sign Language certified; or VRI.

Concern: There is little to no access for individuals with electro-magnetic field sensitivities to healthcare facilities. Page: 5-77
Recommendations: The GCD advocate for the US Access Board adopt a Wi-Fi free access standard; Wi-Fi free areas should be established for hospitals, urgent and emergency healthcare facilities. The Department of Hearing, should require all hospitals and urgent/emergency healthcare facilities to have a Wi-Fi free (shielded) examination/bed room to serve patients with electro-magnetic field sensitivities.

Concern: There is little to no access for individuals with multiple chemical sensitivities to healthcare facilities. Pages: 5-104
Recommendations: The Department of Health should require all hospitals and urgent/emergency healthcare facilities to have a chemically free examination/bed room to serve patients with chemical sensitivity and

adopt the Centers for Disease Control and Prevention's Indoor Environmental Quality Guidelines for hospitals, urgent care and emergency healthcare facilities.

## Government Services

Concern: Beaches lack beach/surf-wheelchairs would allow people with disabilities access onto the beaches.
Page: 5-30
Recommendation: The Governor's Commission on Disabilities (GCD) advocate for additional funds to purchase beach/surf-wheelchairs at public beaches.

Concern: State and local government ADA Coordinators are not performing legal functions of the office. Page: 5-51
Recommendation: The GCD provide training on the ADA requirements for state and local government ADA/504 Coordinators.

Concern: Courtrooms and jury deliberation rooms are not fully accessible to persons with disabilities. Page: 5-92
Recommendations: Courtrooms and jury deliberation rooms must have an accessible path between them. In older facilities with stairs to the jury deliberation rooms, trials must be moved to an accessible facilities to accommodation members of a jury who is unable to climb stairs.

Concern: The East Providence Post Office is not accessible to persons with disabilities, in particular to those in need of a wheelchair or other assistive technology. Page: 5-63
Recommendation: All post offices comply with the US Access Board's regulations.

Concern: There is little to no access for individuals with electro-magnetic field sensitivities to government services, schools, and other government funded services. Pages: 5-68, 5-71, 5-75, 5-80, 5-81, 5-82, 5-91, 5-95, 5-97, 5-98, 5-105, 5-110
Recommendations: The GCD advocate for the US Access Board to adopt a Wi-Fi free access standard; Wi-Fi free areas should be established in government facilities with hardware and insulation from electro-magnetic fields.

Concern: There is little to no access for individuals with multiple chemical sensitivities to government services, schools, and other government funded services. Pages: 5-23, 5-72, 5-104
Recommendation: The GCD advocate for the US Department of Justice to adopt an accommodation standard for government services, schools, public housing, and other government funded services.

## Religion

Concern: Some houses of worship are not accessible. Page: 5-30
Recommendation: The GCD should conduct a workshop on accessing religion in conjunction with the RI Council of Churches, Board of Rabbis of Greater RI, Roman Catholic Diocese, Islamic Centers, Buddhist Temples, and other faith communities.

## Roadways and Sidewalks

Concern: Accessible crosswalks are in hazardous areas that are dangerous to cross, especially for persons who may take longer to cross. Pages: 5-17, 5-52, 5-54, 5-58, 5-60, 5-61, 5-62

Recommendations: Require an assessment of the safety of pedestrians with disability before the installation of curb cuts, signage, and crosswalks, and require pedestrian crossing signs alerting to motorists when crosswalks are on the downslope of a hill.

Concern: Accessible parking spaces and disability parking placard requirements are not being enforced properly. Page: 5-11, 5-21, 5-50, 5-52
Recommendation: Create public service announcements to inform the public of disability etiquette and other related issues, in possible collaborations with universities, chamber of commerce, and police department. Remind police departments of their obligations under RIGL 31-28-7.3 Disability parking enforcement program.

## Independent Living Concerns and Recommendations

### Adult Services

Concern: Funding cuts for adult services have hurt the quality of adults with disabilities. Pages: 5-29, 5-31, 5-32, 5-39, 5-43, 5-58, 5-59
Recommendation: The GCD advocate for restoration of funding of adult service funding to pre-2008 levels.

### Education

Concern: Students with disabilities are not being properly accommodated for success in schools, especially for children with language based learning disabilities, are deaf or hard of hearing. Page: 5-18, 5-36, 5-26, 5-36, 5-85
Recommendation: The Department of Elementary and Secondary Education should ensure all children have the accommodations needed for success.

Concern: Students with disabilities across Rhode Island are suspended from school at rates more than twice as high, on average, as their representation in the student body[2]. These disproportionate suspension rates, like those that impact racial minorities, begin in the earliest grades, and are often for low-risk behavioral issues that could be addressed in other ways. Page: 5-29
Recommendation: The GCD advocate for the enactment of 2015 H 5383[3] and S 299 SUB A or their 2016 versions. These act would direct all school superintendents to review discipline data for their school district, to decide whether there is an unequal impact on students based on race, ethnicity, or disability status, and to respond to any disparity.
Concern: There is little to no accommodations for students with electro-magnetic field sensitivities by schools. Page: 5-75
Recommendation: The Department of Elementary and Secondary Education should adopt an accommodation standard for elementary and secondary schools serving students with electro-magnetic field sensitivities.

Concern: Students with disabilities are not being properly accommodated for success in college, especially for children with language based learning disabilities. Page: 5-27
Recommendation: The GCD should conduct a workshop on accommodating college students with language based learning disabilities.

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[2] ACLU of Rhode Island June 2015 report http://riaclu.org/images/uploads/Suspended_Education_Final_060415.pdf

[3] H 5383 http://webserver.rilin.state.ri.us/BillText/BillText15/HouseText15/H5383.pdf and S 299 SUB A http://webserver.rilin.state.ri.us/BillText/BillText15/SenateText15/S0299A.pdf

## Employment

Concern: The lack of job supports for self-employment and entrepreneurs for working age adults with disabilities. Page: 5-38, 5-40

Recommendations: CommerceRI collaborating with the Office of Rehabilitative Services, Department of Behavioral Healthcare, Development Disabilities and Hospitals, the Department of Labor and Training and the Governor's Workforce Board should increase awareness of and inclusion of working age adults with disabilities interested in self-employment in: Urban Ventures[4]; Betaspring[5]; Social Enterprise Greenhouse[6]; and other micro and small business accelerators. The Department of Administration revise the purchasing regulations by incorporating the provisions of RIGL 37-2.2 Disability Business Enterprises[7] and 37-2.4 Habilitation Procurement Program[8].

Concern: Employment of people with disabilities isn't an intregal part of the state's economic development plan. 5-67

Recommendation: The Governor's Workforce Board, Secretary of Commerce, Secretary of Health and Human Services, and Director of Labor and Training should implement the National Governor's Association's "A Better Bottom Line: Employing People with Disabilities: Blueprint for Governors":

a) Make disability employment part of the state workforce development strategy;
b) Find and support businesses in their efforts to employ people with disabilities;
c) Be a model employer by increasing the number of people with disabilities working in state government;
d) Prepare youth with disabilities for careers that use their full potential, providing employers with a pipeline of skilled workers; and
e) Make the best use of limited resources to advance employment opportunities for people with disabilities.

## Financial Supports

Concern: Family members are not compensated as caregivers. There is a shortage of affordable home care options. Page: 5-2, 5-46, 5-33, 5-34, 5-36, 5-37, 5-47, 5-48, 5-52, 5-57, 5-60

Recommendation: The Secretary of Health and Human Services should authorize parents to receive caregiver stipends for adult children with severe impairments.

Concern: Supplemental Security Income (SSI) benefit is not enough to pay for a person's basic needs. Page: 5-7, 5-38, 5-53, 5-93

Recommendation: The GCD advocate for the state's SSI benefits to be increased annually that matches the Social Security cost of living adjustment.

## Healthcare

Concern: Navigating the children's and adult's healthcare system is difficult, cumbersome, and families are not receiving the proper assistance. Page: 5-2, 5-3, 5-54, 5-45, 5-97

Recommendation: The state should shift to a one-stop service for all human service needs, including: a single point of entry for all services; one benefits web portal; and peer navigators and/or benefits specialists to assist citizens through the eligibility process for services.

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[4] http://www.urbanventuresri.org/

[5] http://www.betaspring.com/

[6] http://segreenhouse.org/

[7] http://webserver.rilin.state.ri.us/Statutes/TITLE37/37-2.2/INDEX.HTM

[8] http://webserver.rilin.state.ri.us/Statutes/TITLE37/37-2.4/INDEX.HTM

Concern: Services for people with traumatic brain injury are not sufficient, the state does not have a comprehensive treatment center. Page: 5-103
Recommendation: The GCD advocate for increased funding for in-state traumatic brain injury services.

Concern: The criminalization of symptoms of behavioral health and the lack of sufficient behavioral healthcare prior to release and aftercare creates a revolving door. Page: 5-52
Recommendation: The Departments of Corrections and Behavioral Healthcare, Development Disabilities, and Hospitals should create a supportive housing program to provide additional housing for individuals with disabilities coupled with long term support services and case management to stabilize the lives of former convicts with behavioral health needs.

Concern: Untrained/licensed workers administering injectable medications, specifically epi-pens and insulin that are medically necessary. Page: 5-94
Recommendation: The Department of Behavioral Healthcare, Developmental Disabilities and Hospitals (BHDDH) provide training to staff, including and providers regarding who are qualified to administer injectable medications.

Concern: Proper sanitary supplies are not being provided to persons by the state. Page: 5-59
Recommendation: The Secretary of Health and Human Services should reconsider shifting to single ply adult diapers.

## Housing

Concern: Finding information regarding the range of housing options is difficult, cumbersome, and persons are not receiving the proper assistance. Pages: 5-1, 5-4, 5-9, 5-14, 5-31, 5-42, 5-53
Recommendation: The state should shift to a one-stop service for all human service needs, including: a single point of entry for all services; one benefits web portal; and peer navigators and/or benefits specialists to assist citizens through the eligibility process for services.

## Transitioning

Concern: There are not enough adult assisted living “slots” to meet the needs of young adults transitioning into the adult service system. Page: 5-13
Recommendation: The Secretary of Health and Human Services and the Commissioner of Elementary and Secondary Education should create an early identification database to identify young adults two years prior to their transition into adult service system, to properly budget for the increased caseload.

Concern: Navigating the adult human service system is difficult, cumbersome, and persons are not receiving the proper asistance. Pages: 5-2, 5-7, 5-8, 5-13, 5-14, 5-30, 5-37, 5-46, 5-95, 5-96
Recommendation: The state should shift to a one-stop service for all human service needs, including: a single point of entry for all services; one benefits web portal; and peer navigators and/or benefits specialists to assist citizens through the eligibility process for services.

Concern: State budget cuts are creating difficulties and agencies are not cooperating effectively. Page: 5-59
Recommendation: The GCD advocate for the restoration of disability service funding to the pre-2008 level.

Concern: Guardianship and the guidelines for guardianship are complicated and difficult to navigate. Pages: 5-44, 5-53, 5-55, 5-57

Recommendation: The RI Disability Law Center and/or RI Parent Information Network should produce an easy to read booklet regarding the guardianship options for families.

Concern: Persons with electro-magnetic sensitives are not being properly accommodated. Page: 5-84, 5-88, 5-90
Recommendation: The GCD should request the US Access Board adopt a Wi-Fi free access standard; Wi-Fi free areas should be established in government and healthcare facilities with hardware and insulation from electro-magnetic.

## Transportation Concerns and Recommendations

### Paratransit

Concerns: LogistiCare is ineffective and takes too long to reach individuals whom require the service. The older system used for RIde, with multiple vendors including Maher and Cozy is better than the current system in place. Pages: 5-7, 5-20,
Recommendation: Office of Health and Human Services and RIPTA assess the level of LogistiCare and RIde passenger satisfaction with the current systems.

Concern: The RIde time window for pickups and arrivals (½ hr) create many difficulties for people (i.e. employers want their employees to report to work on time and not leave before the end of the workday). Page: 5-18, 5-25, 5-26, 5-31, 5-37, 5-39
Recommendation: The time window for RIde's standing order passengers (traveling the same days and times on a fixed basis) should be reduced from ½ hr to ¼ hr.

Concern: RIde vans cannot accommodate larger motorized transportation vehicles/devices. Page: 5-14, 5-62
Recommendation: RIPTA should purchase / retrofit wheelchair lifts & tie downs to accommodate larger and heavier wheelchairs.

### Public Transit Buses

Concern: RIPTA and RIde fare increases are unreasonable and put added pressure on low income riders with disabilities. Page: 5-10, 5-13, 5-54
Recommendation: The General Assembly should require RIPTA and RIde to adopt a sliding scale based on income for low income seniors and persons with disabilities.

Concerns: RIde and RIPTA services are not statewide and underused RIPTA routes may be eliminated. Page: 5-13, 5-19, 5-23, 5-37, 5-43, 5-46, 5-59, 5-60, 5-62
Recommendation: Expand public (RIPTA) and para-transit (RIde) service to serve the entire state.

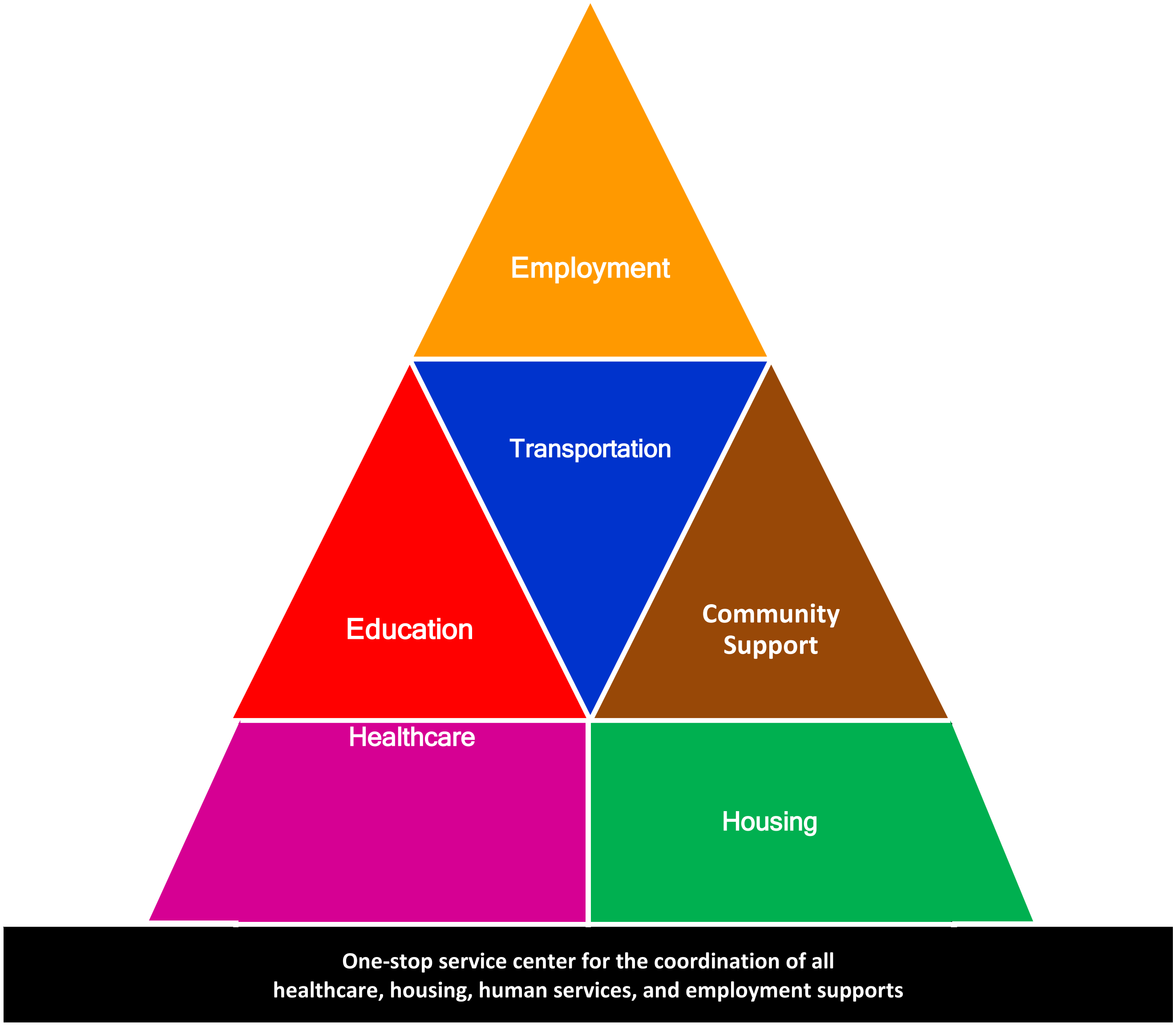
Concern: RIPTA buses cannot accommodate larger motorized transportation vehicles/devices. Page: 5-14, 5-62
Recommendation: RIPTA should purchase / retrofit wheelchair lifts & tie downs to accommodate larger and heavier wheelchairs.

Concern: At Kennedy Plaza the when the bus pulls up, there is no announcement indicating which bus route it serves. Page: 5-6
Recommendation: RIPTA's automated stop announcement system should be in use when buses pull-up to Kennedy Plaza and other RIPTA hubs.

Concern: This year's 25th ADA Anniversary Celebration was not accessible for RIde and RIPTA passengers. Page: 5-61
Recommendation: The Governor's Commission on Disabilities should locate all of its events on public bus routes.

Concern: Special events often times are inaccessible or extremely limited to RIPTA & Ride passengers with disabilities. Page: 5-63
Recommendation: The GCD advocate for accessible transit service to major events, such as Bristol 4th of July Parade, Chinese Dragon Boat Races & Taiwan Day Festival, Jazz Fest Newport, Newport Folk Festival, Wickford Art.

# 3. Commission's 2016 Legislative and Administrative Initiatives



### Healthcare/Medicaid employment support services needed to sustain paid work[9]; to remain maximum independent

- **a) Legislative:**
  - i) Advocate for increase the level of funding for:
    - (1) In-state traumatic brain injury comprehensive treatment center;
    - (2) Parents to receive caregiver stipends for adult children with severe impairments;
    - (3) Annually increase the state's share of Supplemental Security Income (SSI) benefits to match the federal SSI benefits cost of living adjustment;
    - (4) Incontinent supplies (double ply adult diapers);

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[9] **§ 40-8.7-4 Definitions** (3) "Employment Support Services" means activities work including: benefits counseling; supervision; job coaching; vocational evaluation; case management; job development; customized employment; job training; transportation; training; tools; equipment; and technology, subject to Centers for Medicare and Medicaid Services approval.

        - (5) Adult services for individuals with developmental disabilities; and
        - (6) Respiratory therapist services in nursing homes;
    - ii) Advocate for the restore the 2008 eligibility rules / level of services for children in the Katie Beckett program and children with autism spectrum disorders;
- **b) Administrative:**
    - i) Promote and expand the use of the RIGL 40-8.7 Health Care Assistance for Working People with Disabilities (Sherlock Plan);
    - ii) Advocate for the right to medically necessary brand name drugs without requiring two generic failures before allowing brand name**;**
    - iii) Advocate for funding of drop-in peer support behavioral healthcare services**;**
      Establishment of a process for the Commission to take a position on Medicaid Regulation Changes, using the Legislation Committee;
    - iv) Recommend the Department of Health s require all hospitals and urgent/emergency healthcare facilities to have: on-call sign language interpreters readily available; licensed American Sign Language staff; or Video Reporting Interpreting[10];
    - v) Recommend the Department of Health require all hospitals to have a Wi-Fi and chemically free examination/bed room to serve patients with chemical sensitivity or electromagnetic sensitivity and require the use of the Centers for Disease Control and Prevention's Indoor Environmental Quality Guidelines for personnel to use when in those rooms;
    - vi) Recommend the US Access Board adopt a Wi-Fi free access standard for a free examination/bed room in hospitals, urgent and emergency healthcare facilities; and
    - vii) Refer the assistive technology concerns to the State Rehabilitation Council.

**Housing supports need for successful employment**

- **a) Legislative:**
    - i) Advocate for additional funding of the Neighborhood Opportunities Program[11];
    - ii) Advocate for the creation and funding of supportive housing programs for:
        - (1) Homeless individuals with disabilities; housing coupled with services and case management to stabilize in permanent housing at affordable rents for persons receiving Supplemental Social Security Income (SSI); and
        - (2) Former convicts with behavioral health needs; housing coupled with long-term support services and case management to facilitate re-entry into the community; and
    - iii) Advocate for current service level funding of the Home Modification program.

**Education needed to become and remain employable**

- **a) Legislative:**
    - i) Advocate for the enactment of the 2016 versions of H 5383[12] and S 299 SUB A acts would direct all school superintendents to review discipline data for their school district, to decide whether there is a disparate impact on students based on race, ethnicity, or disability status.
- **b) Administrative:**
    - i) Recommend the Department of Elementary and Secondary Education ensure all children have the accommodations needed for success; especially children with language based learning disabilities, deaf or hard of hearing**;**

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[10] In consultation with the RI Commission on the Deaf and Hard of Hearing

[11] The Neighborhood Opportunities Program provides Family Affordable Housing - housing for very low-income families; and Permanent Supportive Housing - housing for disabled and special needs persons coupled with essential services.

[12] H 5383 http://webserver.rilin.state.ri.us/BillText/BillText15/HouseText15/H5383.pdf and S 299 SUB A http://webserver.rilin.state.ri.us/BillText/BillText15/SenateText15/S0299A.pdf

- ii) The Employment Committee and/or RIPIN conduct workshops on accommodating college students with language-based learning disabilities; and
- iii) Request the Department of Elementary and Secondary Education initiate a 5-year look-back study on accommodations for elementary and secondary school students with chemical sensitivities or electro-magnetic field sensitivities.

**Community supports needed to obtain and remain employed**

- a) **Administrative:**
  - i) Ensure replacement voting machines are fully accessible and used at all elections, including financial town meetings and all polling places are accessible;
  - ii) Conduct training for managers of retail and grocery store and other businesses on accessible layouts;
  - iii) Request the US Department of Justice to adopt a Wi-Fi free accommodation standard on what steps retail or grocery stores and other private businesses should take to serve customers with electro-magnetic field sensitivity or chemical sensitivity;
  - iv) Recommend the Department of Environmental Management purchase additional beach/surf-wheelchairs at state beaches;
  - v) Provide training on the ADA requirements for state and local government ADA/504 Coordinators;
  - vi) Recommend courtrooms and jury deliberation rooms have an accessible path between them. In older facilities with stairs to the jury deliberation rooms, trials must be moved to an accessible facilities to accommodation members of a jury who is unable to climb stairs;
  - vii) Recommend the Congressional Delegate require all Post Offices comply with the US Access Board's Accessibility standards;
  - viii) Request the e US Access Board adopt a Wi-Fi free access standard, for government facilities with hardware and insulation from electro-magnetic fields;
  - ix) Request the US Department of Justice adopt a chemical sensitivity accommodation standard for government services, schools, public housing, and other government-funded services;
  - x) Conduct a workshop on accessing religion in conjunction with the RI Council of Churches, Board of Rabbis of Greater RI, Roman Catholic Diocese, Islamic Centers, Buddhist Temples, and other faith communities;
  - xi) Recommend the Department of Transportation require:
    - (1) An assessment of the safety of pedestrians with disability before the installation of curb cuts, signage; and crosswalks (including audible signaling); and
    - (2) Pedestrian crossing signs alerting to motorists where crosswalks are on the downslope of a hill; and
  - xii) Create public service announcements to inform the public on the use of disability parking and remind police departments of their obligations under RIGL 31-28-7.3 Disability parking enforcement program.

**Transportation to education, employment, job training, health care, etc.**

- a) **Legislative:**
  - i) Advocate for maintaining the existing RIPTA/RIde service areas and adequate & stable funding;
  - ii) Advocate for expanding the RIPTA/RIde service areas/hours beyond the existing service/hours to provide a statewide service;
  - iii) Advocate for the establish a sliding scale fare (based on income) for both RIPTA & RIde low income passengers with disabilities;
  - iv) Request the Office of Health and Human Services and RIPTA assess the level of LogistiCare and RIde passenger satisfaction with the current systems;

v) Advocate for shorten the time window for RIde's standing order passengers (i.e. traveling to work the same days and times on a fixed basis) reduced from ½ hour to ¼ hour;
vi) Recommend RIPTA purchase / retrofit wheelchair lifts & tie downs to accommodate larger and heavier wheelchairs and scooters.
vii) Request RIPTA ensure the automated stop announcement system is in use when buses pull-up to Kennedy Plaza and other RIPTA hubs to alert passengers with low or no vision.
viii) Recommend accessible transit service to major events, such as Bristol 4th of July Parade, Chinese Dragon Boat Races & Taiwan Day Festival, Jazz Fest Newport, Newport Folk Festival, Wickford Art, Charlestown Seafood Festival, and other high attendance events.

### Shift from a multi-departmental service delivery system to one-stop service center for the coordination of all healthcare, housing, human services, and employment supports

a) **Administrative:**
   i) Advocate for a single point of entry for all services;
      (1) Similar to the Benefits Bank Web Portal[13] with
      (2) Peer Navigators and/or Benefits Specialists to assist citizens through the eligibility process for services.
   ii) Recommend the Secretary of Health and Human Services and the Commissioner of Elementary and Secondary Education create an early identification database to identify young adults two years prior to their transition into adult service system, to properly budget for the increased caseload; and
   iii) Request the RI Disability Law Center and/or RI Parent Information Network should produce an easy to read booklet regarding the guardianship options for families.

### Resulting in Employment

a) **Administrative:**
   i) Recommend the Governor Implement the National Governor's Association's "A Better Bottom Line: Employing People with Disabilities: Blueprint for Governors":
      (1) Make disability employment part of the state workforce development strategy;
      (2) Find and support businesses in their efforts to employ people with disabilities;
      (3) Be a model employer by increasing the number of people with disabilities working in state government;
      (4) Prepare youth with disabilities for careers that use their full potential, providing employers with a pipeline of skilled workers; and

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[13] Similar to the multi-state Benefits Bank.
The Benefit Bank is a web-based service that simplifies and centralizes the process of applying for many state and federal benefits for low- and moderate-income individuals and families. Through its eligibility-screening tool, The Benefit Bank can ensure that people are fully aware of the benefits to which they are entitled and, as an expert system, it helps maximize the benefits and tax refunds they can secure. The "one-stop-shop" concept of The Benefit Bank reduces the amount of time needed to apply for benefits. Further, the information a person enters is stored securely, so an individual who wishes to reapply for benefits, apply for new benefits or file future tax returns simply needs to enter his or her username and password to initiate this new action.
The Benefit Bank is a free service. No consumer can be charged for using The Benefit Bank online service. If an organization provides counselor candidates, a computer, a printer, Internet access and a phone in a setting that is respectful and private, they can offer The Benefit Bank online service. From the start, The Benefit Bank has been structured to assure the privacy and confidentiality of all client data.
Developed for use by a wide range of community based, faith-based, governmental, job-training, healthcare or social service agencies, The Benefit Bank can be part of a community-wide response to poverty. The Benefit Bank not only provides the opportunity to help neighbors but also provides information for organizations to more effectively advocate for policies that had better serve their communities. An innovative public-private partnership of state/local governments and a broad, statewide coalition committed to helping neighbors move towards self-sufficiency by utilizing The Benefit Bank, has resulted in tens of millions of dollars being returned each year to low and moderate income individuals and families.

  (5) Make the best use of limited resources to advance employment opportunities for people with disabilities[14].

ii) Advocate for improving the school to adult transitional services / employment / post-secondary education;

iii) Advocate for maintaining a range of employment options**.**

iv) Advocate for involving CommerceRI[15] in increasing awareness and inclusion of working age adults with disabilities interested in self-employment in: Urban Ventures[16]; Betaspring[17]; Social Enterprise Greenhouse[18]; and other micro and small business accelerators.

v) Advocate for the Department of Administration to revise the purchasing regulations by incorporating the provisions of RIGL 37-2.2 Disability Business Enterprises[19] and 37-2.4 Habilitation Procurement Program[20].

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[14] The Governor's Workforce Board, Secretary of Commerce, Secretary of Health and Human Services, and Director of Labor and Training

[15] CommerceRI collaborating with the Office of Rehabilitative Services, Department of Behavioral Healthcare, Development Disabilities and Hospitals, the Department of Labor and Training and the Governor's Workforce Board

[16] http://www.urbanventuresri.org/

[17] http://www.betaspring.com/

[18] http://segreenhouse.org/

[19] http://webserver.rilin.state.ri.us/Statutes/TITLE37/37-2.2/INDEX.HTM

[20] http://webserver.rilin.state.ri.us/Statutes/TITLE37/37-2.4/INDEX.HTM

# 4. 2014 Annual Disability Statistics Compendium: Rhode Island

The Source for all the tables is the: Annual Disability Statistics Compendium: 2014, published by the Rehabilitation Research and Training Center on Disability Statistics and Demographics. For more resources, including help using the Compendium, please visit www.DisabilityCompendium.org.

## 1. Population and Prevalence

Tables 1.3 - 1.7 Civilians Living in the Community for the United States and States, by Disability Status and Age: 2013

| Area | Total | Disability | | No Disability | |
|---|---|---|---|---|---|
| | | Count | % | Count | % |
| USA | 314,746,745 | 39,892,960 | 12.7% | 274,853,785 | 87.3% |
| Rhode Island | 1,036,046 | 131,583 | 12.7% | 904,463 | 87.3% |
| Under 5 years old | | | | | |
| USA | 19,968,015 | 162,224 | 0.8% | 19,805,791 | 99.2% |
| Rhode Island | 54,166 | 271 | 0.5% | 53,895 | 99.5% |
| 5 to 17 Years | | | | | |
| USA | 54,291,314 | 2,945,743 | 5.4% | 51,345,571 | 94.6% |
| Rhode Island | 158,264 | 10,454 | 6.6% | 147,810 | 93.4% |
| 18 to 64 Years | | | | | |
| USA | 196,541,629 | 20,714,303 | 10.5% | 175,827,326 | 89.5% |
| Rhode Island | 668,448 | 66,444 | 9.9% | 602,004 | 90.1 |
| 65 Years and Over | | | | | |
| USA | 43,945,787 | 16,070,690 | 36.6% | 27,875,097 | 63.4% |
| Rhode Island | 155,168 | 54,414 | 35.1% | 100,754 | 64.9% |

Tables 1.8 - 1.13 Civilians Age 18 to 64 Living in the Community for the United States and States, by Type of Disability: 2013

| Area | Total | Disability | Count | % of Total | % of Disability |
|---|---|---|---|---|---|
| USA | 196,541,629 | 20,714,303 | | | |
| Rhode Island | 668,448 | 66,444 | | | |
| USA | Hearing Disability | | 4,140,213 | 2.1% | 20.0% |
| Rhode Island | | | 12,136 | 1.8% | 18.3% |
| USA | Vision Disability | | 3,886,268 | 2.0% | 18.8% |
| Rhode Island | | | 12,063 | 1.8% | 18.2% |
| USA | Cognitive Disability | | 8,652,119 | 4.4% | 41.8% |
| Rhode Island | | | 29,387 | 4.4% | 44.2% |
| USA | Ambulatory Disability | | 10,398,470 | 5.3% | 50.2% |
| Rhode Island | | | 30,384 | 4.5% | 45.7% |
| USA | Self-Care Disability | | 3,688,107 | 1.9% | 17.8% |
| Rhode Island | | | 11,573 | 1.7% | 17.4% |
| USA | Independent Living Disability | | 7,236,800 | 3.7% | 34.9% |
| Rhode Island | | | 22,995 | 3.4% | 34.6% |

## 2. Employment

Table 2.1 - 2.2 Employment–Civilians Ages 18 to 64 Years Living in the Community for the United States and States: 2013

| Area | Disability | | | No Disability | | |
|---|---|---|---|---|---|---|
| | Total | Employed | % | Total | Employed | % |
| USA | 20,714,303 | 7,031,023 | 33.9% | 175,827,326 | 130,487,197 | 74.2% |
| Rhode Island | 66,444 | 22,784 | 34.3% | 602,004 | 459,153 | 76.3% |

[21]

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[21] All statistics from published by the Rehabilitation Research and Training Center on Disability Statistics and Demographics. For more information please visit www.DisabilityCompendium.org

[22]

Tables 2.3 & 2.4 Employment–Civilians with Disabilities Ages 18 to 64 Years Living in the Community for the United States and States by Type of Disability: 2013

| Area | Hearing Disability | | | Vision Disability | | |
|---|---|---|---|---|---|---|
| | Total | Employed | % | Total | Employed | % |
| **USA** | 4,140,213 | 2,080,228 | 50.2% | 3,886,268 | 1,537,721 | 39.6% |
| **Rhode Island** | 12,136 | 6,303 | 51.9% | 12,063 | 4,298 | 35.6% |

Tables 2.5 - 2.6 Employment–Civilians with Disabilities Ages 18 to 64 Years Living in the Community for the United States and States by Type of Disability: 2013

| Area | Cognitive Disability | | | Ambulatory Disability | | |
|---|---|---|---|---|---|---|
| | Total | Employed | % | Total | Employed | % |
| **USA** | 8,652,119 | 2,050,529 | 23.7% | 10,398,470 | 2,482,199 | 23.9% |
| **Rhode Island** | 29,387 | 7,332 | 24.9% | 30,384 | 5,818 | 19.1% |

Tables 2.7 & 2.8 Employment–Civilians with Disabilities Ages 18 to 64 Years Living in the Community for the United States and States by Type of Disability: 2013

| Area | Self-Care Disability | | | Independent Living Disability | | |
|---|---|---|---|---|---|---|
| | Total | Employed | % | Total | Employed | % |
| **USA** | 3,688,107 | 560,044 | 15.2% | 7,236,800 | 1,107,671 | 15.3% |
| **Rhode Island** | 11,573 | 1,619 | 14.0% | 22,995 | 4,288 | 18.6% |

## 4. Poverty

Table 4.1 - 4.2 Poverty–Civilians Ages 18 to 64 Years Living in the Community for the United States and States: 2013

| Area | Total | Disability Poverty | % | Total | No Disability Poverty | % |
|---|---|---|---|---|---|---|
| USA | 20,611,329 | 5,910,517 | 28.7% | 173,350,136 | 23,576,736 | 13.6% |
| Rhode Island | 65,000 | 18,133 | 27.9% | 579,952 | 68,243 | 11.8% |

## 5. Earnings

Table 5.1 Earnings–Median Earnings of Civilians 16 Years and Over in the Past 12 Months for the United States and States, by Disability Status (in 2013 inflation-adjusted dollars): 2013

| Area | Total | Disability | No Disability | Gap |
|---|---|---|---|---|
| **USA** | $30,032 | $20,785 | $30,728 | $9,943 |
| **Rhode Island** | $31,836 | $22,249 | $32,218 | $9,969 |

## 6. Veterans

**Table 6.1 Service—Connected Disability Rating- Civilian Veterans Ages 18 Years and Over Living in the Community, by Disability Status: 2012**

| Area | Total Veterans | Has a Rating | 0% | 10 to 60% | 70 or Higher | Rating not reported |
|---|---|---|---|---|---|---|
| **USA** | 19,677,519 | 3,599,455 | 211,773 | 2,208,186 | 965,943 | 213,553 |
| **% of USA Total** | | 18.3% | 1.1% | 11.2% | 4.9% | 1.1% |
| **Rhode Island** | 64,325 | 9,023 | 434 | 5,577 | 2,480 | 532 |
| **% of RI Total** | | 14.0% | 0.7% | 8.7% | 3.9% | 0.8% |

Table 6.3 Poverty–Civilian Veterans with Disabilities Ages 18 to 64 Years Living in the Community for the United States and States: 2013

| | | | | | | |
|---|---|---|---|---|---|---|
| **USA** | 1,878,149 | 325,892 | 17.4% | 8,326,520 | 621,714 | 7.5% |
| **Rhode Island** | 4,405 | 224 | 5.1% | 25,180 | 1,408 | 5.6% |

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[22] All statistics from published by the Rehabilitation Research and Training Center on Disability Statistics and Demographics. For more information please visit www.DisabilityCompendium.org

## 7. Health Insurance Coverage

**Table 7.1 Health Insurance Coverage–Civilians Ages 18 to 64 Years Living in the Community for the United States and States by Disability Status: 2013**

| Area | Coverage % | | Gap % |
|---|---|---|---|
| % | Disability | No Disability | |
| **USA** | 84.0% | 81.2% | 2.8% |
| **Rhode Island** | 87.7% | 83.4% | 4.3% |

**Table 7.2 Health Insurance Coverage–Civilians with Disabilities Ages 18 to 64 Years Living in the Community for the United States and States by Type of Coverage: 2013**

| Area | Private | Public | No Coverage |
|---|---|---|---|
| **USA** | 44.1% | 51.3% | 16.0% |
| **Rhode Island** | 45.3% | 55.9% | 12.3% |

## 8. Health

**Table 8.3 - 8.6 Health Behavior–Persons Aged 18 and Over, by Disability Status: 2013**

| Area | Smoking | | Obesity | | Binge Drinking | |
|---|---|---|---|---|---|---|
| | Disability | No Disability | Disability | No Disability | Disability | No Disability |
| **USA** | 25.4% | 16.2% | 40.1% | 25.0% | 11.5% | 18.0% |
| **Rhode Island** | 26.9% | 14.6 | 37.1% | 24.3% | 12.8% | 19.3% |

## 9. Social Security Administration Programs

**Table 9.1 & 9.3 Supplemental Security Income–Number of Recipients of Federally Administered Payments: December 2012**

| Area | Total | Eligibility Category | | | Under Age 18 | | |
|---|---|---|---|---|---|---|---|
| | | Aged | Blind | Disabled | Total | Blind | Disabled |
| USA | 8,262,877 | 1,156,188 | 67,725 | 7,038,964 | 1,311,861 | 5,940 | 1,305,921 |
| Rhode Island | 32,644 | 3,185 | 179 | 29,280 | 4,769 | 9 | 4,760 |

**Table 9.5a Social Security Disability Insurance–Number of Beneficiaries: December 2013**

| Area | Total | Type of Beneficiary | | |
|---|---|---|---|---|
| | | Worker | Adult Children | Widow(er)s |
| USA | 9,850,966 | 8,624,654 | 976,978 | 249,334 |
| Rhode Island | 42,000 | 36,927 | 4,245 | 828 |

**Table 9.5b Social Security Disability Insurance–Number of Beneficiaries by Disability Type: December 2012**

| Area | Total Disabled | Congenital Anomalies | Endocrine, Nutritional, and Metabolic Diseases | Infectious and Parasitic Diseases | Injuries |
|---|---|---|---|---|---|
| USA | 9,850,966 | 32,317 | 315,916 | 130,222 | 377,920 |
| Rhode Island | 42,000 | 107 | 902 | 343 | 1,179 |

**Table 9.5c Social Security Disability Insurance–Number of Beneficiaries by Disability Type: December 2012**

| Area | Diseases of the– | | | |
|---|---|---|---|---|
| | Blood-Forming Organs | Circulatory System | Digestive System | Genitourinary System |
| USA | 26,616 | 759,477 | 151,207 | 153,454 |
| Rhode Island | 98 | 2,319 | 571 | 360 |

**Table 9.5d Social Security Disability Insurance–Number of Beneficiaries by Disability Type: December 2012**

| Area | Diseases of the– |
|---|---|
| | |

| [23] | Musculoskeletal System and Connective Tissue | Nervous System and Sense Organs | Respiratory System | Skin and Subcutaneous Tissue |
|---|---|---|---|---|
| USA | 2,663,430 | 930,096 | 264,404 | 22,408 |
| Rhode Island | 9,336 | 3,544 | 983 | 107 |

Table 9.5e Social Security Disability Insurance–Number of Beneficiaries by Disability Type: December 2012

| Area | Neoplasms | Intellectual Disability[24] | Other | Unknown |
|---|---|---|---|---|
| USA | 276,508 | 3,465,366 | 23,182 | 258,443 |
| Rhode Island | 1,130 | 19,805 | 124 | 1,092 |

**Table 9.5f Social Security Disability Insurance–Number of Beneficiaries by Disability Type: December 2012**

| Area | All Mental Disorders | Autistic Disorders | Developmental Disorders | Other Adolescent Disorders | Intellectual Disability |
|---|---|---|---|---|---|
| USA | 3,465,366 | 37,08 | 12,054 | 11,535 | 829,097 |
| Rhode Island | 19,805 | 214 | 69 | 113 | 3,895 |

Table 9.5g Social Security Disability Insurance–Number of Beneficiaries by Disability Type: December 2012

| Area | Mood Disorders | Organic Mental Disorders | Schizophrenic and Other Psychotic Disorders | Other |
|---|---|---|---|---|
| USA | 1,348,953 | 338,344 | 506,755 | 381,482 |
| Rhode Island | 8,623 | 1,578 | 2,219 | 3,094 |

## 10. Medicaid and Medicare

Table 10.1 Medicaid–Medicaid Payments by Disability Status: Fiscal Year 2011

| Area | Medicaid Payments ($) | | |
|---|---|---|---|
| | Total | Disabled | Disabled as a % of Total |
| USA | $364,460,000,000 | $155,784,000,000 | 42.7% |
| Rhode Island | $1,606,000,000 | $691,000,000 | 43.0% |

Table 10.2 Medicaid–Medicaid Persons with Disabilities Served (Disabled Beneficiaries): Fiscal Year 2011

| Area | Number of Beneficiaries | | |
|---|---|---|---|
| | Total | Disabled | Disabled as a % of Total |
| USA | 68,372,045 | 9,791,456 | 14.3% |
| Rhode Island | 221,041 | 38,290 | 17.3% |

Table 10.4 Medicare–Medicare Enrollment by Type of Entitlement: July 1, 2012

| Area | Number of Medicare Enrollees | | | |
|---|---|---|---|---|
| | Total | Aged | | Disabled as a % of Total |
| USA | 49,682,146 | 41,255,471 | 8,426,675 | 17.0% |
| Rhode Island | 191,420 | 155,581 | 35,839 | 18.7% |

## 11. Special Education

Table 11.1 Special Education–Students Ages 6 to 21 Served under IDEA, Part B, as a Percentage of Population: Fall 2012

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[23] All statistics from published by the Rehabilitation Research and Training Center on Disability Statistics and Demographics. For more information please visit www.DisabilityCompendium.org

[24] Intellectual disabilities are further detailed in tables 9.5F and 9.5G

| Area | Number | | Part B as a % of population |
|---|---|---|---|
| | Population [1] | Students | |
| USA | 67,529,839 | 5,693,441 | 8.4% |
| Rhode Island | 222,263 | 21,255 | 9.6% |

**Table 11.2 Special Education–Children and Students Served under IDEA, Part B, by Age: Fall 2012**

| Area | Age | | | |
|---|---|---|---|---|
| | 3 to5 | 6 to 11 | 12 to 17 | 18 to 21 |
| USA | 735,890 | 2,631,472 | 2,700,531 | 361,538 |
| Rhode Island | 2,910 | 9,101 | 10,542 | 1,612 |

**Table 11.3a Special Education–Students Ages 6 to 21 Served under IDEA, Part B, by Select Diagnostic Categories: Fall 2012**

| Area | All Disabilities | Specific Learning Disabilities | Speech or Language Impairment | Intellectual Disabilities |
|---|---|---|---|---|
| USA | 5,693,441 | 2,268,098 | 1,032,729 | 415,697 |
| Rhode Island | 21255 | 8290 | 2966 | 797 |

**Table 11.3b Special Education–Students Ages 6 to 21 Served under IDEA, Part B, by Select Diagnostic Categories: Fall 2012**

| Area | Emotional Disturbance | Multiple Disabilities | Hearing Impairment |
|---|---|---|---|
| USA | 359,389 | 124,722 | 68,069 |
| Rhode Island | 2,024 | 348 | 140 |

**Table 11.3c Special Education–Students Ages 6 to 21 Served under IDEA, Part B, by Select Diagnostic Categories: Fall 2012**

| Area | Orthopedic Impairments | Other Health Impairments | Visual Impairments |
|---|---|---|---|
| USA | 52,052 | 757,904 | 24,987 |
| Rhode Island | 74 | 3458 | 57 |

**Table 11.3d Special Education–Students Ages 6 to 21 Served under IDEA, Part B, by Select Diagnostic Categories: Fall 2012**

| Area | Autism | Deaf-Blindness | Traumatic Brain Injury | Developmental Delay |
|---|---|---|---|---|
| USA | 440,592 | 1,281 | 25,020 | 122,901 |
| Rhode Island | 1,911 | 6 | 55 | 1,129 |

**Table 11.4 Special Education–Educational Environment–Students Ages 6 to 21 Served under IDEA, Part B that Spent 40 Percent or More Time Inside Regular Class: Fall 2012**

| | Number | | Greater than 40 percent as a percent of students in all environments |
|---|---|---|---|
| Area | All Environments | Regular Class | |
| USA | 5,693,441 | 4,604,585 | 80.9% |
| Rhode Island | 21,255 | 17,049 | 80.2% |

**Table 11.5, 11.6 11.7 Special Education—Students Ages 14 to 21 Served under IDEA, Part B, Left School, by Reason: 2011-2012**

| Area | Graduated with Diploma | Received a Certificate | Dropped Out | Died or Aged Out | Graduation Rate % | Dropped Out % |
|---|---|---|---|---|---|---|
| USA | 247,596 | 53,564 | 77,797 | 7,058 | 64.6% | 19.7% |
| Rhode Island | 1,260 | 4 | 158 | 95 | 83.1% | 10.4 |

## 12. Vocational Rehabilitation

**Table 12.1, 12.2 & 12.3 Vocational Rehabilitation–Applicants, Closures after Services Initiated or Completed, & Closures with Successful Employment Outcomes Federal Fiscal Year 2012**

| Area | Applicants | Closures | Successful Closures | Rehabilitation Rate |
|---|---|---|---|---|
| USA | 560,222 | 319,144 | 177,172 | 55.5% |
| Rhode Island | 2,251 | 2,096 | 602 | 28.7% |

[25]

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[25] All statistics from published by the Rehabilitation Research and Training Center on Disability Statistics and Demographics. For more information please visit www.DisabilityCompendium.org

# 5. Testimony

## 27 July, 2015 South Providence Forum

CASEY GARTLAND: Welcome, everybody, to the public forum to identify concerns of people with disabilities and their families. I want to mention before introductions that there are bathrooms right outside here, to the right. And in a moment, I'll have the panel introduce themselves individually. First, the purpose of these forums is to identify concerns of people with disabilities and their families in order to assist the state develop programs to improve quality of lives for people with disabilities. To ensure everybody who wants to speak gets a chance, please keep comments short and to the point. If you have a critical problem that needs to be addressed, panel members will be available at the end of the forum to direct you to the proper agency for help. After the forums are completed in early August, the sponsoring agencies review testimony and prepare recommendations, which are also posted on the web site by the end of November. The recommendations and transcripts will be printed and sent to state officials and members of the General Assembly and recommendations will be used to develop policy and legislative initiatives for the next year, or until accomplished. If you picked up a packet, on the inside cover, there are what past forums have done. The Rhode Island Disability Law Center's panelists are available to register anyone who is a citizen and not currently registered to vote at the end of testimony. People can also file a change of address if they moved since the last election. At this point, I will have the panel introduce themselves, and identify who they are affiliated with.

MEREDITH SHEEHAN: ...for the National Multiple Sclerosis Society.

CARMEN BOUCHER: I am at the Rhode Island Department of Health, at the Office of Special Health Care Needs.

CHARLES MESSINA: Attorney with the Rhode Island Disability Law Center in Providence.

KAREN RUSSELL: I am a vocational rehabilitation counselor for Office of Rehabilitation Services.

CASEY GARTLAND: I want to ask that you register in the back, and there are assistive listening devices if needed. We ask that you speak slowly and clearly so the person transcribing can get correct spelling for the notes. Identify not only your name, but which city or town you live in. So with that, we're going to start with the first speaker, if anyone has decided to speak, anyone want to say something to the panel?

MEREDITH SHEEHAN: I wanted to mention for the transcript, at the MS society, I do a lot of advocacy work for people, we have about 2000 people registered in our chapter location, we do Live with MS, and an issue, we're consistently hearing how challenging it is to pay for home modifications, and they need to, make a bathroom accessible, a ramp into their house, lower their kitchen counters, anything that would be necessary for someone with MS or any disability, or an aging population to stay in the house they own without needing to move, and be able to stay safely and independently. So one of the pieces of legislation we did submit this year through the National MS Society was what we call the Rhode Island livable home tax credit establishing a tax credit program within the state, on your state income taxes that would allow you to deduct expenses paid for certain home modifications, your basic ones would be included in that. And we did, it didn't pass, obviously, so we'll continue to work on it this year, but I wanted to be sure it was brought up as an issue, how hard it is for people to stay in their homes and pay for home modifications, to keep them safe as opposed to being prematurely admitted to a nursing home if they fall, or have to leave their home for some reason, they don't really want to do so. So I'm hoping, I've met with some people with the Department of Health, and working with AARP and OSCIL and other agencies like that, for a host of

Independent Living

people, like I said, with disabilities or the aging populations. I just wanted to be sure I got that in the record.

CASEY GARTLAND: Any questions from the panel about that? For those of you who are going to speak, if you wish to speak, the job of the panel is to listen and ask questions to elaborate, to be sure everything is in the notes. They might interact only as much as you have questions. With that, is there anybody else that would like to come forward and speak anything for the record? Well, we're here until 5:45, we might have people come in and out, so we can reopen.

Independent Living

MR. MARTINS: So, my name is Antonio Martins and I live in North Providence. And something I was thinking about while listening to the forum is about my own personal story in regards to my father recently diagnosed with Alzheimer's. One of the things we experienced as a family is the concept, in order to get him any services we basically have to strip him of his rights and thinking about the progression of the disease, he's not completely incoherent, he does have input into his own care, things he likes and does not like, and they have a direct effect on his health overall because whenever we try to force him to do something he is not in agreement with, it doesn't go well, delays services, all kinds of things. One of the issues we experienced as a family overall is finding any, it was easily enough to find providers but to find somebody who could advise on just whatever the process is, because the doctors would make this referral and then we would talk to this one, and then they would make a referral to a different one, and then it was like you could do this but you have to collect all of this paperwork ahead of time. And one of the things we are finding as a family with dementia and Alzheimer's, they are not very good record keepers and it's something that starts a long time ago to trying to find the back story and figuring out what happens, it's a little bit as a family, difficult, and then, it's difficult also to rally the different providers so one of the things we had to do, my father had lost his social security card so we had to go down to the office and apply for a new card and they wanted to speak to him directly and they were asking him a litany of questions, he's not going to respond to you, and at the end, it's all the same anyways so it's just kind of like that sensitivity and having somebody who could guide families through the process overall, so this is what's coming next, these are things you should start to think about. My parents are first generation in this country, so long-term planning; all of those kinds of things are not things that were in their ideas about what they wanted for themselves. We have tried, I think its service called The Point, you had to call and tell your story, and they were helpful, I think everyone tries very hard to be helpful but there is no direct path where you just fall into this path and these people will take you through. That's one of the things I have done in my profession, I work for early intervention, so once you are qualified for the program and we're connected with a family we take you through the process and one of the last things we do before a child turns 3 is finding the person to take them through the next steps in their journey for finding services for their children if still required so I definitely found that was something lacking for my own family and people in the situation one way or another is to find a dedicated, I don't know if the right term is service coordinator or social worker, whatever it is, to help a family, these are the things you need to start thinking about next. Because it's difficult, my father has Alzheimer's, my mother has mental health issues so it's difficult for each one of them to help the other and as a family the only services, thing, we have been able to find is basically putting them each in their own different home which doesn't help either one of them per se but my father has a nice place to go during the day now but my mom can't go with him because she has a different diagnosis, she offer today volunteer but she has to pass background check that is she won't pass because of background checks so keeping older couples together in older age with competing histories is something we haven't found a solution yet. So that's just one of the things I was thinking about as sitting in the back and thought buy bring it to the attention of the panel. So that's my own personal story. But my professional story, working with families with young children, what we're find ago lot of, as well, is just access to really pointed and good mental health services. It's something we are finding that it's hard for families to find. Particularly in Rhode Island, they're pretty good about making the initial phone calls and they have been able to establish quite a few agency that is our families can pick up with, but, I mean as we all know, people with mental health issues at the time they need them most are also the time when they're less stable so we're find ago lot of issues in regards to, you miss an appointment, back at the bottom of the list and really getting agencies to talk to each other so that's something we find a lot in our work and also I find that for families that enter into the DCYF process, having really good professional help for parents and their own parenting skills because these parents have a lot of requirements sometimes to get their own children back, rightfully so, but at the same time with a high level of requirements does not come a high level of support. We try to do the best we can to act as a stopgap but we're find ago lot of these nonprofit organizations that existed in the past like parents as teachers and a couple of the different ones, there was a great program who were older peep who will had raised several children would volunteer to come in and work with these parents to impart some parenting and coping skills which is really in essence what they need. It's just harder to find these kinds of programs and we make a lot of referrals so the agencies out there but they are not always the best fit for the families that we deal with. The majority of the families who get involved with DCYF and have children removed, almost inevitably they had the same thing happen to them so they didn't grow up with great examples or someone to impart to them coping with stressors of life and managing high need. So it ends up being kind after cycle over and over. So those are just the things I was thinking about while listening to some of the concerns you brought forth so I figured I would share them today.

CASEY GARTLAND: I have a question in regard to your first situation; did your family contact the department of elderly affairs?

MR. MARTINS: I find more of an issue with timing sometimes, called The Point; someone was on vacation, left a message. I know in our case our father was referred today a place in Woonsocket, they were great but he quickly out grew their ability to support and then needed something specific for families or for adults with memory issues. And by the time the point got back to us we had already found a different place. So it was really kind of, it's just the quickness have you to deal with things sometimes. The other thing I am finding in regards to work, for my father, is that you can quickly outgrow a facility and there isn't necessarily a mechanism to have the next facility ready and the people are really helpful like if I wanted to put him in a nursing home, like 24/7, people have that idea about it but I don't feel that is the thing we need or want for him as a family right now and that's the part that's harder is figuring out who can help us maintain him at home. Because when we first got in diagnosis my father started attending places during the day, because of his diagnosis, my mom's diagnosis got kicked off so she ended up in Butler for a while, they are very happy as a couple, lived together for 40 years, so that sudden switch of now he goes elsewhere, those that was really difficult for her. I imagine even apart from their diagnosis, I'm sure it's something couples and families deal with. With my brother and myself, extended services, 7:30 in the morning until 5:00, basically my work schedule so I have to leave early to pick him up at 5:00 and if my brother can't in the morning or myself in the afternoon so extending existing services to be more friendly towards families with a traditional work schedule. I can't even imagine if you have a second shift or something where it would be hard tore find care for a family member. But like I said everyone has been helpful, it's just the transition of taking you onto the next set of people. I feel all the people we have dealt with are very well intentioned and knowledgeable, it's just figuring out all of this working together. I know how to be a good son and take care of my dad, per se, but not like necessarily a doctor or social work other for that population and they come with their own set of rules and even in regards to like for social security in particular, they have missed deadlines for applying for Medicaid and for this and that, and it wasn't something I was thinking about in terms of having to manage for them. And even this past October when it came time to renew by the time we figured out what had happened all of the agencies that were willing to work with you to figure out the best augmentative insurance, they were all booked up, sorry, we filled up months ago. So I know they are now like in that Medicare, that doughnut whole and quickly going through the little resources that they have. So it's just kind of hard, I feel the pre-emptive work where you get on the wait list sooner rather than later is what's missing and it may be particularly in my family because of the way we figured out what was happening for them, but even in regards to the doctors, we got lots of referrals to other doctors, not any referrals to social services.

MEREDITH SHEEHAN: Has the Alzheimer’s Association –

MR. MARTINS: We haven't contacted them, I didn't know there was one.

MEREDITH SHEEHAN: There is a wonderful -- MS society, we have case managers on staff who kind of help people in similar situations but with MS obviously but I can, actually, I can give you the number, my girlfriends work there. There is a National Alzheimer’s Association but then there is a local branch as well right here in, at least, in New England but I think there is a Rhode Island office, as well. And in fact I know about them because I have seen lists of, like, series like educational series that they do, there was a four part one but some is for a care giver to go to, as well. For support and things like that, buy did he feel reach out to them. If the structure is similar, to the MS society they probably can offer some help. MR. MARTINS: For us, it was primarily finding him someplace during the day, get doctors setup then concentrate on what long-term would be. My brother took time out of work, I did, which is open to us as a family but putting everything on hold is difficult. So, I thank you.

FEMALE SPEAKER: So it's located on Waterman Street in Providence. ALZ.org. You can Google Alzheimer’s Association of Rhode Island and you'll be able to find it.

MR. MARTINS: Thank you so much.

CASEY GARTLAND: Last four or five minutes.

MS. MONROE: I'm not even from the state.

CASEY GARTLAND: That's okay.

MS. MONROE: Okay. I am Milly Monroe from Seekonk, moved there from Rumford. The reason I am here, I have disabled children. But one in particular, my youngest daughter in particular, is in such a crisis right now because of the state funding situation. And you can understand all the issues all you want, but when you're actually dealing with it, it’s heart breaking to see. I know I am not the only parent going through this. There are hundreds of them. Like I was saying, my youngest daughter, she has lived in semi-independent, in an apartment, geez, for well over 20 years. The apartment that she is living n she's been there for 14 years and how I know that exactly is because she was told that her agency is no longer going to support her staffing at night. Because she has to take medication, she needs 24 hour supports. And they -- that SIS thing makes me crazy. She consistently, over the years, has been on tier C. She is able to be in her own apartment like I said, but with supports. Well, they just came out, lowered her to a B. How convenient was that? Nothing has changed. She is brain damaged. And as far as I know, brain damage doesn't go away. Nothing about her has changed. She has gone through breast cancer, that whole journey with her. And she goes to work, she works on the base, she works part-time, but she is always

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saying, you know, I'm going to get 20 years, I'm going to retire, I'm going to get a check and that's all she thinks about. So even on a bad day, when she thinks she is having a bad day, I'll say, but, Donna, you can't quit, what's going to happen if you quit? She goes, yeah, I won't get that check. But she does beautifully with a little support. But now because they've cut her, the SIS has put her to a B, they're saying they can't support her any more like that. Now they want her to go into shared living and, well, let me back up a little. She has been totally unbearable to be around because she does not want to lose her apartment. So she is still, she's still in turmoil, and so I did the “what if” thing, but what if, what if you had to live somewhere else, where would you like to live? And she said, well, I just want to stay here. I've been here for 14 years and I do good and when the state comes to check my apartment, they say it's good. And she's all so happy about that so, trying to redirect her, it's difficult because, like I said she's acting out, I'm scared to death she's going to run away so when I mentioned shared living, she goes, mom, that's foster care, I'm not going to go in foster care. And you can call it what you like, but, it's her perception, she knows that it's foster care; you can call it any fancy name you want. But it means, to her, she's not going to have an apartment. It just tears me up to think that all these years and years and years of making these kids be the best, their personal best, of what they could be, that it's all being just...thrown away. And it's not right. And she cries and cries and says, it's not right, mom, it's not right. Now I have my other daughter, Denise, that you know, she keeps saying, mom, what are we going to do? Saying that she can't go again to a group home. The funding. And it's trying to find another apartment situation where there's staff available. She has always lived all by herself. So I don't know where all of that is going to end. But, it's not right. It's not fair.

CASEY GARTLAND: And have you spoken with her DDD social worker, you said?

MS. MONROE: Yes, I have. I have spoken to Jodi. Jodi is great with me. But it's just so hard to get your head around because all their life, the goal, we always worked on and they always went along, went along, went along. To get as far as they are and through no fault of their own, it's all just being demolished, it's not right. CASEY GARTLAND: Any questions from the panel?

MS. MONROE: That's my two cents.

CARMEN BOUCHER: You identified you don't live in Rhode Island but do.

MS. MONROE: They all do, all of my children.

CARMEN BOUCHER: so you are testifying for the adult children that you have that are residents of Rhode Island and those are the issues.

MS. MONROE: Yes, and they vote, by the way, they all vote. Keep that in mind. I wish, you know, I wish I could vote in Rhode Island, but I moved just down the street, just over the line. And so -- that's it. That's what I have to say.

CASEY GARTLAND: Thank you, very much.

MS. MONROE: Thank you for listening.

CASEY GARTLAND: So I guess that's the conclusion of today's testimony. Thank you very much for coming. And we have four or five more the rest of the week, there is a list if you want to get one as you walkout.

## 28 July, 2015 Warwick Public Forum

BETH PINKHAM: Can everybody hear me okay? Good. My name is Beth Pinkham from Ocean State Center for Independent Living. We are hosting the forum here this afternoon. I want to welcome everybody. The purpose of the forums is to identify concerns that people with disabilities and their families have in the state of Rhode Island. So that the state can develop programs to improve the quality of lives that persons with disabilities can live. To ensure everyone has a chance to speak, please if you have comments, keep them short and to the point. If there's more information that we need to give, we will be able to meet with you afterwards. So please, you know, keep that in mind. After the forums are completed in August, they will be used to help develop the agenda for the year for the commission. That way moving forward, whether there's legislation that needs to be proposed or budget issues and so forth they will be able to do that. They will be on the website, posted on the governor's commission website probably by November. So you can keep checking for that. And also if anybody wishes to register to vote or change their voter registration, we do have a staff person from Rhode Island Disability Law Center here this afternoon to help you out with that. So I am going to pass the mic on down the line and let the other panelists introduce themselves and let you know where they are from.

JANE CANNATA: Hi. I am Jane Cannata from Office of Rehab Services.

BOB FRICKLAS: Welcome, everyone. I am Bob Fricklas. I am from Meeting Street.

DEB BELANGER: Hi my name is Deb Belanger I work at Rhode Island Parent Information Network.

KATHY KUIPER: My name is Kathy Kuiper. I work at the Office of Special Healthcare Needs Department of Health.

MEREDITH SHEEHAN: I am Meredith Sheehan, communities program for the National Multiple Sclerosis Society.

KATE BOWDEN: I am Kate Bowden. I am a staff attorney with the Rhode Island Disability Law Center.

BETH PINKHAM: And just as a bit of housekeeping, if anybody needs restrooms or anything, if you go out the door you came in and go to the right, you should be all set there too. So again we are here to listen this afternoon. We will start with folks that checked in that they have a comment that they would like to make. The first person that we have is Barbara Henry. We will let you -- why don't we bring the mic down to you so everyone can hear.

Transportation

BARBARA HENRY: Hi. I am Barbara Henry. I am -- my first concern is I am blind and I cannot drive and I take RIPTA, the bus. I take the bus and I take the RIde program. Can you hear me? Okay. So my first concern is the RIPTA bus. It is not really accessible for someone who is blind. For instance, at Kennedy Plaza, when I wait for the bus, which is every day, multiple times, sometimes throughout the day. When the bus pulls up, I have no idea what bus it is. For anyone else here who is blind or legally blind or maybe elderly who is just their sight is a little off, it's stressful. There is no -- they do not announce the bus. And I feel that they really discriminate against anyone who is visually impaired or maybe if you are even print disabled or anything to that matter. So I have to go and just ask people what bus this is and I feel like it places my safety at risk. And now its summertime there's more people at Kennedy Plaza. And I have some people that appear to be just a little suspect that come up to me and say oh, I think that's the bus you want to get on. And I don't really appreciate that. I really feel that RIPTA does discriminate against people who are blind in terms of this. They renovated Kennedy Plaza. They put on the bus stops in Braille the bus stop letter. But they didn't put the number in Braille, which I don't understand for the life of me. That makes no sense. So I still don't know -- I have to ask a total stranger what bus stop I am at. So I really feel that I just feel every day when I take the bus, also when I get on the bus. Today, for example, I waited at a bus stop for years the bus stop was physically there. They removed the bus stop. I'm not aware of that. And so I'm standing there with the assumption that the bus stop was there. And they removed it. How am I supposed to know that? The bus driver stopped but who's to say the next bus driver wouldn't have stopped? These are some real concerns I have. I feel that RIPTA does discriminate against people who are blind. Thank you.

BETH PINKHAM: Thank you, Barbara. Next we have Heather Schey.

Transportation

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HEATHER SCHEY: I am Heather Schey. My biggest concern is transportation but it's LogistiCare. I have a twin who is also visually impaired. And I have also been left -- their cars are not qualified to be on the road some of them. My sister was left waiting for her ride with LogistiCare for four hours. My sister was also told on an appointment the morning of they couldn’t get anyone there because they just didn't have enough drivers. I think that LogistiCare needs to go back to RIde to become effective again and it was very efficient. My sister needs counselling and she will no longer use LogistiCare. And is on SSI (Supplemental Security Income) only, can't work, and doesn’t have the money for our RIde program, which is one of the highest in the New England area for $4 each way. So I just think that LogistiCare needs to go back to RIde. I think the contract needs to be broken, whatever that takes. Because the other point was I didn't -- when LogistiCare was contracted out, I, myself didn't know when it was or how that happened. And I think it was a surprise to a lot of my friends who are now stuck with using it if they don't have enough money to use RIde to get to their appointments. If people think that LogistiCare is running smoothly, it's not. It's that the complaints were never heard or never dealt with so people just stopped complaining. Thank you.

BETH PINKHAM: Thank you, Heather. Next we have Kristin Clark. Here you go.

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KRISTIN CLARK: Hi. Kristen Clark. I am actually here for a friend of mine. She and her son are both disabled, they are on SSI. They got -- they were found eligible for Section 8 and SNAP[26] last year. . And the SNAP office at least the Wakefield SNAP office has piles, piles and piles of folders. I mean you can physically see them in the office. And my friend has gone through a really traumatic experience dealing with SNAP because they don't have enough staff there. And I don't know if the people who are hired are hired to be difficult and belligerent or if not having enough staff makes them so stressed out that they become belligerent. But my friend is not one of these people who come in with an attitude. She's very respectful, very polite and she has experienced nothing but hostility from these people. I helped her with the initial eligibility process for SNAP. She got it and that was okay. There were some problems with the SNAP card not working sometimes when she would be at the market, which was a humiliating experience. And that was food that was going to be wasted because it had to go back to wherever. And then she received her recertification packet in February from the Providence SNAP office and the return address was Providence SNAP office. So she sent all her information back to there. Her appointment was a phone appointment. Her original appointment. She did miss that. That was her fault. She called and apologized and made a new appointment. The letter she received confirming the time and date of her new appointment stated that she could either do the call or she could go into a field office. But she would need to get there at least half an hour before her scheduled phone appointment. So she wanted to make sure there were no difficulties so she had all her paperwork with her. She copied everything. She copied bank statements so she could show everything to show that she is eligible. She got to the office. The Wakefield office. And the woman who came out and waited on her, I just couldn't believe it. It sounded like something out of The Twilight Zone. So hostile. Well, you sent it to the wrong office so I can’t do anything. And finally she agreed to take her in. And she looked at her computer and said, oh, you are getting the call now. Since you are not there, your benefits are going to be cancelled. My friend started to have a panic attack. She didn't understand why this person was so hostile to her. And she said but I have all the information and I thought that it was going to be in the computer and would be put in the computer from the Providence office, so that any field office would have it. And

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[26] Supplemental Nutrition Assistance Program, formerly Food Stamps

Wakefield is her home field office. And the woman said, it takes weeks, months for the information to get through. That's why we prefer the phone appointments. That's not my friend's fault. So she -- she was left with no idea of whether she had -- she was going to receive any food stamps for July or not. Oh she was also told that she had not given information about how much she pays for her Section 8 as opposed to how much Rhode Island Housing does. She did. There was no room for it on the original form so she put a sticky note on it. The person who did the intake for the original eligibility determination saw it. But he made a mistake and he put in the total amount paid by Rhode Island Housing. The combination of Rhode Island Housing's amount and her amount. They based how much -- what amount of food stamps she would give her on that and they blamed her that they made the error and they told her she would have to pay it back. She's on SSI! Her son's on SSI. She doesn't have any disposable income. There's no way she can pay this back. So she's just a mess. And again, it may not be totally these people's fault because they are in a no-win situation. They clearly do not have the staff to handle the amount of paperwork that's coming into them. But at the same time they don't have to be nasty. While she was there for her appointment she saw some other people come in who needed a translator and they had a toddler with them. And the two people there, one person was going to call the translator and the one who dealt with my friend said oh well, I will get to it and she left them there for an hour, and with a toddler. It's hard to occupy a toddler for an hour and keep them out of trouble. So I just was stunned by this whole process and I was so glad -- my son is also disabled. Perspectives are his service agency. I received a letter -- well he received a letter in the mail to inform us of these forums. I was so happy that these forums were going to be taking place because it's hard to get the word out, which do you talk to, and who can pass on the information to the pertinent people. So that's why I am here. Thank you.

BETH PINKHAM: Thank you, Kristin. For anyone who just came in, is there anyone who wanted to comment to the panelists at all? Did we get to everybody? Oh, okay. All right. Does anyone have any follow-up questions or comments or anything?

AMY STONE: It's Amy stone. I was just curious as to how come there's no one from BHDH on the panel. That's a big issue I thought they should be here.

ALYSSA: They are coming to the other ones. It's just --

AMY STONE: I did the wrong one. I understand.

BETH PINKHAM: If you check in they can tell you which ones.

AMY STONE: Thank you.

KATE BOWDEN: Can I make a comment? Please don't allow that to dissuade you from saying anything because this will be transcribed and they will be made aware of things that are said. So we hope to hear from you if you have concerns.

AMY STONE: Sure. I will stand back up {LAUGHTER}. Thank you. I would say I guess my concerns fall within the education services and the transition within to adult services and I'm curious as to your take on this within your schools as to how things are going through that because of the consent agreement with DOJ and things in place it's a scary time for are families that are transitioning their children into adult services because the service providers are in a really tough place and aren't really able to provide services for the newly transitioned group age of students coming through. And really its self-directed supports seem to be the only option for them. That's a scary thing. And with all the changes with the Employment First Initiative, things are just a tough time for those families right now, for the students that are 18, 19, 20, 21, 22. Some are still sitting at home and I was just curious as to -- I think BHDDH has made some improvements that I've seen regarding having assist schedule earlier, getting materials earlier, but

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even though they have that, there's no place to go afterwards. Also with the adult providers having to change their sites to be integrated as opposed to the segregated options which is wonderful for some, absolutely, and very difficult I think for other students that really need that space and that time for part of their day. And I was just curious as to where we might be heading in the next nine years of our ten-year plan with DOJ. That's all. Thank you

BETH PINKHAM: Thank you. Any other questions, comments, follow-up from anybody? Quiet crowd today. Okay.

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JIM HICKEY: Anything you say here they follow up on this is this what happens? My name is Jim Hickey. And a friend of mine is on -- well, I've seen a lot of people on Section 8 and I don't know if this involves that. I am just going to state it any way. And when we went down to the office for this person on disability, in a wheelchair with no legs, but when we talk about the Section 8, the guy says, I told him that the landlord that he's with now -- we tried to get him to a different kind of housing. He said well you give up the Section 8. It's a gold ticket. You don't want to do this. They keep trying to talk him out of it. The guy really can't deal with this because the landlord he's with has to get extra money. When you get Section 8, I thought they get a certain percentage, 25 -- I don't know what it is. I know it used to be 25 percent. And he's not the only one. This is prevalent throughout the Section 8. Landlords request extra money on the side for these Section 8's. When I talked to this guy -- oh I never heard such a thing. There's no such thing. Really, you are behind the times. You are not out with it. You are not out on the streets. This goes on -- and if I know about it, like three or four different cases I know it must go on, on and on. So I just thought I would bring that up that extra money is being put out for these people to get these homes that are on Section 8, and that really lowers their income even more. So not only are they paying 25 percent, they are giving out an extra couple hundred dollars. I know that for a fact and why people here -- why nobody else knows that, I don't know. I mean, all you have to do is ask a few people out there. They are afraid. This guy's afraid for his life and this place that he's at. He's afraid they are going to do anything. They take dogs and they mess in front of his door. What they do is unbelievable. So I've taken a personal interest in trying to help this guy get a decent apartment. They are trying to put him in a place where there's no handicapped accessibility. They keep trying to talk him into this. The guy is really -- I mean people in that disability -- I don't understand it myself because I am not disabled. But I can see it in his eyes that he’s scared and afraid to do anything. Jim, don't say this. Don't say that. Don't do this. But there's just a point where somebody out there really has to step in and watch over these people because they are scared. Thank you.

BETH PINKHAM: Thank you. Any follow up with that or any further comments, questions? Again, for folks that just came in, I don't know if anybody has any comments or any issues they want to bring to the panelists today. If you can just state your name, please.

WILL BEAVAOIN: Sure. I am Will Beavaoin, I guess the concern that I have has to do with the whole Medicaid redesign and the lack of people who receive services that are involved in the process of Medicaid redesign. I know that the people who are doing the work, sure after all have the best intentions. But a key constituency is missing from the table and I find that very concerning. So, I'd like to bring that forward as an issue. It becomes very frustrating to try to advocate when you are not at the table. So, part of the problem has to do with the fact that from the beginning, the constituents haven't been at the table. So all this has willed forward. Lots of new things have happened and people who are involved in the everyday life of having disabilities are not allowed a voice in what happens except in a reactive way. So we are already behind. We can't catch up. Everything is always reactive. So I think it's an important issue. Thanks.

BETH PINKHAM: Thank you. Any questions, follow-up, anybody? Again we have a quiet group today. Anything any of the panelists want to add while this is going on? Well, as we said, all of these comments will be taken into consideration and the transcript of today will be posted on the Governor's Commission website in the fall. Probably around November. So you will be able to see, you know, that comments were brought forward and go from there. We will be here, you know, for a little bit yet. So if anybody wants to stay and ask any of us, you know, more individualized questions or whatever, you know, we will be here. Otherwise, thank you for coming today, everybody.

KRISTIN CLARK: One question, the paperwork I got said this is from 2 to 4. I don't know if other people will be coming that couldn't come.

BETH PINKHAM: We will be here until 4. Anybody is welcome to say that wants to stay until then. But yeah, we will be here until 4 if somebody comes, we are scheduled to be here from 2 to 4 but I don't want people to feel held up if they said their piece or whatever. Yes, Barbara,

BARBARA HENRY: I have one more thing I would like --

BETH PINKHAM: Let me bring you the mic.

Transportation

BARBARA HENRY: Hi, my name is Barbara. I have another concern I'd like to bring up regarding RIPTA and also the RIde program. I have been going to meetings and RIPTA is proposing that all disabled people come this October pay a dollar. All disabled and elderly passengers pay $1 every time you get on the bus. I don't know if anyone here is aware of that. And if the bus goes -- my concern is also -- I also take RIde. That RIde will go up. And I'm sorry, a young lady over here mentioned that it is true. We pay one the highest prices in New England for RIde. And if RIde goes up to $5, that's a lot of money to go one way on a RIde van. So I just really think that for most of us here who cannot drive cars and you really rely on, you know, RIPTA or RIde to get around, I really hope that you will really just advocate your concerns because they are really pushing for this, come October that everyone who is disabled or elderly, and you do pay $25 for that bus pass. It's not free. That we are going to pay $1. So I do believe that RIde will go up. Thank you.

BETH PINKHAM: Thank you. Any -- anybody else? Comments? Follow-up? Questions? As I said, we will be here until 4. But thank you all for coming and -- we will see where everything goes.

BETH: I have one more person who wants to make comments. So I am going to let them go.

Accessibility

DOUGLAS WOODWORTH: I am Douglas Woodworth and I am Deaf. I was at Rhode Island Hospital last month. I had surgery. And the day I was being discharged, I asked for VRI, which is video relay interpreting. It's a TV screen where there's an interpreter there remotely. And it wasn't available. They had to wait for an interpreter to actually come and interpret for me for my discharge which took a couple hours. I also had a friend waiting to give me a ride. I felt like Rhode Island Hospital should have the VRI service as back up to a live interpreter because as it's needed, there's quick access. For example, another hospital like Kent County does have a VRI services. So I think that Rhode Island Hospital should have one as well. Thank you.

BETH PINKHAM: Thank you very much. Okay. We have one more person, Trent who has a comment to make. Let me just give you the mic. State your name and we will be all set

Accessibility

TRENT FERRARI: I am Trent Ferrari. And my concern is that people with all kinds of disabilities that have a placard that park in handicapped spots. It is such an issue for me because every single where I go and there isn't a day that goes by that I do not go to a parking lot in Rhode Island. I have to say that people in Rhode Island are incredibly uneducated and rude about people with disabilities. They don't care. They are disrespectful to them. And they put their shopping carts in the handicapped spots all the time. They have two good legs they can't walk from here to there. I put it back where it belongs. I have MS. I used to be a runner all my life since I was

19 and now I have MS. Okay I had to work through it and get through issues. But I am not a miserable person and I don't go blaming anyone else for it. I do what I've got to do and most of us do that. But people that are so entitled that they think that they can put their shopping cart last week at Dave's same thing. She gets out of her car over here she puts her bundles in and she gets out and she puts it right in the one next to me. I was sitting there because I had just gotten right back in. Of course I got out of my car and I said you are not going to leave that cart there. And she looked at me and I said you have two good legs, use them. You know, I am sick and tired of having to police what the police should be doing in this state. And in wintertime I go to Trader Joe's and they plow all the snow in the two little handicapped spots that they have. I go in there and I say to them, look out your window. Look where you have them plow the snow. Oh that was a big mistake. I am sorry. But it sat there for three months because God knows the snow didn't melt that easily this year. And you know, every single day it's a whole other issue. Today I was reading on Facebook about -- I don't know exactly where it was because I was in a hurry reading it trying to get into an appointment -- but Starbucks, okay, they banned a gentleman from going into their store because why? He had issues of people that are parking in the handicapped spots and Starbucks said you are banned from coming in here because you are harassing our customers. Now this has got to stop. I mean, when is it going to stop when people are aware? I read when Channel 10 did their thing about a year ago about it; that the people that wrote back on-line were so nasty saying you are nothing but a bunch of fat entitled people who are too lazy. No. This is not the case. We are disabled people and I would love to park at the end of the parking lot and walk in. And sometimes I will say to someone as they are going in, would you mind taking this cart or do you need a cart? They are like no. No thanks. I am all set. Whatever. They never think that the reason I am asking is so I don't have to return it and you know, God forbid anybody help anybody. This is my pet peeve is the placard is never enforced. I went to Wrentham and I parked in a handicapped spot in Wrentham. I got a $350 ticket because my Rhode Island sticker had expired. I mean, and I am -- it's funny. It's weird because I am always the one yelling and screaming about all this stuff and I am the one who gets $350 ticket. So I quickly renewed it and sent it and they let it go, of course. But it's just to the point where it's just unfair that they don't enforce the law and so many times I went to the compassion center one day. Get it, the compassion center. Okay. Some guy was parked in handy capped spot and I said to him, excuse me, do you have a placard. He said to me, go F yourself you F and Fn J. And I am like really, well I guess that's a no. So get the hell out. You know? I am just sick -- this is how I get. I get crazed and every single day, twice a day, Stop & Shop where to do they put the handicapped spots? The middle of the building where there is nothing but a big long wall and where the doors are, of course, there are two. And I think it's because the parking lot people that run the parking lots make so much money on the parking lots because I complained to Dave's and Dave's said we don't own the parking lot. You have to take that up with the parking lot people. Of course they pass the buck because nobody wants it deal with the issue. However, I asked them why is it that they are so far away when there's so many spots right next to the door and the handicap is over there. Like what good does that do handicapped people in the snow? In the rain? Or in hot weather or in any other time? So these are my pet peeves and thank you. I will give the floor back to someone else. But we have to do something about this because I'm tired of fighting with people over this and I seem to do this all the time with people. It seems like I constantly have to chide someone about being in the wrong place. So

BETH PINKHAM: Thank you very much

TRENT FERRARI: Yeah, well, thank you

BETH PINKHAM: Any follow-up, questions, concerns? Okay. Well, it's on record now. So thank you.

TRENT FERRARI: I am glad it's on record. Does that mean something will be done about it? Will there be more enforcement? Will there be a push towards having policemen all the time. People have threatened to beat me up because there was a guy sitting in a car one day waiting for someone and they didn't have -- it was Stop & Shop they didn't even have a card. I said do you have a card and he started calling me filthy names and acted like he was going to get out. Yeah -- and I'm like, so I got my phone out and took a picture of the license place and said I will call the police on you. He says you do and you will be in big trouble. Well, you know what? This is absolutely ridiculous. My life shouldn't be threatened because I'm asking them to do something that's right. And it's totally unenforced and that’s my beef. The cops are always ready to ticket you if you forget you’re directional. But something like this that's really important to a lot of people in this state, they could care less about it.

DEB BELANGER: Can I ask a question? I just want to ask, is there -- because I don't know this. If there's a phone number where we can report those. Is there anywhere other than -- that you are aware of or anyone else is aware of?

Accessibility

TRENT FERRARI: I have no idea. But you know, these parking lots as I was going to say and I had kind of got by me -- they have to meet a specific quota for I guess -- these parking lots are a mammoth, okay. And they have two little spots. And then the rest of them, they put over there so that they meet their quota. But putting them over there, just because they are meeting a quota does not help the people of Rhode Island who need them. Okay. All the ones in the front should be handicapped. I don't understand where they are coming from that they think that way. They are obviously not handicapped, okay.

BETH PINKHAM: Again any questions? Any follow up? Anybody have comments? See what the next hour brings.

TRENT FERRARI: Look I just want to say one more thing because I don't want this to be about me. When I do this, I am vigilant. Not so much for myself. I can actually still walk. It's difficult but I can. I watch other people that pull up that are in wheelchairs, that have real special needs and it angers me. You know, okay. So for me it's an inconvenience and that's fine. I mean, it's not fine. But nevertheless, there are so many people that have real special needs in this state that -- that makes it so difficult for them to just go out and go to the market. Every day easy thing that all of us do every day that we don't think second thought of. And these people it's an actual outing for them. For them they have to really work out and go in to get their groceries. They shouldn't have to work twice as hard once they get there. So it's about other people, like I'm saying. I don't feel special and entitled. I'm saying in general people need to be aware.

BETH PINKHAM: That's good. I think -- all right. I think we will -- again, we appreciate people's comments and we will be here if anybody wants to come and talk with any of us about their specific information or questions. We will be here until 4 just in case anybody else pops in. But again, thank you, everybody.

TRENT FERRARI: Thank you for having this. As you can tell I am bubbling over the top with this and I have had nowhere to put it. And when I saw it in the paper, I thought, oh my God. This is like my prayers have been answered. Somebody might listen, you know? So I thank you all for taking your time and this day to come here and actually listen because I think we need more of this to be able to get along and communicate and just to hear what issues that we all have. Maybe not everybody shares them but if people are more aware of it, they might be a little more kind. I think they don't really -- they are not doing it to be mean necessarily. They just don't think of it because they don't have that problem. You know? So I just think that it's great that you are all here too.

KATE BOWDEN: Thank you.

TRENT FERRARI: I know you do. You wouldn't be here if you didn't get it. All my friends are sick of hearing it, really. Here we go again. But no --

Transportation

WILLA TRUELOVE: Hi, my name is Willa Truelove. Okay. Thank you. You can tell me to slow down or whatever. My comments today are about RIPTA and I feel like people in the state need more access to transportation and facilitating those processes. The Governor's Commission on Disabilities and The State Rehabilitation Council need to talk about what customers of RIPTA who have disabilities are needing to be able to go back and forth with the people at RIPTA because transportation is definitely inadequate at this time and we need to do better.

BETH PINKHAM: Thank you. Okay. We do have within more person joining us for comments so I will turn the mic over to Carol.

CAROL DORROS: Carol Dorros. I just want to thank you for having this forum, first of all and I am sorry that I am coming late. I was interested in hearing what other people had to say but I didn't make it for that part. My son is 19 years old, about to turn 20. And biggest issues are significant cognitive and language delay and hearing loss, which deafness which contributed to that most likely, with some physical pieces that are less important. But so my understanding is this is a forum to talk about concerns

DEB BELANGER: Statewide.

Independent Living

CAROL DORROS: Statewide concerns. Okay. So we are entering into the adult world. And what I find concerning is that although there's been some wonderful work, particularly by RIPIN to help people understand what you need to do, it's very helpful. But I feel like it would be helpful to have a guide person, a person. There is a guidebook. I know there's a guidebook. But it's very -- you know there's a lot that goes into the next planning piece for your child with disabilities. And I really would love to have a personal guide, person. I'm not exactly sure how that would happen. You know, I'm sort of seeking out various people to find the people who seem to think like I might. But anyway, so that was my biggest concern. And my other biggest issue is employment, which I'm sure is a comment you have heard many times. I'd like to understand what the benefits are to employers who hire people with special needs. My understanding is that there are some tax benefits. But making those as well known and making those benefits significant so that -- because my question is why would they hire my son, even though he does have a lot of great characteristics when there are so many people who don't have jobs, you know, who may have more cognitive ability? Now he does bring other things. I understand that. But I think employment is going to be one of our major issues. Those are my two biggies.

KATE BOWDEN: May I ask a follow-up? You mentioned a cognitive delay. So I don't want to get too much into the detail of the disability itself. But is your son a person who you would hope would be headed for the adult services through DDD, the division of developmental disabilities? Is that something that has been discussed with you? Yes. So you would hope to have more hands-on guidance in the transition from school support to the adult services world, is that what you are saying. I see you nodding, yes. I think that's a very valid issue to raise and it will be in the transcript and this will be forwarded to legislators and decision making folks.

Independent Living

CAROL DORROS: I have one more thought. Thank you so much. I think it's really terrific that there was the expose a few years ago and things were changing in the state. So my bent is towards having folks be as integrated as possible in the world, in general. And I've been surprised at how calm the organizations I've been dealing with, which is a limited number, seem to be about the changes, which is great because they must have it under control.

However, we went to meet with the organization we have been working with -- I guess I'm concerned about having an agency be willing to take us on because my understanding was, you are supposed to go and interview the agencies and you know, figure out the one that is right for you. We have been working with this agency for four years and then we went to meet with the adult people and they are like, well, we are -- we are really not sure we can take you. I'm like, really? Now, of course, that could be much more complicated than I am understanding, you know, that it's about his needs or something. I didn't get that impression. It's more about they're kind of full. So just a concern about quality agencies being able to meet the needs of folks that are out there. Particularly if you don't want to do like a full day program. Like if you just want to do something like we just want them to be work support. We are thinking about doing self-directed. So that's my other concern that there are quality agencies and that there's enough to go around.

DEB BELANGER: Can I ask a clarifying question? I have my own -- {LAUGHTER} I don't know if it's on though. Okay. So I just want to -- the last point I just want to state back to what I think I am hearing you say is we need to have agencies available for families, number one, that many -- some of them are full. But they also have the flexibility and the supports available to do kind of creative thinking around adults. So that we are not maybe just putting people in little boxes, maybe, or something -- really have that level of flexibility, is that what I heard you say

CAROL DORROS: Yeah. Because the idea I guess is to prevent isolation of folks, you know, with special needs and what I experienced at least partially is that some -- also looking at making sure people aren't just getting around doing -- around that by labeling it a different way. But yes, I think you got it.

DEB BELANGER: The other thing I would add about the first statement you made around needing a person, because I think it says that we can give some feedback as far as -- RIPIN does have staff that is now working over at BHDDH although they may not be able to sit down with you for hours and hours and kind of, you know, I shouldn't say case management. But they can answer a lot of the questions and give you some next steps so you can access that actually by calling RIPIN's resource center and they can make that connection with the staff that is assigned over there. That's just a little extra piece and we are working on that.

CAROL DORROS: Thank you. Good to know.

BETH PINKHAM: Thank you. Thank you very much.

KATE BOWDEN: Are we going to go on intermission now? Intermission until 4 or if someone else arrives.

BETH PINKHAM: Yeah.

Independent Living

CAROL DORROS: Okay. I forgot about housing. Major concern about where he's going to live other than with us. And the fact that in order to get him into a group home or a living situation, if that was our choice, we'd have to be, as I understand it, terminal or unable to take care of him. That's my understanding. So maybe somebody can speak to that. I mean I know there are some other possibilities for living situations. But that seems a little harsh to have to wait that long.

KATE BOWDEN: I can follow up.

CAROL DORROS: Great.

KATE BOWDEN: Just so everyone is aware. Through DDD it's my understanding if the person needs residential care, they can get residential care. You don't have to be dying or dead or terminating parental rights.

CAROL DORROS: What's the definition of "needs residential care"?

KATE BOWDEN: I don't have the definition off the top of my head. You do not have a legal duty to provide housing passed 18.

CAROL DORROS: Right. But there don't seem to be choices. I think that definition -- I'm not trying to just, you know, pin you on something. But I think the definition of "needs residential care" actually would be important

KATE BOWDEN: Yes. And that would be through the process where they meet with you, do the assess and assist needs, that is how it's determined through the BDHH process where they look at needs and they assess funding and what the person in the family are looking for. That's a good question to ask the folks at DDD while you are going through that process.

CAROL DORROS: Right. Okay. Thank you. Anybody else wants to speak to that actually.

BARBARA HENRY: Can I say something?

BETH PINKHAM: I'm bringing the mic over. Here you go.

BARBARA HENRY: Hi. My name is Barbara. My son is 15 and he has autism and he has very limited speech and he has cognitive delays and everything you were saying I completely understand where you are coming from because I have no intentions of my son living with me the rest of my life. We are all going to die. We are not going to live forever. So I understand where you are coming from. I'm going to give you some very good advice. Get a good pair of sneakers. If I were you, I would really start getting out and on your own. Look -- start just going around and looking at everything on your own because you may call someone and they may give you some advice and that agency may have closed down a year ago. They may not even exist. And they may have had very good intentions on what they told you. But it just may not even be there anymore. And I started looking at things when my son was like little. And I think it's going to give you -- just keep a notebook or however you argue your things and really just -- because I think there's a lot of -- people are going to start giving you tons and tons of information and you are going to get a little overwhelmed. So if you can keep a notebook or however you stay organized and just keep that somewhere very private and it's going to help you just, you know, stay anchored. You know, I really think it will help you a lot. I hope that helps you in some way. Get involved with other parents that are in a similar situation. My son doesn't have hearing issues so I don't have that commonality with you. But I would definitely get involved with just other parents that are more on the same train of thinking that you are, that you are starting to think ahead and that you realize that your son is not going to be living with you and what are your next steps.

CAROL DORROS: Thank you.

BARBARA HENRY: You are welcome.

BETH PINKHAM: Thank you. Any other comments or thoughts.

KATHLEEN KUIPER: Can I follow up with that? Housing is an issue especially for folks with special needs. There are options out there and the options can be confusing and they can involve a really long wait but your son is young, and so are you. So this is the perfect time to get on those waiting lists and I would be happy to speak with you after and to give you some guidelines or some hints on where to start with that and on a side note my son is 25 and he is not on my couch. He has his own apartment and he does receive supports 30 hours per week from the state. So it is possible. And has many of the same challenges that your son has, others not all the same.

BETH PINKHAM: Thank you. Any other comments, follow up? Okay. We actually are just out of time. I guess we can think about wrapping it up, if there are no more questions or there seem to be others coming in. So again thank you everybody for coming. Thank you for the comments and we will be looking for this information to be posted later in the fall on the website and there will be more out there as things develop from all the information we've gathered today. So thank you.

## 29 July, 2015 Middletown Public Forum

MS. WARD: If you haven't signed in, could you just sign in, please, it helps us to keep track of who is here and if there's information we want to share, we'll have a record. I'm going to start, my name is Linda Ward. I'm a commissioner on the Governor's Commission of Disabilities. In my real life I'm the Executive Director of Opportunities Unlimited. I want to thank you for coming to the forum today. We will look at the speaker list and call you up in order. If you haven't signed up and you want to, feel free, we will stay here the whole two hours, even if we're done. Rest rooms are out here. I don't know that there's a public phone anywhere. But I'm sure most people have a cell phone. The purpose of these forums is to identify the concerns of people with disabilities and their families in order to assist the state to develop programs to improve the quality of life for people with disabilities to ensure everyone wants to speak gets a chance keep your comments short and to the point. If you have a problem that needs to be addressed the panel members will be here at the present end of the meeting to direct you to the proper agency. Again, we're not going to get into answering your specific question during the course of this. After the public forums are completed in early August, and there are -- one tomorrow?

MR. NUNNELLY: Two tomorrow. One Friday.

MS. WARD: Woonsocket, and then East Providence. So after they're completed in early August the sponsoring agencies will review the testimony and prepare recommendations will which will be posted on the website by the end of November. Recommendations and transcripts will be printed and sent to state officials and members of the General Assembly. Used to develop policy for commissioners until the next year. If you need to register or change your address, feel free, we have it setup back there. Ask the panelists to introduce themselves.

MS. MCCABE: I'm Kath McCabe, senior counselor with the Office of Rehab Services, and I cover Bristol, Barrington, and Warren.

MR. ADAE: I'm Brian Adae. I'm a staff attorney with Rhode Island Disability Law Center. I'd like to thank everybody at opportunities unlimited for hosting this particular and reiterate that voter registration is available. We're delighted to see everybody here participating this public forum giving us input, and another way to do that is to ensure that your voice is heard.

MS. POLSELLI: I'm Colleen Polselli, Rhode Island Department of Health Office of Special Needs.

MS. MERRIMAN: I'm Jodie Merriman.

MS. WARD: We also have assistive listening devices available in the back if anybody needs one, and we'll try to keep it to ten minutes each speaking, which isn't usually a big problem. And that's it. So, Annette, you're the first one up to speak.

MS. MS. BOURBONNIERE: I usually like to follow a bunch of people.

MS. WARD: Actually, you're the third person, and the first one.

MS. BOURBONNIERE: I --

MS. WARD: Can I interrupt you? Could you identify yourself by name?

MS. BOURBONNIERE: My name's Annette Bourbonniere, and I have a -- I can spell that for you, B-O-U-R-B-O-N-N-I-E-R-E. One of the questions that I have, and this would be for Mr. Adae, is there any movement to changing the whole voter ID law? I have seen a lot of people actually not vote because of it, and I, presently, went and did a protest vote, you know, going without it. And they don't count your vote for days, the election's over and all decided before they ever look at your vote.

MR. ADAE: Part of it, again, we're here to listen, and that's our primary role. But, informally, I'm generally, aware. We do have, at the disability law center, as a resource, we do have PNA protective and advocacy for voting rights. That's part of why we have a piece out there. Kate Boden in my office is the primary contract. I don't really know, I think the best thing to do is continue to make your voice heard. I do know that there had been some conversations with the new secretary of state with Nellie Gorbea, and she had indicated her desire to reverse some of what had been done as far as voter ID, to facilitate people being able to vote and not put up as many road blocks, as it seemed like that occurred. Again, I don't know that much about it, but I would encourage everybody, in addition to making your voice here heard about that issue and specific instances you may have heard about, and perhaps you have written about, I love reading your column is to continue to voice those concerns so that they are heard. Hopefully, it will be the political will to have some movement. Not that I have a bias one way or the another.

Accessibility

MS. BOURBONNIERE: Of course not. The other issue I would like to see addressed, the Department of Transportation listening to people with disability when they put in things like crosswalks in dangerous locations. In particular, we've had an issue where they put a new one in across the Memorial Boulevard across from Nikolas Pizza, and the sidewalk across is not useable by anybody with a wheelchair. So the problems with this crosswalk -- it's a problem for anybody, I believe it's dangerous because you can't see the crosswalk when you're coming up the hill, they claim you can, but you really can't. The second problem is if you put someone in a wheelchair, which is already low profile, if you're already having trouble seeing if someone was there. Low profile, it's like skeet shooting, but the problem then gets compounded because there is no useable sidewalk on that side of Memorial Boulevard. Before they put the crosswalk in, I talked with them about not doing it for that reason, that there was no sidewalk, and their response was that they would widen the sidewalk. Unfortunately all they did is create a bump out where it's easy access onto a sidewalk. So a person in a wheelchair not only is a high risk crossing, but then once there, has to either go back across the street because can't go anywhere on the sidewalk, or has to roll in the street. They claim that they measured it and got a particular measurement, but what they did was measure from curb to wall, and didn't take into consideration the great big parking meters that are in between, and I mean, that's a big obstruction. So, I mean that really needs to be addressed and they should really listen to people with disabilities before doing such things. It's a big concern I have because we've already had pedestrian deaths here.

MS. WARD: We could bring that back to Chris in the office. I can't ever remember Chris' last name.

MR. ADAE: I was wondering if it was a state road, town or city road.

MS. BOURBONNIERE: That was DOT that was state.

MR. ADAE: Whether they had input in that.

MS. WARD: They should. So that's why we'll bring it back to Chris Degrave.

MS. BOURBONNIERE: It is a state road, and we talked with them before they did it and they decided they were doing it anyway and made it clear they had no intention of correcting it.

MR. ADAE: Thank you.

MS. BOURBONNIERE: Somebody else can have a turn now.

MS. WARD: Okay. Well, I have Paul -- I'm going to mutilate this -- Delpape.

Transportation

MR. DELPAPE: Thank you. Pleasure to be here. Couple things I'd like to talk about and one of them the lady to my left just spoke about the voting. I had a little incident of voting for our town budget, and I do live in Tiverton, Rhode Island. I had called town hall to ask if they were going to have a new mark voting machine there for me to vote on. They said we don't usually have that on elections such as, you know, budget voting and stuff like that. So that kind of upset me a little bit and I called the board of canvas arrests and I spoke to a gentleman and told him what I just said, and he said there's no reason they cannot have a machine over there. All they have to do is call and ask for it and I said how much and he said it was free. I called back town hall and told them what was said to me, and they said they were going to look into it, and I got a call back about 20 minutes later and said we will have the machine here for us. So my point is, I don't care what kind of election it is they have these machines. Let's not hamper us, let us be part of the system and let us vote. I don't care what kind of election it is. The machine is there for us to use, we should have every right in the world to use it. No questions. So, anyway. I don't know each time I go vote whether it be a simple election or a national election, but I'm going to have to call Tiverton Town Hall to find out if they're going to have a machine there for me. Granted, there aren't that many blind people in the town of Tiverton, but there are some. Whether it's used or not, it should be there. And another point I'd like to bring out about the machine is this machine is not just open for handicap people. Anybody can utilize this machine. You say, well, everybody can see what I'm voting for. Well, not true. You have a headset, put it on; you can block the screen so nobody sees anything expect you just hearing what’s being read on the ballot. The other issues I've been fighting for 15 years and still fight being it, and nothing seems to happen. The RIde program. As small as this state is, everybody in the state should have the right to have a means of public transportation. Tiverton, many years ago did have the RIde program, but, of course, bottom line is, State of Rhode Island doesn't have any money to support it. But yet we do have bus service, and I believe it is four or six busses a day either three in the morning -- I know some in the morning and some in the afternoon. But yet, we can't have a RIde van because when I called, I was told that it was an express bus, so therefore the RIde van can't go there. Well, I disagree. If a bus goes to Tiverton, the RIde van should go there, too. I don't care what kind of a bus service it is. Express, local, snail, we should have the right. We're not asking for a lot. Whether you be blind, cripple, wheelchair bound we just want transportation so we can get from point A to point B, and I don't think that's a lot. And that's the two things that really disturb me a lot. And I'm here because EP is having what I believe, either on Friday -- that's out of my way. I came to the closest one. Thank you very much.

MS. WARD: My understanding the machines are supposed to be available at all election sites. We'll follow-up on that.

MRS. BRIANOTTI: If we don't call, we don't know it's there.

MS. WARD: We'll definitely follow-up with that.

MR. ADAE: In addition to that, Mrs. Brianotti. I want to give you some contact information from my office.

MS. WARD: It only took the second speaker to get to transportation, so I appreciate that. Usually the first thing on the list, so... And then we have Susan Mello.

MS. MELLO: My name's Susan Mello. I'm a deaf rights advocate for the State of Rhode Island. I don't have cards or anything, but I do help other people that have hearing impairments. And my question was years ago, any child that was deaf or hard of hearing used to be able to go to the state, Rhode Island School for the Deaf for free. And my son is deaf, and I have been fighting the last six years to try to get him to go to Rhode Island School for the Deaf. So, I'm wondering what has changed, and why it's not open to kids that are not within the district.

Independent Living

MS. MERRIMAN: I can probably help you about that after.

MR. ADAE: May I join in?

MS. MERRIMAN: Sure.

MS. WARD: Doesn't look like anybody else has signed up to speak expect the gentleman who just came in do you want to speak at all?

MR. PIMENTAL: I'm sorry?

MS. WARD: Do you want to speak? I don't know if you have.

MR. PIMENTAL: I would like very much to speak. Unfortunately, it's going to be a topic that you've heard before.

MS. WARD: That's okay. We don't care.

Transportation

MR. PIMENTAL: My name is John Pimental. Full disclosure I'm the state vice president for the National Federation of the Blind, and no surprise what I'd like to talk about is transportation. And I have two or three different topics, but they're all inter-related, pretty intensely. The first, I'll start by tagging onto what my friend Paul Delpape just said. There are certain areas of the state which are inaccessible by disabled paratransit. A great example is Tiverton. I actually have clients from Tiverton. I run the diabetes program for INSIGHT, and it's the only program in the state that works with specifically, with blind and visually impaired diabetics. Those of you who aren't familiar with diabetes may not be aware of how challenging it is to manage diabetes and all the things you need to do to manage it, seem to require vision, or at least seem to require vision. So that's a really important and valuable service to offer. And yet there are places in this state that are inaccessible that I have clients that can't come to INSIGHT for free by the way, for counseling and training because they have no way to get there. Tiverton is one of those places. On a larger sense, travel within the state, as Paul said, I hate to repeat him, but again, travel within the state, it's a small state. There's no reason why every area of this state should be, should not be accessible. As the GCD knows, and this is my topic number two, I'll do it as quickly as I can so I don't seem like I'm belaboring a point, but the GCD last week had a big event to celebrate 25 years of the American's with disabilities ability. They invited all the community organizations that work with disables people to come to the event so we could give literature and have a table to interact with all the people. And celebrate how much we've accomplished with the ADA that event was health at fort Adams in Newport. Which we discovered was inaccessible to the RIde program. There is no disable para transit. So the disabled people who were supposed to be served by the event were excluded from it. I think that speaks volumes to how much awareness there is and sensitivity there is to the disabled population in the state. I think that needs to be addressed. There is no reason why that event couldn't have been held at a venue that was accessible. It's simply that no one thought of it. Disabled people are not top of awareness in our state. My third topic again which is inter related is I think there should be a real emphasis by the GCD and all other organizations in the state to prevent and minimize fare increases to the RIPTA program. It's very clear from the notes coming out of the ATAP meeting that they're planning on fare increases and they say are directly going to impact elderly and disabled people. They're seeking to do away with the $25 unlimited bus pass. Which many elderly and some disabled people use. They're talking about cutting bus routes. It's very clear that fare increases are in the works. I understand budgeting I work in business for 25 years. I understand you need to meet budgets. But you can't balance your budgets on the portion of your population that is the most under served and the neediest. In the blind, I speak for the blind population in particular, because in the blind population, I know for a fact, I'll give you a statistic there's 70 percent unemployment. Not only in this state, but everyone. So the raise fares that affect these people directly, I believe are unconscionable. I see it coming and I feel it's coming through a slight of hand back door -- I'll go on record as saying it's going to happen, it's going to happen in the near future. I think this is very important, if fares are raised for a bus service, automatically, that means that there is double that amount of increase for anyone who uses the RIde program or disabled para transit. If a bus ticket costs a dollar now, its $2 on a RIde van. If you raise the bus ticket price to $1.50, you've added money to every single trip every person takes. I think this needs to be addressed to prevent that from happening and I think it's one topic that affects everyone in this room and we should be very aware of, once it happens, I'm sure we're going to be told it's too late, already gone through, and the decision's already been made.

MS. WARD: Go back to Paul.

Transportation

MR. DELPAPE: I would like to take you back in history for a minute if I could. Back when the ADA first started and was brought into play, granted, they have done a lot. But I want to talk about the RIde program. Way back then, the RIde program, to a degree was very independent. There were outfits such as Cozy out of Pawtucket, there was Rhode Island Ambulance, there was Maher out of Newport, who is still active to a degree, I guess, with the RIde program and maybe one or two others. It was great. The negative I have to say about it is since RIPTA took it over, it's been a disaster. I think RIPTA bit off more than it could chew and they should have never got involved, never. Because they're just pushing us, all handicaps, not just blind, under the bus. Thank you.

MS. WARD: Let me just respond to where that event was held last week. I sort of was a late comer to it all. Didn't know sort of the logistics to it. The purpose was to also celebrate that historic building made accessible. We dropped the ball on not making sure you could get there. But I think that, it's not an excuse, we spend a lot of money making buildings and places accessible, but you can't get there to enjoy you cannot access it. But it's a lesson learned for us. It goes back to; if you can't get there it doesn't matter if you can get in. We really need to keep pushing on the transportation issues. And I do apologize this happened. Shouldn't of. If we do an event again, it will be something we pay close attention to.

MS. BOURBONNIERE: I was not involved in the organization of it, and you're not very often going to hear me say something very positive about Newport, I'm pretty discouraged about Newport. There was an option that all of us have, and that is, the old port marine and Jamestown Ferry, both of them provide service from Perrotti Park, which is on the bus line. If you can get to the gateway center, there was transportation via water and the old port launch was made accessible, I'm going to say five years, maybe a little bit longer ago, and let's see, I guess five, just about four or five years, and Jamestown just this past year. So, I'm sorry you didn't have that information, because that was something that we all, you know, had access to. Actually, would improve, adds to the atmosphere of the whole event by being able to go by water. Again, that was not publicized very well, it's too bad.

MR. PIMENTAL: To my knowledge, it was not publicized at all. Certainly the information that I received telling me about the event made no mention whatsoever of how to get there. So, I mean who would anyone who is not from Newport know that that was available?

MS. BOURBONNIERE: You're right. I've tried to let people know that it existed, but can't really advertise for people.

MS. WARD: When we sponsor something, we'll just have to do a better job. When we don't it's a lesson learned. It won't correct it, we'll move forward. Make sure everything we problem. Try to do things at time, 4-6 is much better than 6-8, we've discovered. There are mistakes made, but we will make sure it doesn't happen again.

MALE SPEAKER: To that point, if I may. And this is, go back in time to meetings I've attended in the past, find my comment I've repeatedly asked why we can't have more of these meetings from 6-8. There's an automatic assumption on the part of many people that disabled people don't work. For those of us who work, means I have to take time off work, which I had to today, and take a reduction in pay or use vacation time in order to attend. If there were a single meeting offered. If the meeting was at Peace Dale, I'd be more than happy to take a bus. I think it would just show greater sensitivity that there are disabled folks who are working for whom it's a real challenge to be able to take time off during their workday to come to these meetings.

MS. WARD: We did 6-8 here last year, had a terrible turnout. I don’t know if we have a 6-8s this time.

MS. GLEASON: We tried it the past couple of years, and no one.

MS. WARD: I think maybe five people or something. I think it's a point well taken and maybe we can look at the Providence one as being a little later. We did it at the library.

MS. GLEASON: It was the south Providence Public Library.

MS. WARD: Kind of the center of the state. Think about doing one there. That's all who have signed up. Does anybody else have anything they'd like to say? I have a maybe from Diana. Have you gone from maybe to yes or no?

Accessibility

DIANA: I don't know. One of my beefs is people parking in handicap spots that don't have stickers on their car, and rarely do I see the police doing anything about it, specific lie. Shaw's and stop & shop's lots here in Middletown. Since the dollar tree opened up where the Home Depot center is, there's no curb cut from the parking lot to get in there. A lot of older people shop there because nothing in the store is over a dollar. Smaller items, so you don't have to buy so much of it. A lot of older people are single and it's a popular place. There's one at Aldi’s and not one until you get to the left end, I guess, by the new pizza place.

MS.WARD: This is in?

DIANA: Home Depot Middletown, off of this road.

MS. WARD: I'm not from here, so just trying to figure out if it's a state road.

DIANA: No. No. It's private. And the stores are together, and every now and then there will be a curb cut there, but specifically a store that is shopped so much. They're open until 11:00 at night. People going in there, a lot of people going in to get, the kids do to get snacks before the 9:00 movies. Probably that time on Fridays and Saturdays. I'm thinking of older and handicap people like myself that get out of the car and look and how am I going to get my foot up over that curb?

MS. WARD: Thank you. Could you identify yourself?

Accessibility

MS. SCHULTZ: Jackie Schultz. My attention was really just to hear what's going on. I had attended a meeting in Chicago recently about elections, and one thing that was very disturbing to me was that the GAO did a study in the 2000 elections on access to polling sites where only 16 percent in the entire nation where considered fully accessible and when they did the other study again in 2008 that only 27 percent were fully accessible. And we've been doing something called NCOA, national change of address where we're trying to get people's accurate addresses from the United States postal service, and something hit me and broke my heart a woman sent her form back saying that she had macular degeneration and she's unable to vote and that's so not true. And what I wanted to do is come here and listen to the kinds of issues in our community so we can address some of them and I encourage each and every one of you talk to your local canvassing office to express your needs. Use your voices as you are doing right here because the more we hear the more things will change. As far as the voting is concerned, please, please let us know, talk to us, tell us what the issues are with voter identification, those votes are counted that night or that morning and that's usually a provisional ballot. I stay up to do this. The voter’s identification for our purposes very helpful to make sure people get the right ballot. Our town alone was four different ones and verifying identification and addresses helps us to make sure you're voting for the right district or the right representatives to help you.

MR. PIMENTAL: May I make a comment for president lady who just spoke? You're not going to believe this but as a Portsmouth resident, I'd like to comment on the accessibility in Portsmouth.

MS. SCHULTZ: It's awful, that's why I'm here.

MR. PIMENTAL: I have had excellent results. Good experiences and I vote every election and I've had excellent experiences in Portsmouth, I have to say. In fact, at one of the polls, I walked in, and the person taking the registrations told me sign here, and actually put a signature guide on the line for me without being asked. Which just impressed me. You would be amazed how the little teeny things can be impressive. The other thing I'd like to say -- the other thing I'd like to say, as INSIGHT as part of their community groups, we run community groups in nine different areas of the state, where ever you live in the state, even in Westerly or wherever, the far stretches, we hold a community group on a monthly basis. Somewhere in the year, we will have an auto-mark machine and give people a chance to learn how to use it and actually get their hands on it and practice with it.

MS. WARD: Paul.

MR. DELPAPE: I'd just like to flip back to the RIde program again. The other thing I feel very strongly about, as small as this state it, and John mentioned it, there's no reason why every corner in this state should have transportation because you can take other states bigger than ours, which we could probably fit this state this state in there once or twice. They have much better transportation as far as the RIde programs concerned. I feel very strongly, and it's only going to get worse. I feel the three quarter mile barrier needs to go away.

MS. WARD: I'm not supposed to express my opinion, but I so agree on that three quarter mile thing.

MR. PIMENTAL: There are areas in Warwick from which blind and visually people can't get to. INSIGHT located in Warwick. This is a big city, for Rhode Island. And yet, there are areas that are inaccessible and clients that can't come to us, and I think that's a huge, a huge issue.

MS. WARD: I agree. Anybody else have anything that they want to say or anybody else wants to speak? Okay.

Transportation

MR. DELPAPE: If time allows, I'll throw in one more comment, if I may, regarding transportation. I'm sorry. The other thing that doesn't often get mentioned, every single year or two, RIPTA talks about cutting underserved bus routes, eliminating this or that bus route. Of course their reason is to save money for bus routes that are under used. I think it's important to know that every time they cut a bus route they save five or six times as much money not from eliminating that bus, but because every time they eliminate a bus route that three quarter mile kicks in and eliminate all the para transit service to that area. It's kind of a back doorway to save money on the backs of disabled folks.

MS. WARD: Well it's been an issue that's been on the forefront of the GCD and if there's any ability -- I think the biggest voice is the voice of those who rely on it. I know they've been doing public meetings at some of the senior centers and there's been a big out cry from the seniors about it, I think that's what we continue to do. Wait one minute, Paul.

PAUL: Another thing, I'll be called a rat, but I spoke to Bob Cooper about a month or two ago, he's on the Governor's Commission, one of the head ones down there, he did tell me about a Bill 5144 that was supposed to be in the budget. I don't know if it ever got there or not. It was supposed to involve transportation about the RIde program. I don't know if it ever made it or not.

MS. WARD: I don't know.

MS. GLEASON: I'm not sure, Bob's actually out this week but I can talk to him Monday and try to find that out.

PAUL: Thank you.

MS. GLEASON: You're welcome.

MS. WARD: We just had somebody walk in who wants to speak.

CAROL: For privacy reasons just like to use a name like Carol. If you need to know my name, you might recognize me from the ten years that we've been together.

MS. WARD: I was hoping I was going to see you, I was a little worried when you weren't here.

Independent Living

CAROL: Well you should be worried. You should be. Okay. So, per HUD published document quote, "The movement of secondhand smoke between units can't be controlled in multi-family buildings. Ventilation and other air-filtration technologies can't eliminate the risks caused by secondhand smoke exposure." The document continued that the elderly and disabled are especially vulnerable due to chronic health conditions and inability to physically escape second-hand smoke. Smoke free policies provide housing stability for residents with respiratory conditions such as asthma or COPD. Adults who breathe in second-hand smoke experience immediate adverse effects on their cardiovascular systems, which can trigger heart attacks. Other contaminants, including deodorants and household sprays can't be used. They are inadequate for disabled persons with respiratory impairment. They have, as we've discussed, before this forum and all the affiliated organizations including the disability law center for ten years, asking for relief from this situation that has caused cardiac complications, interference as reported to Brian directly and other members affiliated with this, other things that no disabled person struggling for their health should have to be regularly exposed to. Port ability is an absolute essential requirement as based on the level of knowledge of the providers. Inadequate knowledge of the providers. A person, disabled -- a disabled person with respiratory and cardiac impairments can't possibly, reasonably be expected to go through a waiting list process. I had project-based housing operations, including 811 and 202, and the only ones that we apparently provide any kind of knowledge of disability law to. A member of this forum who has been here in the past who is not here today, ten years ago addressed this when he was affiliated with the independent living center. And his only recommendation was to get on the wait list because of the structure of the units there is in anticipation that there may be protection from second-hand smoke and other respiratory and cardiac irritants. After ten years on the wait list, I was offered a unit, which has third-hand smoke and history of smoke in it, recent construction, only one bedroom one bedroom which does not satisfy my absolutely mandatory requirement for two bedrooms, and the other problem with it, of course, is that it's project based, 811 funded so it provides no port ability in there and you find the obvious respiratory impairment of the place, the larynx dysfunction and it goes to the lungs, that some people can't control through medications because of side effects and have a long, long time of experience with that. So where are we? We're still running around, being told there's nobody in the state who is responsibility it is to address this. Or, you can do a fair housing suit against a particular element. And they will investigate it. I'm sorry, that's not the policy procedures and accessibility actions that we need. It's not just a personal problem, it's a very serious personal problem that is literally killing me, but it's a global problem that affects every child with asthma, or who is potentially, a pregnant woman, with, you know, it's a great report. You should all get on-line and get it. Its de bunked all the nonsense about oh it's too expensive, and smokers will be reluctant to it. It's very easy to read. It's got the facts, the figures, the data, but where is the accessible housing now today while people get around to learning what we've known? How many years have we known that something is a carcinogen? Smokers have a 20 percent more chance of getting sick even though they're nonsmokers. That's it. I don't have the voice to speak anymore to people that continue to refuse to hear and take appropriate action for this disability. It's just as important as mobility, hearing, and vision.

Respiratory impairment -- well, to quote the American Lung Association: "If you can't breathe, nothing else matters." Thank you.

DIANE: Could you clarify what she is saying, specifically, is this housing, under HUD?

MS. WARD: Well, I don't like to speak for somebody else, but basically there are issues around smoke and other chemicals because we have that occur in apartments. If you feel up to it?

CAROL: The EPA refers to them as contaminants. The CBC, I'm sorry. They're issues that affect everyone's health. Some people are privileged enough not to have lost their life savings even though they had a lucrative career and be in their own private home and manage their own detached living space. This report specifically addresses what they're calling now affordable, or HUD affiliated, financed, their use of the word multi-family, but they're saying it applies to multi-unit. People that have fragrances on. Despite the fact you ask every year. It's a barrier to a disabled person with respiratory disabilities. Particularly if they cannot manage it. This is specifically for the, you know, people that need HUD assistance because they've been reduced to nothing because of the fact that inadequate options have caused the decline of their health so that they cannot get restored enough to go out and restart their career or find some other adequate alternative. It's people improvised by the need for their housing that they'll get sicker in, because of other people -- The only "reasonable accommodation" that has been suggested is to get an exception to the payment -- which do not even come close to paying for a detached home in an area that the outdoor air quality could be adequate enough to maintain some semblance of health. And seriously who is going to pay $2,000 for a home when the payment standard doesn't let you go a fraction of that? But that is the only solution that has been offered. And, just get on the phone, even though you're too improvised to have long distance or cable TV or the other things people take for granted you're supposed to get on the phone and find every housing authority and ask if they have any nonsmoking any respiratory impairment disabled accessible units available. Well, first thing they're going to do is say yeah, right, I'm going to deal with this problem? Then you're supposed to call property management companies and ask for which of their tax credit units might still be within payment standards so that you can port your section 8 voucher to them. So far, none of them have come up with that, if they're even nonsmoking or transitioning from non-smoking and there are multiple years, ten year's wait. First you have to go through the qualification, do you qualify in the housing payment for that particular city or jurisdiction of the housing authority. Then you have to get them to work with you to give you the payment standards and utilities. Then you have to call around to every private person you can find and every housing complex and you already know the probably very unrealistic there's going to be anything, but who has somebody who has severe respiratory and cardiac complications, they have the stamina to do that? No, they don't, and no one in this state has been able to come up with a disability -- anybody for ten years. It's even worse now because the payment standards are so inadequate for addressing these disability needs. So, I don't know if I answered your question. Or if anybody has any more questions? It's something that everybody needs to pay attention to for their own health. But, it's particularly necessary when, when your health is so impaired that you can't possibly do the only things that people are saying have to be done. It's an impossible task.

MS. WARD: Thank you. Anybody else want to speak? And if not, we will be in recess in case anybody else comes in here to speak. Okay. We'll be here. If anybody changes their mind. We'll be here from now until six. Thank you. (RECESS)

## 29 July, 2015 Wakefield Forum

MEREDITH SHEEHAN: All right, good afternoon, everyone. My name is Meredith Sheehan and I am the community program manager for the state of Rhode Island for the National Multiple Sclerosis Society. We were very happy to sponsor today's public forum. I want to welcome you all here today. I want to point out quickly before we get started there are accessible restrooms available, should you need them throughout the afternoon. They are right through that door and just to the right. You will see them right there. The purpose of -- I will read a few housekeeping things before I have the panelists introduce themselves. The purpose of these public forums is to identify the concerns of people with disabilities and their families in order to assist the state to develop programs and to improve the quality of the lives of people living with disabilities. To ensure everyone who is here today gets a chance to speak, please keep your comments short and to the point. If you do have a critical problem that needs to be addressed, the panel members will be available at the end of the hearing to direct you to the proper agency for help. After the public forums are completed in early August, the sponsoring agencies will review the testimony and prepare recommendations, which will also be posted on the website by the end of November. The recommendations and the transcripts will be printed and sent to state and Congressional offices and to the members of the general assembly. And the recommendations will be used to develop policy and 2 legislative initiatives for the next year or until they are accomplished. The Rhode Island Disability Vote Project, voter registrars are available to register anyone who is a citizen and not currently registered to vote where they live or if you have a change in your address since the last election, we can update that information as well. I'm going to just start with Barbara and we will go down the line here to introduce the panelists to you so you know who is going to be listening to your concerns today.

BARBARA POLICHETTI: I am Barbara Polichetti with public affairs with the Rhode Island Public Transit Authority, RIPTA.

TERESA SCARAMUZZO-DIMATTIA: I work for the office of rehabilitation services.

DEBORAH GOLDING: I am Deb Golding and I work in the office of the special needs in the Department of Health.

ANNE MULREADY: I work for the Rhode Island Disability Law Center. We are the nonprofit federally funded law office that represents people with disabilities in Rhode Island on disability issues

MEREDITH SHEEHAN: Thanks.

CASEY GARTLAND: Can I sit back there? I am Casey Gartland and I am a senior director with Perspectives Program, the adult section

MEREDITH SHEEHAN: Thank you. Wonderfully talented people on the panel today which can respond. Their job isn't to get into a debate with you, you know, to have this conversation here but they are definitely here to listen to you. If there's anything on the more personal nature, whether they have a break or towards the end of the hearing feel free to approach them individually. So we do have several people who did sign up to speak today. So I will just go down the list as you came in. If you could just -- we do have a CART reporter doing a word for word transcript. So if you could just speak clearly and do state your name at the beginning, that would be helpful. So first we will have Robert Romero.

Transportation

ROBERT ROMERO: Good afternoon. I will speak as clearly as I can with my cold. Romero, Robert. Two questions. What can you do to improve the RIde programs services from my perspective? My son needs to use it and it doesn't seem reasonable to me that he should be riding around on a small bus for two and a half or three hours each way. And if he's starting a program at 9:00, it doesn't seem reasonable to me that the bus should come and pick him up at a quarter to 7 or 6:30. My second question is how does one become a member of this panel, this commission? And I will sit down and listen to your responses.

BARBARA POLICHETTI: I will take the first question since it's for transportation. I am not an expert in our RIde program but I don't think there your son should be on the bus for two and a half hours. Our times are regulated and monitored by the FTA. So afterwards, I would like to get a little more information from you. We have a very good management team down in our RIde division. So I would like to get some information to look into that. So, that will hopefully allow us to address that. As to what we can do to improve it, for people who don't know, RIde is the State's -- RIPTA's paratransit service run in accordance with the Americans with Disability Act. In order to qualify for the RIde program, you have to qualify under the ADA guidelines and our RIde administrators are very good at getting people qualified, making sure people that need it are qualified. It's door to door service. It's by appointment. And it's $4 per RIde, I believe.

ROBERT ROMERO: Round trip or one way?

BARBARA POLICHETTI: I have to double-check on that. I didn't bring anything with me. So there are very specific guidelines that govern RIde, A, federally. And then transit wise, I am still learning because I have been at RIPTA for seven months now after 35 -- don't do the math you will get my age -- 35 some odd years in the newspaper business. So I am still learning transit. There are some very specific federal regulations which I find interesting that I am still learning as to where paratransit is offered. So we talk about like what can make it better. Under federal regulations paratransit i.e. the RIde program is offered only within a certain distance. I can look at you, within our fixed route. The RIde vans won't run where we don't have fixed route service. That was a big education to me. So some of the things we hear that might make it better -- I'm not sure if we can do under regulation or if we even have the finances but one thing we have done recently, that we are excited about and would like to build on this is I think this gentleman knows, you have call and make an appointment. Then you get a pickup window and that window narrows as you get closer to your time. And up until -- I believe it was two months ago when we launched the app in the website, the only way people could find out about the narrow window was to keep calling. And of course people were calling to make an appointment. They are calling to cancel an appointment and calling my pick-up window is 9 to 11 a.m., am I near the 11 or 9 a.m. side? What we just did is we contracted with a private company who developed an app for us. That information can now be -- you can watch it on your phone. If you don't have a Smartphone you can get it on your computer. And if you don't have any of those things, you can still call in. But our hope is, speaking to improving the service, is it will reduce the volume of calls coming in and you will be able to monitor your window, plan accordingly like when you need to step outside particularly in cold weather. One of the things we need to do is continue to build on that technology and use more technology to make access to information about the program more readily available. That would be my -- so we are very happy that we launched that. We would like to expand it and maybe find some other uses to have technology make access to your service and information about the service more accessible

CASEY GARTLAND: I will attempt to answer your second question. The commission is appointed by the governor in terms of three-year terms, if I'm not mistaken. Chris may know better than I. However you don't need to be a commissioner to serve on some subcommittees. I am a commissioner now but at first I was in the election assistance committee. I was not a commissioner. I was involved in registering people that we provide services to vote. We do have various subcommittees that you are welcome to attend and join if you would like. We welcome all the help we can get from the commission, whether it be in the main commission or the subcommittees. And there is a website you can access if you just type in any search engine Rhode Island Governor's Commission on Disabilities www.disabilities.ri.gov and it will tell you membership and the committees.

DEBORAH GOLDING: There is the office of special needs brochure right here. There's a number of committees that they run that you might be interested in. There's a brochure right here. You can get one.

MEREDITH SHEEHAN: Did you have any follow-up questions?

ROBERT ROMERO: No, thank you.

MEREDITH SHEEHAN: Okay, thank you. We will move on to Tia Beckman

Independent Living

TIA BECKMAN: I am wordier, I am not as brief. Tia Beckman. I spoke years ago at a forum like this when my son was in school, tears, my heart. Things have not changed, so I am here again. My son is now a young adult. He lives with dyslexia, like 20 percent of our school population. Dyslexia means it's putting sounds, two syllables decoding. Some people have troubles with sound, some people have troubles with symbols. My son was with the sounds. It affects reading, especially reading to learn, writing, spelling, speech articulation. It does not go away. It's a specific part of the brain. It does not go away. My son is intelligent. In fifth grade he was 95th percentile in science, across the nation. By the time he was graduating from high school, it was -- we were lucky that he graduated. He did not have a method to learn. Being able to sound out words means you can learn new vocabulary through reading. He could not do that. He never got the treatment in school. He had been diagnosed. He had been identified in by Second Grade. He did not learn how to learn. He had to memorize what was said in the classroom. Again, he had the phonological problems. So even that was difficult, keeping up with the classroom lecture. His method of getting through school was memorizing what the teacher said and passing the tests. He could not write quickly enough. He not read well enough to read somebody else's classroom notes. Tape recorders were not allowed in school. So how was he supposed to learn? There are coexisting conditions that might happen with dyslexia that could be difficulty with math, difficulty with the handwriting, there are others. I will probably think of them. Like many others with dyslexia, he would memorize the shape of the words. So if he was taught the material, he could -- the words would jump out at him and he would read from that. So he could pass reading comprehension tests very well because the reading comprehension tests on standardized tests are familiar subject matters. So since he always passed reading comprehension, the school was not decoding sounding out of words was not important. I called up RIDE, Rhode Island Department of Education, and I asked them about due process and they said that the districts have independence where what is important to the district the state will enforce. What is not important to the district the state will not enforce. So many of the districts throughout the state, reading comprehension, fluency is important. Speed of reading. Fluency happens -- can be compensated with extra time but my son had decoding problems. Due process was not going to work for him. So as a parent, I had no options, no recourse. Federal law says that dyslexia should be identified and treated. Since 1950s, there has been ways of treating reading, not the others, but reading, the Ortan Gillingham. It started in the 1930s and 40s, we are talking prewar or post World War II treatment and our schools are not doing it. Most districts are not doing it. We have a few really good districts. So what I'd like -- so now my son is not able to attend college. And yet 95th percentile in science. We are missing out on a really smart kid. So what would I like? I would like the state of Rhode Island to determine that dyslexia is to be identified and treated with scientific research, evidence based reading programs. Many districts try others. They don't work. I would like teachers to be taught what dyslexia is. I have asked teachers what is it. They think its letter reversals. It is not. I would like teachers to be aware of the parts of the brain and the coexisting conditions, how it affects learning, treatment, and how to compensate. I would like parent support groups and mentoring for the students. I would like psych community awareness. Many of these kids, you can imagine my son going through school, having difficulty understanding the lectures, having difficulty writing and having difficulty reading and he went through 12 years of school that way. Studies have related it to post traumatic stress. So I would like the psych community to be aware. I'm trained as an occupational therapist. I did not learn about it in school. So we are not just talking about teachers. We are talking about the population. I'm not picking on any -- so I would like -- because there are a lot of practical aspects to dyslexia and I would like the OT community to be aware. Speech pathologists are generally aware now. I would colleges to be aware that students with dyslexia are not being identified and treated. I have spoken with a couple of colleges. They expect the students to come in and identify themselves. And I said, what about these students who come in and say, I don't know how to learn. I don't know what is wrong. Because the students are not being identified and treated in the public school system. And she said, but it's by federal law. I said, it's not being done in the state of Rhode Island and many other states. I'm not even picking on this state. So I would like colleges to be aware and to have recourse. The people that I spoke with said we don't have any tools available for us to identify these students and help them. We have to have them declare their disability and we know what tools to give them. I believe that this is an opportunity and I'm really excited I've had this vision for years that there would be a statewide conference. In some states they require teachers to know about all of the learning disabilities, what they are, why they are, how they affect learning, and the compensation and treatment techniques. This is mental health, a specific learning disabilities like dyslexia, autism, ADD, I would love to have a statewide conference and invite other states, have continuing education units for the OT community, the teachers' community, the psych community, the social worker. I think we could -- it could be phenomenal. This is a wonderful time to do it because we have the technology to provide education for the visual learner, which is OT, which is dyslexia, autism and ADD. So I hope that something will happen. Thank you.

MEREDITH SHEEHAN: Thank you very much. Does anybody have any feedback or comments at this point? That was really wonderful testimony. Thank you so much. We will -- just so you are all aware all of the transcriptions do get compiled. We have work groups. We have committees that -- you know, take each issue whether transportation or education. We really are very thoughtful about that process. So you know even if we don't have all the answers for you today just know that, you know, it will be thoughtfully looked at in the months to come.

ANNE MULREADY: Can I just comment briefly. I think there was legislation filed to require that schools use evidence based scientifically based instruction. I don't think it went anywhere. But I think it's been filed for a couple of years. That would be something to visit

TIA BECKMAN: I have been one of the gang. And I have been speaking up there. And the House passed legislation for identification and treatment but the Senate has been dealing with it. And the Rhode Island Department of Education's vision is for mostly for culture, race, and economics. But I don't see anything about what I call different kinds of minds so.

CASEY GARTLAND: Well to add on what Meredith said if you look inside the first page of that packet you have, you will see some outcomes that we pursued and successfully worked on in previous years.

MEREDITH SHEEHAN: Thank you so much. Thank you. Okay. Next we have Goldie William.

GOLDIE WILLIAMS: Hi. Goldie Williams. I am with the Chariho School District, a parent with a son who will not give a 504 plan to. I will talk to them about that later. But I was wondering how you can investigate a school district who keeps kicking out kids out of their plans, who need it. And second, I was wondering how you propose a law to fine those school systems or districts.

CASEY GARTLAND: I don't know that our panel has answers to that. Obviously you have two parts there at least and when it comes to laws, that's something you want to work at legislatively. As for oversight for each school district, I imagine that you also would access RIDE --

GOLDIE WILLIAMS: I've tried. But -- I called the legal department. Never got back to me.

ANNE MULREADY: If I can -- this is --

GOLDIE WILLIAMS: And I got the Rhode Island Disability Law Center -- I am filling out the paperwork right now.

ANNE MULREADY: And I just would say that the Office of Civil Rights at the US Department of Education

GOLDIE WILLIAMS: They turned it down.

ANNE MULREADY: Okay. They look at 504 eligibility issues.

GOLDIE WILLIAMS: They turned it down. They said go to RIDE.

MEREDITH SHEEHAN: Thank you. Bretta Combs.

BRETTA COMBS: Bretta Combs. Thank you. Hi. So, I am here just speaking -- this is also my multiple visits. I have been to a couple of these. I think back in 2006-07 when cuts were made in 2008, I believe about 38 million dollars were cut at that time and then matching funds were also lost and you know that really made, you know, really made our system almost impossible. And now I think Governor Raimondo is not opposing $91 million in cuts. So my concern is knowing there are some current inconsistencies. I am certainly interested in saving Medicaid dollars and having thoughtful conversations about this proposal. But I'm questioning the sustainability and I'm frustrated quite honestly. I do private work in adult services and we have been reinventing Medicaid for over 20 years and you know, families are angry and they are frustrated and our system is acting as a deterrent to us getting good quality services for many of our adults with disabilities and our elderly. So you know, a few things that I hope to accomplish in coming today to speak with you is specific to some of the key initiatives that I see -- I did read the entire proposal many times. But in just thinking a little bit about the key initiatives on the cheat sheet, there were a few things where they make reference to the pilot, the coordinated care program, and the definition, and then also the targeted community based programs for individuals who need intensive services. And I think for myself and some of the families that I work with, it would be very helpful for us to get an idea of like what would that look like for individuals to navigate their way through those two proposals. Can you provide a sample of what that would look like from start to finish? I know for myself, I have one key contact at BHDDH that I can pick up the phone and a dozen of phone calls I can make and I don't reach somebody. That is very frustrating for myself and for some of the families that I talk to. So that is one of the things I am hoping to be very something that maybe you can consider is to maybe provide a sample of what it would look like for an individual to go through one of the few key initiatives like the piloted care program or the targeted community based program. Like what would that look like if I were an individual, young woman 26 years old with you know Autism or Down Syndrome, what would it look like for me to go through one of those two programs? What would that look like? That be would a big help for me. Another concern I have is just when we think about reinventing Medicaid and what we want to do in saving dollars, again I am more than interested in trying to do that. But I hear a lot of things in the proposals and how they are saving the money about piloted or expanded or enhanced or improved. And that kind of -- those verbs worry me a little. I don't know how you really define some of those. Like my improvement, what I define to be improved may be different from yours which may also be different from yours. So when we make reference to enhancing the eligibility determinations, what does that mean when we talk about enhancing something versus expanding opportunities? For one individual, expanding opportunity may be stepping outside of their house whereas others it may be volunteering at a pet shelter. That is another concern I have, just wanted to express my concerns. I think the dollars that we are cutting are pretty devastating to our system for both our adults with disabilities and our elderly and our veterans. Thanks.

MEREDITH SHEEHAN: Any comments? No. Okay. Thank you. Okay. We have Diana Juliana

Accessibility

DIANA JULIANO: Diana Juliano. I feel worse than when I came here, honestly. Part of it was for myself but hearing everybody else's story -- when you affect children, you are a decaying society. I was on the beach today and I had spoken to someone at parks and recreation because I couldn't get on the beach because they moved everything. The toilet is over there. This is over here and I almost died on that beach. Thank God the lifeguard, that place was where it was because I couldn't get anybody to help me the way it is now. And then I saw a girl come in, about 14 with a family, two crutches, braces on her legs. Somebody said they have those big things. Oh no there is only one of them somebody has it. They don't bring it back. They take it for the day. It's too hard for the sand, the walker that is why I was sitting at the edge. But I thought this is wrong. My cousin is superintendent of Special Ed in New York, I mean; I can't believe what is going on in this state. I am trying to move here for six years. I first came here 44 years ago. I got disabled six years ago. And I called everybody you could think of because I said I can't believe, all I get is dead ends. No, there's no bus by you. Charlestown, South Kingstown, so you die. You are in Exeter, so you die? I don't understand it. There's no quality of life. I went to URI, they got so much money, the gerontology department. Had a big thing on active aging or whatever it was. And I couldn't get access to the pool. I couldn't get access to go to Christ Our King. Oh there's no handicapped. You better watch, they tell you. There is a very unfriendly atmosphere. I have been telling that for 20 years and I am handicapped. Well, I mean I am from New York. But besides that, I am a nurse and I would fight for my patients like I want to fight for myself and others there who maybe don't talk. I can't believe what I am hearing. Because I don't think any of you really can address these things. And for myself, it's -- I once read its better not to have an idea at all unless you can act on it. I have been trying to see how I can get verbal. I get a call when Gina was running. I don't live here all year-round so I couldn't really vote. Oh, the Nat is so good. You should know, write it down. Like here she sat here how many years nag I feel like maybe I am not supposed to live here. You read what is the best place to live. Don't go to Rhode Island because the taxes will kill you. Even on TV, listed don't come here. But if you are here, where are you going? It's a beautiful state but this here has me more downtrodden than anything else about myself. So I try to -- you can't believe what I tried here because so many things happen to me while I was here that I had to try to access everything. And when I was going to this meeting, I must have said to somebody, I have been trying to get someone from the senior place to call me. The woman heard me. She was from there. Afterwards she said, I am going to call you tomorrow. But they couldn't call me because my number wasn't 401. They said they can’t make the phone calls if it's not 401. Hello, it's not a long distance phone call. It's a cell phone. And so for two and a half years I am spinning my wheels. Town hall, call over here. I never knew that -- really the senior centers are like little governments. I never heard of such a thing. So I was like no, it can't be. Then when the guy happened to, in the center said I remember you but you don't have a 401 number. Well, what does that have to do with the price effects? The phone won't let them call out to give me any information. She happened to hear me say because here's a place for seniors and URI, parking lot is here. The entrance is down there. And then when you get there, there's stairs, somebody open the door. More stairs and I have a walker. I had picked up a man that I met in a shelter what happened with Irene to get out of the -- and he said don't worry about it. I will fund it. I can walk better than you. So you have a place for people with -- and what's -- where's the access? When I went to the shelter place, the intake guy said I know you. Really? Two years later. He said yeah I picked you up at the beach. He said we just finished talking about Rhode Island drivers. They hear the sirens. They don't move. I almost died on the beach. My heart rate went to 14. So I mean I could address every single thing with the story because I don't give up easily. But you know, but you can deal with yourselves. You can't see children deal with it. So I mean I am trying to find out how I can get involved that somebody listens. I don't want to just keep on talking and no one seems to have, oh, you can't -- I can't. I call Whitehouse's office. I just am amazed, amazed. Anyway -- I am frustrated. I am sorry. I want to talk any more --

CASEY GARTLAND: Have you called the Governor's Commission on specific access issues?

DIANA JULIANO: No, no, because --

CASEY GARTLAND: I was curious.

Transportation

DIANA JULIANO: Because this was the first -- my friend saw and said you have to go. You have to go to this meeting. So really what I need to do is find out how I could verbalize -- I am an outsider in a way coming in here even though my family came here years ago. I do think I have some valuable things to say and I have been through a lot when I am here. But as I said, I have a full life, children didn't yet. You know, and I use handicap in New York. When they pick you up, there's a half hour window. They are obligated to pick you up on the way back. Not up here. They may not come at all. You are stranded. No such thing in New York. You may have to wait but you say thank you, I got the RIde and you wait a half hour. If you can't wait and you have the money, you take a taxi and they reimburse you. I am not saying it would be the same thing but like he stayed two and a half, are you crazy? If it's cold -- what are you going to get pneumonia out there? I don't know how the system works. I called RIPTA about this here. There's no way down there. I said well, you have to move. Where? Well you have to give me an address. Oh so I should -- before I buy a house, move -- if I have to do that, I will stay in New York where I have the handicap, I have whatever. I mean, as I said, she knows. I want to move but everything -- something stops me all the time. Anyway --

DEBORAH GOLDING: There's a fairly new brochure, Accessible Rhode Island. Have you seen --

DIANA JULIANO: I saw that but you know what? I spent a couple of years calling -- oh my God you have no idea, you name it. And I thought, I'm not going to be eligible for this. I could drive right now but if I can't I have no family up here. So what do you do? At this meeting, they identify two things. Lack of housing, affordable housing in Rhode Island. And no transportation. And suicide, if you don't get that socialization and seniors when they try to kill themselves will succeed. So what's happening? I mean, what's the outcome of that? That was their own conclusion. So you isolate people. Put them in the community. And they can't go anywhere. And Rhode Island, this is just for seniors too, has the most number of seniors over 85 years old. It's a shame what they are doing here. They are so happy about the wind farm. Why don't you show the world that the country what you can do allowing your seniors that healthy. What are they doing that they were able to get like that. I'm serious. I have been very impressed with the seniors up here because they are frugal. They are not paying this one to do that, this one to do that. They are good at doing all themselves. I tell my friend, get somebody to pay it. No I can do it. But what I am saying, it's a shame. It's really -- they have another thing that they can be premiering, and they don't. They just are letting it go by. It seems like nobody was watching the shop. You know?

MEREDITH SHEEHAN: And you live in Charlestown?

DIANA JULIANO: I live in South County, across the street is Charlestown.

MEREDITH SHEEHAN: They have a senior center.

DIANA JULIANO: I go to the one in Wakefield because I can still drive. This was years of finding out this trip, that trip, this -- you know? It's -- it hasn't been easy for whatever reason. I could have just let it go but it's not my nature so I kept on trying. I couldn't figure it out. I kept calling the same place. No it couldn't be. It can't be. Well it is. But like she's saying, I'm not hopeful things are going to change, honestly. That's all in God's hands. But I think there's just so much that any committee here can do because that's not what they are focusing on. You know, their priority is the wind, the energy -- which is fine but not when you have the seniors and -- moving or whatever. And cutting and cutting and cutting. It's -- oh my God. It really is too much. And this just reinforced that. Oh my God. Thank God I have to leave early. I don't know how much I can take of hearing this. Honestly.

CASEY GARTLAND: Thank you for speaking up.

MEREDITH SHEEHAN: Thank you so much. Just --

DIANA JULIANO: I will take one of those

MEREDITH SHEEHAN: The resource that Deborah mentioned is actually really good. I know this organization really well. I don't know if you are all familiar with that

DIANA JULIANO: This is not the government.

MEREDITH SHEEHAN: This is called Accessible Rhode Island and it is -- I think they have some state and federal funds that they got to put this together. The reason I know that is because the people who head it up, the woman has MS, so I work with her through the Society. And they actually went -- they had kind of field people who went out across the state to beaches, restaurants, any public place you can possibly think of, and they are all reviewed on this website. And you can read about how accessible they are, how the parking is, if there's a stair to get in, really bathrooms. So you can go on. If you know I am going to go to Matunuck State Beach, how does it rank in terms of accessibility? This is a fabulous, really comprehensive. If you want to go out to dinner, it's informational. We have them. But it's a really good website. They've done a ton of work putting it together. So it is really good.

DIANA JULIANO: Is that the one that has the evaluation form?

MEREDITH SHEEHAN: I believe so. I think it's on the website. Okay. Great. So Donna Gilton.

Independent Living

DONNA GILTON: It's like the hotel Hilton but it is with a G, Gilton. That's it. Okay. What I want to speak to and I probably won't be long, my brother is -- he's under Perspectives at this time. He goes to what used to be at the LaPlante Center and he lives in a group home in North Kingstown and I live here right around the corner in Peace Dale. The reason I want to say something especially after hearing everybody else talk is a few years ago we had the experience -- and my mother was still alive and still relatively well at that time -- this is under Governor Carcieri where there was a big attempt for the state to get rid of group homes and we had to go to a series of hearing. And then I remember coming to a hearing similar to this and what was happening was the state was cutting and cutting and cutting and cutting. And LaPlante was -- it had been a good program and it had deteriorated and it eventually Perspectives took them over and seem to be doing okay now. But what concerns me is, I mean, and then I used to teach at the university. And I experienced this in my department and at the university too. It's sort of like where the state is cutting and they are trying to make us do more and more with less and less until we are doing everything with nothing. That's what is going on. And I am also concerned about the lack of coordination between all of these agencies. So those are my two concerns. How long can the state continue to cut before there's really no services left or before we have real poor services? And when do we start cutting? Just cutting cancer can't be the answer. Those are my two concerns and that's it.

MEREDITH SHEEHAN: Thank you. Okay. Gayle Tazwell.

Independent Living

GAYLE TAZWELL: Hi, Tarzwell, Gayle. Thank you. I appreciate the opportunity to address you today. I come as a mother of a 29 year old Down Syndrome woman who receives services, adult services through DDD and also as a local attorney who does a lot of estate planning for families who have children with special needs and who have issues with eligibility for DD funding. So what I particularly wanted to address is the policy of the state, particularly BHDDH concerning paid caregivers who are family members and I've come across this on two different aspects. And other states, family members are eligible to be paid caregivers when Medicaid dollars are involved but our state, especially on the BHDDH side has given a very chilling effect and implicate -- have implemented policies that are anti having family members be paid and I will give you a couple of examples. In the first is self-directed services that are funded with Medicaid, DDD money. And parents, guardians, stepparents and even people who hold powers of attorney for people with disability are ineligible to be paid caregivers for self-directed DDD funding. Totally cannot do it. They are excluded. I'm personally not looking to be paid caregiver for my daughter. I am blessed that she's high functioning and that I can have paid caregivers come in and take care of her for enough hours so that I can work as an attorney and also be her mom. But I do have access to other families who will tell me stories. For instance, an elderly mom who is guardian for her Down Syndrome son. She wants her nondisabled son to be co-guardian right now so that when mom passes there will not be a hiatus where the son does not have a guardian. And she went to an informational session on self-directed services. She receives or her funding and utilizes it through Ocean State Community Resources and was told that if her son, her adult nondisabled son becomes guardian, he will no longer be eligible to be paid as an options worker. So that stopped her guardianship proceedings immediately so what do we have, a situation where now we have to wait for mom to pass away and then moms -- then son without the disability has to race into probate court to become guardian for his Down Syndrome son. Does that make sense? No it doesn't. Even other states -- as I said, do allow Medicaid funding to be used for paid caregivers and even the Medicaid funded personal choice program that's on the DHS side in Rhode Island allows paid families to be paid caregivers. But not on the BHDDH side When we come to DDD, there's definitely a distrust of allowing family members to be paid. Now I will put on my lawyer hat for a minute and I prepare many special needs trusts for families who have children with disabilities. There's two kinds of trusts. There's the trust with the parents money. We call those third party trusts. I will not address those today. Then there's the ones called first party trust and those are funded with the money that belongs to the person who has the disability. So quite often it will be a person that has had an injury, either at birth or through an auto accident, become injured, become disabled and then they sue and they get a settlement and then the settlement has to go into a special needs trust called the first party special needs trust and it has to have a payback clause. So the deal is you put the money into the trust now. Immediately eligible for Medicaid but when the person with the disability dies, whatever is left in the trust has to be paid back to Medicaid, okay. So that's the kind of trust I'm talking about and I do prepare those trusts for families who have this kind of situation. But what has happened is that we attorneys are being told now from the Executive Office of Health and Human Service when we draft these first party trusts that we shall not put in any provisions in those trusts that allow paid family caregivers. We are being told not to put that in the trust. So -- these are irrevocable trusts. We can't even change them if the policy changes in the future except by going to superior court and asking for a change. So that's having a very chilling effect on having family members being paid like in other states. And we got the very odd situation -- and this is especially with severely involved folks who have big settlements where the family member, like a mother, in my case I know of a mother who has a child and requires tube feeding. Has to be fed by tube. And she can -- the trustee of the trust who is a bank is saying because of this chilling effect, you cannot get paid to feed your own child. We can pay a stranger who has the qualifications but we will not pay you. So we are going to pay more money to have a nurse come in and feed your child but we can't pay you. And this mom says to me, I cannot work outside of the home and even have my own health insurance covered because I have to stay home and feed my own child. The trustee won't pay me to feed my child. It doesn't make any sense. I'm just hoping that some of the policies can be changed so that the unpaid hours that parents -- many parents are children with disabilities put in can be recognized and that this perception of abuse -- and I'm sure that there have been abuses and maybe that's what colors the division or BHDDH's thinking on this. But it has to change because it's not right and it's certainly not in the trend of the company. This particular woman that I speak of went to Disneyworld. She saw another mom with a child just like hers and the mom said, I'm being paid in Colorado to take care of my child. The mom came home and said, why am I not being able to be paid for my own child's trust that was set up because of her disability? Why am I not being able to be paid to take care of her? Thank you.

CASEY GARTLAND: Can I ask you a question. Have you ever been shown a regulation of the parts that allude to that? We've heard about that and I have yet to see it.

GAYLE TAZWELL: I have not seen it

CASEY GARTLAND: Wondering if you have

Independent Living

GAYLE TAZWELL: I have not. I get my information from David Reese who is the executive director of OSCCR, Ocean State Center Community Resources, one the fiscal intermediaries for the Options Program. My daughter receives her DDD services through an options plan. And we love it. We are very grateful that Rhode Island has that option and as I said, I am not looking to be a paid caregiver there. But you know we have people who are going to secede to be guardians with folks with disabilities then they are categorically denied to be paid caregivers under the present scheme.

CASEY GARTLAND: I want to make sure -- because I would love if you have point to it. They never referred to a regulation that this is based on

GAYLE TAZWELL: No. And it shifts. When we first started options with my daughter, let's see, it would be eight years ago. Siblings who are not under the same roof as the person with the disability were allowed to be paid. But if you were a sibling living under the same roof of the person with the disability, you were categorically denied the opportunity to be paid. Now I have heard that that -- that rule changed. That siblings living with siblings are going to be allowed to be paid employees under a self-directed DDD plan

CASEY GARTLAND: We actually did, within the last year the DD community achieved a minor victory, siblings can be shared living providers. We achieved that. I think you are right. Become more aware with the exception of that area

GAYLE TAZWELL: Okay.

ANNE MULREADY: I had a quick question about the trusts that you mentioned. Did you mention it was a separate Medicaid policy around not allowing family members to be paid from the trust either?

GAYLE TAZWELL: From the trust, right.

ANNE MULREADY: Is that OHHS.

GAYLE TAZWELL: It's EOHHS legal counsel that has given attorneys who work in this area a checklist of the types of features that the trusts must have or must not have. And one of those features is that a family member may not be paid as a caregiver and they even added as a trustee, which is contrary to Rhode Island law that allows trustees to be compensated. But this is what we are being told to put into the trust and every one of these payback trusts are screened and reviewed by legal hopefully before they are funded. Sometimes they have to be funded ahead of time to keep the Medicaid eligibility. But prudence dictates and this is what they want, and every single year the trustees are requested. Again there's nothing legally but -- requested to provide accountings. So this is where the lawyers at EOHHS are going to say, oh, you trustee, paid a mom to feed her own child. Not allowed. So the trustees are chilled because they don't want to find out that they've paid something and then -- within a year, oh no. You weren't allowed to use the trust money that way. Put it back. Medicaid thinks because of the payback clause and what a payback clause says is that anything that's left in the trust when the child dies, the person with the disability dies, goes back to pay whatever Medicaid tab that person has run up during their lifetime. And they do it just like a hotel bill with your Social Security number at any point in time you can find out what the Medicaid tab is. And the payback -- so Medicaid lawyers think of this trust as Medicaid money. They think of it as theirs already and the trustees account, because they don't want to wait 20 or 30 years and be paying out money under the assumption that it's an acceptable disbursement from the trust and then find out oh no, trustee, you shouldn't have done that. So the trustees are very conservative about how they do this. And thus I get a situation where the mom calling me up and saying the trustee won't pay me to feed my child a tube feeding. Or the trustee won't pay me to do this. You know, you have situations where children need 24/7 care and the money's there. And the parent is willing and the parent can't work outside of the home. I mean, you know, you can't hire people for more than 40 hours or you are paying them time and a half. All of those rules apply. And so you get a parent that says, all right. I will be willing to work but I would like to get paid because I can't work outside the home.

ANNE MULREADY: So that -- and that is just by legal counsel checklists, not a regulation

GAYLE TAZWELL: As far as I know. Yes. Its policy and it's having a chilling effect. It's broadcasting loud and clear to the trustees and to the parents. This is not going to fly. So don't ask and don't do it.

BARBARA POLICHETTI: This is Rhode Island.

GAYLE TAZWELL: This is Rhode Island.

BARBARA POLICHETTI: That other mom ran into someone from another state Colorado. So -- and I apologize this is not my area but I wanted to make sure I was understanding because it's fascinating and frustrating

GAYLE TAZWELL: Yes.

BARBARA POLICHETTI: So even though this may in some cases involve the disbursement of or eventual reimbursement of Medicaid funds what you are saying is there's a Rhode Island rule or a policy pertinent to -- involving federal funds and that same rule or policy you may go to another state and --

GAYLE TAZWELL: That's correct. In fact I was talking with David Reese yesterday and he said when it comes to this particular issue, Rhode Island is in the minority. Other states -- and the trend is towards paying family caregivers with Medicaid dollars to take care of their own children.

AUDIENCE MEMBER: Usually they cost less if a family member --

GAYLE TAZWELL: Of course, it costs less. Exactly. According to this mom, even a CNA cannot tube feed her child. Cannot, okay. I am bless that had I don't have a child that requires tube feeding. But she said -- it would cost so much more to hire a person who is eligible to feed her child than just to pay me to do it. And I know how to do it. I have been doing it. And of course, she said I can't work outside the home because I have to be available for her feedings. And I don't even have the ability to have a job with benefits. That's what she asked me and I said, I would tell you today her situation and I see it from the parent perspective. I see it from the attorney perspective.

Independent Living

TIA BECKMAN: I will add to it. My father just passed away but during the decline, he had to have caregivers at night. Many times we couldn't count on the caregiver. We hired an agency. We could not count on the caregivers. So fortunately, I was five minutes away and I'm so thankful that I had that special time with him. But it's not only a mother wants to, it's hired help. You can't rely on them.

GAYLE TAZWELL: Thank you.

MEREDITH SHEEHAN: So, on the list I had that was actually everyone who signed up to speak, however I know that a few people have come in since we started the forum today. So if you did come in late and you wish to speak, if you just want to raise your hand. We can have you give your testimony.

Independent Living

ELLA WHALEY: Ella Whaley. I just -- I am a retired schoolteacher from North Kingstown for 32 years. I served on the school committee in this town for eight years. I just finished with eight years on the town council. Still doing a lot of advocacy, school department in South Kingstown has a lot of -- it's conference calls me. I am a Florida resident now. I am here for four months and Florida for eight, so I don't even know if I have the right to speak. But here I am. Doing a lot of educational advocacy here in South Kingstown as well as neighboring towns. I am just very still concerned about the language based learning disability and I know that there was some legislative acts setting up a committee with dyslexia and I am not sure that that got the traction that it needed. I know there are some recent bills. I want to resurface all of that. I really see a need for the state to take some action and really do some training and process to identify children with language based learning disabilities. So that was my first. I would like to thank Tazwell for bringing her testimony to the forefront and I support all that she has said. I am also the mother of a child with a disability who is 26 and we are trying to transition her into some housing. Kenyon Avenue permanent housing she is number five on the list. So when that gets up and running we are hoping that she is successful and we can realize before we pass away that we have taken care of her. The thing that I really would like to bring, you know, to the forefront is the cuts in the Medicare. I have been blessed also with David Reese and options and very happy with the plan that my daughter has. But I really would hate to see any more cuts, you know, with the Medicare. And I also have many questions -- if somebody could just put me in the right direction for the flex bus. Is there any information that I can get in reference to that?

MEREDITH SHEEHAN: Barbara just stepped out.

CASEY GARTLAND: When she comes back in she can discuss the flex bus

AUDIENCE MEMBER: There is stuff on the internet

ELLA WHALEY: The internet, okay. And I guess my understanding of that is my daughter will be able to call and she will get somebody to pick her up and somebody to drop her off.

ROBERT ROMERO: That is between the flex and the RIde too.

Independent Living

ELLA WHALEY: There is a difference between -- I know this is probably not like a question and answer thing. I will have to get more information on that. The other thing is as I attend special education meetings for families with children with disabilities and I may have a question, I call and let me tell you I have been doing this for a very, very long time. And when I call up to the Department of Education, sometimes there's not a phone call returned. I used to be able to pick up the phone and call Paul Ponterelli, all of the attorneys up there. And I know its short staffed, but I mean it really is a need that needs to be addressed. And then it's -- again it's a question -- I am just going to throw it out there. I don't expect an answer but if somebody could get back to me. I also would like to know if the state offers the school districts any kind of education to educate and get a baseline for children that are nonverbal, okay. I don't see on your list that you have turned, you know, out today that anybody is a specialty on this board for children that are nonverbal. And I really see that there may be something lacking in the schools with trying to address some of the needs with the children. So I don't know if that has an answer or somebody can let me know later.

CASEY GARTLAND: If we don't have the answer here we take these in the notes and someone could get back to you. So make sure -- did you register when you came in?

Independent Living

ELLA WHALEY: I have my name up on this sheet here. To reiterate what Gayle said, I do have a son who now is in Montana. But he was able to get paid to help us out to take care of my daughter. The problem that we had is once we are in Florida and my daughter wants to take a vacation, there's nobody. It's when they leave the state of Rhode Island, again, that that policy that you have. You know, there's no paid worker that is going to be able to take her even to the cape for, you know, maybe a weekend or something like that and I think that people with disabilities are entitled to vacations just as their nondisabled peers. I think that is something to add to Gayle's list. That's it. I thank you very much for having the forum.

MEREDITH SHEEHAN: So, Barbara's with RIPTA. So if you wanted to re-ask the transportation question.

BARBARA POLICHETTI: I apologize

Transportation

ELLA WHALEY: I am looking for information on the flex bus. My daughter is hopefully going to be successful over at the Kenyon Avenue permanent housing. We are almost into Charlestown and you have been to one mile from a bus line. Like there's no transportation. Even as a town council member I have tried to get our senior van to if they are going out to green hill to pick up somebody, and there's a child with a disability. There's another students out there who is at URI who, you know, is blind. She couldn't even get a RIde to URI. There's just a lot lacking with transportation. So my daughter hopefully is going to be moving into town and I just needed information on the flex bus. If you wanted to fill me in later, that would be fine

BARBARA POLICHETTI: That would be great because I can go back to planning. I can take a look at what is available. And I will get your information and I will get you any information that we have on flex services in this area

ELLA WHALEY: Okay. Thank you very much. Thank you.

MEREDITH SHEEHAN: Anybody else? Anybody who has joined us recently and would like to speak. Sure, absolutely.

CAROLYN MAXWELL: I just ran in so I am not sure.

MEREDITH SHEEHAN: Would you mind coming over here -- the air-conditioning it's a little hard to hear. That would be great. Thank you so much.

Independent Living

CAROLYN MAXWELL: My name is Carolyn Maxwell. And I am a resident of Kingstown. I have a daughter Emily who is going to be turning 23 soon. We currently have a self-directed plan. To give people an easy grasp, which it's not easy about Emily. I kind of call her my kindergarten kid. We are working at that academic level. And she has a hearing loss, which makes it even more complicated for her to be integrated into the community. Most people cannot communicate with her. And so after looking, knowing that the transition years were coming and looking at programs available and finding none, we found ourselves really needing to be creative about it. The last year of school, Emily's teacher of the deaf who had worked with her as a consultant in the South Kingstown school system, Emily began her education at the Rhode Island School for the Deaf. But then we moved back to my childhood home when we said six years in preschool.

Independent Living

What's the plan? You know? Everybody else was moving on and growing up. And you know, here's Emily. So we created a program with the teacher of the deaf within the South Kingstown school system. Last year Mrs. Flexure sent home a gift. It was a small collage, little wallet sized pictures she photographed Emily's hands signing LOVE. And of course, I thought it was fabulous. But then when I showed it to other people, you know, their hearts melted as well. So I said, well we might have something here. And we began a business called love letters by Emily. And we are on Etsy and we are kind of around town too. We have been given shop space at Spangles in Wakefield. We are at Bagels in Kingston. We are -- I wanted to see if this was a viable plan. The year before Emily completed school, we started an Etsy shop. And I set it up and she came home and turned on the buttons and turned on the shop. And an hour later somebody in Ankara, Turkey, had posted one of our prints. And from there, her hands are in 41 states and coast to coast in Australia, and in the United Kingdom and Canada. So, with all that said, I haven't worked since Emily was born in my profession of being a teacher. And the four years that I've devoted to this, there have not been any paychecks for me. When Emily was about to turn 18, I started and I called the Office of Rehabilitative Services and said this is a plan, kind of what support can we get? And we were told that unless Emily could really work 40 hours a week in an integrated setting after being supported for a year with a job coach, we really would be referred back to the developmental disabilities kind of department. And of course, now they are saying oh we never would have said that. But I said, well, I am the one person. You talked to hundreds, thousands of parents. But I remember the conversation that I had because it was singular. Anyway, with all of this going on and cleaning off my dining room table every night of the project of the day, and you know, what we put in our bank account is not going into our pockets. It's buying more materials and supporting us in a way to keep it going. So in the second round with ORS, we came in saying everything is on our family computer. I have to kick everybody off when I say I've got Etsy orders to do. Emily always had a communication system in school that consisted of a computer and a printer and an iPad with promo quo to go. And I was saying we need that plus an iPhone which will allow, you know, communication with her support staff or if we are sliding credit cards through it at events. This is our wish list. So we approached ORS again and they did a first situational assessment and paid a company $1,500 for it. And they decided they needed more information. And these people, meanwhile we were not given any further, you know, equipment or things. And I felt it was like, well what are you doing with Emily now, with nothing new, nothing provided? And they did a second round of situational assessment for $1,500, and a year's worth of meetings now and then where an interpreter was paid for. So I'm kind of -- going, adding things up in my head saying, okay. We could have gotten everything on our list and been flying now. But all -- and I know there are rules and regulations. But it all came back to she needs to be in an integrated environment, earning a paycheck. Which again won't impact her SSI funding, which is a huge part of raising Emily. So with the requests that I write out paychecks for $100 a week for her and insure her for workman's comp because she is working for us in our home, and all of that. I said we don't have $100 in orders every single week. Where am I going to get this money to pay her and totally rework our SSI benefits? And come to find out they put in an order for $1,500 of technical support, computer support for somebody to come and sit down at our family computer and all. And I said, I can go to the Apple store and ask all my questions for free. You know, you don't have to spend that money. And then the upshot was, well, why don't you go to Goodwill and see if you can find a refurbished computer. So I'm totally beyond frustrated and wondering, you know, where to go on this. And in our self-directed plan we always have unspent money. Emily is a tier D, and even though we pay our workers usually more than the average because they come to us with sign language skills. They have to. And a car to -- she wants to be out and about in the community. They have to have reliable transportation and all. So again, but we would have somebody sitting at our dining room table every night if I filled all the hours that our funding would pay for. And in the meantime, people are telling me we used to be able to write in the computer in one of these plans. Or we used to be able. But the one thing I wanted to say tonight was Emily needs more than people to make this plan work. And if we had any other options for Emily -- I'm not sure I would be doing it. There's so many things about this I love and we call it a mother-daughter business and you know, we are there -- my sidekick and all. But you know, again there are moments when I think, well, what if Emily hadn't had all these challenges. So along with that, we've had people come and go and say things like -- Oh, in Michigan my special needs sister can go to school until she is 26. Everyone looks at Emily and wonders why she isn't in school because she's petite. She hasn't developed as most typical kids. And again I said for everything to change at the stroke of 21 and losing all the technology equipment in the school system that is used on a daily basis and not provided unless we, you know, save up our money, you know. Again, ORS says go out and buy a computer or what you need and put it on your credit card. And then, you know, pay it back over how many payments it takes. I'm sorry. I just -- you know, other people seem to get access to what they need or the people who are doing the situational assessment kept saying don't go buying address labels. We want to provide that for you. But you know. And then it was -- you know, the computer that, no, no. We are not going to provide that for you or anything else. We would love to. And in the meantime, we have RIPIN. We have the Center for Excellence and Advocacy calling and saying could we use you as a success story? And I said, I don't feel like a success story here. I have been just working as hard as I can for as long as I -- she's been with me that it really -- it really is a difficult stretch now to imagine not to have all the support that we did have when we were in the school system and to really come up with a very creative, very productive lifestyle for her and still it's, what can you provide for your daughter? And I just want to share with you. This is the manual alphabet. I will just use the chair. After I saw her LOVE, I sat her down and took the pictures and this is the alphabet, all Emily's hands. And we've made kind of graphic renditions of the first idea. We just worked with 401 Studios on the Main Street of Wakefield for them to come and victimize our design, which is another whole area of support of what we could do if we had something to work with. But we bundled our earnings and our money that's come in and have put in our first T-shirt order and are very excited about, you know, again, presenting it on Etsy or some of the events that we've done. We were invited by Tech ACCESS to be vendors at the New England -- help me out --

AUDIENCE MEMBER: Assistive technology conference

CAROLYN MAXWELL: -- in November. And typically a table fee there is $450. But it was waived. And we had people standing in line, arms full of prints. And we came up with $500 that day. But I said, think of it. If we had been the typical exhibitor, you know, we would have come home with $50, you know? They invited us back and they've expanded it. They decided we loved having Emily there so much that we are going to invite other vendors and it's called "bringing access to life" and we've also been asked for Emily to sign ACCESS and make that a print that they are going to pass out to all 50 of their presenters who come. So again, I could not be prouder of Emily or what we've been able to accomplish. But it's really been on our own. And I just felt strongly enough that I wanted to come here tonight and share with you. This was a local article when we first started out. And this was done by a phone conversation with a reporter and I didn't know how it was going to come out. But for her to come up with the headline or the title, love letters by Emily educates. I thought you know, she got it. She really did. Tia, we went to high school together {LAUGHTER}.

Transportation

TIA BECKMAN: We went to grammar school together.

CAROLYN MAXWELL: That too. Anyway, my work here is done {LAUGHTER}. I just really wanted to share with you. One last blast is we were invited by the Justice Resource Institute in Massachusetts. They have a program called Full Circle Arts, which is a store front in Natick, Mass, and Westboro. They have clients with a day program and they make a variety of crafts and sell them. But their clients can't produce enough for all the locations and all the farmers markets that they do. So they said, would you like to be consigners. And we took our things up. And then after I saw the shop, she opened the door and it was, you know, a huge kitchen where they were all going to have a meal together and besides the crafting and the store front, they do meals on wheels and a whole variety of day programs and I keep saying, oh my goodness. You've figured it all out of what so many people could benefit from or anything that's Warwick or south would be huge. And I said, I've spoken with David Reese at options and he said if you can find the funding, we'd offer options as the umbrella for this. But again, you know, I don't know, you know, it's really hard to have every day go by and think how much time should I be spending and what doors should I be knocking on and who should I share this with. But it's just frustrating that across the state border there seems to be a setup and they've gone to several locations. They are so successful and it just seems to be a really model program that someone could be taking a look at and saying, hum, wouldn't that benefit a number of people and take love letters by Emily off my dining room table. So -- Thank you

ANNE MULREADY: Can I just ask a quick question for clarification. You said you were looking for a computer and some equipment and I assuming the equipment is kind of to make the computer accessible to Emily? So some of this is assistive technology and some of it is a business computer

Independent Living

CAROLYN MAXWELL: Yeah. Well since much of the business is internet driven, it's, you know, plus she has a Facebook page she maintains and it gives her, you know, kind of a connection with -- and you know, we write out the text. She types it in. The photographs, she's involved in. So it's an integral part of it. Or if we need to show her, you know, where we are going. We will print out the picture of the store in Natick and she will have an understanding of what -- but we need these things at our finger tips and again, it's all been family provided in a way. And I've said, you know, I am not asking for any more than our fair share. A lot of our money goes unspent and wouldn't it be wonderful to be able to go down the list or have someone really validate the need for things. Which I am fine with. But it just doesn't seem to be available to us, the way the system is now.

MEREDITH SHEEHAN: Okay.

CAROLYN MAXWELL: Thanks

MEREDITH SHEEHAN: Thank you so much. Great story. Yes

Independent Living

BRETTA COMBS: If I could just piggyback again on Emily's meant -- Bretta Combs. So, again, I do just want to piggyback some of the comments that Emily's mom made regarding how the funds are allocated. It's all exclusively staffing. So that is a challenge and there are sometimes needs that are specific to the individual with disabilities, where families will attempt to try to seek reimbursement maybe or funding that would support some of the things that some of the adults with disabilities might need. For example, technology or I work with a young woman who uses those Bose noise-cancelling earbuds when she goes out into the community because she has very heightened acuity to certain sounds. Without those she wouldn't be able to navigate her community. And we have tried lots of different devices that have been expensive and the parents essentially have yard sales on Saturdays to pay for it. So you know, some of the families that I've talked to have remortgaged their homes so that they can have funds available to buy some of the supplies and assistive technology devices that their children need because -- I know you probably are thinking, no, really? Yeah, really. Like they are remortgaging their homes, refinancing their homes so they can afford to buy some of this. One of the adults I also worked with -- some of the funds at the end of the year do go unused because we have an incredible turnover in staff. We had a horrible winter and staff cancelled. And you know, days and days and stretches and the money goes unused. And it goes back into the pool and I understand. Again, I am completely open to having these thoughtful conversations about saving dollars. I do want to do that. However, there's also other needs that aren't being met with the current structure that is in place. So I just wanted to piggyback on that point that I do think there is a need for us to figure out a vehicle to get some of these other no staff, non-direct care needs met

MEREDITH SHEEHAN: Thank you. Is there anybody else? Okay. So, it's about 5:30. We are here until 6:00 or a few minutes before. So if you -- feel free. You don't have to stay until 6:00 if you said what you wanted to say. You are obviously welcome to leave. If you did want to have any private conversations with any of our panelists, I am sure they would be willing to talk to you as well. We will -- if anyone else comes in in the next half hour or so, we will reconvene.

DEBORAH GOLDING: I will put these back on the table.

## 30 July, 2015 Zambarano Forum

FEMALE SPEAKER: I'll bring the microphone over to you, you'll be able to ask that question to the person on the panel or to me. Let me introduce to you our panel. (Inaudible).

THE SPEAKERS: We can't hear you.

FEMALE SPEAKER: (Inaudible).

FEMALE SPEAKER: Everybody hear her?

FEMALE SPEAKER: Oh, come on. (Inaudible) access point Rhode Island, I provide support for folks with disabilities (Inaudible).

FEMALE SPEAKER: (Inaudible).

JENNIFER MCCARTHY: I'm Jennifer McCarthy, I work here at the facility overseeing rehab services, physical theory, operational therapy, speech therapy, psychology, social work, and therapy recognition and also our community (Inaudible) that are affiliated with Zambarano.

MEREDITH SHEEHAN: I'm Meredith, I'm the community programs manager for Rhode Island for the National Multiple Sclerosis Society. I work with our clients who have MS who live in Rhode Island, providing patient education programs as well as service to all of our health care professionals in the state who treat people with MS.

KATE SHERLOCK: Hi, my name is Kate Sherlock, I'm from the Rhode Island Disability Law Center. We are Rhode Island's designated protection and advocacy system, and provide free legal advocacy on disability related issues for folks with disabilities. We come to the public hearings to hear from you about issues that are affecting you so that we can be informed as we set our priorities for things that we will work on in the coming year, so we appreciate you coming here today.

COLLEEN: Hi, I'm Colleen, from the Rhode Island Department of Health, Office of Special Needs and Disabilities.

KAREN: I'm Karen, I'm from the Division of Developmental Disabilities.

FEMALE SPEAKER: I'm from (Inaudible).

FEMALE SPEAKER: Maureen is our interpreter today, so I want you to be able to, for anybody who is not able to hear, Maureen is here to give you the interpretation. Let me say that last year we were very successful with this particular forum, in being able to help somebody be discharged back to the community. So, if you have a question, or if you have a problem, let us know what that is today, and I'll come down to you with the microphone and then I will come back and I'll give you the microphone to the person that wants to answer it. Raise your hand whoever has a question and would like to speak about it. Your name.

Independent Living

FEMALE SPEAKER: (Inaudible) in her late s, and she has psychiatric issues, she's also very functioning. She's about to fail out of (Inaudible). I am wondering, is there anything in the state that is between Eleanor Slater and the freedom of a regular group home for someone? She has (Inaudible), OCD. The alphabet soup. She's been in state care since she's been about. Can you tell me, what options or housing are there out there? They are recommended a locked facility (Inaudible).

FEMALE SPEAKER: Does anybody want to tackle that question?

FEMALE SPEAKER: Does your daughter have services through a community mental health agency yet?

FEMALE SPEAKER: Yes, she does, she's had them for quite a while through the Providence Center.

FEMALE SPEAKER: I know that the Providence Center does have different levels of community living for security purposes. My recommendation is to work through them because we've discharged from our psychiatric side to the community often through the Providence Center utilizing those services. They will have a better knowledge of what they can offer or what the community has to offer for your daughter.

FEMALE SPEAKER: I'm just warning you all, I am going to trip before it's all said and done.

FEMALE SPEAKER: My other question, on the flip side of what you do, how do you voice the criteria to get into Eleanor Slater for psychiatric or mental health issues?

FEMALE SPEAKER: So what would have to happen is the agency that your daughter is serviced through, they would fill out an application online to Eleanor Slater Hospital. A doctor has to complete the application, and list what her diagnoses are. And what would happen is that application gets submitted and reviewed by our medical protector. And then it's given to our social services department where they go up to do a site visit and determine level of eligible at that time. They would have to do an interview, get records. You have to go through that process to determine the eligibility. That's how it's done. But there is an application online for Eleanor Slater Hospital, and for community social worker, I'm assuming she has one with the Providence Center, would be responsible for filling that out and submitting that and getting the necessary paperwork. Okay?

FEMALE SPEAKER: Hi, if your daughter wanted to get in touch with us, I can't promise that I will have representation, but I will at least provide a little counseling. We are from the Rhode Island Disability Law Center. If you got the packet, our phone number is on there. It is - - .

FEMALE SPEAKER: Does that answer all your questions?

FEMALE SPEAKER: Yes.

FEMALE SPEAKER: (Inaudible) Mental Health Advocates Office to see what they're doing, not only for each person, but global. (Inaudible).

FEMALE SPEAKER: Anything else that you'd like to ask? You're all set. Who else now would like to pose a question?

FEMALE SPEAKER: (Inaudible) I just wanted to speak about (Inaudible). I just wanted to speak and say thank you to Zambarano, it was quite a journey for us for getting her here. I have to say the level of care, comfort, kindness, has been unparalleled, and at her quarterly

Independent Living

meeting, they have addressed all of her issues that Jen was talking about, like speech, physical therapy, and all the different therapies that my sister has been able to receive. It has made her quality of life much better than what it was before she came here. One summer I just had to put a bag in my car because she was kicked out of her ten-year home. And it was very, very difficult. And we didn't understand about (Inaudible). And she has received beautiful care here. At the quarterly meeting, this is the only way I can thank them publicly and let them know that the level of services is unparalleled. My mother also died from this disease and my grandmother. The only thing I would like to request is the level of care here, the quality that deal with here on a daily basis are so wonderful that I pointed to, this is like a beautiful painting in a not so beautiful frame. And it's a little concerning (Inaudible). For any way for those that are here always, maybe they don't really have the opportunity to be discharged. It's their home, and if I could get them into (Inaudible) (Laughter) I will do that. My grandmother was at the IMH in Cranston, and this is back in the late. It was a very scary place. I was a child, and we would take her out at home for Sunday dinner, and going here, or bringing her back home, was almost traumatic. And this is no way near that. But it's a beautiful location. I would like some things to be done that would benefit not only the people that are here, obviously, but the people who work here to come into a place that's as beautiful and welcoming as they are. That is my one wish. And they also take people out. Sometimes there's a waiting list. They can't always go out when they want to because of transportation. So if the transportation buses without either be augmented, getting the additional ones so more people could have an opportunity to go out. It's nice to get away for a while and have that little reset, art, baseball, whatever it is, allowed to take them to a beach. They have my thanks. Thank you.

FEMALE SPEAKER: I just want to add to that, when it became apparent when you and I were talking on the phone, I'm Kathy that you talk to all the time that her sister was not going to survive if she remained in the home she was. And it's not that the home was dirty or it was horrible, but the home wasn't here. And they were not sensitive to her needs. And loading up people with psychotropic medications, so I begged them on my hands and knees to take this patient, because I knew if she didn't get here she wasn't going to survive. That's how bad it was. And to see her here today and put a name to the face, that makes me very happy. Her sister is a wonderful advocate, too. She was a little nervous when I mentioned Zambarano to her, but once she was here I didn't hear, so I assumed everything was fine. This is the most wonderful place in the world. If you follow what the new director is saying, she does want to make aesthetic changes to both hospitals. Don't ever judge a book by its cover. Some people think they walk into some of these facilities and they see all these lovely curtains, I look at the care. You can walk into this hospital any time, and the patients are always clean. I put people in here that were absolutely at the bottom of the level of the care they could be at and come back six months later and could barely recognize them. I'm a very big fan of Zambarano. Who else now would like to pose a question? Nobody has a question. You would like to? Wait a minute, Kate, I think this question is for you. She hasn't gotten any ID cards.

FEMALE SPEAKER: So, I won't get into generally what your ID situation is, but if my answer doesn't help you, we can meet with you individually. The state gives out free ID cards for people. If you have the information you need to get one of those, one of the places that they give them away is at the Rally for Recovery in September that is held around Roger Williams Park in Providence. Not the park with the zoo, but the one down the hill from the State House. But if you contact the Secretary of State's office, they can tell you other ways to get that. If that is not sufficient, please call us up and we can talk about that.

FEMALE SPEAKER: Okay? All right. You're welcome. I saw a lady back here that wanted to ask a question.

FEMALE SPEAKER: It's more that I wanted to tell a story.

FEMALE SPEAKER: Oh, all right. She's going to tell a story.

Independent Living

FEMALE SPEAKER: I have a friend who's, years old. And four years ago he fell and broke his femur, and he has an intellectual developmental disability. Kate, do you remember this story? Anyway, he has a guardian. For four years until now he remains in that nursing home, more because the guardian finds it convenient to keep him there. I want to know if there's any recourse for his friends to be able to say, hey, you know, maybe you could try, whatever?

FEMALE SPEAKER: Let me ask you something, what would you like to do? You'd like to have (Inaudible) where would you like him to go?

FEMALE SPEAKER: (Inaudible) group home. He still isn't walking. I guess while he is in the nursing home he was recovering from the break and slipped and broke his leg again.

FEMALE SPEAKER: Take the Mike.

FEMALE SPEAKER: Sorry.

FEMALE SPEAKER: So he fell and broke his leg again. And that was probably four years ago. So he just remains there. But friends of his have been there and visited and said, you know, is this really where you want to be? And he always says no. But the guardian says that that's where he's going to be.

FEMALE SPEAKER: Well, in my guardianship, the board has a right to participate in his care. So, I mean, guardianship is not the ultimate dictation. We're having this problem with a lot of guardians.

FEMALE SPEAKER: So, an individual can challenge a guardianship in a number of ways. They can challenge a guardianship with clinical evidence that they can make their own decisions. They can challenge a guardianship with evidence that they can utilize alternatives to guardianship. And they could challenge it with a combination of those things. Even if the individual remains under guardianship, we take the position that it's the guardian's job to effectuate the individual's wishes if possible. But the individual, themselves, has to be willing to want to make that challenge. So, for us to be of help. Other people might be able to figure out another way to do it, but we take direction from the client. And, you know, family/guardianship challenges, sometimes there are other people who want to make them more than the individual does just to keep the peace in the family, so.

FEMALE SPEAKER: Would this person be willing to call the Disability Law Center?

FEMALE SPEAKER: He's (Inaudible) by the guardian. So if I connect with that individual, and there are, he has a good number of friends who all kind of support him, and will be there to support him. He's all excited. But then he talks to his guardian about it, and one of us will get a call from the guardian basically saying, shut down.

FEMALE SPEAKER: You know something, what you can do is call my office. Write this number down.

FEMALE SPEAKER: I have your number. Advocates in Action.

FEMALE SPEAKER: I thought I knew you. Okay. Call my office and ask for myself or Donna. I can start a lot of trouble, can't I, Kate.

FEMALE SPEAKER: Sometimes for me.

FEMALE SPEAKER: Well, I mean, everything is not perfect. Who's the next one who wants to ask a question? There has to be something else. Come on, don't be shy. This is especially set up for you.

Independent Living

CINDY: Hi, good afternoon, my name is Cindy, (Inaudible) registered nurse and have pretty much been representing state employed nurses for about that long, as well. I have just a thought about (Inaudible). Just a couple of nurses that I represent (Inaudible) they work for nursing homes and hospital patients looking for (Inaudible) I'm not exactly sure how people get sort of brought to the forefront, if it's through the agency, itself, or if it has to be a family, or if the client (Inaudible).

FEMALE SPEAKER: Now, are you referring to somebody who is a patient here, or a patient at a nursing home?

CINDY: No, I was referring to this lady's.

FEMALE SPEAKER: She knows enough to call my office. Usually it comes into my office if it's a long-term care facility, or it's Eleanor Slater and it's in this hospital and you don't feel that the people are listening and the person wants to be discharged. Then I'll come up, review the chart, sit down with the families.

FEMALE SPEAKER: (Inaudible).

CINDY: Okay.

FEMALE SPEAKER: (Inaudible).

CINDY: Oh, okay.

Independent Living

FEMALE SPEAKER: I thank you all for coming. I appreciate the opportunity to ask this question, too. Some years ago we had to make a decision for my mom to be placed in a long-term care facility, of course we chose here. And for obvious reasons. I can tell you that even for somebody who worked here (Inaudible) it is an incredibly cumbersome system, this long-term care system of ours. There's not one place where some people can really get an answer. There's not one place where there's a point where you can enter into it. In fact, several times I got wrong information about the application process to this hospital from our own, at that time, which was MHRH. So I'm wondering, it seems like there's multiple avenues, still. And for someone who is trying to access the system, I think usually it's when they're at their most stressed out time. It's a very difficult time. Oftentimes we're not thinking clearly. What we need is, I think, a route that is easy to navigate, that the steps are clear to follow. And even now I, well, not that I don't think that's the case, I know it's not the case because (Inaudible). So I would just, you don't need to respond. I just offer that as a suggestion.

FEMALE SPEAKER: Last night I took one of those monkey surveys. I can never get over that word. And it was supplied by health care (Inaudible), that's actually an agency for the State of Rhode Island. It's always looking to improve. The main thing they were asking is to set up a (Inaudible). One of the things, when I answered all the questions, I felt that you need a person to talk to. That's the first thing. You can have all these, you know, I have to laugh when they talk about patients, you know, using the internet and families. Do you know how many people that are in their is and that know how to use a computer? Not that many. You need to be able to talk to somebody on a basis. They are working on that one right door. So, that is in the works. They were supposed to be working on it before. I don't know what happened to it. But I do definitely believe a lot of times things could be a lot better if you had a person to talk to, instead of going on a website, which most people can't understand. To my knowledge, you can't ask the website a question, so. Anybody else? Come on. Everybody is just happy, nobody has any questions.

FEMALE SPEAKER: There's no air-conditioning in here.

FEMALE SPEAKER: We need air-conditioning in here.

FEMALE SPEAKER: Not just here, I'm guessing the whole place.

FEMALE SPEAKER: Kate wants air-conditioning for the whole place. We'll make that a direct request to the director.

FEMALE SPEAKER: The basement is on the second phase of air-conditioning, but the actual air-conditioning on all the rooms above this, every room has its own air-conditioning. Not a wall unit (Applause).

FEMALE SPEAKER: I'm hot.

FEMALE SPEAKER: Excuse us, Lady Jane, she's hot. I always tell this to my husband, everybody's cool but you. Would any of the panel like to get up and do any discussion? It's a little hard to be the MC here with no questions. Does anybody want to dance? (Laughter) hold on.

FEMALE SPEAKER: If you don't have questions, does anybody have any issues that are of concern to them that they would like the Governor's Commission, or any of the other panelists, to be focusing on?

FEMALE SPEAKER: Come on. Don't be shy.

Transportation

FEMALE SPEAKER: I showed up really late because I was trying to get out of work to get here. I don't know what's been covered so far. I'm a half hour late. I live in this town. I work in Providence. And I just know that transportation is a real issue in this area. So I don't know if people discussed that.

FEMALE SPEAKER: Nope.

FEMALE SPEAKER: Because I can't imagine, I work with people looking to get jobs, and I can't imagine trying to do that in this town. Because there's way, if you don't have a car, you can't get around. I'm just wondering if anybody has spoken to that.

FEMALE SPEAKER: I can tell you in the last year and a half the State of Rhode Island has went through some major changes with transportation. They now have an outside vendor that's doing a lot of the transportation. The people that would handle this transportation would be RIPTA. Now, I don't know if anybody here is writing that dough down and would like to attack RIPTA.

FEMALE SPEAKER: (Inaudible) it is limited. And usually for somebody with a disability you can arrange for a RIde bus to actually pick them up and take them. Zambarano is a stop town for the RIPTA service. There's a spot near the IGA that is a stop. And Harrisville, Mapleville, there is a route all the way around. Then they have the flex bus that runs between. So, I don't know if that helps at all. But our social workers here do coordinate with RIPTA and the RIde program to get our patients, you know, rides into the community that they may need, and about the state. I don't know if that's something you can look into.

FEMALE SPEAKER: Does that help you?

FEMALE SPEAKER: Yes and no. The people I work with have certain physical disabilities, so they don't need RIde.

FEMALE SPEAKER: All right. Anybody else?

Independent Living

FEMALE SPEAKER: My name is Karen Tamodio, and I'm from the Glocester. I also work in long-term care. I came today because I have a brother, he’s. And he lives in a home. And -- I don't want to get emotional here. I work full time at a nursing home, and I am having problem now for quite some type, he goes to Seven Hills, is finding someone to help care for him at the house when I go to work in the morning. And I tried all kinds of agencies, Seven Hills, tried to get somebody from the community to be able to be a caretaker so I can go to work in the morning, and I still have not been able to get that help. And as he's aging, his dementia is causing an issue. I was wondering if there was another avenue I can go to for some kind of help. I was paying finally out of my pocket. It's kind of draining me financially. I was wondering if there was some other agency available?

FEMALE SPEAKER: Who wants to take that?

FEMALE SPEAKER: Hi, does your brother have, your brother should have, in addition to day support hours, he should have community support hours?

FEMALE SPEAKER: We haven't been able to find anybody in this rural area.

FEMALE SPEAKER: So it's finding a person to fill that. Okay. You can look into it and see what you can do to help, but, you know, there are a lot of vendors who are having some staffing shortages. So, hopefully, that will be corrected soon. We are working on that. And hopefully there will be more people available for the hours.

FEMALE SPEAKER: Have you heard of the Personal Choice program?

FEMALE SPEAKER: No.

FEMALE SPEAKER: Who would like to explain that? I'm no expert on this.

FEMALE SPEAKER: (Inaudible).

FEMALE SPEAKER: That's when you can hire somebody.

FEMALE SPEAKER: She can.

FEMALE SPEAKER: You can. Great.

FEMALE SPEAKER: So, (Inaudible).

FEMALE SPEAKER: They do send me statements about what they're spending on him, but I don't know that, they told me that I would have ten hours, but I don't have any help. I've been waiting a couple of years. And he has Down Syndrome. I don't have any family to help me with that.

FEMALE SPEAKER: (Inaudible).

FEMALE SPEAKER: I'll give you my card before I leave today, and you e-mail me. You use e-mail, right? And I'll send you a list of people that can help you out, especially at DHS with a personal choice worker. Unless anybody can do something else here. What?

FEMALE SPEAKER: Yeah, there's an option through Division of Developmental Disabilities. You have a choice of working through an agency, which is Seven Hills, which you're doing. Or you can do Personal Choice, which means you can choose to develop your own program and your own -- and hire your own staff.

FEMALE SPEAKER: You have options, right? Mix it up with Personal Choice, which is different.

FEMALE SPEAKER: (Inaudible). I'm not the disability expert.

FEMALE SPEAKER: Right. So you could speak with your brother's social worker and ask about what your options would be about maybe doing a day program, and then taking the community support hours and seeing if you can do something with that.

FEMALE SPEAKER: Yeah, it's just finding people.

FEMALE SPEAKER: Yeah, finding people, there's a big problem.

FEMALE SPEAKER: I mean, it takes a long time. It's been years.

FEMALE SPEAKER: (Inaudible).

FEMALE SPEAKER: I got a card.

FEMALE SPEAKER: She's going to give you a card so you can call her. Remember, I'm long-term care, I'm not disability. So I got it all mixed up. Kate was good enough to tell me that.

FEMALE SPEAKER: Kathy didn't really get it mixed up, it's just that there are different names for different things. And when you are a client of the Division of Developmental Disabilities, you can go to an agency, or you can do, like Deanne and Karen described, there is a different waiver, which there isn't supposed to be anymore, there is a different waiver called Personal Choice. And that is a waiver that was started by the independent living movement years ago. These people waved the right to have / care and decided to have less than / care and hire their own staff. It's a different waiver. (Inaudible) client of the Division of Developmental Disabilities probably doesn't need to go in that direction, but maybe does, so you can explore it. But options like Deanne described and like Karen explained would be a way to choose your own staff and stay as a client for developmental disabilities.

FEMALE SPEAKER: Remember, if you're a certified nursing assistant, are you a certified nursing assistant or a nurse?

FEMALE SPEAKER: (Inaudible).

FEMALE SPEAKER: How many times have I spoke to you on the phone? (Laughter). What you can do, Karen, is this: You can also take my card when you leave and you can contact her. So we'll do something to be able to help, because that's a tough situation. It's nice to put a face to the name.

FEMALE SPEAKER: This is just a little suggestion, because it sounded to me like you're saying you can't find a person, not like -- so somebody in the same circles, care.com is one place that has people that posts positions, I'm looking for this person to do something with my brother, or there's people that post what their jobs are. I posted things on Craigslist. Maybe outside of the regular circle. I think we all go to ABC, but maybe if we think outside the box.

FEMALE SPEAKER: You're the director of nurses, you have certified nursing assistants that are (Inaudible).

FEMALE SPEAKER: (Inaudible).

FEMALE SPEAKER: Everybody? But, I mean, sometimes, like she said, things will come up and you'll be able to think of something. There's a lot of people that are advertising in Providence that are looking for jobs. Get a copy of the Providence (Inaudible). Who else?

FEMALE SPEAKER: This is crazy, because the other night I was watering the flowers in my yard. And there was a gentleman down the street who had a stroke. He has a personal care attendant. She parked near my house and got out the car and started conversation with me, left me her card, and said if you ever need child care or elder care, I'm an extra set of hands. And I found it a little strange, telling you the truth, and I snapped a picture of her business card just to have it, because I said, gee, you're never going to know when you're going to need this. After this I'll give you her number, and she's right in Burrillville. I don't know if that will help you or not. This is very odd.

FEMALE SPEAKER: Anybody else on the panel that would like to do something to address? No more? Come on, somebody has another question. Somebody has a problem we can help you with. Somebody has a challenge that you need help with. The voted ID card, she answered that question, right?

FEMALE SPEAKER: If I haven't, you can call us.

FEMALE SPEAKER: You can call the Disability Law Center. You have that, I think, with one of the handouts she gave you. Okay? Give me one just in case. Have your social worker work -- who's your social worker? Shannon, Shannon will help you with that. Okay. But you got Kate's number there. You can call and ask for Kate. Kate will remember. Nobody else?

FEMALE SPEAKER: Does the disability (Inaudible), do they have a plan, maybe someone could tell us what the plan is (Inaudible) what is the plan for the Commission about disability changes (Inaudible)?

FEMALE SPEAKER: She wants to know if there's any plans for the upcoming year on changes that you're working on.

FEMALE SPEAKER: The Commission takes the information from the public forums and (Inaudible) based on the issues that have come out of the forums. Every year we try to highlight those with legislators. We monitor legislation, (Inaudible) right now the things that we're looking at are housing, transportation, access to health care, and employment. Particularly, (Inaudible) persons with disabilities because Rhode Island is lacking in our ability to get jobs for people with disabilities. Percent, folks with disabilities in Rhode Island (Inaudible). That's pretty much the plan. Public access for buildings, state buildings, public buildings, have good access for people and (Inaudible), all of those things. (Inaudible) issues with people from all walks of life (Inaudible). We're really looking for direction from the public. (Inaudible) we encourage as much participation as possible. We try to do a lot of advocacy, training of legislators. There's a lot of new legislators this year. There's a lot of new people. We have a lot of people in the state capital. (Inaudible).

FEMALE SPEAKER: Okay. We're going to end the formal part of this session, but we will wait around in case anybody wants to come up to us personally and ask the question if you're too shy. And we'll try to accommodate whatever your need is. I thank you for coming up today. I thank you for your participation. I hope this helped. I hope we can get some answers for you. Thank you, very much.

## 30 July, 2015 Woonsocket Public Forum

CARMEN BOUCHER: Good afternoon, thank you for coming to this public forum, my name is Carmen Boucher, I work at the Rhode Island Department of Health.

FEMALE SPEAKER: Can't hear you.

DORIAN HAVERS: Doesn't appear to be on.

CARMEN BOUCHER: Good afternoon, my name is Carmen Boucher, I work for the Rhode Island Department of Health, I want to welcome you here today and thank you for coming. The purpose of the public forum is to identify the concerns of people with disabilities and their families in order to assist the state develop programs to improve the quality of life of people with disabilities. To ensure everyone who wants to speak gets a chance, please keep your comments short, and to the point. If you have critical problems that need to be addressed, the panel members will be available at the end of the hearing to direct you to the proper agency to help you. After each public forums are completed in early August, the sponsor agencies will review the testimonies and prepare recommendations which will also be posted on the web site by the end of November. Their recommendations and the transcript will be printed and sent to state agencies and congressional officials and to the members of the General Assembly. The recommendations will be used to develop policy, legislation, initiatives for the next year or until they are accomplished. The Rhode Island Disability Law Center panelist will be available to register anyone who is a citizen and is not currently registered to vote. He will do that at the end of the testimonies. I would like the panel to please state your name and address the agency you work for.

FEMALE AUDIENCE SPEAKER: Can you pass the microphone around?

CARMEN BOUCHER:

MATTHEW BLAIR: My name is Matthew Blair and I'm an attorney at the Rhode Island Disability Law Center.

MARGARET KNOWLTON: Head of school at Meeting Street, which is a nonprofit agency in Providence that works with children and young adults from six weeks to age 21 with and without disabilities.

MELISSA CHARPENTIER: Hi, I work for Seven Hills Rhode Island. Seven Hills is an organization that supports, from birth to the elderly, programs, people with intellectual disabilities.

MALE AUDIENCE SPEAKER: Couldn't hear.

DORIAN HAVERS: Hi, I work for the Office of Rehabilitation Services and our agency services individuals with a disability of all ages to help them find successful employment.

CARMEN BOUCHER: I want to remind everyone that we have two exits, well, three in this building, and two emergency exits one located next to me, the other one in the back and the other one on the side and there is also a lady's room and a gentleman's rest room just outside the door. I would like to remind everyone to please sign the sign-in sheet. If you are going to speak or just attending, that will be fine but it would be great to keep a record of the people that participated. We also have assisted listening devices available for anyone who needs them. The person in the back will help you with that. So we ask each speaker to identify themselves and spell out their names and just say the city and the town that they live in. So we are going to start by having Stella.

STELLA LACASSE: Stella Lacasse, I only have questions, can I just ask my questions?

CHRISTINE: I think she needs to use the microphone.

STELLA LACASSE: Your handicapped parking, is there a time limit?

MALE AUDIENCE SPEAKER: City hall has two hours.

STELLA LACASSE:Is there a time limit when you park, some people can stay there for days, and if you need somebody that needs that parking spot, they can't, you know, somebody is there. Is there a time limit? And who can you call? You know what I'm saying?

Accessibility

CARMEN BOUCHER: Yes, I comprehend what you're saying, what we're doing, we also have -- in writing, we may not have the answers to your questions, and I apologize for that. We will try to brain storm between the panelists by the end of the testimony to see if we have any answers for them but I don't know.

CHRISTINE: Is your question that people are leaving their cars there for an extended.

STELLA LACASSE: Sometimes. I live where there is only one of them and it's being abused and people that need it, they have no place to park.

CARMEN BOUCHER: Are they disabled themselves, the people that are -- are people driving the vehicle disabled.

STELLA LACASSE: They come to visit, they can't find a parking spot, they'll park in a handicapped place and just leave, we don't know who it is.

CHRISTINE: Do they have a placard.

FEMALE AUDIENCE SPEAKER: Some of them don't.

CARMEN BOUCHER: That's different, I just want the microphone, if the person does not have a plaque in the car then definitely the police could be called.

STELLA LACASSE: Who do you call?

FEMALE AUDIENCE SPEAKER: She said the police.

STELLA LACASSE: The police? What if it's like a housing authority, you know...

MATTHEW BLAIR: Manager of the housing complex.

STELLA LACASSE: They don't do nothing, we call them they don't do a damn thing.

MATTHEW BLAIR: I'm not supposed to answer too many questions but I know each city has its own division that's in charge of parking for people with disabilities, so, first idea would be go to management because they are supposed to be in charge of it and if they're not doing anything you could go up to the city and try to get them to enforce it.

STELLA LACASSE: Go to the city?

MATTHEW BLAIR: I think so. But management first.

CHRISTINE: You can also file a complaint with the Governor's Commission on Disabilities.

STELLA LACASSE: I don't have any information on numbers or anything like that to call.

CHRISTINE: We can make that available to you.

STELLA LACASSE: Okay, I appreciate that. And is there a minimum, a handicapped -- that you need or.

CHRISTINE: There are guidelines for the number of handicapped spaces required depending on the total number of spaces in a given lot so there are guidelines available.

STELLA LACASSE: Okay. And how close to the building does a handicapped -- some of them are so far away, you have to walk a mile for crying out loud.

CHRISTINE: Well the spaces that should be the closest, as close as possible. But in some cases, because of perhaps a tree or whatever, it's not going to be as close as you might like. So it has to be looked at and checked out.

STELLA LACASSE: But it should be as close to the entrance.

CHRISTINE: Yes.

STELLA LACASSE: But it isn't. So, you can't do nothing about it.

CHRISTINE: You should file a complaint and have it looked at, investigated.

STELLA LACASSE: Now would a handicapped placard if you're any place and they're all taken, can you park any place, even if there is a meter you have to feed, and not feed the meter.

CHRISTINE: In the state of Rhode Island you are not required to feed a meter if you have a handicapped placard that is hung.

STELLA LACASSE: That is what?

CHRISTINE: That is hung up appropriately.

STELLA LACASSE: Okay, good, thank you.

MALE AUDIENCE SPEAKER: So you don't have -- she's got a handicapped plate and because of, we take her everywhere, so you're saying all the disability places are full, the parking -- like, you pay for.

CHRISTINE: The, it's a metered space and you have a placard, you don't need the meter.

CARMEN BOUCHER: Can you identify yourself, sir?

CHRISTINE: Your name?

MALE AUDIENCE SPEAKER: Arthur --

STELLA LACASSE: So there is no time limit to park in a handicapped place, you can park two or three days in a row, 3 days? That shouldn't be. Okay. Thank you.

CARMEN BOUCHER: Charles.

Accessibility

CHARLES LEMOINE: If you want to read about it. Charles Lemoine (CL), I live at 174 St. -- Street. Charles Lemoine, 174 St. Barnaby (sounds like) Street, Woonsocket Rhode Island. I have a few things about, in Woonsocket we have an ADA but he thinks, he's not for us as much as he is for his personnel manager, he hires people in the City of Woonsocket. He thinks he's going to do that more than he's got to do ADA because he doesn't get a stipend for the ADA part of it. It's not my fault they gave him the job, so, I have to deal with him and a lot of times, I have a letter over here, I don't want to read it, but it says he has to answer me as the ADA person, saying, he's going out of his way to answer me. In which, I'm still waiting for the answer because on that letter it doesn't say what's going to happen. The other thing is, when our parking, they don't have signs in the parking lots, and I brought it up to the city, it's like talking to me (sounds like), because. What they do is they call the government on disability and do there, they say, well, we can't do anything because they're already in business so they already got a license. So, my question is, who do which go to before they get their license? They should be following the ADA laws because it's 25 years, a City of Woonsocket, I have been fighting them for three years to get things like this so I can hear the meetings, the city of Woonsocket goes in and out, this one doesn't, so I recently asked them for something like that and I don't know if they're going to give it to me on August 3rd, but if they don't I'm going to have to file something, I don't know, the government on disability, where I file (sounds like). And there is a place called, on South Main Street, well, their handicapped sign is in, the driveway is here, the ramp goes like this, for you to park, but the sign is here. And you can't, you know, it doesn't show any, you know, for us to park there. So, that's one thing, I brought that up. I brought up, over here, at the Family Dollar, if I want to bring her in there, I can't get her out on the sidewalk to go into the store because there is a lip on the thing. I tried to get them to fix it but there again, because they've been in business, they -- I guess go after the owner of the parking lot because two different people own the parking lot, I had found out. And they are just not doing anything, the City of Woonsocket says we can't do anything because they're already in business. My question, again, is, who do you go to before, who is responsible to make sure they have handicapped stuff for us people that are handicapped? I'm not only hard of hearing, I have back problems, I am disabled from the State of Massachusetts, it's more than just my hearing. So, and, I know, it says you could have eight feet wide for a regular car and a van is supposed to be eleven feet wide. Some of them are not. I imagine some of them are not. But, that's not so bad is they have one side is handicapped, they have like a cross, a walkway, then it goes to a place where it's a curb in the same crosswalk and that's Haritan (sounds like) plaza on front street. One of the -- I was applying to, state of Rhode Island, meaning hand capped disability people and I have complained to two cities so it's not something I am trying to hide. Some of the people from the state of Rhode Island talk to me, I just say my name and they know who I am because I call a lot because there are a lot of different things I find that isn't right and I believe they should fix it. Like all the lights in Woonsocket, near the police station, they won't fix that one, for people to cross the streets and they finally fixed the others but I had to fight for months to get that done. I guess that's it for today because I am not thinking of anything right now. After I'm done talking I will think of something. But, it is what it is. Thank you very much for listening to me. Oh, I did have one question for you, you said you were with Seven Hills and you said you were for young people and older people, what do you do for the older people?

MELISSA CHARPENTIER: We do have an adult aide health program and we do the right (sounds like) home program, shared living for elders and people with disabilities to stay with their families.

Independent Living

CHARLES LEMOINE: I have my wife home with me because I would rather have her home than a nursing home and stuff. I am lucky, I do get help in the morning and in the afternoon, and I have an aide that comes in to help her get ready. But today she had to help her get ready to come with me. Thank you very much for your time.

CARMEN BOUCHER: Just to remind anyone that comes in, if they could please sign in, that would be very helpful. Sheila.

Independent Living

SHEILA TURNER: My name is Sheila Turner (ST). I read an article in the paper where Raimondo, they're planning on speaking about incarceration for people with mental illness. I have a son who has mental illness. Cognitive disorders, learning disability, et cetera, et cetera. My problem is, he is a compulsive shoplifter. He has been diagnosed with all these different issues since he was about eleven and a half/15 years old. My problem is, I've been going back and forth to court, frequently, since he was 11 and a half years old. The issue that I'm having now is that by him continuing doing these different actions of shoplifting, he has a disease; it's a mental illness that keeps having him to go back and forth, back and forth into the system. The question I want to know, he is not a murder, he is not abusive. Why can't they just put him someplace that he can get the help that he needs to help with his sickness? The prison is not helping him. The prison is just making it worse. I had him out as of July 6th, for example, he was back in the ACI on July 11. I had to go find my son to transport him to Butler Hospital myself. I wanted help. By him being over the age of 18, he is liable to sign himself in or out, he doesn't have to stay if he doesn't want to. If they're mentally ill and sick. How does he know that he's sick? He don't know. So, if harm comes to my son, and I hate to say it, but it might be, I don't want the police officers come knocking on my door, telling me, it was all my son (sounds like), I don't want him to harm no one else, which he has not been combative but who's to say he won't become combative then I'll hear the news reports come to my house saying, did you know this, did you know that? No. I'm crying out for help, I had a judge who tried to help me in Massachusetts, he felt so bad because Rhode Island does not have the money or the facility to place older people to get the help they need. And I'm wondering, what can I do? Now I know, excuse me, sir, you're a lawyer. I know that, for me, to get whole, what's that word you say, guardianship for him, he would have to sign the papers. Each and every time he gets out of jail, I try to keep him long enough, I know him like a book, to get the papers signed. I can't do it. He keeps being admitted. How can I get the papers signed so I can have full control of him because I adopted him when, one years old (sounds like), ex-husband -- I had him since after birth, had him since age of 3, he has no facial expression, wouldn't speak on his own, I need help to get him signed documentation to give me full authority to take care of him, medically, and financially. Financially, now, SSI, they know that I control his money, whatever. But every time he goes to jail, the money stops. But I just need him to sign papers giving me full rights to his situation.

DORIAN HAVERS: How old is your son, Ma'am?

SHEILA TURNER: As of now he's 22 years old. He's been through the system since he was 11 and a half years old, I had him in the Women and Infants Hospital when he was first born through the program they have for people when they have narcotics and drugs he went to that program to the age of 18. Then at 11 and a half years old he stopped going to the group homes. At the group home. Then I had him into a living facility as of last year, he couldn't stay there, he was not there a year before they had to discontinue his living status there. Now, I have lost my job, and last August, I am now living with my father who has dementia and I'm dealing with two people. I would like to have my son someplace safe that I don't have to worry, I don't have to have sleepless nights worrying about him. He has been in prison off and on at the age of, I mean, since he's been an adult, 18 years old/19 years old. As of last November he was locked down in the seg, segregation, but November or December, until July 6th. I couldn't even go see my son. I kept calling the prisons and so far the guards they know me, the people in the prison, I call out to them all the time, burn their ear off, I want to know how my son is doing because I know he has mental illness, he needs the medication and he won't take it. Now he's back in jail again. Now he's locked down in seg again, I still can't see him. So I don't want no harm to come to him, I just want him safe and I know a lot of the homes in the state of Rhode Island are not state homes, they are nonprofit homes. He needs a facility that is going to be locked down that he can have one-on-one communication with somebody and if he let go, I may find my son dead.

CARMEN BOUCHER: Julia --

Transportation

JULIA LAMIERE: Julia Lamiere (sounds like), here on behalf of my sister, Antoinette Dufrane (sounds like), and she’s been blinds for almost 7 years. And she now she's been on dialysis for almost a year and a half, I remember years ago because she is now on Medicaid, years and years ago they had the bus for dialysis go up towards McArthies and Walnut Hill Plaza and now they stop at that tool prays, Price Rite, she is legally blinds, she cannot see nothing in front of her face at all, why can't we get the buses to go back up to at least the dialysis place so she won't have to pay $4 back and forth. She can get off the bus and stuff but in the meantime she's paying, she has the bus pass to go in the city but to go to dialysis she has to be put right there to get off the bus, to go there. Otherwise she, that's almost $96 to $100 something dollars a month taken out of her disability checks that she had to pay out of her own money. We have tried everything to get Medicaid, I've tried, and I don’t know what I’m doing wrong. Seems like I'm missing $40/50 but I'm trying to do everything honestly to get her on that but I can't. But that's one of my problems. Another problem is every time and I have gone walking with her in the wintertime, making her know the streets, being on dialysis, when you're really sick like that, the doctor will tell you, walk. Do a lot of walking, help yourself into the sun, get the vitamin D because you need it. She has had a lot of operations so she does do a lot of walking but in the meantime, she goes on the sidewalks, and like that party place on Front Street, she lives on Bernon Street, 148 Bernon Street, so she walks around the park and they put their stuff, the advertisements in the middle of the sidewalk, a blinds person can't see that. One day she took a balloon home with her. It wasn't funny but people were kind of laughing at us, bad enough she's blinds that people need to have things in the middle of the sidewalk so she can walk. So the balloon got stuck on her cane and all that, oh, take the balloon anyway. I mean, insulting over insulting. So that's another thing. I wish you would try and communicate with these young kids, even the adults, what a white and red cane is. She will be walking across the street and she makes sure no one is coming because she leaned by the Carol (sounds like) Center in Mass, we sent her there for six months to learn how to cope because she does have letter own condo, she cooks and everything else but walks by herself so she will be halfway crossing the street and a car comes flying by not knowing what a red and white cane is, one of these days she will get hit but you know what she says? That's life. She goes in the crosswalk, too. That's another thing. But, there's a couple things. I'm new at this but these are some of the things I have been coming up with, going with her and seeing these things. But I'd like to have those issues straightened out to help her out, would probably make life easier for her but that bus thing would really help, to be at dialysis because she goes there 3 days a week and it take a lot of toll on her money.

Accessibility

CARMEN BOUCHER: Anyone else who would like to speak? Approximate.

CHRISTINE: We have --

MARK THERRIEN: The bus doesn't go to Walnut Plaza anymore because there is not enough business. It's not about access, there aren't just people that want to go there, there isn't much there anymore.

FEMALE AUDIENCE SPEAKER: A lot of people go to price rite. Price rite is right here. Dialysis is like two houses from there. Just two houses.

MARK THERRIEN: But very few people take the bus to dialysis, usually they take nonemergency medical transportation, the vans or.

FEMALE AUDIENCE SPEAKER: Vans cost $4 each way.

MARK THERRIEN: That's RIde. From transit perspective, it's about market and not enough people take the bus there, that's why we don't go there.

FEMALE AUDIENCE SPEAKER: She's willing to take the bus there as long as she's dropped off there, she'll wait for the next bus.

MARK THERRIEN: I understand but that's why the bus doesn't go there, there isn't enough business in Walnut Hill Plaza.

FEMALE AUDIENCE SPEAKER: That's too bad. Thank you.

FEMALE AUDIENCE SPEAKER: I'm not sure if I'm in the right place here.

CARMEN BOUCHER: Excuse me, Ma'am, if could you please state your name and city.

JOANNE CORMIER: I'll stand up, I want to be sure I'm in the right place, Joanne Cormier (JC), Woonsocket Rhode Island. On (inaudible), I'm not sure if I'm in the right place but I'm willing to try and find out where I should be. I have a granddaughter with Autism and my daughter who has custody of her. I am the grandmother and I was trying to see a place for her to go, a school for her to go instead of going to Globe (sounds like) Park which I don't feel is getting what she needs and she refuses to listen or do anything and I was just wondering if there is a way that I can do it myself or, I don't have custody or anything. I just want to help her to learn because she is a lovely little girl. She's fun, and it breaks my heart. If you can help me I'd appreciate it. Thank you.

MARGARET KNOWLTON: Can I respond a little bit to that. So in regards to the custody issue and who has the rights. I know from a school that takes students in from schools like Globe Park or other public schools across the state, the parent has to make that decision with the School Department, so the School Department has to agree.

JOANNE CORMIER: But she hasn't reached out at all. She doesn't reach out.

MARGARET KNOWLTON: Right, so I think that's a whole separate issue on how you advocate for your granddaughter but I know because your daughter is legal guardian she would need to do that from the School Department perspective so you're in a tricky situation there.

DORIAN HAVERS: I'd like to add something, too. Obviously since you don't have custody, again, there is not anything that you can do directly. But, just to let you know, perhaps your daughter might be struggling just because she is not sure how to advocate for her daughter. There is an agency for the state called Rhode Island Parent Information Network. They help parents in the state, everything from learning your rights within the education system to learning skills on maybe how to advocate and how to get the information that you need. Maybe if she had a little more information she would feel more comfortable even knowing how to navigate the process so that might be something that you can kind of work together to do. Maybe if she had you helping her through the process and using the right resources you would be able to get it done.

JOANNE CORMIER: Thank you. She does have someone from Seven Hills coming in to help, 20 years old, unexperienced, just to help a little bit with her but doesn't seem to be really doing anything.

DORIAN HAVERS: How old is your granddaughter.

JOANNE CORMIER: She has a birthday in August and she will be 7. My daughter is lazy, that's her problem.

SHEILA TURNER: It's sad that the child has to pay the price of a mother's ignorance to help their child because that child cannot speak for itself. So it's you trying to keep, you know, get into your daughter's head is about your daughter, not hers.

JOANNE CORMIER: My daughter is mad at me right now, she won't even let me see the kids. I need help.

CARMEN BOUCHER: Anyone else like to speak.

CHARLES LEMOINE: Can I speak for a second time?

CHRISTINE: So if you're interested in contacting RIPIN, they can be reached at 270-.

FEMALE AUDIENCE SPEAKER: Wait a minute.

CHRISTINE: I see a pad. 270-0101. And we have cards in the back, Carmen will bring to you and you can contact them also.

CHARLES LEMOINE: We go, people go to the Family Dollar Store.

CARMEN BOUCHER: Can you please identify yourself.

Accessibility

CHARLES LEMOINE: Sorry, Charles Lemoine, 174 St. Barnaby street in Woonsocket, people go to family dollar store on Clinton street and if you're in a chair or, (inaudible) mentioned to me earlier she goes in there and there is stuff all over the floor. Two weeks ago I called, I went to the fire department and asked for a marshal to go to the Family Dollar store, there was nothing on there, I went to the manager, he knows who I am because I complained when there is stuff on the floor. I said I have never seen your store so clean. I went in there about an hour ago and everything was on the floor. There's boxes, there's stuff in the aisles, on the push cart. So you can't get around. She goes in there, she ain't going to go around. I can't bring letter in any ways because they don't have the opening to get her on the sidewalk. But I'm just mentioning that because me and the woman over there were talking earlier and she did mention, I mentioned Family Dollar and she said, yeah, we go in there and there is stuff all over the floor. So, just trying to bring it up again because I want somebody to try and fix it for us.

CARMEN BOUCHER: We're going to be take ago ten-minute break just to give the interpreters some time to rest. We will resume again in ten minutes.

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CARMEN BOUCHER: We'd like to start again. If there's anyone else that would like to testify, or say anything, we really would like to thank everyone that has taken the time to come here today. We are heave until 6:00 so if you know of any friends or anyone that has any concern that would like to come and testify, they also have different methods, you can actually write up letters and send them, as well. In the back, we have a lot of different resources and actually, there is one that has, information about what the public forums, the comments of different individuals have actually made changes on the state so it's kind of nice, sometimes, to see where your concerns have been going and how they have made a difference. As you know, some things can go very quickly, others can take a little time but because of dedication of taking time to come here today and express your concerns that makes a difference. You are making a difference for yourselves and for the state of Rhode Island, for the individuals that are not able to be here today so we thank you for that. I just want today give opportunities to let you know that you can still come if you think of other concerns you have, to say them. And if not, like I said we will be here until 6:00. Thank you.

FEMALE AUDIENCE SPEAKER: (SL) Thank you for making this available to us. Thank you.

## 31 July, 2015 East Providence Public Forum

GRACE PIRES: Can I have everybody's attention? So it's time to start the forum. Welcome, everyone, thank you for coming out today, a beautiful day. Some of you may have wanted to go to the beach. My name is Grace Pires, I'm facilitating this forum today, president of the National Federation of the Blind of Rhode Island. So welcome so, first thing I will let you know, if you need to use the rest rooms, if you leave this room, back of the room is the door and take a left, they are the next two-doors, ladies and men's room. Purpose of the forum to identify the concerns of people with disabilities and their families in order to assist the state to develop legislative policies to improve the quality of life for people with disabilities in Rhode Island. We'll be taking testimony and once the sponsoring agencies will be listening to the testimony in the beginning of August and preparing recommendations. And once the testimony is reviewed, the transcript will be available on the web site by the end of November, and the recommendations and transcripts will be sent to congressional and state officials as well as the General Assembly in order to help them to develop the policies for the next year or until the initiatives are accomplished. I'm going to, ask those of you who wish to speak, please keep your comments short and to the point so we have enough time to speak from anyone that wishes to speak. If there are critical issues brought up, please wait until the end and meet with one of the panelists that will be here until the end and they can help you direct you to the appropriate agency that you need assistance from. I would ask that anyone who hasn't signed in, please go to the back of the room and sign in, the attendance sheet, take any literature you wish and if you wish to speak please indicate so so we know who wishes to speak. Now I'll ask the panelists to introduce themselves and their affiliation and then we can begin.

CARMEN BOUCHER: From the Rhode Island Department of Health.

JODI MERRYMAN: Casework supervisor at the Division of Developmental Disabilities at BHDDH.

FEMALE SPEAKER: Meeting Street.

JOHN VALENTINE: Office of Rehab Services.

JACK RINGLAND: From the Rhode Island Statewide Independent Living Council and I want to say, happy birthday, ADA. (APPLAUSE)

JACK RINGLAND: 25 years. Got somebody down that end.

CATHERINE SANSONETTI: One of the staff attorneys at the Rhode Island Disability Law Center.

GRACE PIRES: If anyone wishes to register to vote or change addresses for voting, Catherine can assist with that.

CATHERINE SANSONETTI: We brought some literature and there is a pamphlet about voting rights and we can help you so that is correct.

GRACE PIRES: All right. So, I'd like to ask Cheryl Morrisen to come up and speak. Please spell your first and last name for the CART and what city you are from.

FEMALE SPEAKER: Okay, I don't know if you want me to --

CHRISTINE: Wherever you're comfortable.

Independent Living

Accessibility

CHERYL MORRISON-BREWTON: I'll stand right here, I'll be brief, my name is Cheryl Morrison-Brewton, I come from a family with several disabilities, my mom passed away two years ago, she had mental illness most of her life and I have four grown children, 3 with disabilities, they are all grown between ages of 29 and 34. My oldest daughter was diagnosed with multiple sclerosis four years ago, raised my children in Chicago, I am from Rhode Island but moved her up here because her husband would not care for her, anyway, I currently live with my son, 29 years old who has schizophrenia, I have another daughter with schizophrenia effective also lives on the tenth floor, Rumford Towers and my concerns is I currently am job seeking but most of, for several years I was a respite care provider until the past February because my son is going through transition of not taking medication so there's been a toll, I'll just say that but prayer does help. My concern is, I heard about this yesterday through a friend. When my mom passed away, prior to her passing, for several years, I was her care, you know, I helped care for her. Indirectly as far as she was in a nursing home and I was her voice, her advocate, but, what disturbed my spirit when I received some of her, because I always received her billings and I wanted to question some charges, well, I wasn't allowed to because I didn't have the authority in that way. Each though I was the one for years, you know, it wasn't a question of when it was billing or when would sign her in and out of nursing homes, I advocated on her behalf. But when she passed away, that was my concern, I, oh no, I didn't have access, so I couldn't question any billing. I feel that that's not right, personally. So that was one of my concerns. My other concern, I try to advocate on behalf of others where I live as you know Rumford Towers elderly and disabled, people there, the crosswalk at 1 Pawtucket Avenue and 152, I know of a lady that did get hit a few years ago and several came to near misses including myself. I brought it to, you know, called in with IDOT (sounds like) about it, bottom line, nothing has been done. I feel it should be readdressed. I have personally stopped traffic to help other people cross the street. But my concern is it shouldn't have to come to somebody's passing or injury or, come to, become be disabled for that to be addressed. A perfect example of a, the down in Wakefield at Main and, I'm not sure what the other crossing area is down by the CVS because my oldest daughter with MS lives down there, but they have an awesome, good safety traffic light there, it's, you can hear it so if you can't, fur' blind, you can hear it, and it gives you, all traffic stops, and that was a result, my understanding of, of somebody that actually got hit, was in a wheelchair so then somebody finally got that into place, to help the people there. Also designated areas in Wakefield, they have flags, they have like a flag that you can use to cross and that is so, I mean, it is so, so helpful to drivers, even that could be an implement. So that's what I wanted to see, if those issues can be addressed. That's really why I came. Thank you.

GRACE PIRES: Thank you, we appreciate you coming.

JACK RINGLAND: I'd like to make a couple comments about that. One is, have you ever attended an ATAP meeting? Accessible Transportation Advisory Committee, they meet at RIPTA. I don't know, some of your questions could be helped there, but also, I believe there is somebody from the Department of Transportation or a transportation liaison that attends the meetings and maybe the issue of crosswalks, I just came back from Washington, D.C., and I swear they must have the longest crosswalk walking things. And you know how a lot of the crosswalks have the 10, 9, 8, 7, whatever, these were like, 60/65, they were a minute long. They were very long. Even just for like two or four-lane streets, not wide ones but I cross Pennsylvania Avenue and that thing must have been five minutes long. And around here, what do you see? Ten seconds? Fifteen seconds, maybe. They can reprogram those things. There is enough traffic to do it and I don't understand why. But the department of transportation might help. I know in Bristol, they have a crosswalk at a popular intersection that does not have any lights because Bristol is not big on traffic lights but that intersection, they have a barrel on each side and it has flags in it. You raise the flag and walk across. Just hope that somebody recognizes it. Sometimes people don't even see the little signs that are put up in the middle of the crosswalks. Because if you look at them they're all --

CHERYL MORRISON-BREWTON: I did call, did not get any response. On the other hand regarding, anyway, so I didn't get a response on that. Also, one more thing I did want to say, why is there not, I was told because of quote unquote money reasons why there is not respiratory therapists in nursing homes. It would be not only a help to my mother but many others. People are concerned, thank God for those who are, about the quality of life, why would you not want a respiratory care therapist in a nursing home. Those were my concerns, I appreciate your feedback.

FEMALE AUDIENCE SPEAKER: I just want to make a comment about the accessible transportation committee, I am the chair of it, and that meeting discusses RIPTA issues. We really don't discuss crosswalks there. And the Department of Transportation person has hasn't attended a meeting in years there. So I just want to make that clarification. You're more than welcome to come to an accessible transportation committee but we talk about RIPTA issues mostly.

CARMEN BOUCHER: Can I ask a question? First of all, thank you so much for coming and sharing your concerns and questions and your experience, it makes a big difference for us and for the individuals not able to come here. And you will make a difference because of bringing the concerns over, that could change Rhode Island, or will continue to work. I would like some specifications on your issue, are you concerned with a sidewalk and someplace in Pawtucket or can you please clarify that for me.

CHERYL: I will, in Rumford, right after Rumford Towers many people can tell you they almost got hit, a lady has gotten hit and she recovered, she was even wheel chair bound because, now, I walk pretty moderately. Before Providence who referred me over to, I called city hall who referred me over to, RIDOT, the Department of Transportation.

GRACE PIRES: I think they would be the ones to put in the, to make any changes.

CARMEN BOUCHER: Do you know the person at the Department of Transportation, the ADA transition coordinator, manager, his name is Mark Therrien.

FEMALE AUDIENCE SPEAKER: Can people speak up? We can't hear.

CARMEN BOUCHER: There is a gentleman, if you give me your address, I can try and put you in touch with him, his name is Mark and he is in touch with the ADA, the Department of Transportation, and he would be a good contact person for you.

GRACE PIRES: If you can stay at the end we can pass on that information for you.

CHERYL: I want to say one more thing very quickly, also, the concern was, again, it seems to be a transportation problem, my daughter that does have MS, she doesn't have, she, for a few years she did not have access until her son just graduated, to her son's high school because RIPTA, that's a RIPTA issue does not go down her son's street but it goes all around other areas but it didn't make sense because RIPTA doesn't go down Curtis corner and she has MS, we had that issue and that hasn't been resolved but that's a RIPTA problem.

Transportation

JACK RINGLAND: Are you referring to the RIPTA public bus or the ADA?

CHERYL MORRISON-BREWTON: She is connected with ADA through the RIPTA program. But because RIPTA, through the ADA, they only go where, along, wherever the bus is going, on that route, but my point is, her school, for example, is less than a mile down the road from, for example, along the regular route. In other words, if it ain't right on the route of the bus transportation, they're not providing that service and she's disabled and she has MS. So, that's just one, like each if she wants to get grocery store, often she'll come our way just to go places she needs to go because RIPTA won't go there although they go in surroundings areas.

JACK RINGLAND: There is, the ADA has a rule where they will only g what is it, Angie?

CHERYL MORRISON-BREWTON: 3/4 of a mile.

JACK RINGLAND: 3/4 of a mile outside, if you have a RIPTA route down the middle of this room, they'll go 3/4 of a mile each side, that's the limit that they can go.

CHERYL MORRISON-BREWTON: I'll have to check that.

JACK RINGLAND: That would be something to check out and tell them. The other thing is you have to be very specific on your directions because I believe that ADA is scheduled out of somewhere in the Midwest because that's where the program was developed or something and that's where it's administered so they have no idea. You could say I want to go to Providence Place Mall, they have no idea what that is but everyone in Rhode Island knows where it is.

CHERYL MORRISON-BREWTON: Thank you, I'll let others go ahead.

GRACE PIRES: Next person is Maria Amaro.

MARIA AMARO: I didn't ask to speak, I'm sorry.

GRACE PIRES: Okay.

FEMALE AUDIENCE SPEAKER: I'm just here representing the plan of Massachusetts and Rhode Island (sounds like). We deal with -- for the disables so I am just gathering information and hearing about people's concerns. So, thank you.

GRACE PIRES: Okay, we don't have any other signatures, is there anyone else interested in speaking?

CATHERINE SANSONETTI: Does anyone else want to speak that hasn't signed up.

Independent Living

GAIL PEET Yes, I would like to, yes. Is this the best place over here? Okay. It would be nice if there was a microphone because it's very hard to hear some of the soft spoken people. My name is Gail Pete (GP) and I am here for my daughter Catherine Peet who is 45 years old and there she is. She is a person. She should be consulted about changes in her plans like what kind of diapers do you want? Don't have someone sitting in an office say, oh, they cost too much, okay we'll change it. One arrived unknown to us were things you wouldn't use for a puppy pad. It's abusive. It is outrageous. There is no dignity to what the state has provided. They are sitting in our basement, I had to go out and find different diapers, which now I'm paying out-of-pocket. I called the company in Ohio that made the brand we have been using for 15 years. They said, and I don't know where the state gets off doing this, the state has forbidden their product to come into the state. Really? Free enterprise doesn't exist? So, at the moment, I get a letter, try this other vendor, they don't know. Okay. Some people have no one to speak for them so they're victims, that's what they are, they're victims created by our system. The next thing, cost of care. Our neighbors allow most people to keep $1,500 to $2,000 of their money. Our state just went up $20 so now it's just under a thousand. Can you live for a thousand dollars, rent, clothes, food? What are these people? You want to keep these people in poverty? That's what's going to happen. My taxes, I provide the house, just went up to $1,400 a quarter. Okay. You know what food has done, up 10%. Come on. These people need to keep the money they've got. Their parents provided them to get more money by putting them as a disabled person on their Social Security, the state wants it. For what? So we can be relegated to a poverty level. And the next thing: Ever go to the hospital and be disabled? Guess what. You can't have your care givers come in and take care of you and feed you and bathe you. Because somebody might be double dipping. So let's punish the patient. She couldn't have her staff who were now unemployed basically because they couldn't get paid, and the hospital admitted they had no staff and once they log rolled her into bed without talking to her, she became totally outraged and wouldn't let them touch her. So now, wasn't the goal to get her better as fast as we can and get her out of there? If she wouldn't let anyone feed or bathe her, we're not going very far. Out of my pocket, I paid her staff to come in and we gave her 24 -- they didn't do medical care, they did personal care and helped feed her. The hospital staff came in, oh, Catherine, eat. Her staff comes in, hey, Kate, you're not eating. Oh, okay. It is knowing, it's like if a mother can't go into their child, the child will not thrive and you know it. This is policy and it needs revisiting. Ask us who have to live with it. Ask the person that has to wear the diapers how long this diaper will last. Maybe through a half a cup of urine. Where are you going to go? You're going to be wet all the time. Really, the person that is are involved, advocates are wonderful. But when you're the one being subjected to somebody else's great idea to save money, more laundry, more rashes, more infections, does that save money? Please, let's look at the big picture, okay? And I agree with this lady in the crossing the streets. Try and get across some of these streets, when you have right turn on red, they're practically running over you and you haven't even -- I've had the same thing happen, people walkout and I'm like, oh my God. So, anyway, please, look at some of these policies, they are hurting the people we think we're helping. (APPLAUSE)

Accessibility

GRACE PIRES: Anyone have any comments?

JACK RINGLAND: Angie had her hand up.

GRACE PIRES: Angie. We're going to take a break though, can you hold your comment, please?

ANGELINA STABILE: Sure, I can hold.

CHRISTINE: Talk among yourselves.

GRACE PIRES: We don't have to all sit here.

MALE SPEAKER: So when you use the mic, it's only for the listening device so please speak up.

GRACE PIRES: All right. We're starting now, ready, Ange?

ANGELINA STABILE: My name is Angelina Stabile, I'm from East Providence. And I have many things to say. I'm on many committees, I am on the legislative committee of the government's Commission on Disabilities, I'm chair of the Accessible Transportation Committee, and most probably, I belong to the National Federation of the Blinds in Rhode Island and I am Vice President of the Greater Providence Chapter. So that's a little bit of my -- I attend many public hearings and meetings and I try to change things for the better, for all. However, I am very saddened

Transportation

to realize that at our ADA celebration for, at Eisenhower House, that there was no accessible transportation for people to get there. What people had to do was take the nearest RIde bus or fixed route bus to a location and take a taxi or Uber or depend on the kindness of strangers to get to the event and I just find that very sad. We are celebrating. ADA, 25 years of the ADA and yet it's a hassle to get there. It's nice that it's wheelchair accessible and all but a lot of disabled people don't have the money or whereabouts to take two vehicles to get to the place. The second thing I want to say is, regarding RIPTA, and RIPTA knows how I feel, I have said it mean times at the Accessible Transportation Committee meetings, Rhode Island is a very small state. People say it's the size of a postage stamp and I don't want to stand by, we can't have statewide transportation and why state parks like in Newport, that disabled people can't get to. Or people who can't afford cars would like to take the city bus, the regular fixed route RIPTA bus to get there. It's just sad and I think it's awful and outrageous and whatever adjective people want to use. That is all I have to say. I ran out of things. People stole my thunder before. That is all. Thank you, have a good day.

GRACE PIRES: Anyone have comment or questions, Angie?

CHERYL MORRISON-BREWTON: I concur on behalf of my daughter who has multiple sclerosis. I also concur on what she has spoken because my daughter does experience that, she is just another example of many. My daughter that has multiple sclerosis that lives in Wakefield and some stores she cannot get to because RIPTA won't, will pass by the road but won't, because she doesn't have access to some grocery stores, some particular ones, and she actually relies on, when my sister can take her into, actually, closer to where I live and I live in East Providence. So, it is an issue. And again, like I mentioned about my daughter's son's school, there are times we have walked there or had, because even cabs, for example, there is very few cabs you can get in Wakefield, for example, because of the area she lives in, but she lives in a beautiful area but I have to say, I am very thankful and grateful, I have to say this on a positive note, for the Jonnycake Center that has been (sounds like) so supportive of her, there is a lady there, her and her husband basically adopted my daughter and I so appreciate their help, I cannot afford a car because I work part-time myself and challenging my two, the two children where I am is challenging enough but I worked most of my life myself, prior to coming here, I used to be a medical biller and have done administrative work, as well, but I know I have to get back out there in the work force because there are need that is need to be met and some of them are not being met and so, I need to do that for my children. But we can pray and hope that there will be change and that somebody will make some changes. It should not have to come for somebody else to get hit out here or get killed or injured or become disabled before some changes regarding some of these things that need to be done such as transportation, et cetera. That's all I have to say.

Transportation

GRACE PIRES: All right, thank you, that was Cheryl, correct?

CHERYL MORRISON-BREWTON: Yes.

GRACE PIRES: Thank you. The next person we have signed up to speak is David Silvan (sounds like), please state and spell your name and say what city you are from.

DAVID SILVA: It's Silvia. I reside here in East Providence, 1086 South Broadway (sounds like). I'm taking this opportunity to speak to you, as you can see, I'm disabled, I have to utilize a scooter to be mobile and every day is a challenge to leave my house, the streets in this city, in many cities, they are not ADA compliant. You have curbs that are six inches high, you have to jump off them or jump up onto, these issues, and I know I brought this up to the city here, after moving here last September, and here we are coming up on a year and nothing has been done. No work was done, haven't seen one iota of work scheduled, correct me, ADA, the cut outs to allow a

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wheelchair or a scooter to go across the street. Transportation, my vehicle that I had that I had to lift this thing up and put it in my vehicle so I could go somewhere, it's gone to the happy hunting ground. And I had to take the RIPTA bus and it's a struggle to get this thing on the RIPTA bus. You can't maneuver it, when you go up the ramp into a regular RIPTA bus, it's very difficult, there's not enough room to come around the corner. I have to physically get off my scooter and I have to lift up the back end to move it over so that I can try to get it through the door, into the space, get into the bus. And it's the same difficulty moving out. Now, you know, there are people on that bus trying to get somewhere, you have a driver getting aggravated because this is slowing down his route. It's taking up time. These buses are not designed to equip a handicapped vehicle like this. I don't know how a person in a wheelchair would manage to get up and around the corner there. At least with this I can, I personal will I have to get out of a wheelchair if you could, and push the wheelchair through, because the passageway can't be, it has to be less than 36 inches. So, as far as the state being ADA compliant with transportation, I give you an F. Furthermore bus stops, you have curbs there. It's convenient when the bus has the ramp that's going to pull and drop the ramp over the curbing but sometimes there is a car parked there and we have to go out into the street to get onto the bus. Total all around poor planning. This state has no idea what it's doing for disabled people. Sorry I am being so negative but I live this every day. You may not recognize me, I'm fighting with the post office next door here because they don't have a handicapped ramp to get inside the Post Office. I have been fighting with them for ten months. And this is ridiculous. It's 2015. We spend millions of dollars over in the eastern, mid-east country and everything else but we can't get a handicapped ramp so that handicapped people can go into the Post Office and do business. I'm a veteran and I find that outrageous that I can't get into that post office and do business. They've offered me, you can buy stamps online, you can do all that stuff but there are some things you just can't do online, you have to go to a post office. Thank God I just got Congressman Cicilline on board and he has just sent in an amendment to change that law to make the Post Office be compliant with the ADA regulations. But you're talking something, I'll be dead and buried before I ever see that. You know, I hope this opens your eyes. We have a big problem here. Disabled people cannot maneuver around it state. There are places I can't get into because the doorways aren't wide enough. You have businesses. There is a business around the corner, I won't mention a name, when I go in there, and they have to open up both doors so I can go in there. And I've asked the owner to correct it, they only would need to do is make one door open in and one door open out which making its easier for a wheelchair or scooter to go through, and obviously he won't spend the money and obviously I don't spend enough money over there to make it worth his while. This is what I put up with every day and in the wintertime forget it, I usually don't leave my house. I don't know what I'm going to do if I'm going to replace my vehicle because I can't really afford to buy another vehicle. Not the way things are in Rhode Island. Registration fees, inspection fees, everything else. I'm on income here that, it's getting to the point I'm probably just not going to replace my vehicle. I am setup with the RIde program but that's not the best thing. I had to go to Cranston a week or two ago, I had a 9:00 appointment, the bus was there to pick me up at 7:00 while we drove around Providence dropping off and picking people up before I could get to Cranston. If I wanted to go for a car ride I would have had somebody drive me up there. I understand and believe me I appreciate the RIde program, it's an asset, it gives me more or less door to door service but the time that you've got, I'm not a morning person to begin with so if I have a 9:00 appointment, I had to be up at 6:30 to be ready to get on this bus at 7:00 in the morning so we could take a ride around Providence picking people up and dropping them off before they got me to Cranston and that's probably something I'll never be able to change because I know the difficulty of trying to arrange putting all this doting. But it's something that's, this is what we have to do. And again, it's a burden on disabled people and I mean I'm not going to get into even being on disability, what little amount of money we're getting. I spent 14 years in the military, served in the Coast Guard for 14 years and I was a truck driver for 15 years and I didn't expect to become disabled at an early age but this is what I've got to do and this is how my country is paying me back for serving them. This is terrible. Thank you.

GRACE PIRES: Thank you for speaking out, we appreciate your comments. Does anyone have questions or comments?

JACK RINGLAND: Grace. I have a question. Anybody here that is disabled try to go to special events by buses and stuff like that? I'm talking, right now the subject of Newport came up, and last weekend and this weekends, there were two music festivals -- last weekend and this weekend there were music festivals, there are music festivals at Newport and I would think both of the music festivals are at Fort Adams and I would think somewhere along the lines I don't know if it's the organizer of the festivals or RIPTA taking things by the horns but you would think there would be special bus service from their hub and downtown Newport over there. Another thing is and I know this from a first-hand thing. I believe the Charlestown Seafood Festival has gone on for 25 years or something like that. And I was told a couple years ago when I went to it and they had a nonprofit booth setup that, and couldn't get help from my council to come down because the bus didn't go there, neither public bus nor an ADA bus went down there so these people couldn't come and help, but, the director of the Chamber of Commerce who does the, or plans the Seafood Festival along with an army of other people said they have been trying for many, many years to have RIPTA put a special route on that would just go down the west side of the state and pick up people at certain places so that they could get down, and it's not just disabled people but anybody. I would imagine people in Providence might like to go to a Seafood Festival where you can buy every kind of seafood possible but you don't have a car so you can't get there. But anyway, they don't do things like that and I don't know how you get them to do things and I agree with Angie, as small as this state is, you can drive the length of it and width of it in an hour, that every place isn't covered by a bus. But it will never happen, unfortunately. They say they're losing money and so on and so forth. So, that's what it is.

ANGELINA STABILE: Can I say something, this is Angie again.

CHRISTINE: Hold on Angie.

GRACE PIRES: We need to get to the next -- thank you, Jack.

ANGELINA STABILE: Hello again. I just want to add to Jack's comments. It's just not the Charlestown, Newport festival or like any, the Seafood Festival in Charlestown or the Newport festivals. In Providence, if I want to go to the Water Fire, I cannot go to the Water Fire because my service stops at an ungodly hour. If you're disabled and take the RIde program and you take, or the fixed route everybody has to turn into pumpkins and go home, we can't enjoy life. RIPTA knows how I feel because I don't stay silent on these issues and they always say, oh, money this, money that, but for projects that they want to find money for, they always find money for all the projects. And every problem, oh, it's the ADA program costs so much money, federal regulations and we're running the ADA program, we're the most generous transit authorities, I don't care about other transit authorities in other state, I care about getting around my state, not Kentucky. That is all, thank you.

GRACE PIRES: Thank you, Ange, anyone else that would like to speak? Okay. I guess we can take a little break and then reconvene in a little bit. If anyone wishes to speak, please sign up or let us know and we can resume.

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GRACE PIRES: We're going to reconvene the forum, Linda, could you please state your name and spell your first and last name and what city you are from.

LINDA DUGAS: Hi, I just walked in let me grab my glasses. I also, my name is Linda -- I'm from Pawtucket Rhode Island and I do have a couple of handouts that I have prepared. So, should I just give them to you now?

GRACE: Could you spell your last name.

Accessibility

LINDA DUGAS: Dugas. I'd like to, I have multiple chemical sensitivities and was chemically poisoned -- years ago, I'd like to discuss an electronic device called the stinger... (inaudible)..Are you able to hear me okay? That employs a lure (sounds like) and my proposal is to ban the use of these insect lures and the reason is they span wide areas for the purpose of attracting biting and stinging insectaries often containing an ultraviolet light. The - lures made of toxins which are manmade toxins can be harmful to animals including humans. Since I was chemically poisoned, I am like a canary in a mine shaft, the canary would probably survive better than I would when it comes to lawn chemicals and smoke, you name it, since I was poisoned. I lived in the same -- across from Slater Park, lived on Slater Park Avenue for ten years and I, at night, if I can, I really need fresh air so I'll put a fan in the window if someone isn't burning or hasn't recently done chemical lawn fertilizers or such things. On July 6th I did that and woke up grasping for breath, my legs were numb, feet tingled. When I was expose to a chemical, I can get a tingling in my feet, dizziness, I was disoriented and I shut the windows but never smelled smoke, knew my neighbors hadn't done chemical lawn fertilizers and was perplexed. Because I live across the street from the park, I have in my backyard a porch, not screened in. And there are mosquitoes, biting flies, all manner of bugs and whatnot and flying things and bees and within Day 2 I realized they were gone, there were none. And I am telling you, I can't use insect repellants and things like that but I use natural things like cat nip and lemon juice, I don't go out at night or dawn but am always fighting these things off and I realized they were all gone, there is not a honey bee, a wasp, no mosquitoes, nothing. At night we turn on the outside light, usually all sorts of bugs start coming, nothing. Same time I noticed Ocean State Job Lot was advertising and it's on the paper I gave, over here, a thing called the stinger which has a lure that goes out for 1.5 acres. And it uses a lure that heats up, I'm talking to the company about it, heats up and goes out for 1.5 acres to draw in these bugs, it's a chemical called octenol (sounds like). And I don't know that's what's happened to me but I have not been able to open the windows, like I say, I have not seen a bug, I called the park and talked to the director to see if they had fogged or done something that would, because they have a lot of events in the park, he said, no, they had not. Talked to several neighbors, when we're talking about 1.5 acres this thing can go out to, we're talking a lot of neighbors. They said they had not. A lot of the lawn care companies are promoting especially seascape, where heaven forbid you have a mosquitoes in your yard they'll fog your entire property, but I have not gone, we are talking 20/30 neighbors, 5 to 6,000 square feet. And I have asked some, some I am nervous go going up to and some people may just say, no, we don't use that sort of thing. I need to find out what's going on. I started researching this. It was just, and I thought, why would anyone get this, it also has a sensor so it comes on at dusk and turns off at dawn. So it goes all night which would explain why I can't open my windows at night. I have also noticed like I said, I have honey bees and wasps and bumble-bees, I have plants and flowers, there is nothing. I have also noticed because it's been 3 and a half weeks, and I have seen a mosquito, a moth, I saw a wasp today but I also found out these lures, it's best if you replace them once a month. For total effectiveness so I have done some research on it. It shows a picture of the lure. It's not just the stinger. I questioned why people that have 6,000, maybe 5,000 square feet, why they would get one that would go an acre and a half then I answered my own question, because that was the one on sale for $49.99. Octenol, it's also called mushroom alcohol, it's a fungus, and they also do a chemical component to it and there have been research studies, it's approved by the FDA but so are a lot of toxic chemicals, it actually is used as a food allergen (sounds like), frightening. And I, some of the studies that have been done says it could possibly result in Parkinson's disease and it also, they did studies with men and women exposing them to it for an hour, they started to get nasal congestion, difficulty breathing and that's from an hour also and symptoms of nausea -- animal studies it's been found to disrupt dopamine and may be involved in Parkinson's. I have included as a study they did with replies for, there was a different kind of fly and again they felt that it demonstrated that it caused, damages the dopamine system. So I think more study needs to be done, when I looked up some of this research, a lot of it, it's approved by the FDA but it would say, does it do this, does it do that? No research available, not available, not available. And I just don't think that people should be allowed to put a toxin in the air that is so wide reaching that I am breathing it in, other people are breathing it in but I can tell you these results, the symptoms I have when I'm expose today a toxic chemical and it's not like I knew about this stuff then got the symptoms, I was trying to put together, why aren't there any flies, honey bees, anything in my yard, after ten years and at night I can literally walk outside, they're gone. And again I'm seeing them come back gradually but it's been 3 and a half weeks. So that's my concern. And I don't think, again, I can't prove it and I'm still on a hunt to find out from neighbor ifs they have it. And if they do I would try to ask them to, I'd offer to buy the device if we could figure out something else. Did you have a question?[ii]

JACK RINGLAND: I don't know whether I can talk loud enough that you can hear.

LINDA DUGAS: I can hear you.

JACK RINGLAND: I don't know whether I can talk loud enough for everybody to hear, but, what you're saying is the device there, the stinger covers about an acre and a half. That's about 34,000 square feet so when you're out looking, you'll have quite an hour. To put it in perspective, larger than a football field.

LINDA DUGAS: I tried to do the math and figure out how many neighbors and I can eliminate the park unless they're lying because that's across the street from me but yeah. Trying to figure out how many neighbors, but I don't know the square footage of their lots so I've talked to about eight different people but the usual suspects, you know, people aren't always nice.

JACK RINGLAND: I mean somebody could be doing it and you're not even knowing about it.

LINDA DUGAS: And I don't want to give anybody the idea, oh they make these things I want one for my yard. I don't want to encourage that. But this is in the 16 years I have had -- when people have done things I have really had a problem, but, not so that it is in the air all the time. And before I knew what it possibly, again, it was like trying to make sense out of this and when I saw the ad, it all made sense and somebody said to me, what are you smelling? I just knew the air wasn't right. I live in Pawtucket so that's part of the problem right there, it doesn't have great air quality but like I said I feel like I'm smelling moldy wet laundry and that's before I knew this was a fungi and it has the component of alcohol and fungus.

JACK RINGLAND: Other thing I would imagine something like that is carried by the prevailing winds so somebody way out of your area could have this device, but the wind is carrying it through your area and beyond, the park and stuff of that nature.

LINDA DUGAS: Most decidedly effected my central nervous system without question, my feet and lips are buzzing. It has diminished somewhat but for a week I couldn't sleep in my bedroom. One hot night, I was just sweating so I said, okay, and I smelled the air and said okay it seems crisp and clear, 4:00 in the morning, open the window, put in a fan, 20 minutes later I was gone and had to leave the room, haven't done it since. I don't know what the solution is but figured I should bring it before this panel.

JACK RINGLAND: Thank you very much. I think there is another comment.

JOHN VALENTINE: Hi I'm from ORS, thank you for speaking here today. First I would like to mention that for the first 21 years of my life I resided at 185 Slater Park Avenue, believe it or not.

LINDA DUGAS: We'll talk.

JOHN VALENTINE: Absolutely. I remember an abundance of insects and flying creatures living there with Slater Park at the front doorsteps. Today I live out in the country, in Massachusetts, and where we have bug problems and things like that and an abundance of them and it's funny you mention this because a relative of mine last weekend had mentioned the stinger to me and I'm on about, where I am is about an acre of lands, small house but out there is always an abundance of lands. I did my research on it myself and immediately was turned off by the product. I eat and drink organic, I am against any chemicals, I grow enormous vegetable and fruit gardens, I'm constantly fighting insects but there are plenty of ways to fight them naturally and I have learned this over many seasons of growing food but I have always been against these things and the product you mentioned octenol is very dangerous, they do put it in food, in my opinion it's very wrong, I have a co-worker who is actually, belongs to organizations to get pesticides out of the country, you go to Europe, they have banned all of these things, people are a little happier and healthier over there I think it's safe to say.

LINDA DUGAS: Except the smoking.

JOHN VALENTINE: Yeah, they do smoke in Europe. But I'm very glad you spoke here today because what you have is a, you're a person with a disability that's not visible but people should take accommodations and it's hurting yourself, it's hurting other people out there who don't even have preexisting conditions. And I would love to chat with you after the forum if you would like to stick around.

LINDA DUGAS: Thank you. I would also like to say, I don't know what to do. I mean, other problems I have had, certainly I'm known by the city council people but when it's something that's not illegal, it's, you know, more than their jobs are worth not to have people that aren't going to vote for them because they are going around saying, you know, we have a problem with somebody in the neighborhood and they just, you can't, you know, they know me well when they were illegally burning last year, someone burning at 10:00 at night and probably because they were renovate ago house and I got whacked good thing. So illegal stuff they'll try to deal with but things like this, yeah.

JOHN VALENTINE: Last summer, there is a neighbor of mine out in the country and he was always illegally burning every two weeks his trash because he didn't want to pay the fees to bring it to the dump. But his whole barn caught on fire, totally devastated. But there are air compressors, propane tanks, explosions, it's terrible for the surroundings people.

LINDA DUGAS: People have told me, move. It took me 7 years to find this, I'll never be able to move. I have a refrigerator out in the garage now, I don't have an oven or washer and drier. I can't have dental work done. When you have MCS your life is changed, it's over, it's done and you just spend every day trying to avoid these situations but this is beyond my control and I'm not sure what to do about it. Thank you.

JOHN VALENTINE: Thank you.

GRACE PIRES: Thank you very much. Is there anyone else who would like to make a comment? Or anyone else wish to express any concerns?

JACK RINGLAND: Most of the people up here on this panel belong to other volunteer councils and so forth beside possibly regular jobs and how many of us have seen at the bottom of agendas and so forth, environmental sensitivity warnings. And you are' aware of them, I'm aware of them, I've never met anybody before that's had that and I'm glad that I have made your acquaintance and heard your story here today because it gives you a different appreciation. You can't always see, I mean, there's nothing there that says you're sensitive to chemicals and stuff.

LINDA DUGAS: Maybe next time we can talk about smart meters, go right into that.

GRACE PIRES: Was somebody interested in making a comment?

Independent Living

ANNE TELFER: Yes. I'm here. My name is Anne Telfer. I actually have a question, twofold, I am a parent of a 22 years old on the Autism spectrum and I am new, returning back to Rhode Island after about 30 years in Michigan and I work for the ARC of Blackstone Valley. So I have been interested in following our governor's strong interest in work force development and improving job, the job statistics, employment statistics which I think need improvement. So I guess I am asking if you all, or if there is a good strong disability community that is part of these discussions because I heard not much.

FEMALE AUDIENCE SPEAKER: Move back to Michigan.

ANNE TELFER: How did you know? Did I say that? Michigan is a little better, it's a lot better. But, yeah, so it's just sort of, I have been here nine months, my son is great, he has an associate’s degree from the community college in Michigan and he has tried everything so we are beginning to sign up with ORS and we will started, but you know, pretty much, he is a really strong kid with great skills and has been to target, he's been absolutely everywhere we all think about and he had worked for two and a half years in Michigan so he had a job, loved it, et cetera. Haven't been able to do anything here. And then I work for an agency where our, we're working hard on employment and vocational training in Pawtucket and there are no jobs. It's a really rough atmosphere.

Angelina Stabile: I know your pain, I am looking for a job, too

ANNE TELFER: My daughter has a job and she won't have one because they are taking away her supports so there you go.

JOHN VALENTINE: Mrs. Telfer, is it? It's nice to meet you, thank you for speaking today. I'm glad to hear you are signed up with ORS for services.

ANNE TELFER: Just starting. Eligibility, right?

JOHN VALENTINE: Eligibility phase, yes. So there has been an intake. Good. You mention your son is 21 years old?

ANNE TELFER: 22.

JOHN VALENTINE: In which town does he reside.

ANNE TELFER: Well we just moved to Riverside.

JOHN VALENTINE: Riverside is actually part of my area, Riverside and East Providence. One of the things I would recommend, whether your son was going to come to my case load or one of my co-workers, one of the things I would like to see is you or your son explore Cove Center (sounds like), they have a program from going on two years old now called Job Corps, clients have mine have had great success there and if your son happens to be on Social Security, I was going to mention we can setup with benefits counselors but that's something I like to see, whether my case load or a different counselor, one of the things you may want to mention is that place and having client goes to that program, it's one of our most impressive vendors because they work on social skills as well which helps with retention rates with employment, not to mention names but a young gentleman who is a client of mine, I had him when he got out of high school and into his early 20s, he worked with cope (sounds like) center, was employed for data entry jobs, 30 hours a week, he also played bass guitar part-time and they helped him find some gigs in the Boston area, it was really cool. They've had a great success rate, I'd like to see you talk to the ORS counselor who works with your son.

ANNE TELFER: The challenge with him, he's a really good kid, has a high school diploma and -- degree, general studies math and science, he's had a job in Michigan. He's not very good at self-advocating, I've been hesitant, I had not a good experience with Michigan Rehabilitation Services, so that's why I have been really slow with ORS here but I'm going to give it a go. I am optimistic. But it's a challenge. It's like -- kid. He has really done well but it's a challenge for him. He doesn't wear the Autism label, and so it's tough. And yet he has, you know, some deficits in social skills but he shakes hands, he has, you know, great eye contact and all that. But it's just been a challenge here so I was just hoping the Governor's improving, you know, or that there is a conversation happening at the state level that we need businesses to hire individuals with developmental disabilities, all disabilities, and I just want to know if we're all represented there somehow.

JOHN VALENTINE: Thank you.

CHRISTINE: Are you saying Cove.

JOHN VALENTINE: Yes.

JACK RINGLAND: Does anybody know of Centene Corporation? There are 26 different places around and I don't know what areas they are in but when I was in Washington, D. C., at a conference this week I heard that Centene Corporation is hiring and they are particularly going after people with disabilities. So, that's one company. The other thing is that I, this is a plug for another group that I belong to called the cross disabilities coalition. Cross Disabilities Coalition is just that, it's a coalition of people with varying types of disabilities. I mean, you have MS society, you have TBI (sounds like), so on and so forth, this is right across the spectrum, you'll see a lot of people with disabilities attending. Anyhow, there are three of us that do the, we take turns planning the meetings and so forth and along with that, our coach/supervisor, Sue Babin who maybe some people know, she encourages us to develop certain programs, educational program, I just got assigned the employer's -- presentation. To quote an old term, hire the hand capped. That old cliché back when. I collected a lot of good information this past week and I am still looking for information because I want to really want to make sure that we make inroads that way. We have several people that have made inroads, we have a good that has works for Shaws for I think it's got to be almost 20 years and loves it, they love him. He wouldn't be there otherwise. And that's just one, there is another one that works for...I want to say it's ADD (sounds like) out on route 295 and 37, somewhere out in there, worked for a number of years, he is the mail clerk, he goes around and picks up the mail and get it is ready for pick up by the post office. And he also delivers the mail. And he does it for quite a number of hours a week. Coincidentally in Washington, D. C., we had a March on the Hill and I was able to see Congressman Langevin said is we've got to get jobs in Rhode Island, we've got to get education in Rhode Island. So I guess we have our marching orders. We just have to see how well it's going to work.

Independent Living

CARMEN BOUCHER: Thank you for coming and bringing up the concern. I work at the Rhode Island Department of Health and we have a transition internship program that we have been very active with. Last year, through the school year we actually had ten individuals with disabilities intern at the program and (inaudible) evaluations. That's one part of what the Rhode Island department of health is doing. Other aspects we're doing based on your question is we have a meeting with the Rhode Island department of administration HR department is a diversity department and directors have been meeting with my director regarding looking forward to opening job opportunities for individuals with different abilities. So that conversation is there and I also know there is support in the union (sounds like) as well so there is a lot of work being done. Our office, office of special needs, working on providing opportunities like you say your son had actually job experience. Some others unfortunately have not had the job experience so they will provide an internship so they could come in and have internship on the skills that they have graduated with and -- those. As well as being connected in a work area. From there, hopefully we move on more into providing jobs but it's been something that has been discussed in a lot of different areas at the department of health and I know for the Rhode Island Department of Administration HR department.

CHRISTINE RANCOURT: And I have a shameless plug. I am Chris Rancourt -- in October of this year we'll hold our second conference geared towards employers around people with disabilities. Goal so to get employers there to share with them the facts as well as the -- around hiring those with disabilities, those are really big issues so that's coming up and hopefully we'll get good results. Again geared towards employers because employers are frequently afraid of hiring a person with a disability and we want to get the word out that people with disabilities can work, should work, are able to work and they may need an accommodation but it's not that big of a deal to provide that accommodation.

GRACE PIRES: Okay. Any other comments? I am just going to, and again -- okay, again else like to make any comments? I am just going to say, I am really glad that the employment issue was brought up, I think that's something that employment is such an important part of someone's life growing up, you wonder what you're going to do so I'm glad this was brought up and employers do need to be educated to hire people with disabilities. Earlier Chris told me she is having that conference, great, because people need to hear from people about hiring people with disabilities. Just because we have a disability doesn't mean we can't work or contribute to society. Thank you for bringing that up. Do we have anybody else who would like to express any concerns or comments?

ANGELINA STABILE: To the woman who has doubts with ORS, I worked with Services for the Blind in ORS, I have a wonderful person there who helps me with everything, he's fantastic, don't ever be afraid of signing up because I have had such wonderful experiences with my counselor. He's just fantastic and I, and ORS, like Services for the Blind has been there for me, they help me with school and everything else. I just, don't be afraid to reach out because there are people that work there. That's all I have to say.

GRACE PIRES: Thank you, Angie.

CHRISTINE RANCOURT: There is one other group I want to bring to your attention, its run out of the Department of Labor and Training, it's an organization, a small group of folks and they run a grant and it's called the Disability Employment Iinitiative. So that's another avenue for you to reach out to and I can provide you with information on that after wards if you'd like.

GRACE PIRES: Okay. I don't know that we'll have anyone -- if anyone else comes up we'll resume but before I break I want to thank everyone for coming in and expressing their concerns. It's very important to let the legislators know some of the decisions are impacting people, as someone said, we are people and people have different needs and sometimes decisions have negative impacts and I'm sure that's not the intention but that's the result so I do appreciate everyone coming out and expressing their concerns and we'll break for now and if anyone else comes out we'll resume.

## 20 August 2015 North Kingston Wi-Fi Free Public Forum

ANGELINA STABILE: Can I have everyone's attention please. Thank you for coming this afternoon. My name is Angelina Stabile. I am here moderating this public forum and the bathrooms are where?

COLLEEN PICELLI: To the left. Right to the left.

ANGELINA STABILE: There's a water fountain and waters and what have you. There's an interpreter here if anyone needs an interpreter for sign language and we have a CART for closed captioning for the deaf. So when you come to speak, please come forward and say and spell your name and please say what town or city that you are from. Now I am going to read you this statement of why we are here convening this public forum. The purpose of these public forums is to identify the concerns of people with disabilities and their families in order to assist the state to develop programs and to improve the lives of people in Rhode Island with disabilities To ensure -- sorry -- to ensure everyone has time to speak, please limit your comments and make them short. And to the point. If you have a critical problem that needs to be addressed, the panelists, the panel members will be available at the end of the hearing to direct you to the appropriate agency and give you proper information. After the public forums are completed in early August -- well this is not early August {LAUGHTER} -- the sponsoring agencies will review the testimony and prepare recommendations which will also be posted on the website by the end of November on the Governor's Commission on Disabilities website. The recommendations and the transcripts will also be printed and sent to state agencies, Congressional officials and to the members of the general assembly. And the recommendations will be used to develop policies and legislation to help the lives of people with disabilities and their families, which will be included in next year's legislative package or until they are accomplished. The Rhode Island disabilities law center panelist will be available to register anyone who is a citizen and is not currently registered to vote or needs to have a change of address form completed at the end of this forum. And now before you entered or before you got your seat, I hope that you signed up for the attendance sheet and if we have time at the end, those who didn't speak can speak and those who want to speak some more, if we have time, we will give them a chance. Now I'd like to introduce the people here at the table. My name is Angelina Stabile. I am on the Governor's Commission on Disabilities' legislative committee and a commissioner and I am also a member of the National Federation of the Blind, Greater RI Chapter vice president. I will start to my right

COLLEEN PICELLI: Colleen Picelli, Rhode Island Office of Special Needs.

CINDY HEBERT: I am here from the Office of Rehabilitation Services.

CASEY GARTLAND: I am the senior director with Perspectives Corporation and I serve as a commissioner on the commission.

MEREDITH SHEEHAN: I am the community program director for the Multiple Sclerosis Society in Rhode Island.

CASEY GARTLAND: Unfortunately we don't have a person from the Rhode Island Disability Law Center.

AUDIENCE MEMBER: Can you speak louder. We can't hear in the back here. Sorry.

CASEY GARTLAND: We unfortunately don't have a representative from the disability -- Rhode Island Disability Law Center. If you were looking to vote today, we are going to need to give you another alternative because we don't have a person from the Disability Law Center.

ANGELINA STABILE: Okay. Now the introductions have been made. Please read the first name of the person who would like to speak.

CASEY GARTLAND: Camile Rees

ANGELINA STABILE: When you come up, speak nice and clear and loud so everyone can hear you and please state your name and spell it and say the city or town you are from.

CAMILE REES: Hello. I am Camile Rees and I have been a summer resident of the Westerly area for almost 50 years. My roots in Rhode Island go much further to the founder Roger Williams. I carry his spirit with me as I do my work as an educator and public health advocate on the subject of electromagnetic fields and health. Personally experienced how difficult

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life can be when one has had an over exposure or acute exposure to electromagnetic fields. When I found myself living on the other side of the wall from somebody's Wi-Fi router. This was 7 years ago. I became severely -- I couldn't focus. I couldn't think straight. I couldn't open my mail, do it downstairs in the coffee shop. I developed heart irregularities, vision changes, skin rashes, a myriad of symptoms that didn't make sense. I finally traced to the wireless exposure. And since after that, once I figured it out, I read the science. Started meeting the scientists. Wrote a book on the subject. Public Health SOS: The Shadow Side of the Wireless Revolution. And I'm here today to tell you that this problem is very real. I have some handouts for you. One being a book on the subject of electro-sensitivity, with over 1,800 references. This was published by a group in the UK called Electrosensitivity UK[27]. You will also be interested to know that just this past week there was a federal disability advisory group that has been recommending taking Wi-Fi out of public transportation and this week we just received word from the Karolinska Institutet in Sweden, the Swedish Academy, the organization responsible for the Nobel Prize in literature in collaboration with various disability organizations and functional impairment experts has decided to enter a new Swedish word called Funcaphobia into their official word list. It is defined as prejudice against people with functional variations. So we are -- in your handout packet, which I will give you in just a moment, you have a list of some of the symptoms, some of the studies, just like a cheat sheet of about 20 different situation studies on what they show when people were too close to this radiation. Ranging from headaches to sleep problems to inability to focus, to all kinds of different biological and cognitive effects. You also have a critique of -- that we put out called -- it was to the national association of independent schools who last year put out a one-page statement saying all clear, Wi-Fi is no problem. So we wrote a critique saying that is absolutely not true and this critique contains evidence of what other countries are doing, especially to protect children from this radiation. You will be extremely surprised to learn what they are doing to limit the exposure of cell phones and Wi-Fi to children in their homes and in schools. Recommended good reading. Then -- one point I know I don't have a lot of time here. So the one point that I want to make is that we -- this radiation is invisible. So we think that it's benign. But it's -- and we think it's a constant everywhere. But in fact, the radiation is variable. And this is a graph, it's about to be published in this study, that shows this is a school. Where depending on the classroom, the peaks, its exposures varied by, you know, by the classroom. And it was actually during those high peaks when the children were experiencing symptoms. It's now been documented. So not only is there variability in the exposure in a classroom or in a room like this, but also the high powered routers they are using in industrial settings, commercial settings are using a much higher power, 5 gigahertz and certain aspects to the technology that are more directional. So in a classroom, mall, coffee shop, one person might actually be getting more of the exposure than the next, very important to understand that. So I just want to say that this problem is legitimate, the former head of the World Health Organization, former Prime Minister of Norria Labruntland has been on record including recently in a video describing her personal electro-sensitivity And how when she was a head of World Health Organization, she couldn't even be in the office when somebody else was using a cell phone or a wireless computer. That's how bad it can get where you can't tolerate it. There are different degrees of tolerance and there are different reasons why some people are more sensitive than others. Sometimes it's a genetic issue. Sometimes it's a child that's got the metal braces that acts more like an antenna in your head. Or somebody with prostheses, metal in their body. Sometimes it's detoxification pathways. There -- or heavy metal body burden. There are many different reasons why one person is different from the next. I am here to show you

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[27] www.es-**uk**.info

that you can actually get significantly better from this. But the only way to do it is actually to remove yourself from these exposures. That's the only way to do it. I had to do it myself. There are people in our society estimated between 3 and 8 percent by different surveys around the world that are experiencing quite extreme symptoms of electro-sensitivity that are impairing their ability to go to work. I couldn't go to an office job if I had to -- I just couldn't do it. If I had to go to a conference for three days on a weekend or something, by the end of the weekend I am totally fried and can't think and I am not right. It's the Wi-Fi. And so there -- you have to remove yourself. People need places to go to be able to have their bodies rebalance. We are fundamentally electromagnetic. Every single cell in our body runs on electricity and electrons. And it's beautifully balanced. There's a harmony to it. We work incredibly well. It's a very complex system. It works beautifully. When we have an external source of energy, manmade frequencies it starts pushing the body in -- and that causes dysregulation that can impact almost every system in the body. It's been documented. So there are these acute symptoms that people are having. There are also the long-term issues which not the subject for today but they are very real, links to various illnesses and the DNA damage for society. So I think I will stop with that. I will hand you -- this is -- these are -- this is a DVD from 200 international scientists that just recently appealed to the United Nations on this issue represented by Dr. Martha Herbert from the department of cellular physiology of cellular biophysics. This is an audio we put out on our children, fetuses and fertility in this. This was two years ago in Stonington Connecticut, not far from here. And these are individual packets for you of some of the things I referenced here. And the last page is an elephant and what I am saying today is this radio frequency in our midst that is never ending is an elephant in the room that is driving a lot of the cognitive problems, a lot of the developmental problems, also in your packet is an article in Boston parent the other day with myself as well as Dr. Martha Herbert an expert professor at Harvard and runs a big autism research lab at Mass General talking about the autism connection that is starting to become clearer. So I am really grateful for your time and hope you take a good look at that.

CASEY GARTLAND: Thank you for your time {APPLAUSE}

ANGELINA STABILE: Are there any questions for this witness?

CASEY GARTLAND: I don't think so.

ANGELINA STABILE: Okay. I would like to move on. Thank you for coming Ms. Rees. I didn't know these things. The next person that would like to speak please

CASEY GARTLAND: Liberty Goodwin. Please make sure to spell your name for the court reporter.

Accessibility

LIBERTY GOODWIN: Yes I will. I am Liberty Goodwin. And I am the director of the Toxics Information Project an information in Providence Rhode Island. We have usually been dealing with toxic chemicals in everyday life and products. However this particular concern has been arising more and more and it has many similarities to the kinds of problems we usually deal with. It is something that -- it's confusing to people because you see so many people out there, you know, they are with their Wi-Fi and they are happy, happy, happy. You think what's the problem? And the problem is, well there are several. And this goes for chemicals and it goes for radiation as well. And one of the huge problems is the absolute difference in sensitivity and susceptibility of different people. And of people of different ages, children, of course are far more susceptible than most adults. There's a complexity to it because people are exposed to all sorts of things, you know. It's not just one thing. And it's over time. And it's not the same level of exposure, you know, continuously. So it's complex. And for this reason, people with chemical sensitivity tend to be invisible. People don't even know they exist because they can't go out, often, and meet in public places and you don't see them. They don't have a cane. They don't have a wheelchair. It doesn't mean that they are not really devastated and they are really sick. And that's something to remember. Another point I want to make is often one of the problems is it's hard to prove quote cause and effect. It's not an immediate reaction and an immediate serious reaction. For example, you know, radiation, if you got a big dose of it, it's going to kill you, right away. But low level radiation and this came out a great deal in my years ago when I was studying nuclear parts for example. Low level radiation may not kill you, it doesn't kill you. But it can cause mutations, which is why it can be a cause of cancer. It's been associated -- there are those associating it with Lyme disease. Mutations in the organisms that cause Lyme disease. So you know, it's complex and I'm just saying just because you don't see, you know, everybody just isn't keeling over from this stuff. It does not mean -- it does not prove that it's not dangerous to many people. And that it can cause serious health effects. Now the other -- one of the other problems with this particular concern is, my God, it is so widespread now and it is so popular. I mean, I can see you trying to wrench an iPhone or laptop from somebody's cold dead hand before they gave it up. Everybody is using it. It's growing. It's so much a part of our society. So I'm coming here and saying oh please GCD, how are they supposed to solve this problem. And the answer is they can't solve the whole problem obviously. But, but the good news is that there are many -- there are things that are doable that are manageable, that can be done as a start and that can have significant, you know, mitigation. Not going to solve the problem completely but that can help quite a large number of people without an enormous, you know, resource being needed to do it. So I was looking and I've given you a sheet of suggestions that I came up with for this. And I went through what calling the lone hanging fruit which can have the most bang for the buck. And what I came up with was first of all schools and libraries. These are public buildings. They are under the control, you know, of the organization or a government body and they can -- you can make changes there. You can, you know, devise things that can be done there and you can suggest things that can be done there. And some of the links that are in that sheet that I handed out are two places where they are already doing things, especially in schools. There's a lot of work that is going on where they are making changes in schools. And that's so important because the kids are the most susceptible generally speaking. There are some adults who are very susceptible too. But in general children are really at the greatest risk. And so there are -- and of course, the first thing is you don't have any Wi-Fi in schools and that can be done. It's a doable thing. The same thing could be said for libraries as well. The other kind of low hanging -- I also want to say something about the backing of the scientists. Not only is it so complex that it's really hard to quote prove with absolute certainty what -- this is what did this because there's so many different factors. But when you are looking at scientific evidence, keep in mind the source because there's a vast difference between the kind of information which is generated by those who have connections to the industry, which is profiting by someone and it's been demonstrated that this can have dramatic effect on what kinds of information they are coming forth with. Just to keep in mind. Besides the schools and libraries, the other thing that really can and should be addressed is smart meters, so-called smart meters. I always put it with a quotation mark around the "smart" part. Smart meters have absolutely no use. They are totally unnecessary. And you know, they expose people without any need to do that. I mean, we are getting along just fine with regular meters for many, many years and these things are just not needed. So the minimum, the minimum should be that people can opt out of them. What really should be done is to say, you know, this is an exposure that should not be out there to people. And it's something that, again, is within the purview of the government to say, you don't need this. And it's affecting people so don't do it. And you know, it's not going to cause a horrible situation if we don't have the smart meters. So those are the main things that I came up with. And I think I would leave it there. I hope -- and I hope to work with the Governor's Commission on providing perhaps additional information. Oh one other thing. I came across in my research all kinds of sites or places where they were talking about things that could be used as barriers to electromagnetic fields that I haven't any idea which, if any of these are effective or you know work -- or they work for something, you know. But it's something to be looked into and researched, I think. Things that you can buy or people are selling things that claim to be barriers, maybe. That's pretty much it

ANGELINA STABILE: Thank you for your testimony. Thank you for coming. {APPLAUSE}

LIBERTY GOODWIN: And you also have the sheet. It will be sent by Bob Cooper on-line because I think it will be simpler for you to just click on the links that way.

CASEY GARTLAND: All right thank you

ANGELINA STABILE: Thank you. Any questions Hearing none, who's the next person

CASEY GARTLAND: Judy Jackson

JUDY JACKSON: I was wondering if I could possibly stand up here in the light so that I could read what I have to say, if you could --

CASEY GARTLAND: If I can ask one question. I apologize because your name -- there may not be a check next to your name which means you want to talk. What's your name? Sorry, Judy, go ahead.

Accessibility

JUDY JACKSON: Can I go back there into the light so that I can read my testimony? My name is Judy Jackson. I live in Boston. And I'm a retired law professor and I want to start out thank you for the opportunity to testify here today. And I want to start out by quoting Dr. Ollie Johannson from the Carolina Institute in Sweden where EHS or electromagnetic hypersensitivity is recognized as a functional impairment.  And this is the quote and it's a very serious quote and it's very, very interesting. "Treating members of the community equally is not something that should be done as a favor nor is it something that any parliament or government should politely request our inhabitants to provide others with. Equality is not something to be done out of the goodness of one's heart. It is something one does because it is expected of every citizen because inaccessibility and discrimination are prohibited by law, thus it is not all right to deliberately make EHS persons symptoms worse. Inaccessibility is not a personal problem. It is a problem for society. Inaccessibility is not about attitudes, it is about discrimination. And discriminatory actions and conduct shall not be dealt with by well-meaning talk about treatment, discrimination is already illegal. At times the view taken of the electro-hypersensitive person has resembled a medical program with frightening overtones, even more frightening is the situation today is and is allowed to be much the same. The entire public debate has been characterized by grand words, commitments and far reaching promises, which have often been shown to lack the necessary effect. This nonchalance and lack of commitment has personally been particularly insulting. Is all this something that we should be proud about? How much simpler, cheaper and more creditable it would have been to have provided the electronic hypersensitive persons immediately with the assistance and solidarity that we like to boast about. An immediate decision on a housing adaptation grant, disability allowance and so forth would have been self-evident. Now we have instead endured almost 30 years of hostilities with big losers, namely the electronic hypersensitivity persons and their next of kin. I say there must be an end to nonchalance, lack of consideration, indifference, and lack of respect or the part of society. Never accept discriminatory treatment or an insulting special treatment. Stand up for others rights and in this way you will stand up for your own future. I would like in closing to quote the very wise words of the late Yan Aberd a freelance writer in Trohan, Sweden. Everything that happens to us human beings only happens as long as we accept it. For how long will your authorities and their civil servants accept it? Would they demand the same type of proof it was about themselves, their children, their mother, their father. Let me read that one more time. Everything that happens to us human beings only happens as long as we accept it and we should quit accepting it. Thank you very much {APPLAUSE}. Would you like a copy of the testimony?

COLLEEN PICELLI: Thank you

JUDY JACKSON: For the record. Thank you.

CASEY GARTLAND: Would you like to speak? Again please state your name for the record.

Accessibility

PAUL KLINKMAN: Paul Klinkman from Providence. I wanted to write down the minimum that you need to know in order for you to take action. This won't go one-tenth as deep as Camilla Rees went. We know that electromagnetic waves can magnetize the iron atoms and the hemoglobin of red blood cells, causing the red blood cells to clump together. This lowers their ability to carry oxygen to the body. So it's physically possible for Wi-Fi to directly affect human physiology. The power of electromagnetic broadcasting shouldn't be underestimated simply because you can't see it. I have a picture here of a man holding up a florescent bulb under a 220 kilowatt electric wire. The bulb is glowing from the power in the wire. We humans are the first Wi-Fi lab trials. We know that electromagnetic waves are suspected of causing short-term health effects in a class of Rhode Island citizens that I will call Wi-Fi canaries. We know that it's also suspected of causing morbid illnesses such as leukemia in the general public. Therefore, the Governor's Commission on Disabilities should look into passing prudent regulations that reduce the general public's exposure to Wi-Fi. Simply moving a Wi-Fi broadcasting station farther away from human beings, perhaps up into an attic may improve a building's habitability for Wi-Fi canaries. Difference from two feet from a Wi-Fi station within a cabinet and sitting 20 feet below a broadcasting station would be a hundredfold power difference. The Wi-Fi signal in nearly all computers should certainly be uncompromised in a distance of 20 feet. At home, we own an all in one router and Wi-Fi broadcasting station. We keep the Wi-Fi button in the off position and we hard wire each of our computers to the internet with cables. We've gotten rid of the problem. Smart meters at homes are for some people unnecessary electromagnetic pollutants and health hazards. Forcing pollutants on people is wrong. {APPLAUSE}.

ANGELINA STABILE: Thank you for your testimony. Next speaker please.

CASEY GARTLAND: Mary Adkins.

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MARY ADKINS: Adkins. My name is Mary Adkins and I am the Rhode Island regional director for Citizens for Safe Technology. I am a volunteer public health educator and I spent the last five years trying to educate both the public and our state officials and school officials about the dangers of the electromagnetic radiation. Previously I worked for the Department of Defense on an Undersea Weapons program. So when my two children became sick from Wi-Fi in schools, I did my homework and I had the background to do it. And what I found was frankly horrifying in terms of the amount of science that has been in existence for decades about this harmful technology. I honestly am speechless at this point because I can't even begin to tell you what I have gone through as a parent and as a citizen of this state because of my own electro-sensitivity and that of my children's. And I never in my wildest dreams imagined that I would be standing here talking to you people about this issue and how it has destroyed our lives. My two children were essentially forced out of school because the school refused to acknowledge that this is a disabling condition. And unless one has 25, $30,000 to go out and hire an attorney, you pretty much can't do anything about that. When there's a difference of opinion between the school and the parents, and at the meetings that you go to for a disabled child, there's usually ten school officials and one parent. You don't have any recourse. You can go to the office of civil rights. But they don't have the task of debating differences of opinion between school officials and parents. So what's your other option? To go to the Department of Education, the one pushing the technology. So there's a big, big loophole in our system when it comes to disabled children, especially those with invisible disabilities. And someone needs to fix that. And it's been around for a very long time and I'm not the only parent who has experienced it. Pretty much every parent I know who has a child with invisible disabilities gets put through the ringer like I have. And I've spent an inordinate amount of time trying to get the accommodations that my children needed and could not fight this beast, the school system to get what they needed. My children were damaged. They have irreparable health issues because of this. And what really angers me the most is none of it was necessary. We have had hard wired connections in our schools for years that worked perfectly fine. But there are some very large companies and very powerful people who decided that a fortune could be made off of Wi-Fi in schools and getting a wireless device into the hands of every child in every classroom in every school in every state in the country. Can you imagine the mind boggling profits that are being made? And they are being made at the expense of our children and my children are two of those casualties. And I just need to respectfully correct something that was said earlier. I think Liberty you may have said it where you said low radiation cannot kill. It absolutely can. With chronic exposure.

LIBERTY GOODWIN: I said instantly. I didn't say it couldn't kill.

MARY ADKINS: The low level radiation which is what Wi-Fi is, what everybody claims it's harmless because it's low level is absolutely -- it's an untrue statement. In fact, most of the science would substantiate that in many cases the lower the level, the greater the biological effect. If you look at it in terms of vaccines, as an example. A vaccine is actually a very minute amount of the disease you are trying to prevent. And what does the body do with that minute amount? It reacts and it reacts very strongly. The same is true for this radiation. Though it may be a low level, it has really egregious harmful effects that my two children experienced and that I see many other children experiencing. And perhaps mine were the first to fall, for whatever reason. Genetics, early exposure, we had Wi-Fi in our home before most people had it. But regardless, when their disabling condition was identified and brought to the attention of the school, you would hope that the system would work. But it does not. Particularly when the disabling condition is inconvenient for them. So in the midst of this wireless frenzy when my two children were identified as being made ill from it, it was too inconvenient for them to step back and think about how they would accommodate children like this. And frankly they didn't want to acknowledge children like this because if they acknowledged that my children get sick, they would have to acknowledge that other kids get sick. And when I made a phone call to the Department of Education, someone told me there -- a representative who I will not name -- that they had received many other calls about children getting sick. Nobody's doing anything about it. So I sent big stacks of paperwork to the school committee. First the principal, then the superintendent. Then the school committee. Then the Department of Education where I was told we don't get involved with health and safety issues. Really? Really? You don't get involved with health and safety issues in your schools? So I was told to go to the Department of Health and I went there too and sent them stacks of research and basically got a similar response. We are not ready to act on this issue. Well, in the five years that I have been waiting for someone to act in my local school, five teachers have died. Teachers and staff members. Multitudes of children are sick. In fact one of the headlines was about the "alarming increase in absenteeism" and as far as the students that I know who are friends with my children, symptoms I see coming home are those of microwave sickness. But their parents, most of them don't even know that Wi-Fi is in the school or even if they do know it's in there, they don't know that it emits a class 2 B carcinogen, neither do the teachers who are working in that environment, which is a direct violation of a state hazardous substance right to know law. So in my public school, these five teachers who have

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died, am I saying the Wi-Fi killed them? I am not saying that. Do I have my opinion about it? You bet I do because I know of them personally. She was my neighbor and a friend. She was 35 and she's dead now. And she didn't know that there was radiation coming out of those routers. I knew. My kids were getting sick and I did my research. And I knew why they were getting sick. But this teacher, she had a right to know. And in fact there's a state law that says she has a right to know because this class 2 B carcinogen is on the international research on cancer list. People have a right to know about the toxic substance in their workplace and I would argue that as a parent, I have the right to know if it's in my child's classroom. But they install that Wi-Fi without ever telling the parents. And then when I finally did know about the Wi-Fi and did educate myself and realized it was radiation, microwave radiation coming out of it and tried to take steps to protect my children, who at that point were now disabled because of it. This loophole in our special education laws allowed the school to continue discriminating against them. Something has to be done about that and I would be happy to talk to any of you or whoever the committee, you know, consults with to try to change this. But it doesn't just happen for kids with disabling sensitivity to EMF it happens to a lot of children who have invisible disabilities. There is no recourse. There is no avenue to resolve it other than hiring a lawyer, with tens of thousands of dollars for most people it's just not possible. In terms of our own daily struggles being electro-sensitive, it's -- it's almost funny it's so bad. I will give you an example of veterinarian, just to explain how egregious it is that we can't get the most basic things in society like everyone else can. I called my vet to make an appointment for my dog. And I had chosen that vet because they didn't have Wi-Fi. So as I was making the appointment I want to check, nothing's changed in the office right? Oh no we have Wi-Fi now. Okay. Well, I can't access the office if there's Wi-Fi because I get very sick from it. Can we have the vet come and see the dog in the parking lot? No, we can't do that. Okay. Can the vet come out, collect the dog, bring her back in the building, do the exam, and bring her back out? No, we can't do that. But we have a mobile van. Great. The mobile van can come to your house. Great. Does the van have Wi-Fi? Yes. Well that would need to be shut off because when you are parked in my driveway, I can't have you doing that because we have severe sensitivity. Oh we can't do that. Okay. And we go back and forth and back and forth. And finally, you know, I am trying my best to be polite throughout this whose process, trying to assert my rights under the ADA to get the access I am entitled to like everyone else. I offered suggestion after suggestion, doable suggestions. The first was asking to shut them off. I asked one could we come at the end of the day where you can shut it off and it wouldn't impact anything. No we can't do that. We need your file. Could you print out the file beforehand? No we can't do that. You see the absurdity of this? This is what my life is like every single day trying to get the most basic things to live, whether it's taking the dog to the vet, going to the grocery store, getting my car serviced. The doctor that's a good one. Let's talk about the doctor. Can't get medical care in the state of Rhode Island. I have one doctor who has been gracious enough to accommodate me. Cannot get a doctor that will accommodate my children. We have to go out of state for care for them. I cannot access a hospital in the state of Rhode Island. I cannot access a medical clinic in the state of Rhode Island. The disabling symptoms that we suffer are quite severe and can be life threatening. Heart arrhythmia is a very common symptom for people with disabling sensitivity. To step into a hospital with industrial strength Wi-Fi running is a life threatening situation for people with disabling sensitivity and I am not the only one. I know many, many people across the country and in this state who are affected like this. We need to be able to get medical care. We can't get it. I've spent the last five years talking to representatives of my local hospital and after five years, I still don't have access to my hospital. Something has to be done about that. And the thing that's so infuriating is it's not rocket science. There are shielding materials that can be used. There's ways to set

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up safe access, like safe corridors where there's shielding put into place so that EMF doesn't permeate, where you get someone in and out without exposure. It's not that hard. People just don't want to do it. Because to admit that it might harm me or my children would be to admit that it might harm someone else. And I think the light bulb goes off that gee, we don't want to be held liable. So let's just pretend this doesn't exist. Well there's international outrage in the scientific community about the fact that this exists. We are not going to talk about whether it exists any more. It does. And something has to be done because people are being shut out of society. I cannot safely access 99 percent of the things that most of you can access. I cannot. Whether it be a grocery store, a health food store, a medical clinic, a YMCA, a recreational center, a public beach where they are putting Wi-Fi hot spots all over the place. This is outrageous because as far as I know, there's no civil right that says people have a right to check their Facebook 24 hours a day in a public place. But I'm pretty sure there's a law called the ADA that ensures my right to access those public places. And there's a big disconnect here in that people are so engrossed with the convenience of this technology that those in positions of power seem to not understand that this has created an egregious barrier to access for everything, for people who suffer from this. And the numbers suffering are growing. The impact on the state, if you want to look at it purely an economic standpoint is something that everybody should consider too, because what I see is I see huge numbers of children developing ADHD, very common symptom because what the radiation does to the neurotransmitters, I see huge numbers of children developing Autism, also tied to the use of this wireless technology. I see lots of people going on disability, not able to work. Where do you think that burden ends up? It ends up on the state and it ends up on all of us. Paying more and more and more taxes. And when the liability hits, and it will because it's hitting now in Europe, we are all going to be paying for that. So my position is if people want it fry their brains with their cell phones or their Wi-Fi, go right ahead. But do it in the privacy of your home and make sure your wall is shielded so you are not affecting your neighbor. But don't fry me. Don't fry my kids. I'm angry because I have been doing this for five years now and I've struggled for years with my own health issues and watched my children suffer like you cannot believe. And when I get people from state agencies saying things like, oh, well, there's no consensus or whatever. You try sitting up with a child throwing their guts up all night every night for three years because of the Wi-Fi radiation that he is exposed to in school because of what it does to the mass cells and the massive amount of histamine that gets produced and the mucous. You try staying up with a child every night for three years while they throw their guts up. And you think about what that must feel like. And to know that I can't safely access a hospital without then putting my child through that again is crazy. It's crazy and I am begging you people to do something because I've gone to various state agencies. I've written letters to the governor. I've written to the Department of Health and the Department of Education. Nobody wants to hear this because everybody thinks Wi-Fi is great. Wi-Fi is the worst thing that ever hit this planet. And we are all paying a price for it and it's getting worse and worse and worse and right now I got two children who are literally pushed out of school. Now I am watching all their friends come home sick and I am watching my friends, teachers getting sick and dying. And I want someone to do something about it. We should not even be having this discussion. The fact that we are is insane. Insane. And when I worked for the Department of Defense, if I were to ignore the kind of evidence that I have brought forward to my school officials, to my state Department of Education, to my state Department of Health, if I were to have ignored that kind of evidence in my position, you can bet my head would have rolled. This is outrageous that no one is doing anything about it. There's no more excuses. So I'm begging you people to have some kind of moral fortitude to stand up and do something as you are sitting on this commission because the people I've already gone to aren't doing a damn thing and people are suffering, people are getting sick, and people are dying. Children. So I apologize if I come off rather strongly but this has gone way too far for way too long and there's no excuse for it. It's one thing when I went to my school committee and said, God you guys didn't know this. I didn't either. I had it in my home. I didn't know. But now that you know, please do something about it. What was their response? They put in more. They put in more. And five teachers and staff dead now. Was it the Wi-Fi? I don't know. I don't know. But I know the one person that was a friend of mine she told me her symptoms. They were symptoms of microwave sickness. She's dead now. And she was perfectly healthy until she spent time in that school. Given there is a state law that required her employer to post a notice in big bold letters to say there's a toxic substance in your workplace, that didn't happen. And it should have. It should have. A lot of this is in my written testimony which I've e-mailed in and I will give you a hard copy as well. But yeah, I am angry. You bet I am. I've had two kids who have needlessly suffered for years because of this technology. And now, now that we are lucky enough, frankly, to know what's made us all sick, and we are trying to, as Camilla said, reduce our exposure and get well because the only way you can get well is to avoid it, we can't go anywhere. We can't go anywhere. We can't go to the hospital if there's an emergency. I had two now. I couldn't get access to care. I have if go out of state. I can't go to 99 percent of the grocery stores in the state. I can't go to the YMCA, the bowling alley, the movies, Wi-Fi is everywhere. We can't turn it off. That would just ruin our business. We couldn't function. Well, in many cases, like the veterinarian, if I am the last person of the day, and you flip a switch and you shut off your Wi-Fi, what's the impact? They couldn't answer me. There is no impact. It's no different of an impact than if you have a big thunder storm which we have many sometimes in the state of Rhode Island and the power goes out for half an hour. Well if that doesn't impact you, you just turn everything back on when the power comes back on. How is me coming at the end of the day and you flipping a switch going to impact you terribly? It's not. But there's just so much ignorance out there that they just don't want to do it and they don't think they have to do it and the veterinarian's office, that example I gave you the classic line was, well we don't have to accommodate people like you. This isn't real. You know? I'm sure people with chemical sensitivity have heard that before too. Are you going to they will Martha Herbert a Harvard neuroscientist and child -- what is she? Child neurologist. Are you going to tell her it's not real? She's spoken very publicly about that. David Carpenter, a world renowned expert in electromagnetic field, tell him it's not real? Are you going to tell the scientists who have signed declaration after declaration after declaration about the sheer numbers of people being harmed? That kind of response that I got from the veterinary office manager, whoever he was, that's part of why we are here talking to you because the public ignorance is incredible on this issue. Nobody's talking about electromagnetic fields and this radiation making people sick because the industry is so powerful and they have so much money that they dump into advertising and everything else that you don't see the studies on TV that you should. You don't hear about it in the media. Who is the primary advertiser in these numbers? They are. They are. So what we really need from our state officials is help. We need help educating the public. We need the state to start enforcing their own laws. There's a state labor law right now, hazardous substances right to know law, 28-21-2, paragraph 13. That says any toxic substance on the international agency for research on cancer list, any carcinogen on that list should be reported to workers so they know about the toxic substance in their workplace. If my friend had a big sign in her teacher's lounge telling her about that toxin and her employee workbook maybe she would have said when she got sick, I am getting sick because I am being microwaved but she didn't know she was being microwaved. That shouldn't have happened. That shouldn't have happened. I contacted the state labor department too. I've had no response. I mean, I'm just flabbergasted at the apathy that I see on the part of people who should be able to help. And I'm also flabbergasted at how quickly people are falling when they are exposed to this technology. Five years ago when I started this people like oh, well I have Wi-Fi and it's not bothering me. But you know, they only are home for half an hour day or whatever they shut it off at night or they never heard of Wi-Fi's and they don't is it. They use a cell phone but they are not affected. A lot of those people are sick now and a lot of them are on multiple medications an their kids are coming home sick and the kids have special needs and ADHD and they are on Ritalin and what has changed? The Wi-Fi in the school that is what changed. So I would argue that teachers have a right to know. Anybody working in a school has a right to know. So do parents. There's a toxic substance in our schools, the parents need to be notified so they can decide do I want to risk exposing my child? If somebody had told me that they had put Wi-Fi in and that Wi-Fi was emitting a class 2 B carcinogen which is the essential as described to me by a scientist who knows better, the equivalent of a weapons grade microwave. And by the way there's over 2,000 studies cataloged by military alone about how harmful this radiation is. If someone had given me informed consent and said this is what we want to expose your kid to, there's no way in the world I would have exposed my children to that. But nobody told me. Nobody told me. And they shouldn't be allowed to not tell you.

CASEY GARTLAND: We need to make time for other people. I apologize.

MARY ADKINS: It's all right.

CASEY GARTLAND: We have a long list of people and we have a half an hour left

MARY ADKINS: I hope I have given you some idea just how big the problem is and the lack of access in large part is due to ignorance and I think if there were more signs up, more people being informed about what is really coming out of these devices, you might actually get more public support and people understanding the need for accommodation. But we just don't have that public knowledge yet. So thank you. Sorry for going on and on {APPLAUSE}

CASEY GARTLAND: Peggy Patton

PEGGY PATTON: Thank you. Peggy Patton from Wayland, Massachusetts. It seems like no one has mentioned addiction. People are so addicted do their cell phones that they -- it's the last thing they want do is turn them off or turn off Wi-Fi. There is such strong addiction. And it is an illness. It's not a personal thing. They don't understand it. It's -- and that's the main problem we have here. I have been working to educate people about microwave radiation since 1998. It's been a long time. And now it was so easy to pass laws then compared to now because now everybody's addicted. I mean, young people they love their little cell phones. They have their little kids walking around with them. It is just awful. But even worse than that are the wireless meters on the sides of our houses. I ran off NSTAR[28] three times and they waited until I wasn't home and put on the electric wireless meter. I haven't slept careful -- I haven't slept well since it went on. In 2013, I had cancer for the third time. You want to know how I got cancer? I look to the wireless junk in my house. Now my town wants to put on a water meter on the side of my house, a wireless water meter. I don't know what I can do if we don't meet at a town meeting but anyway. Actually the department -- the local department of public works is now one of the commissioners mentioned the other night was on television. He said well, I guess all the people will be coming with their little wired hats on. Ha ha. They are making fun of us, people who are trying to educate people and stop the wireless revolution and it's

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[28] NSTAR is now Eversource Energy

Ad*www.eversource.com/*

just terrible that a governmental commissioner would talk that way. I have here from -- in November of 2013, William F. Senate Corporation Counsel for the City of Boston submitted testimony to the FCC regarding inadequacy of the US radio frequency exposure guidelines. Counselor Senate wrote "the 1999-2000 judicial challenge to the FCC's 1996 rules never reached the issue of electro-sensitivity as a cognitive disability under the Americans with Disabilities Act, the ADA. Here again an agency responsible for ADA implementation acknowledges that the impairment might be disabling but has promised merely further inquiry. After more than a decade, that investigation remains unopened. The dockets have been updated with massive additional evidence so that crippling effects of RF radiation on the emitted minority that are suffering more at minority of US citizens. The FCC and its sister regulatory agency shared responsibility for adherence to the ADA and should replace promises with serious attention to a serious medical problem. This is one area where the FCC could lead in the advice of electro sensitive persons about prudence -- of prudent avoidance. On your commission, it would be wonderful if you would help the people of Rhode Island so they don't have the exposure like they have now. Thank you. {APPLAUSE}

CASEY GARTLAND: Patricia --

ANGELINA STABILE: Thank you for testifying.

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PATRICIA BURKE: Thank you. I am sorry I have to read my testimony. Patricia Burke from Massachusetts. My sister and her husband graduated from URI and my niece will be graduating but I won't be -- I went to college with someone who became an airline pilot and he is renowned for his abilities to smell leaking jet fuel and he is valued as being gifted in his profession. I have the ability to detect artificial radio frequencies but I am not described as gifted. I am described as suffering from a fabricated illness called Nocebo[29] where I only imagine that I am being impacted by radio frequencies. At a town meeting in Massachusetts, an employee recently told the community that when they planned to install the wireless water meters, the tin foil hat crowd will appear. The urban dictionary states that the tin foil hat is the number one fashion accessory for unemployed conspiracy theorists around the world. And provides the synonyms of wing nut, further and paranoid. I am portrayed as opponent to environmentalism, economic growth, technological innovation and the freedom to connect and ridiculed as a Luddite. But I am none of these things. The name calling and ridicule will continue until we decide to act. We have the capability to validate the adverse reactions to radio frequencies. For example, using a protocol developed by the American Academy of Environmental Medicine. The individual is placed in an EMF clean environment. The frequencies are introduced while monitoring the heart rate and other quantifiable variables. It's not rocket science. Magda Harvas[30] has done research linking cordless phones to measurable heart rate provocation. We have the tools. The question is whether we have the ethics. The same cast of characters who created the tobacco wars are fueling the manufactured debate about radio frequency limits and health. For the ESHS populations not just a question of being excluded from the workplace or being denied access to healthcare, education or religious services, social events or democratic processes such as hearings like this. It's a question of whether we have the right to live in our own homes, free from assault, or to live anywhere at all. If I lived in Russia and reported that the copper water pipes on my home were pulsing radiation, that activates my brain tissue on my heart, I would not be characterized as a psychiatric patient. If my friend were to complain that the tin ceiling in her kitchen is trapping radiation signals from the basement meters that bounce off her stainless steel

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[29] In medicine, a **nocebo** is an inert substance or form of therapy that creates harmful effects in a patient.

[30] www.**magdahavas**.com

appliances and disable her in her home. She would not be displaced or ignored. An EMF hygiene investigation would be performed and the damaging frequencies would be eliminated. In India, industry sponsored research is not permitted to influence public policy. India recently lowered its radio frequency exposure limits to one-tenth of the previous threshold based on the bio initiative report findings which the US has ignored. We have no epidemiological data for the juxtapositions of exposures today and no premarket safety testing. What with have is mounting evidence of crippling effects. Thank you.

CASEY GARTLAND: Deborah and I don't know if I can say the last name.

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DEBORAH LOUTH: Louth. I wasn't going to speak today because I am really not certain of what to say. Except I do have a personal story and unlike Mary Adkins an out there activist I like to keep a low profile. And I don't want to be targeted. I don't want to be laughed at, thought crazy. All those things. So I just stay under the wire. I've never had a cell phone. I haven't watched television since 1988. Very sensitive what goes in my head. It affects me. And never used a microwave and the cordless phones, they are lethal as well from my point of view. So I can walk into a mall and go over to a threshold and feel zapped by whatever is going on in there. And that was before Wi-Fi. So I've stayed for the last 30 odd years with majority apart from a lot of what is going on. I didn't get a computer until 2005 and that's when I got on the internet. And I could not stay on the internet for any length of time, 20 minutes or whatever. So it wasn't until I started going to the library. I'm from Hope Valley by the way and the Hope Valley Library. And -- what do I know about Wi-Fi? I didn't have a clue. I see FIOS on trucks and I didn't know what that meant. So I just know that when I was in the library when my computer went down, I was using theirs. All sorts of crazy things started happening. My eye sight went off. Just all the symptoms that many people have spoken about here today that I experienced. They sell jewelry -- I lost several pieces of it -- that ward off electromagnetic vibrations and I forgot my bracelet. I do energetic things. I shut my chakras[31] down when I go out. I don't go to movies. I don't -- I just have done this all my -- the last years without knowing anything about anybody. So I just knew I sensitive. I even had chemical sensitivities and that kind of thing. But hey, you got to live in this world, you know? I eat a lot of natural foods. I am healthy. I do cleansings and fasts and this is how I keep myself healthy. And I don't have a husband nor children. So that's helpful because I don't have to have all the things that everybody else has to have. And I don't have the activist mentality because like Mary, which I am so grateful for Mary, because I don't have children. She does. She's got more of an incentive. So I just kind of -- I'm not -- I don't take in a lot of things. So Verizon had this special and they said, well, we can give you this and blah-blah blah and your internet will be faster, beep beep Ba Ba. She is writing all that down there. I am watching what I say {LAUGHTER}. So, I said oh great, it will reduce my bill. So they came in and I had several people there that day. And we were doing something. And I live on eight acres so I was outside doing my thing. They were there for two hours. I didn't know what was going on. So then -- I don't know. They showed me this thing they put in my office and I'm self-employed so I don't have to go into the other people's offices and stuff. So they showed me that wireless router thing and I walked into my room and right away I got blasted. I thought that was weird. And I didn't say anything. They left. And I used to sit in this one chair in my kitchen table where I ate and did all sorts of things. And I just realized I couldn't sit there anymore. So I started taking another seat. Then I would now wouldn't even want to be in the kitchen. So three weeks later -- oh, I know. On the computer, it was just like the library. I really got majorly affected. Negatively. So I went down to my cellar three weeks later and there's this fleece type structure with these flashing

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[31] In Indian thought, the centers of spiritual power in the human body.

lights on it and I said, what the -- is this? And -- anyway I called them up and said I have FIOS. I said you have to get this out of here. Now I know, the fleece was right where that chair was where I sat. Okay. So then -- oh they weren't going to take it out. Oh no. They weren't going to take it out. I had to fight and fight and fight. Finally I said I'm sick. You know, I will get the doctor, blah-blah blah-blah. I will take you to -- I just was very nasty. You got to get this out of here. Or else I know, I will rip the wires right out. And I said you got to get it out or I will rip these wires out. And well it took them five weeks and they came, okay. And they took it out. And after that, I felt so much better. Then I met Mary Adkins and through -- I am an herbalist. I am part of an herb group. So in this herb group, I guess I have been in ten years. Before all the cell phone and the tablets and all of that, and we always had much social interaction. So all of a sudden now, we are in the group and somebody says something like, okay, let's look up -- what is Comfy plant look like the. They have their cell phones and note pads and no one is making eye contact. So I started getting sick there too. What do I mean by sick? It's not debilitating where I am nonfunctional. But if I have to stay in say a conference type of thing which I can't go to -- I am an astrologer too. We have conferences. I can't go to those. I do go. I want you to know I do go. I put my bubble protect. I do all this stuff. So Mary says to me, well you are not as bad as I am. If you can do that, but the next -- it takes me days to get back to normal and get back to balance. So Mary said to me, she can't go to the herb groups either. It's just wonderful, we share lots of information. I try to impress upon them the fact that they are all highly addicted. I watched them first become enamored, then entranced. And then enslaved by these electromagnetic devices. And because I never had them. So -- and I'm clear. Unless I get in a lot of that -- I can't go to the beach any more. I'm in shock that I can't go to the beach because of all of the people having their devices with them. So I feel that we live in an electronic prison and I'm wondering behind the scenes what's the point of this? Why is it happening? What's the people behind the scenes are running the world, what's the purpose of all this? Everyone is getting sicker. More people are on medication. I'm just amazed -- I don't take one thing. No medication. I do a lot of herbs though. I put my bare feet on the ground and hang out with nature. So that's -- some of those are some of the things that I do to stabilize and balance in order to live in this world. But I am rather lonely. I don't -- I can't go many places, even my family. I have a big family. Brothers and sisters kids and grandkids and -- not me. But grand nephews and nieces. And Christmas time, I get fried. Totally fried. Mary won't go to her family's. I can't do that.

MARY ADKINS: It's not that I won't. I can't because of the smart meter next door

DEBORAH LOUTH: They have smart meters. Oh okay, all right. So, that's my story. I just -- I am surprised I am speaking because I don't want to be known because I don't trust the government. I don't trust all the powers that be that allow this all to go on and I feel that we as a people got to stand up an say, no more. Once people are -- I think that being -- I think everyone is being dummied down by the TV, the electronics, the computers, and they are disrupting the communication between the cells in the brain and people -- they are dummied down. I'm sorry. You know. And they are unaware. Let me just say that they are unaware. And we are here today is bringing awareness to a situation that could get worse, will get worse. Thank you very much for listening {APPLAUSE}

CASEY GARTLAND: Unfortunately we have four minutes left and six people to speak. We have Sam Parish. Just keep time in mind.

ANGELINA STABILE: If you could shorten it so everyone can speak. Thank you.

SAM PARISH: Don't worry mine is short. Sam Parish. I am a civil engineer, 12 year Rhode Island resident. I've got three kids. Just want to thank you for the opportunity to discuss this issue. The needs of the people with electromagnetic sensitivity. I have 20 years construction experience. A lot of those projects have involved ADA improvements. And I have

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five years specifically with experience with electromagnetic fields. I spent three years in a nuclear power plant, measuring the effect. I've spent a lot of time in utility corridors and industrial plants and industrial pipelines and measuring these fields and seeing the results on the meters. So what I want to say is we have a great opportunity here right now to address some solutions within the framework of the ADA. Everything is totally doable. We have the engineering. We have the tools. If you look into my testimony I submitted all the knowledge you can ever imagine about shielding, about you know the products that are out there, field cancellation, all -- there's so many ways to reduce electromagnetic fields and incorporated into building design. We have that, okay. So I would be happy to provide any solutions or talk to anybody else about that. From working in this field and thinking about it for many years now, I want to tell you that wireless infrastructure is not sustainable, okay. It's not sustainable because every device you put on the system compounds the exposure of microwave radiation, okay. So maybe a little bit over here is one thing. But I'm telling you the more things we do with wireless technology, the worse it's going to get. So solutions are everywhere and the tech industry can do the work rounds. They can solve the problem after we tell them it needs to be solved. They will grumble a little bit and they will fix it, okay. So I'm here to help as an engineer and there's a lot of other engineers and specialists that can help with this. And all of these situations are physically solvable in the industry. So thank you very much

CASEY GARTLAND: Thank you

SAM PARISH: If you have any questions I would be happy to answer them

CASEY GARTLAND: I think we have a lot of questions but I think our heads are swimming so I think we will just listen

SAM PARISH: Sure, no problem

SHELLEY MCDONALD: Shelley McDonald. Hi everyone I am a teacher here in Rhode Island and a few years ago I was like you. I was like everyone else. I could walk into a mall and walk into a doctor was office and walk into work and I didn't get sick. And something happened over the past couple of years. Wi-Fi came in. I can't access my job any more. I walk in there and I get sick. There are industrial grade Wi-Fi routers in every classroom, above my head. And during the summer, it's great. I can avoid all these places, which is a little bit sad. I avoid restaurants. I avoid the movie theater. I avoid the mall. I avoid most public pleases because of the exposure I get and the way it makes me feel. And the way it makes me feel is I will leave work for a day of work with unbelievable migraine and inability to focus. I feel dizzy and sick and it takes a very long time for that to go away. So it gets to a point where it's disabling. To do your job effectively, you need to be able to think clearly and to focus and I can't do that anymore. So we are looking at a problem and we are looking at that problem in schools and so, it's affecting me. I am a healthy adult woman. I can't imagine how it's affecting my students and that's really why I am here today. I just want to make sure that you are aware of it. It is a problem. The biggest problem with it is, as other people have said, it's invisible and a lot of people don't get affected right away the way some of us might. And so we are looked at as crazy. We are laughed at. We are ignored. I have contacted -- I have spoken to my administration, the school. I've spoken to the Rhode Island Department of Health. I've spoken to the Rhode Island Department of Education. And I get ignored. In some cases, I have been verbally bullied. I am unable to get anyone to hear my concerns or take me seriously at all with two doctors' notes. It's because nobody knows that this is an issue. So that's the big thing that we need to get through right now. It is a problem. It is a real thing. It's affecting a lot of people. And I hope that you can help us. Thank you.

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ANGELINA STABILE: Thank you for your testimony. Any other people

CASEY GARTLAND: Mary Volk, if I am pronouncing it

>>: She left. Is there still --

CASEY GARTLAND: Yes. You are next. You are Mary --

CHARLENE SMITH: I am Charlene Smith and I don't know if I checked the right box.

CASEY GARTLAND: It's okay. I have people ahead of you but why don't you go ahead

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CHARLENE SMITH: I will be really quick. Like a lot of the folks here, horrible EHS. Super productive in my younger years, worked, worked. I was a real estate agent. Had the phone glued to my head for more hours than I'd like to admit. Developed lots of hearing loss on the right side and subsequent full-blown EHS symptoms. What do I do now? I avoid everything, like the folks -- I avoid the malls. I avoid getting blasted. My symptoms kind of take hold and I am in bed with a migraine for days on ends. It is disabling. It's a really horrible disabling situation that I am in. I avoid the beaches because everyone has their cell phones. You kind of say to yourself, okay what can we do? And I think it's great that you are here. Public awareness. We really need to get the message out. It's a class 2 B carcinogen. There's no dispute about that. We can kind of have some type of public awareness campaign. Class 2 B carcinogen, this stuff, the items. I don't know. And kind of start there. Opt out for the smart meters. That's easy. Like Shelley said, the schools, the libraries, it's horrible. To subject those kids to that, it's just -- it's just awful. So that's it. Kind of short and sweet. But I'm affected. It stinks. And maybe you can try to do something about it

CASEY GARTLAND: Thank you for coming forward

CHARLENE SMITH: Thank you

CASEY GARTLAND: Stephen Dahl.

Accessibility

STEPHEN DAHL: It's Stephen Dahl. I am from Kingston, Rhode Island. The reason I am here today is to protect my children. Greta and Eric Dahl who will be in third grade and kindergarten respectively this fall at West Kingston elementary, an excellent school which our family loves dearly. In the summer of 2004, Sysco wireless transmitters were installed endangering my children. I work in the public schools as a substitute and my wife works at the university, all have Wi-Fi. The landmark Supreme Court decision that affects our discussion of Wi-Fi in public places today was ratified to the detriment of our political process in 2010. Citizens United versus FCC, a grueling of 2010 unlimited political spending, calling funds free speech. Dissenting justice Stephen said the citizen ruling would threaten to undermine the integrity of elected officials across the nation and furthermore a democracy cannot function effectively when its constituent members believe laws are being bought and sold. The tech industry has become one of the top 10 biggest lobbyists, opensecrets.org a watch dog group helps us to follow the concealed money from 2012-2013, Sysco Systems political donations were 950,731. In 2012, the electronic manufacturing and equipment industry contributions skyrocketed to a record 54.6 million. That same year 2012, Sysco Systems, the top contributor to democratic senator Sheldon Whitehouse of Rhode Island. That same year the state general assembly approved the wireless class initiative which allocated 20 million dollars of our tax dollars to upgrade wireless infrastructure. It all of the state’s public schools during the following five years, so now my children have Sysco Wi-Fi in their classrooms at West Kingston elementary, our dear school. Our district even had it installed at South Kingstown Inclusionary Preschool called skip, SKIP, where the students don't even use it. Last Tuesday, at a South Kingstown School District meeting, I spoke with South Kingstown School's IT director after presenting myself to the regular committee I was dismissed by the chair and told to talk in the hall with him. After saying my statement, which was that I thought it was not safe. Because it was like having cigarette smoke maybe 60 years ago. Okay. Regarding SKIP's or cigarette smoking, regarding SKIP's Wi-Fi installations he said, this is Mr. Snow, they couldn't turn down the free money. And he -- derided people like -- well, to name her, Mary Adkins. Thank you, Mary. Numerous {inaudible} point to susceptibility of our youngest as the most vulnerable to electromagnetic frequency danger or the need for more study. That comes up quite often in the journals you will find because more study is needed. Since industry has deep pockets, the reviews are showcased when their findings support industry or defunded when their findings suggest great harm. Such harm was found in two -- back in 2005 I was reading it the University of Washington, I {inaudible} University of Washington about cell phone -- guy was working on cell phones and research and it was defunded when the research from Motorola observed damage to human DNA. So this is looking not -- this is our generation. We are not going to be able to reproduce. How about that? Regarding Wi-Fi, pediatric Martha Herbert of Massachusetts General Hospital and Harvard Medical School has found findings in Autism consistent with electromagnetic fields and radio frequency radiation this by initiative 2012 report, this 1800 studies showing potential for biological harm from nonionizing radiation devices, Wi-Fi and devices. Why is the onus on us as parents? Why aren't our leaders in government protecting us from harm? This lack of protection violates the very foundation of law, the public trust doctrine in which our life, liberty and per suit of happiness depends. It is your job, government people thank you for being here, I appreciate it. To protect us and not to profit from us. It is your job to question the sales people, even the World Health Organization not take their word for our safety. We need to do the reconnaissance. We need to do it. Short-term convenience cannot trump long-term safety. I don't want my children getting disorders or cancer now in five years, in 20, any time. I don't want any disorders. I don't want my children to be a part of any bloody experiment. I have more studies I can share with you. I have journals all over the place. We got four studies suggesting Wi-Fi exposure more than -- blah-blah blah -- about how children are affected. I have the protection of health risks of radio frequency fields from wireless telecommunication device see page 114. This is a scientific journal called -- oh fiddle sticks. What does it say? Journal of toxicology and environmental health part B, critical reviews and based on review of the literature the panel recommends further study, further research and potential health effects in the area of nonthermal effects. Sensitive material, electronic fields, journal of pediatrics abstract what rapid advances in electromagnetic field EMF technology and communications are increasingly children are exposed to EMF earlier ages. Consistent epidemiological evidence of association between childhood leukemia and exposure to low frequency ELF magnetic fields have led to classification of international agency as a possible human carcinogen. And I could go on. Mother Jones, et cetera, et cetera, at infinitum.

CASEY GARTLAND: Sharon Phillips but you wrote maybe.

SHARON PHILLIPS: They covered it

CASEY GARTLAND: You still want to speak?

SHARON PHILLIPS: A lot of wonderful things, I'm sure. Thank everybody who has talked because it's so important to talk about this. One thing that I wanted to mention is that there's so much on the internet. If you go to YouTube and key in Wi-Fi in schools affects microwave radiation, there's just so much. There was a film that came out a couple years ago now called Take Back Your Power. It's by a Canadian producer. It's won international awards. It's on the internet. That's on YouTube. So you can go and watch it. And it's about microwave radiation through cell phones, cell phone towers, Wi-Fi, and smart meters. And it's also -- it's about the health effects and it's also about the government spying on us, using smart meters, which they know when we are home. They know when we are not home. They know when we are using our televisions, our, you know, our appliances. So it covers that aspect of it and I think that's an important aspect that's as important as probably the health effects are more important. People dying. But also we need to know about this.

Accessibility

And so if you haven't seen the film, it's called Take Back Your Power. Probably everybody here has. If you haven't seen it, it's called Take Back Your Power and it's on YouTube. Yeah. So anyway, and another thing I just wanted to mention has to do with the smart meters and that is there is no opt out for smart meters because the way it works is it goes from one house to the other. So the person at the beginning of the block gets the burst of this radiation and then from his house, his house acts as a transmitter to the house right next door. That person gets a burst. So say you are number three at the line and you opt out, it goes from number two to number four right through your house. So there's no such thing as an opt out. So we are quite literally, you know, not being given any choices here. And not being able to, you know, the way it's set up. That's why I think we all need to be aware and we need to address this so that we don't -- my personal thing is I have a little grandchild who is in a school and I -- it just very frightening to me what's happening to children and like our -- the grocery store I go to for quite a while, Stop & Shop in Westerly and also in -- now in Connecticut, they request a dollar donation for kids with cancer. And I say, what are you talking about? Get rid of the Wi-Fi. Maybe we won't have kids with cancer. We never did before. And one woman said to me, well that's because it just wasn't publicized. We didn't know about it. But you know, really, kids never got cancer. It was very rare for adults to get cancer. Very rare. You know, Woody Allen used to joke about it. He had a brain tumor and we would laugh back in the 70s. It was just so rare. So anyway, I mean there's a lot we are exposed to right now but I think the radiation is a big piece of it. So take a look at that film.

CASEY GARTLAND: I have one person who signed up before you. Do you mind? Cecelia.

Accessibility

Independent Living

CECELIA DOUCETTE: Cecelia Doucette. All right. So thank you for holding this open forum today. In the summer of 2013, I learned all wireless and cellular devices operate off of high levels of airborne radiation that can cause infertility, brain cancer, breast cancer, behavioral issues, DNA damage, and more. Children and fetuses are especially more vulnerable because their systems are still developing. Their skulls are thinner. They are absorbing it deeper into their tissues. And it's causing DNA fragmentation. As former President of the Ashland Education Foundation and the grant coordinator for Ashland Public Schools in Massachusetts, I actually helped to bring wireless devices into our district so I felt morally obliged to raise this issue. Our school committee researched the history, the science, the manufacturers and the lobbyists. Health advisories are buried in fine print so they realize that most folks, themselves included, did not know that Wi-Fi poses harm. Ashland Public Schools rolled out best practices for mobile devices to keep safer distances and turn off Wi-Fi when not in use. Framingham, which is one of Massachusetts's largest towns is also looking to do this. While scientists strongly recommend using only hard wired connections, I was grateful our school committee at least put precautions in place as a first step. Then I realized the rest of our citizens didn't know about the potential harm and our public health officials didn't appear to either. I spoke with our town manager, assistant town manager, department of public health, and nobody knew. They reached out to the state of Massachusetts and nobody at the state level knew, in the department of public health two years ago. They are however starting to look at it. We are very grateful for the work that folks that others have done in this field. So once I got the attention at the school level, I looked at my own home and said, oh my gosh, I just bought my daughter a laptop for Christmas. And for whatever reason our reproductive organs are one of the most susceptible areas as well as our eyes and our brain. So I look over and see my 16 year old daughter sitting there with a laptop on her lap, and so, what we did is -- we rewired everything. We have wires running directly through an ether net cable to their laptops. I've taken all of the cordless phones out and they are off the charts high on radiation as well. I had turned off the router and called up our internet service provider to find out how to turn off the router because it's bundled with all of our -- the triple plate you get from your internet provider and they gave me a code to request on-line. I pop in and turn it off when my daughter needs to print something wirelessly we pop it on for two seconds and then we turn it off again. So at home this is totally doable. So I bought a Wi-Fi radiation meter and when I realized that folks in my town didn't know about it, I went and met with Senator Karen Spilka in Massachusetts she and I were fortunate to work together on the education foundation so I went to her office hours at the local coffee shop. I asked if I could measure her cell phone and that -- the laptop that her district assistant brought with her. And both of them measured off the charts. So she was very kind to put me in touch with a lawyer in her office and last fall we worked on drafting a small piece of legislation which in January she introduced a Senate Bill 1222 called An Act Creating a Special Commission to Study the Health Impacts of Electromagnetic Fields because as so many of you have said, we've got to get the word out there. This is very toxic and it has very high compounding effect. So if you are not feeling sick yet, what are the odds? We are swathed in this now wherever we go today. So the utility smart meter -- oh, a couple other things. So we did the ether net cables to our daughter's lab tops and turned off the Wi-Fi and disconnected the router and put our phones in airplane mode win we were not using it. That's nice tip to anybody knew to this. Don't stick it in your pockets or your bra. We've seen a lot of cases of young girls and women who use it as a pocket, getting breast cancer. It's also impacting our fertility here and we are now seeing men get breast cancer because they are carrying it around in their shirt pocket. So put it in airplane mode if you are out and about with your phone. That smart utility meter is the only thing that I can't control in my home and I am very grateful to Patricia Burke and others who are working on the smart utility meter issues in Massachusetts. So how did we get so over exposed to radiation? Harvard University's Norm Elster published a report on June 30 out of the law school, doctor for ethics at Harvard, detailing how FCC leadership has suppressed critical scientific findings which is likely how our citizens and the public servants have been kept in the dark. And I have submitted to you folks through e-mail what that is. But it's called captured agency and it's an exposé on how the FCC has somehow gotten us all to this point where we are now crazy, busy, with Wi-Fi everywhere we go. So, when I went to our own department of public health, our leaders just a wonderful man, also a selectman in a different town. So he gets this. And he said CeeCee my hands have been tied. We don't even have the authority at the local level to say where a cell tower can go. And I went really? And he said yes because the FCC through their deep pockets and wealth have been able to put laws into place to say that if anybody has a health complaint because of these cell towers, you can't come complain to us. So he assumed with the cell towers that their hands were similarly tied with Wi-Fi but it's not. What happened with Wi-Fi is our government thought it would be a great opportunity to make some money. So they put all of the Wi-Fi licensing up for bid right at the time that the dot comers were coming through. So a lot of the dot.com’ers bought licensing for Wi-Fi and the industry doesn't have a lock on it like they do with cellular. Don't be fooled into thinking you can't do anything because you absolutely can at the local level. That's why we need your help. Okay. And then another bit of good news that happened over the summer is Berkeley California just unanimously passed a historic right to know ordinance after industry killed a similar measure in San Francisco. Consumers will now be handed safety information every time they purchase a cell phone. So Harvard law professor Lawrence Lesick is a first amendment expert and is prepared to defend this ordinance, pro bono. He and another gentlemen wrote this. They will defend it pro bono to the Supreme Court for Berkeley and any other municipality that wants to do this. They are powerful people ready to back you because they are going crazy that we allowed this to happen. So I hope the Governor's Commission on Disabilities will do what is best for Rhode Island citizens and provide radiation free living, learning, and working spaces for those who already are impacted electro hypersensitivity, and help to implement policy that will prevent others from becoming disabled. Thank you for your time and consideration {APPLAUSE}.

CASEY GARTLAND: Would you like to speak now?

Accessibility

SHERRY WIDYK: Hi. My name is Sherry Widyk and I have had years of cell phone use because I was a contractor and I've always put the cell phone in my right pocket and I was diagnosed with breast cancer in 2014. So I can attest to the fact that it's a -- such a detriment and especially now with the iPhones where everybody is going like this and young people are just going like this. All these wireless devices. They are held in positions. They are not up to your ear. They are at body parts that cannot get rid of the heat, okay. Your microwave radiation is cooking you. And it's cooking these parts and especially in children. So anything that you can do to limit that especially for school children. I mean, I'm older and I'm now fighting a battle for my life and I can't go into places that have these super routers because my heart beats like this. And I come out like this. And that's not something in my head. I've seen my poor sister with migraines. I've seen her son having to go out of school. She's home schooling him and people think that that is insane. But it's not insane when you get sick. And she is sick. Her son is sick. People are getting sick. And until people -- the governing authorities understand there's a class of people who are getting ill. They are getting sick. They are getting cancer. They are dying. And then it will become the reality that this was the smoke, the cigarette smoke in the 1950s where every movie had somebody smoking because they were promoting it and every ad that we have now on television is promoting wireless devices. So I feel like these people are the pioneers. They are strictly the pioneers. They are the grass-roots. But they need to get that message to the people like yourselves that have the impact to say, stop. We want to do a little more homework on this before we affect and lose a generation of children. Thank you

CASEY GARTLAND: Thank you {APPLAUSE}. I want to --

Accessibility

MARY ADKINS: Can I say one more thing, if we have another minute because I would like to talk about something? Mary Adkins. I neglected to talk about the smart meter issue in Rhode Island. Do any of you know what that is or what that means? So currently we have what is called automated meter reading meters AMR and the initiative across the country is to go to what is called a smart wireless meter which is an AMI, which stands for advance metering infrastructure and basically that means going from the one way transmission meters that we have now to two-way transmission meters that talk both to the utility company and back. And we are -- I think we are the only state actually that doesn't have a full-fledged smart meter program and I am begging this committee to ensure that we don't go down that road because all you need to do is go on-line and look at some of the smart meter websites to see literally hundreds and hundreds, probably thousands, I think at this point of testimonies from people who have been injured by the radiation from these devices who claim that once that meter was put on to their home they started suffering seizures, migraines, headaches, weakness, dizziness, fatigue, heart palpitations. The sheer number of testimonials is just staggering. And the film Take Back Your Power that Sharon mentioned is very informative as well. I want to quickly relate a story of a friend of mine who had four stage cancer who lived here in Rhode Island and by the time I met her she was already pretty ill. And we found out that the AMR meter on her home was transmitting microwaves into her home 24 hours a day and she was already sick from chemotherapy and different things associated with her illness and she called the utility company to have them replace the meter. And they went back and forth, back and forth. And they were very rude to her and at one point the representative from the utility company said, well you would have cancer by now if it wasn't safe. So, long story short she finally got them to agree to take the meter off. And they didn't show up for the appointment. So then she called again and called again.

Finally she got a letter from her doctor and they basically never changed the meter and she is dead now. I want to say my friend would be here but she can't. And to have something like that happen in the state of Rhode Island is just unconscionable. When people are ill, when they have medical conditions, whether its electro hypersensitivity or something else, and they don't want to be exposed to this, because it either worsens its condition they already have or for someone like myself, the device itself is disabling to me and my children. We should have the right to not be exposed. The problem with the smart grid is that there is no opt out, as other people have said. The neighbor -- the meter on your neighbor's house is going to infiltrate your home whether you have a meter or not. The accompanying infrastructure and the repeaters and all of the infrastructure that gets erected will infiltrate your home whether you want it or not. And if you live in a multifamily home or apartment complex, there's no opt out. There's just not. Opt out is a nice little marketing mean that got designed to make us all think we were getting something when people started making noise about this. Well we are not getting anything. It's a fraud, frankly on the public. And I want the Commission to understand the ramifications of going down the road of the smart grid. If you look at what is already available on-line, you will see there are literally tens of thousands of people sick and why do we want to do that? Why can't we learn from what's happened elsewhere? There's absolutely no need for these meters, you know. Reading them the way that they have been reading them for decades' works perfectly fine. People's utility rates also skyrocket. This is what has been reported in other states because of the meters being placed in their home. Why, I don't even want to get into. But the point is there's no benefit and there's egregious health effects from them. I know a young girl who is 29 years old living in a tent in New Mexico who has daily seizures just from standard electricity never mind cell towers around her if she has to go somewhere and she got that way from a smart meter that was not installed on her own house in the State of Maine. But on the house next door. Okay. So you don't have to have one on your house to become ill. And I think people are just very, very unaware of how important this issue is and our public utilities are just sort of running over everybody and saying this is the way to go. This is the way of the future. Maybe the way of the future wireless isn't the way to go. Maybe it's not worth the risks and certainly as someone who has been impacted by this personally I can tell you it absolutely is not. And our public officials need to get educated about this. They need to stop ignoring the science. They need to start looking what is happening in people in other parts of the country. They need to stop this. So that's all I wanted to say. {APPLAUSE}

CASEY GARTLAND: Thank you. Before I -- I want to explain our role here because some of the testimony I think we feel that you guys feel we are commissioners. Not all of us are commissioners on the Governor's Commission. We are here as volunteers to listen and pass this testimony on to the commission who will therefore take it to the legislation. I want to be clear. We are not underestimating the fact we will be able to bring this forward and hopefully concentrate it into some good policy changes. But I want to make sure, not all of us are commissioners

ANGELINA STABILE: And those of us who are commissioners, I am a volunteer. I don't get paid or anything. I am a volunteer. I can bring this information to the people that matter. But I am just like you, the fact that they can choose to listen to me or not listen to me. I am just a volunteer. So I just -- I am going to do my best. I am getting an education. I never heard of these things before. And I am going to do my best to bring it to the proper authorities. But I can't guarantee anything.

MARY ADKINS: Can I say there are many of us in the audience here who would be very, very happy to meet with anyone from the Commission or any member of government about this issue because there's a growing public health crisis and people need to act. They need to act quickly

CASEY GARTLAND: Great. If you all registered we have your contact information. That is the purpose. We often invite people to attend meetings during legislation

CHARLENE SMITH: One really critical thing, we didn't talk about today -- Charlene Smith from Massachusetts -- when Xfinity changed our routers in 2014, all new routers in the houses. The old ones traveled 100 feet. The new ones travel 400 feet and much stronger. So what's happening is you drive through any street in Massachusetts and Rhode Island, and you are going to get hit. Whereas back prior to July 2014 this wasn't the case. This is another thing this radiation -- Xfinity did that

CASEY GARTLAND: Thank you.

Accessibility

CAMILLE REES: Can I say just a few more things briefly -- Camille Rees -- about Xfinity[32] and everything their doing. They are using part of the router in the home to be able to transmit other people's data through your home. So they basically established your house as a Wi-Fi hub that other people's information is going to be going through. And I don't think people understand the significance of those exposures. You can opt out but they don't really advertise that fact. And everybody needs to know they should opt out and get a hard wired router. Just want to follow up on what Cecelia said about the Harvard report that is recently out this summer called Captured Agency by the Edmond J. Safra Center for Ethics[33]. Two things in that that were new to me. There's the universal service fund collects 16 percent off of all -- everybody's phone bill for interstate calls and that was originally set up to be able to provide -- have enough capital to provide land line service to people in remote areas. Today the multi-billion dollar cell phone companies apply to get that pot of money and they have gotten 40 billion dollars from the universal service fund to allocate into putting, spreading Wi-Fi in schools and libraries. So what I say is we need to legally look into how do we apply -- how does your commission apply to get a few billion dollars to look seriously at what these choices are that are being made? You know, it's a big fund of money. So you know, it's really -- these telecom companies are already making billions of dollars and yet they are just being -- they are being given all this additional money to infiltrate schools with it and push it on to school districts. And the other thing was in that report, they did a survey as part of that report and they found that only 1.5 percent of people are aware that there is -- that the telecom act of 1996 took away state and local government's rights to resist antennas on health or environmental ground. There's a huge ignorance problem which has been the theme of a lot of people today. And it also showed that very significant percentage of people, if they knew that there were indeed health risk to this radiation, a very significant, of varying degree would limit their own use, protect their children, and go back to the land line and reinstall the land line. So the report ended -- it tried to end on a hopeful note saying well maybe this is the time for the FCC to unshackle itself from industry and -- because they are obviously tied to it. If they don't there is ultimately going to be a legitimacy issue for them, as the public increasingly finds out about the known, well documented, known for many decades risk to these technologies.

ANGELINA STABILE: Thank you for your time. This concludes our --

CASEY GARTLAND: How much more time do you need?

CECELIA DOUCETTE: Cecelia Doucette. I was fortunate to make some progress in my school district. A woman in a town next to me had a son coming home from school sick and she tried working with the school to get some accommodations and the administrator, it's a private, very prestigious school didn't want to help. And she tried six ways to Sunday to get this school to help make appropriate learning environment and they have not helped. So she on the 12th of August this year filed in the United States

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[32] www.xfinity.com

[33] http://ethics.harvard.edu/news/new-e-books-edmond-j-safra-research-lab

district court for the district of Massachusetts X -- they are not using real names because they don't want to jeopardize their son, 12 year old minor you suing -- mother and father suing under fictitious names for privacy reasons, they are suing the school by and through its board of trustees and Rupert Gufuston as the defendant. This will be very interesting to watch unfold because they are legally bound to provide a learning environment for this student and they are not fulfilling the commitment. So in testimony in their suit, they have letters directed to the school from four world known scientists in the US and abroad, some of them were mentioned here today too. I will submit this but we will send along the full court case for your consideration.[iii]

CASEY GARTLAND: Please do

DEBORAH LOUTH: I would like to mention one thing, Department of Education -- Deborah Louth -- a friend told me, I don't have the facts but a little town in Tennessee they have taken out all of the land lines. That is frightening.

## Rhode Island Email Testimonies

Good morning -

Thank you for holding the Disabilities Forums throughout the state in the next few weeks. It is all too common for those of us with “different abilities” to feel our concerns go unheard and this is a perfect opportunity for us to speak up about issues and situations that impact us.

I have a condition called Ehlers Danlos Syndrome. It is hereditary, degenerative, there is no cure, and the only treatment is the management of symptoms. Our bodies do not manufacture collagen correctly so our ligaments don’t support our body structure, all of our joints dislocate and sub-luxate easily and multiple times each day, we bruise easily, our skin and tissues tear easily and take twice as long to heal than the average person’s, and we are in constant, chronic pain. Though most of us must wear and use supportive devises (braces, splints, orthotics, canes, walkers, wheelchairs, scooters, etc), for the most part we “look normal”.

Accessibility

I wish to bring to your attention today the fact that I (and most likely many others with other mobility issues and disabilities) am being denied one of our most basic rights and privileges as Americans and Rhode Islanders - to serve on a jury. I have lived here for 48 of my 58 years and up until just a year or so ago I had, oddly enough, never been called to report for jury duty. A year or two ago I was thrilled to receive my letter, as I had long desired to do my civic duty and serve on a jury in my state. As it is difficult, painful and unstable for me to walk without aids, I use a scooter, a rolling walker, or a cane at all times. I was very happy to see, at the bottom of the letter I received, a number to call the court house downtown if I had any questions about handicapped access. I called, explained the mobility aids that I use, and a very helpful man assured me that the building was completely handicapped accessible, and there were ramps that would take me directly to the security line into the building. I was thrilled! However, he went on to ask me if I could climb stairs at all. I was confused, but I told him I could not climb more than perhaps a curb sized step or two, and that with difficulty and only if I was using my cane. He then informed me that while the building and court room were handicapped accessible, the jury deliberation room was up a good number of stairs and - if selected for a jury - I would have to go up and down those stairs to that room several times. I was heartbroken. I told him that would not be possible for me, and was there not an elevator or ramp of some kind, since he had just told me that building was completely handicapped accessible?? He told me no, unfortunately, while the building itself was ADA compliant with ramps for access, the jury deliberation room was not. I could certainly report for jury duty, but if I was chosen, I would not be able to serve on a jury if I could not climb the stairs to the jury deliberation room.

I ask you - does this make sense??

I am asking that a way be found to restore this most basic right and privilege to the mobility-challenged citizens of our state. Thank you.

Diane Weeks

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GREETINGS! The JAYCEES would like to submit for possible discussion, comments regarding the statewide public forums being conducted by the Governor's Commission on Disabilities.

Since we are all volunteers, it can be sometimes difficult to attend these valuable public discussions yet wanted to offer some commentary toward an issue that effects those on Disability (and poor elderly) via the SSI Program and a bill that is now pending in the Congress - The Supplemental Security Income Restoration Act of 2015.

Independent Living

What is SSI? SSI is a safety net program administered by the Social Security Administration (SSA) that provides a very basic income to older adults and people with disabilities with no or only limited other income and resources. Approximately 8.4 million Americans rely on a monthly Supplemental Security Income (SSI) benefit to pay for their basic needs including rent, food, transportation, utilities, and healthcare co-pays.

How much money do people on SSI have to live on? The full monthly federal benefit is $733 for an individual and $1,100 for a couple, well below the federal poverty level. In fact, the individual benefit level is just 75% of the federal poverty level, falling far short of the amount of income support that seniors and people with disabilities need to meet their basic needs. For most recipients, SSI is their only source of income. Others receive small pensions or Social Security benefits, but these other benefits count against the amount of assistance they receive in SSI benefits. In addition to the strict income eligibility limits, SSI recipients must have assets below $2,000 to qualify for the program. The current program rules effectively require recipients to live below the poverty line, leading to homelessness, hunger, and illness among older adults and persons with disabilities. It’s time to update the SSI program to better serve our nation’s lowest-income seniors and people with disabilities.

Why is the SSI benefit inadequate to meet the needs of today’s poor seniors and the disabled? Most of the SSI eligibility rules have not been updated since the program was signed into law by President Nixon in 1972. For example, the amount of income a beneficiary is allowed to receive from other sources (such as a pension) without having their benefits reduced is $20. The cost of living today is more than 5.5 times what it was in 1972, meaning $20 today is equivalent in purchasing power to about $3 in 1972 dollars. In addition, the asset limit for the program - $2,000 – has not been updated since 1989.

How will The Supplemental Security Income Restoration Act help low-income seniors and people with disabilities? Under the Act several needed updates to the program’s eligibility rules will be made.

- Individuals will be able to save up to $10,000 and couples will be able to save up to $15,000 for emergencies such as car repairs, new roofs, and other unexpected expenses without losing benefits.
- Individuals will be able to receive up to $112 monthly from other sources, such as Social Security benefits or pension payments without a corresponding loss in benefits.
- Individuals who are able to work will be able to earn up to $364 a month without being penalized.

- Individuals who live in households with others, including family members, will no longer be penalized with lower benefits through the in-kind support and maintenance provision.
- Individuals who transfer assets (even small amounts of money to a family member) will no longer suffer harsh penalties.

These modest but needed fixes will provide much needed relief to our country's poorest seniors and people with disabilities, reducing instances of hunger, homelessness, relapses of illnesses and premature death.

We are grateful to many dedicated organizations that provide substantial information, support and activism for our nation's elderly and disabled citizenry in making improvements in such lives and lifestyles a significant part of our overall community. Please feel free to call or contact me anytime and thanks for the opportunity to exchange valuable public policy proposals for today's Elderly and Disabled Citizens.

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Dear Council members,

I am unlikely to be able to attend a public forum and would like to share recent experiences with my son's transition to adult services. I have contacted many state officials regarding the limitations of the SIS assessment tool's ability to address complex medical situations. The tool has led to the state violating its own rules and regulations regarding my son's services.

Independent Living

Devon is turning 21 in September and I am his legal guardian. Devon has high functioning autism. Were it not for his complex medical conditions, he likely would be capable of living semi-independently with assistance. Although Autism, his social skill deficits, behavioral challenges and anxiety are his predominant challenge in his ability to interact with the "real world," his disability is compounded by being medically fragile.

At age 6 Devon was diagnosed with insulin dependent diabetes. He had a benign brain tumor at age 9 requiring a craniotomy and had post-operative obstructive hydrocephalus requiring placement of a VP shunt. Three years ago he began having seizures related to his prior craniotomy. The seizures are fortunately well controlled. The problem with the SIS is it does not address insulin and other high risk drugs.

My son's SIS[34] was administered by a social worker who was seemingly trained in the instrument. I found her to be argumentative, condescending and difficult to work with. I brought copies of medical documents supporting Devon's need for medical supplemental services and she refused to take them at the completion of the SIS. Nowhere in the SIS is there a medical question about high risk injectable drugs. State regulations require insulin to be given by an RN. Registered nursing licensure requires the RN to administer insulin and the task cannot be delegated to another individual who is not an RN. My review of all state departments, including the Division of Developmental Disabilities, have similar policies requiring all injectable high risk drugs, such as insulin, to be given by the RN unless the individual is able to do so themselves. The only injectable drug that does not require an RN to administer it per policy is an Epi-Pen.

I was astounded that I was told at the SIS that I would need to save the medical documentation for my appeal. I was also shocked that with many individuals with developmental disabilities having complex medical needs, a computerized tool administered by a social worker was the instrument that was used to determine what level of funding was going to be used for adult services.

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[34] Supports Intensity Scale assessment

At this time, my son's case is being appealed and a decision is pending. I have addressed this information with Charles Williams, Director of Developmental Disabilities. I was referred to him by Ms. Maria Montanaro who declined to address the issue herself. Mr. Williams called me personally and is working to resolve the issue. Unfortunately, however, I have found that he and other authorities at the Department of Developmental Disabilities were unaware of their own rules and regulations regarding insulin administration. They seem to be unaware of any other individuals with a developmental disability that are insulin dependent diabetics. I find this hard to believe.

Independent Living

I believe the SIS is flawed. If the state has rules and regulations, the SIS must be modified to be compliant with the written rules. A simple questions asking "Does the individual use any injectable medications" would be sufficient to address the issue and alert staff to review the SIS accordingly.

I urge you to consider the importance of these issues. Using a flawed tool like the SIS and to have social workers who have no medical back ground to be administering and reviewing the results is problematic. As a physician, I find the lack of knowledge of state personnel concerning. I do not think that social workers or state officials understand that even minor errors in high risk drugs like insulin can lead to death or other serious medical complications within a few hours.

From a Commission standpoint, it is important that you consider the impact on the disabled individual. Because my son is diabetic, his medical disability will preclude him from receiving appropriate developmental disability services as an adult if he does not receive an appropriate level of funding. No day programs will consider him because he requires the availability of an RN. Day programs will not accept the liability if the funding level is inappropriate. So the state will effectively discriminate against my son because of his medical disability.

It is my hope that you will consider that the systems flaws need to be corrected to protect individuals with medical and developmental disabilities in the future.

With highest regards,

Ethel Condon M.D.

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Dear Members of the Commission, I heard that you were having a series of forums throughout Rhode Island to engage in dialogue with disabled Rhode Islanders and understand their needs and how better to serve them. This is an excellent idea and I commend the Commission for taking this important action.

Accessibility

I would like to take this opportunity to talk about the needs of EMF-Sensitive Rhode Islanders and offer information about what is going on in New York State on related matters. The Woodstock Library (Woodstock, NY) always disables the Wi-Fi for forums upon request. Recently, they have shown movies having to do with wireless health hazards and had a discussion forum on wireless smart meters and attendant health hazards. The Wi-Fi, which is the main issue since it is a continual emitter, is shut off and signs are posted at the door of the library to ask people to shut off their phones. An announcement is made at the forum as a reminder. Even where people forget or don't comply, the majority does shut off their phones upon request and this helps improve the electromagnetic environment in the room tremendously to the point where it is tolerable by many, if not most, electromagnetically sensitive people. In addition, the fluorescent lights directly over the audience are turned off. This protocol is in line with the directives of representatives of the United States Department of Justice ADA Division. USDOJ states that state and local government need to make accommodations for EMF-sensitive people; it is particularly necessary when this class is affected by policies under discussion. In addition, the Department of Public Service (DPS) is putting together a forum that has no Wi-Fi in a building not near a cell transmitter and with phones turned off in the room in order to hear directly from EMF sensitive people, who are affected by their policies, and in order to comply with the law. The building owner at their NYC forum couldn't or wouldn't disable the Wi-Fi, so the DPS is setting up an additional forum in Albany that is accessible. CBS news has run at least half a dozen stories on this problem in the last few weeks; the New York broadcast indicated that 5% of the population cannot tolerate Wi-Fi. This is in line with estimates cited by an EU consultative body. (A 2012 EU resolution says this problem is growing exponentially.) The California Department of Health put out a report in 2001 (14 years ago) that stated that 3% were EMF sensitive. Besides the legal requirement to accommodate, it is important for government agencies to hear directly from EMF sensitive people about a myriad of issues, including but not limited to the fact that they have almost no access to critical services, including courts, libraries, doctors' offices, libraries, schools, etc.; this is both a disability and a public health problem; any discussion on reasonable accommodation needs to account for the scope of this problem and provide a healthful environment for all building occupants. This view is espoused by the Access Board which stated in a 2005 report that was written in conjunction with the Nat'l Institute of Buildings Sciences that hard wired connections are preferred, and if Wi-Fi is used, it should be confined by foil-backed drywall and not spilling into the entire building, unfettered. Thank you for your consideration.

Sincerely,
Deborah Kopald,
Review Editor, Frontiers in Public Health

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Independent Living

Good morning, I am writing in response to the article that I read on RI Futures, regarding a recent forum where some of the clients expressed concern about accessibility and treatment by RI DHS SNAP offices (particularly in Wakefield). For the past 15 years, I have managed the state's contract to conduct SNAP Outreach – and our goal is to increase access to SNAP by providing assistance to potentially eligible clients, helping them apply and retain their benefits. Additionally, I chair the SNAP Advisory committee, a monthly meeting of advocates, social service representatives and DHS administrators to discuss ongoing issues with SNAP (programmatic, procedural, and individual).

While I was not surprised by the contents of the article, I wanted to reach out to you and the commission to make sure that people know that we are available to assist clients and to offer any information that we might be able to. While we do not have any magic tricks, and cannot always solve individual's problems, and we are not able to change DHS staff attitudes, we are often able to make headway where individuals struggle.

If you would like more information about what we do or if you think we might be able to assist you in the work that you do, please feel free to contact me. Additionally, over the years we have had representation from folks in the disability community participate on the advisory committee (it is open to all) but I do not think that we have had anyone recently (Linda Ward comes to mind and that has been awhile). We would welcome participation by a representative of the commission at our meetings, and if regular attendance is not possible (I know that we are all over-committed), I would very much like to invite you, or a designee to come and make a presentation to our committee at one of our upcoming meetings.

I look forward to hearing from you.

Sincerely,
Kathleen Gorman, Ph.D.

Director,
Feinstein Center for a Hunger Free America
University of Rhode Island

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Independent Living

Hi, I wasn't able to attend the meeting you had on July 30 for people with disabilities and I've been having a continual problem I was hoping you could help me with. I would like to know why is it a huge problem to get in touch with anybody, and have somebody have the decency to return a call or reply to a letter, from the Woonsocket DHS office? I was notified in March (I believe) that I wasn't eligible anymore for the Medical Assistance Program because I am getting $1,049 from Social Security Disability each month. I had no problem with that. Then on May 4th 2015 I receive another letter from the Woonsocket office of DHS stating that my eligibility for RI Medical Assistance has been re-determined and that they have found me now eligible for Medical Assistance coverage. I wanted to know why am I now all of a sudden eligible. Since May 4th, I have called the Woonsocket DHS office twice (each a week apart) and both time I was transferred to a person but got their voicemail both time. It was two different people (I don't remember who) and I left a message both times. I never got a call back. Then I wrote a letter to the Woon. office stating that I would like to know why I am all of a sudden eligible for Medical Assistance coverage and what exactly does it cover. I also asked if they could tell me how I can get a replacement Medical Assistance anchor card. After about 3 weeks of not receiving a reply, I sent the same letter again, and this time I addressed it to the attention of the Supervisor. After another couple of weeks of not getting a reply, I decided to send a letter to the Warwick office of the DHS. I only asked them if they could tell me how I can get a replacement Anchor card. About a week later, they didn't just tell me how I could get a replacement card, but they actually sent me an actual Medical Assistance Anchor card, without any hassle. Why can the Warwick office accomplish this but the Woonsocket one can't? So my question for you is why has it been so impossible for me to get anybody in the Woonsocket DHS office to simply respond to my inquiry about a replacement card and especially to explain to me what exactly my coverage is and how does it work? What really upset me was when the letter I addressed to a supervisor at the Woon. office still went unanswered. To me that is totally uncalled for and very bad public service. As of today, I still haven't received any kind of reply from the Woonsocket office of the DHS.

Christopher Talabac

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Accessibility

Hello, I could not tell you the exact date that my sickness began, but I clearly remember when it stopped. Almost six years ago, I bought a house, soon after I began to feel sick. I was under stress at home and had insomnia. I I assumed my sickness was a result of this and was seeing a doctor for the insomnia. My life was completely changed after a few years. I just planned on going to bed at 4:30 pm, right after work. My eyes hurt so much I would be holding my head and eyes by 3:00 in the afternoon. I forced myself to go to work every day and suffered. I really was only able to work, get groceries and gas....the bare minimal. When I stayed home I would be nauseated by noon. It was awful. I finally confided to one of my friends that I felt disabled. I really didn't know what to do. I got another job which was not in an office .I noticed that the headaches would seem to alleviate about a half hour after I left my house and began telling my clients that I felt better at their houses.( They were elderly and had no Wi-Fi.)

Last year in May I saw a flyer about this Wi-Fi sensitivity, and it listed all of my symptoms. Nausea, headaches, chest discomfort...I really thought my own problems were due to stress but I would try anything not to be sick. I went home and unplugged my modem, rewired in my computer, inactivated my wireless printer, and basically rewired in everything I could that was wireless. I really did not have much hope but was going to try this for a few weeks to see if there was anything different. The first week I didn't think much about it, I don't remember feeling that much better, but the second week. It was a miracle! I felt normal again, healthy. I still had all the same stress but the headaches and nausea were gone. I had cox come and re wire my computer. When the man came I explained why I was doing this and he said that he believed me, also he told me his brother lived in France and that they already knew this I recently purchased an iPhone and within 2 days had the same sick feeling. I have to turn off the cellular feature and am now having problems with the phone. Also I went on a trip where I was staying in an apartment with Wi-Fi and the headaches returned. This is real! I work in private homes with elderly people, but I am terrified if or when she dies because I truly do not think I could work in an environment where there is Wi-Fi.

This will affect my life.

Thank you for reading this.

Sincerely,
Elizabeth Monteforte,

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## Rhode Island Written Testimony:

Sam Parish, Civil Engineer
20 Year Veteran Infrastructure Rehabilitation Technology Specialist
Rhode Island Resident 12 yrs.

CREDENTIALS REGARDING EMFs:[iv]

TESTIMONY:

Accessibility

As a civil engineer who has field tested and measured the effects of electromagnetic fields (EMFs), I would strongly suggest this Commission consider the following two (2) solutions to guide decision making regarding electrical infrastructure development and maintenance programs to meet the needs of the growing number of people with disabling sensitivity to EMFs. Evidence to support these solutions is also provided.

1. **The electric power industry has put forth health concerns from over forty years of research on EMF management.** We already know how to engineer and build infrastructure to **cautiously reduce power frequency (60-Hz) EMF exposure.** The Commission can lean on the industry for guidance **to accommodate people with sensitivity to EMFs.**

2. Understand that cell phones, wireless routers and cell towers emit wireless radiation **which is a compounding form of environmental pollution.** Wireless networking is **not a sustainable technology** for many reasons to be explained including cyber security and adverse health effects. "Wi-Fi" has already begun to be **rolled-back and removed from installations** in schools and public facilities **globally. Conventional wired networks are exceedingly more secure and appropriate for the majority of municipal government and public infrastructure.** Light speed fiber optic technologies are maturing and increasingly available.

By accommodating people disabled by EMFs, Rhode Island has another opportunity to lead the nation in progressive enhancement of civil infrastructure for the disabled. It is my belief that current health effects research overwhelmingly demonstrates that adverse health effects do occur from EMF exposures, and I would urge that any decisions made regarding civil infrastructure **consider "what can be done" to reduce these exposures, in the absence of clear regulations** within frameworks developed under the ADA. A "precautionary approach" to technology emitting EMFs has already been adopted by many other governments across the US and around the world (see "International Policy Actions on Wireless" on www.ehtrust.org website), as well as reports provided by our own electric power industry.

EMFs ARE FUNDAMENTAL TO THE ELECTRIC POWER INDUSTRY

- EMFs - "New concept" for general public, but fundamental to electricity
- Health effects have always been a concern for the electric power industry
- Engineers and contractors have the knowledge and technology to manage power frequency (60-Hz) EMFs already.

The fundamental properties of electromagnetic fields (EMF) have been understood and practiced by engineers and scientists for over **100 years**. Standard tools for electricians are non-contact voltage pens and amperage clips which measure EMFs to determine voltage. The technology employed in present day engineering of nuclear power generation plants, solid state computer hard drives, power distribution and shielding systems demonstrates how well we have mastered the science.

**Concerns regarding health effects and interference with electronic equipment has formed the basis for over forty years of research on EMF field management by EPRI (Electric Power Research Institute).** Established in 1973, the Institute's research and development program spans every aspect of generation, environmental protection, power delivery, retail use, and power markets. EPRI provides services to more than 1000 energy-related organizations in 40 countries (mostly electric utility companies).

The following referenced report produced by the EPRI has provided guidance for engineering and design of electrical systems and electrical code globally since 1999 publication. Here is the opening statement and introduction to the report:

**REPORT SUMMARY**

*Concerns about possible health effects of electric and magnetic fields (EMF) as well as problems associated with interference of power-frequency fields with sensitive electronic equipment, have driven the need for information on reducing fields from electrical facilities. This report assembles knowledge gained from a range of research efforts into a useful reference book for professionals involved in engineering aspects of EMF management.*[v]

ENGINEERING ACCESSIBILITY FOR PERSONS DISABLED BY EMFs

### Power Frequency (60-Hz) EMF Mitigation

Engineering solutions already exist to provide persons suffering disabilities from EHS safer (Low-EMF pollution) access to facilities providing medical care, basic goods, services, libraries, courts, state and local buildings, schools, public transportation and public spaces. As with all infrastructure projects, design considerations, especially regarding EMF mitigation have cost implications. **There are engineering design firms and consultants who perform EMF testing on a daily basis who specialize in this type of work.** Power frequency EMFs (60-Hz) radiating from electrical AC powered lines and commonplace electrical equipment is confined by relatively short distances. For 120-Volt unshielded residential equipment, EMF distances of 10-feet are common, while fields from high power lines generally extend a few hundred feet. The magnitude of these fields is a function of the Amperage (or load) being carried at that moment by the conductor.

Power frequency EMFs (60-Hz) can be mitigated by:

1. Increasing the distance between power source and person
2. Applying shielding to the power source
3. Installing active field cancellation systems
4. Install smart systems which reduce power (voltage) to sources when not in demand

**Wireless, or Radio Frequency (RF) Energy or Radiation Mitigation**

Wireless RF energy is different from the predictable electromagnetic fields radiating from power lines. The electromagnetic energy from RF devices extends outward from source equipment beyond the immediate vicinity (within a few feet) where a "feedback loop" from the emitting device is measurable. **Like waves in the ocean**, the fields propagate until they are attenuated (reduced) by building materials, structures or elements present in nature.

**Microwaves emitted by cellular communication devices have a much higher frequency and shorter wavelength than larger radio waves.** For decades, scientists performing experimental studies on health effects have been challenged with replicating a specific frequency exposure for technology that is constantly changing. These scientists, whom are experts in the field of bio effects, have been providing overwhelming evidence that microwave radiation (which is increasing the fastest in environmental exposure levels), produces a wide range of adverse biological effects on the human body including the neurological and reproductive systems.

Most individuals are not aware of the safety warnings associated with cell phone devices. There are no device manufacturers in the wireless technology sector that will say their product is "safe." The statement is always "our product meets federal (FCC) guidelines." These guidelines are presently 15 years out-of-date. Please visit www.ehtrust.org To watch edited video of Massachusetts State House Briefing: Public's Right to Know About Cell Phone Safety, expert testimony provided June 10, 2015 for more info.

**Wireless radiation** from cellular towers, Wi-Fi routers and cellular phones (listed here in decreasing EMF power density output) **must be shielded or eliminated to provide a healthy and low-EMF building or environment. Two solutions exist to protect people whom are EMF disabled:**

**1. Terminate purchasing of wireless equipment, remove existing equipment and install only hardwired Ethernet or fiber optic networks**

**2. Install shielding and establish RF SAFE ZONES (both corridors and rooms). Shielding configuration would be similar, but using less expensive shielding materials than those used in X-ray and electrophysiology suites in hospitals.**

Because shielding from microwave and other radio frequency EMFs can be accomplished with metal foils, specialty paints and mesh that are readily available, the materials are generally less expensive than shielding systems used in MRI's, electrophysiology labs and cardiac catheterization labs. Installation and configuration of microwave shielding however, remains complicated and expensive, especially for retrofit projects. It is much simpler and cost effective to **build hardwired infrastructure** in place of shielding from wireless networks. Fiber optic systems are virtually EMF-free with exception of signal conversion at endpoints.

Radiation emitted by wireless technologies, which produces biological effects in all humans, is detectable by persons with EHS from hundreds to thousands of feet from the emitting source equipment. Similar to X-rays, wireless RF radiation penetrates almost all building materials except metal and shielding meshes - from which it often reflects and finds other angles of entry into spaces. To visualize what effective shielding has to attain, it is similar to trying to hide from a flashlight beam.

**Recommended actions for this Commission are as follows:**

- **Stop installation of Wi-Fi routers in public infrastructure and spaces.**
- **Stop roll-out of any "smart meter" programs.**
- **Stop roll-out of any DOT corridor broadband programs.**

Wireless technology has expanded and changed quickly over a very short time period. The Wireless Association has virtually unlimited lobbying power and monetary resources to increase this growth. Like many other environmental pollutants not caught in-time, the backlash and cost to human health is almost unimaginable. This has already been evidenced by a growing number of people who are suffering from electromagnetic hypersensitivity globally, and the fact that World Health Organization (WHO) is currently under immense pressure to develop the framework required to recognize, diagnose and treat EHS as a legitimate condition within medical communities.

"ALL THINGS WIRELESS" IS NOT SUSTAINABLE

**"The Internet of Things"** commonly refers to the proliferation of industrial, commercial and household devices which are now capable of connecting with a cellular or Wi-Fi network. Said differently, the devices are communicating via one-way or two-way signals, electrical energy, **sent in the form of RF microwave radiation (or an electromagnetic field).**

As leaders and decision makers guiding public policy, this Commission must continue to ask the question: ***"What can be done to reduce exposure from electric power facilities should health effects research demonstrate that adverse health effects may actually occur?"***

Unfortunately, the convenience of wireless technologies and ease of implementation has made it a choice of many decision makers. While there are numerous applications of this technology in industries that are worthwhile, very few applications of wireless technology in the realm of public service and public infrastructure are absolutely needed. For example, please ask yourself why the following concepts may sound like bad ideas if health effects research demonstrates that adverse health effects actually occur from EMFs, and this technology has to be rolled-back and pulled out:

- Public Broadband?
- Public Wi-Fi Hot-Spots?
- Broadband Government Safety and Security Networks?
- Digital Government?
- Wi-Fi in Schools?

The electromagnetic fields radiating from each wireless device on a network, regardless of type, continue to overlap and compound the exposure levels of every public space the devices are installed. This is not sustainable.

## WI-FI IS LESS SECURE THAN WIRED

Control, security, reliability and speed are the primary benefits of hardwired networks. Veteran network administrators acknowledge this fact. Physical connection is required to access hardwired networks, which means the network will also not be overloaded with non-business critical traffic, for example, streaming wireless media on personal devices.

Network cyber security depends on the weakest link in the chain of components operating on the network. Each link in a chain of "smart" devices on a wireless network must be protected by security technology that involves encryption protected hardware and/or software. Wired networks are protected by both security technology and physical connections.

Malware and cyber-attacks on public service networks are a real and growing threat. In wireless networks, a basic password allows "shared" network access with devices which often do not have adequate security technologies "on board" or may already be compromised. In addition, wireless networks extend beyond the physical walls of the office, giving attackers another potential route of entry. **Wireless networks are simply not secured to the same extent as wired infrastructure. Hopefully this helps the Commission with future decision making regarding network technologies.**

Light speed fiber optic network technologies are now mature and now have become cost effective technologies and are worth investing public money. **EMF disabled persons cannot function in a society with "all things wireless" and it is a healthier, safer and more cost effective choice for everyone to avoid wireless technology altogether.**

## SPECULATION ON AUTO INDUSTRY AND WIFI IN CARS

The following opinion regarding public service fleet vehicle Wi-Fi option is offered: Some automobile manufacturers recommend mounting vehicle antennas in such a way as "to provide maximum RF shielding" for vehicle occupants, as well as minimizing EMF interference from engine / dashboard components. This antenna location concept is apparent in most of the new automobile models released today - as it is now typically placed as far from the driver as possible, and located on top rear of the metal roof (shielded cab). Most in-auto Wi-Fi is usually connected via "optional" networking sync, requiring owner activation and smartphone integration (shared EMF emitters and liability). This industry has wisely positioned itself to mitigate potential backlash should health effects research demonstrate that adverse health effects occur from wireless EMF exposures.

## HOME AND OFFICE WIFI FREE SOLUTIONS (FOR REFERENCE)

- Add additional Ethernet wiring to key locations of home & office - most houses can be done in a day with licensed electrician
- Cox / local internet service provider (ISP) will replace wireless modems with a wired modem upon request
- Wired Ethernet router such as TP Link TL-R600 VPN
- Wired Ethernet switch such as TP Link TL-SG1024DE for more Ethernet ports, connect this to the router

- Android tablets with docking stations for HDMI TV input and USB to Ethernet adapters work great on airplane mode
- Windows PCs and Apple laptop PCs connected to internet via Ethernet to USB adapters work
- Most Android GPS navigation apps including Waze work in airplane mode, AFTER destination is entered.
- inReach / Delorme mobile devices offer text messaging and GPS navigation anywhere in the world via satellite
- OBIHAI - Google Voice Compatible Internet Phones are great, cheap and free service
- Android phones - FYI most applications are both downloadable and functional in airplane mode when connected to internet via Ethernet to USB adapters - Google Nexus series
- Future smartphones will have one way paging / text message capability to allow operation full time alerts in airplane mode. For now, can carry your smart phone and an old school one way text pager - can try PagersDirect $20/month.
- One way paging services can be used with Google inbox filters and Google Voice to forward critical text messages to pager. Can keep smartphone in pocket in airplane mode. Can turn on and respond if important.

Supplementary Reference Report Attached (PDF) to This Testimony[vi]:

My concern has to do with people (like myself) who spent time in a nursing home and were able to return home with CNA services. We've been having trouble filling all the slots for services. I am authorized for 70 hours a week. Luckily my husband has been able to fill in the important hours needed. I have four different agencies for CNA services and another agency for nursing services. They have not all been consistent in filling their respective hours. This has prevented my husband from working outside the home. One major problem I see is that CNAa's are not paid enough, per hour. Another problem is that, without full coverage by CNAs, my husband can't do any work away from home, and because he is my husband, he cannot be hired by an agency as a caregiver, and get paid. Any questions please e mail me.

Thank you for asking for comments.

Laure Manning, South Kingstown

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Dear Governor Raimando:

Independent Living

My name is Nick Cioe (see-oh) and I am a 33yr old native Rhode Islander returning to the state with my wife (also a native Rhode Islander) and three children (5, 4, 2) after a 7 year absence. During my time away from Rhode Island I earned my Master's and Doctorate in Rehabilitation Counseling & Administration with a specialty in Brain Injury Rehabilitation. I had worked in the Brain Injury field with Sargent Rehabilitation and worked in mental health with Brown University prior to leaving in 2007. Currently, I am working as the Program Director at the Center for Community Independence (CCI) – a progressive community-based brain injury rehabilitation company in Boston, MA.

Upon returning to the area, I reestablished communication with people I had known in the field and did some research to gain a sense of what had changed in the 7 years I had been gone. Much to my dismay, the information I received suggested little if anything had changed in the service delivery system for people who have experienced brain injury…especially in comparison to what had evolved in the four states (Illinois, Kentucky, New Hampshire, Massachusetts) I lived/worked in during my time away. One individual who had been trying to establish a treatment center in Rhode Island explained how he has been searching to find someone qualified for the last 5 years but no one either had the skills or was interested in coming or staying in the state.

While I will not pretend to have a full grasp of the state's efforts to address the needs, commission minutes and organized efforts at the state level seem to be insufficient and lack luster at best. A neurologist friend informed me that the state does not have a concussion protocol, which seems unimaginable given the hospitals and expertise in the state. In communicating with members of Sargent Rehabilitation's leadership team, I learned they too see the need and are trying to grow to help serve the countless in need without access to services.

Personally, I am in the trying to get my state licensure in place as the first step in the process of determining whether or not to remain in Rhode Island. However, being from the state and having lived and owned homes elsewhere I am concerned about the state's future and livability for young families. I will not buy in Warwick, despite it being where my wife and I grew up, because of the quality of the school district and high school (Toll Gate) I graduated from in 2000.

I greatly appreciate your efforts to solicit information from those invested enough to provide it. I am willing to contribute to any efforts made to address the service delivery system for individuals with brain injury in the state.

Sincerely,

Nicholas J. Cioe, Ph.D., CRC

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EMF TESTIMONY
R.I. GOVERNOR'S COMMISSION ON DISABILITIES
JAMIE ORR, SOUTH KINGSTOWN

I always *was* sensitive- the first one to notice any smell, from soured milk to a dangerous gas leak. This perceptivity was probably the consequence of a traumatic, breech birth combined with a prolapsed umbilical cord. Oxygen, gas, and ether were all given to my mother during delivery, and a cerebrovascular incident most likely occurred. It was in 1949 when the obstetrician told my parents, "A lucky day 1 in 1,000 chance of survival."

Accessibility

While the CYI left me with a profound sensorineural hearing loss in one ear, my other ear was exceptionally acute and no one could ever tell that I was hearing-impaired. In fact, I compensated for other visual, ocular-motor, and vestibular neurological problems, as well (by developing a left center of gravity).

As an adult, I was a professional educator for thirty years who lived a successful, productive, healthy life. During that time, it was possible to avoid or control environmental "insults" to my central nervous system (i.e. alcohol, drugs, cigarette smoke, moldy places, even sugar and salt intake, all of which can affect brain functioning and balance).

My first reaction to synthetic fragrance came in 1983 when I was a guest in someone's home. I encountered freshly laundered, *scented* bed sheets. Over the years, as the use of cigarettes became socially unacceptable, they were supplanted by the pervasive use of chemical fragrance. I became less able to avoid exposures.

The fragrance or chemicals "behind the scent" provoked a neurological reaction in me within seconds. Depending upon the type of chemical, I would experience mental overstimulation or cognitive depletion. I could react with headaches or hyperactivity. In the worst instance, semi-paralysis would occur. In that circumstance, I knew *who* I was, I knew *where* I was, I knew *what was happening,* but I was unable to think clearly, speak coherently or take action. I had to be told what to do so that I could get to into fresh air immediately.

As consumers embraced synthetic chemicals, public bathrooms, buildings, gatherings, and outdoors spaces became increasingly dangerous for me. Health care providers were regularly resistant and uncooperative so visiting medical facilities was, and still is, a problem. (Exposing patients to fragrances constitutes knowingly barring their access to safe health care. See the attached CDC Indoor Environmental Quality Guidelines. Appendix A, DOC #0205-CDCH-09-013)

Eventually, I learned about the condition of Multiple Chemical Sensitivity, but I did not identify with the many sufferers who felt ill and knew how they had been poisoned. I often had incidents of being affected, but I recovered quickly and completely when triggers were removed. I was not *sick.*

Because my school district enacted ADA accommodations for me including a designated fragrance-free classroom, I was able to continue to work. Administrators, parents, and children were very supportive. Unfortunately, I inevitably felt forced to take an early retirement because my supervisor could not persuade a staff member to stop wearing a fragrance which triggered my worst neurological reaction. As an employee, the woman had the *right* to wear scent, but I was afraid of incurring permanent cognitive brain damage.

I became aware of my EMF sensitivity when wireless devices became ubiquitous. At first, I didn't believe it. Having reactions without knowing the person sitting next to me had an active cell-phone or a library had installed a WiFi site, convinced me. I can best describe my experience as feeling as if I am a lightning rod or a radio antenna. I cannot stand the physical sensation which is something like being a silent tuning fork

Depending upon the strength of the signal, I also experience pressure in the injured portion of my brain, a headache, mental confusion, or agitation. I attribute these responses to central nervous system hypersensitivity resulting from my cerebrovascular incident.

With strict avoidance of certain chemicals and EMF exposures, and with a lot of effort educating the people I come in contact with, I remain a healthy, un-medicated, active, sixty-five year old.

As a person who has lived a full life with invisible disabilities in a far less chemically and electromagnetically polluted world, though, and as a former teacher holding several regular and special education certifications, I fear for the health and safety of our children.

I wonder: if I had been born into our environment as it is today, would I have been able to compensate so well? Or, would I, too, have developed more developmental delays and autistic characteristics?'

It is my sincere hope that the State of Rhode Island will actively fight for the recognition and legitimization of two debilitating health conditions: Multiple Chemical Sensitivity and Electromagnetic Sensitivity.

I look forward to a future when I will no longer be denied health and safety by people in my environment, when I will be able to live my life comfortably in public.

US CENTERS FOR DISEASE CONTROL AND PREVENTION

CATEGORY: Safety Management Document: # 0205-CDCH-09-013 (Excerpt)

Date of Issue: 6/22/2009

PROPONENT: Office of Health and Safety. Office of the Director

INDOOR ENVIRONMENT QUALITY POLICY

APPENDIX A CENTERS FOR DISEASE CONTROL AND PREVENTION INDOOR ENVIRONMENTAL QUALITY GUIDELINES

PART C. BUILDING OCCUPANTS

1. Non-Permissible Products
   Scented or fragranced products are prohibited at all times in all interior space owned, rented, or leased by CDC* This includes the use of:
   -Incense, candles, or reed diffusers
   -Fragrance-omitting devices of any kind
   -Wall-mounted devices, sm11lar to fragrance-emitting devices, that operate automatically or by pushing a button to dispense deodorizers or disinfectants
   -Potpourri
   -Plug-m spray air fresheners
   -Urinal or toilet blocks
   -Other fragranced deodorizer/re-odorizer products

   Personal care products (e.g. colognes, perfumes, essential oils, scented skin and hair products) should not be applied at or near actual workstations, restrooms, or anywhere in CDC owned or leased buildings.

   In addition, CDC encourages employees to be as fragrance-free as possible when they arrive in the workplace. Fragrance is not appropriate for a professional work environment, and the use of some products with fragrance may be detrimental to the health of workers with chemical sensitivities, allergies, asthma, and chronic headaches/migraines

   Employees should avoid using scented detergents and fabric softeners on clothes worn to the office. Many fragrance-free personal care and laundry products are easily available and provide safer alternatives.

   *References to CDC also apply to the Agency for Toxic Substances and Disease Registry

(ATSDR)

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SUGGESTIONS RE: EMF/WIFI CONCERN

To Bob Cooper at Rhode Island Governor's Commission on Disabilities (GCD), 8-20-15

Bob: I'm delighted that GCD has responded so promptly and appropriately to the concern about forums being non-accessible to those impacted by EMFs. As we both realize, this is a huge, wide-spread problem, and may seem intimidating to GCD, with its limited power to solve. However, I think there is a piece of it that is small enough, yet important enough, on which to focus. I see two areas that could be explored: public buildings & "smart meters".

"SMART" METERS: This could be low-hanging fruit, despite resistance from the companies involved. These replacements for existing none-EMF meters are totally unnecessary and even a job-killer. "If it ain't broke, don't fix it".

SCHOOLS & LIBRARIES:I suggest that work could be done on minimizing exposure in schools - and, hopefully, in libraries as well. It is happening already elsewhere. We can't tear the Cell Phones & Laptops from consumers' resisting hands. However, these some of these two types of public buildings could be at least places of some refuge from the bombardment of EMF/WIFI emissions.

Below is a quick set of links indicating both concern and action in other locales that might serve as a starting point in thinking about what might be done in Rhode Island. Note that there are also quite a few ads online re: devices claimed to shield against EMFs. However, it would be a bit of a job to figure out if any are really effective.

I hope you and others at GCD can find time to "consider the possibilities" over the coming months. There is no perfect solution, but some of the mitigating options described might be helpful.
Blessings, Liberty G

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Liberty Goodwin, Director, Toxics Information Project (TIP) 401-351-9193, www.toxicsinfo.org

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EXCERPTS FROM AMERICAN ACADEMY OF ENVIRONMENTAL MEDICINE STATEMENT ON WIRELESS RADIOFREQUENCY IN SCHOOLS: www.aaemonline.org/pdf/WiredSchools.pdf Nov. 14, 2013. The AAEM strongly supports the use of wired Internet connections, and encourages avoidance of radio frequency such as from WiFi, cellular and mobile phones and towers, and "smart meters." The peer reviewed, scientific literature demonstrates the correlation between RF exposure and neurological, cardiac, and pulmonary disease as well as reproductive and developmental disorders, immune dysfunction, cancer and other health conditions. The evidence is irrefutable… In May 2011 the World Health Organization elevated exposure to wireless radiation, including WiFi, into the Class 2b list of Carcinogens…There is consistent, emerging science that shows people, especially children who are more vulnerable due to developing brains and thinner skulls, are being affected by the increasing exposure to wireless radiation. In September 2010, the Journal of the American Society for Reproductive Medicine Fertility and Sterility, reported that only four hours of exposure to a standard laptop using WiFi caused DNA damage to human sperm. In December 2012 the American Academy of Pediatrics, representing 60,000 pediatricians, wrote to Congress requesting that it update the safety levels of microwave radiation exposure especially for children and pregnant women.

Wifi In Schools www.wifiinschools.com/ A website helping the public realize that wireless internet, or WiFi, emits radiation that causes a myriad of serious health effects, including damage to DNA, cancer, and infertility. Research shows that autism, ADHD, and other behavioral problems are also associated with wireless radiation exposure. Many scientific and medical experts have issued warnings because of the evidence before them. (See links on page)

EMF Exposure in Schools www.emfs.com/article/emf-exposure-in-schools

Many school officials and parents believe that Wi-Fi, "smart meters", or other sources of EMFs in the school are the cause of health concerns…

Teachers Unions In Germany, UK, USA & Canada Who Have Done Their Research Do Not Support WiFi In Schools, November 11, 2014, www.safeinschool.org/

Why Are Youths And Young Adults At Greater Risk? Investigation on Wireless Impacts on Children - Cell Phones, Wi-Fi, and Cordless Phones www.emfwise.com/children.php

EMFs in Schools www.electricsense.com/category/emfs-in-your-life/emfs-in-schools/

WiFi Radiation Free Schools List.

EMF in Schools – EHIB, www.ehib.org/emf/pdf/EMFinschools.pdf California Electric and Magnetic Fields Program A Project of the California Department of Health Services .

EMF and Schools http://fms-corp.com/emfbuildings_schools.php4 FMS has assisted numerous school districts in addressing EMF concerns in both new and existing school buildings.

## SMART METER REPORTS

Smart Meter Dangers: Solutions For Smart Meter Problems_California gives its residents an opportunity to opt out of its Smart Meter Program. https://smartmeterdangers.wordpress.com

Meter Radiation Exposure Can Be Up To 160% Greater Than Mobile Phones www.emf-health.com/updates/2013/10/smart-meter-radiation-exposure-160x-greater-than-mobile-phones.htm October 6th, 2013 | According to Daniel Hirsch, California radiation expert and UCSD instructor, one smart meter can provide up to the full body radiation exposure of 160 cell phones. Hirsch provides this information in his Comments on the Draft Report by the California Council on Science and Technology “Health Impacts of Radio Frequency from Smart Meters”. Hirsch criticizes the industry-influenced CCST report that incorrectly minimized smart meter risks, based on the widely distributed industry-generated Tell Associates report.

Smart Meter Dangers: Constant Microwave Emission

www.emf-health.com/updates/2013/10/smart-meter-dangers-constant-microwave-emission.html October 7th, 2013 Concerned about the potential dangers of smart meter radiation? A WUSA news station reports that digital smart meters installed by PEPCO utility have been emitting microwave frequency signals at a much higher frequency than the company claims. In this report, frequency signals that send data to the company have been found to occur at about 4-6 times per minute, as opposed to every 4-6 hours as Pepco claims. Some residents have complained of dizziness, headaches and other health issues since the smart meters were installed.

Public Health Physician: No Evidence Smart Meters Are Safe

www.emf-health.com/updates/2013/10/public-health-physician-evidence-smart-meters-safe.html

October 6th, 2013 Physician and former Director at the New York State Department of Health Dr David O. Carpenter talks about the impact of Smart Meters on our health. **“**The question to ask… is what is the evidence that smart meters are safe and have no adverse health effects? The answer to that questions is: there is no such evidence. In fact, while no-one has actually done human health studies in relation to people living in homes with Smart Meters, we have evidence from a whole variety of other sources of radio-frequency exposure that demonstrates convincingly and consistently that exposure to radio-frequency radiation at elevated levels for long periods of time increases the risk of cancer, increases the damage to the nervous system, causes electro-sensitivity, has adverse reproductive effects, and a variety of other effects on different organ systems. There is no justification from the State Department that Smart Meters have no adverse health effects.”

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**EMF SUSCEPTIBILITY & LEGAL REDRESS**

Australian Government Ordered To Compensate Worker With Electromagnetic Hypersensitivity www.gsma.com/publicpolicy/australian-government-ordered-to-compensate-worker-with-electromagnetic-hypersensitivity

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## Out-of-State Emails

You must recognize Microwave Sickness[vii] as a disability and do something about it.

Accessibility

As someone very active against so-called and misnamed "smart" meters here in Arizona, I field calls often from people injured by EMFs and suffering from Microwave Sickness. When I first got involved in the issue over 4 years ago I was skeptical about people's health issues. Not any more. I have read independent studies (as opposed to industry sponsored ones) and I have seen what EMFs can do to people. Below are just a couple of Arizona stories, one on YouTube, one in print.

Watch and listen to Sedona "smart" meter victim, Marianna Hartsong, as she recounts everything that happened to her after APS installed six "smart" meters surrounding her property last April. **Smart Meter Hell in Sedona**: http://www.youtube.com/watch?v=WHk3cLf85Dk

On page 12 of the June 2014 Flagstaff Noise you can read about Phoenix "smart" meter victim, Bob Rhodes, and how he got seizures after his APS "smart" meter was installed. He didn't know what a "smart" meter was or that he had one. But when he found out and then had the "smart" meter removed, the seizures stopped.[viii]

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Re: Electromagnetic Hypersensitivity and Disability

In November of 2013, William F. Sinnott, Corporation Counsel for the City of Boston, submitted testimony to the FCC regarding the inadequacy of U.S. radio frequency exposure guidelines. http://apps.fcc.gov/ecfs/document/view?id=7520958343

Accessibility

Counselor Sinnott wrote: *"The 1999-2000 judicial challenge to the FCC's 1996 rules never reached the issue of "electrosensitivity" as a cognizable disability under the Americans with Disabilities Act. ("ADA")*

*Here again, an agency responsible for ADA implementation acknowledges that the impairment may be disabling but has promised merely further inquiry. After more than a decade, that investigation remains unopened."*

*"The dockets here have been updated with massive additional evidence of the crippling effects of RF radiation on an admitted minority – but a suffering minority – of U.S. citizens The FCC and its sister regulatory agencies share responsibility for adherence to the ADA and should replace promises with serious attention to a serious medical problem. This is one area where the FCC could lead in advice to electro sensitive persons about prudent avoidance."*

The U.S. has not addressed this issue, and is pursuing wireless smart utility meters and infrastructure, placing industrial-scale Wi-Fi in schools, overriding local zoning protections for the placement of towers and antennas, and planning to eliminate land-line phone service. The U.S. is fueling explosive growth of the wireless industry while overrunning evidence of harm to human health and the ecosystem.

Internationally, there are positive responses unfolding to the emerging health crisis and human rights abuses because individuals and communities are taking action to turn the tide. For example, in the Italian state of South Tyrol, the Precautionary Principle has been legislated for RF[ix].

France took unprecedented action in early 2015 to ban Wi-Fi in pre-schools. http://www.powerwatch.org.uk/news/2015-02-05-france-Wi-Fi-restrictions.asp

The European Union failed to adopt the recommendations set forth by the European Economic and Social Committee, which are attached to this testimony, but individual nations are moving independently to review their radio frequency policies.

Other nations including Italy, Austria, Bulgaria, India, and China, representing over 40% of the world's population, already have a safety limits far more protective than the U.S. The militarized economies of the Five Eyes nations (Canada, US, UK, NZ, and Australia) are catering to radar, weapons, and surveillance interests. Health Canada's Safety Code 6 guidelines, similar to the FCC guidelines, have come under heavy attack.

This week, the mainstream press was reporting that air conditioning in commercial buildings caters to men, and discriminates against women with lower body mass. Most Americans are unaware that the wireless standards in place in the USA were based on the physiology of adult military men. They are only designed to protect against acute short-term exposures, and not chronic long term exposures or juxtapositions created today. Additionally, the standards only address thermal, or heating impacts, and ignore biological impacts. They have never been tested for women, children, and fetuses, or for wildlife impacts, including pollinators.

Other nations that seek to protect the health of their residents have established limits 10 to 100 times lower than those in the US based on evidence of harm at lower protection levels. This includes Russia, which prohibits against tissue stimulation and reproductive rights.

The U.S. National Academies of Science identified 20 inadequacies of radio frequency research in its 2008 report, including lack of data for:

a) Exposure of juveniles, children, pregnant women, and fetuses both for personal wireless devices (e.g., cell phones, wireless personal computers [PCs] and for RF fields from base station antennas.)
b) Variability of exposures to the actual use of the device, the environment in which it is used, and exposures from other sources.
c) Multilateral exposures.
d) Multiple frequency exposures.
e) Exposure to pulsed radiofrequency radiation.
f) Location of use (both geographic location and whether a device is primarily used indoors or outdoors).
g) Models for men and women of various heights and for children of various ages.
h) Exposure to others sources of RF radiation such as cordless phones, wireless computer communications, and other communications systems.
i) Exposure to the eyes, hand or the human lap or parts of the body close to the device.
j) RF exposure in close proximity to metallic adornments and implanted medical devices (IMDs) including metal rim glasses, earrings, and various prostheses (e.g., hearing aids, cochlear implants, cardiac pacemakers, insulin pumps, Deep Brain Stimulators).
k) Sufficiently long exposure and follow-up to allow for detection of effects that occur with a latency of several years.
l) Lack of information concerning the health effects associated with living in close proximity to base stations.
m) Research that includes children, the elderly, and people with underlying diseases.
n) Research on possible adverse RF effects identified by changes in EEG (electroencephalogram) activity.
o) Lack of information on possible neurophysiologic effects developing during long-term exposure to RF fields.
p) Studies focusing on possible adverse RF effects identified by changes in cognitive performance functions.
q) Effects of RF exposure to the sensitive biological targets of neural networks.
r) Possible effects of RF exposure on fetal and neonatal development.
s) Possible influences of exposure on the structure and function of the immune system, including prenatal, neonatal, and juvenile exposures.
t) Possible influences of RF exposures on the structure and function of the central nervous system, including prenatal, neonatal, and juvenile exposures.
http://web1.env.state.ma.us/DPU/FileRoomAPI/api/Attachments/Get/?path=12-76%2f22714jntat6.pdf

An unknown percentage of U.S. citizens may suffer from adverse impacts of exposure to microwave radio frequencies. Only a very small portion of the population has been fortunate enough to receive an appropriate diagnosis from medical providers who are trained to recognize the emerging syndromes, for example by practitioners in the American Academy of Environmental Medicine. Many U.S. citizens may be treating symptoms, for example by taking sleeping pills or being treated for digestive challenges or ringing in the ears or heart arrhythmias, without knowing that their radio frequency exposure has been increased by the installation of wireless utility infrastructure, or additional telecommunications nodes.

Adding insult to injury, like Lyme disease, the condition of sensitivity to EMF and ELF has been dismissed and ridiculed by industry claims that it is a psychological condition, known as the nocebo effect (tin foil hats - it's all in the their heads). This attitude has not been challenged by the dominant culture or by human rights advocates who enjoy the conveniences of wireless technologies.

In addition, while many physicians smoked during the tobacco wars, many health care practitioners hold a presumption of innocence towards wireless devices.

Rather than requiring epidemiological data that links exposure to disease after the fact, we already have the capability to conduct simple testing to determine that there is a relationship between exposure and biological impacts. Dr. Magda Havas' work on heart rate provocation, the Austrian Medical Association diagnostic criteria, and Dr. Belpomme's work in France are examples. The protocol of the American Academy of Environmental Medicine is to place the patient in an EMF-clean environment, to introduce frequencies, and monitor the physiological response.

The science is available; the question is when, where and how the U.S. will begin to access the moral and ethical imperative to take action.

The Harvard Center for Ethics published a report "Captured Agency, How the Federal Communications Commission is Dominated by the Industries it Presumably Regulates," by Norm Alster.

*"The Federal Communications Commission sits at the heart of a bipartisan Washington web of institutional corruption that has for many years championed corporate interests, typically at public expense. Echoing industry, the FCC has ignored the growing evidence that wireless technologies pose serious health risks."*

*"The FCC's network of corruption doesn't just shield industry from needed scrutiny and regulation on matters of public health and safety. Sometimes it just puts its hand directly into the public pocket and redistributes that cash to industry supplicants."*

Many individuals are experiencing toxic trespass in their own homes due to the encroachment of RF, and have become refugees and denied access to health care, education, religious community, and participation in government.

Rhode Island, like France and South Tyrol, could take the lead to question the science that forms the basis of policy.

I have attached the fraud complaint that has been filed with the MA Attorney General concerning the DPU smart meter mandate, which was based on the testimony of career tobacco scientist Peter Valberg. The responsibility for peer-reviewed science that provides proof of safety has been shifted to sufferers to provide evidence of harm.

Rhode Island could play an enormous role in making a place at the table for those who are already in harm's way. Late lessons from early warnings have been repeated in many forms, but wireless toxic trespass is unprecedented in scope and risk to nature and human health.

Thank you,

Patricia Burke, Millis MA

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To whom it may concern,

Electromagnetic and radio frequencies (herein "EMF") are being introduced into human living environments and public places in quantities never before seen in human history. We are now exposed to thousands of times safe levels of this radiation.

Accessibility

Insurance companies refuse to insure against the harm cause by environmental EMF because they know that exposure levels are harmful and are not being contained.

This is not a problem for "the disabled", although many disabilities are being caused by excess EMF exposures to the public. EMF effects every living thing.

Because I am an activist with some videos online I am contacted constantly by people desperate to find relief from exposure to EMF. For those who have no other choice I recommend sending legal notice to the power company to provide safe and lawful analog metering, and, if they fail timely to do so, for the customer to install their own safe analog meter on their power company's default. I have provided close to two thousand (2000) analog meters and legal notice templates to customers who simply found me by random chance on the internet. This indicates that the problem is massive and people are desperate for solutions against the invasive and harmful metering. Lawsuits are underway and will soon explode against everyone who is complicit in promoting the unlawful and harmful "Advanced" metering.

A 7-minute video I released on YouTube ("Smart Meters"

https://www.youtube.com/watch?v=8JNFr_j6kdI) has been viewed by nearly 2 million people without any promotion from me whatsoever. It was simply considered important enough by two million people that they shared the video with each other.

I prepared a special video for those who develop public policy on utility metering. Please view that video at: https://www.youtube.com/watch?v=UPLSwAm9DkQ

Thank you,

Jerry Day, Producer, Burbank, CA

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To Rhode Island Governor's Commission on Disabilities:

Accessibility

Thank you for taking up and being willing to hear testimony on the topic of EHS or Electromagnetic Sensitivity. I live in Worcester, MA where National Grid has installed 15,000 wirelessly communicating Smart Meters and supporting microwave relays as part of a Pilot program. Since late February, 2014 I constantly experience tinnitus & insomnia from the radio waves generated by the AMI - Advanced Metering Infrastructure network installed by National Grid for its Smart Meter Pilot Program here in Worcester. Other symptoms I've increasingly had in the last 18 months are; leg cramps, slight headaches, heart racing and occasionally vertigo.

I am certain these are from RF waves: The ringing changes in intensity as I walk one block to the next; sometimes I will hear two or three "rings" of slightly different frequency that sometimes combine so that I hear a low frequency buzz that sometimes brings on headache. These increases in ringing are always in the same places, near the same buildings. In some parts of the city ringing is not noticeable or much less noticeable than those places where I notice it much more. I often don't notice Ear Ringing inside vehicles. I attribute such absence or attenuation of tinnitus to the shielding effect of the metal enclosure though this is only if radio waves come from a higher angle above the ground. I still get ringing inside a vehicle if the source is near street level or else somewhat farther away so that it's at lower angle so that it comes through the window(s).

I first noticed this ringing when taking the MBTA commuter rail in the late 90s. My ears would ring if I was sitting in front of, behind, next to or across from someone using a cell phone. I did not notice this while near cell users out in the open. I attribute this to the fact that a cell phone is instructed by the cell tower base station to increase its RF output to maintain Quality of Service while transmitting through the metal enclosure of the train.

Yet I am relatively well-off compared to a Worcester woman who is so adversely affected she had to electrically shield a room in her house. She has a hard time at meetings, having to leave in less than an hour because of the Wi-Fi or even where there are fluorescent lights.

May I suggest a concrete accommodation (it would go right along with one that is already widely practiced: Request people to "Please turn off cellphones" not only to reduce distractions but for those sitting near a cell user who are electro sensitively affected.

Another accommodation now being implemented by the Ashland, MA schools is educating their students to minimize their own exposure and that of their neighboring peers by downloading their work from Wi-Fi, turning off their own connection when that is done (Airplane Mode), then reconnecting to submit their work when it is completed[x].

Thank you for your interest.

John Provost, Worcester, MA

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Thank you for holding this forum. I feel it is vitally important for the population to understand this growing problem, not only for our own health but for all species on Earth.

I became sensitive to Wi-Fi around 2009 when I had to be rushed to the hospital with severe heart palpitations and anxiety, having no idea what was happening, never having experienced any of these symptoms in my life. Overnight in the hospital, they kept me admitted as the symptoms were considered a possible heart attack, I was found to be fine, no problems with my heart after lots of tests. So what caused this? I had to find out.

Accessibility

I had been living with a constant drain of brain fog, heart palpitations, ringing in the ears, and general irritability and insomnia. Since I needed to find out what caused all this I started researching. I discovered the problem could be Wi-Fi related and found others online suffering from the same symptoms and from there my research took me to discovering my house was full of Wi-Fi and a new digital meter had been placed on the house previously without my knowledge. (I have since realized that the general population has no idea what so ever that their meters have been ‘upgraded’ to smart meters. Ask them and they have no idea what you are talking about) I had the house tested for RF and found both of our speaker systems and printer were always on Wi-Fi! and our computers, etc. We went about disabling or eliminating all of these electronics and made sure the digital meter was not emitting RF, until the house was clean. My health surged back to wellness!

Currently I feel like a prisoner in my own home. If I go to a mall my brain fog gets so bad I have to go home. I cannot visit friends for very long since they all have Wi-Fi or dect phones and I simply cannot tolerate that any longer. I do not own a cell phone. I cannot shop at the supermarket because it has Wi-Fi now. When my husband accidentally has his phone on in the house I know it! He is amazed that I can feel it.

It is increasingly hard for me to go out. Even on trips there are towers everywhere, sometimes 2 or 3 in the same area, especially near the exits, so all restaurants and hotels are off limits for me at all exits. All hotels seem to have Wi-Fi now-so I stay home. Many hotels have towers on their roofs now and our water towers have been fitted for Wi-Fi all over the county.

I have lost my way of life, many friends and had to sell my condo recently because they just went total Wi-Fi throughout the building. I had just spent lots of money updating it only to have to sell it because I couldn't stay there at all.

I am most concerned about our children. I am a retired school teacher and to think of these children surrounded every day at school and then probably at home, everywhere they go!!

We must address this now. We cannot wait the 50+ years that it took for tobacco to be discovered as a cancer causer, heart disease causer, autism, Parkinson's, Alzheimer's, etc. Please, help to stop this madness now before it is too late.

Thank you,

Gayle Zentz, Sarasota FL

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To Whom It May Concern,

My name is Janet Johnson. I raised 4 successful children and had a career as a teacher of visually impaired children. I have two Masters Degrees in Education. I was disabled by effects of microwaves for 20 years and continue to have health problems as a result.

Accessibility

Microwaves injure people in different ways. For me, it occurred because I had several large mercury amalgam fillings held in place with thick steel pins. Mixed metals in the mouth cause a battery effect, and cause mercury to break down faster. Exposure to microwaves also causes mercury in the teeth to volatilize and break down. I had both these conditions because I was living in a house that had very high EMFs. I developed mercury toxicity which went undiagnosed for many years. It was like having Alzheimer's except that I also became chemically and electrically sensitive; exposures to either chemicals or microwaves made my mental confusion worse.

With treatment, I am now able to function normally for the most part and work one day a week, but I know that EMFs destroy lives. We need education and prevention, because use of microwave gadgets is rising rapidly, and research tells us to expect a huge increase in illness (not only neurological impairment like mine, but also cancer, birth defects, autism, sleep problems and more).

You do not need to be a scientist to understand that microwaves alter cells and can cause cancer. Physicians use microwaves to heal broken bones that are not mending. Exposing the gap in the broken bone to microwaves, increases cell division and mends the gap in the bone.

Microwaves have the same effect on cancer cells--it causes them to divide more rapidly.

Thank you for your efforts in educating others.

Sincerely,

Janet Johnson, Bolton, MA

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Accessibility

I understand you are setting up a public forum for people with sensitivity to RF and EMF to express their concerns. Although I do not live in Rhode Island, I would like to commend you for investigating what is a major growing public health concern. Accommodations MUST be made for the electro sensitive who are experiencing increasing difficulties in their daily lives due to the vast proliferation of RF/EMF at levels thousands of time higher than normal background radiation. Having had a personal occupational exposure to a very high EMF that left me hypersensitive, I can testify to the difficulties of living in a world without respite from exposure. Although I pay what I consider to be an extortion fee to opt out of having a smart meter, I experienced a definite exacerbation in my symptoms very shortly after (within a period of days) the meters were installed in my neighborhood. My home is hard wired and I have special filters installed in outlets to absorb the harmonics ("dirty electricity") produced appliances, etc., in addition to the large spikes in these harmonics that can be produced by RF from surrounding smart meters. I also work at home. I measure RF in my home with a meter and it is becoming increasingly difficult to maintain a safe atmosphere INSIDE MY OWN HOME! This represents an invasion of what has been classified by the WHO as a potential carcinogen into every sphere of daily life and constant INVOLUNTARY exposure. Hundreds of studies (if not thousands by now) have demonstrated nonthermal biological effects of RF and nonthermal mechanisms of harm from RF have been identified by top level scientists. The FCC standard of thermal-only damage resulting from tissue shock, heating and burning from a limited exposure to an adult male are completely outdated and, as stated by the EPA over a decade ago in correspondence to the FCC, not demonstrated to be protective, especially with respect to sensitive populations. It is long past the time for a biological safety standard. In the meantime, more and more people are being permanently damaged by exposure to HUGE AND GROWING levels of unsafe RF. Please take action now to provide accommodation before the damage gets any worse and more human and nonhuman populations are irretrievably damaged while we continued to fight for a sane, biologically protective safety standard.

Thank you for your consideration,

Alexandra Ansell, West Melbourne, Florida

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Dear Rhode Island Governor's Commission on Disabilities,

Accessibility

I am writing you on the issue of wireless radiation, my family’s health and the health of other people in Rhode Island. My daughter has a health condition and her Doctor has stated and given us a letter clearly stating that electromagnetic fields (which includes wireless radiation) should be reduced for her. However we are increasingly finding that there are few public places we can even go without getting high doses of wireless radiation. Wi-Fi is going in to all buildings and schools and businesses.

We started homeschooling and have made many and simple changes in our life which have significantly decreased exposures to our family. However, what about the library? What about walking into community buildings that our taxes pay for?

I have friends and family in Rhode Island and visit at least twice a year for weeks at a time. I had thought going to Rhode Island would be a break, but we found we could not access many restaurants, retail stores, and most especially libraries due to the widespread proliferation of Wi-Fi.

The libraries in Rhode Island have such wonderful programs for children. Yet there are wireless routers in the rooms above the children's heads. Why?

One day we had hoped to go to a library program but were shocked to find that even in the room where the children were doing an art project there was a router above their heads. The kids are not even using the Wi-Fi yet they are still being exposed. Why?

This radiation has been shown to increase oxidative stress on the body which in turn results in exacerbation of health issues in people with immune issues such as my daughter. Please see Igor Yakymenko's Oxidative mechanisms of biological activity of low-intensity radiofrequency radiation.

The American Academy of Pediatrics has called for a reevaluation of the current government policies on this radiation because the state the children are more vulnerable and current standards do not protect them. Why would we have this radiation in the library? Read the Letter here.

My family is not alone. There is a growing number of people disabled by the radiation emissions from wireless devices (Wi-Fi, cell phones, "smart" wireless utility meters, etc.) and these people are being shut out of society. Some estimates state that 5% of the population has symptoms such as debilitating headaches, dizziness, rashes and tinnitus from this radiation. Scientists state the numbers will be much higher in the coming years because of the unprecedented exposures to young children in schools.

Government policy has not kept up with the pace of the saturation of this technology. Please take a look at these resources for more scientific information on this emerging issue[xi].

Everyone has a right access public buildings and yet this right is being denied. It is imperative that you take the time to explore this issue and to allow my family and other families' access to public buildings in the state of Rhode Island.

The Rhode Island Governor's Commission on Disabilities has a responsibility to stand for access to all. Currently people cannot access public buildings in Rhode Island and your Commission has an ethical and moral responsibility to take action.

The Canadian Parliament just issued a report calling on the Canadian government to change its inadequate wireless "safety standards". (The US and Canada share similar regulations, among the highest in the world). You can read the report here

In the Canadian Parliament Standing Committee on Health of the House of Commons "Radio Frequency Electromagnetic Radiation and the Health of Canadians", one of the recommendations is that "the Government of Canada continue to provide reasonable accommodations for environmental sensitivities, including electromagnetic hypersensitivity, as required under the Canadian Human Rights

Act”. They also state that the government should “develop an awareness campaign relating to the safe use of wireless technologies, such as cell phones and Wi-Fi, in key environments such as the school and home to ensure that Canadian families and children are reducing risks related to radiofrequency exposure. “

Thank you for taking action on this issue so that all may access public buildings in Rhode Island.

Sincerely,

Theodora Scarato LCSW-C, Maryland

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Dear Rhode Island Commission on Disabilities,

Accessibility

Thank you for taking a closer look at the issue of electro-hypersensitivity. This term is actually not ideal because it leads people to think that people who are "electro-hypersensitive" are somehow "different" from most people and that they are a rare breed. In fact, if you take a look at some of the 21,000+ studies available at http://www.emf-portal.de/ then it becomes clear that if you have cells and DNA, then you are "electro sensitive." One more apt description of this condition proposed by researcher Magda Havas is "rapid aging syndrome."

My wife became electro-hypersensitive in 2010. Her story is available here:

http://mieuxprevenir.blogspot.ch/2014/03/switzerland-waves-make-me-ill-testimony.html

I have attached the text of an essay I wrote inspired by this experience. Here is the link for the online version:

http://www.spiritofchange.org/Summer-2015/All-I-Really-Need-to-Know-About-EMF-I-Learned-After-My-Wife-Got-Sick/

One of the first things you will find in your research on the subject are studies that attempt to prove EHS is rooted in the mind because "EHS" people can not distinguish between a real wireless signal and no wireless signal in a laboratory situation. Below is a recent letter I sent to the New York Times[xii] after their publication of an article about Berkeley's new cell phone ordinance. The link in the last paragraph about the debunking of the NOCEBO effect is critical reading in light of these industry-funded studies. Even if these studies were not designed to fail, by the time my wife got into the lab she would likely be feeling sick from exposure to EMF - not the ideal state for distinguishing between real and false signals. But depending on the type of exposure, she often pays most dearly for leaving the house later that evening with an inability to sleep.

Thank you again for considering this issue. I understand that Rhode Island has a history of leadership in regards to issues of disability.

Sincerely,

Jonathan Mirin, Shelburne MA

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To Rhode Island Governor's Commission on Disabilities:

Accessibility

I neglected to add that the "Best Practices" set forth by the Ashland, MA School Committee constitute stop-gap measures for minimizing RF exposure in environments already awash in EMF/RF until hard wired connections can be reestablished in place of the Wi-Fi now being deployed. Wi-Fi, cellular & cordless devices still transmit radio frequencies even when they are not being used so better not to have them at all or else turn them off or physically unplug them to make a space be low EMF and more truly accessible to all.

Cordless phones, come to think of it, have given me a headache after using on long calls (20-45 minutes) in a store I used to work at. Dr. Devra Davis & many other expert contributors to The Bioinitiative Report, as the Ashland story concludes, urge hard wired Internet & corded phones as a solution even while supporting technology.

Finally, when I had Ethernet (hardwired internet)

I experienced some excitability, restlessness, impaired ability to focus and sleeplessness when that line was "live". IMHO, even hardwired routers should be turned off when not in use.

Wi-Fi banned from nurseries in France
http://ehtrust.org/france-new-national-law-bans-Wi-Fi-nursery-school/
http://www.powerwatch.org.uk/news/2015-02-05-france-Wi-Fi-restrictions.asp
Ontario schools keep faster, safer cable connections
http://safeschool.ca/

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To: The Governor's Commission on Disabilities

Accessibility

The following is my written testimony that I am submitting to the Rhode Island Governor's Commission on Disabilities. I writing not about issues of mere concern, worry or risk, but rather about established problems, hazards and substantiating evidence that prove that there are direct damages to humans and many other living organisms in our environment caused by manmade digital, pulsed, radio frequency microwave radiation, or RFR for short. I attest and affirm that the following statements are true, accurate and within my personal knowledge. I am a graduate of Brown University with a degree in Biology and Medicine. I have completed medical school courses in Biochemistry, Physiology, Pathology, and Histology. I have read and quantitatively evaluated many peer-reviewed, Supreme Court Daubert Rule-admissible scientific studies that conclude direct damages to humans from RFR from mobile communications infrastructures, including Wi-Fi installations in public schools and other public buildings. Regrettably, when I return to Brown University for alumni/alumnae events, I cannot access Rhode Island hotels, restaurants, retail stores, medical facilities, schools & my own university because of the widespread proliferation of Wi-Fi in Rhode Island. I am an expert in measuring and mitigating exposure to RFR: the toxic pollutant that is emitted 24/7 from mobile communications facilities, such as cell phone tower antennae and industrial-strength wireless access points -- equipment that is being deployed quite close -- in fact much too close -- to the state's most-sensitive populations: the children who attend public schools in RI as well as the growing percentage of the population who have become permanently allergic to these signals -- individuals who are electro sensitive. I have received advanced training in measuring and mitigating exposure to RFR from the International Institute for Building-Biology & Ecology (http://hbelc.org). I used this training and a calibrated professional RFR meter to make a Supreme Court Daubert Rule-admissible measurement

Independent Living

(http://rfemf.com/counter.html#calcs)of the RFR in my daughter's public school kindergarten classroom. The school exposed these 5-6 year olds to RFR that was over 1,400 times higher than the FCC RFR guideline, over the course of the 2013-2014 school year. I filed an OSHA complaint against the Petaluma City Schools District, which lead an agreement by the FCC Office of Engineering & Technology and Federal OSHA on how to calculate total RFR exposure over time, the only measurement that really matters, as is self-evident to anyone who has considered exposure to another familiar source of electromagnetic radiation -- the sun. If one gets unprotected exposure from the mid-day sun for 30 minutes, one might might get some color, but would otherwise be fine. If, however, one gets unprotected exposure from the sun (laying naked in the sun, without clothing, shade or sunscreen for 365 consecutive days), then one will experience sunburn, permanent skin damage and possibly skin cancer. Certainly, it is self-evident to each of us that 365 days x 12 hours/day results in more exposure than 30 minutes. The same applies to exposure to RFR from Wi-Fi. Total exposure over time is what matters. The fact that the FCC RFR Exposure Guideline does not consider total exposure over time from all antennae in the environment proves that the guideline is not scientifically reliable in any way. The FCC RFR Exposure Guideline is merely a grandfathered-in number based on science from 1982, that the FCC/Wireless industry (acting in concert) uses to get wireless products approved and sold to the public. The Guideline is not and has never been a safety standard, as is clearly explained in the following presentations:

7/15/15 Presentation Opposing California Bill AB-57 http://rfemf.com/law/ca/ab57/slides/ 4/8/14 Presentation, Encouraging Wired Internet Access in Public Schools http://rfemf.com/img/2014-0408-Susan-Clarke-RF-EMF-MW-Bioeffects.pdf http://rfemf.com/background.html#clarke.

There are much safer, higher bandwidth, more secure and more cost-effective options for all RI public schools and public buildings: fiber-optic, coaxial and copper Ethernet wiring for all Internet access in these buildings. The analysis shown at the following URL . . . http://rfemf.com/neglect.html . . . shows that wireless installations cost twice as much as equivalent wired installations in schools ($12 per user for wireless vs $6 per user for wired) and result in bandwidth this is much, much lower (7.5 mbs per user for wireless vs. 125 mbs per user for wired).

Wired internet connectivity is faster, more secure and provably safe for all residents of RI. Wired should be the only form of internet connectivity allowed in RI public schools and public buildings, as this accommodates the health needs of both the children of RI and electro sensitive population. The Americans with Disability Act mandates that the state of RI accommodate the needs of these important populations. Please consider carefully the following sources that I am including in my written testimony[xiii].

Thank your for considering my testimony and making the responsible decision to ban Wi-Fi from all RI public schools and public buildings, replacing it with safe, secure wired internet access.

Regards,
Paul McGavin, San Francisco, CA
InterSight, LLC

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To Whom It May Concern:

Accessibility

Thank you for holding a forum for Rhode Island citizens who may suffer from electro hypersensitivity. I received an email about this Thursday, August 6th. I was supposed to have an In-Person Hearing before the PA Public Utilities Commission, presided by Administrative Law Judge Darlene D Heep, July 29, 2015 but Shawane L Lee, Counsel for Philadelphia Electric Company (PECO) filed a Petition for Interlocutory Review the day before.

By way of background, PECO deployed an AMI 'Smart' Meter on my house May 23, 2013 and shortly thereafter I experienced these symptoms of EHS:

1- irritability
2- severe HTN
3- an Increased number of migraines with vomiting
4- L ear pain with moisture
5- bilateral cerumen impaction requiring medical intervention
6- temporary L hearing loss, secondary to above
7- papules on scalp at bilateral temples
8- occasional visual floaters, 10-15 minutes duration, and possibly most troublesome was
9- waking up nightly at 3AM with palpitations driving me from my bed for a couple of hours resulting in fatigue upon rising at 7AM

The gist of my Complaint is that in June 2014 when I called PECO's Customer Service their Representative offered no course for remediation and when I suggested that I acquire an analog meter and have my own electrician install it threatened me with charges of "Theft and Tampering." "We will be watching you!" she warned.

I hired an attorney and while waiting for him to familiarize himself with the issue I hobbled to the 3rd floor guestroom nightly for improved sleep. It should be noted that in 1991 I sustained vaccine-induced Guillàin Barré Syndrome, sensory variant, and still walk with crutches. August 4th 2014 my attorney sent a 'Notice of Self Help' to Craig Adams, the President & CEO of Exelon Corporation and within short order received my initial callus response from Shawane Lee stating that they could offer no remediation as they only carry AMI meters in their inventory. I purchased an analog meter and a licensed residential electrician installed it on August 26, 2014.

Between December 12 through January 9th 2015 I received two 10-Day Shut-Off Notices and one 72-Hour Shut-Off Notice from PECO despite that I was available to allow them to inspect the meter socket as indicated on the Notices. They do not except the monthly reading I call in, and despite 21 years history as an electricity consumer over-estimate my kWh usage for which PECO automatically withdrawals monthly from my checking account.

Quite frankly I have only become familiar with the issues of EHS a year ago. That said, years ago I had two microwave ovens given to me and quickly donated them elsewhere. For a short while I had a cordless telephone and got rid of that, too, because I noticed that it hurt my ear with extended use. All four telephones in my house are landlines; my TV and computer run via cable. My employer issues me a cell phone which I use less than 10 seconds per day, some days, otherwise it is turned Off and carried in an EMF-shielded pouch for emergency use only. I called Comcast when I learned that I was being blasted with Wi-Fi from my modem/router and they were able to turn it off remotely. (Based on the conversation it seems they don't get many requests like that.)

I've made liners of Argon/silver mesh fabric for my hats for protection from cell towers when I drive around so guess I can be characterized as a 'tin-foil hat lady' by a mean-spirited person –or industry apologist.

PECO would like to gag my Testimony and not allow me to speak about their meter causing "deleterious health effects." Legally they want to lump me into the group they've bullied who requested 'Opt Outs' —as opposed to recognizing that I endured having a 'Smart' Meter for a long 15 months— because PA Act 129 doesn't allow 'Opt Outs.' On July 29, 2015 the Honorable ALJ Darlene D Heep issued an Order for Abeyance which assigns a new Docket # and requires that every 45 days PECO and I provide updates –unless we come to some agreement or a new Hearing is Ordered before then. Personally I am fine with this going on indefinitely.

Friends and supporters commend me for being "brave" for standing my ground on this position but in fact I do not have a choice because I simply cannot tolerate a Smart Meter on my house. Feel free to call me at my home if you have any questions: (215)

849-1698. I hope that Rhode Island decides against deployment of this dangerous and economically wasteful technology on their citizens.

Sincerely,

Susan Kreider, RN, Philadelphia, PA

Note that the opinions expressed herein are my own although many are backed by decades of research.

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Accessibility

I suffer from reactions to wireless technology and recently started getting migraine headaches after installation of 6 smart meters in a basement below my bedroom. Since that time I have installed protective coverings on them all and have also had a wireless router moved up 1 complete floor above where it had at first been installed in a hallway above my apartment in Berkeley, California. Have begun to feel much better. I urge you to do the same wherever possible. Too bad we are the guinea pigs for untested wireless technology and its long term and short term effects on humans and other living creatures. We are creating our own destruction in the end.

Sheila Goldmacher, age 81, Berkeley, California

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Accessibility

On behalf of Citizens for Safe Technology, and myself, I would like to voice a complaint regarding the proliferation of Wi-Fi technology in towns and cities, for which you are accepting comments at this time..

Additionally, as the EMR Policy Institute states, "The EMR Policy Institute Mission Statement - We believe that the unfettered use of electromagnetic radiation (EMR) - radiofrequency/microwave radiation (RF/MW) present in all wireless and communications technologies, as well as the extremely low frequencies (ELF) present in power line supplies - is ill advised given research that has accumulated over the last two decades. The Mission of The EMR Policy Institute is to foster a better understanding of the environmental and human biological effects from such exposures. Our goal is to work at the federal, state and international levels to foster appropriate, unbiased research and to create better cooperation between federal regulatory agencies with a stake in public health in order to mitigate unnecessary exposures that may be deemed to be hazardous."

My personal complaint is a severe tinnitus (ringing in the ears) and vertigo, which I have suffered from for over two years.

Also, it is a scientifically researched fact that these frequencies are causing distress and migratory confusion among the animal kingdom, especially to bees, whales, and migratory birds.

I respectfully request that you assess the grid of cell towers, smart meters and all Wi-Fi technology and enact a plan to reduce our exposure to harmful EMF frequencies. So doing would set a precedent for other States to follow.

Sincerely,

Diane Heath, Bend, Oregon

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I have RF sickness as an immediate and permanent reaction to smart meter infrastructure.

Accessibility

I can access no public places or public services at all anymore and because this is a physical reaction being defined as psychological in my State of Oregon I can’t even access mental health services as they will no longer allow emails from clients and there are no landlines here, no payphones, and no other way to communicate other than in person (in a Wi-Fi'd environment) or cell phone (absolutely cannot physically use without adverse health effects). All hospitals and clinics are Wi-Fi'd and cars are now Wi-Fi'd , public transportation exposes me to hundreds of wireless users .

Accommodations necessary for people with radiofrequency sickness

Below is a list of accommodations necessary to allow people with radiofrequency sickness to once again participate fully in public and community life. It is divided into two categories - one for transmitted radiofrequency radiation and one for radiofrequency exposure from “dirty” electricity.

Transmitted radiofrequency radiation accommodations:

Salzburg, Austria radiofrequency radiation safety limits adopted nation-wide (1microW/m2 inside and 10microW/m2 outside - lowered as necessary to prevent biological effects because our experience shows that levels should be below 3microW/m2).

Public places (including transportation) free of locally provided wireless internet service.

Transmitters on wireless devices turned off in public places - detectors should be installed at entrances to remind people.

Hospitals use only wired internet, wired in-building networks, and wired devices within the hospital, also protects privacy.

Cell and broadband antennas situated at a distance from hospitals and residential areas such that Salzburg radiation limits of 1microW/m2 not exceeded inside the hospital or homes.

Medical clinics use only wired in-office network, internet service, and devices on dedicated networks, not broadband on power line technology.

Require access to landline telephones and non-wireless internet service on dedicated networks, not broadband on power line technology, be maintained nationwide.

Mandate exemptions to requirements for RF/EMF emitting technology for affected individuals - e.g. wireless tire pressure monitors, V2V communication, GPS systems, wireless usage monitors on refrigerators, freezers, and dryers, etc. - with enough flexibility that as new wireless technology emerges it is covered under the exemption and also require manufacturers to provide such “stripped down” models for affected individuals at the same or lower price.

“Dirty” electricity radiofrequency accommodations (www.electricalpollution.com):

Kazakstan “dirty” power standard adopted globally - maximum of 50 G/S units on Stetzerizer meter on building wiring. (www.stetzerelectric.com)

All new energy efficient lighting installations must be low radiofrequency lighting e.g. incandescent lights or properly engineered undimmable LED lights with no ballast and no pulse width modulation so they do not cause “dirty” electricity. (Additional benefits - LEDs are more energy efficient than fluorescent lighting and do not emit UV thereby allowing greater access for people with lupus.)

Use of tiered lighting instead of dimmer switches (also saves energy).

Replacement of all buzzing (arcing) fluorescent fixtures with LED fixtures, as above. Arcing is an important source of RF.

Broadband on power lines is deliberate pollution of the electrical signal with pulsed modulated radio frequencies and should not be allowed on the electrical grid, where it becomes ubiquitous even with in private homes, or within buildings since it also causes functional impairment for many people.

DEANNA L. MUNSON, Oregon

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Accessibility

I have been electro sensitive for nearly 20 years and have been at times driven crazy by it. I am English, but lived in Australia for 40 years, where it first started, around the time the wireless phones became operable. Because of Wi-Fi, I have become addicted to sleeping tables in order to sleep.

I now live in Greece in an attempt to get away from it all, having traveled from place to place to find a place that did not affect me badly.

I wish you all the best in your commendable endeavors.

Regards

Sarah Benson, Naxos Island, Greece

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8/11/2015

To whom this may concern:

Accessibility

Please enter these email comments and attached documents into the hearing record to be held August 20, 2015 in the matter of Disabilities, in particular, Consideration of Electro hypersensitivity [EHS] as a Disability. Please acknowledge receipt of this email with a reply noting "Comments Received." Thank you. Note these comments are also included as the final attachment above.

My name is Ed Friedman and I'm providing testimony from Maine at the request of RI residents. I support the recognition and addition of electro hypersensitivity [EHS] as a qualifying disability in the state of Rhode Island. My background is in a wide variety of sciences and I have done field work from the Arctic to the Antarctic in geology, glaciology and wildlife ecology. Since 1996 I have been chairman of Friends of Merrymeeting Bay, an environmental non-profit engaged in research, advocacy, education and land protection. For the last four years I've been lead complainant in a smart meter proceeding before the Maine Public Utilities Commission [MPUC] resulting in a multi-year investigation into the health and safety of smart meters. MPUC Docket 2011-00262. We have had one win in the Maine Supreme Judicial Court and have another appeal there pending at the present time.

Attached please find the following documents to be entered into the record. A brief description or discussion follows each listing[xiv].

In conclusion, EHS is a real not psychological problem. Whether disease or functional impairment is immaterial in the sense its end result is a disability. EHS is growing in prevalence and because of the debilitating effects, demands greater recognition and accommodation. While exact biological mechanisms of injury remain unknown, a number of possibilities have been suggested. In the face of strong correlations between exposures and symptoms, evidentiary observations of injury, thousands of "lay witnesses" and thousands of studies showing biological effects of RF/EMF exposure going back over 50 years, concrete actions should be taken to address and minimize further exposures and deal responsibly and compassionately with those in society injured by exposure. Many of us believe RF proliferation to be the most toxic threat of our time and believe those with EHS now are harbingers of an electronic "silent spring," proverbial canaries in the coal mine offering the rest of us a warning of things to come. I hope the Commission takes this relatively recent threat seriously and formalizes a commitment to minimize future injuries from RF/EMF while helping those affected by it in affording them equal access opportunities without harmful exposures.

If you have questions for me I can be available by phone. There is a great deal more information available at: www.mainecoalitiontostopsmartmeters.org including our expert testimony you may refer to and many great links to research in this field.

Thank you for your consideration.

Ed Friedman, Bowdoinham, ME

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Hello, my name is Pamela Steinberg, and I am providing testimony from Worcester Mass., at the request of Rhode Island residents.

Accessibility

A forum on EMF-related disabilities is important to me because I suffer from exposure-related acquired electromagnetic hypersensitivities (EHS). , which began in the Fall of 2013 when the utility National Grid began installing a wireless smart meter pilot program in our city. My problems with wireless radio frequency emfs (RFs) began when I suddenly started having headaches, tinnitus, nausea, dizziness, difficulty concentrating, slurred speech, jaw pain, profound fatigue and weakness, heart palpitations and sleeplessness. This has been an ongoing problem since that time and I now experience these symptoms whenever I am exposed to cell phones, Wi-Fi, cordless phones, Bluetooth devices, GPS, smart meters, and even CFL and fluorescent lights. This has greatly affected my activities of daily living, my ability to work, and my access to public spaces.

The World Health Organization's International Agency for Research on Cancer (IARC) has categorized RF emissions as Class B human carcinogens; the same classification as lead, asbestos, benzene and DDT. RFs are linked to cancer, neurological disorders, infertility and autism-spectrum disorders. There is mounting evidence of genetic and epigenetic damage that carries on to subsequent generations of people. RF emissions from towers, antennae and power lines are also known to cause illegal pure tone noise violations, to which most people are insensible, but not me and other sensitive people. I and others hear and feel these human-made electromagnetic frequency fields, and it is very uncomfortable. In fact, we can't NOT hear and feel them, and that's beyond frustrating.

Warnings by scientists, military experts and medical professionals are sufficient to raise deep concerns about the health hazards of electromagnetic fields arising from wireless technology. And despite the fact that in 2008, the National Academies of Science identified 20 shortcomings in RF research, including a lack of data on multilateral/multiple frequency exposures, RF has become ubiquitous. The telecommunications industry and utilities are installing towers and antennae at an alarming rate and with impunity; providing no monitoring of emissions for violations of FCC limits, and no action plans for mitigation of harmful effects of the technology, or liabilities for such harm.

At the website, www.antennasearch.com, you can enter any address and find out where wireless towers and antennae are nearby. The site provides information, including the type of emitter class, power wattage/output, and ownership of all the towers and antennae within four miles, and displays a map of their locations. You may be shocked to see how many towers and antennae are operating in urban areas like Worcester, Boston, Cranston and North Kingston, 24 hours a day, 7 days a week, in perpetuity and in synergy; permanently altering our environment with synthetic toxic RF air pollution.

Finally, I would add that my worst nightmare has now been realized, as I am hearing about babies and children developing Acquired Electromagnetic Hypersensitivities; toddlers who are inconsolable until taken to remote areas where there is no cell phone coverage, who then feel better, only to be sickened again when returning to their homes. Kids getting sick in schools that have Wi-Fi. These stories will become more numerous as time goes on if we do not take action to limit RF in our environment. It's bad enough that adults have to suffer from this preventable, exposures-related disability, but it's truly tragic and heartbreaking - it's criminal - when it affects our innocent children and grandchildren. We must move to put public health before industry profits!

Thank you for holding this forum and for the opportunity to testify about my experiences with electromagnetic hypersensitivities.

Sincerely,

Pamela D Steinberg, Worcester MA

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I am 65. I was a psychiatric social worker, a stock market investor, a successful type A person. I became EMF sensitive 7 years ago.

Accessibility

I am supersensitive to smart meters and cell phone towers.

If a person is open-minded, there is a lot of science about the dangers to EVERYONE of Wi-Fi, smart meters, etc.

I won't add it to my email as I'm sure dozens of others have sent you links.

Daniel Berman, Portland, OR

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I was very happy to learn that Rhode Island is paying attention to the consequences of electrical hypersensitivity. I recently assisted someone in drafting a letter regarding the disability of her daughter, made much worse by a transmitting meter that she is paying to opt out of. I do not know if the letter has been signed by the attending physician but it should be. Her daughter is so ill that she cannot leave the upper floor of the house. I know someone else in Arizona who cannot drive down the highway because the cell towers give him epileptic fits or seizures (I forget which it is). I know a young lady who has lost 3 young friends to brain aneurisms, all heavy cell phone users. I sleep with an aluminum shroud around my bed to deflect much of the emissions from a nearby tower and have gone off the grid to avoid a smart meter in my basement.

Judy Kosovich, Washington, DC

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To: RI Governors Commission on Disabilities
Honorable Commissioner:

Thank you for holding the forum to address the health impacts from Wireless technologies and to better understand the disability of Electromagnetic hypersensitivity (EHS).

I am a parent of school aged children in Massachusetts and I am writing to share my concerns as they personally affect my family. My children's school installed high density, industrial Wi-Fi in the academic year of 2013-2014 without my prior knowledge. What they didn't know is that chronic exposure to high density Wi-Fi, and the intense EMF fields which are created by these systems, can trigger a cascade of symptoms known as the disabling syndrome of EHS.

Wi-Fi emits constant pulsed Radio frequency electromagnetic fields, Non -ionizing radiation. Consideration of the volumes of peer reviewed, but as yet unaccounted for in US FCC standards, demonstrates biological effects and many of the mechanisms which are now understood to cause harm to human biology. Biological effects occur at levels far below the current FCC thermal standard. The current FCC SAR standard is admittedly not protective of children and women nor does this standard preempt a states right to protect its most at risk citizens via adoption of more protective standards and or adoption of precautionary ordinances to inform their public about reducing exposure. Most citizens, and school administrators, are unaware that the radio frequency spectrum range that includes cell phones, WI-FI and other common wireless devices was classified as a 2B possible human carcinogen by the World Health Organization in 2011. This is the same carcinogen classification of Lead, DDT and other toxic agents.

Technology *is* a vital tool for education, but *safer* wired technology, that does not emit microwave radiation, exists and must be considered in the interest of public health and our children. We must as a society take precaution in the spaces where children are unnecessarily and chronically exposed- our schools, day cares etc.

The American Academy of Pediatrics has expressed in a letter to the FCC regarding current exposure limits (known a SAR) children are more severely impacted by exposure:

"Children*, however, are not little adults and are disproportionately impacted by all environmental exposures, including cell phone radiation. In fact, according to the International Agency for the Research on Cancer, when used by children, the average RF (radiofrequency) energy deposition is two times higher in the brain and 10 times higher in the bone marrow of the skull, compared with mobile phone use by adults…it is essential that any new standard for cell phones or other wireless devices be based on protecting the youngest and most*

*Vulnerable populations to ensure they are safeguarded throughout their lifetimes."*

**– Dr. Robert Block, President of the American Academy of Pediatrics, 2012.**

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Many doctors, including the AAP's own subscribing pediatricians, however are currently unaware of this syndrome and are not trained to recognize or diagnose it. I can tell you seeing is believing and EHS is *real*. In my situation, seeing my children experience symptoms on a daily basis *only* at school, it is clear that this is not psychosomatic as some often dismiss it with relief. Furthermore, a child, fully unaware of the symptoms of this syndrome, does not exhibit debilitating headaches, with and without bloody nose, chest pain, nausea, dizziness, extreme tinnitus etc, in the school environment as a normal occurrence. This is what began upon the wireless upgrade at my children's school. At least nine other of their peers and some teachers have experienced the same types of symptoms since our system was upgraded, some more acutely than others. All other possible causes and environmental factors at the school have been ruled out and the presence of these symptoms at school is troubling and disabling to my children and their peers that currently suffer. School administrators are unequipped to assess health risks and need guidance from legislators and Disability commissioners who have done their due diligence on this matter.

These children deserve protection under ADA both at school and in public places where they have no choice but to be exposed though unwillingly. EHS and the symptoms I described are crippling. It is impossible to even seek medical care without being exposed as medical establishments have installed the technology for convenience when other safer wired options are available. They have done so blindly in most cases unaware and uniformed of the risks of exposure to themselves and those they seek to serve.

The US Access Board considers EHS as a disability if it so ***"severely impacts one or more major life activities such as neurological, respiratory or other functions of an individual that it substantially limits one or more life activities."*** A child's ability to learn and think without neurological impairment surely qualifies. Children who suffer are deserving of the utmost protection under this federal statute.

Long held concerns have been repeatedly expressed by the scientific and medical communities in the US and around the world with regard to use of industrial strength, high density Wi-Fi and wireless devices in schools. Overexposure to wireless frequencies can trigger EHS and in the short term it can be crippling. Physicians trained to diagnose this syndrome are seeing more and more patients with symptoms consistent with EHS. Society is skeptical of this disability but those who suffer especially children are in need of accommodations.

Many governments are taking a precautionary approach in light of this WHO classification and mounting evidence of health risks for children. Experts are calling for safer fiber optic or Ethernet connectivity NOT wireless to protect children's health. Using Ethernet or Fibre Optics for internet connectivity is faster, more secure and does not emit RF radiation.

*Note: manufacturers fine print in fact suggests reducing exposure to RF radiation WIfi/3G etc if you are symptomatic or otherwise concerned. IPAD Users Guide p.3 attached.*

Public health Policy should be governed by science especially when it comes to our children's health and safety. Please complete the proper due- diligence on this matter of public health and safety. Until this technology can be proven to be safe, mitigate exposure to our children in school where they are chronically exposed without consent.

I recently attended a hearing in Massachusetts on a bill in the Senate before the Joint Committee on Public health. The number of citizens impacted by Wireless radiation that turned out to express their concerns in the heat of the summer was startling. Their testimony as to the deterioration of their health and its subsequent impact on their families was heartbreaking. EHS is clearly a disability.

I have attached several documents that will help to inform you of the risks, what certain countries and Governments are now doing to mitigate this risk, and *what can be done* to protect your citizens now as this is a controllable environmental health risk that must be addressed.

Thank you for your consideration and for your diligent review of the facts about RF /EMF. I greatly appreciate your consideration on behalf of children and those who suffer.

Respectfully,
H. Davis, Massachusetts

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EMFscientist.org

August 8, 2015

**To: Governor's Commission on Disabilities**

**Regarding: Statement for August, 2015 Public Forum on Disabilities**

**Attn: Mr. Bob Cooper, Head of State Disability Commission Staff, Administration and Advocacy**

Dear Sir/Madam

We understand that you are planning to hold a Public Forum on disabilities in Rhode Island; we urge the Commissioners and the public to listen closely to and take seriously, the testimony from citizens who are functionally disabled, or who are speaking for those who have this kind of disability. We are particularly concerned the about proliferation of Wi-Fi in public buildings/outdoor locations and the national campaign to install wireless "smart" utility meters, that are creating chronic and involuntary exposure conditions to radiofrequency radiation.

Accessibility

I direct EMFscientist.org and on May 11, 2015, we submitted an International EMF-Scientist Appeal to the United Nations and to the World Health Organization, now signed by 206 scientists from 40 nations who have published peer-reviewed electromagnetic field studies that demonstrate that exposure conditions from electricity and wireless communications are capable of causing harm.

The Appeal states, “Numerous recent scientific publications have shown that EMF affects living organisms at levels well below most international and national guidelines. Effects include increased cancer risk, cellular stress, increase in harmful free radicals, genetic damages, structural and functional changes of the reproductive system, learning and memory deficits, neurological disorders, and negative impacts on general well-being in humans”.

One of our recommendations is that “medical professionals be educated about the biological effects of electromagnetic energy and be provided training on treatment of patients with electromagnetic sensitivity.”

Among the signators to this Appeal are two Editors-in-Chief of international scientific journals, the head of a major Indian government-sponsored EMF research program, the UNESCO Chairman for Life Sciences in Armenia and, significant representation by scientists who have been conducting peer reviewed EMF research for decades. The Appeal is attached and also may be viewed at EMFscientist.org.

The International Agency on Research on Cancer has classified non-ionizing radiation as a possible human carcinogen (Extremely Low Frequencies used for electricity were classified by IARC in 2002 and Radio Frequencies were classified by IARC in 2011). These classifications were then adopted by the World Health Organization (WHO). Since then, many concerned scientists and medical doctors have been calling for the WHO to create new disease classifications under the International Classification of Diseases that would enable recording the incidence of electromagnetic hypersensitivity as a disease entity. If this were done, global approach to understanding and treating environmental health conditions like electromagnetic hypersensitivity, such as, more research, improved treatment modalities and health insurance reimbursement for services rendered to the affected population would be encouraged.

We think that the issues and related unmet needs for those disabled people in the population with functional impairments caused or aggravated by environmental exposure to electromagnetic fields, specifically from wireless broadband communications networks in this case, need to be addressed by this commission and all related commissions and organizations across this nation.

Sincerely,
/S/
Elizabeth Kelley, MA Director EMFscientist.org

Email: ekelley@emfscientist.org
*Note: A signed hard paper copy will be faxed to confirm the signature.*

EMFscientist.org

**To: His Excellency Ban Ki-moon, Secretary-General of the United Nations**
**Honorable Dr. Margaret Chan, Director-General of the World Health Organization**
**U.N. Member States**

## International Appeal:

## Scientists call for Protection from Non-ionizing Electromagnetic Field Exposure

We are scientists engaged in the study of biological and health effects of non-ionizing electromagnetic fields (EMF). Based upon peer-reviewed, published research, we have serious concerns regarding the ubiquitous and increasing exposure to EMF generated by electric and wireless devices. These include–but are not limited to–radiofrequency radiation (RFR) emitting devices, such as cellular and cordless phones and their base stations, Wi-Fi, broadcast antennas, smart meters, and baby monitors as well as electric devices and infra-structures used in the delivery of electricity that generate extremely-low frequency electromagnetic field (ELF EMF).

**Scientific basis for our common concerns**

Numerous recent scientific publications have shown that EMF affects living organisms at levels well below most international and national guidelines. Effects include increased cancer risk, cellular stress, increase in harmful free radicals, genetic damages, structural and functional changes of the reproductive system, learning and memory deficits, neurological disorders, and negative impacts on general well-being in humans. Damage goes well beyond the human race, as there is growing evidence of harmful effects to both plant and animal life.

These findings justify our appeal to the United Nations (UN) and, all member States in the world, to encourage the World Health Organization (WHO) to exert strong leadership in fostering the development of more protective EMF guidelines, encouraging precautionary measures, and educating the public about health risks, particularly risk to children and fetal development. By not taking action, the WHO is failing to fulfill its role as the preeminent international public health agency.

**Inadequate non-ionizing EMF international guidelines**

The various agencies setting safety standards have failed to impose sufficient guidelines to protect the general public, particularly children who are more vulnerable to the effects of EMF.

The International Commission on Non-Ionizing Radiation Protection (ICNIRP) established in 1998 the “Guidelines For Limiting Exposure To Time-Varying Electric, Magnetic, and Electromagnetic Fields (up to 300 GHz)”[xv]. These guidelines are accepted by the WHO and numerous countries around the world. The WHO is calling for all nations to adopt the ICNIRP guidelines to encourage international harmonization of standards. In 2009, the ICNIRP released a statement saying that it was reaffirming its 1998 guidelines, as in their opinion, the scientific literature published since that time “has provided no evidence of any adverse effects below the basic restrictions and does not necessitate an immediate revision of its guidance on limiting exposure to high frequency electromagnetic fields[xvi]. ICNIRP continues to the present day to make these assertions, in spite of growing scientific evidence to the contrary. It is our opinion that, because the ICNIRP guidelines do not cover long-term exposure and low-intensity effects, they are insufficient to protect public health.

The WHO adopted the International Agency for Research on Cancer (IARC) classification of extremely low frequency electromagnetic field (ELF EMF) in 2002[xvii] and radiofrequency radiation (RFR) in 2011[xviii]. This classification states that EMF is a *possible human carcinogen (Group 2B)*. Despite both IARC findings, the WHO continues to maintain that there is insufficient evidence to justify lowering these quantitative exposure limits.

Since there is controversy about a rationale for setting standards to avoid adverse health effects, we recommend that the United Nations Environmental Programme (UNEP) convene and fund an independent multidisciplinary committee to explore the pros and cons of alternatives to current practices that could substantially lower human exposures to RF and ELF fields. The deliberations of this group should be conducted in a transparent and impartial way. Although it is essential that industry be involved and cooperate in this process, industry should not be allowed to bias its processes or conclusions. This group should provide their analysis to the UN and the WHO to guide precautionary action.

**Collectively we also request that:**

1. children and pregnant women be protected;
2. guidelines and regulatory standards be strengthened;

3. manufacturers be encouraged to develop safer technology;
4. utilities responsible for the generation, transmission, distribution, and monitoring of electricity maintain adequate power quality and ensure proper electrical wiring to minimize harmful ground current;
5. the public be fully informed about the potential health risks from electromagnetic energy and taught harm reduction strategies;
6. medical professionals be educated about the biological effects of electromagnetic energy and be provided training on treatment of patients with electromagnetic sensitivity;
7. governments fund training and research on electromagnetic fields and health that is independent of industry and mandate industry cooperation with researchers;
8. media disclose experts' financial relationships with industry when citing their opinions regarding health and safety aspects of EMF-emitting technologies; and
9. white-zones (radiation-free areas) be established.

Release date: May 11, 2015

All inquiries, including those from qualified scientists who request that their name be added to the Appeal, may be made by contacting Elizabeth Kelley, M.A., Director, EMFscientist.org, at info@EMFscientist.org.

*Note: the signatories to this appeal have signed as individuals, giving their professional affiliations, but this does not necessarily mean that this represents the views of their employers or the professional organizations they are affiliated with.*[xix]

# 6. Index

# 7. Notes

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[i]

[ii] July 30, 2015

Re: "The Stinger" and other electronic, flying insect "zappers" that employ a lure.

Proposal: To ban the use of these insect lures.

Reason: They span wide areas for the purpose of attracting biting and stinging, flying insects to a hanging device, often containing an ultraviolet light. The insect is then electrocuted.

These bug zappers do not differentiate between nuisance insects and beneficial ones.

Lures made with toxicants (manmade toxins) can be harmful to larger animals, including humans.

Linda C. Dugas

HOME> SHOP > NOSQUITO NS 16 MOSQUITO ATTRACTANT

N0squito NS16 NOsquito Mosquito Attractant

Price $6.99

Model Number: NS16

Dimensions: 8.75" x 0.00" x 6 00" in

Weight: 0 14 lbs

Color: Orange

The NOsquito NS16 Mosquito Lure from Stinger is an EPA approved lure proven to attract mosquitoes.

**How it Works**

When used with all Stinger Insect Killers, the NOsquito Octenol lure can optimize mosquito attraction - luring more mosquitoes to outdoor insect killing devices. Attracted mosquitoes are drawn into Stinger insect killers where they are electrocuted and fall harmlessly to the ground or tray.

**Features:**

Compatible with all electronic insect killers

EPA approved; independent lab tested

Lures mosquitoes that may transmit West Nile Virus

Easy to install

Replace every 30 days for optimum performance

Not available for sale in Canada

This package contains one lure.

This product is eligible for a uSave discount of $0.70 and ships U PS Ground for free to uSave members (a $4.95 value). Join or log in during checkout

NS16

1-Octen-3- ol

**Properties**

Chemical formula

1-Octen-3- ol octenol for short and also known as mushroom alcohol is a chemical that attracts biting insects such as mosquitoes. It is contained in human breath and sweat, and it was once believed that insect repellent DEET works by blocking the insects' octenol odorant receptors 1-0cten-3-ol is a secondary alcohol derived from 1-octene. It exists in the form of two enantiomers. (R)-(-)-1-octen-3-ol and (S)-(+)- 1-octen-3-ol.

**Contents**

1 Natural occurrence

2 Uses

3 Health and safety

4 See also

5 References

**Natural occurrence**

Octenol is produced by several plants and fungi, including edible mushrooms and Lemon balm. Octenol is fom1ed during oxidative breakdown of linoleic acid.

!t is also a wine fault, defined as a cork taint, occurring in wines made with bunch rot contaminated grape

**Uses**

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Octenol is used, sometimes in combination with carbon dioxide, to attract insects in order to kill them with certain electronic devices.

Its odor has been described as green and moldy or meaty; it is used in certain perfumes.

**Health and Safety**

Octenol is approved by the U.S. Food and Drug Administration as a food additive. It is of moderate toxicity with an LO 50 of 340 mg/kg.

In an animal study, octenol has been found to disrupt dopamine homeostasis and may be an environmental agent involved in Parkinsonism.

**See also**

Among the proposed naturally occurring environ mental agents for PD etiology, the role of fungi and their metabolites has never been elucidated, despite their ubiquitous presence around us.

However, the presence of fungi and their metabolites has been li n ked with poor indoor air quality and adverse health effects. The quality of indoor air is especially important, because in the United States, people spend almost 90% of their time indoors interestingly, exposure to fungi has been linked to the presence of neurologic and neuropsychiatric signs and symptoms, including movement disorders and loss of balance and coordination. Fungi are known to emit complex mixtures of alcohols, aldehydes, acids, ethers, esters, ketones, hydrocarbons, terpenes, and sulfur compounds and are responsible for the characteristic moldy odors related to damp indoor spaces.

In an attempt to develop an inexpensive, invertebrate model for studying the possible toxicological effects of fungal volatile organic compounds (VOCs) associated with indoor environments, we turned to a Drosophilamodel. Using this model, we reported the toxicity of a variety of fungal toxicants, including 1-octen-3-ol, trans-2-octenal, 3-octanol, 2.5-dimethylfuran, and 2-octanone, at concentrations of 2.8-14 ppm. Out of this screen, l-octen-3-ol was one of the most potent agents and selectively damaged the dopamine system at high level s of exposure. Given its ubiquity in the natural and built environment and recognizing the prevalence of PD long before neurotoxic chemicals such as paraquat or MPTP were synthesized or used, we decided to further investigate the role of l -octen-3-ol as a possible etiological agent for PD.

Inamdar. Arati A. et.al. "Fungal.Derived Semiochemical 1-0cten·3.OI Disrupts Dopamine Packaging and Causes Neurodegeneration." Proceedings of the National Academy of Sciences of the United States of America 110.48 (2013) 19561-19566. PMC. Web. 28 July 2015.

Fungal-derived semiochemical 1-octen-3-ol disrupts dopamine packaging and causes neur…

In summary these data demonstrate that I -octen-3-ol damages the dopamine system, most likely through disruption of dopamine handing. These findings arc of particular interest given recent epidemiological studies that have raised the concern of neuropsychological impairments and movement disorders in human populations exposure to mold; and water-damaged buildings. Increased incidence of PD is seen in rural populations. Where it is usually attributed to pesticide exposure. However, the prevalence of mold and mushroom in these environments may provide another plausible risk factor for the development of PD.

Furthermore, 1-octen-3-ol is known to be present in human sweat. Being an oxidative product of linoleic acid, an essential fatty acid. Its excessive endogenous production in the body may contribute to human vulnerability to developing PD. Our studies in Drosophila suggest that the common fungal VOC 1 -octen-3-ol may contribute to Parkinson disease, particularly in people who have a genetic susceptibility. Further epidemiological studies will be needed to test this hypothesis. Additionally the toxic effects we have demonstrated for 1-octen-3-ol implies that other plant and microbial VOCs should be screened for their possible neurotoxicity.

[iii] To the Rhode Island Governor's Commission on Disabilities,

Thank you for examining the need to help those suffering from electro hypersensitivity (EHS) from electromagnetic radiation. I am a parent in Ashland, Massachusetts and two years ago I began hearing about potential harm from our beloved Wi-Fi devices. I am a technical and professional writer by trade, so I began to research this issue. The amount of information I found was vast, and to help keep the information reference able, I created a simple Google Site. Feel free to peruse Understanding EMFS as a supplement to your own research.

I opened the conversation with our town leaders, and after much research and debate, last fall Ashland Public Schools implemented the attached *Best Practices for Mobile Devices*. I then met with MA Senator Karen Spilka and used an EMF meter to measure the excessive amount of radiation coming from her cell phone. It was then that she understood just how potentially harmful quick adoption of all our Wi-Fi technology could be. She introduced Massachusetts Senate Bill 1222 to begin looking into this at the State level in hopes of informing our constituents. The bill went to hearing last week.

While Wi-Fi harm may come as news to us, thousands of studies have been done on electromagnetic radiation, and the scientists who have done them are gravely concerned for the health of our citizens. Just this past May, 190 scientists from 39 nations sent an Appeal to the United Nations and the World Health Organization to protect our citizens from Wi-Fi radiation. You can access it here, and view a three-minute video of Dr. Martin Blank from Columbia University announcing the Appeal.

With every illness, our individual biochemistry causes us to respond at different levels of exposure. Those who are already sick are the proverbial canaries in the coal mine: as the cumulative effects of being bathed in Wi-Fi radiation 24/7 mount, the number of adults and children suffering with EHS is growing. Doctors in environmental medicine understand the issue more than mainstream doctors who have not been trained. Please see the attached position paper from the American Academy of Environmental Medicine.

I hope you will carefully review the non-industry sponsored research and look at what other countries are doing to safeguard their citizens, and support those in Rhode Island who are already suffering.

Thank you for your time and consideration, please let me know if I can provide additional information.

Respectfully,
Cecelia Doucette, Ashland, MA

[iv]CREDENTIALS REGARDING EMFs:

- Dominion and Exelon Nuclear Power Facility Clearance 2012-2014
- Performed three year evaluation of plant cooling water systems, plant off-gas, other systems for **Electromagnetic Field (EMF) induced electrochemical corrosion.**
- Assessed electrical isolation of high-purity stainless alloy and other metallic cooling water system components using radio frequency electromagnetic signals and both **AC/DC resistance and voltages**.
- Performed close interval surveys (CIS) and direct current voltage gradient (DCVG) surveys **to determine elevated voltage potentials along plant utility corridors**.
- Managed pipeline current mapping (PCM) via radio frequency transmitter and receiver to determine current leakage and pipe construction defects.
- US **NRC Radiation Worker Trained**
- Massachusetts Bay Transportation Authority (MBTA), Boston, MA 2012-2014
- Managed and performed **power line induced stray voltage interference field measurement** in multiple MBTA facilities, branch lines and National Grid utility corridors and measured effects on cathodic protection systems and infrastructure
- Installed grounding equipment and voltage testing for MBTA worker safety and equipment protection from **power line induced voltage along counterpoise system (installed to mitigate stray voltages) and substation ground faults**
- MBTA / Hingham Municipal Lighting Plant (HMLP) Utility Corridor - Surveyed Installed **stray current remote monitoring** devices multiple locations
- Managed installation of $7 million dollar **Magnetic Resonance Imaging (MRI)** Unit, Cardiac **Catheterization** and **Electrophysiology Labs**, Resurrection Medical Center, Chicago, IL, 2000-2003
- Steel Tank Institute (STI) SP001 AST System Inspector Licensed 2012-present
- City of Boston Licensed Drainlayer (**Municipal Utility Contractor**) 2005-2008
- Railway Worker Protection (RWP) Trained, MBTA 2012-2014
- OSHA & HAZMAT 24 HR Certifications
- CIVIL ENGINEERING - BACHELOR OF SCIENCE, May 1997 - Valparaiso University, Valparaiso, IN

[v] The EPRI funded report is referenced as follows: Electric and Magnetic Field Management Reference Book: First Edition, EPRI, Palo Alto, CA: 1999. TR-114200 (over 500 pages)

The **importance of the following paragraphs** also taken from this report produced by EPRI, cannot be overemphasized. Please read:

**Background**

*"Electromagnetic interference of one electrical device with another electrical device has been a concern in the electrical business since its beginning. More recently power frequency fields from electrical facilities have been found to interfere with the proper operation of sensitive electronic equipment such as computer monitors, electron microscopes, and medical diagnostic and monitoring equipment.* ***A related concern has been the possible effects of electric and magnetic fields on human health. The interactions of electromagnetic fields with the human body received careful attention during World War II when sailors warmed themselves in the beams or radar antennas and reported***

***various health problems. Concern about health effects from exposure to power-frequency electric and magnetic fields surfaced in the 1960s with reports about illness patterns of Russian substation workers. A decade later, epidemiological studies reported correlating a surrogate for 60-Hz magnetic fields with childhood leukemia.*** *Those studies are still continuing with no conclusive results.*

*The basic question that initiated engineering work on EMF management was "****What can be done to reduce exposure from electric power facilities should health effects research demonstrate that adverse health effects may actually occur?"*** *Engineers also have to deal with equipment sensitivity to power frequency fields that may create operating problems. These matters have formed the basis for over twenty years of research on electric and magnetic field management.*

**Objectives**

- *To investigate a wide variety of options for reducing exposure to power frequency electric and magnetic fields*
- *To assemble results in a reference book*

**Approach**

*Work was divided into three primary areas of investigation: transmission, distribution, and shielding. Options to reduce fields in each of these areas were developed, tested and in some cases demonstrated on actual utility systems. Utilities can now choose which option best suits their specific needs if field management becomes necessary."*

*This EPRI report continues for 500 pages and covers:*

*Basic EMF Principles*
*EMF Measurements*
*EMF Management for Distribution / Transmission Lines*
*EMF Shielding*
*Residential, Commercial, Institutional and Industrial EMF Management*
*Health Guidelines, International Standards, Extensive References*

[vi] **The Cell Phone Problem - EHHI Study on Cell Phone Technology, Exposures, Health Effects**

Source: www.ehhi.org

Publication Date: 2012

Printed Page Length: 75

This study of Cell Phone Technology, Exposures, Health Effects was developed and managed by Environment and Human Health, Inc. The study presents findings from non-industry funded research lead by a (10) board member panel of experts, including (5) M.D.'s, Past Commissioner of Health for the State of CT, Past President of the American Public Health Association, Former Chair of the CT Energy Advisory Board, Past President of the CT Forest and Park Association, Past Chief of Environmental Epidemiology and Occupational Health at the CT Dept. of Health, Past Deputy Director of the Public Health Practice Group of ATSDR at the National Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia, (6) Professors and Associate Professors at Yale University spanning Pediatrics, Obstetrics, Gynecology and Reproductive Sciences and Department of Molecular, Cellular and Developmental Biology, Division of Reproductive Endocrinology and Infertility, Oncology, and Yale Cancer Center. Report walks through the science, health risks, laws, policies and current regulations.

[vii] Merriam-Webster Medical Dictionary **microwave sickness** *noun* **Medical Definition of *MICROWAVE SICKNESS*:** a condition of impaired health reported especially in the Russian medical literature that is characterized by headaches, anxiety, sleep disturbances, fatigue, and difficulty in concentrating and by changes in the cardiovascular and central nervous systems and that is held to be caused by prolonged exposure to low-intensity microwave radiation

[viii] The article is copied below.

The June Noise is here: http://thenoise.us/editions/0614x.pdf

BOB RHODES AND HIS SMART METER: FORMER BOEING ANALYST LINKS THE NEW ELECTRIC UTILITY METERING TECHNOLOGY TO HIS 2-YEAR BOUT WITH SEIZURES & INSOMNIA STORY & PHOTO BY CHARLES SEIVERD

Bob Rhodes is an active 71-year old living in the planned community foothills of northwest Phoenix. After serving in the Navy (non-combat) for 3 years in the late 60s and working for Boeing as a financial analyst for 25, he had earned a decent retirement & health package and has been enjoying leisure life since 1998. He's been healthy all his life, no chronic conditions or major operations, and his family history points to inherited vigor, with his mother living to be 95, his father to 82, both staying out of hospitals until their final years.

But in 2010, Mr. Rhodes' health began deteriorating inexplicably. He first struggled with bouts of insomnia, which he had never before had in his life, and he'd awake with a start in the early morning, his heart palpitating, his body in a cold sweat, and his mind unable to calm itself back to sleep. Within the following year, he developed epileptic-like seizures where his body would shake for one to two minutes, he would lose consciousness, and he would "come to" estranged from his immediate surroundings.

Recalls Mr. Rhodes: "I continued with the insomnia and seizures for the next two years. The doctors I saw during that time could not tell me a thing about why this was happening. The story of those two years and my interactions with the medical profession is a long and involved story … In a nutshell, I was having a seizure approximately every 4 weeks, at 3 in the morning while I was asleep in my bed. Like I said this went on for 2 years. All tests I took showed nothing wrong with me. I asked why these seizures only occurred at 3AM while I was in bed. No answer."

His health care professionals, while not being able to provide an explanation for the sudden onset of his condition, prescribed anti-seizure medication, which allayed his symptoms slightly, lessening the severity but not their frequency.

Then one day in February of last year, his wife received an email from a friend, which headlined: "Are Smart Meters Making You Sick?" "My first thought was: 'What the hell is a Smart Meter?" So Mr. Rhodes began tirelessly investigating, pouring over hundreds of internet pages, and discovering his symptoms were akin to others across the nation who had linked their illnesses to the presence of a recently-installed wireless electric meter by power companies wishing to "streamline" meter-reading operations. Mr. Rhodes quickly identified his electric meter as being one of a handful sold to utility companies — from the German technology giant Elster — and a call to his electricity provider — Arizona Public Service, which services a majority of the state's households — confirmed the meter had been installed in 2010, only months before his ailments began.

Observes Mr. Rhodes: "When APS puts things in front of the Arizona Corporation Commission [the state's utility regulatory agency], they say these smart meters will help people control their electricity charges, they'll know what they're using, when they're using, how they can save money, and I realized that meter was installed three years ago, and I never once in my monthly billing received anything that said, 'We installed a smart meter in your house and you're going to be able to save money!' I've never seen anything like that, they never indicated they changed out meters. The first time they put it on I was not aware of it. I don't think anyone is aware of it." But the timing of his seizures fit the documented relay of information emitted from an individual smart meter — via high frequency radio waves — to wireless neighborhood "mother hubs" that collect household data and send it back to APS: early every morning, a short signal sends information about the day's electricity usage, then every 4 weeks, a longer signal sends monthly information just before a posted billing cycle. What resounds in Mr. Rhodes' case was the fact that his smart meter was installed on the outside wall of his bedroom, just three feet away from the pillow he used at night. "After two years of this hell, I was at the lowest I've ever been. I was depressed, I was sick every day. A list of things I had. And I thought, 'I can't take it any more,'" notes Mr. Rhodes, contending his symptoms subsided immediately after he phoned APS and ordered the Elster Smart Meter removed from his house. The smart meter was taken out in early March 2013, his last documented seizure was March 17.

Since that time, Mr. Rhodes diligently vacated the space he sleeps of wireless appliances — modem, telephone, and computer devices all have been taken out of his bedroom and he reports his insomnia and seizures have vanished. Still curious and undeterred, he made an appointment through his doctor with a neurologist at the Boswell Medical Center, with whom he confided his past two years of illness and his suspicions of the smart meter link. After hearing his witness, quizzing his wife, and evaluating his prognosis, the neurologist conceded: "'I believe the smart meter was a factor in your seizures.'"

Continues Mr. Rhodes, "The RF waves from the smart meter were a factor in the seizures. He said the hyper-sensitivity I developed during the years I spent with that thing there cannot be cured. So he wants me to stay as far away from the RF wave equipment as possible, he wants me to take an anti-seizure drug which will readjust my brain chemicals to normal consistent levels and hopefully work to keep brain functions from reaching a seizure level. He says RF waves were a factor, not the factor, but a factor. As far as I'm concerned, they were the factor."

For its part, APS still does not "officially recognize" health problems associated with smart meter installation, yet has posted a "counter point" video on its "smart meter customer benefits" webpage asserting the radio frequency waves emitted from smart meters are of "similar magnitude" to household wireless appliances. So far, the utility company, which posted profits of $382 million last year, has laid off close to 500 meter readers statewide while continuing a smart meters installation initiative that has swapped an estimated 70% of household meters in its territory. In Sedona, where controversy surrounding smart meters has erupted into special city council meetings and official city policy, an estimated 22% of APS' customers have "opted out" of smart meter installation by calling the company's hotline at 800-253-9405. The Arizona Corporation Commission — which held open meetings on the topic in September 2011, March 2012, and May 2013, and maintains an online docket at edocket. acc.gov (doc# 11-0328) — filed testimony from hundreds of Arizonans who've sustained negative effects from smart meters, has tabled APS' requests for an "opt out" fee of $75 initially and $360 annually, and has directed the Arizona Department of Health Services to conduct a thorough study. The parameters and results of the DHS study is yet to be released.

Queries Mr. Rhodes: “I wonder how many people are having insomnia and don’t know why. And the answer could be that smart meter.”

**| Charles Seiverd is collecting smart meter testimonials & welcomes personal leads.** charles@thenoise.us

[ix] Here is an English article about the decision, and the links at the bottom of the article lead to official German government pages re the item/topic:

http://kompetenzinitiative.net/KIT/KIT/progress-in-south-tyrol-applying-the-precautionary-principle/

*Innovations at the State Parliament of South Tyrol (Landtag Südtirol): In a decision from 10 June 2015, a responsible implementation of Wi-Fi and cell phone networks as well as RF radiation exposure guidelines has been announced. The majority of the State Parliament decided allowing the application of the precautionary principle.*

*Motivated by sustainable progress and political responsibility, this decision mandates the state government, among other things:*

1. *To replace existing wireless networks whenever possible with networks that emit less radiation at schools, preschools, hospitals, nursing homes, and other public facilities…*
2. *To establish a working group whose mandate it is to assess these new technologies and their exposure levels. With regard to wireless communication technologies, mobile Internet access, and public health, the working group shall clarify which technologies emit less radiation and provide sustainable technology options…*
3. *To start an education and awareness campaign that informs about possible health risks, especially regarding the unborn, infants, children, and adolescents and that develops guidelines for a safer use of cell phones, smartphones, and Wi-Fi …*

[x] See: Wi-fi Technology: Is the Honeymoon Over? Ashland school committee issues best practices for Wi-Fi use. By Cece Doucette, Ashland Town News, 8/15, page 14

http://www.localtownpages.com/sites/default/files/newspaperpdf/2015_8_ashland.pdf

Both Israel and France have curtailed Wi-Fi in Schools. I am part of a group concerned not only with the health affects of RF/EMF but with other issues peculiar to Smart Meters. Our site is: http://www.worcesteroptsout.org/#

[xi] Guidelines of the Austrian Medical Association for the diagnosis and treatment of EMF related health problems and illnesses (EMF syndrome)

The Austrian Medical Association has developed treatment guidelines for this sensitivity.

12/2015 The European Union's European Economic and Social Committee (EESC)

Document on electrohypersensitivity.

Dr. Olle Johansson and Dr. Isaac Jamieson November 4th 2014 Presentation.

Dr. Erica Mallery-Blythe’s Working Draft on a Summary of EHS detailing the science in full.

Dr. Marino's Research summaries.

5th Paris Appeal Congress, 18th of May, 2015, Royal Academy of Medicine, Belgium, IDIOPATHIC ENVIRONMENTAL INTOLERANCE: WHAT ROLE FOR ELECTROMAGNETIC FIELDS AND CHEMICALS?

Doctor’s talk on Electrosensitivity: Clinical Diagnosis and Management – Dr Erica Mallery-Blythe (UK)

Watch Video of Talk

[xii] Letter to the New York Times

Read the original article and other responses at http://www.saferemr.com/

Dear Ms. Sullivan and Ms. Pogash,

Like Drs. Hardell and Carlberg, I read your July 21 article "Cellphone Ordinance puts Berkeley at Forefront of Radiation Debate" with "interest."

I understand very well that it must be challenging, as journalists not aware of being touched by this emerging public health crisis, to give the specter of EMF biological impacts much credence. Perhaps I am a slow learner, but it took me about six months to accept that wireless technology was wreaking havoc on my wife's nervous system despite repeated evidence that this was the case.

I am writing to you both because of what our family has lived over the last five years but also as a lifelong reader of the New York Times. Like so many people around the world, I have always considered the Times the best newspaper I have ever read. While I have never expected the paper to offer a tremendous bias in favor of "the 99%" as we might call it, quoting exclusively MD's and scientists ready to parrot industry-funded "research" seems out of character. Why not contextualize Dr. Bushberg with the California Medical Association's or the American Academy of Pediatricians' takes on the subject? My confidence began to erode while witnessing Nick Bilton's being "thrown under the bus" as Microwave News described it, for digging into some of the independent research (thousands of studies to choose from!) and deciding to take a few small steps to protect himself and his family. The telecom industries' heavy hand in shaping science and policy re: EMF health effects is well documented. You can watch the excellent French documentary "Microwaves, Science and Lies" with the password "waves." In 1994 someone at Motorola wrote a memo to their media advisors saying they had "war-gamed" the science. Eleven years later, smart meters are being rolled out in my home state of Massachusetts abetted by testimony to the Mass Department of Public Utilities by tobacco scientist Peter Valberg of product defense firm Gradient.

In the spirit of a fresh start, would you be interested in sending one of your European correspondents to Switzerland to cover the French-language premiere of our play "Innocenzo", the world's first theatrical treatment of electromagnetic pollution and electro-hypersensitivity on September 12 and 13? Or perhaps an article looking into the debunking of the NOCEBO effect re: electro-hypersensitivity? I am happy to put you in touch with adults, teens and children in the U.S. and Europe whose whose lives have taken on the hues of a nightmare and whose families, colleagues, and classmates think they have a mental problem, in part because of an industry-dominated media, rather than a physiological reaction to EMF exposure. This reaction now comes complete with bio-markers thanks to Dr. Belpomme in Paris. As you might imagine, the suicide rate in this group is quite high. Please see the end of Dr. Erica Mallery-Blythe's recent presentation at the Commonwealth Club as a case in point. Your unbiased inquiry could save lives!

Sincerely,
Jonathan Mirin

[xiii] WHO's International Agency for Research on Cancer Determines RF/MW Radiation is Group 2B Human Carcinogen

https://www.youtube.com/watch?v=s4E2i5XFX9M

http://monographs.iarc.fr/ENG/Monographs/vol102/

https://lennarthardellenglish.wordpress.com/2014/12/08/moving-radiofrequency-radiation-from-group-2b-to-1-as-a-human-carcinogen/

http://www.pathophysiologyjournal.com/article/S0928-4680(14) 00064-9/fulltext

Sources of Primary Scientific Research and Scientifically-Based Exposure Guidelines to RF/MW Radiation

http://www.emfscientist.org

http://www.powerwatch.org.uk/science/studies.asp#masts

http://www.justproveit.net/content/studies

http://www.magdahavas.com/category/from-zorys-archive/

http://hbelc.org/pdf/standards/sbm2008.pdf

Additional Primary Scientific Sources

Peer-Reviewed Research Concluding Adverse Effects in Humans, 1988-2014

Lepp 2014-U (Mobile. phone use associated with college students' anxiety, lower grades)

Teksheva 2014-I,O,U (Adverse effects of schoolchildren's health determined from RFR)

Mueller 2014-U (Laptop note-taking is detrimental to learning, relative to handwriting notes in university setting)

Coreau 2014-O,U (Heavy mobile phone usage associated with brain cancer)

Xiu-Juan Su 2014-O,U (Prenatal magnetic field exp may have adverse effect on embryonic development)

Hardell 2013-U (Results of SCENIHR mistaken due to omission of positive studies)

Griesz-Brisson 2013-I,U (Prompt brain reaction, cardio-vascular changes when exposed to mobile phone RFR)

West 2013-O,U (Multifocal breast cancer in young women who kept phone near breasts)

Gomez-Peretta 2013-I, U (Direct assoc between exposure, sleep and fatigue confirmed w statistical significance)

Lv 2013-I,O,U (fMRI shows acute low-freq fluctuations in various brain areas with RF/EMF exposure)

Byun 2013-U (Lead & RF from mobile phone use assoc with ADHD in children)

Cam 2012-U (Significant increase in single-strand DNA breaks with 15-30-minute mobile phone use)

Balaguru 2012-I,O,U (Spinal cord acts as antenna, w induced elec voltage, current dist & nervous system changes)

Sana 2012-U (Laptop use lowers students' grades, distracts)

Wood 2012-U (Use of digital technologies has detrimental impact on learning in college classroom setting)

Hagstrom 2012-U (Avoidance of EMR/F reduces symptoms)

Barghava 2012-U (Increased salivary & blood flow and volume of ipsilateral carotid gland in heavy users)

Hamzany 2012-U (Increased salivary oxidative stress, and decreased albumin, protein, & amylase activity in users)

Hardell 2012-U (Increased glioma, acoustic neuroma) ,2009-U (OR=3.3 for astronoma w ipsilateral use >10-yr latency; highest risk for &lt; 20 yr of age) , 2007a, 2006a-U (Increased risk of brain tumor 3-fold w mobile phone use 2K-3K hours, danger for young people), 2006b, 2005-U (Increased brain tumor risk in use of cell &cordless phones), , 2003b, 2002, 2001, 2000 (Tinnitus), 2002a&b (Brain tumors), 1999-U (Elevated brain tumor risk), 1998-O (Testicular cancer)

Eskander 2011-I,O (Signif decr in ACTH, cortisol, other hormones w base station exp, particularly w long durations)

Dode 2011-I (High rates of cancer in people living closer to cell phone towers)

Avendano 2010-I, U (Wi-Fi from laptop reduces sperm motility)

Augner 2010-I,O,U (Dose-dependent changes in immune indicators incl. cortisol and alpha-amylase in humans)

Khurana 2010-I,O (Neurobehavioral symptoms and cancers consistently shown in epidemiologic studies of base station RF radiation)

Johansson 2009-I, U (Disturbance of immune system and increased cancer risk from electromagnetic fields), 2004-I,O, U (electrosensitivity is irradiation damage), 2001-I, U (cutaneous mast cells altered in healthy humans at TV/PCs), 2000-I, U (mast cells, histamine from E & H fields), 1999, 1998, 1995-I,U (human provocation: dermatitis)

Oberfeld 2009-I (Hazards to mobile phone users and inhabitants near base stations)

Sage & Carpenter 2009-I,O,U (Wide variety of problems result from low-level RFR exposure)

Kundi 2009-I (Base station health needs more study)

Hallberg 2009-I (Decrease in public health post-1997, with factors such as GHz radiation increase), 2005 (Malignant melanoma), 2004 (Malignant melanoma associated with TV-FM rollout, not UV), 2004 (Long-term sickness and mobile phone use), 2004 (Mobile handset output and health), 2002 Huttunen 2009-I (EM sensitive persons react to TV-FM signals)

De Tommaso 2009-U (GSM phone influences brain electrical activity)

Sirav B 2009-I (Dosimetry: Ankara tower vicinity levels 4x> than ICNIRP standard)

Hardell 2009-U (OR=3.3 for astronoma w ipsilateral use >10-yr latency; highest risk for &lt; 20 yr of age), 2007a, 2006a-U (Increased risk of brain tumor 3-fold w mobile phone use 2K-3K hours, danger for young people), 2006b, 2005-U (Increased brain tumor risk in use of cell &cordless phones), 2003b, 2002, 2001, 2000 (Tinnitus), 2002a&b (Brain tumors), 1999-U (Elevated brain tumor risk with cell phone use), 1998-O (Testicular cancer)

Abramson 2009-U (Mobile phone use associated with cognitive function changes in young people)

Milham 2009-O (Firefighters' cancers due to EMF/RFR rather than inhaled carcinogens), 1996, 1988, 1985, 1982

Blettner 2008-I (More health complaints within 500m of base station)

Divan 2008-I,U (Cell phone exp pre- & post-natally assoc. w emotional problems, hyperactivity at ~5-6 yrs of age)

Merzenich 2008-I (Slightly elevated childhood leukemia rate within 2km of TV-radio transmitters)

Baste 2008-O, I (Infertility and lower boy:girl offspring ratio in military men who worked &lt; 10m from high-frequency aerials)

Agarwal 2008-U (Cell phone users have reduced sperm count)

Barth 2008-U, I (reduced cognitive function in cell phone users: decreased reaction time, altered working memory and increased number of errors in exposed persons)

Panagopoulos 2008-I,U (Infrastructural harm is more consistently seen than phone usage harm)

Goldsworthy 2008 (Many illnesses arise from electromagnetic smog)

Hardell 2008 (Mobile phone usage and cancer)

Goldberg 2007 (The body has become less functional due to RF radiation)

Hung 2007-I,O,U (The general public experiencing wide range of symptoms from many sources of env RF radiation)

Preece 2007-I (OR=2.7 migraine, 3.7 headache, 2.7 dizziness within 1-3 km of military antennae)

Clark 2007-I (RF, ELF associated w increased estrogen excretion; women w less nocturnal melatonin sensitive subgroup)

Ha M, 2007-I (AM RF associated (OR 2.15,) w child leukemia, brain cancer), 1993 (Cancer elevated near AM antenna)

Regel 2007 Pulsed RF: dose-dependent effects on sleep, the sleep EEG and cognitive performance. Altpeter 2006-I; 1995-I (Alterations in sleep quality, melatonin levels & cycle in vicinity of transmitter)

Abdel-Rassoul 2006-I (Neurobehavioral effects in inhabitants near mobile phone base stations)

Hutter 2006-I (Headaches, concentration problems, cold hands/feet in inhabitants near base stations), 2002 (Effects on health and wellbeing)

Huss 2006-I,U (MDs: patients attribute sleep disords, headaches, fatigue to base station proximity, mob. phone use)

Faucon-U, I 2006 (EEG effects in epileptics and healthy subjects exposed to GSM signal)

Krause 2006-U (Mobile phone signal alters 4-8 Hz EEG in children during cognitive processing)

Eliyahu 2006-U (GSM signal to left side of brain slows left-hand response time)

Esen 2006-U,O (Evoked neuronal activity latency lengthened with mobile phone usage)

Aalto 2006-U (PET scans: mobile phone radiation induces decrease in rCBF, regional blood flow, beneath antenna)

Abelin 2005-I (Causal relationship between shortwave radio transmission and sleep disturbances)

Balikci 2005-I (Headache, irritation, forgetfulness, clicking sounds)

Meo 2005-U (Mobile phone radiation associated with impaired hearing, earache, blurred vision)

Burch JB & Reif 2005a,b-O, 2004-O, 2002-U, 2002-O, 2000-O, 1999a-O. 1999b-I, 1998-O Eger 2004-I (Significantly elevated cancer in 10+-year inhabitants &le; 400m from cellular transmitter; these fell ill on average 8 years earlier; after five years' exposure, relative risk 3x higher than in those at &gt; 400m)

Oberfeld 2004-I (Fatigue, irritability, headaches, loss of memory and appetite, dizziness, concentration difficulty, sleep, visual and cardio disorders, in inhabitants near two base stations), R&#246;&#246;sli 2004-I, U (Sleep disorders (58%), headaches (41%), nervousness or distress (19%), fatigue (18%), concentration diffs w EMF/R exposure)

Al-Khlaiwi 2004-U (Mobile phone radiation associated w fatigue, headache, dizziness, tension, sleep disturbance)

Wolf 2004-I (4.15x increase in cancer in inhabitants near cell phone transmitter)

Bortkiewicz 2004-I, 1997, 1996, 1995 (Dysregulation of cardiac function with exposure to RFR)

Lonn 2004-U (Increased risk of acoustic neuroma associated with mobile phone use 10+ years)

Bortkiewicz 2004-I (Neuro problems in inhabitants near base stations)

Kundi 2004 (Elevated risk for neoplastic diseases)

Hyland 2003 (Non-thermal RFR produces illnesses in living beings)

Santini 2003 and 2002-I (Symptoms in inhabitants near base stations), 2001, 2000, 1999

Zwamborn 2003-I (Cognitive effects of RFR from communications systems)

Navarro 2003-I (Neuro problems in inhabitants near base stations)

Hocking 2003-I (Decreased survival for childhood leukemia near TV towers), 1998, 1996, 1995 Huber 2002-U, I (EMFs e.g. from mobile phones alter regional blood flow and sleep and waking EEG), 2000 Croft 2002-U (Acute mobile phone operation affects neural function in humans)

Michelozzi 2002-I (Elevated childhood leukemia within 6 km of base station), 2001-I Kimata 2002-U (Allergic skin reaction from mobile phone radiation)

Weinberger 2002-I,O,U (The human head as antenna and brain tissue as radio receiver)

Santini 2001-I (Symptoms from RFR base stations are well known), 1999 S&#246;dergren 2001-I,O,U Stang 2001-I (RF Radiation role in development of uveal melanoma)

Cherry 2000 (Flaws in exposure standards), 1999 (Cell phones threaten human health)

Borbely 1999-I (Pulsed high-frequency EM field affects human sleep and sleep EEG)

Cocco 1999-O (Occupational risk factors, including EMR, for nervous system tumors)

Moszczynski 1999-O (Immune system effects from occupational microwave exposure)

Santana 1999-O (Brain neoplasms in naval military men)

Borbély 1999 (Pulsed high-frequency EMF affects sleep and sleep EEG)

McKenzie 1998-I (Childhood leukemia and exposure to broadcast radiation)

Dmoche 1998-O (Immune compromise in men exposed occupationally to microwave radiation)

Braune 1998 (Increased blood pressure during exposure to RF field)

Hocking 1998-U (Symptoms associated with mobile phone use)

Mild 1998-U (Symptoms of digital and analog cell phone users)

Villoresi 1998-I,O,U (Myocardial infarct and geomagnetic disturbances: morbidity and mortality)

Pikin 1998-I,O,U (Effect of geomagnetic disturbances on blood coagulation in persons with ischemic disease)

Lai 1998 (Low-intensity RFR affects nervous systems: mechanisms thereof)

Frey 1998, 1995, 1993, 1988 (Mechanisms of headaches and cancer with exposure to RFR)

Johnson-Liakouris 1998 (RF sickness from modulated microwaves)

Smigielski 1998-O (Diurnal blood pressr, hrt rate w exp to RF), 1996-O (Cancer morb w occ RF/MWR), 1988, 1982 Dolk 1997a & b-I (Elevated cancer rates near FM and TV transmitters)

Hocking 1996-I (Cancer incidence and mortality increase with proximity to RFR towers)

Grayson 1996-O (Increased nervous system tumors)

Kolodynski 1996-I (Cognitive and neuromuscular problems in children near base station)

Beall 1996-O (Increase in nervous system tumors in electronics industry workers)

Tynes 1996-O (Breast cancer in female radio and telegraph operators)

Milham 1996-O (Increased cancer w magnetic fields), 1988-O (Increased mortality, malignancies: amateur radio operators)

Mann 1996-I, U (Cell-phone pulsed radiation effects on human sleep)

Gurfinkel I, U 1995 (Geomagnetic disturbances and effects on capillary blood flow)

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Ouellet-Hellstrom 1993-I,O,U (Miscarriages in physical therapists using radio- and microwave diathermy)
Maskarinec 1993-I (Childhood leukemia cluster near radio tower in Hawaii)
Sandyk 1992 (Pineal gland and spontaneous abortions: melatonin and magnetic therapy) Levels?
Larsen 1991 (Reproductive effect of high frequency RF exposure)
Goldoni 1990-O (Hematologic changes with occupational exposure to microwave radiation)
Johnson 1989 (Childhood nervous systems tumors associated with parental use of electronics)
Nilsson 1989-O (Microwave effects on central nervous system – study of radar mechanics)
Wang 1989-O (5-HT changes in workers exposed to microwave and high-frequency radiation)

[xiv] 1. Smart Meter Health Effects Survey. This survey was evidence in MPUC Docket 2011-00262 submitted by Dr. Richard Conrad as Exhibit 9 by Friedman, et al. As co-author of the survey, I knew utilities, telecommunication companies and regulators typically opine that EHS is psychosomatic in origin. Yet as someone deeply involved in the smart meter issue with no disability and not EHS, I was hearing from hundreds of people around the world having similar adverse health effects following the installation of smart meters. The observational evidence was speaking for itself. People from all walks of life worldwide, exposed to countless variables, were having similar reactions to the same thing: radiofrequency radiation [RFR]-emitting smart meters. This was the only thing they had in common. RFR is a form of electromagnetic radiation [EMR or EMF] and those who develop sensitivities to these forms of radiation are deemed EHS. In our proceeding we knew our hundreds of lay witnesses would be discounted by utility experts from Exponent [the consultants for Central Maine Power] who put a happy face on tobacco, asbestos, and run-away Toyotas among other product defense issues, so we designed an objective survey to see if our observations would be borne out in a scientific manner. With over 200 respondents we found 42% began suffering one or several symptoms typical of EHS [see histogram #2] following smart meter installation but before they knew the meter had been installed. This is not to say the other 58% did not suffer new or worsened symptoms after meter installation but only that they knew the meter had been installed so we couldn't definitively separate cause and effect. We also looked at relationships with other Wi-Fi technologies: cell phone, Wi-Fi routers and computers and found in roughly 40% of respondents, new or worsened EHS sensitivities with these technologies following smart meter installations. As I wrote in the discussion of results: The inability to use these common tools severely inhibits our respondents in their personal and economic lives. Their ability to live normal lives in the 21st century has been severely compromised. This change in ability to use these devices is directly correlated to smart meter exposure. This is another way of saying RF exposure can lead to development of EHS and this, whether a disease or functional impairment can create a major disability with life-changing consequences. I encourage deliberators in this RI proceeding to read Comments in Survey Appendix 6 where respondents were given the opportunity to enter health-related comments of up to 300 words. My words cannot do justice to the pain and suffering 3 to maybe 10% of our population is experiencing at present with acute EHS symptoms but they had a forum in Appendix 6.

2. Bar Graph of New and Severe Symptoms from Smart Meter Exposure. This is a graph showing % of EHS symptoms present in Maine smart meter survey. Percentages are derived directly from Appendix 3 in survey.

3. Testimony of Dr. William Rea in MPUC Docket 2011-00262. Dr. Rea has had probably more experience diagnosing and treating EHS than any other practitioner in the US.

4. Hallberg and Oberfeld Letter. This letter published in the journal Electromagnetic Biology & Medicine plots EHS prevalence over the years [beginning in 1985] and extrapolates forward. Based on past EHS incidence and current RF/EMF proliferation, the authors project some level of EHS sensitivity in 50% of the population by 2017.

5. Austrian EMF Guidelines. These are 2012 guidelines from the Austrian Medical Association for diagnosis and treatment of EMF related illness and syndromes.

6. Johansson, 2008 EHS Functional Impairment. In contrast to Austria, Sweden considers EHS a functional impairment, not a disease or illness. As such, equal access is important for those affected with this impairment.

7. EHS-Disability Policy in Sweden. This fact sheet from the Swedish Institute discusses how important equality and dignity are for those with impairments living in a democracy.

8. NIBS Indoor Environmental Quality Final Report. This 2005 report of the National Institute of Building Sciences with support from The Architectural and Transportation Barriers Compliance Board. The Architectural and Transportation Barriers Compliance Board (Access Board) is an independent federal agency devoted to accessibility for people with disabilities. The Access Board is responsible for developing and maintaining accessibility guidelines to ensure that newly constructed and altered buildings and facilities covered by the Americans with Disabilities Act and the Architectural Barriers Act are accessible to and usable by people with disabilities. On pg. 4: "The Board recognizes that multiple chemical sensitivities and electromagnetic sensitivities may be considered disabilities under the ADA if they so severely impair the

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neurological, respiratory or other functions of an individual that it substantially limits one or more of the individual's major life activities. The Board plans to closely examine the needs of this population, and undertake activities that address accessibility issues for these individuals." And on pg 11 under "Barriers & Issues": Electromagnetic Fields: For people who are electromagnetically sensitive, the presence of cell phones and towers, portable telephones, computers, fluorescent lighting, unshielded transformers and wiring, battery re-chargers, wireless devices, security and scanning equipment, microwave ovens, electric ranges and numerous other electrical appliances can make a building inaccessible. The National Institute for Occupational Safety and Health (NIOSH) notes that scientific studies have raised questions about the possible health effects of EMF's. NIOSH recommends the following measures for those wanting to reduce EMF exposure – informing workers and employers about possible hazards of magnetic fields, increasing workers' distance from EMF sources, using low-EMF designs wherever possible (e.g., for layout of office power supplies), and reducing EMF exposure times."

9. Pall, 2013. The exact mechanisms of how RF/EMF act on biological organisms are unknown but the same can be said for tobacco after all these years. Ignorance is no excuse for not acting. Observational evidence and strong correlations need not wait for legal causation to take proper precautions. Pall suggests one possible mechanism of action for EMFs may be through voltage-gated calcium channels. He finds that activation of these channels can block effects of EMF exposure ergo they may represent a pathway for EMF into the body.

10. Yakemenko et al 2015. This important review covers experimental data on oxidative effects of low-intensity radiofrequency radiation (RFR) in living cells. Analysis of the currently available peer-reviewed scientific literature reveals molecular effects induced by low-intensity RFR in living cells; this includes significant activation of key pathways generating reactive oxygen species (ROS), activation of peroxidation, oxidative damage of DNA and changes in the activity of antioxidant enzymes. It indicates that among 100 currently available peer-reviewed studies dealing with oxidative effects of low-intensity RFR, in general, 93 confirmed that RFR induces oxidative effects in biological systems. A wide pathogenic potential of the induced ROS and their involvement in cell signaling pathways explains a range of biological/health effects of low intensity RFR, which include both cancer and non-cancer pathologies. The authors conclude low-intensity RFR is an expressive oxidative agent for living cells with a high pathogenic potential and that the oxidative stress induced by RFR exposure should be recognized as one of the primary mechanisms of the biological activity of this kind of radiation. They also cite that indoor background RFR in industrialized countries increased 5,000-fold from 1985 to 2005.

[xv] http://www.icnirp.org/cms/upload/publications/ICNIRPemfgdl.pdf

[xvi] http://www.icnirp.org/cms/upload/publications/ICNIRPStatementEMF.pdf

[xvii] http://monographs.iarc.fr/ENG/Monographs/vol80

[xviii] http://monographs.iarc.fr/ENG/Monographs/vol102/

[xix] ***Signatories***
***Updated July 31, 2015***

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