PUBLIC FORUMS TO IDENTIFY THE CONCERNS OF PEOPLE WITH DISABILITIES AND THEIR FAMILIES

July 25th – July 29th 2016

Prepared by

The Governor's Commission on Disabilities

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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

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Public Notice

State of Rhode Island and Providence Plantations
Public Forums to Identify the Concerns of People with

During the week of the 26th 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 25, 2016, from 4 – 6 PM
Rogers Free Library, 525 Hope Street, Bristol
Hosted by RI Statewide Independent Living Council and National Federation of the Blind

Monday, July 25, 2016, from 4 – 6 PM
Warwick Library, 600 Sandy Lane, Warwick
Hosted by Opportunities Unlimited

Tuesday, July 26, 2016, 4 – 6 PM
Kingston Library, 2605 Kingstown Road, Kingston
Hosted by the National Multiple Sclerosis Society, Greater New England Chapter

Wednesday, July 27, 2016, 4 – 6 PM
Cumberland Public Library, 1464 Diamond Hill Road, Cumberland
Hosted by RI Department of Health

Thursday, July 28, 2016, from 4 – 6 PM
Middletown Library, 700 W. Main Rd, Middletown
Hosted by Opportunities Unlimited For People with Differing Abilities

Thursday, July 28, 2016, from 4 – 6 PM
Jesse M. Smith Library, 100 Tinkham Lane, Harrisville
Hosted by Seven Hills Foundation

Friday, July 29, 2016, from 3:30– 5:30 PM
North Providence Union Free Library 1810 Mineral Springs Ave, North Providence
Hosted by Perspectives Corporation

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. Language interpreting is available from Dorcas International Institute of RI and requests can be made to 784-8675 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

Gina Raimondo, Governor

Public Forum Sponsors

Brain Injury Association of RI

Bridgemark Addiction Recovery Services

Dorcas International

Goodwill Industries Inc.

Hamilton Realty

IN-SIGHT

Living in Fulfilling Environments, Inc.

National Federation of the Blind of RI

National Multiple Sclerosis Society, Greater New England Chapter

Ocean State Center for Independent Living

Office of Rehabilitation Services

Opportunities Unlimited, for people with Differing Abilities

Perspectives Corporation

RI Commission on the Deaf and Hard of Hearing

RI Department of Health, Office of Special Healthcare Needs

RI Department of Human Services

RI Disability Law Center

RI Governor’s Commission on Disabilities

RI Public Transit Authority

RI Statewide Independent Living Council

Seven Hills RI

Sherlock Center for Disabilities, at Rhode Island College

United Healthcare Community Plan

Friends of the Public Forums

Alliance for Better Long Term Care Ombudsman

Goodwill Industries of Rhode Island

Ocean State Center for Independent Living

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Community Concerns and Recommendations

Civil Rights/Accessibility Concerns and Recommendations:

Businesses

Concern: There is little to no access to restaurants in the town of Newport, only one restaurant was found to be accessible for a person in a wheelchair. Pages: 61
Recommendations: The Commission should submit legislation to increase the RIGL 44-54 Disabled Access Credit For Small Businesses.

Parking

Concern: The new design of Broadway in Newport has created barriers for parking. The stone roadway prevents a van from using a wheelchair ramp, as the ramp becomes stuck between the stones. There is one disabled parking spot across the street, but that requires using a ramp in the one lane of oncoming traffic. These barriers raise concern for the redesign of the bus station and Washington Square. Page: 59
Recommendations: The Commission should inspect Broadway to determine if the paving stones conform to the Federal Accessibility Standards. Penalties should be assessed for failure to design and construct to the Access Code.

Sidewalks

Concern: The sidewalks in Newport were found to be inaccessible to a tourist in a power wheelchair, causing that person to utilize the street, and subsequently hitting a hole that almost caused a fall. Page 60
Recommendations: The Commission should encourage individuals with disabilities and others to photograph access barriers. Those photographs should be sent to the Commission, identifying the street and intersection(s) as well as the date taken. Penalties should be assessed for failure to maintain sidewalks to the Access Code.

Transportation

Concern: Frequency of RIPTA bus service and RIde link to RIPTA buses. Pages: 77, 78
Recommendations: RIPTA should expand and advertise the availability of Flex service.

Voting

Concern: The voter ID is a barrier to voting accessibility for those with disabilities and mental health issues, and discriminates against the disadvantaged. Page 59
Recommendations: The Secretary of State should advertise the Voter Photo ID program.

Discrimination, DCYF

Concern: The Department of Children and Families is using disabilities as a bias when determining parental capabilities and custody. It does not appear that they are trained to be sensitive to those with disabilities, or to understand or appreciate what limitations there might be for those with disabilities. Pages: 24
Recommendations: The Commission should submit the National Federation of the Blind's model parent legislation, modified to include parents with other disabilities.

Panhandling Harassment

Concern: Since the panhandling laws were disbanded, it appears that the use of public transportation and going through Kennedy Plaza is met with harassment and begging for money, which is even more difficult when some individuals can't see the people approaching them. Is it possible to make some public areas panhandle free? Page: 28
Recommendations: The Commission should support efforts to expand services for the homeless, as a means of reducing confrontational panhandling.

Education/Employment Concerns and Recommendations:

Business and Employment Funding, Supports

Concern: Lack of funding and supports for self-directed business and employment programs. The current guidelines leave a gap for those attempting to create their own business and employment opportunities. Page 41
Recommendations: The Director of the Department of Administration should issue revised purchasing regulations that incorporate the 2011 & 2012 amendments to RI 37-2.2 Disability Business Enterprises and RIGL 37-2.4 Habilitation Procurement Program.

Discrimination

Concern: The use of a job coach would be preferred for employment skills and training, but it appears that employers do not want to hire someone that has a second person following them around for all shifts. Page: 74
Recommendations: The different job training entities, netWORKri, Office of Rehabilitation Services, Career and Technical Centers, Job Corp, and community based providers need to coordinate their on-the-job employer incentives and services. The Office of Rehabilitation Services should be able to place their clients into mainstreamed OJT slots and wrap their assistive technology and accommodations.

High School Athletics

Concern: Requesting legislation that aims to protect high school athletes by requiring all school districts to have an athletic trainer that is not a coach or director of athletics. To be on-site, and if somebody had a concussion, the athletic trainer could remove to the athlete from the game and require a Doctor be seen, and a parent or coach can't say that kid needs to go back in to the game until the Doctor or Athletic Trainer has cleared the athlete to return safely. Page: 60
Recommendations: The Commission should support the 2017 version of 16 H 7639 An Act Relating to Education -- School and Youth Programs Concussion Act (that requires all school districts to designate an athletic trainer to be available for high school athletic practices and games.)

Integrated classrooms

Concern: The all or nothing system meaning if you are not low functioning in social or adaptive skills you can't be self-contained. Page: 84

Job Services & Training

Concern: The employment options available, such as a Janitor, does not train for sustainability or future independence, it offers minimal skill training instead of scaffolding. Page: 73

Law Enforcement & Emergency Personnel

Concern: Requesting the establishment of training programs for law enforcement[1] and first responders that provide information on veterans with combat-related trauma, PTSD, or traumatic brain injury to prevent wrongful arrest, discrimination, or injury to the person or professional. Page: 61
Recommendations: The Commission should sponsor legislation to require law enforcement personnel training to include interactions with the range of people with disabilities.

Support Staffing, Sign Language Skills

Concern: A continued struggle is finding people to staff a self-directed plan, which means that a lot of money being turned back to the state because people with the necessary sign language skills are not available. This creates a burden on the family and individual. A family member must then provide the care and have the necessary training, but cannot work themselves while providing that care, or accept the money provided by the state for that very purpose, despite the lack of skilled staff. Page: 41
Recommendations: The Office of Rehabilitation Services should fill the second position. Recruit job coaches, vocational counselors and other service providers with American Sign Language skills.

Training

Concern: Individuals are frustrated, they are aware that training for a career may not be possible, but also know they are capable of learning how to do more than work as cleaning laborers, there needs to be an in between. Page: 73

Transitioning and Supports

Concern: Everything that had been mandated by an individual education plan (IEP) for assistive technology, a computer, internet access, an iPad with language supports, etc., all disappeared. Having to then rely on the family computer and iPad, but quickly found out it was being out grown and that more supports were needed. Page: 40
Recommendations: The transition planning process should include discussions with the young adult with a disability and parents the difference between school based services and the adult systems.

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[1] 2016 RI Public Law, Chapter 93, (S2401) Section 42-28.2 -Police Officers – Commission on Standards and Training was amended by the General Assembly, and enacted on 6/17/16, to include section 42-28.2-8.3. Educational requirements – National certified mental health first aid training. http://webserver.rilin.state.ri.us/PublicLaws/law16/law16093.htm

Healthcare Concerns and Recommendations:

Caregiver Card

Concern: A spouse was denied entrance to the compassion center for not having a medical marijuana caregiver's card. Individuals may not be able to make appropriate decisions in terms of the product and comparing it to their needs and possible interactions. Denying someone assistance when they need it creates an undue burden if not able to pay the $125 fee, especially given the high cost of the medical marijuana that is not covered by medical insurance. Page: 23
Recommendations: Recommendations: Contact DHS regarding the plausibility of giving out assistive caregiver cards at no cost; have them be clearly differentiated from patient cards; limited amount per person

Durable Medical Equipment

Concern: Families are limited in options for lifesaving respiratory equipment and services for children and individuals. This creates difficulties with getting the needed equipment with only two options, either Lincare [2] or New England Home Therapies because the only other organization that does respiratory equipment and absolute therapy does not accept new clients with ventilator issues, putting individuals at risk. Page: 20
Recommendations: To contact OHHS/DBR/BHDDH and discuss potential Medicaid issue with contact Jen Wood at OHHS. Also cannot staff the hours, so contact DBR/BHDDH? Suggest a higher level of training for staff; legislation for certificate, so CNAs can take on more responsibilities

Medicaid, Qualifying

Concern: Expensive Psychiatric medications and care are required for severe mental illnesses, but are not completely covered by private insurance. This puts access to those medications at risk due to financial burden. Medicaid is supposed to be a safety net, yet has determined in this instance that the individuals do not qualify for any Medicaid program to help them get their required medication and care. Page: 62
Recommendations: To contact Charlie Fogarty at DEA and discuss the concerns.

Medicaid/Medicare Co-pays

Concern: Medicaid will not cover co-pays if someone is in the Blue-Chip advantage plan. Prescriptions that are limited in this type of plan, the plan won't pay for them, and Medicaid is supposed to pick that up, but it does not. Even with spend down; Medicaid does not pay specialists or alternative care or testing. A CT scan at Rhode Island medical imaging is $342 if paying cash, with the Blue-Chip plan it is a $150 co-pay, or a little less than half up front which is a financial burden to those on a limited income. This equates to individuals going without, or not paying their bills. Which is costing the state, as a whole it is losing millions of dollars, the population is suffering, and the business climate is poor for service providers. Pages: 33, 35

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[2] Lincare is a national provider for home patient assessment, supplies and clinical education using teams made of RT's, LPN's and RN's. http://www.Lincare.com

Recommendations: To contact Charlie Fogarty at DEA and discuss concerns. Also, discuss Legislation for Health Insurance Agencies and for Pharmacists-suggest address copays

Medicaid/Medicare Reimbursement

Concerns: Medicare is reimbursing ten dollars less now for the same normal services ten years ago. Medicare and Medicaid together used to pay for the services, but now they do not, and most of the service providers in our state do not accept that due to low reimbursement. Neurological testing is expensive and Medicare won't cover it. The Medicaid reimbursements being so low, no Neuropsychologist in the state will accept it. Pages: 32, 34
Recommendations: To contact DHS and discuss the expenses.

Pain Management/Alternative Therapies

Concerns: The state is very lacking with pain management-type services. Not the prescribing of the drugs, but the other modalities that helps beyond the prescription medications, services and coverage. Page: 35
Recommendations: Discuss about Legislation having insurance cover to help those that need services. We would start by contacting the insurance commission.

Staffing and Training

Concern: Staffing and workforce issues are definitely a problem. Not every individual can find trained staff to help, and many require an RN rather than a CNA, as with G-tube feeding, making it even more difficult. Family members can be trained to provide this care, but CNA's can't, placing a burden on family members and caretakers. Could new training or certifications be looked into? Page: 20
Recommendations: To refer and look up Durable Medical Equipment then contact DLT/SIM and to also contact OHIC.

Therapies, non-covered

Concerns: There are a lot of therapies that could be beneficial, but are not covered under medical. Without medical or social security covering it, and SSI being utilized or taken away as income for HUD, affording them is a barrier to therapy options that are needed or beneficial. Page: 66
Recommendations: To refer to HUD for any options as well as
Contacting Sen. Reed and Sen. Whitehouse's office.

Traumatic Brain Injuries Services

Concerns: The Traumatic Brain Injury Fund, created in 2005 through a surcharge on speeding tickets has disappeared. Pages: 32, 60
Recommendations: This was only for one year; appropriations followed up through OHHS; concern has been addressed by multiple entities.

Housing / Independent Living Concerns and Recommendations:

Air Quality

Concerns: The problem in residential second-hand smoke and other gaseous contaminants, including deodorizers and fragrances for persons with cardiopulmonary conditions and other chemical sensitivities. Page: 63
Recommendations: The plan is to forward any concerns to RI Housing.

Discrimination

Concerns: Landlords refusing to rent to families using
Section 8 housing vouchers. Page: 68
Recommendations: To forward to the Commission for Human Rights, Fair Housing Unit.

HUD Section 811

Concerns: Rhode Island Housing received an award with its partners, BHDDH and EOHHS to house approximately 150 people into project-based housing. Page: 70
Recommendations: This is not a complaint, just providing information.

Medical Deductions

Concerns: Medical expenses should be deducted for household income before determining the HUD 30% rent payments. Page: 27
Recommendations: The plan is to forward information to HUD; is highly likely that employer falsified income information to federal department.

SSI/SSDI as Income

Concerns: Pages: Why is Social Security Disability benefits treated as income for determining our rent, when SSDI payment are needed for disability related expenses?
Pages: 27, 65
Recommendations: Refer that a contact is made to HUD; federal law vs. interpretation

Communication

Concerns: It would have been really great if there was more communication between the provider and the parent. Even though my son is over 18, he still requires that assistance.
Pages: 26, 75

Disability Insurance

Concerns: It is very difficult getting disability benefits if your IQ is slightly above the threshold, borderline intellectual disability. Page: 72
Recommendations: Support Legislation for Development Disability ombudsperson.

Integrated Consent Decree

Concerns: I am a little bit concerned about the closing of the day center and the threat of all day centers being closed because they are supposed to be in the community. Page: 21, 22, 23
Recommendations: Will refer to BHDDH for any concerns of all closing day centers.

Program Qualifications

Concerns: People need to be aware of the independent living programs, how to get those programs, how to access those programs. What are the qualifications to be in those programs Pages: 28, 73
Recommendations: Will refer to OSCIL and/or SILC for any concerns and how to get people to access programs.

Service Animals

Concerns: Protecting service dog from vicious dogs, when walking the streets. Page: 29
Recommendations: Work toward finding out more ways to enforce leash laws.

Services/Programs

Concerns: There are no independent living services out there for these kids. If there is, I don't know about them. Page: 72

Staff Qualifications

Concerns: The staff is underpaid. In the last two years, four staff had to be dismissed from Perspectives for interfering with my daughter, either verbally or physically. Page: 22
Recommendations: We are taking all concerns and will share them with BHDDH.

Support Integration and Follow-up

Concerns: I don't feel entities are going to be following up on him and making sure he's going to be okay. It's kind of like throwing him out there and hoping for the best. Page: 76

Supported Living Arrangements (SLA)

Concerns: There are many clients who need a group home. I have concern about supported living arrangements. Page: 22
Recommendations: It is best to refer these concerns to BHDDH.

Transition

Concerns: Families that have young adult children living at home and are very much interested in exploring housing options for their adult children, particularly as they grow older. Page: 19
Recommendations: To speak to BHDDH about exploring options.

Commission’s Legislative and Administrative Initiatives

Citizens with Disabilities in the United States and Rhode Island

Population and Prevalence[3]

Tables 1.3 – 1.7 Civilians Living in the Community, United States and Rhode Island, by Disability Status and Age: 2014

Area	Total	Disability		No Disability	
		Count	%	Count	%
United States	313,890,422	39,674,679	12.60%	274,215,743	87.40%
Rhode Island	1,039,789	145,887	14%	893,902	86%
Under 5 Years Old					
United States	19,771,799	153,635	0.80%	19,618,164	99.20%
Rhode Island	54,856	0	0	54,856	0
5-17 Years Old					
United States	53,668,474	2,900,395	5.40%	50,768,079	94.60%
Rhode Island	157,415	9,369	6%	148,046	94%
18-64 Years Old					
United States	195,537,213	20,460,136	10.50%	175,077,077	89.50%
Rhode Island	667,555	78,439	11.80%	589,116	88.20%
65 Years and Over					
United States	44,912,936	16,160,513	36%	28,752,423	64%
Rhode Island	159,963	58,079	36.30%	101,884	63.70%

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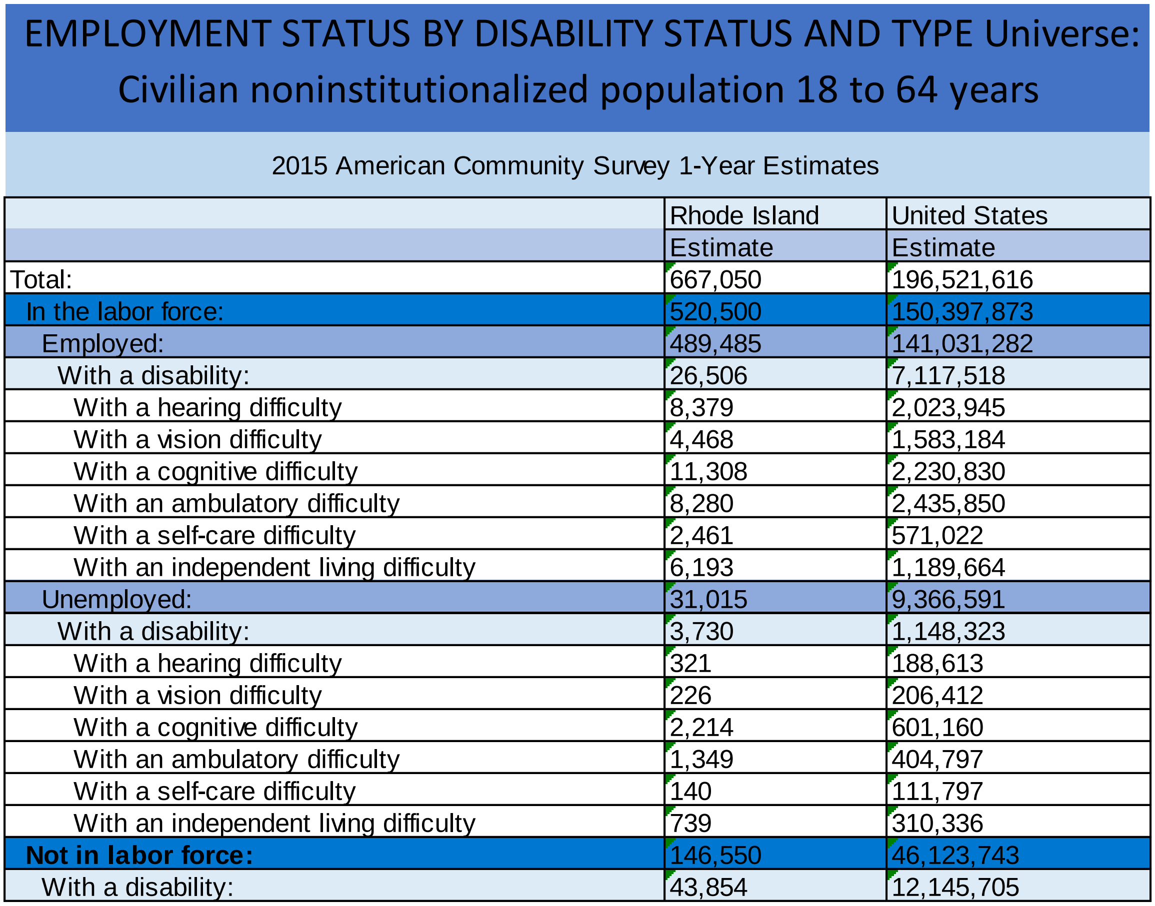
[3] Data are based on a sample and are subject to sampling variability. The degree of uncertainty for an estimate arising from sampling variability is represented through the use of a margin of error. The value shown here is the 90 percent margin of error. The margin of error can be interpreted roughly as providing a 90 percent probability that the interval defined by the estimate minus the margin of error and the estimate plus the margin of error (the lower and upper confidence bounds) contains the true value. In addition to sampling variability, the ACS estimates are subject to non-sampling error (for a discussion of non-sampling variability, see Accuracy of the Data). The effect of non-sampling error is not represented in these tables.
While the 2015 American Community Survey (ACS) data generally reflect the February 2013 Office of Management and Budget (OMB) definitions of metropolitan and micropolitan statistical areas; in certain instances the names, codes, and boundaries of the principal cities shown in ACS tables may differ from the OMB definitions due to differences in the effective dates of the geographic entities.

Employment[4]



EMPLOYMENT STATUS BY DISABILITY STATUS AND TYPE Universe: Civilian noninstitutionalized population 18 to 64 years

2015 American Community Survey 1-Year Estimates

	Rhode Island	United States
	Estimate	Estimate
Total:	667,050	196,521,616
In the labor force:	520,500	150,397,873
Employed:	489,485	141,031,282
With a disability:	26,506	7,117,518
With a hearing difficulty	8,379	2,023,945
With a vision difficulty	4,468	1,583,184
With a cognitive difficulty	11,308	2,230,830
With an ambulatory difficulty	8,280	2,435,850
With a self-care difficulty	2,461	571,022
With an independent living difficulty	6,193	1,189,664
Unemployed:	31,015	9,366,591
With a disability:	3,730	1,148,323
With a hearing difficulty	321	188,613
With a vision difficulty	226	206,412
With a cognitive difficulty	2,214	601,160
With an ambulatory difficulty	1,349	404,797
With a self-care difficulty	140	111,797
With an independent living difficulty	739	310,336
Not in labor force:	146,550	46,123,743
With a disability:	43,854	12,145,705

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[4] Data are based on a sample and are subject to sampling variability. The degree of uncertainty for an estimate arising from sampling variability is represented through the use of a margin of error. The value shown here is the 90 percent margin of error. The margin of error can be interpreted roughly as providing a 90 percent probability that the interval defined by the estimate minus the margin of error and the estimate plus the margin of error (the lower and upper confidence bounds) contains the true value. In addition to sampling variability, the ACS

Poverty

Tables 3.1 Civilians Living in the Community, for the United States and Rhode Island, Poverty Rates : 2014

	With Disabilities			Without Disabilities			
Area	Count	Poverty	%	Count	Poverty	%	Poverty Gap**
United States							
Under 5 years	148,541	50,456	34.00%	19,304,614	4,607,731	23.90%	10.10%
5 to 17 Years	2,837,660	924,033	32.60%	50,095,670	10,103,792	20.20%	12.40%
18 to 64 Years	20,349,020	5,744,797	28.20%	172,583,524	22,508,075	13.00%	15.20%
65 and Over	16,160,513	2,093,101	13.00%	28,752,287	2,161,792	7.50%	5.40%
Rhode Island							
*Under 5 years	–	–	–	54,030	12,746	23.60%	–
5 to 17 Years	9,145	2,528	27.60%	147,205	26,355	17.90%	9.70%
18 to 64 Years	77,086	22,820	29.60%	566,336	65,565	11.60%	18.00%
65 and Over	58,079	7,842	13.50%	101,884	7,668	7.50%	6.00%

* Based on a sample and subject to sampling variability

**The difference in percentage points of poverty rates between disability and no disability

Tables 3.2 Civilians Living in the Community, for the United States and Rhode Island, Change in Poverty Rate Gap : 2013 to 2014

Area	Poverty Gap 2013 *	Poverty Gap 2014*	Poverty Gap Changes**
United States			
Under 5 years	11.30%	10.10%	-1.20%
5 to 17 Years	13.50%	12.40%	-1.10%
18 to 64 Years	15.10%	15.20%	0.10%
65 and Over	5.80%	5.40%	-0.40%
Rhode Island			
*Under 5 years	-0.30%	–	–
5 to 17 Years	11.30%	9.70%	-1.50%
18 to 64 Years	16.10%	18.00%	1.90%
65 and Over	1.40%	6.00%	4.60%

*The difference in percentage points of poverty rates between disability and no disability.

**The difference of the differences in percentage points of poverty rates between disability and no disability between 2013 and 2014

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[5] Source for Tables 3.1 &3.2: U.S. Census Bureau, 2014 American Community Survey, 1-Year Estimates, American FactFinder, Table B18130; http://factfinder.census.gov; and http://disabilitycompendium.org/statistics/poverty Tables 3.1-3.17.

Law Enforcement/Justice System

Table 12.1 Civilians With Disabilities in the United States and Legal Terms

	Yes %	No %	Notes
Understanding the Terms of Guilty and Innocent	55%	45%	*Some reversed the two meanings, % not available
Believe They Could be Arrested for Having a Disability	38%	62%	
Would Disclose Having a Disability if Arrested	50%	50%	
Would Speak With Police Before Speaking to a Lawyer	58%	42%	
Believe Arresting Officer Would Protect Them	68%	32%	

Table 12.2 Rates of Violent and Serious Victimization Against Persons With Disabilities, by Disability Type: 2009-2013

	2009		2010		2011		2012		2013	
	Violent	Serious	Violent	Serious	Violent	Serious	Violent	Serious	Violent	Serious
Disability Type										
Hearing	16.9	7.3	10.6	4.5	17.1	8.2	20.2	10.7	16.9	8.4
Vision	28.6	8.6	24.9	12	23.2	10.5	25.2	7.7	29.8	11.9
Ambulatory	20.5	6.2	19.7	8.2	22.6	10.5	30.5	14.5	32.2	14.7
Cognitive	46	12.4	43.5	17.9	50.5	23.5	63.3	23.6	66.8	25.1
Self-Care	18.3	3.9	17.8	7.9	27.3	12.3	27.2	11.2	26	9.3
Independent Living	24.4	6.1	26.4	10.2	25.3	11.6	28.6	12.1	32.4	13.6

*Note: Based on the noninstitutionalized U.S. residential population age 12 or older. Estimates are based on 2-year rolling averages. Rates are per 1,000 persons age 12 or older, except for independent living disability, which is per 1,000 persons age 15 or older

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[6] Source for Table 12.2 and Statistics:
Bureau of Justice Statistics, National Crime Victimization Survey,2008–2013; and U.S. Census Bureau, American Community Survey, 2008 – 2013 http://www.bjs.gov/index.cfm?ty=pbdetail&iid=5281

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Table 12.3 Percent of Violent Crime Reported to Police, by Victim's Disability Status, and the Reporter: 2009–2013

Victim's Disability Status	2009	2010	2011	2012	2013
Persons With Disabilities	54.30%	47%	47.20%	48.60%	47.50%
Single Disability Type	49.80%	47.50%	54.80%	53.30%	45.90%
Multiple Disability Type	60.70%	46.50%	41.10%	44.20%	49.10%
Persons Without Disability	43.50%	47.50%	50.50%	45.90%	44.20%
Person That Reported to Police	**2009**	**2010**	**2011**	**2012**	**2013**
Respondent					
With Disabilities	71.30%	79.50%	72.30%	64.20%	57.80%
Without Disabilities	60.80%	62.90%	61.20%	57.80%	58.40%
Other Household Member					
With Disabilities	7.2%!	3.0%!	3.60%	3.70%	5.70%
Without Disabilities	10.40%	9.40%	12.30%	13.10%	9.60%
Someone Official					
With Disabilities	8.00%	3.4%!	2.4%!	3.00%	7.10%
Without Disabilities	8.10%	9.50%	8.40%	6.70%	8.60%
Someone Else					
With Disabilities	10.70%	8.30%	15.80%	21.90%	22.50%
Without Disabilities	12.40%	10.00%	9.50%	12.00%	13.20%
Police at the Scene					
With Disabilities	2.0%!	3.9%!	2.6%!	4.3%!	4.00%
Without Disabilities	5.80%	5.70%	4.50%	6.70%	7.90%
Offender was a Police Officer*					
With Disabilities	(--!)	(--!)	(--!)	(--!)	0.4%!
Without Disabilities	0.9%!	1.2%!	1.0%!	0.2%!	0.30%

*** (--) Less than 0.05%**
(!) Interpret with caution. Estimate is based on 10 or fewer sample cases, or Coefficient of variation is greater than 50%.

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[7] Source for Table 12.3 and Statistics:
Bureau of Justice Statistics, National Crime Victimization Survey,2008–2013; and U.S. Census Bureau, American Community Survey, 2008 – 2013 http://www.bjs.gov/index.cfm?ty=pbdetail&iid=5281

Testimony

July 25, 2016 Warwick Forum

BETH PINKHAM: I guess since we are a little after our time, we are going to get going. I want to welcome everybody to the governor's commissioner's forum. Thank you for taking the time -- can you hear me? Is that better? Okay. Maybe I was holding it too far away. The folks up here -- I didn't want to overdrive things. So thank you all for coming. Our main goal for today is just to hear from folks and see what kinds of concerns people have. So we are not going to get to the -- necessarily to the bottom of problems today. But we do want to hear what's going on so we will be here from 4 to 6 to do that. A little bit of housekeeping. If you go out through the doors and to the right, men's and ladies' rooms are there. If you need to use those, they are around for you. Other than that, I think we are going to move on and just introduce the panel. My name is Beth Pinkham and I am with Ocean State Center for Independent Living or OSCIL[8]. I will keep the mic going.

CHUCK MESSINA: Good afternoon. I am Chuck Messina, a staff attorney with the Rhode Island Disability Law Center[9].

JUDITH DREW: Hi. I am Judi Drew. I am representing the Governor's Commission on Disabilities but my day job is program director for the rehabilitation counseling program at Salve Regina University[10].

CASEY GARTLAND: My name is Casey Gartland. I am also a commissioner. During the day I work for Perspectives Corporation[11] as a senior director.

VALERIE WILLIAMS: Valerie Williams, Office of Rehabilitation Services[12].

JEANNE FAY: Jeanne Fay. I am a benefits counselor at the Paul V Sherlock Center on Disabilities at Rhode Island College.[13]

DEBORAH GOLDING: I am Deb Golding. I work at the health department, office of special needs[14] and my focus is adolescent health transition.

BETH PINKHAM: Thank you everybody. We are going to start out. We do have a couple of people signed in that did have issues they wanted to address. So I guess we will start with Pat Beauchemin. We will let you start with what you are here to say.

PAT BEAUCHEMIN: Thank you. Good afternoon, everyone. My name is Pat Beauchemin. I am a school social worker with one of our school districts here in the state. And I also represent the Rhode Island School of Social Worker Affiliates[15]. I am here because I speak with a number of families who have

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[8] http://www.oscil.org/
[9] http://ridlc.org/
[10] http://www.salve.edu/graduate-studies/rehabilitation-counseling
[11] http://perspectivescorporation.com/
[12] http://www.ors.ri.gov/
[13] http://www.ric.edu/sherlockcenter/
[14] http://www.health.ri.gov/specialneeds/
[15] In Association with The National Association of Social Workers, http://www.rinasw.info/

Independent Living

young adult children living at home and are very much interested in exploring housing options for their adult children, particularly as they grow older. You know how difficult that is when adolescents and then young adults live in the same household. It becomes a challenge. And these families certainly want to be able to support their young adults with options for housing. They know that -- they would like to see them be more self-sufficient. However they know that there is a very delicate balance around providing additional supports for these young people. I think it may be time. We have seen these families raise their children and receive all kinds of wonderful supports through the public school systems and receiving services, both within the schools as well as outside the schools, in the community. And as they move into that of young adulthood, it becomes more of a challenge. And it is for that reason I'm coming to you today to sort of raise that issue and to encourage the Commission to begin to gather these people to come together to explore where they might be able to go. I think as the Commission begins to take a lead here, you will find that there will be numerous families that would like to be able to discuss this; and look at some of the options perhaps in other parts of the country that might make sense and expand some of those options for their young adult children. That's my piece. Thank you for the opportunity.

BETH PINKHAM: Thank you. Are there any questions or follow-up comments from anybody? Okay. Next we have –

JUDITH DREW: Excuse me. Can I just make one comment?

BETH PINKHAM: Yes.

JUDITH DREW: So I think one of the things that should be an important take away for everyone here in the audience is one of the reasons why the governor's commission holds these public forums so we can identify some of the needs that are happening in the community that can then result in legislative initiatives. So that's our primary goal. So I love what you suggested, Pat. And one of the things we can do is taking this back to the commission. I don't know that it would be our role to get people together. But we can sure begin a dialogue with interested parties and see if there's a legislative action of some kind that we can begin to discuss for the next legislative session. Just keep in mind we are looking at things that we can help advocate for and make a difference in terms of legislation. Would you want to add anything to that?

CASEY GARTLAND: I think you had it perfectly.

JUDITH DREW: Okay.

BETH PINKHAM: Okay. Next is Tara Townsend. There you go.

Healthcare

TARA TOWNSEND: Hi, good afternoon. My name is Tara Townsend. I am the mom of an eight year old boy who is medically fragile, special needs, trach vent[16], and G tube[17]. He lives in Warwick and goes to the public school system. And I also am a family voices coordinator at the Rhode Island Parent Information Network[18]. I am here more with my mom hat today but the issue that I am going to discuss, I also hear from a lot of our families especially in the medically challenged community of children. The first issue is around workforce and nursing, particularly. I know that families are having a really difficult time -- not getting the hours – but having the hours staffed in their homes whether it's a nurse, a CNA[19] is a little bit more readily available. But some of our kiddos have to have RNs. And we, you know, we need hours other than just the Monday through Friday, nine to five. You know, I am here now and my mom's home with my child because she is the only other one who can really take care of him. So that's -- staffing and workforce issues is definitely a problem. You know we've talked in the past about CNA certification programs which might be nice to give CNAs a little higher level of training so that, you know, not specifically if a kid has a trach but a G tube. A CNA can't feed the child or give the child meds. A parent or RN[20] has it do that. Why? Why can't we just build up our workforce a little bit with our people who are already out there? I'm sure they've been in CNA status for a while. Maybe they want to get to an LPN[21] or get a certification where they can have a broader knowledge base of experience and be able to help out more families. So that is my first issue. And my second issue is with durable medical equipment and most specifically with companies. Rhode Island is extremely limited in who we have available to serve our children. Pardon me. But when your child needs lifesaving equipment and services and you have difficulty getting them, it's very weary and troublesome. We have Vanguard and as many people know Vanguard[22] is no longer an agency in Rhode Island. So now we have switched over to Lincare[23]. We have pretty much two options, either Lincare or New England Home Therapies[24] because the only other organization that does respiratory equipment and absolute therapy is not accepting new clients with ventilator issues. So we switched over to Lincare and have been with them for about eight months now and we are still having issues. It took about six months for us to get our order correct, supply -- the correct supplies we need. And we just went through a whole issue of filing complaints and whatnot with them because we waited about five months for a trach to come in. And we are not the only family that this is happening to. And so a lot of families have switched over to New England Home Therapies. But when we interviewed them, they don't have the same ventilator tubing that my child had. So it's like do we get a trach or do we have the vent -- vent equipment and there are other options. But he's been on this ventilator with this same equipment for eight years. He's doing well, hardly ever hospitalized. So why switch something that's working well? And so I'm not sure where the problem lies if it's within Lincare, if it's within, you know, the process of approval with, you know, the health plan. Although they said it wasn't on their end when we went through this whole process. So it seems that Lincare feels like it's an expensive item and they don't need to order it as often as we need -- we

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[16] Invasive mechanical ventilation requires the placement of a tracheostomy tube into the windpipe to deliver air directly into the lungs. The patient and caregivers must be trained in the care of the trach and tube to prevent complications such as infection or clogging of the tube. http://www.nhlbi.nih.gov/health/health-topics/topics/trach/livingwith

[17] A gastrostomy feeding tube (G tube) is the placement of a feeding tube through the skin and the stomach wall, providing nutrition directly to the stomach. https://medlineplus.gov/ency/article/002937.htm

[18] www.**ripin**.org

[19] Certified Nursing Assistant (CNA)

[20] Registered Nurse (RN)

[21] Licensed Practicing Nurse (LPN)

[22] http://vmecpap.com/index.html

[23] http://www.Lincare.com/

[24] http://bioscrip.com/

have been prescribed it. So you know, there are not really a lot of options, like I said for DME[25] companies. To recruit or get contracts with people who are maybe outside the state is something that would be worth looking into. If they can, you know, get -- Lincare has been known for working with adults and now they have taken on this child population. They are just having a hard time with it. And families should have other options. So, thank you for taking the time to listen to me today. I appreciate it.

BETH PINKHAM: Thank you, Tara. Are there any follow-up comments or questions? Anybody? Those were the two people that we had that, you know, mentioned that they had concerns they wanted to speak about. Is there anybody that didn't get to sign in or indicate that they wanted to speak that has an issue they want to speak about or any? Okay. We have -- hang on. Give your name for the CART reporter.

Independent Living

FRANCOISE PORCH: Yes. Thank you. My name is Francoise Porch. I have a 32 year old daughter which is with perspectives. I am a little bit concerned about the closing of the day center and the threat of all day centers being closed because they are supposed to be in the community. In my mind, my experience tells me that in the community often means on the streets. Referring to President Reagan closing all the mental health facilities, where supposedly were being replaced by community clinics and housing, blah, blah, blah, never happened. We ended up with people on the streets, by the millions. They need to be more in the community, but they also have their own community and their own community is valuable to them. My daughter has friends within the community at the Perspective Day Center. And this is summertime. It can be 90 degrees and very humid outside. Where are they going to go? To the park every day in the community where nobody else is there because it's too hot? And what are they going to do in the winter? Where there is no longer a place -- there should be both. You don't have to be forced to a day center if you don't like it, if you don't enjoy it. But it should be available for those who want to go to a drum circle, to do various activities, and be together as well if they want to. And my second point is there are issues about locked doors. My daughter lives in a group home that does a locked door because she's a dedicated escapist. She once was found on Division Road and fortunately a nurse was coming for a shift, saw Olivia by the roadside, stopped and opened the car door and Olivia hopped in. She could have hopped in into any car or she could have been killed. She also had night terrors and would want to leave the house in the middle of the night. And that led to terrible night tantrums, staff being hurt, and my daughter being hurt because they had to intervene to prevent her from going outside. Once the door was locked, hopefully she cannot vault over a 6 foot fence and she doesn't have battles in the middle of the night to try to leave the house. So these were my two points. I don't know if they are relevant but I didn't know exactly the aim of this meeting.

BETH PINKHAM: You have the floor. So go ahead. Thank you. Any other comments? Anybody else that has an issue they want to present at the forum? Okay.

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[25] Durable Medical Equipment (DME)

Independent Living

PAT ABBATE: My name is Pat Abbate. I am the mother of a 45 year old DD[26] son. He goes to a day program. I have a couple of concerns. One is about consent decree[27]. You know, we are obligated to follow the mandates of the consent decree. But from what I've seen, the centers have not been given the funding they need to implement this. Just from a practical point of view, if they have to get clients into the community, they will probably need more vans. It's going to be more expensive for gas. They need more staff. There will be more one-on-one. Hopefully they will find jobs for all of them.

That's extremely doubtful. They've taken away programs and workshops that a lot of the clients felt fulfilled in doing. So that's my, I have a question. Why hasn't the state or why hasn't someone from the state asked the federal government for additional funding to implement this decree? I've never heard, I've never heard, this is a federal mandate. But I've never heard that the Feds have done anything to help us implement the consent decree. And in some cases I don't think implementing it is practical. That's a whole other issue. My second concern is about placement of adults. My son's getting older. I'm getting older. I'm concerned about the closing of group homes. I don't know what's happening with the group home that was closed in Mount Pleasant after the unfortunate incident there. I don't know if anyone knows. Maybe you can respond to it. Will that be reopened? I think there are many clients who need a group home. I have concern about supported living arrangements. You know, you look at -- just the story about the child in the paper this week who was in DCF custody who went from placement to placement to placement. I see that happening with a lot of DD adults. The supported living couple or individual who takes someone only has to sign a one-year contract. And I have no idea how often DD clients end up being moved from place to place. I've heard of some. And that is an un-normal setting. I think being in a normal group home that's stable is much better for most of these clients. They like stability. I think people take DD clients with good intentions. Often their circumstances change. They get married. They get divorced. They have more children. They go back to work. And for a lot of reasons they just simply can't keep the DD client. Then what happens? They are there for a couple of years and they are somewhere else for a couple of years. So I think we really need to take a good look at what's happening with group homes. That's it. I don't know if you can answer some of my questions about funding or the group home in Mount Pleasant.

BETH PINKHAM: Any comments, anybody?

CASEY GARTLAND: At the risk of violating what Judi pointed out earlier which is our role is really not to answer the question so much as taking information. Some of us do have information and some will be glad to talk to you afterwards maybe.

PAT ABBATE: The other thing is the governor asked for 8 million dollars this year for the DD budget. Mostly to increase salaries for the staff, who absolutely deserve it. And the legislature only approved five million. And I don't know why that happened. I mean, they have been cut year after year after year. They certainly need -- they need five times that amount.

FRANCOISE PORCH: If I could add to this the question of the staff being underpaid. In the last two years, four staff had to be dismissed from Perspectives for interfering with my daughter, either verbally

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[26] Developmental Disability (DD)

[27] Integrated Consent Decree is an ADA and Civil Rights Division official order to serve individuals with intellectual and developmental disabilities (ID/DD) in the most integrated service setting appropriate for their needs, and negating serious risks of segregation. https://www.ada.gov/olmstead/olmstead_cases_list2.htm

or physically. One of the cases ended up with a three month jail sentence and a nine month -- what do you call it -- brace anklet. There is a big concern about recruitment. And the most able of them most of the time leave because they cannot keep finances together on their salaries.

BETH PINKHAM: Thank you. Anyone else that has any comments they'd like to make? Or concerns?

JUDITH DREW: Beth, can I -- Francoise, I want to respond to what you said. I don't want you to take our silence on this as not understanding the issue. We are concerned as a commission. We represent a variety of programs and areas that deal with people with disabilities. And we are very concerned about the training, consistent employment, the skill development and the salaries that these people deserve. That doesn't mean that we can do anything about it. But we want you to know that we are not unaware of that. Just so you know.

BETH PINKHAM: Thank you, Judi.

Healthcare

SUSAN SHAPIRO: My name is Susan Shapiro. I am speaking as the spouse of a partner with a disability, but also on behalf of a number of people that may not be able to be here and that may not yet have confronted the issue. But my husband has a medical marijuana card. And when we went to the compassion center to purchase this for his needs, he did not feel comfortable going in alone and I was denied entrance because I did not have a caregiver's card. To get the caregiver's card, I was going to have to pay $125. Now I'm in a position to be able to afford that. But there are a lot of people who cannot. There are a lot of people with family members who are adults but may not be able to make appropriate decisions in terms of the quality of the product that they are getting and comparing it to their needs and how it's going to interact with what their needs are. And so I feel like denying someone assistance when they need it is kind of an undue burden and especially to add on that $125. The cost of marijuana is extremely high and again, it's not covered by medical insurance. So it's adding to that burden. So I just thought I'd raise that issue.

BETH PINKHAM: Thank you. Is there anybody else at this point? Okay. Well, I guess what we will do then is take a quick break. People are welcome to stay. We will be here until 6. As comments come to mind or whatever, please let us know and we will certainly listen. But, you know, otherwise -- thank you for coming.

BETH PINKHAM: We have someone else who would like to speak.

KATHERINE RICHARD: Good afternoon. My name is Katherine Richard. And I have a sister who is developmentally disabled and deaf, profoundly deaf from birth. She's currently in a group home in Warren, which is also affiliated with the Corliss Institute[28], and she lives with three other developmentally disabled Deaf women. She's fortunately has worked out very well and the group home has done a wonderful job. She goes to a day program. And she’s very happy. She had been severely depressed. She was living alone and both our parents passed away and they had been very involved. She's made a remarkable change. She's happy. She's much more interactive, and much more confident. She's doing very well. But when I hear about the possibility of some of these group homes closing, I become terrified because she clearly cannot live alone. She has a lot of learning disabilities in

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[28] http://corliss.org/

Independent Living

addition to her deafness. So I guess my question is where can I go to find out more about this? And what can I do to ensure that she will be in a safe place where she's getting her needs met? Thank you.

BETH PINKHAM: Thank you.

CASEY GARTLAND: I will answer first in case somebody else wants to answer on the panel.

KATHERINE RICHARD: Thank you.

CASEY GARTLAND: One thing I always encourage parents and family members to be involved with is the legislators. Make sure you are also in touch with them to make sure your concerns are being heard at least. That's one area. In terms of staying apprised of the changes in the system in the state of Rhode Island, there are several very good outlets that cover some news like that, your local newspapers as well. Another one called DD Olmstead News[29]. I can send you a link to. It sounds like, I don't know if it's affiliated with the changes in the state of Rhode Island but it's a person who is keeping track of all the changes that have come down from the consent decree. There are various places you can get that information because it sounds like you want to stay apprise from where it's coming from, where it's being directed, and where it's going from. That is another site I would encourage you. I can give that to you during the break or afterwards.

KATHERINE RICHARD: Thank you.

BETH PINKHAM: Okay. Any other comments or -- just state your name for the CART reporter.

Civil Rights

MEG UNDERWOOD: My I name is Meg Underwood. I live in the city of Warwick. Our concern is as a family we are dealing right now with DCYF[30] and feel as though DCYF is using disabilities as a bias in when they determine when custody is involved and that kind of thing. They are not apparently trained to be sensitive to those with disabilities or to understand those with disabilities or to even appreciate what the limitations are. They just sort of look at anybody with a disability under one lens and it's a discriminatory lens. So we are very concerned about it. We certainly would like to see something done. We have reached out to legislators, child advocates, all of this, Epilepsy Foundation, every organization we can think of. But certainly if it's happening to us, it's happening to others. And we certainly would like to have that looked into. Thank you.

BETH PINKHAM: Thank you for your comments.

JUDITH DREW: Meg, could you clarify what your thoughts are about how your family member's being discriminated against?

MEG UNDERWOOD: Without getting into too much detail?

JUDITH DREW: Right. Yes, without getting into a lot of detail.

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[29] http://olmstead-ddnews.org/

[30] Department of Children, Youth & Families (DCYF) www.dcyf.ri.gov

MEG UNDERWOOD: My, my daughter has epilepsy and so they are trying to use, they are ordering tests for her that they are not ordering for the other person involved because of her epilepsy to challenge her capability as a parent because she is epileptic[31].

JUDITH DREW: Why don't we talk about this off line a little bit, okay?

MEG UNDERWOOD: Okay.

CHUCK MESSINA: Just to be clear, this is not in a divorce situation?

MEG UNDERWOOD: It is not in a divorce situation, no.

CHUCK MESSINA: Thank you.

BETH PINKHAM: Any other comments, questions? Well, we will take another break then. Thank you everybody.

CHUCK MESSINA: We just want folks to know that there's an opportunity to provide comments on state funded services and that involves Medicaid funded home and community based services. So the office of health and human services, OHHS as everyone knows is in the process of implementing Federal Rules to promote community integration of residential and day services that are funded through Medicaid. So the rules will help implement homestead requirement for community integration. So OHHS would like to get feedback from individuals and family members about how integrated their services currently are. On the back we have a flyer. It's in the back. So everybody please take one. It's an informational flyer. But on the back of the flyer is information on how to contact OHHS. In the early fall, there will be an opportunity to comment on OHHS plan to make sure that existing Medicaid funding settings will be able to comply with the new rules over time. So we really invite the public to make comments and let OHHS know your feelings. Thank you.

July 25, 2016 Bristol Forum

GRACE PIRES: Hello, everyone. I'd just like to welcome everybody, and thank you all for coming. My name is Grace Pires and we're going to start the forum, officially. So my name is, as a said, Grace Pires, I'm the president of the National Federation of the Blind[32]. The first thing is a little bit of housekeeping. As most of you might know the rest room is right outside this door on the right hand side. The purpose of these annual public forums is to identify the concerns of people with disabilities and their families in order to insure that they have improve the quality of life, and the -- excuse me for a second. Take my bracelets it was distracting me from what I was trying to read. In the interest of time, although we will probably be okay today, in the interest of time, please keep your comments short and to the point,

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[31] The National Council on Disability has resources for parents with disabilities, to know and protect their rights and their children. http://www.ncd.gov/publications/2012/Sep272012/
Also, they have collaborated with the Christopher & Dana Reeve Foundation to provide a toolkit.
http://www.ncd.gov/sites/default/files/Documents/Final%20508_Parenting%20Toolkit_Standard_0.pdf

[32] http://nfbri.org/

and basically the testimony that's going to be taken is going to be reviewed and it will be posted on the website by the end of November, and also we send to the legislature and congressional officials. If there's anything that's a critical need, please wait until the end and meet with one of our panelists at the end so that they can direct you to the correct agency for help. And then I'm just going to have the panelists introduce themselves and where they're from. Once that is done, when you do the testimony, state your name and what city you're from, all right. So I guess I can start with you.

KAREN RUSSELL: I'm Karen Russell. I serve in the West Warwick and South County region.

ALEX SPIGELMAN: I'm Alex Spigelman; I work with the Rhode Island Disability Law Center[33].

KATHLEEN KUIPER: My name is Kathy Kuiper; I'm based with the Rhode Island Department of Health Office of Special Healthcare[34].

GRACE PIRES: If anyone needs an assistive listening device, please let us know. The other thing, the Disability Law Center, if anyone needs to register to vote, usually they can do that; is that correct?

ALEX SPIGELMAN: That's fine.

GRACE PIRES: Or if you need a change of address or something. And did everyone sign up that's here? Just make sure you sign up. Whether you want to speak or not is your choice, just so we can take attendance, all right. I guess we can start with the first person. Barbara Henry.

Accessibility

BARBARA HENRY: Hi, everyone. My name is Barbara Henry, and I live in Riverside, Rhode Island. And I actually have a challenging situation in my life. I'm not going to go into private matters about it right now, but I am facing something with a state office, and when I read the letter that I got, it said the second page, you can appeal the decision. So, I felt that the decision was wrong, and this was last week, I got the letter, and so, of course, I went to the Pastore complex to appeal this decision and when I got to the building, I was told that the agency that I needed to deal with, that was on their letterhead, was not even in that building; they moved 2015, September, and it says on this agency's letterhead "You can mail your paperwork to this address." And I just found that really absurd. If I would have mailed my paperwork instead of physically going down there, my whole appeal paperwork would have got lost in the shuffle. So a worker there told me, no, it's in building such and such, and I found the building and when I got to the building where this department that I have to specifically deal with, when I approached them and I said I was told that you guys moved last year, it was just, "Oh, yeah, yeah." But meanwhile, I can't stress it enough, if I was to have mailed my paperwork in, I would have never got my appeal. The whole process would have just, and I find that just crazy. That on their letterhead, to say if you want to appeal this decision to mail your paperwork to...that makes no sense to me. I really don't want to go into my private, in front of everyone, but if there's someone who can, I can talk to privately about this, I would be more than happy to, because when I do, I was told I have, I got to the appropriate worker that I need to deal with but when I go appeal this decision the first thing I'll say to that committee is how can you have this on your letterhead when so many families and people are going to get lost in the shuffle? And will not be able to appropriately appeal this decision. Thank you. I hope I made sense.

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[33] http://ridlc.org/

[34] http://www.health.ri.gov/specialneeds/

GRACE PIRES: Thank you, Barbara. Basically your concern is they're providing misinformation as far as the address, correct.

BARBARA HENRY: Yes. Yes.

CHRIS: Barbara, its Chris. I'll talk to you about this.

GRACE PIRES: Are you done, are there any other comments?

BARBARA HENRY: No. I'm done. Thank you, Grace.

GRACE PIRES: Thank you.

KAREN RUSSELL: Is there anybody else who would like to speak?

PATRICIA GUNN: Yes. My name is Patricia Gunn.

GRACE PIRES: What city are you from?

Housing

Housing

PATRICIA GUNN: Newport. I have two children with disabling conditions, one of them lives with me, my 29 year old son. We live in family housing, public housing, so, it's supposed to be affordable, but the, my son gets a disability check, but I want him to work and he works, he cleans in some of the clubs downtown. Everything is based on income, so that's where the issue is. And then, to judge his income, you sign some paperwork that's sent to the employer for them to figure out the rent, and this, I didn't see it until I got the notice for the rent, and ours went up $300 a month. So that should be, that's a huge jump, and so, it's like okay, I don't like it, but I want to know why. So, I did get the paperwork that was sent to the employer, and it was totally different than what his paychecks are. And, the rent, if what was written on this form was true, then the rent should be raised that amount, but it wasn't, and my housing manager seems very resistant to correcting this. And also, he's paying for his medications, and I was told that they could not deduct what he's paying for his medication from his income because he's not the head of household. So, I don't know why that is, if, in fact, it's a true statement that HUD has a policy for? I know that your rent is based on your gross income, but then there are certain allowable deductions and certainly, for people who need medication to maintain a balance and function in society for the rest of their lives, they really need their medication, and I feel it should be deducted from the income that is counted in determining their rent. So, right now, I visited the employer today, because I could not believe that he would, he, himself, would fill out this form in the incorrect manner. I'd like to know what letter is sent with the form so that he would have an idea on what is expected when he fills it out, and then I believe that I have not agreed that this increase of rent is, in fact, what should be, so I have refused to sign the paperwork, because that would indicate an agreement, to me, and I want to get this situation ironed and smoothed out so that we can lead a calm life, and live and let live, less stress, less stressful life. I mean, when I look at people, homeless people on the street, I say how does this happen? You know? And where's their mother? Because I'm my son's mother, and he is not going to be taken advantage of by a system that is going to create, for him, outcomes like some of these other people that you see. There's a reason for it. And sometimes, fighting the system is too great an issue for them to do alone, and so, it doesn't get done. When it doesn't really have to be that they're homeless on the streets. And they should have access to the medications that they need. So, I'm fighting a personal issue, but I also see this as part of the larger issue of homelessness, of people not being on their medications, and not getting the proper medical treatment.

GRACE PIRES: Okay. Is there anything else?

PATRICIA GUNN: No. I think that's all for now.

GRACE PIRES: Thank you for sharing your story with us. Is there anyone else?

KAREN RUSSELL: Is there anyone else that would like to speak?

Civil Rights

ROBERT SANCHEZ: Actually, Robert Sanchez. I was just thinking of something. I use public transportation to get around, and since Rhode Island has disbanded the laws on pan handling, every time I have to go through Kennedy Plaza it seems I get harassed and I can't see people coming towards me and people seem to come out of nowhere and they're constantly begging for money. So I'm wondering if they can make certain public areas pan handle free. It's tough. I'm from Warren, even there, for the past two days I've been having people jump out in front of me asking for money, and it's tough especially if you're trying to get somewhere and trying to concentrate where you're going and then you get distracted because you have 20-30 people coming up to you. Give me money, I'm homeless, I'm poor, I'm hungry and I understand that. I think people should donate to organizations to help them, but is there any way you can protect us from getting harassed?

GRACE PIRES: That's a good point? Thank you. Anyone else who would like to speak, comments? Okay. No one else has arrived that would like to speak?

MS. SCHULTZ: No.

GRACE PIRES: Anyone else have any official comments they would like to make?

Independent Living

PATRICIA GUNN: I do, about the forms that need to be filled out. When a person is sent the forms from the DHS, or other organizations, specifically social service or something like that, are there people to help them fill out the forms? Or they're just left to their own devices to do the best they can?

KATHLEEN KUIPER: I know the Rhode Island Parent Information Network[35]. It's not just for parents and families; it's to help individuals, as well.

GRACE PIRES: Okay, great. Thank you. That's a good question because I know sometimes people do have those issues. Is there anyone else? All right, I know this is a little unorthodox, but since there's nobody else, I actually do have something I'd like to bring up. Not for me, personally. There have been a couple of times, it's regarding the, I guess the law that's on the books about dogs, where a guy, a teen

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[35] Rhode Island Parent's Information Network can assist, as well as URI SNAP Outreach Project for assistance with SNAP forms, and 211 is also a good resource for connecting with further assistance.

Independent Living

was attacked in Providence by a dog. (Inaudible) He was hurt and back in service and it was pretty serious. He was attacked by two pit bulls and there was another time, maybe last spring, where both the dog was hurt and so was the handler. So, it brings concern about how safe, you know, what happens when people let their dogs loose? It's not -- they could really hurt someone, especially if they see a dog with a handler. It doesn't make those of us who might need a service dog particularly safe walking the streets. I just wondered about that, if there was any kind of resource or any laws to keep people safe. I guess if there's no one else who wants to speak we can take a little break and if anyone else comes in, we can resume.

ALEX SPIGELMAN: Before we take a break, I just want to raise one thing, if that's okay?

GRACE PIRES: Yes. That's fine.

ALEX SPIGELMAN: Right now, the State Office of Health and Human Services is working on interpreting federal rules regarding integration, and regarding people living in group homes, living in assisted living. They're looking for feedback. I know a lot of you commented here today, and if you have, either lived in integrated housing, or know people who would want to comment, then there's another opportunity to comment to OHHS[36], and we have little flyers available if you want more information so you can ask me and I would be happy to give you a copy of that flyer so you guys can comment.

GRACE PIRES: Okay. Do you have the flyers here with you, or?

ALEX SPIGELMAN: Yes, I do. They're right over at the sign-in table.

GRACE PIRES: If anybody would like to take a flyer, they're at the sign-in table.

FEMALE SPEAKER: I'm sorry, what does "integrated housing[37]" mean?

ALEX SPIGELMAN: Well, first of all, let me; excuse me for mixing things up. They are, there's different sorts of -- okay. The people have the right under a court case to live in most integrated setting appropriate. And most, most integrated meaning most community based. So, that can be, you know that would be different for every individual, but the goal is to really support that effort. To give people as many opportunities as they can to be in the most integrated setting appropriate for them. So, that's what we're talking about here, and we're looking at, you know, how the state is doing, in essence, when it comes to that. So, for instance, if you know anybody who is having trouble, they might want to comment, you might want to comment. That's what I'm talking about, the idea of integration, being in the community.

GRACE PIRES: Does that clarify, Barbara?

BARBARA HENRY: So, is it for a person with a physical disability or cognitive disability or both or...

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[36] Executive Office of Health and Human Services (EOHHS)

[37] Integrated Housing stems from the Consent Decree, which is an ADA and Civil Rights Division official order to serve individuals with intellectual and developmental disabilities (ID/DD) in the most integrated, or community based, service setting appropriate for their needs and freedom of choice, and negating serious risks of segregation. https://www.ada.gov/olmstead/olmstead_cases_list2.htm

ALEX SPIGELMAN: It varies from, you know, it varies, it really does. So, I wouldn't limit it to one disability or the other.

KATHLEEN KUIPER: Excuse me, Alex; is this for someone who is receiving services under developmental disabilities?

ALEX SPIGELMAN: Yes.

KATHLEEN KUIPER: It would be under that? It wouldn't be under mental health or behavioral health, it would be developmental disabilities, or would it be both?

ALEX SPIGELMAN: I would say -- well, let me back up. Can you clarify your question a little bit in terms of -- are you talking about just basic integration basic living in the community that sort of thing, or are you talking about the comments, specifically?

KATHLEEN KUIPER: What I'm asking is for integration within the community and that you're looking for comments, are you looking for people that receive services under developmental disabilities, under BHDHH[38] or something more general?

ALEX SPIGELMAN: Well I think, I'd be happy to give you a copy of the flyer. I think it explains things better than I can.

KATHLEEN KUIPER: Thank you.

ALEX SPIGELMAN: No problem.

GRACE PIRES: Do you want to read the flyer, maybe?

ALEX SPIGELMAN: I've got it. It's a two-sided flyer. Sorry.

KAREN RUSSELL: Thank you.

ALEX SPIGELMAN: So, it's entitled, "Opportunity to Comment on Community Integration of Medicaid-Funded Home and Community-Based Services." Text reads: "In January, 2014, the centers for Medicare and Medicaid Services (CMS), announced new rules that will potentially have a far-reaching and positive impact on the nature of residential and day service settings funded through Medicaid as part of home and community-based services, or HCBS. The final rules took effect in March, 2014, and had three basic requirements: One: All HCBS settings must; Be integrated in and facilitate full access to the greater community; Optimize autonomy in independence in making life choices; be chosen by the individual from among residential and day options, including non-disability specific settings; ensure the right to privacy, dignity, respect, and freedom from coercion and restraint; Provide an opportunity to seek competitive employment; Provide individuals an option to choose a private unit in a residential setting; and, facilitate choice of services and who provides them. Two: Residential settings must not look like institutions, and residents must have the same degree of access to their communities as their

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[38] Department of Behavioral Healthcare, Developmental Disabilities and Hospitals (BDHHA)

neighbors who are not receiving HCBS. In addition, residents must have: A lease, or other legally enforceable agreement to protect from eviction; Privacy in their unit, including entrances lockable by the individual, necessary staff may have keys as needed; choice of roommates; freedom to furnish and decorate their unit; control of their schedule and activities; access to food at any time; visitors of their choosing at any time, and physical accessibility for the individual. Three: A person-centered planning process must be used to plan for and provide HCBS services. CMS gave states five years, until March, 2019, to transition into compliance with the HCBS rules. "The rules I just read." States must create Transition Plans to describe how they will come into compliance, get public input on their plan, and submit their plan for approval to CMS. Through the Rhode Island Office of Health and Human Services, OHHS Rhode Island has been coordinating its transition planning for HCBS. There are several opportunities for HCBS users and the public to comment on Rhode Island's Transition Planning. Please see reverse for ways to comment. "Second side or page two: "OHHS will be publishing a revised State Transition Plan shortly -- with CMS approval. The plan will include: The state regulations that need changing to be compliant with the HCBS rule; and a list of HCBS settings that appear to be institutional and will need to make changes over time in order to continue to receive Medicaid funding. HCBS settings are considered institutional and not community-based if they're: On the grounds of an institution: i.e.: Hospital, nursing facility or intermediate care facility for individuals with intellectual disabilities (ICF/ID); or have the effect of isolating individuals receiving HCBS from the broader community. Settings that isolate are often designed specifically for people with disabilities and people with a certain type of disabilities. To provide people with disabilities multiple types of services and activities on-site, including housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities; with limited, if any, opportunity for people with disabilities to interact with the broader community; or to use practices that are used in institutional settings or are deemed unacceptable in Medicaid institution settings. People will disabilities -- and this is the important part for you guys -- people will disabilities and the public have two opportunities to provide comments to the state about HCBS services, about how they are now. One, they can comment on whether certain HCBS services are community-based. OHHS has been interviewing individuals and providers and is currently assessing individual setting compliance. Now, comments about specific settings can be made to BHDDH for development disability services: i.e.: residential settings, day and work programs. You can contact Christine Botts, Christine with a "C," Botts - Christine.Botts@bhddh.ri.gov; or OHHS for all other services: i.e.: Assisted living, shared living, or adult day care. Contact Linnea Tuttle, linnea.tuttle@ohhs.ri.gov. You can comment on Rhode Island's Transition Plan, which will be published soon on the OHHS website at: www.eohhs.ri.gov." So, those are the contents of the flyer. If you'd like a copy, it's right at the sign, in table. If you have any questions, please feel free to contact us.

GRACE PIRES: Okay. Thank you. I didn't realize it was so lengthy.

ALEX SPIGELMAN: I should have warned you. I'm sorry.

GRACE PIRES: It is okay, any other comments, questions? Anybody else come in?

KAREN RUSSELL: No.

GRACE PIRES: Okay. I guess we could take a little break and then come back.

MS. SCHULTZ: We can just take a break, that's fine.

CHRIS: We're here until six, it doesn't make a difference.

GRACE PIRES: All right. I guess we can talk among ourselves.
(Recess 4:34- 4:42 p.m.)

GRACE PIRES: Mark Aubrey. Can you please state your name and address, and city?

MARK J. AUBREY: Of course. It's Mark J. Aubrey, from Warren, Rhode Island.

GRACE PIRES: You don't need your address, just your city.

Healthcare

MARK J. AUBREY: And thanks for having this. I actually spoke at one of these back in 2006, way back when and the health department asked me to be on their disability advisory committee and we got a grant from the CDC, so anyone treating in the emergency room for any type of head or brain injury get a paperwork packet. That has all fallen apart, that needs to happen again. That's through the Brain Injury Association of Rhode Island. We advocated pretty hard for that. Actually, in 2005, testified and advocated for the traumatic brain injury fund bill and passed. The state's been collecting a ten, and then a $20 fee for anybody writing a speeding ticket, and that money is actually supposed to add spine to that. Myself personally, I could not treat in-state. I got sent to (Inaudible), and I got sent to Spalding. This was in place to guarantee health care services with traumatic brain injuries and spine injuries for people in Rhode Island to be able to stay in Rhode Island. The state has been collecting this money at the traffic tribunal all these years. It's still a law; I don't think it's been amended. The state has refused to acknowledge it or release the funds. I found out through Bob Cooper that the account exists. What needs to happen now is that money needs to be allocated and it was supposed to be directed to either I think Department of Business Regulations in the State of Rhode Island and that was going to actually create a position or some type of, you know, so they wouldn't have to hire anybody else or take money from the state. It's a self-funding fund, and other state, what’s an example of Louisiana has spent $1.6 million this year out to people with those types of injuries. They got the services they need, and that attracted more businesses into the state, more health care service providers. It's a guaranteed funding source to attract and keep health care providers in the state. I found out that PARI[39] has gone out of business and a few other persons who own companies that provide health care services and rehabilitation services with people with traumatic brain and spine injuries have decided not to open business in the state because there's no guaranteed source of funding. Leads me to my next thing; why is Medicare reimbursing ten dollars less now for the same services ten years ago. That doesn't make any sense. I've been doing this for the past 23 years and I need the same type of normal type of services, but yet, Blue Cross, or actually Medicare and Medicaid together used to pay for the services, and now they do not and most of the service providers in our state do not accept that. Somebody who has Medicare can sign up for Blue-Chip through Blue Cross. Blue Cross has fought every single thing that my doctor has prescribed for therapy, testing, and for treatment, and these are normal, routine things. This is nothing out of the ordinary. And I've been on the phone with the office of health care, not health care services, but the Health Care Commissioner, back then it was (inaudible). It was supposed to put a stop to that. But it seems now they have no short to enforcing reimbursements to health care providers in our state: Doctors, et cetera. With the fund in place that would take pressure off the insurance companies, and people would get treatment and then

Healthcare

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[39] Paraplegic Association of Rhode Island (PARI)

they could work out some type of reimbursement. My thing is now, is that the fund must be enacted, as is law. The denial of Medicaid to persons with disabilities in our state is -- for myself, I probably made three, four, five hundred dollars more than what was supposed to be the 125, so I was put on a spend down program where I had to spend my money for services and then submit that for bills then I'd be accepted but they don't go back and pay for anything. Fast forward now I have Medicare, Blue-Chip advantage, I have to wait until August second for that to kick in. For some reason, LINET[40] is not recognizing that I need help, and insurance for coverages and I know this is happening to the whole population. So basically, we're getting scammed out of our health care insurance, the providers are getting scammed the low reimbursement rates. The whole quality of health care -- I throw my hands up. I have a huge pile of bills, I have them in my car, and I don't even open them. These are just year after year of bills from hospitals, emergency rooms, Memorial, Rhode Island Hospital. I went to Saint Anne's because I owed them money. So the hospitals aren't getting paid, doctors aren't getting reimbursement, luckily I found a couple of doctors who will write off the $40 co-pay. Medicaid will not cover if you're in the Blue-Chip advantage plan. They won't pick up the co-pays. When they pay for the prescriptions that are limited in this type of plan, this plan won't pay for them, Medicaid's supposed to pick that up, they're not. So the state, as a whole is losing millions of dollars and the population's suffering and the business climate is horrible for health care service providers. Back then we worked on increasing the Medicaid rate so people could get services, I don't know if I'm wrong, but the federal matches what the state pays so the state spends more money, they get more money from the federal government to help offset that. So now the state's spending less and we're one of the last states to include Medicare, Medicaid type of plan that works, and that's not acceptable. Office of rehab services, went through you guys, which was great, but I don't know where the funding is as far as your department is concerned, but back in 2011, I put in, I was actually working, but I had the testing and I couldn't get past that plateau here you go to this type of employment, I was still in the medical state. There could be other sources beyond that. Me, I just turned to artistic stuff, photography, acting, I found my own supportive working accommodation. (Inaudible) pretty easy day, they feed you. With the traumatic brain injury, I can take more with my heart, instead of trying to figure it out, putting the numbers together and so forth and the practicality of actually working steady part-time work towards some type of gainful employment, different jobs. What needs to happen is the health department, I don't see, is the health department here?

KATHLEEN KUIPER: You were saying a lot of great stuff and I'm hoping that I can look at the notes later because I'm sure I missed details of your story, and I would like to get a little more information from you later. I would like to connect you with someone who would be able to help you better than myself.

Healthcare

MARK J. AUBREY: That would be great. That would be awesome, thank you. The Health Department needs to get the disability and health advisory committee on schedule. People left, it was -- that needs to happen again. Gives us a sense of purpose as for, you know, just to be involved, you know, on a volunteer basis and then actually, with a grant I think from the disability law center got a traumatic brain injury grant they came down to the brain injury association resource center, and educated us on how to testify at the State House for several health care bills, which is fantastic. And we did, and that creates a bridge back from being just in the house really not doing too much, that's life, but little bridge back into the community and enabling a sense of

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[40] Medicare's Limited Income NET Program (LINET). https://www.cms.gov/Medicare/Eligibility-and-Enrollment/LowIncSubMedicarePresCov/MedicareLimitedIncomeNET.html

purpose. And it creates a healthy environment for everybody. Puts us out in the public eye as good examples, or just an example of he's not so bad and we're not bad for the economy, like a lot of others will have you think or actually anybody who treats for -- I'm sorry if I'm repeating stuff you're probably aware of all this. I was going to ask if there were any questions.

KAREN RUSSELL: We've been asked to take notes not as a way we can answer questions or give you information. But I do have something to be helpful I want to be sure I have your issue down clearly. You mentioned that Bob Cooper said the account still exists.

MARK J. AUBREY: It does.

KAREN RUSSELL: Did you say guaranteed?

MARK J. AUBREY: Funding, health care services related to traumatic brain injury and spine injury was supposed to be added but it wasn't[i].

KAREN RUSSELL: Spinal wasn't. Okay, guaranteed funding for health services for those with brain injuries in Rhode Island.

MARK J. AUBREY: Testing, neurological testing is quite expensive.

KAREN RUSSELL: Yes.

Healthcare

Healthcare

MARK J. AUBREY: Medicare won't cover it. Medicaid reimbursement is way too low. No neuropsychologist in the state will accept that. Blue chip they just fight it and pay as less as they possibly can. So that was the offset to all that. And if anybody like say if somebody got in a car accident. Like me, I was injured at work. I had full Blue Cross of Rhode Island at the time, the best plan. They said I couldn't use that at the time to treat initially for my injury. I had to go through all of the Workers' Comp insurance which is not true, and this needs to happen as well, because they're supposed to pay everything up to the first two weeks or a month then it switches over to the Workers' Comp and they go after the insured. Same formula works for auto accidents reimbursements rates for one insured to the other. And it ties in with the office of rehab services, that's the catalyst of getting people back to work, but that's the preventive thing is like, kind of cannot a get there from here so to say medically speaking. Just trying to fight for, you know, just to see a doctor and have therapy, physical therapy, OT, speech that whole realm of stuff, including chiropractic and massage therapy, and dental care, because I got hit with a backhoe, crushed my jaw, lost a lot of my teeth, spine injury, but yet I was okay according to the Workers' Comp insurance doctors until I saw real doctors and so forth. And another thing in our state is the next, I think it's the end of September; it's the next appointment date for every single pain management type of facility in our state. It's very lacking with pain management-type services. Not the prescribing of the drugs but the other modalities that helps beyond the prescription medications.

KAREN RUSSELL: Okay. So, I have another question.

MARK J. AUBREY: I appreciate it; I had a little caffeine to help a migraine earlier.

KAREN RUSSELL: I don't know if we're going to get copies of the notes. Until Workers' Comp insurance covers it's supposed to be covered --

MARK J. AUBREY: If you have insurance through the employer or other means, it is supposed to be covered.

KAREN RUSSELL: For two weeks to a month you said.

MARK J. AUBREY: Different states have different laws.

GRACE PIRES: If you have an injury they always ask.

MARK J. AUBREY: Every single referral from the emergency room down is denied. That is because they want you to see all these other doctors, and you're not able to treat correctly.

KAREN RUSSELL: Have you contacted for the bills or the hospitals have you contacted the patient financial advocate for the hospital.

MARK J. AUBREY: Yes. Yes, some of that's written off.

KAREN RUSSELL: Great.

Healthcare

MARK J. AUBREY: But it doesn't cover the specialists, and the alternate testing, like Rhode Island medical imaging. Through the Blue-Chip plan it's a $150 co-pay for a CT. If you pay cash, it's $342. So to me if you're going to pay a little less than half up front, that's a little tough when you make anyone on any type of disability is making under a thousand dollars a month. So it's virtually impossible to live and pay for those types of services.

KAREN RUSSELL: You mentioned Medicare, spend down.

MARK J. AUBREY: Medicaid.

KAREN RUSSELL: Medicaid spend down, you have to spend the money out right. So is it Medicare that you have, then?

MARK J. AUBREY: Well, it was both. Medicare was the primary Medicaid is the secondary.

KAREN RUSSELL: Yes.

Healthcare

MARK J. AUBREY: The Medicaid would not kick in until you spent that certain amount of money, of which you're offered. Which me, I was like $500 over, so I had to spend that to qualify for the Medicaid, but they won't go back and pay the alternate bills. Not just the $500 but I actually owed quite a bit more at that point. So, they're not covering what is supposed to be covered, and again, the doctors and testing facilities have to write that off and we end up paying for it via the write off on the taxes, so we're paying twice for services that we're not receiving.

KATHLEEN KUIPER: After all this if you could come up and I could get your phone number and your name I would like to make sure I have all that information.

MARK J. AUBREY: Absolutely. Most definitely, and I'm sorry, I don't want to take too long.

KAREN RUSSELL: That's fine. Everyone here has already spoken that's here right now.

MARK J. AUBREY: I'm sorry; it's kind of a broad range of issues.

KAREN RUSSELL: Please, don't be sorry, we're here for you to speak your mind.

Independent Living

MARK J. AUBREY: Community access points create a bridge into the community. There are art groups, film groups; these get people out back into the community on a volunteer-type basis of just being there. Just present among people and enabling to socialize, or re-socialize again. You find of forget how to do that. You don't feel well enough to be around those types of settings. So that kind of helps the progress. Water fire is great. And music, type of festivals and there's another festival, Rhode Island film festival and southern New England film, music, and art festival. You actually participate in that. You watch short films and other films people have submitted from all over the world. You actually get to judge those. And it makes it inclusive. Myself, I got certified on cameras via the every single cable television station in our state has a community access program where people can go for free and create a television show or learn how to use that type of equipment and so forth, and I did that 15 years ago. This was a great thing to get back into the community. So I'm just thinking of different ways of rehabilitative, self-rehabilitative services, that initiate some type of employment process, you know, which I've gotten work from it throughout the years. Not lately, but it's a great access point. There's so many other ones out there that I'm not listing, but if there was a generated list, maybe it already exists, but if there's a list of those type of non-profits, community access points that are out there and available, just to hand out that would be wonderful. Actually just get the word out and probably much easier now with e-mail and so forth.

GRACE PIRES: All right. Thank you very much for sharing your concerns. And I guess, does anyone else have testimony in the meantime?

KAREN RUSSELL: No.

GRACE PIRES: Unless there are any questions or other comments from anyone else here, we can take another break and resume again if someone else comes in. (Recess)

GRACE PIRES: We're going to reconvene so that mark can make additional comments. Go ahead. Are we ready?

MARK J. AUBREY: Ready. Every single person in the State of Rhode Island who is disabled and treating with doctors, therapists, and testing modalities, should be reimbursed at a higher rate because it's more work involved to treat that person. And there is actually more work involved to actually get reimbursement to be able to treat that person and to make up for the offset that they have to write off that the insurance won't cover anyway, in treating that person. Another legal issue is transportation. Any person with disabilities in our state, there's a law, not sure of the statute, that exempts persons with disabilities from having to pay vehicle excise tax. Some towns in the state recognize it; others do not. The choice was given to each town whether to accept it or not. I was given the option, told from the town tax collector to file a referendum with the town and go before the Planning Board in order to get them to accept that. And for me, they're violating my rights as a person with disabilities to have transportation and be able to go out in the community and go to appointments and apply for work. I should not have to not pay my electric bill and eat less for two months, in order to pay for an excise tax bill on motor vehicles that there is already an exception for anyway.

GRACE PIRES: So just to clarify the first part of your comment. You were advocating for a higher rate of reimbursement for Medicaid procedures, for doctors, therapists and such, correct.

MARK J. AUBREY: They should get paid more.

GRACE PIRES: I guess the rate is pretty low, so okay. I just want to make sure I understood.

MARK J. AUBREY: Yes. Because most of the doctors -- well, as an example, my chiropractor stopped accepting Medicare and Medicaid and even Blue Cross, Blue-Chip because the rate of reimbursement is too low, and that's wrong. And that's denying me pain management modalities. That's just kind of stating, observation, well, go see your doctor and get prescribed pain medicine, which creates a whole other syndrome of health problems in terms of side effects.

CHRIS: What were you saying about the excise tax in cars?

MALE SPEAKER: There is a law that exempts real property tax for a person with disabilities, if you own a home or, they have the same for Veterans and persons who are in poverty. And a person with disabilities and poverty are hand-in-hand, but most of the towns in our state aren't recognizing that and they're still enforcing, charging the full tax rate for person's who own their own vehicle.

CHRIS: Would the person with the disability have to be on Medicare or Medicaid?

MARK J. AUBREY: No, they do not they would have to be, in proof, to show, actually, yes, show a Medicare card if under 65, as in proof of disability.

KAREN RUSSELL: Or Medicaid, was it also Medicaid?

MARK J. AUBREY: Medicaid, I think would need some other -- because Medicaid would fall under the poverty exception, so that would be in a different exception, but pretty much the same type of exception for ownership of transportation.
KAREN RUSSELL: Thank you.

GRACE PIRES: I think Medicare would be more accepted because usually that's a needs-based insurance. Is there anyone else, any other comments, questions, clarifications?

MARK J. AUBREY: Initialization of grants that were already, I don't know how to say it, processed in our state. Health and human services received a grant for traumatic brain injury services. That grant needs to be reinitialized. I believe it was through the CDC that supplied the grant. The health department received a grant from the CDC to provide information packets to everyone who receives a head injury via the emergency room, and that needs to be reinitialized.

KATHLEEN KUIPER: Those letters do go out from the health department, but they have to come from the hospitals first so what happens in the emergency rooms, they're the ones that collect the information that there is a brain injury, and then that generates a list. That list comes and, I believe, it goes through injury prevention department at department of health and then the letters are sent out. But I'll tell you a lot of those come back because the addresses are incorrect, so that is a problem.

MARK J. AUBREY: Yes. And there is an actual information packet of what to do, resources, and it directs them to the Brain Injury Resource Center in Rhode Island.

KATHLEEN KUIPER: Yes, it does. Yes.

MARK J. AUBREY: But that, I guess the grant has ended and that needs to be reapplied for. Not rewritten, just reapplied for.

GRACE PIRES: All right, anything else?

MARK J. AUBREY: Thank you.

GRACE PIRES: Well, thank you for coming. I appreciate it. We appreciate your testimony, and I guess we'll probably be adjourning shortly.

MARK J. AUBREY: Nice to meet everybody. Thank you very much for doing this, it's awesome. I know it's your job, but thanks for doing a great job. Have a great night.

July 26, 2016 Kingston Forum

MEREDITH SHEEHAN: Welcome, this afternoon, everyone. My name is Meredith Sheehan, and I am the community program manager for the National Multiple Sclerosis Society here in Rhode Island. And I wanted to welcome you all to our third, I guess, public forum, sponsored by the Governor's Commission on disabilities. A few housekeeping items before we get started. If you need a rest room, this afternoon, it's right outside the door. Very easy to find, also there is an elevator back down to the lower levels if you need it. We do have a CART reporter here in front, transcribing the entire testimony today so if you could speak loudly and clearly so she is able to accurately record your testimony that would be very helpful. All the testimony that gets recorded today will be reviewed over the fall by the Governor's Commission on disabilities and their legislative committee. They will be reviewing that. I sit on that committee and we will be reviewing the testimony throughout the fall determining which issues have come up throughout the public forums and how we can look for solutions for those issues, either legislatively or in other ways. So, again, these forums have been so helpful over the past many years, to help us help Rhode Islanders with the issues they are living with related to disability. We have a wonderful group of panelists today. I will have them go down the row and introduce themselves; their job today is more to listen, to the issues that come up throughout the afternoon. They're not necessarily here to engage and go back and forth with you, however, often times panelists will have some, maybe a follow-up question or some, a resource that maybe they can guide you to so that may happen, as well. But again, it's more to listen, so when we're reviewing the testimony later we have people who were here who can remind us what was said or give thoughts after the fact. So we'll start with ORS.

TERESA O'BRIEN: Hi, I am rehab counselor 2 for the Office of Rehabilitation Services for the state.

ELISABETH HUBBARD: I am from the Rhode Island Disability Law Center, and if it's okay, if we could plug the two documents I brought with me, I will put them in the back shortly. The first is, it's election season, and we do give people advice on voting rights and we do run hot lines on election days so I'll put this here if you are curious about voting rights, please take a flier and call our office with questions. The other is currently the state is taking comments regarding the home community based service waiver, which is all Medicaid services that is offered in the community. People who reside in group homes or apartment type living for people with disabilities. They are seeking sort of an input to be sure they are fully integrated in the community and something a community has is available so if you or somebody you know is receiving services in the community and would like to comment about how much you feel that is integrating in the community, what access you or your loved one has, the state is looking for input about that particular placement. So I will put this up front, there is information about how you can comment on that and more comment about the changes in the bill if you want to look online. Thank you.

COLLEEN POLSELLI: Hi, from the Rhode Island Department of Health, Special Needs Office.

GINNY STACK: Hi, from Sherlock Center on disabilities at Rhode Island College.

CRISTY RAPOSO: Hi, from RIPTA.

MEREDITH SHEEHAN: Thank you so much. On the back table there was a sign-in sheet, so I have those of you who signed up so far and if you hadn't signed up but after you hear other testimony, if you would like to sign up, we welcome that. You could just let me know; we can go back and sign up on another sheet. And also, there is a packet on the back table with the upcoming public forums, which try to do locations throughout the state. So the listing is there, as well as a listing of sponsors and contact information. On the inside sheet, it's always very interesting to see how successful these public forums have been in the past and again how the testimony has really helped us come up with solutions. There are outcomes on the inside page that are great to look at, you can see all that has been accomplished, pretty much as a direct result of these open forums. So if you want to take a look at that that would be great. We do have two ASL interpreters here. If you need them, they won't necessarily be up here the entire time, but if you do require interpretation, interpreters, we can just call them back up. So please just let me know that. And also if you are hard of hearing, we do have assistive listening devices on the back table so feel free to go back and the woman at the table can help you with that, as well. So, I think with that, we covered all of our housekeeping items. We can just get right underway. So, the first person who signed up was Carolyn Maxwell. Do you want to sit or would you rather stand? Just, as long as the CART reporter can hear you.

Education/Employment

CAROLYN MAXWELL: Maybe if I just turn my chair. Well I'm here on behalf of my daughter, Emily Maxwell who is now 23. And I spoke at last year's meeting held at the Peace dale library and several people encouraged me to put my thoughts in a letter and send it off. It took me until March to do that. And one day, Emily sat down and we sent copies to Maria Montanaro, Governor Raimondo, Langevin and Senator remediated and several months went by and no word from anyone. We did attend a meeting by, a town gathering, (inaudible) in Warwick and the focus was very much on transportation that year, that afternoon, and we didn't have an opportunity to speak in the two hours that we were there. So, again, we have just experienced many difficulties after Emily turned 21. She is someone with a congenital heart defect that affects her energy and physical activity, very much so, in a work environment. She has microphthalmia[41], with vision in only one eye, a bilateral hearing loss resulting in deafness, and a reliance on communication through sign language. So that severely limits her ability to communicate with most of the population. She also has had spinal fusion surgery. There are OCD behaviors, celiac disease and significant developmental delays, her neurologist has stated she will never lead an independent life and as we were approaching 21 I kept looking at her and thinking, what we are going to do when the bus doesn't come any more. And her teacher of the deaf, last year in school, sent home a little gift and she photographed Emily's hands and it was LOVE in a frame. And I started showing it around, and an idea popped into my head, and I sat down and photographed Emily's hands and we have the alphabet, and many LOVE designs, and started a little business called love letters by Emily. We opened up a shop on Etsy and started with level local contacts, we are Kingston residents at the fair weather house nearby. And this is something we have given our all to for several years now. This is Emily. And she is holding up our latest T-shirt design, we put love Rhode Island across the front. As we were trying to move on and get things going, everything that had been mandated by her IEP for assistive technology and her use, a computer, and internet access, an iPad with language supports, and everything, disappeared. And we started relying on the family computer and the family iPad. But quickly found out we were out growing that and needed some supports so we contacted ORS. And Emily went through two situational assessments. When the assessors mentioned that they could accomplish it all in one standard amount of time. And through the course of that year, the end result was that Emily was deemed unemployment in an integrated setting; being too disabled. But as I was, you know, always asking for suggestions about job training or what did they see her future as being, there were never any answers. But I know there are people who are hired to create jobs or, you know, figure something out. But here, we had done that. And we have shown success. And saying, but we just need the kind of support, and after the meeting last year, people started coming up to me and said, gee, I got $17,000 to help with my business and I got $33,000 from ORS for my business needs and all. And to really be shut out of any support has been extremely difficult for us.[42] ORS told us that

Education/Employment

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[41] Microphthalmia is an eye abnormality that arises before birth. In this condition, one or both eyeballs are abnormally small, and may or may not result in significant vision loss. https://ghr.nlm.nih.gov/condition/microphthalmia

[42] The GCD recommended in 2015 to advocate for involving CommerceRI15 in increasing awareness and inclusion of working age adults with disabilities interested in self-employment in: Urban Ventures; Betaspring; Social Enterprise Greenhouse; and other micro and small business accelerators.

if we paid Emily $100 a week in wages, and also insured her for workman's comp and also if all of the people currently working with her our self-directed program would become certified job coaches, then they could continue to work with Emily. Otherwise, we would have no staff. Their stipulation was that everyone needed to be a certified job coach. And I have a teacher with a master's degree from Gallaudet University working with Emily who is not about ready to take the job coach certification class. Emily just, and our situation does not fit in with what the guidelines and the regulations are, and that's a problem. I know they're in place for a reason, but, again, we are left out of any support from that and in terms of assistive technology or a business computer, all of these are generated on the computer. Our store is internet based, most of our business, and to be told, why don't you go to goodwill and see if you can find a cheap refurbished computer, it's just very disheartening. And then, when we put all of this, all of our story into words and tried to contact people and we see no response, which was kind of strike two. Another element that continues to be a daily struggle is finding people to staff our self-directed plan, the fact that a lot of our money is turned back to the state because I can't find people with American sign language skills to fill the hours and supervise Emily and take care of her medical needs the way she needs and deserves. And yet, I hear that parents in Massachusetts are able to be hired, or siblings who live at a different address in Rhode Island are able to be hired, but I have maintained my certifications as an elementary schoolteacher but have not been able to work because I have been taking care of Emily. I have the sign language skills. I have the art, for me to hand the, all of the materials and try to make the prints, or have our staff make prints and say, I'm really not as good a paper cutter as you are, and give me back things, that we can't even take to the craft fairs. It's just, everywhere we turn, and we are struggling. And I think we are looking for it, still, some support, or some changes to be made. And I think that pretty well sums up the situation that we're in.

Education/Employment

MEREDITH SHEEHAN: Comments, or. ..? Thank you very much. I remember this from last year. But, the artwork is quite beautiful. So I hope that, again, all of this will be reviewed throughout the fall and you know, thank you for bringing it up again, we will see if there is any way we can offer some assistance down the road. Thank you so much for coming out. Next are Warren and Mary. You can stay seated or stand up, whatever is easier for you.

MARY DRAKE: I think you can hear me, and that's the important thing. We have a daughter, 43, and she lives in a group home since she was 25 by her choice and she is very happy there. And she is a cancer survivor. She had cancer at 38. Ovarian cancer and she is a survivor. And there are many things that we have done since staying in the hospital with her for four weeks, all day, all night that I stayed with her that you can't expect to have now, which I understand that. But I am interested in the shared living that's going on now, and what will happen to her if they close group homes and how they manage the shared living, what the funds are, medical and such things as that, very simple.

Independent Living

MEREDITH SHEEHAN: Okay, great. We do have someone on our legislative committee who works for Perspectives Corporation which is one of the operators, is that where she is? Okay (yes) so I can talk to him and see what the situation is. I don't know much about the shared living situations, but,

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http://www.gcd.ri.gov/2015%20Public%20Forums%20on%20the%20Concerns%20of%20People%20with%20Disabilities%20Report%2011-30-2015%20Adopted.pdf , page 3-2

I do know Casey Gartland, so I can talk to him and see if there is anything that he knows about that. Or about what the situation might be. Thanks again for coming out. Okay, Donna Gilton.

DONNA GILTON: My situation is similar to the couple that just spoke up, my twin brother is in a group home and I am concerned. So far so good, but I am concerned about what will happen if they close down his group home.

MEREDITH SHEEHAN: Okay.

DONNA: I am very worried about that.

MEREDITH SHEEHAN: Yeah, we don't have a group home representative on the panel today. But like I said, they will be part of the discussions going forward, absolutely. Dottie Darcy.

DOTTIE DARCY: I am just here observing, I actually didn't put down that I wanted to speak.

MEREDITH SHEEHAN: I'm sorry, yes.

DOTTIE: I have a 21 year old just entering the adult system, and, but since I have your attention, I see problems just, we're very, very -- the adult system and with the transitions, some of the things, getting away from the centers, getting away from group homes, there are far too many of our loved ones who cannot handle, are not appropriate for the changes that are being proposed. And I don't, I am very concerned that that fact is not getting addressed. Very many of our loved ones are not appropriate for community activities; behavioral issues, what have you, whatever the reason. And they need a secure place to be, and yet still learn. So, I guess I did have two cents.

Independent Living

MEREDITH SHEEHAN: Sure.

DONNA: My brother also goes to a day program and I am worried about that, too. I'm with everybody on that side.

MEREDITH SHEEHAN: Okay.

DOTTIE: The changes being proposed are not appropriate for, you're missing a large part of the population and their needs by just implementing what you're proposing, what the various agencies are proposing.

MEREDITH SHEEHAN: So I don't have anybody else signed up but if anyone wanted to make additional comments or add to the discussion.

Independent Living

CAROLYN: I would like to tag along with the programs, everybody is always asking what day program is Emily in, and I said, we have looked around long and hard, but, again, don't find the kind of language support first. And if there is anything that comes close, it's RHD in Pawtucket but I cannot put Emily on any kind of transportation or transport, you know her to Pawtucket on a regular basis. There really needs to be either a satellite program or, again, there are some wonderful programs around and about, I often mention full circle arts in Massachusetts. We are actually consigners in their shops, and they sell Emily's art, and send us our portion of the check every month. But they have a store front. And along with their clients making items to sell in the stores, they do meals on wheels, and swimming, and round out a day program. But again, there really isn't anything in southern Rhode Island for anything like that.

AUDIENCE MEMBER: So I am being kind of ignorant because I am not sure what the proposed changes are, so, where can I look that up?

MEREDITH SHEEHAN: There is legislation that was proposed last year, is that right? What I am particularly referring to is the federal mandate, I guess, that the, sort of the workshop type centers, sheltered workshops, I'm sorry, all these centers need to be down and there can be no one in them, and none of that, and the transition of individuals from group home settings, which I guess is more expensive, to sort of shared living arrangements, or I guess support with family, what else they're proposing, to get people out of sheltered type workshops and into the community, and to do things in the community. My perspective from the little time I have spent is that the problem wasn't the sheltered workshop, it wasn't the building, it was what was going on in the building. You have a lot of our folks, they still need a secure building, you know, a second home, where they can learn and grow, continue to learn and grow. They're not going to do it out in a scary place like Wal-Mart. They're going to act up. Wal-Mart is going to call the police on them because they're scared. We have people like that in the population. It's fine if somebody is fairly high functioning, doesn't have any type of behavioral issues, or very mild behavior issues, all this movement of people from sheltered workshops into community based employment, that's fine, but it only, in my mind pertains to a percentage of the people whose needs need to be met in this state. So that's what I am referring to, sheltered workshops. And that's what, and, and that's true, it's terrible that so many people were just sitting there doing the same old thing when they could have been doing so much more and sheltered workshops were supposed to be so much more, but they weren't. But, I really, you're throwing out the baby with the bath water here. I think you just need to do what's needed, not throwaway the whole thing.

MEREDITH SHEEHAN: Good explanation, thank you.

TERESA O'BRIEN: I can respond to that a little bit. I don't think the department of justice came in and said we have to close all sheltered workshops. I think the sheltered workshops they came into, there were some people in there that clearly could have been challenged a little bit more, absolutely. So, I don't think it's going to that, hopefully it's not going to go that far in the spectrum that they'll say no one can be in a sheltered workshop because clearly some people need a nurse next to them, a physical therapist and occupational therapist and clearly Wal-Mart doesn't want all of those people being there as health supports. Elisabeth can probably touch on this, too.

ELISABETH HUBBARD: The investigation started out with a school that had a workshop on-site and there were allegedly students that should have been receiving education and the workshop during school time that should have been offered, or, experiences in the community, and that did not happen. In this case, they found people who were able to, would have been able to work in the community and to work toward that. I think there is also an issue with people who are older and have worked in sheltered workshops for a long time. And I think that -- I don't think there is as much as a rush to say, close the sheltered workshops tomorrow, most of the consent decree focusses on people transitioning, assessing everyone who is transition age to see what supports they might need to be able to work in the community. And work, the focus, really, I think isn't to throw people into the community and see if they sink or swim. I think the purpose of the consent decree and I think what we're trying to move towards, and we would like to see happen is identify what supports are needed to get people in the community, how do we come up with the staff that might be needed or the training that might be needed, how do we create a work environment where somebody who, with a disability can feel they're part of the team and feel included. And, what supports might be, to be sure that we change our perception of what a person with a disability can do. So I think (inaudible) to find supports that's needed and the disability law center to be sure the law is followed as good as we can.

AUDIENCE MEMBER: What I think is missing from what you said is to help some people work as they can. Because --

ELISABETH HUBBARD: I think it's to the extent they are able to.

AUDIENCE MEMBER: This is just what I think I am observing is that the agencies out there maybe don't understand that, they seem to think that all of the buildings need to be shut down. And they're working on it. And that's what they're doing and I'm saying, really? That's what we're running into, the agencies; maybe they need some communication, somber communication because that's what --

ELISABETH HUBBARD: I think they're trying to develop programs where somebody who, not everybody will be able to work in the community and work independently, you know, as a stock person in, you know, a department store. Some people might need more or might need things that are more creative. And I think in all those instances, there is the ability to have job coaches and staff. And I think that BHDDH can provide job coaching and things like that to help people work as much in the community as they can. I don't think it's so much that it's a communities or nothing, it's trying to get people to the extent that's possible out in the community.

MARY: If they close the workshop who is there to help them find these things if they're closing the workshops?

ELISABETH HUBBARD: I don't know how to respond about closing workshops, I don't know of any.

MARY: Oh I have heard, and they did have, you call them sheltered workshops but when my daughter first went and she goes to (inaudible) center and they did have piecework and work the kids did and my daughter worked at ocean pharmacy and she worked, she worked a couple hours, six hours a week but then because of the money they said, well, they can't work or do anything unless they get paid the minimum or the wages. So they took that all away from them. They already had things in place but they took it all away and the sad part is now, why they're doing all this is because they don't have enough money. So they want to close everything so they can take the money and then let other people take care of my child. That's my problem.

ELISABETH HUBBARD: You can feel free to contact our office about situations like that. Where you feel services are being changed or services that were in place are being taken away, you can always contact our office and talk to somebody.

MARY: Oh, I have, we're very in the loop.

ELISABETH HUBBARD: As I said, I don't want to talk too much. We can talk one to one and I think after wards would be a better time.

DONNA: I am also concerned because, I mean, there is a move to close down the group homes and the day programs and my brother is in both. And the group homes, I mean, okay, they were sheltered workshop but they were gathering places, places could go and meet their friends. People had transportation to get to the day program. And then the group homes have their own things going on. And if you are shutting down both and from what I was told I think they were trying to put everybody into jobs in the community but the people had to be able to get to those jobs on their own or have transportation and they were going to be placed with foster families and more responsibilities would fall on the family. I'm hearing a lot of horror stories about both of them, I am very worried.

TERESA O'BRIEN: but it's good we are bringing them back into people's attention. I know there were two groups yesterday and I heard a lot of the same concerns. So this is great. And this will get reviewed by everyone.

DONNA: I hope so.

TERESA O'BRIEN: the whole point of these conferences or these meetings. So, thank you.

AUDIENCE MEMBER: And you said a key thing, if anyone has concerns, one to one, an individual situation, but what we are describing for you is not an individual situation. The agencies said, are thinking that they need, we have to get everybody out of our workshops, we have to get everybody out of our homes. And that's what they're doing. So BHDDH, everybody else, how often do you get the agencies in the room and let them know what's going on, or what the expectation is. Does that ever happen? What kind of communication is being done to the agencies? Because it sounds to me like there is some disconnect perhaps?

MEREDITH SHEEHAN: Yeah, I know, obviously the Governor's Commission on Disabilities does do their best, to certainly communicate to agencies like BHDDH about individual cases like this that might come up. We have representatives from BHDDH come in and other agencies to meet with our legislative committee, you know, sometimes after these forums. So, the information does get passed. I can't say, at least from the Governor's Commission on Disabilities stands point, to BHDDH, right, in a formal sense, certainly, come the fall, when all five or six forums are over and we have gone over this testimony, certainly if this is a recurring issue, then it would be probably a priority issue, a priority legislative issue, for the Commission next legislative session in January, absolutely. So, yeah, other than that, I'm not quite sure.

WARREN DRAKE: It seems that it's just a matter of money. Perspective's budget has been cut for what the last eight years, ten years? And in some respects, part of that is a good thing, they have become very streamlined. I am not saying they got rid of dead wood but I think they operate much better than they did before. But a constant cut in money, they're paying their people very poor wages. So poor that many of them only work for short period of time and then they leave and get a better job. Now our daughter has been there 15 years and she loves it. And it is a wonderful place. And the staff is wonderful. But, Perspectives has been putting people in the community. They find them jobs, some work at Wal-Mart, Stop and Shop, an art studio, and different places like that; they have a number of people they support that live in apartments. Now they need staff to stop by every day and make sure everything is clean and neat and make sure the groceries are all set but these clients are able to live like that. Our daughter can't. She needs to be watched 24 hours a day. You can't set her in a chair and say watch television while I go to the grocery store. You might be gone ten minutes; God knows where she might end up. She's just not able to control herself and who knows what would happen. So you say we'll put her in the supported living. Well, all you have to do is read the paper every couple weeks and read about foster homes and everything like that and the problems that are happening with people that are not disabled living with these families. So is the service going to be any better? Is the selection period for these people going to be any better, or any different than what they're doing now? And what happens if you get somebody that slips through the floorboards here and our daughter goes and lives with them and God forbid there is something that doesn't work out right. It's not just my daughter; there are a whole bunch of clients that need this group home, that's where they need. They need the structure, on the hour supervision, the medication controls, and the transportation to get where they need to go. And if you destroy that, I mean, what's going to happen to these people? It's taken how many years to remove these clients from places like Lad school that started out to be a fabulous place, turned into one not so good. This is such a much better program. When we made, when the state of Rhode Island made the changes that they made to create these group homes and let private companies like perspectives join in with the state, we became one of the best states in the union as far as how we took care of our disabled people. And now it's going the other way. And it all comes back to money. If perspectives and the state got the money they need and I'm not saying gazillion dollars, just get them back on track so they can hire and retain the staff, keep some of these places open, be able to buy a new van so they can take them into the different places they need to go. That's really the bottom line. It is. It's all money. I know things have been bad but things are getting so much better now. The economy is getting better. Interest rates are low. People are buying cars, house sales are going up. So the economy is getting better, the state of Rhode Island is getting multimillion dollars more than planned in sales taxes, gambling revenue, I know it has to be spread across a lot of organizations but you need to take care of the people that can't take care of themselves. That's all I have to say, probably too much.

AUDIENCE MEMBER: He brought up the only point I was thinking of bringing up. My son has only been in the system, adult services for like 3 months and he is with Perspectives and it is going better, I think, than some other people, unfortunately, for you, I feel bad for everybody, but that is a concern. He has had, it's been 3 months, a dozen workers. And you never know, it's very frustrating because how can they work on the same goal, item, and who is going to show up. That's really frustrating. And it's, I'm sure it's, I can't imagine what these people get paid, I am guessing it's not a whole heck of a lot. So that is not helpful to accomplishing goals, and getting a routine, these kids need routine. That's really disruptive.

MEREDITH SHEEHAN: Definitely come up. We have a woman who sits on our committee who runs opportunities unlimited, Linda, and she is constantly saying that, her, the best she can pay workers is 10 or $11 an hour, they can go to Panera or somewhere and make 13 or 14. So the staff turnaround is, has been a constant issue, I used to live across the street from a group home and we saw the same thing. It's hard.

AUDIENCE MEMBER: It's got to be harder in a group home.

MEREDITH SHEEHAN: Definitely.

DONNA: I have to tell you, getting into history of Governor Carcieri, they tried to close the group homes before and people protested and prevented it and this time, I have been to a couple other meetings and my brother, where he goes, it used to be the LaPlante Center and it was both the day program and group home and perspectives took that over and I think has done a good job so a lot has happened with that, and from what I could gather from the meetings, they were claiming that they were getting pressure from the legislature, I'm not making this up, to place 100 people in 3 months which was impossible, they said so far we have placed 1 or 2 because we are trying to be very careful where we do put people so from what I gathered it sounds like a lot of pressure is coming from the legislature because they don't want to do the funding. That's the impression I get.

LINDA FABRE: Hi, my name is Linda Fabre, I am kind of wearing two hats today, I am from RIPIN, Rhode Island parent information network so parents that have younger adults looking for transition information, that's a great source, great source. And so, please call the call center; you have questions and about health concerns.

AUDIENCE MEMBER: I did.

LINDA: But, I am a parent of a disabled child, a lot of the staff that work there are. And he is 14, so we're looking at that whole transition piece and RIPIN does help with that and providing information. But I think my big concern is my son has had severe mental health needs over the years and unfortunately, he has been hospitalized many times. And one of the problems is, for me living in South County, is that the services in South County have been very limited and when he has been hospitalized, of course he has been at Bradley or butler, for a parent having to travel that distance is very, very hard. We don't have any inpatient psychiatric care down here in South County. And there is very limited number of psychiatric, you know, clinical centers down here. And so, I do worry about going forward with him, as well, and how his transition will look. And because of his severe behavioral issues, he is much better now, but, how is that going to look for him and how is he going to make it in independent living situation and be able to manage to do things on his own. Even though he is, he is not considered low functioning but his behavioral issues are a huge barrier for him. So, my concern is mental health services in South County. He is such an outdoorsy type person, he really is this country type person and it pains me to think that the way he might have to live is by living up in the city, because of the limited services down here. And then he would be very far from us. And of course, these are the things that have you in mind. How is my child going to fit in this community?

MEREDITH SHEEHAN: Okay, any further thoughts right now? Well I really appreciate all of the openness and the stories and again, I can't tell you how critical testimony like this is as we go forth to try to shape possible legislation, regulatory issues, and things like that. So again, I really appreciate it. We, the panel, we're here from 4:00 to 6:00, we need to stay the whole time in case anybody comes in at the 5:00 hour, after work, if you have already said what you had to say, you obvious don't have to stay, we will let you leave. So we will take a break. If there is anybody you wanted to talk to one-on-one, feel free. Again, rest rooms are right outside the door.

July 27, 2016 Cumberland Forum

DEBORAH GARNEAU: Okay, we are going to get started. The Governor's Commission on Disabilities runs these public forums every year during the anniversary of the Americans with disability act. And, the purpose of the forum to hear from the community around concerns, or successes, but mostly concerns about the system of care for people with disabilities and other services, trying to access throughout the Rhode Island service delivery system. So, the information from the forums that's shared can be here publicly or also in writing. And these testimony and information goes into forming the legislative agenda for the Commission and we are open and wanting to hear. The panelists will not necessarily provide feedback but if there is something that we can answer and respond to, then we certainly will. I am Deborah Garneau.

KATHY McCABE: From the Office of Rehabilitation Services, otherwise known as ORS and my case load is in the East Bay of Rhode Island, I cover Bristol, Barrington and Warren, I'm here to listen to what you have to say today.

DEBORAH GARNEAU: Right on cue.

MATTHEW BLAIR: My name is Matthew Blair, as you can see I am with the Disability Law Center, we are a nonprofit legal organization that helps people with disabilities in certain kinds of cases, I am here to listen and if anyone has anyone questions about things cans I can talk with them later. I am also here to tell you we are soliciting comments, not us, but there is something, afoot in the state which is everyone who has disabilities or family members of people with disabilities has an opportunity to comment on new regulations about home and community based services in. They put forth some regulations and the state that administers it are looking for people to hear how it will affect them and how they would like to see the regulations put into play so I will put forms over there and you can take a look. And, we also do voting stuff, if anyone has questions about how to register, if you can register, that kind of thing, please let me know and I will try and hook you up with that, too, thank you.

ARTHUR PLITT: Commissioner for the Governor's Commission on Disabilities.

DEBORAH GARNEAU: So, as we call speakers, if you can remember to state your name and the city and town that you're from for our recording purposes. Arthur, did you want to go first, or?

ARTHUR PLITT: Let me wait, if there's anybody else.

DEBORAH GARNEAU: So, Deborah.

DEBORAH MASLAND: Can I talk from here? My name is Deborah Masland, and I am a mother of four, among other things but we will talk about me being a mom right now. I live here in Cumberland. We have been in the state, in this town for over 20 years. My two boys are 32 and 30, and then we have two daughters, one 24 & Olivia is 17. Three of my children have diagnosed special needs. My 30 year-old, we discovered he had something, connective tissue disorder called Marfan[43] syndrome, it can affect a lot, all of your systems, including some concerns about your heart, particularly the aortic root which could be dilated so much it could spontaneously burst and be obviously life threatening. People

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[43] Marfan syndrome is a genetic disorder that affects the body's connective tissue. Connective tissue helps to hold the body's cells, organs, and tissues together and also helps to control how the body grows and develops. There are also several disorders related to Marfan syndrome that cause people to struggle with the same or similar physical problems. Marfan syndrome is a serious condition, and some complications can be potentially life-threatening. Although there is no cure for Marfan syndrome, advances in medical care are helping people live a normal lifespan. http://www.marfan.org/about

with Marfan should have regular heart appointments, regular echocardiograms and things like that. My son is an artist. He is independently contracted sometimes. And has been unable to secure insurance for lengths of time because he gets, he makes too much to be able to qualify for Medicaid, most times, if he's, if there is a look back, depending on how far people look back to apply for Medicaid so he has gone ten years without an echocardiogram because he couldn't afford the test. This spring, he had a, some sort of a break and ended up at the Jane Brown unit in Rhode Island Hospital and has since been diagnosed with bipolar, he went in with no insurance and he subsequently was able to secure insurance as a result he has been having to live with me and not working. So he was able to get our state insurance. And be able to setup some appointments. The gaps that I found for this sort of situation, which was kind of new to me, because I have navigated systems of care for children, but for young adults such as my son, he was, got great care at the hospital, they diagnosed him, prescribed some medication then sent him home with a list of referrals so he called some places to refer, they did not help him get insurance, we worked on that through a communication organization supported him through getting the insurance but he was discharged and told to call some places to setup appointments for med management and those kinds of things. The places he called were hard to get a hold of and when they finally did setup an appointment for him, he wept in and still had not gotten the insurance yet; it was going to start the next month. They took an intake, when he called back after he had the insurance to setup appointments they couldn't find his information and they were not sure what happened. So, here is somebody who is still reeling from the fact he discovered he had bipolar, had had, truly a psychotic break, he was doing better but frustrated with the system. And it continued even getting the appointments so I want to put it out there that a little better care coordination or patient care coming out of the hospitals and into the community, I see gaps there. My daughter, Aiyana, adopted from Korea, she has had from the time she was probably preteen we noticed some mental health issues and she was somebody we worked with, ended up working through DCYF with volunteer, and having her, she was outside the state for placement because there was no appropriate placement for a while, schizoaffective disorder, she has come back to the state, we were recommended to go through the BHDDH and we, I went to a meeting and said we need the whole acronym, behavioral health, developmental delay because she has a mild delay and may need the hospital piece. We were denied DD coverage and support and were approved for mental health services in the community or have her go to the hospital for a short time, she has been at Eleanor Slater now for two years, was supposed to be six months, she will be 24 next month and I don't know what else there is in the state and I work within the system and I don't know where else she can go. When she's in a very structured environment she has no behaviors at all, she is fine. As soon as she does things on her own she becomes unsafe for herself and others but there does not seem to be training to get her to a less restrictive environment despite my attempts to come up with ideas around there. So I see a gap there. There are also gaps, there was several years ago, temporarily hospitalized at Rhode Island hospital and released back to a group home there were gaps in coverage between there and the community again. Those are just some gaps I would like to highlight for all of you. One positive thing I would like to say is my daughter Olivia you see here diagnosed with intellectual disabilities and seizure disorder because of her more obvious needs, we have been able to navigate through the system very well we are a CEDARR[44] and PASS[45] success story, and with great results and PASS has been a great thing for our family. Amazing thing for our family, allowing her to have a great deal of independence, develop

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[44] http://www.eohhs.ri.gov/Portals/0/Uploads/Documents/CEDARR_brochure.pdf

[45] Personal Assistance Services and Supports (PASS) http://www.rewardingwork.org/en/State-Resources/Rhode-Island/Helpful-resources/Rhode-Island-PASS.aspx

relations in the community and participate in things otherwise she would not have been able to. So that's one thing I think we are doing well for my family. I appreciate this time to be able to talk about some of these things. That's all I have to say.

KATHY McCABE: Olivia, do you work? Are you employed?

DEBORAH MASLAND: Do you go to school? She goes to Cumberland high school, she's 17, yeah.

KATHY McCABE: So is Olivia involved with ORS.

DEBORAH MASLAND: Starting to. She has a work plan that she actually does, she goes to work one day a week in her ESY program.

MATTHEW BLAIR: Could you repeat your daughter' name.

DEBORAH MASLAND: A-I-Y-A-N-A Milton, and this is Olivia Milton.

DEBORAH GARNEAU: People who are signing up, are you interested in speaking?

SANDRA FOURNIER: Sorry, traffic from Woonsocket to Cumberland is not always the easiest.

DEBORAH GARNEAU: For those who have just joined us, this is the Governor's Commission on Disabilities and we are hearing testimony from community members and other stake holders about the service system for people with disabilities and so we ask that as you provide testimony, that you would just state your name and the town that you're from so that we can have it recorded. And for those of you that might not know, what happens with this testimony is that it is looked at thoroughly and used to inform legislation that can occur and setting the legislative agenda for people with disabilities through the Governor's Commission. So, Richard, thank you.

RICHARD MUTO: Yes.

ARTHUR PLITT: Can I just, Deb, could we have an introduction of the panel.

SANDRA FOURNIER: I am Sandy Fournier, assistant vice president at Seven Hills Rhode Island in Woonsocket; I am also the chair opinion of the Rhode Island disability, nursing association and board of director's member. Also volunteer here in the town of Cumberland for the cert team.

DEBORAH GARNEAU: From the Health Department.

KATHY McCABE: From the Office of Rehabilitation Services.

MATTHEW BLAIR: From the Disability Law Center.

ARTHUR PLITT: Commissioner, Governor's Commission on Disabilities.

DEBORAH GARNEAU: Go ahead.

RICHARD MUTO: Richard Muto, I work at the Brain Injury Association of Rhode Island, also on the Governor's permanent advisory commission for traumatic brain injury on the board for the Association of Rhode Island and neuro restorative advisory board, residential program for survivors of brain injury.

FAYE ZUCKERMAN: So we're together. I am Faye Zuckerman, with the Brain Injury Association of Rhode Island; I do their communications and government relations. So, we're here today we have three priorities that we would like to express to you. So, as, or on behalf of the Brain Injury Association of Rhode Island we would like to be placed on the Commission, we would like to have a seat on the Commission, so if that could be a piece of legislation next year, that would be great for us. The other thing is this year there was a piece of legislation, it was 2016 HB 7639[46] and 2016-S2336, that was the duplicate one, it's legislation that would require high school athletes who have a serious injury while playing, an athlete to have an athletic trainer present on the field to make a diagnosis. It was introduced by Deb Kazarian and Al (inaudible), we would like to have it reintroduced and work with the disabilities association with some kind of a group or some kind of, you know, consortium to help push it back through again next year, have it reintroduced. We would also like to introduce an act that relates to the training of law enforcement and first responders on how to, on how people affected by trauma are treated when they're pulled over or when they're in a crisis situation. So, provide information to veterans with PTSD or combat related trauma or the general public, some kind of brain injury, it would be a training program, maybe through the Department of Health, or through State Police that would train officers and first responders on how to handle somebody who has a traumatic brain injury and is trying to communicate but they can't hear it, I can give a good personal example. My sister has Parkinson's and it's very severe, affecting her processing. We were he is courting her through security and when they did the machine, I don't know what it's called, she was shaking, and she was trying to explain and we were trying to explain to the TSA agent that she has Parkinson's and that's why it's blurred and the TSA agent was yelling at her, saying you have to be searched, we have to search you. And because while they were searching her, she couldn't stand still, they brought over the supervisor and he was threatening to take her to a private room and he would not listen to us. He would not hear that she had some kind of a brain cognitive impairment that would not allow her to stop shaking. And after the fact, I went back to the supervisor and said, it took us about 20 minutes to calm her down and fortunately she didn't have a panic attack but she could have and it would have been horrible. So I went back and tried to explain to the supervisor, trying to tell you she has Parkinson's, it's severe, I thought, oh, you were saying she was hard of hearing and that's why I was screaming at her. Really, that's not why, that's not what happened. So if there could be some kind of training for, and we hear stories in our office at the Brain Injury Association of people who have been pulled over by the police and hauled out and accused of being drunk and not able to communicate, so we feel this piece of legislation which has been very successful in Texas and Illinois and other states would be a good piece, it would be no cost to the state. If we could get groups behind it.

SANDRA FOURNIER: I'm glad you brought that up, something we are realizing as people are living more and more in the community and less institutionalization, there is a training program out there for individuals with autism done through a grant here in Rhode Island but we are also seeing it, we need to train our first responders in Alzheimer’s disease. And really, if there was some way of bringing these together, I think we could really move law enforcement and just public health in general forward, yeah.

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[46] On 3/9/2016 The Committee recommended that RI H7639 be held for further study
http://webserver.rilin.state.ri.us/BillText/BillText16/HouseText16/H7639.pdf

RICHARD: Exactly. Not all, not all afflictions are drunk or, whatever, I mean, I am a survivor of brain injury. I have a slight balance disorder now and so, if I were told to walk a straight line, I might not be successful at it. Also, I can touch my nose with my right index finger with my eyes close but not with my left, it goes someplace else, my left side was compromised to some degree so I live in hear having heard stories of people beaten up, there was a lady in her 60s beaten up and thrown in jail overnight because they thought she was drunk and she had a brain injury, she tried to explain and they wouldn't listen so I live in fear of being pulled over for any reason I couldn't pass a sobriety test.

FAYE: Like when you donate an organ, your organs, it's identified on the license, maybe some kind of indication on a license or something that would say this person has, you know, a cognitive impairment so it wouldn't stop them from driving but maybe they have aphasia and can't get the words out, something to help them.

ARTHUR PLITT: Does anybody use a medical alert bracelet?

FAYE: We talked about that, the thing about brain trauma is people may not remember to put it on in the morning or even remember to say they have a brain -- and we thought maybe a decal, but, my daughter drives my car. So, just something that would allow them to communicate, they may not remember they have it or be able to say the words. And this TSA agent said if you used the word Parkinson's, we would have done something completely different.

ARTHUR PLITT: He was hard of hearing.

FAYE: Parkinson's and hard of hearing.

RICHARD: He was hard of hearing.

FAYE: Yeah. I don't know if you have ever experienced anything like that, but the first responders and, they just sometimes they just don't listen. They think you're drunk and they just don't want to hear another excuse, I'm sure they have heard it all and we understand that so if there was some training and some identifiable way.

MALE SPEAKER: Work with the Alzheimer’s and the other issue like that, a way to identify it on the license so the officers know by just looking at the identification what the issue would be.
SANDRA FOURNIER: Sorry, I am a public health nurse, without even having an identifier, our first responders should know how to treat people in a culturally competent way, as health care providers are, I know I work with a lot with the Brain Injury Association; we need to train people better. If we're going to not have people living in long-term care settings, we need to train our public responders better. No matter what the disability is.

RICHARD: Exactly.

KATHY McCABE: It does seem that the two pronged effort may be better, the training and some kind of an identification. You can't assume everybody who is trained will totally pick up on things. But, I don't know, it just seems that it's not a lot to ask for.

SANDRA FOURNIER: When you look at the minimal amount of training that our first responders get on these subjects it becomes evident.

RICHARD: Especially with brain injuries although survivors have a lot of issues with, they all, can identify with, there are many individual issues as well that each person has very individual to their own brain injury. And then, so, memory might be an issue, speech might be an issue, there might be many other issues they themselves only seem to be the ones that suffer in this manner so they need to be able to identify.

FEMALE SPEAKER: And they look very normal.

RICHARD: It's a hidden illness.

MATTHEW BLAIR: Was there a bill proposed this legislative session about training first responders.

FAYE: No this would be the first time, the one introduced was the high school concussion act, that high school, some states have done all sports, little league, and any sport has to have a trained professional on the field so if there is any kind of a head injury they know how to respond to it. Right now there is nobody there on the field. And that was what I had said earlier. The word I was thinking is appointment; we would like gaining appointment on this Commission. We sit on the brain injury trauma commission but we would like an appointment to the governor's Commission on Disabilities. Which I think would be, make sense. I was going to say a no brainer. I am so sorry.

MALE SPEAKER: Way to go, Faye.

DEBORAH GARNEAU: Arthur, what is the process for that?

ARTHUR PLITT: To come before the legislative committee.

DEBORAH GARNEAU: Okay.

FAYE: I think you added somebody this year, I can't remember who it was.

DEBORAH GARNEAU: Okay. All right. Great. Thank you for sharing. Christine.

CHRISTINE D'ANJOU: That's me, it's Christine D’Anjou, I am here as a parent of a 27 year-old but I worked for Seven Hills Rhode Island for 25 years and prior to that I was a special education teacher. I have a 27 year-old daughter, Julie, attends a day program and gets community supports. So, I am actually here on her behalf. She may stroll in here in a wheelchair with her dad later and she will be disruptive, to give you a head's up. I have some concerns I want to put forth, nothing with the agency, it's really more questions to the state. And just things I have observed over the years of my working at Seven Hills, constant funding cuts we have had to services with always more expectations. We want you to do more but we are going to give you less. I have seen this go on for 25 years now and it's at the point now where it's, to me it's become a safety risk for the consumers. The providers don't have enough money to pay the staff well so what you get is real unqualified staff, some that aren't even willing to be trained or the turnover is incredibly awful so it does directly impact on the consumer here. One of my key things to put some more money into that direct support hours, I don't know how you would do that but -- also, medical equipment. Just, it seems to me it's gotten a little bit more difficult lately to access. I know you pick from United and Neighborhood, and I happen to have chosen United but my daughter literally out grew her wheelchair within six months of a new chair, it was a medication thing, switched meds and she gained about 85 pounds so the chair now is about four years old and literally unsafe, it does not meet her weight. And we have to jump through hoops just to get either a newer chair, or modifications to her chair. It's been months and months of another PT eval because it hasn't been the five years. So I don't recall having that much difficulty before when she was younger. I am not sure why that is.

KATHY McCABE: Is your daughter employed at all?

CHRISTINE: She is not. She goes to Seven Hills now to the day program where she does get out in the community. She also has 20 hours of community support. So like the after work hours. They kind of work on her skills to become more independent. But at this point, she has tried a couple of little jobs. She needs absolute full personal care. She has a significant seizure disorder, right now that's controlled but not always. She has disruptive behavior disorder. She has been hospitalized before. And she's very limited cognitively. On, and on, and on. You will see if she comes in. She, our goals for her are to be happy, do something meaningful, become as independent as possible, and to be safe. We're not looking for her to be a rocket scientist. At this point, and I understand like the whole consent decree and the whole push to get people to work and that's great. I think it's very appropriate and perfect for a lot of the folks that we support, but, not for all of them. So that's my other concern is that I think they should be looking at every single level of need and what the consumer is most interested and able to accomplish versus the government telling us what they think our kids need to do. Or our adults need to do. I think they really need to look at that. We have a lot of Julie and her friends a lot of them like to socialize at the day program. That's really their only way of getting socialization on some level. So, I have heard and I don't know if it's true, but other states that claim to be successful in this employment thing, what I understand and again, I am not sure if it's true, is that the success is great for two or three days during the week because the money goes toward all that support to make that happen but the rest of the week they end up home so moms and dads have to leave their jobs. These are people that can't stay alone, obviously. So that's just a fear that I have. I just think it needs to be looked into more on an individual basis than everybody has to do this like the pendulum has gone ridiculously too far. But I feel, very strongly that the money that it would cost to manage all of that would, my ex-husband and I would probably both have to quit our jobs to care for her full-time, then we couldn't afford to pay anything which would cause us to be depressed and cause us not to be able to care for her effectively which would end in emergency placement which would cost the state a lot more money, you get the picture. As much as we want her to be independent and do what she is able to do, I think there needs to be some balance, some happy medium, and that's all. She did receive HBTA and PASS through all of her, I actually started the children's program at Seven Hills many moons ago when it first started and I just recently was promoted to director of compliance and quality assurance for the whole agency so that's all of our adults programs, as well. So I am starting to see the effects of the poor staffing because of the poor funding. Just the stuff that happens. I have only been into it for two weeks and I'm already like ahh.

SANDRA FOURNIER: If I can comment.

ARTHUR PLITT: Well, if you have a question. We're in the really supposed to comment.

SANDRA FOURNIER: I do have a question. The consent decree, seems to mean a lot of different things to a lot of different people and I am wondering how much education you have received on the consent decree.
AUDIENCE MEMBER: Read some of it.

SANDRA FOURNIER: I have read it thoroughly, and a lot of people don't understand the consent decree. It does not mean everybody has to get a job. There is a lot more in it than that.

AUDIENCE MEMBER: I think it's more they need to get out of a center based, what some, for some people that is the only place that they get that socialization. So I think it just needs to be looked at a little bit further. Before it's in stone.

DEBORAH GARNEAU: So individualized programming, you know, working with a plan.

SANDRA FOURNIER: Person centered.

AUDIENCE MEMBER: When she was getting PASS, HBTS, it was her and her worker so we started hooking her up with community things but she needs to be around people with similar needs, or not, she just needs to be around people and I think sometimes if you do a lot of the one-on-one, it takes that away.

SANDRA FOURNIER: Another question, will the HCBS waiver affect PASS and HBTS?

AUDIENCE MEMBER: We'll see.

SANDRA FOURNIER: The final rule for that is out now.

CHRISTINE: I don't know how that's going to go, to be honest. I don't know. I need to educate myself more but I am just expressing, just the surface.

DEBORAH GARNEAU: We appreciate your comments. A couple people came in but didn't checkoff they want to speak.

WILDER ARBOLEDA: I am from the city of Central Falls, here with the planning department. I am here to hear to listen to information, something we are focusing on is making sure there are enough ADA accessible buildings so essentially I am just here gathering as much information as I can again to make it more accessible for everyone. Thank you, by the way, for asking.

DEBORAH GARNEAU: Okay. And Mark?

MARK THERRIAN: No.

DEBORAH GARNEAU: Okay. Joseph, did you want to speak?

JOSEPH BRUZZI: No, thank you.

DEBORAH GARNEAU: Are there other comments from those that are here, anything else that you have thought of?

DEBORAH MASLAND: Deborah Masland, again, as a mom, Christine, was speaking about what the consent decree means to professionals and to parents and the fear that comes out when we hear bits and pieces of information, and as I was saying before, I work at a community organization where we actually try to help educate parents and care givers and individuals about when these things come out and we hear a lot of this a lot of the time about the miss communication and people making decision base the on that. Something else that's very concerning that I have run into recently are the changes in the CEDARR program that's come up where there is a real confusion by other providers and professionals, doctors or whatever, that are still, they still have not caught up into the new CEDARR so I am just wondering and I know there has been a lot of effort on behalf of the state to get information out but somehow we are still missing the mark hitting all populations with this and I'm thinking if Christine is missing something, works in the system, 27 years she has been doing this and I have been doing this for a long time myself and we are still missing things or it's information overload. In my case I focus on one kid at the same time, something comes up, okay, I have to do this. I have a lot of fears about Olivia going, as she goes into adult hood what will her life look like and will she be able to have that individual level of care and will the money be there for her to do that. We'll do our best.

ARTHUR PLITT: Has the transition planning started besides having an ORS.

DEBORAH MASLAND: Yeah, through the school, I have to say the Cumberland high school, public school has been great, through her whole education, preK during transitions in between going preK to kindergarten, elementary to middle school, middle school to high school. High school has been our best experience which I am shocked about. Because it's my first child it's been the best experience and in some ways she is my easiest kid because of the level of support we've accessed because it's so obvious she needs it, it's when kids fall between cracks or seem to be typical yet have needs that are more hidden that you very well expressed, that's where you won't, that's where you don't get the support.

KATHY McCABE: I was going to say, I think we're all learning about this consent decree, at work in progress. At ORS there is a certain group of people working with the clients or involved, I am not one of those counselors but by the same token, we are all learning about it but there isize still a lot of, I think, it's a learning curve.

DEBORAH GARNEAU: Other comments or concerns? If not, we can take like a five-minute break until others join us but we can have more informal conversations that aren't necessarily on the record.

DEBORAH GARNEAU: Okay I'd like to open back up. So again, this is the Governor's Commission on Disabilities and public forum, time to hear testimony from the community. And Daniel, would you like to share something with us?

DANIEL: No, thank you.

DEBORAH GARNEAU: Okay, sorry, anyone else that wants to share anything? Okay, sorry.

ARTHUR PLITT: I will speak up. I have been at several meetings that there is some significant concern and confusion about neighborhood health leaving the exchange and they also offer a commercial product of insurance. And with some of these parents who have kids on Neighborhood and some of the providers of services do not accept Neighborhood Health. Will they have to switch to United or somebody else in order to have continued service from the exchange? And, I don't know the answer. But it does seem to be of significant concern and I think rightly so in this day when insurers are changing rapidly and sometimes it's difficult to even understand what changes on a year to year basis, much less on a.... So I think there needs to be some attention, probably from the underfunded health insurance commissioner. I think that's her title. And the other thing, which I think has been mentioned at some of the other forums, but the transition for adult children, well, children to adult and day care, that again, let's say we talked about underfunding and a lot of the providers are either full up or they are unable to provide any continued care, seems to be an ever growing problem. Even some of the group homes that seem to be closing because of the underfunding are, I think, affecting those in transition. I think we sort of heard from a prior commentator that there was concern about her daughter and I think that may be a larger problem in the future. Perhaps somebody else in the audience might have some concerns?

DEBORAH GARNEAU: Okay. So we can go off record again for a bit, and when somebody else joins us, we can open back up.

July 28, 2016 Middletown Forum

ALYSSA: My name is Alyssa. Linda Ward was originally going to be your moderator today; unfortunately, she is sick. You're stuck with me. Please bear with me because normally I don't do this. The rest rooms are right outside of these doors. We do have assistive listening devices available. We also have CART reporting and American Sign Language interpreters over here if anybody needs them. Because the CART reporter will be putting together a transcript, we ask everyone state their names and speak slowly and clearly. So the purpose of these public forums is to identify the concerns of people with disabilities and their families in order to assist the state in developing programs to improve the quality of life with people with disabilities. To insure everyone wants to speak gets a chance, normally we ask that you keep your comment short, but we don't have that many people here today so don't feel like you need to cut yourself off. If you have a critical problem that needs to be addressed, the panel members will be available at the end. After the forms are completed, the agencies will review the testimony and prepare recommendations that will be posted on the website by the end of November. The recommendations and the transcripts will be printed and sent to state and congressional officials and the members of the general assembly. They'll be used to develop policy and initiatives for the next year, or until they are accomplished. Do you want to say anything?

ANNE MULREADY: I'm from the Rhode Island Disability Law Center, and I have two flyers we left on the table. One is a pretty simple flyer on voting information for those of you who may be registered, or not are yet registered. This, being an election year, you want to register. There are some deadlines for when you need to register and some information on how to look up where you vote in the back. If anybody needs help, I'll be happy to talk to you afterwards or during a break. And we also have, we're trying to highlight another opportunity where you can give important feedback. The state Medicaid agency is coming into compliance with some very far-reaching federal rules about community-based home services. So those rules really were intended to help states implement Olmstead. So they're really supposed to help states make sure people who are getting Medicaid in the community get their services in the most integrated setting. So if you receive Medicaid services in the community that are considered long-term care services, services people with developmental disabilities get, people on a personal choice waiver, people who get homemaker services at home, and you have an opinion about how community-based services are: Good, bad, or indifferent, there will be an opportunity coming up in September to comment on that, and you can also personally comment if you'd like to people listed on this flier about your experience. Right now the state is talking to providers about; I don't know you how they're going to come into compliance with the rules, providers have several years to do so, so they're not out of compliance, but they will be required to come into compliance. Those who are out of compliance, we don't know how many that is, but it is really important that people who use these services, their voices heard in this process. So if you do, and you have thoughts about whether your services are community- based or could be more community-based there, will be some opportunities to talk about that. So there's a flier we put out and also other organizations joined us, it's not just our flier, and I'll be happy to talk to anybody who is interested in this afterwards, as well.

ALYSSA: And panel members, if you can introduce yourself and agency you're from.

COLLEEN POLSELLI: Colleen Polselli (Inaudible).

RORY CARMODY: Rory Carmody, acting chair, actually, now.

KRISTEN LIVESEY: Kristen Livesey, with Office of Rehabilitative Services.

ALYSSA: So we are going to get started with the people who signed up to speak. And again, if everyone could state their full name and the town they're from for the CART reporter.

ANNETTE: Because I'm always so quiet. Thank you, I walked in and I saw your name, and was, like, no it's not connecting.

ANNE MULREADY: None of us match.

ANNETTE: Thank goodness you said what it was. Yeah, I have two things that I would like to bring up. Of course this is another election year, and are we doing anything about voter ID, to get rid of it, to change it. Because I think that it doesn't affect me personally, but I know a lot of people, particularly those with mental health issues, who, you know, getting the ID while it seems like it's not a problem to people that don't have the problem, but for those that have the problem it is a barrier, and it's a big barrier, and I feel that the voter ID law discriminates against these people, people that are disadvantaged, and it bothers me a great deal. I think after the Civil Rights Legislation in the '60s, this should be considered unconstitutional, and I don't understand why it's still allowed to go on. So that's one. The other, my other comment is, the City of Newport, which manages to find new and innovative ways to create new barriers. I mean, they did a good thing, put an elevator in city hall and it only took 15 years to get that, but every time they modify an area, they've made it more and more difficult, more and more challenging for people with disabilities to get -- so, for example the new design on Broadway where the parking is, it's all stones. So you can't park a van there, because you're ramp will get stuck, and you'll not be able to get in or out. And then they turn around, there is a van accessible spot across the street, which only leaves you the room to open your ramp right in the middle of the one lane of traffic. So

Accessibility

essentially, there's no cripples allowed on both ends of Broadway. They think it's not a sign, they think it's not discrimination, but it's much more effective than a sign because you can take down a sign, you can ignore a sign and these are barriers that cannot be ignored. And we try to get involved in the early discussion and nobody really wants to hear it. They're going to redesign the bus station, they're going to redesign the area behind the courthouse, and it's the same people that have been involved in the design of Broadway, and Washington Square that are going to be in charge of those. So, essentially, we're not going to be able to do anything in Newport. This really needs to be addressed. I don't know how to get that done. I've spent years fighting with them, and I don't have any idea. The only thing that ever worked at all was a legal challenge, and that leaves a bad taste in everybody's mouth. But, you know, we are actually less accessible in Newport now than we were 20 years ago. So, if anybody's got any answers to that, we need to find a way to deal with that.

RORY CARMODY: My first question about voter ID, I know the Secretary of State is opposed to the voter ID law and has made promises of looking to get that rescinded.

ANNETTE: It would be nice.

RORY CARMODY: Newport, I think we can ask Chris, one of our ADA coordinators, to take a look at the planning, how it goes into place. Not only parking, but curb cuts, crosswalk signals, and making sure they're including those in the architectural plans to make places more accommodating.

ANNETTE: They ended up meeting certain elements of accessibility, but when they string them together, they're totally inaccessible. And I think this is where a lot of that is coming together. They keep telling me they're consulting him on every step. I know Chris, this is not his work. Trust me, it is not his work. It is not a reflection of what he would recommend. But you know...

COLLEEN POLSELLI: They need to see it as an economic development.
See it as accessible, bring in more people.

Accessibility

ANNETTE: I've been trying; I've had incidents like this every year. This summer at the tennis matches, I met a couple from Tasmania and they found Newport so horribly inaccessible. She could not manage the sidewalks in Newport. They, she was riding her wheelchair -- she has a power chair -- in the street, and actually hit a hole, and if her husband hadn't been able to catch her, she would have gone over. They found one restaurant that they could get to from where they were, and that was the only one that they were able to go to and they could not do any shopping. The only place they could go is the tennis matches, which is a pretty accessible place. So I've actually been trying to talk to the people from the Tennis Hall of Fame and the people from Newport, trying to talk them into leading some kind of movement to make the city more accessible. Because they have the commitment and they've done it. But nobody else in the whole city has the commitment. There's no real willingness. They don't want to look at it ahead of time. Then after, they say, "Well, it's too late."

ALYSSA: Thank you. Robyn.

ROBYN CHAPMAN: I'm Robyn Chapman from the Brain Injury Association of Rhode Island. Our organization, we've been around for 32 years, but really the last two years has been breaking ground and our staff has grown from three people to five in the office. Part of that reason is because we've created an advisory committee that is staffed by survivors and caregivers and we also have a development committee and we have caregivers and survivors on the committee. We have different goals we're trying to reach. My job is I do fund-raising, community outreach. We do things for; we got a grant through the state, which helps. Doreen Grasso, our concussion coordinator, her job is to go to schools and do impact testing and talk about safety. We hired a survivor, Richard Nudo (phonetic), who does the research center. We have a research center for people who want to give us information so we can pass it along to the survivors and caregivers for resources. We also found that some of our resources need to be updated. So, with your, some of your help, with phone numbers, agencies, we want to make sure that that information is proper and it's available to survivors, professionals, and their caregivers. We hired Faith Zuckerman; she does all our marketing, and also the communication piece. And so he is we're out there trying to get legislation. These are the three points that the advisory committee would like me to bring up: One: The Brain Injury Association of Rhode Island would like legislation that would add the BRARI, to add appointment to the Governor's Commission on Disabilities. Second: We want legislation that aims to protect high school athletes by requiring all school districts to have an athletic trainer[47]. And athletic trainer is different than a coach or a director of athletics.

Accessibility

Education/Employment

Their job would be that they're at all -- they can't be at all the games, but they would be on-site, and if somebody had a concussion, then that athletic trainer would say, "Yes, he needs to go to the doctors," and the parent or coach can't say that kid needs to go back in. Safety has to come first, and so it's very important that we can try to get these athletic trainers. It's heard before the House Committee on Education and Health and Welfare, and to help further study that had no opposition, but no society to advocate for that. And then the third is: It's a story about a woman who had a TBI. She was driving in Texas, a police officer pulled her over, this was outside of Houston, sorry, Austin and he stopped her thinking she was drunk. She was explaining to him, trying to explain to him, that she's had a TBI and wasn't drunk, was on medication, and he didn't want to hear it. And so what happened was, he pulled her out of the car, through her on the ground, and gave her another

Education/Employment

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[47] On 3/9/2016 The Committee recommended that RI H7639 be held for further study http://webserver.rilin.state.ri.us/BillText/BillText16/HouseText16/H7639.pdf

2010, R.I. Public Laws, Chap. 22 (HB 7036) Requires the department of education and the state department of health with the Rhode Island Interscholastic League to develop guidelines for informing and educating coaches, youth athletes and their parents or guardians about the risks associated with concussions, including the risk of continuing to play after sustaining a head injury. Among other provisions, this law requires all coaches, volunteers and trainers to complete a training course in concussions and traumatic brain injuries. This law also requires youth athletes suspected of sustaining a head injury to be removed from play and not return until cleared by a medical professional.
http://webserver.rilin.state.ri.us/PublicLaws/law10/law10022.htm
2011, R.I. Public Laws, Chap. 237 (HB 5540)

Amends current law to require coaches and volunteers to complete an annual refresher course in addition to the already mandated training course. This law also encourages school districts to have school nurses complete a training course and authorizes physicians to consult with an athletic trainer when determining whether to return a youth athlete to a practice or game. http://webserver.rilin.state.ri.us/PublicLaws/law11/law11237.htm
(Accessed August 2016)

concussion. So, this gentleman, Mr. Bill Ruth, has started this in Texas where they got a law passed to have law enforcement training, and first responders, in certain persons who are affected by a trauma. We are asking for the establishment for training programs in law enforcement[48] and first responders that provide information on veterans with combat-related trauma, PTS, PTSD, or traumatic brain injury. And so, with the advisory committee and working with Bill Ruth, we are going to start coming up with a plan and how we can come forward and getting the, or our legislators, to see and to listen to. Because I think one of the things that are very common is that we heard not just if you're driving along and you get pulled over, one of our survivors had told us that he was so nervous he was driving and there was a police officer behind him and he actually pulled over. So the police officer turned lights on and came over to him and said, "Why did you pull over?" He said, "Don't know, I thought maybe you were going to stop me." And part of it is that the fear of him not understanding that maybe he's doing something wrong. And then there was another incident that happened, matter of fact Fay's sister who has Parkinson's and has brain cancer, and this happened, actually, in Providence. She was told to put her hands up and because of her Parkinson's. She was shaking, and they were yelling at her to stop shaking. And in the meantime, Fay's trying to explain to the security she can't and he told her to be quiet and continued to yell at her sister and said, "Listen, if you don't calm down, we're going to have to put you in another room and we're going to --" I'm sorry. "You know, make sure that nothing's going on." And then finally after 30 to 40 minutes, after all these people were watching behind her, it was embarrassing, she took her sister down and came back and explained to the gentleman, "What are you doing? Obviously she has a disability. “And we need to be more conscious of how we're treating people with disabilities[49], and with TBIs or ABIs or a veteran who may be going through security. There are a lot of things we're trying to accomplish. It's a lot of work, and with your help I think we could help our survivors, caregivers, and families.

ALYSSA: I'll talk to you after about some of the outreach stuff, because that's what I do for the Commission.

ROBYN CHAPMAN: I don't know how long it's going to be (Inaudible).

COLLEEN POLSELLI: Are you able to link your website to other state agency websites?

ROBYN CHAPMAN: Yes.

COLLEEN POLSELLI: Are they linked?

ROBYN CHAPMAN: Right now, I’m not sure, because we're working on our website. If not, we can definitely get that taken care of that. The Governor's Commission was supposed to go with the police training. We focus a lot on sensitivity and where you might think is. Could be anything from (inaudible) they're getting information within the training period but obviously they obviously need more. Bill Ruth did pass the law in Texas. Now, he's in Boston, but he would like it to be national. So we want to be part of the first. Let our state be, let us be the leader. So, I think it will be a great thing. I can definitely give you my card.

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[48] 2016 RI Public Law, Chapter 93, (S2401) Section 42-28.2 -Police Officers – Commission on Standards and Training was amended by the General Assembly, and enacted on 6/17/16, to include section 42-28.2-8.3. Educational requirements – National certified mental health first aid training. http://webserver.rilin.state.ri.us/PublicLaws/law16/law16093.htm

[49] See Table 2.1

COLLEEN POLSELLI: I can make sure you have that, special needs registry website.

ROBYN CHAPMAN: Thank you so much. We have another panel member.

CASEY GARTLAND: My name is Casey Gartland. I apologize for being late.

ALYSSA: That was all that I had who had signed up to speak when they came in. Would anyone else like to speak, have a comment on what we've been talking about? I just ask again that you state your full name, please.

PATRICIA GUNN: My name is Patricia Gunn, and I have two children with disabling conditions, mental health related. And I just have met an area of disconnect with them qualifying for services for their disability, which they're both on social security disability, so that's been determined that they need it to that degree.

Before the onset, they had been to college and performed very well in high school and later on, but then came, you know, up and down when they had their break then they will need medication for the rest of their lives, and it seems that people look at them and judge maybe that they're really not mentally ill, and they have severe mental illness that they need to take their medications and have access to it and I don't understand at what point does the Medicaid services determine making it that they don't qualify for any Medicaid program to help them get their medicine. Psychiatric drugs are very expensive and the care is, also. So, I'm thinking that, on many private insurances they put a limit on how much they will cover, and I am hoping that Medicaid is, would continue to be a safety net. With them working in the community; is that the role of Medicaid?

Healthcare

ANNE MULREADY: I'd be happy to speak to you afterwards because there are a lot of different areas of Medicaid and sometimes if you don't know which one to ask for you may not get it. So sometimes if you don't ask in the right way you may not find out you're eligibility. Hopefully that will be changing, but sometimes that still happens. I would be happy afterwards to give you my phone number and we can chat.

PATRICIA GUNN: Okay.

KRISTEN LIVESEY: Are they working with the Office of Rehabilitation Services?

PATRICIA GUNN: They have employment. My daughter's panicking right now. They said she doesn't qualify for Medicaid, so, you know, is that immediately cut? She can't work, or before she starts, it gets bigger and bigger like, a snowball.

ANNE MULREADY: So I can say, there are programs that help people who work stay on Medicaid for that reason. Sometimes people have medical accounts, which even part of the insurance if they're working, and might get covered through their employer, isn't going to cover. There are other ways to get on Medicaid, I'd be happy to talk.

ALYSSA: Thank you. Would anyone else like to speak?

Housing

CAROL: I use an alias, because this information is put on the Internet, and it's a privacy issue, because I've been asked in the past some personal things. So you can call me "Carol." I'm here today, as I am every year, to talk about the major life activity of breathing. Specifically housing to protect persons with cardiopulmonary conditions triggered by second-hand smoke and other, what the CDC considers gaseous contaminants, including deodorizers and fragrances. Last year, I informed everybody this wonderful report: Changes in the air from 2014 from the Department of Housing and Urban Development[50]. And I'll just go through a couple of the quotes, as we never seem to get anywhere with this. Basically they say Secondhand smoke, since 1992, classified as a class A known carcinogen causes health concerns for all individuals, but particular children, pregnant women, and people with chronic illnesses, such as heart disease and asthma. Adults who breathe in secondhand smoke experience immediate adverse effects on their cardiovascular systems, which can trigger heart attacks. It triggers asthma attacks. The chances of lung cancer increases 20 to 30 percent, and even in people who have never smoked. The surgeon general concluded the only way to keep children and adults' safe from secondhand smoke is to ban all smoking can indoors. The report further in very easy language goes on to state that the movement of secondhand smoke, between units, cannot be controlled in multi-family buildings. And that ventilation and other air filtration technologies cannot eliminate the risks caused by second-hand smoke exposure. The report continues to state that the elderly and disabled are especially vulnerable due to chronic conditions and inability to escape secondhand smoke. Smoke free policies help provide housing with individuals with conditions with asthma. Housing accommodation provisions for mobility, vision, hearing, intellectual, and emotional impairments are inadequate for disabled persons with cardiopulmonary impairments. I've been asking at least for as long as Annette has been asking for accessibility for her disability, for housing for people who cannot be impacted by secondhand smoke, and other gaseous contaminants. I researched the Rhode Island Housing Resources Act of 1998, wondering why nobody's paying attention to this, and I found in the title 42 that, "Housing is not --" hold on. "Public health and safety are impaired by poor housing conditions, poisoning from lead paint and respiratory disease, asthma, are significant housing related health problems in Rhode Island." It further goes on to say: "Rhode Island, unlike most other states, does not have an agency or department of state government with comprehensive responsibility for housing." So, I will, again, ask, going on my second decade, why we're being discriminated against. We cannot even have housing where we can breathe free from secondhand bad habits of other people, why we have to deplete our resources with medication, expenses, to try to manage this. Why the state isn't doing anything to help us? I'll give you an example. This winter, due to the secondhand contaminants in my apartment, I developed bronchitis and was bedridden for three months paying out-of-pocket for prescriptions. No caretaker, no assistance, no Medicaid, or anything homemaker assistance would provide. Years after waiting on the wait list for the one tax credit property in Rhode Island, I got called saying I was at the top of the list in February. It didn't seem to matter, I was bedridden, and I had to go down there and immediately view the apartment and make a decision, in the middle of February. So I did, and I told them, honestly, I'm too sick to even consider a move right now. I should point out that Newport Heights is a smoking property, so you got the secondhand contaminants coming through the walls. But, so I told them, I need to be put back on the wait list until I am well enough to consider a move. Well, won't you know it, at the end of the mother I got a notice from them saying they were going to remove me from the wait list I had been on for, I don't know, five years or something, and I'd have to start the process all over again. I followed the instructions that they gave me as far as notifying them that I was too sick

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[50] http://portal.hud.gov/hudportal/documents/huddoc?id=SMOKEFREEACTIONGUIDE.PDF

and I needed to be put, you know, on the wait list, maintaining my position for the apartment until when I was well enough to be able to go and look at it and handle a move. I also discussed my handicapped status with the representative from the property management company who advised me that you don't really want to put down that you're handicapped or ask for accessibility or accommodations because then you're often times not called at all or ignored or whatever. So, I lost my place and the only tax credit property on the island; which isn't accessible anyways because of the secondhand smoke. Anybody who knows anything about real estate in Rhode Island knows that there are no affordable apartments. Certainly not anything that HUD considered in their fair market rent range. It's (inaudible) effort to get anything above their payment standards. I've spoken to people until I'm blue in the face about the process, so it just doesn't matter. So I continue to be in a third floor apartment, which I'm taking physical therapy for the arthritis in my knees now because I cannot do stairs I have no one to help me up the stairs with my grocery, I have no protection from the secondhand fumes from the other apartments, and I have a hopeless situation. The only thing, the only reason that I stay there is because its $900, so it's within HUD payment standards, and the landlord hasn't kicked me out yet. But, it's not accessible, and every year I come in here with this data, with information from the experts. I mean, you can't get much higher than HUD for housing, and you know the faults with our system that nobody's paying attention to this as stated in our own title. And I just go why? On another note I wanted to point out if anyone has not seen the movie Life Animated yet, it's beautiful story about Autism, and how somebody, a person who wasn't speaking regained his speech and his ability to function in society by listening to Disney films and connecting with the animation and the way that they open up their emotions and everything. And now the fellow lives in the Cape in his own apartment, and he's working, and I think that's wonderful. I wish I could find a Disney movie that would help me communicate to you all why something as simple as an accessible apartment for a cardiopulmonary impaired person with now with arthritis isn't as important as somebody with another disability. And the final point I want to make, I bring this up every year, you have a blurb in here which I find offensive. It says, "When attending the forum, please use unscented personal care products. Mild fragrances can constitute toxic exposure for a person with an environmental illness." First of all, nobody pays attention to that. Everybody comes in fragranced here, you can tell in my voice, its cracking. It's affecting my breathing, even on medications. I would ask once again that you change the verbiage that the American lung Association Uses in their better breathers flier[51]. "For the comfort and safety of all please refrain from wearing scented personal products." Thank you.

ALYSSA: Thank you. Okay. Anyone else who would like to speak? Okay. We will take a break, then, and if anyone changes their mind and decides that they would like to add a comment, just come find me. Thank you all for coming
(Recess)

ALYSSA: We're going to reconvene for a few minutes. We have someone else who would like to speak.

MELODY O'BRIEN: My name is Melody O'Brien. I'm the mother of an Autistic child. I wasn't sure if this was the right forum. When he was diagnosed at two years old, I had to leave my job to deal with early intervention, PT, OT. My job was not cooperative as far as time off. My husband works third shift, so our schedules are hectic. With that being said, we had to file for Social Security for our son, so he gets SSI. We have now become a low income family because

Housing

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[51] http://www.lung.org/assets/documents/better-breathers-club/Better-Breathers-Club-Packet-Flyer-1504-FFS_v3.pdf

my income was the primary income in our family. When that was taken away we had to move into income-based housing, Section 8. My question is, I'm kind of, I don't understand why his Social Security benefits, cash benefits go towards our rent. And the reason why I say that is if one of us were to have passed away and he were to get survivor's benefits, that wouldn't be included as income. If he worked a job under the age of 18, that wouldn't be included into our income. But because he has a disability and has income to go towards what he needs, that's considered part of our income and is taken away, or put towards our rent. My husband, year after year, has rejected raises because if he gets a raise Social Security goes down and our rent goes up. So we're stuck between a rock and a hard place and don't understand what we're supposed to do. I have personally called Social Security and asked if there was any way to keep medical benefits and cut out the cash benefits even though we survive on cash benefits and they told us the only way to continue medical is go through RIte Care and go through there. The problem is we're paying high premiums the two of us there's no way we can pay for an Autistic child to get services he needs. I've emailed David Cicilline, talked to Teresa Paiva-Weed.

COLLEEN POLSELLI: It is because it goes to the testimony. I'm not really -- we're the Department of Health. I think RIte Care goes through DHS.

MELODY O'BRIEN: DHS, yes, I misspoke.

COLLEEN POLSELLI: But I'm not familiar with how the cash benefits and all that work, because just health policy. Do you have any ideas, Anne?

ANNE MULREADY: I think you're also asking the question about what HUD housing counts as income, and is there a way to whittle away at that because it sounds like you need the SSI benefits as well as.

MELODY O'BRIEN: And that's my whole point. My whole point is it's really hard to try to compensate for his, like, he has an eating disorder. So, we have to grocery shop totally separate from what he eats. We do not get food stamps. Only benefits we get is Section 8 and his SSI. It's not like we get supplemented food or anything like. That should be coming out of his Social Security but the majority is going towards rent. Only being a one-income family, it's difficult. I don't know what to do. It's frustrating as a mom because there are a lot of therapies that could be beneficial, horseback riding, swim lessons that medical didn't cover that in this position, we cannot afford. It's like beating your head against the wall sometimes when you ask the person sitting across the table from you at HUD or Section 8 or within SSI, or Social Security and they don't know policy or how to answer or respond to my question. I had people snap at me at the Section 8 office when we've gone for rent adjustments. Try to explain to them if my husband works a five Friday month, that extra Friday, that extra check is taken out of Social Security, but rent doesn't go down so we have to supplement that income somehow. When you don't have any other income coming in, it's difficult to supplement that

Healthcare

COLLEEN POLSELLI: Have you ever called the Rhode Island Parent Information Network?

MELODY O'BRIEN: Yes, I have. And they said that they believe it's because of the fact that it's to supplement my income, so it's considered my income not my son's, which I don't understand that.
CASEY GARTLAND: Social Security could not give you an answer to that question about who it's attached to.

MELODY O'BRIEN: They said, because he's a minor, and it's in care of me, it's considered my income.

CASEY GARTLAND: I see.

ANNE MULREADY: So I think what the real problem is, I can talk to you later, but it sounds to me like you need to sort of think about is the SSI money worth having? Is there a way to adjust your rent, which you've tried to do on your own, maybe there are other way to do it, and through HUD rules, and then if not, is there a way to just have your son on Medicaid. I don't know, sort of compare and contrast if your son were on Medicaid and not receiving
SSI, would that help? It's a form of benefits planning but we don't have that for kids. So, but I can talk to you afterwards.

MELODY O'BRIEN: Okay. That would be appreciated.

SHARON: Suggest you go to RIPIN and talk with them further. They're usually pretty good at working with these things. They're a great organization and set up to do exactly what you're, try to help you through this kind of thing. My name is Sharon. I'm here representing RIPIN. We can talk.

MELODY O'BRIEN: Like I said, I feel it's discriminatory with anybody with a child with a disability. A normally functioning child who gets a job before they're 18, it's not considered income.

FEMALE SPEAKER: There are a lot of conflicts between different policies and they leave people hanging. We're hearing almost everybody here having those.

CAROL: Just to ease your, you know, there's, you learn to -- where to fight your battles, because you lose your stamina after a while. Social Security income is income. It's income. It's income. It's income. Whether it's fair or not, it doesn't matter, that's the rule. You're not going to change that. The thing that you can do with HUD is, you can, do you know about deducting your medical expenses so you have adjusted gross income?

MELODY O'BRIEN: Right. Yes.

CAROL: And as far as getting the treats, like the horse and all that, you got to find grants, you know. I don't know if you saw that movie I referenced.

MELODY O'BRIEN: Yes, we had gone to, when they had the father had given a seminar at Brown, we had gone.

CAROL: Maybe contact them. They're in the Cape. Maybe contact them. They have a different circumstance, they're not low income, they're rolling in dough, but maybe they know of some foundations. I mean, never give up on the weirdest little things. I've been trying to get medication that costs $97,000, and suddenly this year the doctor said we can help you and then came back and said it's going to be $4,000 month co-pay. On Social Security income, how am I going to pay that? Bing, bang, boom, out of the clear blue sky they said call this number, it's a foundation, and maybe they can help you. So, listen, you know, you're so used to getting so frustrated because everybody wants so much paperwork and every ounce of blood out of you, these people took three pieces of data, over the telephone my social security income amount, my doctor's name and number, and my insurance, my

Medicare insurance ID. She said if you wait one moment, I'll get back to you and son of a gun, she did, and she said you've been approved for a $15,000 grant for a co-pay. I'm like I've been banging my head against the wall and it's all the matter of finding the right person and not wasting time on the others. Knowing the rules, what you can deal with, and what you can't.

MELODY O'BRIEN: We've run into big problems with his eating disorder. Because it's not classified as a typical eating disorder, like the three big, Bulimia, Anorexia, or binge eating. Therapy isn't covered under medical. There is a place in North Kingstown called Alphabet Soup, but she doesn't accept his insurance. Its $185 a visit, he needs to go twice a week. His Social Security doesn't cover that.

Healthcare

CAROL: You learn to become creative. Who would ever think that this Autistic fellow could end up in -- I mean, he's in great shape by watching Disney movies. No doctor, no foundation, nobody told them that. They just, you know, dug in and said what can we do here and they found their own way. Don't let yourself get so frustrated because nobody's out there with a bundle of money or support to help you.

MELODY O'BRIEN: And believe me we totally understand that. We've gone through years of the feeding clinic at Rhode Island Hospital, unnecessary surgeries and procedures. There's been a lot. I know this woman has had success rates with children that suffer like my child does, but when you're told the only person you can go to is the Shriner's and they said we don't have funding when you know in your mind they have burn victims or children who have severe disabilities or issues that need more funding than my child only eating three things, you know, every meal, it's discouraging in a way that it's like, throw your hands up. We've exhausted a lot of our avenues.

CAROL: But look at the bright side, you're not homeless; you do have housing. I can tell a sob sorry of somebody who is a six-figure computer executive who spent their entire IRA down trying to get medical assistance, trying to get assistance. The money would have been worth a million dollars now, who's been homeless, unsheltered because can't go into a homeless shelter because of the secondhand smoke coming out of the pours of the typical people there.

MELODY O'BRIEN: I understand.

CAROL: Count your blessings.

MELODY O'BRIEN: We pay out of pocket. My foundation I started, it's not a 501(c) (3). Me and two other women go into the shelter every Sunday and feed everyone there out of our own pockets a hot meal. Believe me; I understand the struggles of everybody.

CAROL: I think that's wonderful, but I think also sometimes we distract ourselves with other wonderful things, where we really to come in like the family on the cape, come in and solve our problem. So, you know...

RORY CARMODY: Is your son in public school setting.

MELODY O'BRIEN: Yes. He goes to Townsend. He does very well there; he thrives. He's not in -- he has Special Ed resources through his IEP, and he's in the mainstream classroom and only uses Special

Ed classroom when he needs sensory breaks and things like that. The cafeteria is overwhelming for him, the sensory overload is too much, so he goes all day without eating until he comes home and he comes home cranky and upset and he's shuffled off to therapy, social group, or PASS, so it's a long day, and it's difficult. As a parent who should be able to juggle working and your child, it's difficult. It breaks, and there's no way to fix it. Sorry.

RORY CARMODY: No, no. Thank you so much for your testimony. Remarkable parents.

COLLEEN POLSELLI: I know you've probably connected with the Autism Project.

MELODY O'BRIEN: Yes. Autism Speaks, Autism Project, we get all of our service through Children and Balance, which is a great resource for us. There's just, it gets to the point where you understand that if your child isn't severe or low, low functioning, and believe me, we thank God every day, it is difficult for what he has.

COLLEEN POLSELLI: I was thinking about the Katie Beckett.

Housing

MELODY O'BRIEN: We can handle what we have. But financially, it's beyond a struggle. And I understand there are a lot of homeless people, there are times where we are close to homeless, and there was a time where both of us were homeless at one point in our lives. We understand what tent cities mean and living under an overpass means. If my child would make out better if one of us passed away and was to receive cash benefits as a survivor. As a tax-paying family, it's disgusting. We don't know -- there has to be something changed here, because it doesn't work for everybody. It's keeping us in a place where, as you said, fair market value housing, when you go anywhere where a voucher they look at you, most of the time, private renters do not want to rent to you. So there's discrimination within that. You go to a place like the Heights or Chapel Terrace where they accept vouchers it's difficult because we're now putting a child who has sensory issues and social anxiety and fear into an area of people who don't recognize that. And he doesn't play outside. He doesn't -- we can't have him go outside and play because it's not safe for him to go outside and play. So it's every angle is something, and one break would be great. Thank you very much for your time.

ALYSSA: Thank you. Anyone else like to speak right now? We'll go back on break then. If anyone else would like to speak, just come and let me know.
(Recess) (Meeting concluded).

July 28, 2016

Harrisville Forum

CLIFF: I think we're going to get started. Welcome. Welcome, everyone on the panel. My name is Cliff Cabral. I'm vice president at Seven Hills Rhode Island affiliate in Woonsocket and Cranston, Rhode Island, and also operate some programs in New Bedford as well. This is my first time as a moderator. Bear with us. I want to go over some housekeeping items. There is a bathroom to the left, and just want to go over sort of some of the ground rules here. The purpose of these public forums is to identify the concerns of people with disabilities and their families in order to assist the state in developing programs to improve the quality of lives for people with disabilities. To ensure that everyone who wants to speak gets a chance, please keep your comments short and to the point. You may have a little bit longer time today. If you have a critical problem that needs to be addressed, members will be available at the end 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 make recommendations, which will be posted on the website by the end of November. The recommendations and transcript will be printed and sent to the members of the General Assembly and used to develop policy and legislative initiatives for the next year, or until they are accomplished. The Rhode Island Disability Law Center's panelist will be available to register anyone who is a citizen and not currently registered to vote where they live to vote, at the end of the testimony. People can also file a change of address if they moved since the last election. I want to ask the panel members to introduce themselves at this time, along with the affiliation.

LEA: Lea Colardo. I'm from the Paul Sherlock Center, an educational advocate. It's located on Rhode Island College campus.

CINDY: Cindy Davis, Director of Social Work for Eleanor Slater Hospital both in Cranston and Zambarano.

KATHY: Kathleen Kuiper, based at the Rhode Island Department of Health in the Office of Special Needs.

KATE: Kate Sherlock from the Rhode Island Disability Law Center. And Cliff kindly mentioned one of the things we can do, in addition to hearing from the public today, is helping people register to vote. And, in addition to that, we have placed a handout on the table that you can collect, if you wish, which talks about ways for the public to comment on Rhode Island's implementation of the new home and community-based services regulations.

MIKE: Mike Lombardi, Office of Rehab Services, vocational consulate.

CLIFF: At this time we want to ask the speaker to introduce herself and the city or town that you live in, please.

MARYROSE MENSAH: Good afternoon, everyone. My name, Maryrose Mensah, M-E-N-S-A-H, section 811 program coordinator at Rhode Island Housing. Do you guys want to know what that program is?

KATE: I would.

Housing

MARYROSE MENSAH: The 811 program is a HUD initiative. It's a federally-funded program. The goal is to get folks out of institutionalized settings back into independent living. That's why I'm here. I figured we could all work together to get that goal in place. So Rhode Island Housing received an award with its partners, BHDDH[52] and EOHHS[53] to house approximately 150 people into project-based housing. So what that means is

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[52] Executive Office of Health and Human Services (EOHHS)

[53] Department of Behavioral Healthcare, Developmental Disabilities and Hospitals (BHDDH)

we will subsidize the units, and the persons who are qualified can move in. They will pay 30% of their income for rent and utilities. In order to qualify, you have to be between the ages of 18 and 61. You have to fall into the 30% area median income, and you need to be disabled. Rhode Island has taken the program a step further in that we are requiring the folks are either coming from the institutionalized settings, group homes, nursing home, prison, any institutionalized setting where someone can deem them able to live independently with services in place, or be chronically homeless and entered into the HMIS system, the homeless management system for the state. We are in the process of getting that program up and running. We have a couple of RFPs out. One is for a software system for us so we can manage the program accurately, and the second is for developers to recruit units. We do anticipate our wait list for folks will be opening in the fall, and we will be housing our first person shortly after that. So it's another avenue that we have to work with your agencies to help get some of your people into more independent living situations.

CINDY: Is this the same that were just for the homeless before? Is this the same thing?

MARYROSE MENSAH: No. Those were Section 8 vouchers. That’s closed now. It's been closed for quite some time. But they do anticipate an opening soon. What that means, I don't exactly know.

LEA: Does the level of disability affect the process when you make reference to if someone has psychiatric needs, as opposed to –

MARYROSE MENSAH: No. As long as a health -- certified health professional from wherever they're coming from can deem they are able to live independently with services, it doesn't matter what the disability is. They need to be able to comply with the lease requirements. That's it.

KATE: I have a question about the ages. You gave between 18 and 61. So does that include 18 and 61?

MARYROSE MENSAH: Correct.

KATE: I just happen to have somebody needing a place who is 61. Is it at the time of application?

MARYROSE MENSAH: Correct. Because -- well, the program is not geared towards elderly folks who have a lot of --a lot more options. So the age range is HUD's guideline, not ours. So we actually will be having meetings shortly with – we meet every month with our partners at BDHHA. We're going to have meetings with the case managers at the facilities that will be referring applicants. So we have 150 vouchers. Hopefully be able to move that along and get people housed.

KATE: When you said project-based, so the vouchers stay with the location rather than following the person. Is that correct?

MARYROSE: Correct. Right now the RFP units, we're not looking to be in one part of the state. It's a statewide program. We are looking for units that are close to amenities. We want people to be able to have transportation to get to doctors or wherever they want to go, to be near grocery stores, parks, libraries, trying to make sure people are not isolated in the independent living. That's one of our scoring criteria for it.

KATE: Is it already existing counseling, or to be --

MARYROSE MENSAH: It could be either.

KATE: Will the housing be mixed?

MARYROSE MENSAH: They're going to be primarily in tax credit developments. There will be people paying fair market, may have other subsidies, and the units will be integrated into the whole development. It will be integrated in. So if you want, I can give you my contact information.

CINDY: Yes.

MARYROSE MENSAH: My name, again, is Maryrose Mensah. My number is 475-1106. That's my direct line. You can call me any time. Any questions, happy to help in any way I can. We also have a lot of other housing programs, so any other questions about that, we can help with that as well.

KATE: Thank you for sharing with us.

CLIFF: Taking a break?
(Pause)

CLIFF: I think we're going to get started again, folks. So my name is Cliff Cabral, the moderator from Seven Hills. I want to let you know the restrooms are right outside to the left. Just a few housekeeping items. 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 lives of people with disabilities. To ensure that everyone who wants to speak gets a chance, please keep your comments short and to the point, although you might have some more time. We have until 6:00. After the public forums are completed in August, the sponsoring agencies will review the testimony and prepare recommendations, which will also be posted on the website by the end of November. Recommendations and transcripts will be printed and sent to the State officials and to the General Assembly, and recommendations will be used to develop policy and initiatives for the next year, or until they are accomplished. The Rhode Island Disability Law panelist will be available to register, if you are a citizen, to vote where you live, at the end of the testimony. And you can also file a change of address if you moved since the last election. So at this time I just ask the panelists to introduce themselves.

LEA: Lea Colardo and I work for the Sherlock Center at Rhode Island College.

CINDY: Cindy Davis, Director of Social Work for Eleanor Slater Hospital.

KATHY: Kathy Kuiper, based in the Department of Health.

KATE: Kate Sherlock from the Rhode Island Disability Law Center, and, as Cliff said, we can help register people to vote. We also put a document on the back table that people can take, and it tells them how they weigh in on the State's implementation of the new home and community-based service regulations.

MIKE: Michael Lombardi, ORS Services.

CLIFF: I'd ask the speaker to introduce herself and spell your name.

DAWN FIORE: Dawn Fiore, F-I-O-R-E. Speak now?

CLIFF: Yes. Make sure you're loud enough.

Independent Living

DAWN FIORE: Um, I guess what I want to most put out there is the difficulty getting disability health insurance to start with. My son has an intellectual disability along with autism, and it seems that it's very difficult getting disability if your IQ is slightly above the threshold, because he is borderline intellectual disability. I think that there needs to be more support for families -- much more support, job-wise, for these kids. I haven't had a lot of time to prepare, so forgive me.

CLIFF: That's okay. You're doing fine.

Independent Living

DAWN FIORE: I just think these kids end up getting into trouble because they have a lot of time on their hands. If they do not have a disability, these kids are thrown basically to the wolves. There are no services out there for these kids. If there is, I don't know about them. If that's the case, there needs to be more done out there to let parents, loved ones, know what is available. Group homes. As far as I understand it, it's all, again, based on disability insurance. So if you don't have that one thing, those kids, where do they go? What do they do? There's very little out there for them. You know, I just think that they end up sometimes getting in trouble with the law, and it just progresses so that they don't have -- they don't have anything to help them move forward. They're either stuck at home with their adult parents, who are getting older, and they're not going to be able to support them for the rest of their lives. Just needs -- there needs to be so much more done for these kids. And I am saddened that I am the only person here, because it's needed. And unfortunately, maybe the people that need to be here are overburdened and can't make themselves available to be here because of that reason. Because there is no help.

KATHY: What age, if you don't mind?

Education/Employment

DAWN FIORE: My son is 24. You know, other thing with jobs, I find its -- they don't train. If they do, it's to be a janitor, it's to be, you know, something that is not going to sustain them for -- income-wise -- to sustain them for their livelihood. You know, they're going to be dependent on someone else for the rest of their lives.

CINDY: You're talking about your son. I know you're talking more about a whole group. Are you hooked up with developmental disabilities?

DAWN FIORE: From my understanding, developmental disabilities, again, you have to qualify for social security, SSDI, to get developmental disability.

CINDY: Did you say he was borderline intellectual? I mean is he considered –

Independent Living

DAWN FIORE: That was just brought forward recently through an evaluation. So I don't know. Maybe I do not understand the system well enough. So there are so many different entities, and I understand you guys do offer good programs, but there does need to be more done, and I think people need to be aware of those programs, but how to get those programs, how to access those programs. What are the qualifications to be in those programs? Most of everybody that I've talked to, those programs, again, in my mind, were always based on SSDI, and they were very little out there. You could get a few things. You could get ORS, get a couple of things, but, in general, the services really were not there for those individuals.

LEA: So it sounds like you're familiar with ORS.

DAWN FIORE: I am.

LEA: He has been involved with --

Education/Employment

DAWN FIORE: He has been involved with ORS. In my understanding of it, it takes a while to get services from them, and I understand they're probably very overworked in a lot of case load, and, again, it's very few and far between. It's for a very short period of time. And then those jobs -- that job ends, and the grant which its under goes away, and then, you know, they're left, again, for a period of time without, you know -- has been my experience anyway.

CINDY: When he was in school, how far was he able to get? Did he have special --

DAWN FIORE: Yup. He had an IEP. He had services all throughout school. The resources I had to fight for.

CINDY: Of course.

DAWN FIORE: But once school ends, again, it's kind of like you're dropped into the --

CINDY: So did he graduate eventually?

Education/Employment

DAWN FIORE: He graduated, yeah, and went to a job core through Groden Center, so he has been through some of those programs. Mostly social skills programs. But, again, I think the vocational part of it is very lacking for children that are in that in between, you know, that are not so severely developmentally disabled that they can't do certain work, but yet, not quite to the intelligence that the average person is, where they could get a career, or – there are those kids in between. There are those children in between, and they are frustrated. I see him being frustrated because he wants to be the normal person. He wants to be that person. However, he does not have the complete intelligence. But he does have more intelligence than just being a janitor, or -- you know, there needs to be something in between.[54]

CINDY: The questions I'm asking, I'm just focusing on your son, and assuming -- please correct me if I'm wrong -- other folks you're speaking about with like issues –

DAWN FIORE: Right.

CINDY: -- and age bracket. Since he was 18, he's done Job Corps, like you said, social skills, and so that's all that's gone on between 18 and 24?

Education/Employment

DAWN FIORE: Right. He has had jobs that he's gotten on his own. They did not work out. It would have been good if he had like a job coach that could be on the job with him, but then employers don't want to hire people with disabilities who have to have somebody else following them around all day long.

LEA: Well, there are employers out there that would hire them. But -- I have a question about how far in the process with ORS. Did he complete a voc. eval?

DAWN FIORE: Yes, he did.

LEA: They placed him in -- jobs? For a short, like a situational assessment?

DAWN FIORE: Yup. He was in -- he went to The Homestead in the very beginning. He has gone to work at Ciro's Pizza.

LEA: Was that part of the voc. eval?

DAWN FIORE: It was after. Yup.

LEA: And then ORS didn't continue their services?

DAWN FIORE: Didn't, like, follow through, kind of, so to speak.

LEA: That's something you probably have to be a little more persistent with.

Education/Employment

DAWN FIORE: Right. Because he's over 18, it tends to be where they rely on them to follow-up, and he was never good with that. So... you know, it would have been really great if there was more communication between them and the parent, and I know maybe I'm an overly involved parent, or -- I don't know. But even though my son is over 18, he still requires that assistance. You know? To kind

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[54] 2016, RI Public Laws, Chapter 331, (H 7890) Section 42-102-10 of the entitled "Governor's Workforce Board Rhode Island" was amended to read as follows: State Career-Pathways System. -The workforce board ("board") shall support and oversee statewide efforts to develop and expand career pathways that enable individuals to secure employment within a specific industry or occupational sector and to advance over time to successively higher levels of education and employment in that sector. http://webserver.rilin.state.ri.us/PublicLaws/law16/law16331.htm

of guide him, because he doesn't have those skills completely. He has some of the skills. I'm not going to say he's totally -- can't do some things, but he'd forget. You know, he'd forget he had an appointment with somebody last week, and if he didn't tell me, I wasn't there to remind him. You know, and I get that that is supposed to be an individual -- they're trying to gain their independence. They're trying to get them to be independent. I understand that part of it. However, I think there needs to be more collaboration between the parents or loved one, whoever it may be.

CINDY: It doesn't always work that way.

DAWN FIORE: Right. To help them, to bridge that gap, because without that, it's not going to be successful. You know? They need that help. They need that guidance. They need someone to call them and say, "Hey, we had an appointment last week, what happened?" You know? He won't follow up with that and not just leave it, you know.

LEA: I was going to ask if he signed a release for you to communicate with them.

DAWN FIORE: Yes. He did. He's very good with that, I have to say. He's always signed releases, and I didn't have any issue. It wasn't, you know, the type that said, "No, no, no, I'm not going to do that." Um, but...

CINDY: They were involved for a while, ORS, and then kind of faded in the sunset?

DAWN FIORE: Right. It started off with Mike, and then handed off to some other person, and I don't know who that person was. But yeah, it kind of just... went away.

MIKE: I'll check with you after. I will get it squared away.

Accessibility

DAWN FIORE: Yeah. So I just think that if there was more follow-through on other services too, that, you know, kids with disabilities, they need more than just a job, more than just -- they kind of need someone to kind of oversee their whole life, to kind of be their manager, so to speak. Like the old-fashioned kind of social service person that would take on got that job or that voc. eval, and make sure their appointments with their therapists were scheduled. There are so many different entities to deal with that I think, as a parent, it's overwhelming. You know, trying to gather information from this person and gather information from that person, and trying to work and do your own thing, and trying to manage your child, and get them to become independent, is -- it's just frustrating. Very frustrating, because I just feel it's such a lack of connection between more than like all of your enemies together. Like take on a case and say, "Okay, we're going to take Eric and do this with him, so and so is going to follow up with this service and that service." So that the services are connected, because that person is a whole person, they're not just a job. They're not just a, you know, the person that needs to go see their therapist. They need multiple entities surrounding them to become successful adults. You know? I guess that's all I have to say in general. That's... basically how I see it.

CLIFF: Could you clarify other services you mentioned earlier on? Residential, group home. Can you clarify the services that you tried to seek out and have not been successful?

DAWN FIORE: I didn't really delve a lot into that because I always thought that he would be living with us for a while, and now that he has become older, I realize it is more important for him to go on his own, but I don't feel comfortable sending him out to a group home or anywhere else for that matter if I don't feel entities are going to be following up on him and making sure he's going to be okay. It's kind of like throwing him out there and hoping for the best. And, you know, I'm just not willing to do that. I want to make sure he's going to be getting certain services and he's not going to be just -- I don't know -- um, not having services when he maybe needs them for certain things, and it's overlooked, because nobody knows. It's like that gap, that –

Independent Living

CLIFF: You prefer he be supported?

DAWN FIORE: Yeah. I would much prefer him to be supported and knowing that he is going to thrive as an independent person, but without the support of different services, there's no way that I see that happening. You know? And it all falls on the parent. It tends to fall on them to make sure that they get those services, and it's kind of sad, because God forbid they don't have a parent involved, or they don't have someone that's an advocate for them, I don't know what happens to those kids. It's scary. It's very scary to me. It just -- I think there could be so much more done for them. How exactly, I don't know the particulars. I probably need to know more about each individual service. Maybe I need to research that a little bit more, and investigate it.

CLIFF: Questions? Thank you.

DAWN FIORE: Thank you. Thank you for listening.

July 29, 2016 North Providence Forum

CASEY GARTLAND: Okay, good afternoon, everybody. We are going to start the Governor's forum today. Before I introduce the panel I want to introduce myself, senior director at Perspectives Corporation, supports individuals children and adults with intellectual and developmental disabilities, I also serve as a commissioner and we are also sponsoring today's forum. Just some ground rules, if you want to speak hopefully you registered if not you still can, if you could speak as cheaper as possible this is all transcribed and at times you will be asked to spell your name. And the other house rule is the bathrooms are out here to the left if someone needs them. And before we get started I'll read basic ground rules. The purpose of these public forums is to identify concerns of people with disabilities and their families in order to assist the state develop programs to improve the quality of lives of people with disabilities. To ensure everyone who wants to speak gets a chance please keep comments short and to the point. If have you 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 forums are completed in early August, the sponsoring agencies will review testimony and prepare recommendations which also will be posted on the web site by the end of November. The recommendations and transcripts will be printed and sent to the state and congressional officials and to members of the General Assembly. The recommendations will be used to develop policy and legislative initiatives for the next year, or until they are accomplished. The Rhode Island Disability Law Center's panelist is available here to register anyone who is a citizen and not currently registered to vote where they live and to register to vote at the end of the testimony, people can also file change of address if they moved since the last election. Another item, I want to elaborate, when people give testimony, it's not necessarily the panel's job to give you an answer here, they may ask clarifying questions which will help elaborate on the testimony but they will not necessarily provide information. That can be done after the fact. Now, our panel.

VICKI FERRARA: Good afternoon, I am from the Sherlock Center on disabilities at Rhode Island College.

JANE CANNATA: From Office of Rehab Services, services for the blind and visually impaired.

BOUCHER: From the Rhode Island Department of Health.

CASEY GARTLAND: As you can see, we have a couple panelists that may walk in in a little bit here. Speaking agenda, first person is Clarence. Thank you very much.

Accessibility

CLARENCE KETTELL: Clarence Kettell. I've been calling RIPTA about how we can accommodate not just me where I live but it cannot connect the dots. I would like bus 27, like once, even once or twice a week, because I know people take the bus, they say if we call one hour ahead or something, work something out, or, I talk to the North Providence mayor about the city bus, we don't have one. Get the Mancini bus drop us off in Centerdale, but Manton Avenue bus where we are, that would be great, only five minutes, they sit there for like five minutes, Centerdale.

CASEY GARTLAND: So, an additional bus route, to take you from what routes?

CLARENCE KETTELL: Bus 27 once or twice a week, only takes five minutes, brings you to stop and shop, family dollar, Wendy's, if not you get off Centerdale, grab Smith Street to go to Aldi's or Popeye's, or grab bus 19 to go to Wal-Mart. No bus from Centerdale to Benny's at all.

VICKI FERRARA: You're trying to get the bus from there?

CLARENCE KETTELL: Centerdale, where the post office is to Sunset, or North Providence police station, fire station, right there.

VICKI FERRARA: So you want to get the bus in Centerdale at the --

CLARENCE KETTELL: From Centerdale bus, Sunset and back down to Centerdale. It's only five minutes. That five minutes, go to Stop and Shop, or Family Dollar, or something, get out. Because, even when you have a bus going to Benny's, or something like that, you have to go somewhere else. By the time I get home I've been trying, but nobody seems to connect the dots.

CASEY GARTLAND: Have you talked to anyone specifically at RIPTA.

CLARENCE: Meetings right here, RIPTA and the mayor, I said we need a bus, for subsidized housing and they go over a schedule, maybe Wal-Mart one day and, or something, we don't have that. Nothing is available for us.

CASEY GARTLAND: Okay, thank you very much. Okay. Thank you very much.

Clarence: You're welcome, sir.

CASEY GARTLAND: Next, Maryrose.

MARYROSE MENSOH: Hi, Maryrose Mensoh, Section 811 coordinator from Rhode Island Housing, I wanted to give an update on our program and where it's at, section 811 program is a HUD initiative which Rhode Island housing received a grant for. To help link folks that are living in institutionalized housing to get back into independent living. It's a nationwide program. And we are in the process of getting it up and running now. There are some eligibility requirements; you have to be between the ages of 18 and 61. You have to be coming from an, a group home, a nursing home, a prison system, or be chronically homeless, high utilizer of Medicaid that's entered in the HMIS system so if anyone has questions, you can direct them towards me, I'm more than happy to keep you up to date with our program and my phone number is 457-1106. Thank you.

CASEY GARTLAND: Thank you. That concludes everybody signed up to speak right now, at this point, if there is nobody else, we will take a break from the program. We are here until 5:30 regardless. Panelist? We were just about to take a break, do you want to speak? We had only a couple speakers and we were about to take a break until more speakers come in

BARBARA POLICHETTI: I am with the Rhode Island Public Transit Authority, just here to answer questions.

CASEY GARTLAND: So we'll take a break right now.

CHRISTINE RANCOURT: She may want to –

CASEY GARTLAND: Great idea. Clarence, would you mind, now we have two more panelists now, would you give a brief synopsis of your testimony again?

Accessibility

CLARENCE: My name and everything? Clarence Kettell, talk about the RIPTA bus situation, I'd like to get bus 27 where we live, only five minutes where we are, because right now the buses are an hour and a half, I understand as of August 28th, it will be an hour, but trying to get bus 27, even once or twice a week, get us out of our facility. But no buses from Centerdale to Benny's whatsoever, or KFC, have to go to Broad Street to KFC, it's too much for me, during the day, I can't even move, it hurts, I have been calling, trying to accommodate the service. $8 for the RIDE bus, I can't do $8. Thank you.

CASEY GARTLAND: So two new panel members came in, any clarifying questions?

BARBARA: Mr. Kettell has been great talking to our planning staff, you have been really good, and we are still looking at it, we do have the increased weekend, we have the weekend service to your location now which we didn't have before but we are aware of that problem it causes you and I know that you have been asking to have a meeting at the housing complex.

CLARENCE: Nobody ever followed up.

BARBARA: We are working with the mayor's office and want to see what fits with him so nothing scheduled yet but trust me.

Clarence: Five years ago, same thing five years ago, I'm up to here.

BARBARA: I'm sorry, not saying trust me, we will restore the service --

CLARENCE: Losing confidence in the system, I have to walk every day in chronic pain, not just me, everyone; it goes back under the rug.

Accessibility

BARBARA: Can't make promises about the service, but I want to let you know where I sit, four of us have your phone number, if there is a meeting we will call you so I didn't want you to think, we haven't forgotten you, but thank you, and thank you for staying in touch with us.

CASEY GARTLAND: Maryrose would you also repeat your testimony?

MARYROSE: From Rhode Island housing section 81 program coordinator which is a program geared to get folks that are in institutionalized housing settings back into more independent living. There are some qualifications for the program. It's not up and running yet, we are in the early implementation stages but in order to qualify you have to be coming from an institutionalized setting, group home, nursing home, prison, or chronically homeless and high utilizers of Medicaid. So we are in the process of getting the program up and running. If you have any other questions or anything would you like to address regarding the program you can call me, my number is 457-1106.

CASEY GARTLAND: Thank you very much. We had someone new come in, should I have them re-testify again? I'm kidding. We will at this point take a break. We are here until 5:30 regardless.

CHRISTINE RANCOURT: Maybe Catherine could introduce herself.

CATHERINE SANSONETTI: Sorry I was late, there was an accident here on mineral spring. I am Catherine Sansonetti from the Rhode Island Disability Law Center, I am a staff attorney there and today we are just here to hear about the concerns of the community which helps us and the work we do, and setting our priorities every year. I brought some information with me, I will put it on the table in a few minutes and one of them is just getting ready to vote in 2016, this is just some information for people about their voting rights. And we also brought something about an opportunity to comment on community integration of Medicaid funded home and community based services. Just wanted to make mention about that. So there is Medicaid funding for home and community based services and the Rhode Island office of health and human services OHHS, is in the process of implementing federal rules that promote the community integration of residential and day services through Medicaid. The rules will help the state to implement homestead's requirement for community integration. OHHS is seeking feedback from individuals and family members about how integrated their services currently are. On the back of this flier that I will hand out and put on the table, there is information on how you can contact OHHS and how to get in touch with them for an opportunity to comment on their plan to make sure their plan is complying with the rules, the new rules over time as they roll out. So again, it's about community integration, it's a subject that is near and dear to many of us and looking for feedback from the community for the state on that. That's it.

CASEY GARTLAND: Thank you. If there is nothing else the panel would like to say, we can break now.

CHRISTINE RANCOURT: Judi can introduce herself.
JUDI DREW: Here on behalf of the governor's Commission on Disabilities.

CASEY GARTLAND: We're going to take a break now, if someone else comes in to testify, we will reopen this for

Email Testimony

August 24, 2015

Aviation Consumer Protection Division, C-75
US Department of Transportation
1200 New Jersey Avenue SE
Washington, DC 20590

I would like to report an incident on a flight I had booked with United Airlines out of the Theodore Francis Green Airport in Rhode Island.

I was accompanying my sister, Claire White, back to her home in Washington, DC on Monday, August 17, 2015, on UA Flight 3590. We were flying from Green to Dulles International. My sister is 78 years old and suffers from medical conditions that restrict her mobility. She has diabetes, asthma, short term memory loss, and a heart condition, all of which require reasonable accommodations when she travels with commercial airlines. My sister was using a walker that evening to allow her to cover short distances without needing a wheelchair.

Flight 3590 was scheduled to board at 7:09 pm, but was delayed for about an hour. We waited in the area near Gate 9a during that time. Only when the flight was announced as ready for boarding were we able to see, while looking through the window while in line at the Gate, that our plane was located a hundred feet from the terminal, and that the passengers had to descend two landings of terminal stairs and then walk those hundred feet and up another set of stairs in order to board.

I said to the young man in charge of boarding that it would be impossible for my sister to manage this, and I asked him to please get her a wheelchair and to show us another way of reaching the plane.

He replied that he not only didn't know where to find a chair, but also that he knew of no other route we might use to reach our plane. I said that United was obligated by law to accommodate my sister's needs, and to please call someone to get us a wheelchair. He eventually got on his phone and tried to do so, but it was evident that he had never been trained to deal with customers in need of such assistance

The passenger boarding was completed while we were still waiting at Gate 9a. We could now see that the flight was fully loaded and waiting on us, but still no one came with a wheelchair. After another five minutes, a young man approached the worker at the Gate and asked him what the problem was. When it was explained to him, he said he would take care of things and instructed us to follow him.

He left at a brisk pace and soon I was about fifteen feet behind him, and my sister, struggling to keep up with her walker, another fifteen feet behind me. After going about a hundred feet towards the end of the terminal wing, he stopped to open a set of doors and he indicated for us to go through them. Just beyond him I saw three wheelchairs resting along the wall and I walked past him to get one.

As I did so, he asked where I was going. I told him I was getting a wheelchair for Claire, who was now struggling hard to reach us, and who was not going to make it much further. He responded by reminding me that the plane was waiting for us. I again mentioned that his company was legally obligated to provide

accommodations to allow folks like my sister to travel like the rest of us, and he told me that he didn't know anything about that, that he was employed by a sub-contractor and not United, and that he was actually doing us a favor – implying that we should be thanking him and not criticizing him.

I helped Claire into the wheelchair and we entered the elevator and it took us down to ground level, but we were now on the other side of the terminal corridor from our plane. I pushed her in the wheelchair a hundred feet or so to where we could travel under the terminal wing and then another two hundred feet to where our plane was waiting for us.

When we reached it, I helped my sister struggle up the gangway steps, and we proceeded to 4A & 4B, our assigned seats. These, we discovered, were already occupied by two other people. We ended up in seats that passengers were nice enough to change with us so that I could sit beside my sister for the flight to Dulles, as we had originally planned when we booked the trip.

I am concerned that there are personnel working at TF Green Airport and United Airlines who appear completely unaware of the Air Carrier Access Act and its rules designed to minimize the special problems that travelers with disabilities face. I would hope that others dealing with physical limitations will not have to suffer through the same disregard for our laws as my sister did.

Sincerely,
Patrick Brady

September 11, 2015

Dear Mr. Brady:

This letter is in response to your customer service experience at T. F. Green Airport prior to your flight to Washington Dulles Airport with your sister on August 17, 2015. I reviewed your letter with the United Airlines Station Manager, and he has investigated this incident and identified several deficiencies in the performance of his and other agency employees. As identified by the individual you spoke with, who stated he does not work for United Airlines, United contracts their gate agents through a third party. Nonetheless, United Airlines assumes full responsibility for the care and handling of its passengers.

Accessibility

The initial agent you spoke with at the gate was a relatively new hire, and although he received initial training with regard to wheel chair support, the employee clearly did not understand his responsibility as an airline representative. The station manager and I both appreciate your persistence in requesting he call someone for assistance. Upon further investigation, the individual that he called did reach out to the agency contracted by all of the airlines for providing wheel chair service, but they were obviously non-responsive. I spoke with the manager of that agency as well, and she apologizes for the poor service and has addressed the importance of being more responsive to calls with her supervisors. The other individual you came in contact with was also a new hire and was obviously more concerned about the flight being delayed and oblivious to the fact that your sister was struggling to move at his pace.

Needless to say, these individuals failed to provide the level of customer service that United Airlines and the Rhode Island Airport Corporation expect. They have been disciplined accordingly and retrained in ADA regulatory compliance and customer service.

Thank you for bringing this incident to my attention. On behalf of the airport corporation I want to extend my sincere apology for such an undesirable: experience. I hope that this experience does not influence your future decisions in selecting T. F. Green Airport as your preferred airport alternative.

Sincerely,
Alan R. Andrade
Senior Vice President, Operations and Maintenance

October 5, 2015

Mr. Patrick T. Brady
106 Cumberland Avenue
South Attleboro, MA 02703-5605

Dear Mr. Brady:
I was sorry to hear about you and your sister's (Claire White) recent trip with us. We always want to provide the highest level of service, particularly to our MileagePlus members, and it's disappointing to learn that you feel we missed the mark this time.

We do not take complaints of this nature lightly; upon receipt of your letter I immediately contacted our Providence station manager to share the details you provided and to ask for feedback from the staff members involved. I am required to share the information I received although some of it contradicts what you have told me.

There was a Special Service Request (SSR) for wheelchair assistance documented in Ms. White's reservation. That SSR identified her as a semi-ambulatory customer who is able to ascend/descend stairs, but who needs a wheelchair for long distances in the airport.

Our ticket counter agent remembers checking Ms. White in for the flight and telling you that we would provide (wheelchair) assistance to take her to the gate as we employ a vendor (AirServ) for that purpose. She said you declined assistance.

Our gate agent said he made several calls to AirServ after you told him that your sister could not descend stairs and would need a wheelchair for boarding. When our vendor did not respond, the gate agent called our operations agent for help. Our operations agent arrived at the gate and told the gate agent they would wait a few more minutes for the vendor to come, but if they did not, he would provide the service. Our gate agent also said that he was speaking to our operations agent when he said that he did not know where to find a wheelchair. Please understand that the airport wheelchair vendor is in charge of airport wheelchair equipment and they do not typically stage a wheelchair at each gate, so our staff would not know where to find a vacant wheelchair.

Our operations agent said he told you and your sister that you could wait at the gate or follow him to the elevator while he went in search of a wheelchair. You chose to follow him, so he told you to wait at the elevator until he brought a wheelchair back. The elevator is located between gates 9 and 14, but our agent had to walk past gate 14 to find a wheelchair. He

> walked briskly to locate a wheelchair, but he was not in a hurry and did not expect you or your sister to keep up with his pace.
>
> After our operations agent found a wheelchair, he said he returned to the elevator where Ms. White took a seat. He wheeled her to the aircraft as he had to follow a specific path to the plane; for safety reasons customers are not allowed to push airport wheelchairs on the tarmac. He also said that Ms. White was able to climb the few stairs to the aircraft. We are able to provide level entry boarding, upon request, for customers who cannot ascend the stairs of the aircraft.
>
> I spoke with our Providence manager this morning; she confirmed that all of her employees that come into contact with customers receive initial and recurrent training regarding the services we are required to provide for customers with disabilities. Our gate agent is a new employee, but he followed the proper procedure in this situation when he called our vendor first and then our operations agent for help after our vendor did not arrive promptly at the gate.

I feel it is important to explain that we do not require advance notice in order to provide wheelchair assistance; however, it helps our vendor stage equipment and schedule staff in an effort to avoid service delays. AirServ provides wheelchair service to all six carriers at the Providence airport, and they cannot always predict the level of demand at the time of a last-minute request for service. It is our vendor's goal to provide immediate assistance, but when there are delays our staff is trained to step in and help, which is what our operations agent did.

Our goal at United Airlines is to ensure that travel for our customers with disabilities will be as stress free as possible. To help meet this goal, all of our airport supervisors are certified as Complaint Resolution Officials (CRO). These United employees are available upon request, and specifically trained to assist in the event of a disability related service issue. If an agent is not able to resolve the situation our CRO will ensure that customers with special needs are handled correctly and according to policy. Any customer who has disability related questions or concerns during travel may always ask for the assistance of a CRO.

We understand how important seat assignments are to all of our customers, particularly those with special needs. However, seat assignments are subject to change without notice in order to accommodate operational irregularities and for this reason, they are not guaranteed. If there is a seat assignment change and our staff is made aware of the issue, they will try to adjust your seat assignments, when possible, without unseating another checked-in customer. If they are not able to make changes, customers are free to work together to rectify the problem; I was pleased to know that other passengers were willing to help you sit with your sister.

When you fly with United, you expect us to take good care of you and to provide timely, efficient and professional service; clearly, we did not meet your service expectations on this occasion. While I certainly understand your point of view, I did not find that United Airlines violated federal disability regulations when our gate agent had to seek assistance from another staff member to see that your sister was provided with appropriate services.

I assure you that it is absolutely never our intent to purposely inconvenience our valued customers or to cause them distress of any kind. In appreciation of your feedback, please enjoy the electronic travel certificates that are included with this letter.

We appreciate your business and will do our utmost to make your future contacts with United Airlines satisfactory in every respect.

Sincerely,

Diane Grassmann

Diane Grassmann
Corporate CRO - Disability Specialist

October 12, 2015

Ms. Grassmann:

I have received United's response to a complaint that I filed with the Aviation Consumer Protection Division, C-75, on August 24, 2015.
You state you do not take complaints of this nature lightly and that upon receipt of my letter you immediately contacted your Providence station manager to share the details I provided and to ask for feedback from the staff members involved, and that some of it contradicts my version of events.

In ,¶4 of your letter, you point out that your, "ticket counter agent remembers checking Ms. White in fort he flight and telling you that we would provide (wheel chair) assistance to take her to the gate ....She said you declined the assistance." This is true and was never in question because my sister did not need a wheel chair at that point, nor did she anticipate the need for one at any time after that. She was able to move around well enough on her walker to go through security and reach her gate, where she was expecting to be able to enter the airplane as she usually did, through a passenger boarding bridge. This was where our problem first presented itself - as was detailed in our complaint.

In,¶5, you state that, "Our gate agent also said that he was speaking to our operations agent when he said that he did not know where to find a wheel chair. Please understand that the airport wheel chair vendor is in charge of airport wheel chair equipment and they do not typically stage a wheel chair at each gate, so our staff would not know where to find a vacant wheel chair."

I suggest that the Air Carrier Access Act requires the presence of properly trained service personnel who are knowledgeable on how to assist individuals with disability in boarding and exiting the plane, and that equipment to help in doing so must be available to them.

Then in ¶6, you state the operations agent told my sister and me that we could wait or follow him to the elevator while he went in search of a wheel chair, and that when we chose to follow him he told us to wait at the elevator until he brought a wheel chair back.

This did not happen. What did occur is just what was outlined in the original complaint. At no time did the operations agent try to find a wheel chair for my sister. I was the one who got the chair for my sister. The operations agent was leaning against a set of double doors, waiting for us to catch up with him. The airport wheel chairs were resting in plain view about twenty feet or so down the corridor from where he stood, and he criticized me for wasting the time it took for me to get one for Claire, inferring that we were unnecessarily holding up UA Flight #3590. The operations agent never made any effort to find a wheel chair for my sister, and when we did see chairs, he ignored them. It was apparent that the operations agent wanted my sister to use her walker to accompany him down the elevator, under the terminal wing to a point a hundred feet or so away where we could pass beneath, and then another two hundred feet to where our plane was waiting for us. With her limited mobility, an attempt by my sister to accomplish this hike would have failed and also may have caused her further harm.

The remainder of your reply letter is of a similar tone and concludes with your stated opinion that you did not find United Airlines had violated federal disability regulations.

I disagree with this conclusion as to the validity of our complaint, and I'm not the only one that does so. In his response to the same complaint, Alan Andrade, Green Airport's Senior Vice President, Operations and Maintenance, states that your agents... *“Failed to provide the level of customer service that United Airlines and the Rhode Island Airport Corporation expect. They have been disciplined accordingly and retrained in ADA regulatory compliance and customer service."*

In the same correspondence he also states that, *"The initial agent you spoke with at the gate was a relatively new hire, and although he received initial training with regard to wheel chair support, the employee clearly did not understand his responsibility as an airline representative. The station manager and I both appreciate your persistence in requesting he call someone for assistance. Upon further investigation, the individual that he called did reach out to the agency contracted by all of the airlines for providing wheel chair service, but they were obviously non-responsive. I spoke with the manager of that agency as well, and she apologizes for the poor service and has addressed the importance of being more responsive to calls with her supervisors.*

The other individual you came in contact with was also a new hire and was obviously more concerned about the flight being delayed and oblivious to the fact that your sister was struggling to move at his pace."

Finally Mr. Andrade goes on to state, *"Needless to say, these individuals failed to provide the level of customer service that United Airlines and the Rhode Island Airport Corporation expect. They have been disciplined accordingly and retrained in ADA regulatory compliance and customer service."*

Your response letter included two $100, electronic travel certificates; one for me and one for my sister. We do not want them and they are being returned with this letter. Our goal is not to get free tickets. Our goal is to ensure that others with disabilities won't be faced with the same correctable roadblocks that United Airlines placed so unnecessarily in my sister's path.

Your response offers no such assurances and gives my sister and me second thoughts about why we didn't initially follow the advice of other concerned family members who had suggested that we take the story of our egregious treatment at T.F. Green by United Airlines directly to local newspaper and television outlets, and to Rhode Island's elected federal officials.

Patrick Brady

October 13, 2015

Mr. Cooper:
My family had a very bad experience involving ADA violations by United Airlines at T. F. Green Airport on August 17, 2015. I filed a complaint with the Aviation Consumer Protection Division on August 24, and that inquiry is still in process.
The Rhode Island Airport Corporation initiated its own investigation, as did United Airlines, and they reported back to me with opposite conclusions concerning what happened and who was to blame.
It did not occur to me initially that I should have reported the incident to your office, but now I believe that I should have. I recognize that this letter is untimely, but all I really care is that someone responsible for accommodations for the disabled be aware of the incident in question.
I have enclosed my initial complaint with the ACP Division, the results of the RI Airport Corporation's investigation, the results of United Airline's investigation, and my answer to United.
I hope you can find the time to read what I have sent. Anything else I can add would be superfluous.

Sincerely,

Pate Brady

April 21, 2016

To Whom It May Concern,
On or about April 12, 2016 I entered the Kennedy Plaza ticket office to inquire about replacing my elderly/disabled bus pass. I understand that this must be done prior to July 1st with a completed application, and with documentation of my SSI benefits and copy of my R.I. Driver's License.
I inquired about the new fares. I was informed that the regular boarding fare for disabled individuals would be $.50 and a transfer would be $.25, which is 25 % of the current fare's full price. I also asked about the 30 day pass with passengers with the same criteria and learned that there would be no comparable discount for the 30 day pass for those individuals.
Not discounting the 30 day pass is disproportionate to the other fare discounts set forth.
Having spoken to many other individuals, namely RIPTA drivers, as well as community advocates, all wholeheartedly agree with my contention that RIPTA's policy of not discounting 30 day passes for the elderly and disabled is oppressive and exclusionary to a most vulnerable group in our state.
RIPTA is essentially discriminating against specific groups of Rhode Island citizens.
It is my understanding that RIPTA receives federal and state funding as well as benefitting from the state's gas tax. I trust that RIPTA will implement a discount of the 30 day pass for elderly/disabled citizens proportionate to the discounts extended for the other fares.

Peter W. Gerbeville

April 27, 2016

Dear Mr. Cooper

I heard that your department's objective is to give opportunities and supports to people with disabilities. And to reach a person's maximum potential in human development and most importantly for me, self-sufficiency. I am not a person with the disabilities in the original category, but I need to know the answer to my primary question: Does being looked up from the age of 21 to 48 classify as a disability? Can you help me with future housing? Can you help me with future employments? Can you help me with a future mental health counseling post-release?

I had gone to see the parole board and they said for me to obtain a housing and employment plan because they want to see me released. However, I am pretty much unable to do anything on my own here. Being pre-released I will always be characteristically bias against by the public so being locked up for 28 years seems to predispose me to a disability. That's why I need to know if you can help me or lead me in the direction I need to go in.

So please when you find the time can you write me back and help me on my questions. And who do I contact to make a plan to obtain mental health counseling on an out-patient session post-release?

Thank You!
Leroy S. Olney

June 23, 2016

Rhode Island traffic tribunal has been collecting a $20 fee via habitual speeders since 2006. According to Bob Cooper of governor commission on disabilities, the account exist but has not been allocated for of its intended use. Other states have similar brain, spine injury self-funding funds allocating money to healthcare service providers of patients with no insurance coverage and denial of claims 85% are denied of such injury s because the most expensive care & rehabilitation services. Application of services of fund for anyone (survivors) seeking therapy's, doctor s ervices, testing (neurological, neurophysiology) to be paid directly to service provider. Thus attracting critical healthcare service providers (in patient, outpatient) to open and maintain businesses in RI. Denied claims at resolution, filed with fund application would reimbursement to fund.

No one, residents critical injured living in RI should have to leave the state to seek health care services as extra burden and unable to do business in residing state. A simple application process for in state services to provide immediate relief to persons suffering, waiting for prescribed critical treatment. Habitual speeders, driving in our state are directly responsible for causing accident s creating such devastating and costly injuries.

Thank you for signing on to this bill back then. This was not followed through via governor administration change, supporters retiring, passed away, employees and director changes at the RI Brain Injury Association. Medicare, Medicaid does not cover and what they do cover is not enough to obtain Dr. prescribed "normal " testing, referral to Dr. specialized treatment and therapy's needed to maintain health function post injury or acquired brain, spine events. Personally my health, productivity, responsibility and ability to keep up with activities of daily living have regressed due to lack of funding sources to pay for normally prescribed healthcare services. Then enduring several health care emergency s requiring surgery, allergic reactions of prescribed medicines, and extreme painful events from stress of detriment trying to treat as cheaply as possible. The burden on family and friends was not fair to them and to our community of me having to act credible, from a standpoint of avoidable devastation from desperately trying to live, seeking medical care. "Healthcare is (employment), the most important industry being an inevitable part of existence as it is the only thing preventing suffering and death. Infrastructure funding should not be lumped in and overstated more important than guaranteed funding of healthcare services employing citizens most important jobs and creation of a healthy State, of being.

Thankfully yours,

Mark J Aubrey

July 23, 2016

Gentlemen:
Thank you for the forums planned in July which allow people with disabilities and their families to express their views.
We have a 30 year-old daughter, Bonnie, who was born with Down syndrome. Bonnie has been in the adult program with Perspectives Inc., a community-based organization in North Kingstown. Bonnie is assigned one-on-one aides who have patiently helped her become confident in the community: shopping, volunteering at the Rescue Shelter, and engaging in various forms of exercise. As my husband and I are in our 70's, it would be difficult for us to provide the same level of opportunities which have had such a positive impact on her life.
We will not be attending the forums, but want to express how grateful we are for the State's provision of funding which allows Bonnie to participate in the Perspective Inc. Program. In Bonnie's words: "Yea, Hey! Staff day!!" Thank you.

Sincerely,
CC Michael MacLean, Service Coordinator ADS Community & Independent Living

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July 25, 2016

One concern I see is the all or nothing system meaning if you are not low functioning in social or adaptive skills you can't be self-contained. There are some significantly low LD students who might even be global LD. These students are 3 or more grades below (can't count on fingers or write a sentence) yet are put in regular Ed content with same curriculum but many modifications. Some students vary and might have ok skills but one area is so significantly deficient that is like being Ina foreign Lang. Class. I would be great to acknowledge diversity and allow movement between self-contained and resource for these students. Another option would be to allow modified curriculums in possible social studies so they can receive additional instruction in those areas.
Thank you for allowing me to share some ideas.

Iris Ornberg
Special Educator

September 26, 2016

To whom it may concern,

My name is Ronald Harnois; I am currently an unemployed inmate at the RI Adult Correctional Institute (ACI). I suffer from: (1) a progressive form of neuromuscular deterioration of my extremities (especially my legs) and (2) multilevel degenerative joint and disc disease. As a result of these impairments, I am confined to a wheelchair. These impairments among others, substantially limit my ability to: (1) care for myself, (2) perform manual tasks, (3) walk, (4) stand, (5) lift, (6) bend, (7) climb. However, I am able to perform light work, As a directed result of my disabilities, the RI Department of Corrections (DOC) has both excluded me from participating in and has also denied me the benefits of its services and activities. Additionally, the DOC has failed to provide reasonable accommodations.

Prior to my disabilities the DOC had permitted me to participate in and benefit from their employment services at a maximum rate of $3.00 a day- a rate equally afforded to other non-disabled inmates. But has limited my potential pay rate toa maximum of only $2.00 a day- a rate below that afforded to non-disabled inmates. Doc 28 CFR Sec 35.130 (b) (1) (ii) In other words, the DOC has imposed eligibility criteria that screens out individuals with disabilities from fully and equally enjoying and benefitting from their employment services. Doc 28 CRF Sec 35.130 (b) (8) See also, 42 USC section 12132

The Doc currently has me confined to a cell that is neither handicap nor wheelchair accessible. As such, I cannot adequately access the sink, mirror, shelf, or clothing hooks. Despite my documented disabilities, the DOC has denied my requests for a live-in inmate assistant or caretaker. Rather, they informed me that if I were to be assigned to live-in caretaker to assist me, I would be ineligible for employment entirely. Doc 28 CFR Sec 35.130 (b) (1) (ii) See also, 42 USC sec 12132\

Despite that I am confined to a wheelchair, and my documented history of falling, DOC security constantly demand and insist that I stand up for formal counts. They argue that if I can stand up in the shower (which is handicap equipped), then I can stand up for count.

Requests for Relief:

To remedy the discriminatory acts discussed above, I seek the following:
1. A position with DOC employment services that offers a maximum pay rate of $3.00 a day;
2. Back pay from the time I was unlawfully terminated at a pay rate of $3.00 a day; and
3. An assigned live-in assistant or caretaker without losing my eligibility for future employment;
4. A medical waiver to excuse me from having to stand during formal counts
5. Any other forms of reasonable accommodations that can be agreed upon

October 5, 2016

To the Gov.’s commission on Disabilities,

I missed the forum this summer and was hoping to mention something. So thank you for letting me send you a letter instead.

Some years ago Gwen Reeves from the MS Society had mentioned that there was a lack of organization for adult onset disability. At that time I was working fot the Oceans State Center for Independent Living and had worked with her to try and develop some support but we did not get very far about this issue, addressed during the last few years nothing magically change by itself which is why I want to bring the issue up again with you.

Also, many years ago I worked with a group that was trying to form called the Rhode Island voices FOR Equal Representation (RIVER). This was a group of advocates trying to unite a variety of groups and individuals with the goal of increasing power.

First, in no way do I see that groups benefit by being separated. However the very unique issues pertaining to people with an adult onset disability do not get addressed. There is a wonderful group called the Cross Disability Coalition run through the Developmental Disabilities Coalition. The DD council does a great job of unifying many groups to be effective. I wish the voices of adult onset disability could be as powerfully united, but it is not.

So what are some of the lacking pieces? Well we all know that list is long but there are a few broad topics that affect this group that is suddenly confronting course change.

1. Finances. How are people suddenly going to confront the many needs they have when there is no support.

2. Advocacy. Unity helps/.

I know there is much more but I want to raise this issue and hope it makes some sense.

Thank you.

Anna Liebenow

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