



Description of graphic: RI State Seal an anchor in gold behind a blue wheelchair logo. Just below is a blue banner with the state motto "Hope". All are in the center of a ring of 8 blue stars, in groups of 2 separated by the logos for Braille, hearing aids, low vision and amplified phone.

Governor's Commission on Disabilities Legislation Committee's Public Forum Housing Working Group

Monday October 3, 2011 11 AM -12:30 PM
 John O. Pastore Center, 41 Cherry Dale Court,
 Cranston, RI 02920-3049
 (voice) 401-462-0100 (fax) 462-0106 (tty) via RI Relay 711
 (e-mail) disabilities@gcd.ri.gov
 (website) www.disabilities.ri.gov

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|---|--|
|  <small>meeting graphic</small> | <p>Attendees: Gwen Reeve, Convener; Joseph Cirillo; & Kathleen Kelly Absentees: Roger Harris; & Linda Ward Staff: Emily Crowell, Fellow</p> |
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| | Agenda Topics | Moderator/Leader | Time |
|--|--|--------------------------------------|------------------------|
|  <small>meeting graphic</small> | <p>Public Forums on the Concerns of People with Disabilities:</p> <ul style="list-style-type: none"> ➤ Review the Housing Related Testimony; ➤ Identify the Concerns; and Recommend Solutions | <p>Roger Harris, Convener</p> | <p>11:00 AM</p> |
| <p>Purpose/Goal: To identify the housing concerns and recommend solutions addressing those concerns.</p> <hr/> <p>Discussion: In developing solutions take into consideration the following: infrastructure & resourcing; guidance & coordination; quality control; information & referral; professional development & credentialing; & quality of life.</p> | | | |

Accessible Housing Related Testimony

Starting on Page 16, Barrington Forum:

MITCH LONGO: Mitch Longo. Housing I just wonder is there anybody here that's involved with like I don't know if the right word is zoning or ADA compliance.

CHRIS DEGRAVE: Myself.

MITCH LONGO: I live in Barrington and this is a low income housing property they just built and I don't know how they got away with it, but there's 47 units and none of them are handicapped, ADA compliant.

CHRIS DEGRAVE: What facility is that?

MITCH LONGO: Sweetbriar.

CHRIS DEGRAVE: It was a straight Federal project, it was Federal government only subsidized not subsidized by the state. They had to meet Federal and.

MITCH LONGO: It's subsidized by the state because HUD is involved.

CHRIS DEGRAVE: It was Federal money only involved for the project. I just went on an inspection of the facility.

MITCH LONGO: There's no 36 inch doors nothing.

CHRIS DEGRAVE: The accessible units that are built are considered accessible. There are two there. I did do an inspection of one. Construction of the facility is in my eyes, is not the best they could have done. However, they did meet you know, the Federal basic standards.

MITCH LONGO: Because I live there but I tried to get in one of the handicapped units and I couldn't qualify because they said I made too much money for that unit.

CHRIS DEGRAVE: Yeah, there are you know, the Federal standards are a lot different than obviously the State standards and being that, there are a lot of loopholes in everything especially on the Federal side. Because they built one-family homes, instead of apartment buildings, they avoided a lot of the accessibility laws.

MITCH LONGO: There are a lot of handicapped people there and I don't know how they're getting away with it.

CHRIS DEGRAVE: Yeah, I agree.

MITCH LONGO: That's all I wanted to say.

CHRIS DEGRAVE: Just for the record I'm Christopher DeGrave the Assistant State ADA Coordinator for the state of Rhode Island. And I don't make big bucks.

(LAUGHTER)

SHARON BRINKWORTH: So let me understand correctly, out of those units, only by Federal standards only two had to be?

CHRIS DEGRAVE: Correct.

SHARON BRINKWORTH: Is it two for every 30.

CHRIS DEGRAVE: There are no A or B units. It is considered single family home construction and they did not trigger any, they had to, it's very confusing and my boss explains it a lot better than myself, but because it's single family homes, the ADA was technically you know, not triggered in that particular scenario.

BRIAN ADAE: Mr. Longo if I may ask we're not in the position to have individual responses we are here to have individual testimony. But if you would see me afterwards we can look at different things to look at the state fair housing act. Please see me afterwards, thank you.

SHARON BRINKWORTH: Thank you Mr. Longo.

MITCH LONGO: Okay.

Page 24 Warwick Forum:

JULIE DEROSA: Good afternoon, I wrote mine because I cannot remember under pressure and I get a little nervous. My name is Julie DeRosa. I've been employed for the past two years at OSCIL. . Housing I work as a home assistance-- We are a non-profit agency we provide home modifications to persons with disabilities, to increase the accessibility and safety within their homes. We are funded through several grant programs. We work within economic guidelines and provide the most cost effective process as possible. In working for OSCIL we've modified bathrooms from widening doors, installing grab bars or converting tubs to roll-in showers. We modify kitchens, add ramps and stairlifts to increase safety inside and outside the home. This past year we've served 156 consumers addressing many goals for independent living. Just think how you would feel if you were using a walker or chair and you had no ramp to get in and out for appointments or even see your family. What if you were not able to get your wheelchair into the shower or into the door of your bathroom with your walker. It is essential to continue support for the Ocean State Center for Independent Living home access program because as you can imagine these modifications make a significant impact on the lives of the people who do qualify for our program. Thank you. (Applause).

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Kathleen Boland 7/31/2011 10:44 AM

My name is Kathleen P Boland, I have been the advocate for my 90 yr old mother and 55 yr old disabled sister for many years now. Housing Without the assistance of groups like PARI and OSCIL, they would not have been able to stay in their own home. My mother has owned her home for 66 years, and , it is the only home my sister has ever known. As their support needs have changed, PARI and OSCIL have been able to assist me in obtaining the equipment or modifications necessary.

Currently, my mother is in the community waiver Medicaid program, with 35 hr /week home aid, and skilled nursing and PT. My sister is able to act as caregiver on a limited basis, as she is morbidly obese, learning disabled and suffers from severe arthritis. However, they manage on their own, with various family members helping when they are able.

Affordable Housing Related Testimony

Page 63 Middletown:

CATHERINE MAXWELL: Sure I work for Rhode Island Housing. It is a self-sustaining, public corporation. Together with our partners we endeavor to help all Rhode Islanders achieve a safe, healthy affordable home which as you know in this budget environment is indeed a challenge.

I had hoped today to be able to ask the audience and the panel in particular, if you might help us with a kind of a narrow question that we have related to housing and disabled people. Housing As you probably know, we have a Federal Fair Housing Act which protects many kinds of people from housing discrimination. We also have a state Fair Housing Act which protects certain classes of people from housing discrimination.

Among the classes of people that are protected by state and federal law are disabled people. You may not discriminate against disabled people when it comes to matters of housing. It is absolutely against the law. Housing and urban development asks us every couple of years to try to analyze for our state, what the impediments to fair housing choice. That's being able to live in any home you can afford. We all know that there are impediments and there is discrimination and it is terribly under reported. We have been going out to the community doing small focus groups, gone to these listening sessions and if you would not mind, I would like to ask the group and you can answer individually and

maybe we can speak afterwards. I have really two questions for the folks here. The first one is: Do you feel that access to information about fair housing law in Rhode Island is available to you? Do you know what to do if you feel that you've been a victim of discrimination when it comes to housing? The second question is: If you think back to about ten years ago, if you can, if your personal situation was that you were disabled ten years ago, if you can think back to 2001, do you feel that the situation around housing discrimination particularly for folks who have disabilities, do you feel that it is about the same as it was ten years ago? Do you think that things are a little better now for disabled persons who may be seeking housing? Or do you think it is worse than it is ten years ago? Again the first question is, would you know what to do or who to call in you felt that you were a victim of discrimination in a housing matter? And second, do you think when thinking about ten years ago, do you think that things are about the same when it comes to housing discrimination and the disabled community? A little better, a lot better or worse than ever? If anyone would like to speak now that's fine. I think it is always good to share our experiences, certainly very informative to us or if you would like to talk to me later, that's fine, too.

DARLENE THOMPSON: May I ask on the Rhode Island Housing website is this information available?

CATHERINE MAXWELL: There's a link on the Rhode Island Housing home page to a website called "fairhousingRI.org." If you go to Rhode Island Housing, it is on the lower right hand corner. There's a couple of topics. It will take you to fair housing RI website which has lots of resources and information about what the law is and who to contact.

MARY BENNETT: I was asking a question. I'm Mary Bennett and my mother has multiple sclerosis [Housing] and I live in Jamestown. My son is 12 years old. Am I correct that Jamestown is mandated to have a percentage of affordable housing? And if it does not happen, what is the process there and also, I wanted to know isn't it discrimination if there is lack of affordable housing? Isn't that discrimination in itself to afford the common value rent of Jamestown?

CATHERINE MAXWELL: I'm not an attorney, personally. I believe you are right it is a form of discrimination. The process around each city and town achieving a minimum of 10 percent of affordable housing, is a permitting process. Like any land development it takes time to get through. There is often local resistance, as you know to any kind of affordable housing. There's also the cost issue. In many communities the cost of land is very, very high. The economy in general, as you know, we are in a recession, and that is having a profound affect on the ability to finance any kind of construction even for affordable housing construction. The same kinds of cuts that the disabled community is experiencing.

BRIAN ADAE: If I may chime in, speaking as an attorney for the Rhode Island Disability Law Center for those who are not familiar with the Disability Law Center. There's a national protective and advocacy system for folks with disabilities. It is referred to as a PA in every state and territory. I am with the P & A for Rhode Island. We provide representation as well as working on systemic issues. For folks with disabilities and having disability issues among housing. I'm going to suggest that we cannot answer specific questions here, however, my office is certainly open to very specific questions and problems if we can address them. As a matter of fact, I was going to put in a shameless plug at some point. We have our annual priorities survey that we do every year and we try to have consumers and the public responds to the survey. We can identify the areas because we do have services that we can address. I'm going to see that they are over on the table so they could be completed and I can take them back to my office. So, part of that shameless plug, maybe we can provide at least some information if not actual representation for some of these issues. As well some guidance as to which direction and who to call as they are trying to find out as well.

MARY BENNETT: I did not know you existed.

BRIAN ADAE: Not many people do. That information is -- we just had one question from my fellow panel member. The survey on the website, not yet. It should be. It is not there yet. We have to have a long conversation with my director. In the meantime we have the written form and if there are specific questions I'll be available here afterwards. Again, please respond on housing questions so they have this information people don't know about it. I suggest that now, that you are hearing about it. Avail yourself of the opportunity to have those questions answered. Thank you for the opportunity to quasi respond.

Our development assisted living is in conjunction with Rhode Island Housing. We are affordable housing. If our residents are cut \$206 per month to pay to live there, is that a form of discrimination because of disregard for what those people need in order to maintain their affordable housing?

ATTENDEE: I cannot answer that question, but it is a question.

Where would you suggest we go with that?

ATTENDEE: I hear that. I'm not sure. Maybe Rhode Island Legal Services.

BRIAN ADAE: Rhode Island Legal Services does a certain amount of work. The Disability Law Center certainly is a question that could be posed. I did have a question when you were testifying. I forgot, your organization Franklin Court and what else?

St. Elizabeth Court.

Carol is the owner of --

Am I correct, if I recall, that when we look at assisted living there's only three in the state.

Right, and they--

It is 151 waivers in those three facilities. It is the basis of their foundation at all three centers. Then there are other 506 in the state units or slots for waivers as well. In the state with this particular program with SSI we are talking 200 units.

Are you suggesting that they cut \$206 per month would put people at risk of institutionalization i.e: Nursing home or hospitalization if they were unable to survive in the assisted living environment.

That's correct.

That could be an issue. That's a suggestion that may be made at some point.

MARY BRAUN: Yes, my name is Mary Braun. I'm living with multiple sclerosis. **Housing** I was wondering if there's going to be any more section 8 vouchers that will be available that might encourage landlords to be part of the program so there would be more affordable housing for people that need it because baby boomers are getting older. I don't think it will get any better.

LINDA WARD: This is the point where I've broken a primary rule here. We are here to listen. I crossed that threshold. You have concern that there are not enough section 8 vouchers for affordable housing. Without it necessarily in a clustered development.

MARY BRAUN: Wouldn't handicapped people with a documented disability be further up the list or not? Is that discrimination?

LINDA WARD: Historically that's not been a priority. If there's a development sometimes with physical disabilities, most often there's no priority in them. I think we can all agree that there is not enough affordable housing in the state of Rhode Island and I'm really not aware of what the voucher system is at this point.

MARY BRAUN: There was 0 in Newport county a couple of years ago. I don't think that's changed at all at this point.

Page 69:

MARY BENNETT: **Housing** The only thing being brought up is my experience needing affordable housing did include a BCI, so if you have any history of crime in this state you are not eligible for affordable housing. So I don't know where that lands either. If you have a child that is disabled and the parent has been a convicted felon in the state, the child does not get access to affordable housing. How is that helpful?

Page 87 Blackstone Valley Forum:

TANJA BLIKER-UKRAN: My name is Tanja Bliker-Ukran. The co-coordinator and employment specialist for the Cross Disability Coalition. I'm testifying on behalf of the Cross-Disability Coalition an initiative of the Rhode Island Developmental Disabilities Council.

There are four issues that we have identified. My colleague, Christina Baptista will talk about the other two issues at the August 4th public forum. There are two issues very important to individuals with disabilities that I want to comment on today.

They are, safe, affordable housing and employment. **Housing** Our members have expressed the need for more safe, affordable housing to be made available or built and the rehab of abandoned properties to be turned into affordable housing for people with disabilities.

There are many old mill buildings that could be turned into affordable housing. The waitlists for existing Section 8 Housing are very long and in some cases, individuals must wait several years to get into these units. There are more people in need of housing than resources available.

We need more places to live that are safe and affordable.

Housing Discrimination Related Testimony

See Page 63 Middletown Forum above:

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Handout from Linda Dugas' Testimony **Housing**

PESTICIDE/CHEMICAL SAFETY

- The 2008-2009 President's Cancer Panel stated: "At this time, neither industry nor the government confirm the safety of existing or new chemicals prior to their sale and use" (2)
- Enacted in 1976, the Toxic Substance Control Act(TSCA) grandfathered in 62,000 chemicals without a true proof-of-safety provision. Currently out of the known TSCA inventory that contains over 80,000 chemicals, few have been studied for their risks to children* (2,3)
- In the year 2009 out of 22,122 pesticide products up for reregistration by the EPA and FIFRA: 6,224 registered pesticides were cancelled, H. Pesticide products were suspended and 10,860 pesticide products have actions/decisions pending (13)
- The EPA plans to conduct 38,000 pesticide product reviews in the future (13)
- *(The TSCA inventory also contain the inert chemical ingredients that are found in pesticide formulas that are considered "trade secrets" and often are extremely toxic) (21,22,23,24,25)

National Movement:

Neighborhood Notification Laws

- **Neighbor Notification Laws provide the public an opportunity to take precautions to avoid direct exposure to hazardous pesticides**

- Twenty one states require notification and signage 24 to 72 hours prior to; the pesticide application. The posting also indicates the pesticide(s) active ingredient(s), where and when the treatment will occur, the name of the applicator and contact information and how many days to remain away from the treated area (frequently 48 to 96 hours) (45,46)
- Model Law example: Erie County, New York (47) 20

Pesticides Do Not Stay Put:

Pesticide Drift and Migration

- **Pesticide Drift** is the movement of a pesticide through the air away from the intended target site and can be in the form of mist, particles or vapor and is often of great concern
- **Drift occurs during the pesticide application or may occur days or even weeks later** as pesticides volatilize into vapor and are carried long distances by air currents (32)
- **Many pesticides easily migrate thru the soil contaminating ground water, aquifers, well water, rivers and lakes** (33,34)

Severity of the Problem

- Of the 30 most commonly used lawn pesticides (18,19):
 - 19 are linked with cancer or are carcinogenic
 - 13 are linked with birth defects
 - 21 with reproductive effects
 - 26 with liver or kidney damage
 - 15 with neurotoxicity
 - 11 with disruption of the endocrine hormone system
 - 17 are detected in groundwater
 - 23 migrate and leach into drinking water sources
 - 24 are toxic to fish and other aquatic organisms.
 - 11 are toxic to bees
 - 16 are toxic to birds

William & Mary Adkins
September 14, 2011

Rhode Island Public Utilities Commission
Division of Public Utilities and Carriers
Attn: Al Contente, Engineering Division
89 Jefferson Boulevard
Warwick, RI 02888

Subj: Consumer Complaint Against National Grid (Electric) Filed by William & Mary Adkins,
Account # 78266-05026 Housing

Ref: (a) Letter from William & Mary Adkins to RI Public Utilities Commission dated July 15, 2011
(b) Letter from National Grid (M. Albanese) to Mary Adkins dtd August 8, 2011

Encl: (1) Citations From the Medical/Scientific Literature Regarding the Biological Effects of Radiofrequency Radiation

- (2) Professor Olle Johansson's List of Authorities
- (3) Studies Reporting Biological Effects of Radiofrequency Radiation (RFR) at Low Intensities
- (4) Navy Medical Research Institute Bibliography of Reported Biological Phenomena ("Effects")
and Clinical Manifestation Attributed to Microwave and Radiofrequency Radiation, Research Report compiled by
Zorach R. Glaser, Ph.D., LT, MSC, USNR
- (5) Amended Declaration of Curtis Bennett; Morrison v. Portland Public Schools
- (6) Declaration of Dr. David O. Carpenter, MD; Morrison v. Portland Public Schools
- (7) Declaration of Lloyd Morgan; Morrison v. Portland Public Schools
- (8) Declaration of Barrie Trower; Morrison v. Portland Public Schools
- (9) Bioeffects of Selected Nonlethal Weapons/FOIA request dated Dec 13 2006
- (10) Letter from Olle Johansson to California Public Utilities Commission dtd July 9, 2011

Dear Mr. Contente,

We recently sent the reference (a) complaint to the Rhode Island Public Utilities Commission regarding National Grid's refusal to remove an electric meter from our home at 78 White Falls Trail, Wakefield, Rhode Island. This is an Automated Meter Reading (AMR) meter equipped with a radiofrequency transmitter that broadcasts every few seconds, 24 hours a day. Our physicians have advised us we must avoid exposure to this type of radiation. Of particular concern is the life-threatening immune response our youngest son has to radiofrequency (RF) radiation, like the type emitted by this meter. We recently received the reference (b) letter from National Grid saying they are "unable to remove this meter" from our property.

We are requesting our complaint be forwarded to an attorney in your Legal Division for the following reasons. First of all, we purchased our home in April 2011. The AMR meter was already on our home at the time of purchase. Let us make it

clear that there was no informed consent given for this meter. At no time were we told that this meter emitted pulsed RF electromagnetic radiation every few seconds 24 hours a day, or that this radiation would be entering into our home (which we have confirmed by hiring a certified professional to measure it).

We have documented in writing that we want this meter removed and replaced with an analog meter. By refusing to remove it and replace it with an analog meter, National Grid is in violation of **Rhode Island General Law 11-35-1** governing Criminal Offenses by Public Utilities which states: ***"No person shall place any electric wire, apparatus, pole, bracket, insulator, or other device or appliance for the purpose of conducting currents of electricity upon any private property without the consent of the owners or of the agent of the owners."***

On May 31, 2011, the World Health Organization International Agency for Research on Cancer officially classified electromagnetic radiation (like the type emitted by the AMR meter) as a **Class 2B Carcinogen**. (<http://www.iarc.fr/>) This classification applies to all wireless devices and includes cell phones, cell antennas/towers, WiFi, Smart Meters, and AMR meters. This means the radiation National Grid is sending into our home without our permission can potentially cause cancer. Yet National Grid has maintained in phone conversations with us and via correspondence that our current electric meter is safe and the radiation it emits is no different than that coming from our refrigerator.

On the contrary, the AMR meter is emitting pulse-modulated RF electromagnetic radiation. RF radiation (3 Khz - 300 GHz) falls on an entirely different part of the electromagnetic spectrum than that which comes from our refrigerator (60 Hz). In addition, our refrigerator is not actively transmitting pulse-modulated signals wirelessly every few seconds 24 hours a day like the AMR meter is. There are literally thousands of published, peer-reviewed scientific studies documenting that nonthermal, nonionizing RF and/or microwave radiation (like that emitted by this meter) is harmful to human health.

Leading scientists worldwide are calling for changes in scientific policy because of the inherent dangers to human health of RF/microwave radiation. Radiation safety standards (in this country and abroad) are decades old, not biologically based, and were not developed for chronic, cumulative exposure times. They are also not applicable to current pulse-modulated technology. Current standards adopted by the Federal Communications Commission (FCC) are based on 200 lb. healthy adult males, not children, pregnant women, the elderly, or individuals with chronic health issues. It is for this reason that many other countries are restricting and in some cases banning the use of wireless products like cell phones, WiFi, AMR meters and Smart Meters.

Existing FCC safety standards do not protect public health and the FCC is not a health agency. Per the FCC's own website they shift responsibility for wireless radiation safety to the Food and Drug Administration (FDA). The FCC website states: ***"The FDA is, however, the lead federal health agency in monitoring the latest research developments and advising other agencies with respect to the safety of RF-emitting products used by the public..."***

(<http://transition.fcc.gov/oet/rfsafety/rf-faqs.html#Q26>)

Yet the FDA website states the following: ***"FDA does not review the safety of radiation-emitting consumer products such as cell phones and similar wireless devices before they can be sold..."*** (<http://www.fda.gov/Radiation-EmittingProducts/RadiationEmittingProductsandProcedures/HomeBusinessandEntertainment/CellPhones/default.htm>)

This ambiguity confirms that no one at the federal level is reviewing or monitoring the safety of AMR or Smart Meters or any other wireless devices. Therefore, it is incumbent upon our state agencies to take the lead on this issue and make accommodations for people with health issues or those that simply don't want to take the risk. Though the Telecommunications Act of 1996 (written primarily by the industry to deregulate itself) declares this technology "safe," independent science confirms this is simply not true.

Harmful biological effects from this type of radiation include migraines, nausea, vomiting, muscle spasms, heart palpitations and sleeplessness caused by intense bursts of RF radiation. It causes neurological, behavioral, cognitive, auditory, cardiac, and immune dysfunction; genetic damage; as well as leakage of the blood-brain barrier. Please see enclosures (1) through (8), all of which substantiate this type of radiation is unequivocally harmful to living organisms. Although enclosures (5) through (8) are sworn declarations written about WiFi technology, the information contained within them is applicable to AMR meters as well as Smart Meters. This is because AMR and Smart meters subject consumers to chronic, cumulative exposure to RF radiation just as WiFi does.

Please note that Mr. Bennett (in enclosure (5)) has identified and reported an error/omission in Canada's Safety Code 6 which ***"is based on similar international standards as used in the United States."*** This error/omission has resulted in the unlawful irradiation of our citizens from not only WiFi and cell phones but AMR and Smart Meters. People can choose if they want to assume the risk of owning/using a cell phone. People can choose whether they want to install WiFi in their homes. But consumers are not being given a choice when it comes to AMR meters and Smart Meters. These are being forced upon us in our own homes against our wishes.

National Grid's website states the following about AMR meters:

"AMR allows us to collect an actual meter reading without entering your property to read your meter. With AMR, we can automatically read meters by simply driving a vehicle down your street—AMR reads your meter by using very short-range radio frequencies similar to a garage door opener. Each AMR meter has a unique identification code. The reading on your meter is transmitted through radio frequencies to a piece of equipment in the van."

and:

“Are there health hazards or safety issues associated with AMR? No, equipment operates at very low levels comparable to radio waves already present in the environment. All equipment has been designed to operate within state and federal standards.”

(source: http://www.nationalgridus.com/narragansett/home/rates/5_amr_addl.asp)

National Grid's assertion that there are “no health hazards or safety issues associated with AMR” or that the radiation is similar to that emitted by our refrigerator is clearly false, deceptive, and misleading-- blatant misinformation, i.e., false equivalency for the purpose of equivocation. Though we would like to think they are simply misinformed, this hardly seems plausible considering there is a massive effort by leading scientists worldwide to raise public awareness about this issue. Their claims appear to be intended to deceive the consumer.

Garage door openers typically operate in the 300-400 MHz range and utilize a receiver/transmitter that emits only when the door needs to open or close. Conversely, the AMR meter emits pulsed, ultra-high frequencies every few seconds 24 hours a day. The fact that radio waves are already present in the environment does not constitute “proof” that AMR meters are safe. Radio waves are not pulsed, ultra-high frequency emissions like those that come from an AMR meter. And in fact there are a multitude of studies done on standard radio waves showing they also cause adverse health effects. AMR meters do not emit standard radio waves—they emit pulse-modulated radiofrequency/microwave signals.

The deceptive nature of National Grid's statements and the harm caused by RF radiation can be verified by contacting any of the following world-renowned scientists who specialize in the biological effects of electromagnetic radiation:

David Carpenter, MD
Director, Institute for Health and the Environment
University of Albany School of Public Health, New York
Phone: (518) 525-2660
Email: Carpent@uamail.albany.edu

Magda Havas, PhD
Associate Professor of Environmental and Resource Studies
Trent University, Ontario, Canada
Co-author, Public Health SOS: The Shadow Side of the Wireless Revolution
Phone: (705) 748-1011 x7882
Email: mhavas@trentu.ca

George Carlo, PhD, MS, JD
Founder, Science and Public Policy Institute
Former head of a \$28.5M research program for the cell phone industry
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E-mail: dpanagop@biol.uoa.gr

Based on their false and misleading statements, National Grid appears to be violating **Rhode Island General Law 6-13.1-2** governing Commercial Law/Deceptive Trade Practices which states ***“Unfair methods of competition and unfair or deceptive acts or practices in the conduct of any trade or commerce are declared unlawful.”***

By withholding information about potential health effects from consumers and misleading the public about the type and safety of radiation being emitted, National Grid appears to be attempting to deceive consumers. By engaging in this deception they have potentially endangered the health of tens of thousands of Rhode Island citizens--especially children, pregnant women, the elderly, and the chronically ill--all of whom are at higher risk of developing adverse health effects from this radiation. One need only look at the skyrocketing rates of autism, Attention Deficit Hyperactivity Disorder (ADHD), asthma, immune disorders, and neurodegenerative diseases in our state and across the country to see the possible effect this type of wireless technology has had on society's health over the past 15 years.

Despite the fact that the harmful biological effects of nonthermal, nonionizing radiation have been well known in the scientific community for decades, there has been no informed consent on the part of consumers with regard to these meters. National Grid has not notified its customers that the AMR meters installed on our homes emit radiation that is potentially harmful to human health. They have not informed customers that this radiation may cause cancer. They have not informed consumers about the ongoing scientific controversy concerning whether this radiation is safe so consumers can decide for themselves whether they want to be exposed. There has also been no notification to consumers about the potential for these meters to interfere with medical devices. Please see the following website for information about this: <http://ewh.ieee.org/soc/embs/comar/interfer.htm>

If there is no provision in Rhode Island for consumers to “opt out” of AMR meters due to health effects or civil rights reasons there needs to be, and we are asking your agency to take action in this regard. We have a young child who develops a life-threatening immune response to this type of radiation and he is entitled to protection. Under the U.S. Constitution, we as his parents have the right to protect him and National Grid is interfering with our ability to do so. If more consumers were informed about the health consequences of this radiation, we suspect many others might be able to link their health problems to the installation of these meters on their homes. We are fairly certain National Grid also has no intent to inform consumers about the potential health effects from Smart Meters either when they begin to roll these out across the state.

Currently we cannot safely use a portion of our home and property because of the radiation emitted by the AMR meter. Because of this National Grid appears to be in violation of **Rhode Island General law 11-44-1** governing Criminal Offenses/Trespass and Vandalism, which states: ***“Every person who shall willfully and maliciously or mischievously injure or destroy or write upon, paint, or otherwise deface the property of another, or obstruct the use of the property of another...shall be guilty of a misdemeanor and shall be fined not exceeding one thousand dollars (\$1,000) and/or be imprisoned not exceeding one year, and shall be liable to make restitution for the injury or damage caused.”*** National Grid is clearly obstructing our use of our property--both our home and our land--via the potentially carcinogenic emissions of this AMR meter.

National Grid also appears to be in violation of **Rhode Island General Law 11-5-2** governing Criminal Offenses/Assaults, which states: ***“Every person who shall make an assault or battery, or both, with a dangerous weapon...which results in serious bodily injury, shall be punished by imprisonment for not more than twenty (20) years.”*** Certainly the electric meter on our home might be constituted by some as a dangerous weapon in that it is inflicting ongoing “serious bodily injury” to our family. This is confirmed not only by the symptoms we experience which are substantiated by a very large body of scientific research but also by the fact that these same frequencies have been employed as weapons by various governments, including our own. See enclosure (9) for more details.

The Navy Medical Research Institute (in enclosure (4)) compiled an extensive list of scientific studies documenting the wide range of serious bodily injuries this radiation can cause. Assault could apply to other citizens being harmed by this technology as well, particularly because of National Grid's failure to disclose this information to consumers. Please be advised that 35% of the population is estimated to be sensitive to RF electromagnetic fields, which in Rhode Island would constitute approximately 370,000 people.

National Grid is also in violation of **Rhode Island General Law 39-2-3** governing Public Utilities and Carriers/Duties of Utilities and Carriers, which states ***“If any public utility shall make or give any undue or unreasonable preference or***

advantage to any particular person, firm, or corporation, or shall subject any particular person, firm, or corporation to any undue or unreasonable prejudice or disadvantage in any respect whatsoever, the public utility shall be guilty of a misdemeanor and, upon conviction thereof, shall be fined not less than two hundred dollars (\$200) nor more than five hundred dollars (\$500) for each offense.

For each day that National Grid refuses to remove this wireless meter from our home and replace it with a safe analog meter, they are endangering our health and are thus in violation of this law. National Grid is clearly engaged in prejudicial treatment against our family because our reactivity to RF electromagnetic fields is not convenient with regard to their corporate agenda to push this inherently dangerous technology upon an unknowing public in order to maximize profits. They have also invaded the safe haven of our home and provided no accommodation for our family's documented underlying medical conditions, which also may rise to the level of a **violation of the Americans with Disabilities Act as well as other 14th Amendment violations.**

There is no law we are aware of--local, state, or federal--mandating the use of a wireless utility meter. Please also be advised that the proposed National Grid "Smart Meter" roll out in Rhode Island (a statewide installation of an even more advanced and infinitely more harmful type of wireless utility meter) is also not a mandate. **The Energy Policy Act of 2005** clearly states that utility companies are only required to offer advanced metering technology to their customers.

Section 1252 (a)(14)(A) of the Energy Policy Act of 2005 (pgs. 371-372) states: **"...each electric utility shall offer each of its customer classes, and provide individual customers upon customer request, a time-based rate schedule under which the rate charged by the electric utility varies during different time periods and reflects the variance, if any, in the utility's costs of generating and purchasing electricity at the wholesale level. The time-based rate schedule shall enable the consumer to manage energy use and cost through advanced metering and communications technology."** It goes on to state in **Section 1252(a)(14)(B) (pg. 372)** that **"Each electric utility, subject to subparagraph (a), shall provide each customer requesting a time-based rate with a time-based meter capable of enabling the utility and customer to offer and receive such rate, respectively."**

There is no obligation on the part of consumers to accept this offer for advanced metering technology. Yet regarding the AMR meter (and eventually Smart Meters) we are being told we have no choice.

Accordingly, National Grid again appears to be engaged in deceptive and unfair trade practices by telling consumers that AMR meters and Smart Meters are mandatory. This is simply not true.

National Grid is also not informing consumers of the well-documented potential health effects of the RF radiation emitted by these meters, as evidenced not just by the documentation we've provided with this correspondence but also by the fact that Smart Meters are now restricted and/or banned in 43 cities/counties in California due to adverse health effects, among other reasons. The state of Maine (which initially mandated them through their state Public Utilities Commission) has just completed a long legal battle to allow consumers to "opt out" (refuse) them because of all the reasons mentioned above. The states of Hawaii and Maryland have also blocked Smart Meter programs. Similar restrictions/bans are being implemented in other parts of the world as well.

Connecticut Attorney General George Jepsen is currently trying to stop the Smart Meter roll out in CT because he maintains the technology is overly expensive and would not save enough electricity to justify the costs.

<http://www.emfacts.com/2011/02/1357-connecticut-ag-opposes-smart-meters-on-costs/> In many areas of the country where Smart Meters have already been installed consumers have seen their bills skyrocket--in some cases tenfold their usual bill. You can read about some of the outrageous over billing that has occurred (usually with no recourse) here: <https://sites.google.com/site/nocelltowerinourneighborhood/home/wireless-smart-meter-concerns/smart-meter-consumers-anger-grows-over-higher-utility-bills>

This is yet another reason why these meters should not be forced upon consumers.

Although we understand National Grid does not wish to acknowledge the potential danger of AMR meters and Smart Meters, this does not change the fact that the radiation emitted by these meters causes adverse biological effects. Although we understand AMR meters have been in use for some time now (and National Grid is already installing Smart Meters), this is not a justification for continuing to leave a known potential cancer-causing device attached to our home that exposes us to radiation 24 hours a day, 7 days a week. While AMR and Smart Meters may increase National Grid's profits, they do so at the expense of the health and safety of thousands of Rhode Islanders, with no financial benefit to consumers. Not only that, they eliminate meter reader jobs during a time of record unemployment. In our opinion there is no excuse--political, economic, or corporate--that is adequate to justify the illegal and immoral nature of what National Grid is doing.

In addition to violating the aforementioned Rhode Island State laws, National Grid is also in violation of the **United States Constitution and the Rhode Island Constitution.** Under federal law, **"If two or more persons conspire to injure, oppress, threaten or intimidate any citizen in free exercise or enjoyment of any right or privilege secured to him by the constitution or laws of the United States, or because of his having exercised the same, or if two or more persons go on the premises of another with the intent to prevent or hinder his free exercise or enjoyment of any right or privilege so secured--they shall be fined not more than \$10,000 or imprisoned not more than ten years or both."** Per the **Rhode Island Constitution, "No person shall be deprived of life, liberty, or property without due process of law, nor shall any person be denied equal protection of the law."**

National Grid is therefore violating our constitutional rights--both federal and state--by forcing this meter upon us.

In addition, the soon-to-be-rolled-out Smart Meters (and thus the utility companies) will now invade the privacy of all of our homes. Smart Meters monitor appliance usage inside the home and transmit this information over the network of meters in the neighborhood to upload to a central link. This information reveals when you are home and when you're not, what you're doing and when you're doing it. Data about your personal daily habits and activities are collected, recorded and stored in databases, giving a highly invasive and detailed view of your lives to those with access to the information.

The wireless signals being transmitted by a Smart Meter can be intercepted (hacked) by unauthorized and unknown parties and used by criminals, for example, to determine the optimum time to rob your home. Smart Meters are essentially a form of electronic trespassing/surveillance. They are, by definition, surveillance devices, which violates Federal and State wiretapping laws by recording and storing databases of private and personal activities and behaviors without the consent or knowledge of those people who are being monitored. Here is a video that explains this in more detail:

http://www.youtube.com/watch?v=8JNFr_j6kdI

Smart meters are also responsible for a large number of fires and explosions throughout the country and have been banned by many cities because they are not Underwriters Laboratory (UL) approved. See this website for more information: http://emfsafetynetwork.org/?page_id=1280

For all of the above reasons, we are requesting that our complaint to remove this AMR meter from our home be referred to your Legal Division and that your agency also take action to halt the roll out of Smart Meters in our state. Please learn from the devastating health and financial consequences these meters have caused for residents of California. Enclosure (10) provides additional information about the adverse health effects of Smart Meters. This letter is authored by Dr. Olle Johansson of the Department of Neuroscience at the Karolinska Institute (which hands out the Nobel Prize for Medicine). You can also learn more at the following websites:

<http://www.citizensforsafetechnology.org/>

<http://smartmetersafety.com/>

<http://www.smartmeterdangers.org/>

<http://stopsmartmeters.org/>

<http://www.refusesmartmeters.com/>

<http://www.smartmeterdangers.com/>

http://lamesa.patch.com/blog_posts/living-nightmare-how-sdge-smart-meters-led-to-my-headaches-sleeping-ills-hearing-loss

http://www.devvy.com/new_site/smart-meter-081511.html

We would very much appreciate an expedited resolution to this matter since the AMR meter is continuing to cause very serious health problems for our family, obstructing the use of our property, and violating our civil rights. There is no reason why we can't have an analog meter installed, other than National Grid's corporate agenda to profit at the expense of consumer health. We are asking for your help to protect our family, especially our youngest child.

National Grid is engaging in deceptive trade practices when they say there are unequivocally no health hazards or safety issues associated with AMR. It does not matter if this equipment is "designed to operate within state and federal standards," when those standards have been identified by the independent scientific community as being obsolete.

For the sake of example, peanuts are "safe" for much of the population and they are available for sale, but you cannot say they are unequivocally safe for everyone because some people have very severe, sometimes life-threatening reactions to them. A corporation does not have the right to fill your home with peanuts against your wishes, especially when you are allergic to them. Neither does a corporation have the right to fill your home with Lead, DDT, or chloroform (all of which are also Class 2B Carcinogens). But this is, in effect, what National Grid is doing by filling our home with radiation against our wishes. There needs to be an exception made for people with health issues and those who do not want the safety of their homes violated in this way. There must be informed consent. Better yet, these meters should be banned altogether, which is what the state of Connecticut is attempting to do.

We are asking for your help in getting this AMR meter off of our house and replaced with an analog meter that does not emit radiation. We are also requesting your assistance to insure that a Smart Meter is never placed on our home. And we are asking the Rhode Island Public Utilities Commission to take steps to protect the general public from the adverse health effects of AMR meters and Smart Meters because National Grid has not been forthcoming about the potential dangers of this technology.

Sincerely,

WILLIAM ADKINS

MARY ADKINS

Copy to: RI PUC/Legal Division; Gov. L. Chafee; Atty. Gen. P. Kilmartin; Sen. S. Sosnowski; Sen. J. Tassoni; Rep. D. Lally; Rep. S. Dickinson; RI Governor's Commission On Disabilities/T. Flynn; RI Commission For Human Rights/J. Susa; D. Carpenter; M. Havas; G. Carlo; C. Bennett; H. Lai; O. Johansson; M. Blank; D. Panagopoulos (enclosures forwarded via email—please notify sender if not received)

Page 30 Warwick Forum:

JAMES BOUCHER: Good afternoon, everyone. I represent West Bay Residential, the group home agency that I come from. Housing I also represent many of the disability advocate-driven agencies and I'm also here for them. Personally, on my own personal awareness of things, I agree with everybody in this room that the cuts that are happening are affecting everyone. Not only myself and, you know, it does need to stop. Where? When? Why? And how? It needs to be soon and the other three, we'll see, right?

Everything that we have heard here today, everything from the Medicare, RIde, RIPTA, these are all important issues. Sorry I meant to write stuff down.

I've been on my own since I was 16. I moved into West Bay Residential when I was just shy of 21 or just after and I moved in with them in 1996. They are the greatest agency that I know of. They support me as well as they can. If their funding drops and my funding drops, where would I go? I have no family, I have family, but I don't have contact. Many of my friends that I rely on at the agency, who are staff. And my current housemates, one of them is sitting here in the room with me.

He also is reliant on these supports and the cuts affect him, also. So I'm not only here to support myself in this, but I support him and my other housemate who could not make it today.

I just want to leave everyone here with a final thought. Keep doing what you are doing. Keep putting out the word that the cuts need to stop and those that are here representing any state or government outfit, please get out the word that these cuts need to stop here and now. Thank you. (Applause).

WILLIAM GARDENER: Hi, I'm William Gardener also known as Brandon, I use my middle name. I also work at West Bay. I did not plan to speak today. I wanted to come and show my support because I have worked with individuals with disabilities at West Bay Housing for the last eight years. One thing that really affected me was the second lady that spoke, really just overtook me emotionally. I really felt for her. Seeing she mentioned she may lose her home. She has stayed home with her child to care for him. I know that the state, it has been involved with West Bay for the last eight years. You have heard a lot about SLA and moving towards that option. I've known people that have had people move in SLA -- Shared Living Agreement they received X amount of dollars to have an individual move in. It is so sad to me that this woman is working receiving a PCA, paycheck to keep her child home and now, for whatever reason it has been removed, I wish that could be reconsidered by the SLA. Having a family member that has kept their child home as I'm sure it could cost the state much less money than actually having to receive services from a nurse making \$30 an hour.

Another thing that is concerning to me is the regulations. Someone mentioned that the new regulations that are proposed. I've read through the regulations and sat at a hearing at the Arnold Center. Some of them are just very different and require a lot more work from the staff that are supporting the individuals in different ways. Paperwork wise, every 15 minutes for the day program. It is very difficult to account in 15 minute increments because that little bit of time taken extra to do the paperwork is taking away from the time you are spending doing what we are all there for. Another thing to consider is that these cuts are affecting the individuals receiving services but also the staff who are not making that much money. I'm sorry I'm losing my thoughts. The staff are not paid that well and some of these new regulations require that there's a higher staff ratio which is just "how will we do that" pay the staff half as much as what they make now? It is just not possible. This new leveling system that the state has proposed I know that people were being reassigned to levels. It is concerning because the input was not there from the individuals who were actually receiving the support and whether they actually, this new level that they have been assigned to considers all that they need to be supported as they should be. Thank you.

Page 36:

KAREN FLYNN: I'm Karen Flynn and my sister Mary is at West Bay Housing and she is taken care of with great love and care and personal attention and it is amazing the love that she receives. One person in particular, Bob, and all of the wonderful, wonderful caretakers who take care of her. Well, I just want to tell you a little story. Last Sunday I came to pick Mary up. I was going to take her out for a period of time. I returned and one of the clients is now in hospice. When I walked in, her other housemates were there. They were only attending her at that time. I'm sure that one of the reasons is that probably the major reason is on a Saturday afternoon instead of having the normal three or four people, who care for five complicated clients, they only had -- there were only two and there was a nurse there who was attending the client who was on hospice. The two people who were, you know responsible for all of the clients were caring for the person in major need. When I returned, I stayed with them for a while. When I walked away I just said to myself, what is going to happen? I guess, that major cuts were made in the spring, now there will be more cuts supposedly in the month of October or November. Where are all of these wonderful, how will they be taken care of? You know like somebody said, walk around take visits to the homes of people who are young children, well I was with Mary, my sister from the time she was born. There's a lot of care there. My mother had her in her home until she was 29 years old. My father and my mother were very wise and realized that Mary needed to be placed in a situation where she would have the best of care and the best of care was West Bay. The absolute best of care. They made the right decision, but the fear now is what is going to happen to Mary? What is going to happen to Michael? What is going to happen to Karen? What is going to happen to Marie Shipee? All of the people who are under the care of West Bay. It is a worry. It is a major concern. As Bob said, the staff,

they don't make a tremendous amount of money, but you know, they are there for a reason. You know what their reason is? Because they love their job. And we are just very blessed all of these years that Mary has always been with individuals who love their job. (Applause).

LIDYA GOODENSON: I'm Lidya Goodenson. Okay, I just wanted to share a little bit about my brother, Raul Rosa he's at West Bay Residential. Housing He's a wonderful little man. Anybody who knows him loves him right away. When he was born, they told him that he would not see his 18th birthday. He's now 50. I began to have a family and I was taking care of him and I fell down the stairs and I was 8 months pregnant and realized I could not care for him any more. When my mom died, I told her don't worry about Raul because I'm going to make sure he's cared for. It broke my heart to realize I could not care for him any more the way I would like to. When I was at a loss, West Bay Residential was there. We have taught him so much. He can pour his own drink. He has a job. My mother would be so proud. And I can't say enough. I cannot find words to express my gratitude to West Bay. I hate public speaking this is hard for me. I have to share my heart. I know we are all in the same boat. I know that the legislators are trying to do their job but they don't live with persons with disabilities. I would encourage them to visit the homes of the people who are having cuts put upon them. I would like to thank West Bay for all of the things that they have done for my brother. I thank those who fought for my brother. I would beg those in the legislature to do all that they can. Not to bring us backwards, but see that we move forward in a positive direction to help people who have such great needs. Thank you. (Applause).

Page 40 Cumberland Forum:

JOHN GALLAGHER: Yeah. The only other thing, one other thing is a couple of group homes I believe that are closing, too. Housing You know, it's assisted living cuts. It's a place on Central Avenue and I have a cousin who lives there and it's going to close and they're pretty concerned about where they're going to go. But it's a shame that a lot of these people, they don't have much money to do anything with or you know, drink coffee. I'm totally anti-cigarettes, but I know they have these addiction problems with it. I would like to see them have a little more money in their pocket. I know one individual who does odd jobs but he would love to work part-time fed the opportunity.

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SANDY LABOTTA: I guess my concern is more adult reason related. I have a son that we adopted 35 years ago.

. Housing He's borderline where he's not really eligible to live in a group home because they don't feel that his disabilities are anywhere near what he, you know, what the group home type of population is. I feel like there is no, uhm, housing or any kind of uhm, services for someone like him. And I've talked to several people who have you know, grown up kids now that they're dealing with and there is no place for these people to go. Right now, he's living in an uhm, housing for elderly and disabled. We just had a meeting last week with the person who runs the place and she said that he is one step away from being thrown out of the place. And that he had been warned like twice before. Of course, she never communicated that to us and I've always asked her to keep the lines of communication open because I know what my son is like, and he won't say anything that's going on in the place. And so there's been a couple of incidents where he said people are harassing him in the building, people are writing things on his door like foul things and stuff. That's part of his make-up. I don't know if it's bipolar we're dealing with maybe some schizophrenia, I really don't know, I don't know. I don't have a whole lot of background on his family so I have very little to go with as far as that. But he almost needs like a group home type of setting but not as restrictive, obviously, as the other type of setting. He needs to know, he doesn't take his medication. When he was at home, I would give it to him every day and make sure that he had it and his behavior and his you know, everything was kind of more like on keel. But without the medication, he can't function. He's not held a job, I want to say at least two years, possibly three. And you know, basically, because of that, he's not staying on his medication. There's nobody there to say you need to take this, you know? And he'll do it for a while, he'll do it for a week or two or even a couple of months and then he feels he doesn't need it anymore. He feels he's in control, but everyone else around him knows the difference between on medication and off medication. You know, the only solution I have at this point is to bring him back into our house, which would be very disruptive. Human Services And I think almost kind of going backwards with him, where he's finally learned to kind of live on his own and he has his license, he has a car. But he doesn't know how to handle money. He doesn't get that he needs this medication. He doesn't get that you know, the car needs gas to run and so he's run out of gas like I can't tell you how many times. He screwed up his engine because of it, it's like, this kid is like totally dysfunctional. You know, as much as he feels he's functional, he's not. I've looked into some housing and there isn't anything for those kinds of kids. You're either down here or normal. But there's nothing. And even in the school system, he was always put into a special ed class that I felt was not geared to him, but there was nothing else. So they would kind of like appease me by saying we're going to mainstream him into this class and mainstream him into this class but I don't think anything has ever, ever worked and now he's 35 years old and we're not really sure what can be done or you know.

ANGEL MADERA: I'm Angel Medera from Spurwink Rhode Island. Housing You're right there isn't a lot of housing for folks with disabilities. I run a program from Willow Street, it's an 811 program from HUD and it is specifically designed for folks with disabilities. Unfortunately, there aren't enough. Okay? There are several in the State of Rhode Island I could put you in contact with some of those folks my issue is of course, the services for these people who are living

independently are threatened now and folks will be in the same situation your son is in where you'll have a manager threatening to throw them out. So, when you get rid of support services and you lose your RIde program, and you lose some vocational hours, you know, what's left? It's a lot of chaos. So, it's a huge challenge. So if you could find a program that would be great for your son.

LEO CANUEL: Angel, could you define an 811 program?

ANGEL MADERA: An 811 program is a subsidized program where the individual pay a third of their income towards rent. Basically, it's section 8, but it stays with the program. They can't take it with them.

SANDY LABOTTA: See that's what I was trying to get him was something like that.

ANGEL MADERA: They were developed specifically for people with disabilities because there was a complaint of the elderly and their families saying that you know, these folks are a problem in these high-rises or developments and the answer was smaller housing developments, 10-12 units for people with developmental disabilities.

SANDY LABOTTA: Now, are they like, is someone there as far as like the medication aspect of it or --?

ANGEL MADERA: What happens is the individual will then contract out with a supporting agency and that supporting agency will help oversee the medication, doctor's appointments the necessary things and then of course making sure he puts gas in the car or registers his vehicle. You know, you would have an annual plan where all of these services would be outlined and goals on how to maintain those services.

SANDY LABOTTA: Okay. Where does the money come to get into those services?

ANGEL MADERA: It's actually threatened right now with the Federal government because the funding is not there. It's usually money that comes to each state through what they call a SuperNOFA lease¹. Your son and others applying for these funds and then developing an apartment building of that type.

SANDY LABOTTA: Do they have apartments locally for this or?

ANGEL MADERA: They do.

JUDITH DREW: And a waiting list?

ANGEL MADERA: A five year waiting list.

MONICA TAVARES: How is that supported?

ROGER HARRIS: Sorry, I didn't understand what you said.

ANGEL MADERA: SuperNOFA. Program.

JUDITH DREW: How many programs are there like this around the state?

ANGEL MADERA: I manage two of them. Two in the city of Providence. I provide let's see 22 units right now. There are others.

LEO CANUEL: Historically, originally people with disabilities were not supposed to be lumped with elders and when the programs were started back in the '70s I believe, they were supposed to be creating two separate programs, programs for people with adults with disabilities and elders and then they realized that elders have disabilities so we'll throw them altogether, because they didn't know what else to do and thought they would deal with the people with disabilities later and of course they never did. And that's why adults with disabilities can go into elderly housing and originally it was for peep well physical disabilities and we have extended those laws. But it doesn't solve the problem. Other states have a variety of models that work as well. They have supportive living where people live in their own apartment but they have case managers that come in and help them periodically with their need which works very well or congregated housing where you have people living in one particular unit where they have their individual bedroom and a common area and support staff coming in and out. Rhode Island has not matured to that level yet.

ANGEL MADERA: We have extended those services to provide three units in a condo association in North Providence. That's working very well. That's the ultimate model where people can have a decent place to live that's safe and clean and quiet and also provides some supports.

LEO CANUEL: Any other questions and comments for Sandy. Identify yourself.

DEB O'DONNELL-LEE: Deb O'Donnell-Lee, Is there a website we could get a hold of from that gentleman?

ANGEL MADERA: I can provide some information.

DEB O'DONNELL-LEE: Okay.

LEO CANUEL: For the CART services when you start speaking please identify yourself. Because the CART has no way of knowing who is talking. Okay? Again Sandy, please?

SANDY LABOTTA: Human Services Just one other comment, you had said that you know, some people like can live independently with the extra services and so forth, and we actually tried that with my son when he was first living in his regular apartment by himself or with the girlfriend or whatever. But what happened in that situation and what happens

¹ Super Notice of Funding Availability (SuperNOFA) for Economic Development and Empowerment Programs, US Department Of Housing And Urban Development

pretty much all the time with my son is that he feels he doesn't need anybody to help him. So, I hooked him up with I can't tell you how many services. I hooked him up with someone who would come in and help him to grocery shop and get to know what he should have in the house and shouldn't. Because at one point, he had lost like probably 60 pounds. And what he does is when you try to help him like to do things, he pulls away from the family unit because he feels like you're interfering with him. Like he can do it. He doesn't need you kind of thing. So he pulls away from the family unit and as a result, he ends up, you know, like I said, he lost 60 pounds. He wasn't eating; he wasn't doing things right he looked emaciated. When things are really, really bad he'll let you back into his life again. It's always been that kind of back and forth thing with him. We had set him up with work opportunities and they were try to go help him find a job and they even gave him a job coach to help him in the job. The problem there was he wasn't taking his medication. So you could put ten job coaches with him, and it's just not going to work because he's not mentally capable of hanging onto that job. So this is why I feel like you know, there needs to be some kind of housing for people like this because he's actually gotten a job where he was nowhere near qualify. But he's such a BS artist, if I had him sitting here you would think he was a rocket scientist and he's not. But he has a lot of good language basically from school and at home. He can talk his way into anything. You sit there long enough with him, you'll know what you're dealing with. But if you don't if it's just on a little interview, you would hire him with no problem. So he just falls between the cracks.

JUDITH DREW: He's one of the individuals that falls in the cracks and will continue to fall in the cracks and we see this all the time. This is not going to help you but you're not alone that's all I'm going to tell you. It's not much comfort.

SANDY LABOTTA: It's very frustrating.

JUDITH DREW: And it's very frustrating to people like me who provide services and to the organizations that I know provide services because we see that population out there and we can't identify a funding source to help us create the wrap around service that your son needs that's the problem.

SANDY LABOTTA: My daughter is actually a special ed teacher and we were discussing it last week. She said yeah, mom, I wish there was something. She knows what he needs. She is my biological difference but it is there's only a year difference between the two. She knows what he needs and all these kids or adults in that bracket need. She said I just don't know where to get the resources. I wish I did because I would actually start a group home for these kids or whatever. But like I said, there's no resources for that. So when he was under 18 there was all kinds of stuff. But now, nothing.

LEO CANUEL: I did see one private model out on Martha's Vineyard for adults with some type of mental disability and mental health issues where family members got together bought a house and in Massachusetts you can get on the personal care assistance program to provide services. So they used PCAs to provide support service in the house and all of the residents of the house are co-owners of the house. But those were four or as a function of time five families that had resources to be able to do and they're still involved. Basically it's a privately run organization within that one household. It works perfectly for the folks in that household and maybe that's because the government is not involved in it. And I want to congratulate your son because I have my PhD in BS, too. So I'm going to move on. Thank you very much.

(LAUGHTER)

LEO CANUEL: Can we go on to Patty Davis?

PATTY DAVIS: I have a son who is 19. He has autism very severe. He does not talk at all, he doesn't understand any dangers. Human Services When he was younger he practically ripped my whole house apart, jumped out a window. I had to lock my girls in their bedroom a few times. So, you know, he had gotten services from The Learning Center. He was in a Learning Center School and group home. Right now he's in the transition period because he's 19. We are waiting. He did meet eligibility to stay in a group home but I have not gotten a social worker yet because he has to go through the new SIS evaluation system. If I have that right. My question is I just had a permanency hearing with the Court last week for him, so for a year, I think he's safe. But I feel like there is no more permanency in this state. Housing My son I was told there will be no more group homes and he would probably be put in a group home situation, but would it be a specialized group home like the Groden Center. If it's not, I can see him receding back. Which is another one of my concerns, when they see they're doing well, they think, they can bring him back home. He's definitely not doing well enough to go back home. But there are kids where they have periods when they do well and they try to do that. There were so many families from the Groden Center where they got the state to provide a group home. There are five of us, we know our kids will be 21 around the same time, we would like them to be in the specialized group home together because they have the same needs. It doesn't look like that's going to happen. They talk about Housing shared living. Ryan wouldn't fit the shared living that they're talking about right now. My other concern is about the BHDDH spending and training and their consultant SIS evaluation. They haven't started yet. They're still training and evaluating their system. So my son is in a loophole along with everybody in the state because we don't know how long this process is going to take, the evaluations. We don't know when the train something going to be done and all of those people they're training qualified to evaluate our children's needs? I don't want somebody that has just been trained to come in and try to evaluate you know what Ryan really needs. I think he was evaluated by everybody in the state. He's seen all the best psychiatrists and you know, he actually has Dr. Sachs as his doctor. I don't understand where we're going backwards and reevaluating everybody and spending more money when we don't have enough money as it is. I feel like we're going to be cutting services even more and then there's too much of a loophole. I don't know what's going to happen with my son when he turns 21. I would like to know that now. I don't want to wait until he's 21 and they say we're going to put him in

this group home over here and he's not with people that know how to care for him. It would be a very dangerous situation to other people and himself. And I'm not the only family in this loophole. You know, I feel that it's not just like this woman's son that's being dropped in the cracks. I think everybody is being dropped. I've heard from DCYF, oh, your son is doing so good when we go to the IEP and take him home. You know, my boss seems to think maybe you should take him home, they're talking about it. And I'm like, don't you really understand what autism is and how bad it is. When I take him home, I have to do things I don't want to do. I might have to give him soda. I have to lock everything up in the house. I have to spend all of my time with him while he's there, every second watching. I take him home because I love him, but it's not an easy situation. He really needs the specialized group homes and those are threatened right now. So that's my big concern.

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JILL HANKINSON: I understand that, I just don't write well, Hankinson. Human Services And I, too, have a son, seriously disabled with autism. He is going to be 27. He is luckily in a group home that is a wonderful group home. He is well-served by the Groden Center. I agree with Patty. You can't put people with autism in any group home. They have special individual needs. They need specific help and that's what my son is getting there. He's doing very well. I wanted to say that my concern is that, there are three concerns. First is that we keep having group homes for people like my son. I mean you guys are going to be -- a lot of people are coming in who have autism. They are going to be older and you have got to start getting ready for that population. It is really special. That's what I think. Group homes should be there for people who need them, those people especially because they're going to need them. I'm concerned that you fund the people who are there to help the people in the group homes. I'm concerned that that funding be there so that these kids, these adults are safe and they're trained well. I'm also concerned that there be money to make sure that these people are safe. And there are so many ways of looking at safe. I mean, physically safe, they're not molested, that they have homes that are safe. There are just so many things there. Those are my three concerns. That is what I wanted to say. I have to say also, I have an older son with autism who has Asperger's and he's much like Sandy's son. Housing Right now he's homeless. He stays on his meds thank God. He's been diagnosed with schizophrenia. He has been from place to place. He is now living in Providence and he is luckily serviced by the Providence Center and they have done really well with him. I have to compliment the state on the Providence center. Please see that it keeps getting funded. I don't know how the woman there who helps my son is able to take the time to take him grocery shopping once so he knows what to do at the grocery store. God love her because he won't listen to us. Thank God she was there to try to help him. And I will be quiet now. That is what I wanted to say.

Page 75 Blackstone Valley Forum:

NANCY LAUSIER: Housing I am actually an owner of the assisted living facility here in Pawtucket. Seven years ago I bought the building and thought it was a good thing. I'm a social worker by trade. I said that this will work out well, when I took the people that are not elderly, the people with mental illness and development disabilities where there were no group homes for them to go to. My building holds 14 people, eight of which now, have developmental disabilities. Because there was nowhere for them to go. They are problematic people. They cost the state of Rhode Island hundreds of thousands of dollars going in and out of psych units over the years. I get \$1,212 a month. \$55 goes back to them. None of my residents are in and out of psych units. All of them are stable with that little bit of money. I live in the building as of three years ago when the state of Rhode Island decided that there will be no increases.

I could not pay for staff. No problem, get rid of two beds, move in and work my butt off. Pretty much 24/7. It kept my doors up and my residents with a roof over their head and able. Now, they are going to take \$206 times 14 residents. There's one of my mortgages. I will be one of them closing my doors. I will be filing bankruptcy in the process as well. We are in dire straits. This is not doable now. It was doable when I moved in and we managed without an increase. If they take the \$206, I can't stay in business.

KATE BOWDEN: Can you explain what the \$206 is coming from.

NANCY LAUSIER: SSI. Article XXIII. It is going to take the amount of money from the State of Rhode Island contribution to my residents.

KATE BOWDEN: They are changing the subsidy amount.

NANCY LAUSIER: They are. It is one thing to not give me an increase. You know what, I'll find a way, but \$206 per resident. My mortgage, one mortgage is \$2,400. And there's another mortgage that is \$1,500. Then there are the taxes, when the city of Pawtucket graciously reduced the amount of my property value, increased my taxes and I have to pay that, too. I have the fire marshal -- that I need to put doors here and there, where am I going to get them? I can do the doors. I do all of the repairs in the building, too. I'm almost 60. No. Wow. I do the work. Why? There's no money. I will do the work. I have tools, I like doing it. I don't have a problem with that. I can't do it without the \$206. I really, seriously will be giving 30 day notices on September 1st if it is not fixed.

GWEN REEVE: I don't know what to say in terms of that amount of time. What happens to your residents if you close?

NANCY LAUSIER: Here is the question. Here is a good question because I don't see A Better Day represented here. Manchester Manor because I'm sure they are back saying there's no use nothing we can do. Who are we? You know

what, me and these three gentleman here who are my residents decided we are going to come and put in our two cents, if it helps, then you know what, those people that sat back and said "I just can't do it any more" we'll be happy that we came. For us it is worth it. We think that they are so disparaged right now that they don't even have the umph to help themselves. This is a slight representation of my residents. The building holds 16, but I take up one room. I don't share. I draw the line.

I've been living there for three years now. Which, I don't mind. It is all right, but \$206, I will not be able to pay the mortgage. I'm not going to have a choice this time. I found a way all this time but there's no way. I can't do it.

I've contacted a bankruptcy attorney just in case, so, line up the ducks because it looks like my ship is going to sink unless somebody does something. Eight of my residents have developmental disabilities. There were no group homes for them to go to before they came to me and they have a psych problem on top of that. So if there was not room for them then, where will they go now?

ATTENDEE: Why don't you talk about the situation of the group home?

GWEN REEVE: If you want to speak. Why don't we sign you up? Great.

ATTENDEE: Is the reduction scheduled to place?

NANCY LAUSIER: October 1st. I have to give 30 day notices, because the Alliance has to get involved and God knows who else. I don't know where they are going to go. None of my people will qualify for nursing home. You have elderly people you might slide them off and at least if you have to close the door. Most nursing homes are not equipped for dual diagnoses, DD and mental health issues. If they are elderly, they can. Some will not take them. My guys don't qualify. The only place they called was mine. My decision and choice was to take the younger psych population because I have a background in social services. I think they are the best population. They are the greatest.

ATTENDEE: What is the name of your place?

NANCY LAUSIER: Donella's Manor. It is my daughter's name. She was going to take over when I retire. It was here in Pawtucket. 105 Beechwood Avenue in Pawtucket.

GWEN REEVE: One things that you said we are not a panel of legislators. We have not made the laws. Some of us have specific expertise that may help clarify some things. As I mentioned our primary job today is really to listen to what your concerns are and try and get the information from you.

NANCY LAUSIER: My understanding is that it goes back to the Governor.

GWEN REEVE: We take the testimony from all of the forums that are being held around the state. There's eight or nine of them. We put it together and look at where we need to invest our time and efforts with regard to advocacy and legislation. You need to know that we've fought against some of these changes.

NANCY LAUSIER: I'm a member of RIALA and they tried their best, too. The powers that be, just slid it through. You know what? They are not going to file bankruptcy. They don't have developmental disabilities and they don't have mental illness with no money. To them it is neither here or there. To my guys it is. To me, too. Because I'll be homeless, too. I live there.

ROGER HARRIS: Nancy, the Alliance.

GWEN REEVE: It is an Ombudsman. They oversee long-term care facilities and if there are complaints with care.

NANCY LAUSIER: Or crisis such as buildings closing. Just to let you know even before all of this, there have been eight small assisted living residents that have closed their doors over the last four years. That's why there's really nowhere for them to go. I have some of those people in my program.

KATE BOWDEN: Your folks with developmental disabilities get services through the Division of Developmental Disabilities?

NANCY LAUSIER: I have one resident that gets minimum. Human Services Because they go to Generations Adult Day Program. So I don't have to pay for staff to watch them while I run to the restaurant store, Save-A Lot, Dollar Tree and anywhere else I have to go so we can get food at a really, really good price because we have a budget as tight as can be. I want my residents to have quality food so I do the shopping myself and the maintenance and plumbing. I do some electrical but don't tell the electrician. If I have to have a second career I'm going to the kitchen. Because I do that, too. I have a food safety certification and also the Med-Tech.

ROGER HARRIS: Do you do laundry?

NANCY LAUSIER: Yeah, every morning and every night for the residents. I have the residents that help. I have John over here, computers are not my thing. Housing I have a computer geek who lives with me. John was in and out of psych units over the years, costing the state of Rhode Island thousands of dollars. He has been with me 4.5 years he's one class away from an Associates Degree in art. Huh, John? This is what we can do. John can be out there living in an apartment and doing well. He needed a stepping stone. The majority of my residents are permanent. We always have one or two, who are using our building as a stepping stone. John is one of them, we just took a 23-year-old with brain damage when he was an infant. 23, who is unable to even understand what step to take to be an adult. He will pass through, maybe, if we don't close our doors and eventually be gainfully employed and out there, hopefully. The rest of my residents are permanent residents. They have psych issues that will not allow them to live independently. They do well, they are happy. And they love their home, don't you guys?

JOE: Yes.

NANCY LAUSIER: Terry used to live at a home that let him go out in temperatures of 90 degrees in a winter coat and he had heat stroke because he was not being taken care of. It has not happened since, right? Rickey was living in a

home, a home with his sister who was not equipped to deal with four developmentally disabled adults with anger management problems. Rickey came to us from the community and he has been with me since the beginning, seven years. And a year at Ashbury Manor. Now, seven years. Something you want to say about your home?

TERRY: Well, my sister.

NANCY LAUSIER: No about where you live now.

TERRY: I live in Donella's Manor. I clean on Mondays, but I broke her stuff.

NANCY LAUSIER: But it is okay.

TERRY: It is okay. I had to pay for it.

NANCY LAUSIER: John and Rickey both on Monday they don't go to Generations they stay home and we clean the building top to bottom third floor all the way down. They earn a bit of extra money. They get \$55.

RICKEY: I cut the grass. I cut the lawn yesterday.

NANCY LAUSIER: Rickey likes anything with a motor. Huh?

NANCY LAUSIER: Don't forget the power tools. As long as he's supervised he does very well. He likes the circular saw.

NANCY LAUSIER: Generations is an adult day program. Human Services It is geared for everybody. Elderly, to young people and they just moved to Smithfield and they are awesome. It is fantastic. My guys, a lot of my guys before they went to Generations had activities at home. When I bought the building. I was like you have to get out of here and go somewhere and stop looking at the four walls. They started going there and they started to think about other people besides themselves. They've all grown tremendously. They go to Generations sometimes they would like to sit and do nothing. They go because they know I don't have to pay for staff and I can get other things done. Even though a lot of them have a hard time staying awake or paying attention because they are on medications that cause a lot of drowsiness. They get up each and every morning and they go so they can maintain that home. They do this because they know I'm going to do what I can to keep a roof over their head. This is an effort by all of us. They are just as important as the legislators who have all of the money. Maybe more so, because they need us.

ATTENDEE: Thank you for telling us your story.

GWEN REEVE: Do you want to have them speak.

TERRY MALLARD: I just want to say how important this is to us and to everybody. Housing Just think of the things that we are saying as far as I can't explain it, you know, as far as, I don't know where to start is to explain it. Just think of the things we are saying and those things that we are saying means our life, you know. I just want to say that it is so important what we are saying just listen to what we are saying, thank you.

GWEN REEVE: Thank you. That was Terry Mallard.

I live where I live and I don't want to leave it.

ROGER HARRIS: Good job.

GWEN REEVE: How about John.

JOHN: Before I came to Nancy, -- I had dual diagnoses of substance abuse. I could not be trusted to live on my own, I attempted suicide three times. My father had me placed in assisted living. I was there for four and a half years and I've been clean and sober for four and a half years and I've been in psychotherapy for two and a half years. I've finished two semesters at college. I've been making progress. I'm presently looking for employment. I'm not really concerned with what is going to happen to me when these doors close, but this is their only chance at life. This is their only chance at life. They cannot survive in society. What will happen? I don't know what to say.

GWEN REEVE: Thanks John.

ATTENDEE: Congratulations, John.

NANCY LAUSIER: He's more concerned about his little guys. John will find a way. We'll get him hooked up, if it happens. He has good support services and he has come such a long way.

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KATHLEEN KELLY: Thank you. I'm Kathleen Kelly, the Executive Director of the Rhode Island Assisted Living Association. Housing We've come again to talk about the cuts to SSI for people in assisted living. I apologize I don't know what has been discussed prior to my arrival. What I can tell you is that the cut, we've been told that the cut to the SSI program as it relates to people in assisted living was designed to be a cost-saving measure because someone looked at the contributions to SSI that other states have made and saw that in Rhode Island, the contribution was higher than other states.

What they did not know was that Rhode Island opted to contribute more in the SSI program because it is an integral part of providing assisted living services for Donella's Manor and Darlington and A Better Day and Manchester Manor there are two pieces to it. It is an SSI for one level and an integral part of the funding for the state waiver programs that provide SSI services. That was not part of the consideration.

It was in Article XXIII, it never got a hearing because it was understood to be a straight budget savings. No hearing was involved. There are ten providers that fit the profile of Donella's Manor, they will be immediately impacted as I assume given all of the people that are here that you talked about. The people who lived with us in those assisted living providers as someone already said, they are doing God's work. They take care of people, all of those people need is care coordination, medication management, proper nutrition and a roof over their head. This cut is two things, it is not just a

budget cut. Because as part of the budget, the General Assembly reached into the Public Assistance Act and permanently lowered that contribution. It is not like other budget cuts where you can find money in administrative services. The one tiny blessing in this terrible situation is that the cuts are not effective until October 1st. In assisted living we have to give our residents 6 -- 30 days. There's no other option. I'm truly an option. As far as the SSI only people. There's not an option now. Number two is those people who are on SSI and are a part of the Global Waiver Program, as Margaret eloquently said, those people will default to a nursing home. There's no other placement. I would like to point out that the Global Waiver, the whole transition of preventing people. They prevented approximately 150 people from going into a nursing home. We are looking at 175 people that are looking straight at a nursing home. They don't need that level of care.

ROGER HARRIS: Pardon my rudeness. The money that you are referring to the cutting is the same money the \$206.

KATHLEEN KELLY: Yes \$206 per month.

ROGER HARRIS: What is the daily rate? What is it \$38 and change a day.

JUDITH DREW Verses almost \$300 in a nursing home. Kathleen and Margaret, I'm Dr. Judi Drew a Commissioner. I wanted to introduce myself before I ask this question. I hear you talking about the number that will be displaced. We are all concerned. There's been a lot of advocacy at the Statehouse to not have this act be passed.

We were not successful this year. What we are trying to do is establish a legislative and advocacy agenda for this year. You are saying that these people are going to nursing homes. But, in fact, nursing homes, this is my belief; nursing homes in fact are not taking people who are on SSI as you indicated. You are trying to avoid it. In fact, there is a waiting list for more nursing homes. If there are not nursing home beds available for these people. Where will they go?

KATHLEEN KELLY: On the streets.

JUDITH DREW: Many of these folks cannot be in the streets. If you cannot pay the bills and you are filing bankruptcy, there's no choice. You are giving them 30 days notice. Part of what you need to do is work with the nursing homes to identify who will take folks. Based on your prior experience. What I'm trying to figure out and what I would like to include. What does that realistically mean. Where will the people go.

KATHLEEN KELLY: Forgive me residents -- I am brutally honest. It is hard enough to say. They will be homeless. There's no. They will not end up in a nursing home.

JUDI DREW: They will not meet the criteria to get into a nursing home. Some will, but not many.

JUDI DREW: They don't need skilled care.

People on the waiver have a nursing home level of care and it is in the community. That's a little bit different, but what I think will happen from the nursing home is, first of all, you are right there's limited availability in nursing homes across the board. These are state-funded clients.

JUDITH DREW: They will have the lower priority, if any. I don't run a nursing home, but I can tell you that the state has an accountability. They have to be provided for nursing home care. My guess is that they would open some of the beds that have been closed. They are being held as unused. I don't know the answer to that question.

JUDITH DREW: So you have not ask the question, what are your plans? Now, we have to discharge these people what is your plan?

KATHLEEN KELLY: We've asked that question.

JUDITH DREW: What was their response?

KATHLEEN KELLY: The initial response was that they saw the cut at the same time that we saw it, it went through in the budget, they needed time to sort out the fallout. They were able to confirm to us what the anticipated side effects, if you will, were accurate. I can tell you that Director Powell called a meeting yesterday scheduled for tomorrow at 2:00 p.m. where they are together with Medicaid people, state people who understand what is going on that literally happened yesterday afternoon. I apologize for my ignorance regarding this cut. Has the Act passed for this budget year?

ATTENDEE: Yes, but it is not effective until October 1st.

KATHLEEN KELLY: This is for 2012. We don't know what will happen for 2013.

JUDITH DREW: If you look across the country the SSI rates being paid are in line with the South, Alabama, the cost of living there is much less than it is here.

KATHLEEN KELLY: Correct. With all of these cuts, the ones that were made there were no plans for transition for these folks?

ATTENDEE: I'm pretty sure they did not give us a second thought. No doubt about it.

ATTENDEE: I don't work for the state, it was explained to me that it was a straight cost savings. It was not in the Governor's budget. It came out of the House Finance Budget. At that point we advocated long and hard but we were unsuccessful.

GWEN REEVE: We have another speaker.

ATTENDEE: I guess, I don't know everything all of the details, I know enough. Housing What I'm seeing here and hearing people talking about where will they go? They won't qualify for a nursing home. They shouldn't be in a nursing home. That should not even be a question. You are talking about five times the amount of money. What is going on? We had one week to advocate against this budget cut. This all seems a little bit late. I actually came here, I thought we had a pause on the bill that was going to be a month of discussion, they actually did not pass. Now, I'm learning that it did happen. I'm astounded. I'm talking to people about advocating for an increase in the Global Waiver for Alzheimer's dementia. We have people that are 63, they are physically fine. They need to be in a secured unit. If they don't have

\$5,000 to go to a secured unit. They are in a nursing home. 2/3 of people in nursing homes are on the Global Waiver. 2/3s. From what I understand, the population is going down and they are considering closing a few nursing homes so they will fill up the others. There are a few that are filled.

I am -- somebody needs to make sense of this. Somebody needs to do something, someone needs to do something. I'm going to do something. We are wasting money. Can someone please tell me how it makes sense to cut \$206 from someone with nothing? We are talking about I think it is 200 plus people in the state of Rhode Island that they took this \$200 a month from, it is completely unconscionable. If you could sit and talk just money you could advocate for it. You don't even have to care. Someone does not even have to care about these people. They can be totally business and completely successful. You could make the argument that these costs are going to cost -- these cuts will cost us more money down the line. It does not make fiscal sense. I need to know, how can we educate the people that are making these laws and cuts in legislation, how do we translate what is going on down in the ditches and get it out? We could save a lot of money. Increase our waiver but a couple of hundred dollars, now we can accept Alzheimers and dementia without going out of business. Now, you are saving approximately \$4,000 a person. It is saving \$4,000 a person. And they are living a better quality of life. By the way, nursing homes are not required to have Alzheimer's dementia training. People who are 62 and are completely physically fit and are gentlemen who have behavioral issues, they are drugged. Because if you don't have staff that can deal with people that have behavioral issues and are physically fit the only way to control them is with medications. There we go again. Expensive. And taking someone's life and ripping it from them. You know if you need help, if you need someone to talk or you need to whatever it is, I'm here, because we have to do something. Next year, I do have one small question, I'm sorry. The way that the Global Waiver works. This \$206. There's been some question will it be deducted from the share or from the rent/board. Will it be taken from the \$700 for room and board? Or taken from --

ROGER HARRIS: Where are you from?

ATTENDEE: I'm the Executive Director for Darlington Living Centers.

ROGER HARRIS: Eloquent.

ATTENDEE: Thank you.

Page 104 Providence Forum:

MATTHEW FLAHERTY: Flaherty, I came before this committee today to tell you that because of what may be transpiring with the SSI cuts, Housing I live in assisted living but I'm not just a person with a disability I'm a taxpayer, I work for a living as well. And I'm very concerned about those cuts because what might happen is our assisted living due to those cuts may have to close. We at the manor, we call ourselves brothers from different mothers and we really do not want to be separated. We've been together a long time. We like where we live. We want to keep the house and also the thing about

MATTHEW FLAHERTY: Flaherty, I came before this committee today to tell you that because of what may be transpiring with the SSI cuts, Housing I live in assisted living but I'm not just a person with a disability I'm a taxpayer, I work for a living as well. And I'm very concerned about those cuts because what might happen is our assisted living due to those cuts may have to close. We at the manor, we call ourselves brothers from different mothers and we really do not want to be separated. We've been together a long time. We like where we live. We want to keep the house and also the thing about Transportation. RIPTA, I rely on RIPTA to go to work and go home, go to the movies out to eat, and just food and close shopping. I never did drive, but those cuts will affect me deeply and affect my friends deeply. A lot of the friends have the same disability I have which is schizophrenia. But I'm glad with medication and that's another thing they do at the manor, they make sure we have our meds and eat good. I'm very much concerned about that and I don't want to see us have to be separated. We don't want to see the manor closed. Let's try to make Rhode Island a better state than it is now, thank you.

RORY CARMODY: Matthew, there's currently a task force currently be headed by Sandra Powell head of DHS, and eviction notices have to go out before that September 1, so people have to try to figure out what to do in response to that because it's not a good solution. The state thought it would save \$900,000 not realizing people in the assisting living facilities have \$600,000 of that back to the state. So the savings is \$300,000. And a bulb just went off and people realize that. In addition to your brothers 30-40 nuns will also find themselves displaced. And the closer numbers are 500 between the DB waiver. I would suggest to contact Sandra Powell and Eileen Norton. She's another good resource.

MATTHEW FLAHERTY: Thank you.

TIM FLYNN: It's important that you follow-up with the folks that Rory recommends only because you know, it's important to put a face on it. And I think you represent it very well. You state the problems very well and so I just think you would be a very powerful advocate to maintain the program.

MATTHEW FLAHERTY: There is a radio program, NPR, you access the website and you get my broadcast, 24/7.

TIM FLYNN: Really?

MATTHEW FLAHERTY: Yes. Go to the website and you will find my broadcast. It's 4 minutes and 27 seconds long.

Donna Breen
117 Massachusetts Blvd
Portsmouth, RI 02871

July 21, 2011

Governor's Commission on Disabilities
John O. Pastore Center
41 Cherry Dale Court
Cranston, RI 02920-3049

Dear Committee Members of the Governor's Commission on Disabilities of RI,

In honor of the anniversary of the signing of the Americans with Disabilities Act, **I am writing to request no more budget cuts, and serious consideration to restore the funding to Development Disability Programs.**

There has been consistent cuts to the programs that provide and support vocational help and Housing residential assisted living 10 people with developmental disabilities since 2009. It is time to stop cutting the budgets 10 these programs. I work for an agency that supports 700 people and their families with disabilities. I have been employed by this agency for over 10 years. The people, who are supported by these programs, are productive members of the community because of these programs. The people with developmental disabilities, live, work, go to school, and volunteer at many other non-profit facilities. Their quality of life is dependent on these services. Their families are able to work and be productive members of the work force because they have supports for their loved ones.

Hello, my name is Max Zapata and I am representing the Save Our Mental Health Services Coalition, or SOS for short. I am concerned about the following issues, and I would like the Governor's Commission on Disabilities to focus on these in the upcoming year

The SSI match for Housing Assisted Living has been reduced by \$206 a month. That means that some Assisted Living facilities may have to close, and people will end up in more restrictive Nursing Home settings, which are also more expensive, or they will end upon the streets. We ask that the state find a way to keep all people who need it, in Assisted Living.

The Department of Behavioral Health, Developmental Disabilities and Hospitals, or BHDDH, got a grant to start a Certified Peer Specialist program in Rhode Island. Many states have such programs. Certified Peer Specialists are people who have themselves experienced mental illness, who can use their experience to work with their peers in ways that mental health professionals cannot. They work in mental health centers, peer-run organizations, etc. The program in Rhode Island was supposed to be running by this past February, but we have heard nothing further. We are asking that BHDDH have a peer-run Certified Peer Specialist program, meaning that the peer-run organizations should be major players in running this program.

We ask that the Eleanor Slater Hospital receive sufficient funding for all people in Rhode Island who need to be in a long-term psychiatric hospital.

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Manchester Manor ALF 8/2/2011 2:00 PM

Dear Governor Chaffee:

I have spoken to Will in your office a few times already. I just recently had replacement knee surgery; otherwise I would have been at the July 27th meeting held in Cumberland. I have great concern about taking away \$206.00 from each SSI resident Housing I have at Manchester Manor Assisted Living facility. I have a few questions I would like you to answer. This September 1, 2011 will mark 30 years for Manchester Manor and it has been a home for many residents. They are MY family. Where do you plan to move them to? In a new beautiful Assisted Living for \$2,000 to \$3,000 per month? Who will take them? They do not qualify for a Nursing Home! They are very happy where they are. They will end up on the street (where some of them came from), where they will end up not taking their medications. They will spend whatever money they have on liquor and drugs. Most of the residents of Manchester Manor don't even have families. At Christmas time, a local catholic church brings them gifts (clothing, shoes, and other things they can use year round) otherwise, they would have nothing. The only "family" they have is each other, and you are going to take them away from them. I just don't understand your reasoning. These are "elderly" mentally ill people that need protection. Who will take them? I count at least 9 small Assisted Living Facilities in Pawtucket alone. No facility will take them for the monthly payment. My home needs a new roof and a paint job. My residents come first, but with a decrease of \$6,798.00 a month--this will be impossible. My residents keep asking me "where will we go?"..and at this time, I don't have an answer for them..Maybe you do? PLEASE reconsider this option. I invite you to send a representative from your office to visit Manchester Manor and talk to my residents and me.

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Richard Wilkes 8/7/2011 11:08 AM >>>

To whom it may concern:

I apologize for the late submission. I live in the St. Louis, MO area and visited with my father in Rhode Island this weekend and discovered this notice for public forums to identify the concerns of people with disabilities and their families. I am writing to you now, and request this be placed in the public record.

Housing My brother is a developmentally disabled client who currently resides in a group home in Rhode Island operated by West Bay Residential, and is a day program client of the Cranston ARC in Cranston, RI. Due to my father's declining health and recent relocation to an assisted living facility in Rhode Island, I have also assumed guardianship for my brother. I was recently notified of the program cuts that were enacted by the Governor of the State of Rhode Island and the further cuts passed by the State General Assembly. To be honest, I find the current situation appalling and unacceptable, putting our most at risk population at a severe disadvantage.

Fifty years ago, Rhode Island "warehoused" those citizens with developmental disabilities in places like Ladd Center. There was abuse, no individual rights, no support, just a place for these individuals to vegetate. Rhode Island became one of the more progressive states by closing institutions like Ladd, established funding for several day programs like the Cranston ARC and established a progressive system of group homes like those operated by West Bay Residential. When my parents made the difficult decision for my brother to enter a group home situation, it ended up being one of their best decisions. My brother has thrived in this environment. He has friends, he is happy, he has his routines, and has a more fulfilling life. Unfortunately, not many states including my prior residence in New Jersey or my current residence in Missouri are anywhere near the level of care and compassion Rhode Island has developed for this at risk population. It is one of the things that made me proud to say I am a Rhode Island native.

That has changed with the recent budget cuts. The level of care that the State itself has signed off on, cannot be maintained with the current budgets. That will result in change in the level of service and care my brother receives. Although the State has indicated the level of services are not to decline, I have been responsible for budgets myself for many years and know you make compromises and these clients level of service is at a significant risk. What is worse is that many developmentally disabled individuals do not like change to their routine and comfort, my brother included. I do not look forward to his reactions when told he cannot go here, or do this, or that the staff at his facilities are cut back. For Rhode Island's political leaders to take this approach is very concerning, especially knowing my brother was in good hands while I live elsewhere. I no longer have that level of confidence and feel that these decisions are a clear violation of the rights of an at risk population. I am very concerned for my brother, his friends, and all developmentally disabled in Rhode Island and the level support they will be receiving going forward. I am hoping that the State does not return to the days of warehousing our disabled in facilities like Ladd.

I strongly encourage you to restore the appropriate level of funding to ensure continuation of current services. Rhode Island had been a leader in supporting the developmentally disabled and I'm sure, with the appropriate funding, can continue to be. I also am expecting the State of Rhode Island to honor the contract to which they entered in terms of the level of care for my brother.

Sincerely,

Richard S. Wilkes
 953 Chesterfield Villas Cir
 Chesterfield, MO 63017

| Concerns | Recommendations | Testimony on Pages |
|--|---|--------------------|
| 1. The amount of affordable and accessible housing in RI | 1. statewide legislation including language that would assure priority for accessible housing to be given to disabled individuals 2. a legislative counsel to research legislation in other states that gives preference and priority to disabled individuals regarding housing 3. possible federal (or state mandated) criteria in terms of disability to narrow | 16, 24, 63, 69, 87 |

| | | |
|--|---|------------------------------------|
| | scope to a need based spectrum to obtain accessible housing vs. those who need only adaptable housing. | |
| 2. chemical sensitivity- mainly focusing on pesticides | 4. Adopting a neighborhood notification law 5. A legislative counsel to research laws in place in other states and what agency enforces the laws | 124 |
| 3. SSI Cuts- affect housing- | Write a letter of recommendation to reverse cuts as they deeply affect individuals safety net and income | 30, 36, 40, 75, 80, 104, 113, 121, |
| 4. NO ACTION/OPINION | | 124, 47 |



voting check off graphic

MOTION: To recommend the above list of concerns and recommended solutions to the Legislation Committee. JC/KK passed unanimously



alarm clock graphic

Adjournment

Gwen Reeve

12:30 PM



voting check off graphic

MOTION: To adjourn at 12:46 PM by Gwen Reeve, Convener