

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



July 23rd - July 27th 2012

Prepared by
The Governor's Commission on Disabilities

R. Timothy Flynn, Chairperson

Rosemary Carmody, Vice Chairperson

Bob Cooper, Executive Secretary

Gabrielle Mele-Algus, Editor & Mary Brennan Fellow

John O. Pastore Center

41 Cherry Dale Court

Cranston, RI 02920-3049

E-mail: disabilities@gcd.ri.gov

Voice: (401) 462-0100 TTY: via 711 Fax: (401) 462-0106

Adopted on ****

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

Listing of Commissioners (Back of Cover)



RHODE ISLAND AND PROVIDENCE PLANTATIONS
Executive Department
GOVERNOR'S COMMISSION ON DISABILITIES

John O. Pastore Center, 41 Cherry Dale Court
Cranston, RI 02920-3049
[voice] (401) 462-0102 [tty] via RI Relay 711 [fax] 462-0106
[e-mail] bcooper@gcd.ri.gov [website] www.disabilities.ri.gov

Letter of Transmittal

Table of Contents

Letter of Transmittal	1
Table of Contents	2
Topical Index.....	3
Public Notice	4
Public Forum Sponsors	5
Part One: Executive Summary	6
Part Two: Community Concerns and Recommendations	7
Accessibility	7
Education.....	7
Employment	7
Healthcare/Supports.....	7
Housing.....	8
Human Services.....	8
Transportation	8
Part Three: Public Forum Testimony.....	9
1. Monday, July 23, 2012 – Warwick Public Library.....	9
2. Tuesday, July 24, 2012 – Barrington Public Library	20
3. Wednesday, July 24, 2012 – South Providence Public Library.....	29
4. Wednesday, July 25, 2012 – South Kingstown Public Library	39
5. Thursday, July 26, 2012 – Woonsocket Public Library.....	55
6. Friday, July 27, 2012 – Middletown Public Library.....	72
7. Correspondence	86

Topical Index

Accessibility

- Bathrooms, 47, 78, 78
- Chemical and/or Electromagnetic Sensitivities, 73
- Curb Cuts, 79, 100, 101, 104, 105
- Parking Lot, 79
- Ramps, 49
- Sidewalks, 19, 47, 79
- State Buildings, 78

Education

- Accommodations, 29
- Funding, 34
- Learning Disability, 32
- Private School Funding, 32, 40

Employment

- Accommodations, 14, 29, 56, 76
- Back to Work Program, 68
- Discrimination, 58
- Opportunities, 57, 59, 86
- SSDI Trial Period, 59
- Transition, 69
- Social Security Trial Period, 59

Healthcare/Supports

- Affordable Care Act, 42
- Autism, 52
- Blue Cross/Blue Shield, 50
- Confidentiality, [63](#)
- Deaf and Hard of Hearing, 11, 12, 14,
- Donut Hole, 53
- Family Opportunity Act, 53
- Insurance, 50, 68
- Medicaid, 42, 43, 58
- Medicare, 50, 68
- Physicians, 62
- Post Operation, 14
- Pre-existing Conditions, 70
- Social Security, 12, 56
- Social Security Disability Income, 57, 58, 59, 71
- Supplemental Security Income, 18, 44, 52, 68

Housing

- Affordable Housing, 86
- Assistive Technology, 13
- Autism Program, 65
- Chemical and/or Electromagnetic Sensitivities, 74, 75
- Developmental Disabilities Transportation, 15
- Group Home, 21, 30, 41, 45, 63, 65
- Group Home Staff, 31, 66
- Group Home Transportation, 41, 45
- Home Modifications, 13, 14, 34, 35
- Nursing Homes, 36
- Shared Living, 22

Human Services

- Abuse and Neglect, 35
- Allergies, 51
- Autism, 16, 18
- Chemical and/or Electromagnetic Sensitivities, 78
- Deaf and Hard of Hearing, 15
- Developmentally Disabled, 62
- Down Syndrome, 24
- Elderly, 27
- Family Advocacy Network, 25
- Family Court, [86](#), 92, 98
- Governor's Commission on Disabilities, 96
- Halfway Houses, 47
- Office of Rehabilitation Services, 34
- OSCIL, 34
- Programming, 66
- Rehab Act, 34
- Social Workers, 35
- Transition, 16, 62, 64
- Voter ID, 24

Transportation

- Accessible Taxis, 12, 46, 87
- Parking, 13
- RIde, 42, 87, 99
- RIPTA, 13, 99

Public Notice



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

Every year during the week of the anniversary of the signing of the Americans with Disabilities Act (July 26th) the Governor's Commission on Disabilities and over 20 other state and non-profit agencies conduct a weeklong series of public forums to hear the concerns of people with disabilities and their families.

The forums are open for anyone to come in and speak; representatives of the sponsoring agencies will be there to listen. It is important for state policy makers and planners to hear from people with disabilities and their families, their concerns about current services, needs that are not being addressed, and suggestions for improving services and expanding opportunities.

Monday July 23, 2012 6 - 8 pm

Warwick Public Library's Community Room, 600 Sandy Lane, Warwick
Hosted by the Ocean State Center for Independent Living

Tuesday July 24, 2012 3 - 5 pm

Barrington Public Library's Gallery Room, 281 County Road, Barrington
Hosted by the Brain Injury Association of RI

Tuesday, July 24, 2012 6-8 PM

South Providence Library, 441 Prairie Avenue, Providence
Hosted by RI Department of Health

Wednesday July 25, 2012 3-5 pm

South Kingstown Public Library, 1057 Kingstown Road, Peace Dale
Hosted by the National MS Society, Rhode Island Chapter

Thursday July 26, 2012 3- 5 pm

Woonsocket Harris Public Library, 303 Clinton Street, Woonsocket
Hosted by Perspectives Corporation

Friday July 27, 2012 3 - 5 pm

Middletown Public Library's Community Room, 700 West Main Road, Middletown
Hosted by Looking Upwards &
Opportunities Unlimited for People with Differing Abilities

The RI Statewide Independent Living Council requests your assistance.

Your Voice Matters - please take a 10 minute survey - www.RISILC.org/survey

Comments may be made in person during the hearing, or you can e-mail disabilities@gcd.ri.gov,
fax 462-0106 or mail them by August 2nd to

Governor's Commission on Disabilities

John O. Pastore Center, 41 Cherry Dale Court,
Cranston, RI 02920-3049

We ask that you use unscented personal care products. Please realize that what may seem to you to be a mild fragrance can constitute a toxic exposure for a person with an environmental illness.

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

The RI Commission on the Deaf and Hard of Hearing will provide sign language interpreters; contact the CDHH (voice) 222-1204 or (tty) 222-1205 to confirm which forums will have interpreters.

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

For more information or to request accommodation needed, please call: 462-0100 at least 3 business days in advance; arrangements will be provided at no cost.

Requests for language interpreting should be made to 462-2130 at least 3 business days in advance.

Public Forum Sponsors

The Public Forums are sponsored by the commissions, departments, and organizations listed below that provide services and/or advocate on behalf of people with disabilities.

Brain Injury Association of RI, Inc. & Brain Injury Resource Center, Sharon Brinkworth,

Executive Director

IN-SIGHT, Christopher Butler, Executive Director

The James L. Maher Center, Angelo J. Tartaglione, Executive Director

Looking Upwards, Inc., Carrie Miranda, Executive Director

National Federation of the Blind of RI, Grace Pires, President

Multiple Sclerosis Society, Rhode Island Chapter, Kathy M. Mechnig, Executive Director

Neighborhood Health Plan of Rhode Island, Mark E. Reynolds, Chief Executive Officer

Ocean State Center for Independent Living, Lorna Ricci, Executive Director

Opportunities Unlimited for People with Differing Abilities, Linda N. Ward, Executive

Director

Perspectives Corporation, David Ruppell, President and CEO

RI Commission of the Deaf and Hard of Hearing, Steven A. Florio, Executive Director

RI Department of Health Office of Special Healthcare Needs, Deborah Garneau, Chief

RI Department of Human Services Office of Rehabilitation Services, Stephen Brunero,

Administrator

RI Developmental Disabilities Council, Mary Okero, Executive Director

RI Disability Law Center, Raymond L. Bandusky, Executive Director

RI Governor's Commission on Disabilities, R. Timothy Flynn, Chairperson

RI Public Transit Authority, Charles J. Odimgbe, CEO

RI Statewide Independent Living Center, Camille Pansa, Administrator

Part One: Executive Summary

Part Two: Community Concerns and Recommendations

Accessibility

Bathrooms, 47, 78, 78
Chemical and/or Electromagnetic Sensitivities, 73
Curb Cuts, 79, 100, 101, 104, 105
Parking Lot, 79
Ramps, 49
Sidewalks, 19, 47, 79
State Buildings, 78
Voting, 24

Education

Accommodations, 29
Funding, 34
Learning Disability, 32
Private School Funding, 32, 40

Employment

Accommodations, 14, 29, 56, 76
Back to Work Program, 68
Discrimination, 58
Opportunities, 57, 59, 86
SSDI Trial Period, 59
Transition, 69
Social Security Trial Period, 59

Healthcare/Supports

Affordable Care Act, 42
Autism, 52
Blue Cross/Blue Shield, 50
Confidentiality, [63](#)
Deaf and Hard of Hearing, 11, 12, 14,
Donut Hole, 53
Family Opportunity Act, 53
Insurance, 50, 68
Medicaid, 42, 43, 58
Medicare, 50, 68
Physicians, 62
Post Operation, 14
Pre-existing Conditions, 70
Social Security, 12, 56

Social Security Disability Income, 57, 58, 59, 71
Supplemental Security Income, 18, 44, 52, 68

Housing

Affordable Housing, 86
Assistive Technology, 13
Autism Program, 65
Chemical and/or Electromagnetic Sensitivities, 74, 75
Developmental Disabilities Transportation, 15
Group Home, 21, 30, 41, 45, 63, 65
Group Home Staff, 31, 66
Group Home Transportation, 41, 45
Home Modifications, 13, 14, 34, 35
Nursing Homes, 36
Shared Living, 22

Human Services

Abuse and Neglect, 35
Allergies, 51
Autism, 16, 18
Chemical and/or Electromagnetic Sensitivities, 78
Deaf and Hard of Hearing, 15
Developmentally Disabled, 62
Down Syndrome, 24
Elderly, 27
Family Advocacy Network, 25
Family Court, [86](#), 92, 98
Governor's Commission on Disabilities, 96
Halfway Houses, 47
Office of Rehabilitation Services, 34
OSCIL, 34
Programming, 66
Rehab Act, 34
Social Workers, 35
Transition, 16, 62, 64

Transportation

Accessible Taxis, 12, 46, 87
Parking, 13
Ride, 42, 87, 99
RIPTA, 13, 99

Part Three: Public Forum Testimony

1. Monday, July 23, 2012 – Warwick Public Library

LORNA RICCI: Good afternoon. I would like to get started. First, if anyone hasn't signed in, we ask that you sign in. And if you wish to speak, please make a notation of that. There are a couple of rules today. Everywhere you go there are rules. At public forums we are asking for your testimony. We are not going to be asking for any debate going on or the panel is just here rather to hear you. They may ask questions just for clarification. So should you use initials or something or an acronym, they may wish to clarify. But there will not be anything coming from this part of the table, asking you further questions about whatever you are testifying about. It really is an opportunity for you to bring your ideas, suggestions, concerns to a group of people that are very willing to hear your concerns. And it is going to be written down and it goes up through the Governor's Commission. It is then given to legislators to see. So, it doesn't stop here. It will continue to -- the ears and eyes of people who need to hear it and see it. No one else wishes to sign up? Okay. I am Lorna Ricci from the Ocean State Center for Independent Living. I am your host today and I really thank you all for attending. This is one of six forums. If you wish to testify again or have your neighbors or friends come to the forum, you should have it in your packet of information. They are located around the state. There are five others happening in other locations. Just a quick note, the restrooms are out and then to the right. Public phones are out and then take a left. And cell phones, if you could please put them off. We'd rather not have them interrupting people's testimony. If you hear something today that you wish to testify to or you wish to also agree, please feel free to make a notation to yourself or on a piece of paper. And when you come up to testify, you do not have to repeat the same thing. You only have to say, I also agree with the person who just testified about this particular subject. I wish to go on record as agreeing with that. If you wish to -- if you are nervous and don't want to come up -- I hope I make you comfortable enough to do so. But if you wish to send in written testimony, the Governor's Commission is accepting it until August 2. Just need to e-mail your testimony to disabilities@governors.commission.on.disabilities. Disabilities@gcd.ri.gov. Again this also is written in the material that you picked up. And there's a fax number you can fax it to 462-0106. I have to do my hostess with the mostess and read something to you. But it is interesting. It gives more information on exactly what is happening with the material, information today, where it goes. "The purpose of this public forum is to identify the concerns of people with disabilities and their families in order to assist the state to develop programs to improve the quality of life of persons with disabilities. To ensure everyone gets an equal chance to speak, please keep your comments short and to the point. If you have an issue that can be addressed by a panel member, you may wish to speak with that person after the forum." And please, as the host, if I -- all you have to do on the panel is if you say, give me a hi sign that you wish to say more to the person testifying. I will make sure that you two are connected later to speak about services or programs that you might know could help the person. "After the public forums are completed, the sponsoring agencies will review all the testimony and prepare recommendations, which will be passed on to the web -- posted on the website at the end of November. And that's the Governor's Commission on Disability website. The recommendations and transcripts will be printed and sent to the state and Congressional offices and to members of the general assembly." I'm sorry, I have to -- my print is large. "And recommendations will be used to develop policy and legislation initiatives for the next year and until they are accomplished." The Rhode Island disability vote

project, voter registrations -- Rhode Island disability vote project voter registrations are available to register anyone today. If you are a citizen and you wish to register, there's material at the back of the room. Also there's material, if you wish to change your address, should you have moved since the last election. The statewide independent living council is also here today. They are conducting a survey of issues regarding people with disabilities. They really encourage your participation. There's material at the back. The survey is at the back. It's pretty self-explanatory. If you would like to take one before you leave, you can complete it at home and send it in or e-mail it back. You also can do that on-line. There will be more information for you, should you wish to wait for the end of the forum. There are people from the SILC here, Statewide Independent Living Council that could answer your questions. I understand that's pretty much it. I understand there's a message from the Secretary of State's office. Alyssa.

ALYSSA: The state's new voter ID law takes place this year. You need a state ID when you go to vote at the polls. If you want more information as to what is acceptable as an ID or how to get a new one, there are flyers on the back right table.

LORNA RICCI: Did everyone hear that? When you go to the voting booth in November, you need your ID, your license, bus pass, a picture ID. Should you not have one, the secretary of state is providing a voter ID. All it is, is a picture ID. But if you have something with your picture on it, you are all set to vote. Just make sure you bring it.

KATE BOWDEN: Can I clarify on that? My name is Kate Bowden. I am a staff attorney at the Rhode Island Disability Law Center. And yes, thank you for bringing information about voter ID the Secretary of State's office. For this year you will have to prove your identity. But there are some non-photo IDs that will be allowed. So, I just want to clarify that yes, it's -- everybody should be getting a photo ID. But from this year, there are some things that will qualify that don't have a photo. You should educate yourself and along with the Secretary of State's office, my office has materials here that has the specific list of everything. If you have questions or if you have any disability related questions around voting, you can certainly reach out to me. I am happy to answer questions about that.

LORNA RICCI: Thank you, Kate. It's very important. We want everyone to cast their vote this year. We don't want anyone getting to the voting booth and finding out they didn't bring a picture ID with them and maybe don't have other identification. So please, you may want to have a talk with Kate later or call the Secretary of State office or go on their website for further information on this. Now, for our panel, I would like to introduce our very distinguished panel. Judy -- Julie DeRosa is here from the Governor's Commission on Disability. And Kate Bowden is from -- you might want to your raise hand -- Rhode Island Disability Law Center. You just heard from Kate. Jenn Fiske from the Office of Rehab Services. Rory is not here. She may join us. Elizabeth Connallon is from the Brain Injury Association, first time here. I am glad she is here. And Anne Leclerc from the RIPTA, administration -- what is it? Authority -- there we go. I also say RIPTA. Heidi Showstead from the -- Heidi is the person you may want to speak with later about this survey -- from SILC. Carmen Boucher is from the Office of Special Healthcare Needs, that is the Department of Health. And last -- did I miss anyone? And David McMahon is from the department of behavior and health and human services. And thank you, David, for joining us. I would like to get started now. We ask that when you come forward, please state your name. Everything is being transcribed here. This is what is now -- is being written and then will be looked at later and compiled for everyone to read later. So it needs to be clear of who is speaking. So we do ask that you come forward, say your name. If you could, say where you are from. Our legislators like to know their constituents. It's always helpful when it goes before them who in their particular area has a concern. Our first person is Christine Harkins.

Healthcare/Supports:
Deaf and Hard of Hearing

CHRISTINE HARKINS: Thank you, Lorna. My name is Christine Harkins. And I am the president and CEO of Bridgemark Addiction and Recovery Services on 2020 Elmwood Avenue in Warwick. We are a full service addiction and recovery counseling center which includes 53 residential beds, outpatient services, prevention and after care. We are also very proud that we have the only residential services for Deaf in Rhode Island, the only Deaf addictions counselor in Rhode Island, and one of the ongoing programs in the country. So we are very proud of that. And that has raised our awareness about certain things and that's why I am here sharing these concerns. One of them is -- and I would like to share a quick scenario with you. Someone who has a heart condition starts to feel their breathing becoming very heavy. They begin to sweat. Feels like an elephant sitting on their chest. They know that they had a heart attack before. So they know that when they become symptomatic what is going on. They go to an emergency room. They walk in. And in Rhode Island, they get excellent care. Their life is saved. They go back to their family. They go back to their job. They pay taxes and life goes on. When a person who is Deaf and who has a behavioral health issue, an addictions issue, a nonmedical addictions issue feels symptomatic, feels a compulsion to drink again, has done everything their counselor has told them to do that would bit mitigate these symptoms. Yet it is raging inside and they cannot stop the urges and they go to an emergency -- their emergency room, which would be an AA meeting. There's no access there. We have come so far because of organizations like OSCIL and other great agencies that have helped educate all of us as citizens. A Deaf person could walk into a hospital with that heart attack and be taken care of and a life can be saved. With behavioral healthcare issues, that Deaf person can get to an AA meeting. Most of them are within walking distance but once in that room cannot get their medicine. They can't get that information without an interpreter. The only AA meetings that are interpreted in Rhode Island right now is meetings that are -- where interpreters are paid for by the humble budgets of Bridgemark. Although we are more than willing, it's not adequate. There is a whole system in place with our neighbors, Massachusetts, many, many states. But the closest one is our neighbor Massachusetts that has a system already established. Perhaps that's something to study. Whereby somebody can call and say, I am in recovery. I go to AA meetings. I live on Elm Street. Where can I go? They will say, where do you want to go? What is your home AA meeting? We will send an interpreter there. So there's a funding for that. That doesn't exist here. And we are losing lives. We are losing lives. Addiction is bad enough. We've come a long, long way. But there is still stigma. It is still underfunded and people are still dying when AA and other 12 step groups are free. It's free. Think of how much that emergency room visit costs at Rhode Island Hospital or our wonderful Kent County hospital here. Think about -- and AA is free. But that person may still die because they can't get the information. That's one -- that's a great concern of ours right now. Related to that is concern number two. When a Deaf person walks into a medical facility and that medical facility willingly contacts an interpreter referral service to get an interpreter. They may well contact an interpreter service that says they will look for interpreters but may have only four interpreters that they call. The Commission on the Deaf and Hard of Hearing have registered a licensure department in Rhode Island -- has I think at last count over 40 people who are qualified to do sign language interpreting. Not enough, but there are 40 people. Most of those people are certified. The rest I believe are pending. They are on their way. But that's a good handful of folks. But if somebody walks into a hospital in Rhode Island and says, I am Deaf, I need an interpreter. And the person there calls the right extension in that organization to say we have a Deaf person here. I am requesting an interpreter. They on good faith may call an interpreting service, XYZ interpreting services. That service may get back and say, I'm terribly sorry but we have no one

available. My concern is this. If a hospital or another medical service does not in some way -- there's no coordination by where they are told or informed or educated that they have to contact everyone out there. They can't contact -- they can't deal with the interpreter referral service that is giving them perhaps the better deal but only has four interpreters as opposed to the commission on the Deaf and Hard of Hearing that has 40. And one has to ask, is that a clever way of circumventing ADA? We try. We called. They told us they didn't have anyone. We would love to have provided an interpreter. And I know that to be true, my friends, because I am a nationally certified interpreter for the Deaf. It's rather ironic when someone gets back to me and says I have contacted all the certified interpreters of Rhode Island and I have not received the call. Nor have the three interpreters that are working in my residential building that see me and say good-bye, Christine, nice working here at Bridgemark today. And I say oh, hold on. Mary, Bob, did you just get a call from XYZ? No. Would you let me know if you do? Certainly. And no call. So, this has been going on for years and years. And perhaps, perhaps it's just a conversation, perhaps an educational group whatever, but this is a grave, grave concern. People are not getting interpreters in medical emergencies and medical care because we need to make that -- we need to go one step further. Let people know about interpreters, know who to call, but it's not being worked out properly. And having said that, I will say thank you very much. I think these forums are marvelous and I greatly appreciate the opportunity to come and share.

LORNA RICCI: Thank you, Chris. Debbie Raiche.

DEB RAICHE: Hi, my name is Deb Raiche. I am a nationally certified addictions counselor

Healthcare/Supports:
Deaf and Hard of Hearing

and I have been working in the field for over 15 years this September. I have seen the death and disease in addiction of so many people because of underfunding and underestimating the needs that we need to have access not only to medical care but to behavioral healthcare. We need interpreters at AA meetings. Massachusetts has funding that pays for interpreters to go to AA meetings whenever they are required and persons lives are saved when they go to AA meetings. If they have alcohol or drug addictions, they can go into the emergency room. When a person has a heart attack, a life can be saved. As a Deaf woman, as a behavioral health professional, as a wife, as a mother of two sons that are grown, and as a member of the Deaf community, I have witnessed the need for years, please consider interpreters for the 12 steps and recovery group as a priority. Thank you.

LORNA RICCI: Joan Butler, please.

JOAN BUTLER: I can just speak from here. My main concern is -- what is the qualifications

Healthcare/Supports:
Social Security

for a person who is disabled to get Social Security?

LORNA RICCI: This isn't the time to ask questions. Would you like to speak to someone later?

JOAN BUTLER: Yes, I would. That was my question.

LORNA RICCI: That was your question, Joan? What we can do -- would you like to speak with Kate? Kate Bowden, could you speak with her?

KATE: I can say something generic very quickly. If people are interested, you can call our office. We do have a list of lawyers who do that kind of work. My office does not do that kind of work, but we have a referral list. You can call our office and grab materials at the back with our phone number, and they can refer you.

JOAN BUTLER: Okay, thank you very much.

LORNA RICCI: Anna Liebenow.

ANNA LIEBENOW: All right. There were a few things actually that are on my mind. The

Transportation:
Accessible Taxis

first very quickly I want to say to the people that are in the audience, that I had -- the first forum I came to I think was in 06, 07 and I mentioned there

are no accessible taxis. And we just now have accessible taxis. So I feel like the work that happens at these forums, we don't know what keeps coming from it. But it's important to say what we have to say. So, there are a few things that are on my mind in terms of accessibility. I feel like there are a lot of cuts happening to things right now. And I'm really concerned about that. It

Housing: Home Modifications

needs to -- accessibility to people's homes and home modifications. I first started using a wheelchair in Minnesota.

And in the middle of the winter I was able to get help to put a ramp into my home. And that kind of work to people's homes, keep them being accessible needs to be happening. And I know that there really is not enough currently in the way things are in terms of access to home modifications. But there needs to be not just the maintenance of it but it needs to increase.

Housing: Assistive Technology

Another thing is I know -- I am working with people that do assistive technology and provide assistive technologies. Those are all the gadgets that make it possible for a person to live independently. And there needs to be increase of support for that because people need to be able to do those things that make it possible to live on their own. And another piece that I want to talk about is funding.

Transportation: RIPTA

I'm on the board of directors for RIPTA. And I know, I see RIPTA working really hard to save money. However, the bottom-line is that RIPTA does not have enough funding at all. And so a lot of work has been done in the last few years to try and get more funding for them and things have not happened. So, that just needs to be a priority for the next -- for this next legislative session that they get more funding to RIPTA because that allows people with disabilities and people, period, to be able to have access to transportation. So, those are some of my main concerns at this moment. But you ask me tomorrow. There will be more concerns. Thanks, Lorna.

LORNA RICCI: Thank you. George Gange.

GEORGE GANGE: My name is George Gange. I'd like to talk about handicapped parking in

Transportation: Parking

Rhode Island. My background is I have a sister-in-law 43 with MS. Since she can't walk, we take her to all her appointments. I have a grandson, 40 years old, who has never walked. He lives in a group home. And lately my wife can no longer walk. What I find the handicapped -- I used to live in certain places. And other places it's a horror story. You have businesses that have no handicapped parking whatsoever. And I think that's a disgrace. There are some that have excellent parking, handicapped parking. Kent County hospital has them but they let the employees park in it, which is kind of cruel. Then you specifically, there's a liquor store across from the Chevrolet dealer on post road in Norwood. They have something like 50 parking spaces. No handicapped parking whatsoever. People's liquor in Apponaug, they have no handicapped parking. And I have to clarify that some people have a misconception. If you have handicapped parking and you do not have an upright sign that that parking lot -- that parking space is not legal. You have to have the upright sign. I am finding they have them on the surface. That doesn't mean anything. It has to have an upright sign to be legal. And we just had a certain case on post road, across from CVS. There's a beauty parlor there. They spent a lot of money to put in a handicapped space. But there's no upright sign and it's not van accessible, which is another thing. Some people say that the business is too small, that's not so. Any business, even if they have three parking spaces, they should have -- they should have a handicapped space with van accessible with the upright sign. And I can go on and on. Most of my observations has been in Warwick and it's a shame that it's not done. The other aspects too is sometimes people park in the handicapped spaces who do not have a tab to hang in their rearview mirror. And it doesn't seem to be enforced. I don't know. I never hear of anyone getting a ticket. But I guess they do, do it but not to the extent it should be because there's too many

violators out there. On the good side, places like the Warwick Mall, they have excellent everything. They have the push-button doors. They are excellent. And a little place like Newport Creamery in Hoxie. They just did the handicapped over and it's excellent. But the places that disturb me are the ones that do not have handicapped parking. Thank you.

LORNA RICCI: Chris Rancourt, can you speak with him later?

CHRIS RANCOURT: Absolutely.

LORNA RICCI: Henry Tarlian.

HENRY TARLIAN: Good evening. It's a pleasure to address you this evening. I have a very,

Housing: Home Modifications

very brief message. All of our agencies -- I'm the president of OSCIL by the way. All of our agencies are pressed for money.

Tonight I would like to say that I appreciate the funding level we have for the home modification program funded by the state. You cannot imagine the joy that comes with modifying a home to give a younger person, a consumer, the opportunity to live independently. It warms my heart when I see that happen. I just want to go on record to say we appreciate that kind of funding. It's very positive. It has a positive impact on our consumers and we would like to see it continue. Thank you. Brief enough?

LORNA RICCI: Thank you. Louise Arena. Would anyone else like to speak? Would anyone else like to just go on record as agreeing with something that was said? It does add strength to the testimony that has already occurred. Um -

Healthcare/Supports:
Deaf and Hard of Hearing

HENRY TARLIAN: I agree with what Chris said and what this young lady said about the need for interpreters.

LORNA RICCI: Need to interpreters. Thank you, Henry. I think I would like to take a break. Our interpreter probably needs to rest her hands. And perhaps we can come back in five minutes. And if you changed your minds, anyone who would like to come forward, please do so. Even a short couple lines on record is great and it might change something in our state for the better. So, please consider that. We will take a ten-minute break. Thank you. (Return from break)

LORNA RICCI: Excuse me. People are having some great conversations and you are very well welcome to stay here. I did want to give opportunity in case someone decided to testify and maybe they need to leave. So, now is your chance. Does anyone wish to testify -- I shouldn't use the word testify. It's scary -- speak about something that is on your mind. Would you like to? Say your name again.

Employment:
Accommodations

LOUISE ARENA: Louise Arena. Hi. I am a former social worker, business owner. And I taught in Warwick for a couple of decades. And then -- I had disabled kids in -- okay. I am used to talking to a classroom. I did have disabled kids in my class. And then I myself came on disability and still wanted to teach. But the school department does not always make accommodations for folks who are disabled. And I would hope that more people, even in this public sector, would be made aware of what accommodations need to be made, whether they are simple accommodations. I am not the only person. I have been very upset about it. There were several others in our school and in our school system who have trouble with this. That's one. The other thing -- and this is something

Healthcare/Supports:
Post Operation

that I was wondering about, a general thing. When a person is living alone and they need an operation and it's an operation that is going to make them incapacitated for a while, where they wouldn't be able to use a toilet by themselves, where do they go? What do they do? Who do they contact to get somebody to help, if you don't have family members in the area or anybody else who could come in and help you get dressed. I don't even know where to go. And I imagine I'm not the only

person. I've learned over the years that if I have a question, somebody else probably has it too. And that's it. And thank you so much.

LORNA RICCI: Thank you, Louise. Just two questions, Louise. The first -- Louise, what town was it that you were talking about the school system? Just for clarification.

LOUISE ARENA: Warwick.

LORNA RICCI: Warwick, okay. Would anyone like to speak to Louise later about services that would be available for her? Is it an older person or a younger person?

LOUISE ARENA: It's a me person. I am one of them, yes.

LORNA RICCI: A you person, a very young adult person. If anyone would like to speak with Louise, maybe assist her with some services or direction of where to go. Anyone else? I guess we can continue talking -- no, did I see a hand? No. Okay. We continue talking. Please see me if you come up with -- if you would like to testify. Just see me and we will stop and hear you.

HEIDI SHOWSTEAD: Lorna, is it okay just to make a general statement at this point --

LORNA RICCI: Um --

HEIDI SHOWSTEAD: -- about concerns as a disabled citizen that haven't been brought out.

LORNA RICCI: Would you like to testify, Heidi?

HEIDI SHOWSTEAD: If I could.

LORNA RICCI: You know what, we will do it this way. Stay put. There you go.

HEIDI SHOWSTEAD: Hi. My name is Heidi Showstead. I am from the Providence, Rhode Island, area. First of all, I would like to testify on behalf of anybody that receives any type of personal care services, be it -- first of all, on the personal choice waiver, for those individuals, I urge the state to consider not making changes to something that is not broken and to allow people to live as independently as they choose to. Everybody wants a right to independence and freedoms without scrutinization, further training and further questions. Do not fix what is not broken. And treat people on a case by case basis, if you could. Also I would appreciate no further cuts to my friends and people that I care about on the DD system. Enough cuts have been made. Let's look at people as individuals and let them have the quality of life that they are entitled to. Thank you very much.

LORNA RICCI: Thank you, Heidi. Anyone else? Anyone else? Okay. Please see me if you change your minds. Yes? No? Okay. Continue. I know there's a lot of good conversation going on. We need to stay here until 8. But you don't have to, if you don't want to. But go ahead.

LORNA RICCI: Kelly McCorkle.

KELLY McCORKLE: Hi. My name is Kelly McCorkle. I am a disabled vet. I have a hearing loss. And I am also a mother of two disabled children. And I also work for the Rhode Island Parent Information Network. My question is actually more personal than anything else. I like to follow on what is going on in the state so I like to watch capitol television on TV. It's not closed captioned. Unless I actually physically go to a committee hearing and request a CART interpreter two weeks in advance, which is typically the request, I am out of luck. So, that is more of a statement. So, I would like to have you follow up with that. Thank you. Thank you

LORNA RICCI: Excellent. Thank you very much. Anyone else? Anyone else? I had a request, since --

SETH SOBRAL: I do have a question. May I ask a question? My name is Seth Sobral. Hi, everyone. I am new here at the forum. So I just came to watch and it looks like many of you have touched on some access issues. I belong to a church. My question is about getting access for the deaf prisons,

Housing: Developmental Disabilities

Human Services: Deaf and Hard of Hearing

Human Services: Deaf and Hard of Hearing

those people who need some sort of relationship. Does anybody know of any -- if anybody knows of a prisoner who is screaming, how do you communicate with that person? How does that person make a call? Do they use a phone call and do they use the phone book? That is my question to all of you.

INTERPRETER: The interpreter is asking for clarification.

SETH SOBRAL: If anybody knows of a prisoner who is Deaf, if somebody -- if you would like to talk to a prisoner or somebody needs to call a prisoner and is denied that right of information because that person has no idea how to get to that person. For example, if I would like to contact a person who is in jail, who is himself or herself Deaf. How does that happen?

GEORGE GANGE: I can answer that. I retired from the Department of Corrections. And my experience there was the department is very keen on disabled people. And we have lifts because some prisoners live in a wheelchair. If any disabled prisoner needs anything, the department will take care of it, as treatment has to go. That's what I found in my experience as a correctional officer.

LORNA RICCI: Thank you, George. Thank you, Seth. Thank you, Seth.

SETH SOBRAL: I would like to speak with you, George, later, if you don't mind.

LORNA RICCI: Thank you, Seth. Anyone else? Well, a few people are still here. We were going to wait until the very end. But I know that the Statewide Independent Living Council -- I am getting tired -- would like to talk to folks about the survey, and a little bit about it, what kinds of questions might be on it, how good it is to complete it, to help provide the council with what kinds of issues are going on in the community they need to know about, maybe services that need to be put in place, some of the gaps in services. If you would like to speak with Anna or Heidi, they can tell you more. And I would be free to -- we could have the interpreter assist if need be.

HEIDI SHOWSTEAD: I want to make one clarification, Lorna, if I may. It is meant -- it is meant solely to be filled out by people with disabilities 17 years of age and older. And what it is for is, it's a Needs Assessment Survey. And it promotes a lot of the issues that we spoke about related to independent living, transition issues, transportation issues, budget cuts, and funding issues. If you fill out the survey, you can be completely anonymous or if you wish. You can get general information about the council who is also looking for volunteers or fill out -- to be put in a drawing for a Target gift card. But if anybody has any questions or clarifications, they can come to me or Anna Liebenow. The survey flyers are on the information table. And we are more than happy to answer any questions about either the council, themselves, or the survey.

LORNA RICCI: Thank you, Heidi. Okay. I guess we will wait to see if there is anyone else that would like to testify. (Return from break)

LORNA RICCI: Excuse me. We have someone else who has arrived and would like to testify. Kathleen Mihalos. Kathleen.

KATHLEEN MIHALOS: This is my first --

LORNA RICCI: Your first -- no worry. You will do fine.

KATHLEEN MIHALOS: I believe this gathering is for suggestions and ideas as far as -- I have things I'd like to speak about as far as maybe changes in laws and programs in the state of Rhode Island as they pertain to autism. That's where my stake is. I have a son who is nine years old with autism and some of the things that going through this journey with the autism, you think about the future. I know a lot of the programs age out at age 21. But I think a lot of that should be re-visited as far as -- because technically my son is nine, chronologically. But developmentally he could be functioning at the age level of one or two. So I know it's a broad

Human Services: Autism
Human Services: Transition

spectrum. So not everybody falls into that guidelines as far as being higher functioning or lower functioning. So I feel that based that should be visited on a case by case as far as children with diagnosis and evaluation that they should be -- go beyond the age of 21 because it's also known with autism, their brains develop much slower than typical developing child and based on the severity of the child's -- shall I say lack of brain development. Again even though chronologically a child may be 21, they still have years beyond that to continue to learn and grow and thrive. So, again, with the autism, you know, nobody knows. We can't even tell you how someone's going to progress or how they will continue on to progress. So, that's one of the suggestions I had that if somebody could eventually look into that as far as changing the laws as far as DHS goes for services because it's scary as a parent because you feel that once your child becomes 21, like I am -- I talked to every resource like Cedar and you worry because -- you have the uncertainty. And then once they are considered an adult, then it's not so much they're looked at with the ADA or a lot of the traditional therapies to help them continue to learn. Then I know it goes on to like adult services with assistive living as far as like brushing their teeth and just like daily living. But as a parent with a child with autism, yeah, that's all important for him to learn how to make himself a peanut and butter jelly sandwich or brush his teeth or dress. But you still want that curriculum, behavioral specialists, and to get that intensive behavior therapy beyond the age of 21. And then another thing that my husband and I -- we think about -- and also tapping into a lot of other friends. We live in Warwick, but we actually -- I know this isn't the forum for this -- but the IEP laws that really has to change in the process in the state of Rhode Island because that is just so poor. But it took us three years. We didn't have to go to a legal situation in Warwick. But we have our son in a private institution in Massachusetts because Rhode Island can't give him the supports he needs because he is pretty low functioning. Another worry we have is once he becomes 21 -- considered an adult, there's really no -- I know in Rhode Island, it's a -- Groden center is the only one that is from the ages of 12 to 21. So nothing against other medical disabilities. But Rhode Island really should consider opening up specific treatment to facilities or residential living just for adults with autism or children with autism because people who are familiar with autism realize that autism is not your typical mental health problem as compared to having like maybe schizophrenia or mental retardation. It's a complete spin-off of actual mental -- mental problems and the lack of development, should I say, wait for the brain for learning. So, that would be huge if Rhode Island looked into that, like in specific facilities because I have researched throughout the country because we have thought about moving, but my husband is a Rhode Island state employee. So, we are stuck here for a while. But other states in the country do have specific facilities that are geared, specialized for autism. And again, that is just something that, even in the Northeast, there really isn't anything that they have to offer that can be specialized for autism. And the -- it's just because with the autism, you can have like all the hope you want and you are going to reach a point where that miracle just isn't going to happen for you. And it's just going to come with the community effort because there is going to be such a -- the population of these children that have it. And it's really going to become more of like a humanitarian effort because how to care for them and have them continue to excel to the best that they can for their future because we know that autism is nondegenerative and it's non-terminal. So our children are probably going to outlive us and their siblings. And what is going to happen it them after that? And group homes really aren't the right setting for them because, again, they are not going to get the supports, not continue learning that they are going to need because once again, nobody really knows how much they are taking in and how much they are learning. And my son has two neurologists and we learned through them his neurologists at Children's Hospital in Boston and he also sees Dr. McHanis in Hasbro. Textbook tells you the

human brain stops developing around the age of 25. But neurologists will tell you that it's into our 40s. Our brain is still actually like learning and they are -- nothing against geriatric -- and we stop. But it's up until your 40s you are still capable of learning. And again that is just where the confusion comes in with the autism. Everything stopping for them being considered an adult at 21 when again, they might be 21 as an adult, appearance wise, but mentally they are still functioning -- they are not at adult age capacity. So, that is a big concern. And my other thing that we also think about and with other friends of mine with children on the spectrum, as we know in these economic times Rhode Island is going through many cuts, as far as all different programs, especially DHS. Luckily -- well, not luckily. But our son is so severe and low functioning that a lot his programs haven't been cut. But like one program particularly for respite care, parents only allowed to 100 hours per year. And also some of our friends lost. The guidelines have gotten more stringent as far as home based programs through perspectives, Trudeau, Groden, they got cut depending where your child fell and supports needed. One thing that always confuses us because our son had been to psychiatrists in Bradley Hospital, and like -- I think that as far as like the SSI and welfare goes in the state for people who are deemed as like mentally challenged or have mental issues as far as depression or anxiety or even schizophrenia that I know people and people know people. Especially sometimes maybe girls who are on welfare that are single moms who -- you always hear the joke. They just keep having children to get the benefits and whatnot. But some of those girls that we do know of they like have a medical diagnosis to get all types of SSI benefits of like anxiety or depression. Now we know you can't prove that somebody has depression or anxiety. But I think if that is re-visited too in these economic times for not just Rhode Island, other states, to see where that money is being allotted to because it's always the handicapped and elderly that always get cut first, it seems, who sometimes need services the most or need financial assistance. Where with -- the point I am getting at with this, with people

Healthcare/Supports:
Supplemental Security

who say they have anxiety, depression, there is medication that can help those people to have them live -- to like thrive in daily lives, to hold jobs, to get married, and function with their families. As to with my son or with autism, there is no drug that can -- a pill he can

take that can help him with his autism as to a lot of these or mental conditions, there are. So, that is something that I think that people should look into as far as for -- to make cuts or do benefits or even -- say you have a list of people on SS I who fall into certain like diagnosing criteria. Re-visit that and see who are the people who are treatable, who can get medication or are treated. And that will free up benefits or services or funding to go towards other programs for people who really need it that can benefit from it, especially again my area is autism that I care about most. And again, it just goes back that it's a fact that there is no pill or drug that can help autism that can help other different mental conditions. So, that's the suggestions that I have. Does anybody have any questions for me?

LORNA RICCI: Thank you very much.

HEIDI SHOWSTEAD: Lorna, I have a suggestion that may be able to assist her, if I can give it.

LORNA RICCI: You can talk now -- no, do you want to talk privately?

HEIDI SHOWSTEAD: No. It's just a general information piece. I don't know. You seem like a very proactive parent. And I appreciate that because everybody needs parents like you. But you

Human Services: Autism

might want to consider contacting the Sherlock center on Disability who is the Rhode Island, you said, information referral place for people with disabilities. They have parent support coordinators that may be able to connect you to places that -- or information that may be able to assist you. And also I'm sure you are familiar

with the autism project. But don't hesitate to call the Sherlock center because they do a lot of educational advancements, with people with multiple severe challenges. And if you need that number, I will give it to you later on.

KATE BOWDEN: I just wanted to let you know about a resource in case there are other people who can benefit. I work at the Rhode Island Disability Law Center. We are lawyers. We are a nonprofit. We do -- have you used us? I hope it worked out. I will keep it private. But I wanted you to know there's a resource from the Department of Health. They put out a guide for families who have children on the spectrum and a number of families that I worked with felt as if that resource opened some doors for them and it's -- you can get it on their website. It's in a PDF format. It's been helpful to some families. And we also -- if you ever choose to come back to the Rhode Island educational system, the law center has resources to assist families in learning their rights regarding special education issues.

LORNA RICCI: Thanks, Kate. Anyone else? Does anyone else wish to testify? No? Okay. Excuse me. We have someone else who wishes to testify. Patty Arden. Patty.

PATTY ARDEN: That was fast.

LORNA RICCI: Would you like to stand there.

PATTY ARDEN: Not so much testify but see if people have any ideas of -- okay -- how I can solve a problem. It's become a problem, not only for me with disabilities. I have been disabled for six years. And we -- I am from Pawtucket, Rhode Island. And we have a large amount of sports enthusiasts and it came to a big issue in our neighborhood when the police would not answer calls for cars that were parked illegally on our street, blocking, you know, traffic from coming in and going out of our street. These are all people possibly from out of our city. And a good deal of them from within our city. But I started writing to the mayor's office and I finally got some recognition when the rescue vehicles came to pick me up and the rescue squad could not get out of my street and the fire truck was stalled, at a dead stop at the bottom of my street. So now the mayor says he's not going to put up any more no parking signs but he will send the police. There were -- a lull right now because of the hot weather. But the middle of next month, all of this is going to start up again. So, I'm kind of wondering, you know, if -- because the mayor says oh, yeah, I am going to do this thing and the police have been notified to come when there's a phone call for illegal parking. But I don't know if this is going to work out. A lot of people don't speak English. There really aren't enough no parking signs in the street. So -- anyway, that's my problem. So if anybody has any ideas where to go, then I'd like to hear them.

LORNA RICCI: What is the street?

PATTY ARDEN: Hastings avenue. It borders Slater park. The people that want to get into the park are not parking in the park. They are parking on our neighborhood street illegally, most of them. And blocking our driveways also.

LORNA RICCI: Calling the mayor sounds like a good idea. Anybody else have any suggestions? I am not sure -- no? I think calling the mayor probably was the best. It will go on record. Maybe -- the person who has your area, your Congress -- your state rep in your area --

JULIE DEROSA: Your representative.

PATTY ARDEN: I have been to him.

LORNA RICCI: Who is that?

PATTY ARDEN: Doyle.

LORNA RICCI: Try again.

PATTY ARDEN: I guess I really have to be a pest when you come down to it.

JULIE DEROSA: The squeaky wheel gets the grease.

PATTY ARDEN: Thank you.

LORNA RICCI: Anyone else? (RETURN FROM BREAK)

LORNA RICCI: It's 8:00. I guess we are done. Thank you all for coming.

2. Tuesday, July 24, 2012 – Barrington Public Library

CHRIS DeGRAVE: We're going to get started. My name is Chris DeGrave, from the Rhode Island Governor's Commission on Disabilities. I'm a staff member there. First of all, I'd like to thank you all for coming today to voice your opinion on disability issues statewide. Obviously, we want to make sure everybody respects everybody's opinion, so if you disagree, please hold it until the end, and you can stand up and make your own opinion. That's the point of this. If there's other issues you need to approach us about, contact the Governor's Commission on Disabilities at a later time. Understand that everything you say today will be recorded, and it's public knowledge. If you don't want somebody to know you said something, don't say it. Please keep that in mind. Sharon Brinkworth is our moderator here today, and she will be doing panel introductions:

SHARON BRINKWORTH: My name is Sharon Brinkworth, and I'm the Executive Director of the Brain injury Association of Rhode Island. We'll start down with Pat, and also state your name and what agency you represent.

PAT RYHERD: I'm Pat Ryherd, I'm a commissioner on the Governor's Commission.

MIKE MONTANARO: My name is Mike Montanaro, I'm a supervisor at the Office of Rehabilitation Services.

CRISTY RAPOSOV: Cristy Raposov from RIPTA.

COLLEEN POLSELLI: Colleen Polselli from the Rhode Island Department of Health Office of Special Healthcare Needs.

BRIAN ADAE: Brian Adae, I'm an attorney with the Rhode Island Disability Law Center, and if I may put in a shameless plug, part of what we do when we arrive at these forums is to pursue our own agenda, we ask, we have surveys on the table in the back asking what you think should be a legal issue that the Disability Law Center might be able to address. We do this annually. I have envelopes to mail them in, or later you can give them to me at the conclusion, or after we finish testimony here today. The Disability Law Center, for those of you who are not familiar with it, is part of the nationally mandated system for folks with disabilities designated by the state for the advocacy system for Rhode Island. We operate under eight separate federally funded programs. Policy and systemic work and also individual casework, legal services for folks with disabilities and their families. Thank you for indulging me.

RICK COSTA: My name is Rick Costa, and I represent Rhode Island Statewide Independent Living Council.

ANGIE STABILE: I'm Angelina Stabile. I'm a commissioner on the Governor's Commission, and also representing the National Federation of the Blind of Rhode Island.

SHARON BRINKWORTH: We have a couple more people from the Statewide Independent Living Council that I want to recognize, because I know they'll have something to say about a survey that they have. Lisel Rockwood and Anna Liebenow, the two of you. Okay, great. Once we've taken the testimony, then you can talk about what you're going to tell us about the survey you have. Just a little bit to let you know why we're all here and why we do this. The purpose of these public forums is to identify the concerns of people living in our state that have disabilities and their families, in order to assist the state to improve the programs to improve quality of life. To insure everyone who wants to speak gets a chance, please keep your comments short and to

the point. I don't think we'll have a problem. We don't have a lot of people to speak. If you have a critical problem, the panel members will be available at the end of this meeting to direct you to the proper agency for help. And also, after these public forums are completed, and they're going on all week in different locations throughout the state, sometime in early August, the sponsoring agencies will review the testimony, and that's why we're having it all copied, and prepare recommendations, which will also be posted on the website by the end of November. These recommendations and the transcripts will be printed and send to officials and the members of the General Assembly, and the recommendations will be used to develop policy and legislative initiatives next year, or until they are accomplished. So, what is heard at all of these throughout the state, a lot of what's heard, issues, problems, and things, will be turned into legislation that will be submitted by the Governor's Commission on Disabilities. And I know some of us sit on the committee of that group, and all year we monitor that legislation and go and testify in favor of it, or we monitor other legislation, too, that if it would be harmful for someone with a disability, we will let them know that that's our opinion on that, too. The Rhode Island Disability Vote Project, voter registrars are available there so you can register to vote if anyone wants. They can file a change of address if they've moved since the last election. Even if you're not speaking, have you signed the sign-in sheet? We'd like for everyone to sign that. There are also assisted listening devices available. If you need them, see Chris. I think that's all I have to say. Our first speaker that we have today is Carol Araujo. Just stand up.

CAROL ARAUJO: My name is Carol Araujo. I live in Barrington. I'm a mother of a severely multi-handicapped daughter. She has a severe form of Autism, which is called RETT Syndrome. She has been in various group homes throughout her life, some in which we've had to remove her, from some of the other residents being aggressive with her. And so now the past five years she's been in an excellent group home, which is in Riverside, and there's only three women who live there, and they're all docile and they're not aggressive and Tammy has been safe. Tammy's been punched in the eye, she's had acid put in her eye, she has fallen off of vans. She's had quite a bit of different conflicts in group homes. The latest is, of the three girls, one of the girls just passed away. So, there's three women living in this group home, supporting this group home, the one woman passed away. The director of the private group home called a meeting and informed me and the other parent that they were going to have to close the group home. And they sent a letter out stating, because of Joy just recently passing, they do not have enough money to fund it. And that the state is \$24 million behind in money and whatever, and the only choice we have is for her to go to another group home, which has six people, which I've already tried it, it doesn't work. She is, Tammy is multi-handicapped. She can't talk, she can't point, she can't hit. As she's gotten more ridged, she can't even run away from someone. Her voice, her muscles have tightened up quite a bit, she can't even scream. She just had an episode where -- as a matter of fact, I called your office -- we just went through an episode where the bedrail, the nurse had a great idea of putting a full-length bedrail so she wouldn't fall out, and I said, "Please, I don't want that bedrail. She's totally restricted." Well, about three weeks ago, four weeks ago, she got caught in the bedrail, she learned how to push it out, figured it out, no nurse calls me, no nurse called me. I went in to visit on Father's Day. I said, "Tammy, what are these bruises?" She had a bruise here, she had bruising on her eyes. She had black and blue on her chin. I have pictures of all of it. But anyway, that's beside the point. So, it was an error, it was an error on the nurse. She should have never brought that bedrail. We have taken care of it since. But, I would like her to stay in this group home with three young women that are similar to her and she would be safe. Now I'm being told that they have to close the group home because the state will not fund them, and I'm starting to question

this. I'm also being told there's a possibility they may send her and the other girl to a group home in Bristol with six residents. Tammy has been in a group home with six residents, it doesn't work. They discover within six months to a year, the other residents discover that Tammy doesn't scream, Tammy doesn't hit back, Tammy doesn't do anything, you know, they can do anything they want to her. And I would like to keep the group home open. So, that's my -- I feel very firmly, even the other girl that lives there -- I wish the other parent was here, but I would like, David McMahon knows my daughter. Dave McMahon knows my daughter. Tammy has been in every agency.

BRIAN ADAE: May I ask a question? First of all, let me say that this is not the place which we can respond to individual questions, and I'm happy, absolutely happy to talk to you afterwards. As a matter of fact, I'd like to. I've heard Dave's name, he just gave me an indication he has some knowledge of the situation.

CAROL ARAUJO: I should speak with who?

BRIAN ADAE: I'd be happy to speak with you on the specifics. If I can ask some general questions, what provider is she with at the moment?

CAROL ARAUJO: A private agency, Ocean State Community Resources. David Reis is a very nice man, you know, basically, I've been very happy with the group home. The bedrail was a problem.

BRIAN ADAE: If what I can, if you can clarify, the general issue is you're feeling, and tell me if I've got this wrong, you've been informed there are cuts in the state budget, and as a consequence they can no longer afford to fund a group home that's in a small setting? This has three residents in total?

CAROL ARAUJO: Yes, three. Isn't there a waiting list?

BRIAN ADAE: And you're concerned about going to a larger group home that might have a half dozen or more. Is it a particular mix, or just the number you're concerned about?

CAROL ARAUJO: Yeah. I've tried it. I've been with West Bay for five years. I've been with Blackstone Valley for five years. It didn't work. She's been here five years. Five years seems to be the number. But she belongs there, this is her home, and I don't know if I'm being told the right thing.

BRIAN ADAE: If I paraphrase this -- (Phone ringing) Sorry. This should have been off. I think our moderator told us to shut off cell phones -- sorry.

CAROL ARAUJO: Do you have any other questions about the situation?

BRIAN ADAE: What you're trying to say is you don't feel there's enough on the continuum of options for her?

CAROL ARAUJO: They haven't done anything. They just said, "Oh, well, she died." Sent us a Housing: Shared Living letter: We're either going to close it, or ship everybody there. We were told that the state is no longer filling beds, only if they're coming out of a hospital or something? And I said, "Well, isn't there a waiting list?" No. Everything today is shared living. My daughter cannot go into shared living. Never. She's multi-handicapped and she's non-verbal, she has no way of protecting herself.

BRIAN ADAE: The information you're getting, is that from the group home, provider, or from the state?

CAROL ARAUJO: Say that again.

BRIAN ADAE: Where is this information that you're getting that they're no longer filling beds?

CAROL ARAUJO: I guess it's conversation with different people. They didn't word it that way at the meeting, but they called a meeting about two weeks ago, and they're going to let us

know at the end of a month his decision. He's going to let us know his decision. What about mine? The director of the private group home is telling us he wants to close it, and he's going to announce to us at the end of a month, which should be about two weeks, his decision. And I would like to keep the group home. It's the only safe setting for my daughter.

BRIAN ADAE: Understood. And I'd be happy to talk to you after.

CAROL ARAUJO: Thank you very much.

DAVID McMAHON: I'll be happy to attend the meetings with you. We'll untangle this.

CAROL ARAUJO: I'm glad I met you. I was on the phone with your office quite a few times about the bedrail, but it sort of took care of itself. I'll talk to both of you after.

SHARON BRINKWORTH: Thanks, Carol. Did anyone else sign up who would like to speak? Would any of you like to change your minds? Feel free.

CHRIS DeGRAVE: Negative.

SHARON BRINKWORTH: Let's do the Statewide Independent Living Council. They can talk about what they want to tell us now.

FEMALE SPEAKER: Great. So, the Statewide Independent Living Counsel, Rick is the chair, so we worked on a survey. It's called the Needs Assessment Survey, and what it is, is looking at people with disabilities, adults with disabilities, talking about what it is working for them in terms of independent living. So, what is working and what is not working. You were talking about your daughter is a definite example for what is not working for people with disabilities trying to figure out how to live. The survey takes about 15 minutes, it's available on-line. There's pins in the back. There's flyers in the back. If people are interested in filling out the survey, or contacting people to get people to fill it out. Is there more I should be saying about this, Rick?

RICK COSTA: I think you've made all the major points.

FEMALE SPEAKER: So it's a very easy survey for people to fill out on-line. It's RISILC, www.risilc.org, Rhode Island Statewide independent Living Counsel. We work with PARI and OSCIL, and that's a big portion of our survey, and speaking about what those services are doing and where there may be gaps.

SHARON BRINKWORTH: Do you have a deadline on when you want those back?

FEMALE SPEAKER: No. It's going to be ongoing. The sooner the better. There is a \$25 gift certificate to Target. So, if people want -- the survey itself is anonymous, but if you want to enter the drawing, which we did the other day. So if somebody wants to enter the survey, then they get to enter that. It's available on-line. If people want to call us and do it by phone, they can do it. If they want the survey mailed, there are different languages: Spanish, Portuguese. There's graphics, pictures. There's a version that has closed captions, a description of it. So, there are different ways that it's available.

SHARON BRINKWORTH: And do you have extras at the back of the room?

FEMALE SPEAKER: Yes. There are some surveys. There are flyers and blue pins.

SHARON BRINKWORTH: I'll take some of them, too, back to our office, because we have a resource center there, and we have a lot of people that come in from time to time.

FEMALE SPEAKER: That would be great.

SHARON BRINKWORTH: And we'll encourage them to fill that out.

FEMALE SPEAKER: Thank you.

SHARON BRINKWORTH: One of the things we have to do -- you don't -- but we have to stay here until five o'clock. It advertises from three to five; it means people could come during that time. It's not that everyone has to be here at three o'clock, so if we left at quarter of five and someone rushed home from work and wanted to come and say something and there was no one here, we'd be in trouble. Give me your name.

Human Services:
Voter ID

TOM DaPONTE: I was too lazy. My name is Tom DaPonte. I had two lives: 25 or more years in the furniture retail business, and 25 or more years as a sheriff for a county. Probably why you don't see a lot of people here. Now I'm retired, so now I can be here. I've been involved with the Lions, and have attended a couple of the functions with the Sight Foundation, Rick, your organization, the convention they had down in Warwick, I was there last year. It came to mind, I didn't come here for that reason, but when I saw the voter ID, they had an attorney there from Chicago and her goal was to have, to be able to go in there and vote and go in by herself with no assistance, so whatever that entailed. So I just thought I'd mention that. I'm really here because my son has Down Syndrome, he goes to Maher. And that did remind me of a question for him. Where he goes in with my wife, my wife votes twice, but he and my wife goes in the voting booth, but I imagine this year he'll have to have a voter ID like everyone else?

BRIAN ADAE: I think what Dave is pointing out, we have on the back table here voting rights. There's a packet in here, as well as registration forms. And Donna Martin who is sitting there to your right, that's one of the reasons; she's here today, to assist you with the process. Normally we don't respond to questions, but your concern was that somebody going in with them to assist would have to be identified, or?

TOM DaPONTE: My son, he goes with my wife, and the two of them go together. That is fine with us. That other advocate for the Rhode Island Federation of the Blind that spoke at the convention last year, she was advocating a person sight impaired being able to go in by themselves not needing assistance so the facilities are there for them. That's what it reminded me of. One thing that I did want to say, and you have these specific areas that we've just heard, I don't know that I've had any, my wife was in special needs for 30 years in Tiverton, and she spends a lot of time. John goes to Maher. It works out great. It's a ride down there and back. And yet, is that window from January to June, maybe April to June when we're all on edge, "What's the budget going to be like?" And whether -- I haven't gone up to lobby or make a show to the legislators, but I think that's something that puts us all on edge at that time, and then we either wait for word, "Well, your son can't get this. Your daughter can't get that," and that's something that keeps us on edge at that time. There are people who whose politics are lot different than mine, but if I were looking for someone to speak up for my son, I know I could always rely on Chuck Levesque. We do have advocates like that, but yet at that time we are on edge. The other question: I was hearing some of this, and I think of my son, a strapping 25-year-old who is quite limited. He's home with me and my wife. I was a little concerned about the liability of a person like that, where, if he were to hurt someone else or damage something, throw a rock through a window, would the liability automatically go to the parents who are in charge of that child? That question came to mind as I was listening to some of this. I think that's all I have that I'd like to say.

Human Services:
Down Syndrome

BRIAN ADAE: If it helps, kind of looking in the direction, again, not responding, and I can't really give individual legal advice, but on the liability question, I can tell you that whether they're under guardianship or not, generally speaking liability-wise, if you're worried about something physical occurring, that is not something that's going to be a liability to parents, relatives, or guardians. The only time someone is over 18 that the parent would be responsible for something, it wouldn't be a parent, it would be a guardian appointed through probate court in Rhode Island, it would only be a guardian in purposes of finances. So, only for finances. But in any other actions that would be taken, there's no other liability. They're their own person. As a matter of fact, we run across folks who have obtained guardianship over their child once they turn 18 thinking they can absolve them for their actions if they may be unsocial, if you know

what I mean, whether it be criminal, and it, in fact, will not. The only question then will be whether or not they had the capacity to appreciate what they were doing. Whether they should be held responsible for themselves, talking about the disabilities individual. There is no liability, basically, if that helps.

TOM DaPONTE: It does help. It doesn't change my responsibilities, but at least it keeps my mind at ease.

BRIAN ADAE: That's the legal responsibility. I was talking to somebody about this, the feeling we all have, the moral and ethical responsibilities we feel for our family members. If they may engage in some activity, whether they're disabled or not, how responsible we feel we are for that.

DONNA MARTIN: My name is Donna Martin with the Community Provider Network of Human Services: Family Advocacy Network Rhode Island. We support agencies who provide services to adults with developmental disabilities. There's a group was formed, separate from my organization, and they're called the Family Advocacy Network. It formed last fall in response to the state budget cuts that had been passed through the legislature, and the family members from around the state have gotten together on a pretty regular basis and have mapped out plans to provide, or try to help to provide a voice of family advocacy to legislators, to decision-makers, state officials, as a way to kind of bring forward their ideas and concerns, and I'd be happy to share that information with you if you're interested.

CAROL ARAUJO: I would like that.

SHARON BRINKWORTH: Is that something you could tell all of us? Is there a website, name, office, phone number?

DONNA MARTIN: The name is Family Advocacy Network. The phone number is 773-7775. It goes to a voice mail, so you could call and leave your name and contact information. Someone monitors that voice mail, a parent or sibling of a person with a developmental disability. They could get back to you and give you information about the meeting schedule. There's not a website. There's an e-mail address, which is -- I can't recall it, I'm sorry. I'll look in my contacts. Try that phone number, you can leave a message.

CAROL ARAUJO: How often do they meet?

DONNA MARTIN: I believe monthly.

CAROL ARAUJO: Where do they meet?

DONNA MARTIN: Warwick. You could call them, and they could send out a list of meetings. It's information for parents and siblings.

CAROL ARAUJO: Thank you.

BRIAN ADAE: Did you have anything else to add about voting?

DONNA MARTIN: I think Sharon covered most of it. There's a group that came together with the support through Rhode Island Disability Law Center and intended to be a cross-disability voter education and awareness group, and I'm here with lots and lots of voter registration forms. I'm sure you all vote, but as Sharon said earlier, I would remind you that if since the last election if your name has changed, either marriage, divorce, or other circumstance, or if your address has changed, you need to reregister to vote, and I'd be glad to help you out with that.

SHARON BRINKWORTH: Sorry.

DONNA MARTIN: That was the purpose for me to be here.

SHARON BRINKWORTH: I know there was some concern about people who have disabilities not having identification forms; is there any update on that?

DONNA MARTIN: This year the board of elections will accept pretty much any form of ID: A photo ID, bus ID, obviously a DMV issued state ID or driver's license is preferred, but for this election, there are other acceptable forms of ID. I believe they're taking utility bills, and that will work for this election cycle only, but in next election cycle you will need a state issued ID. But the flip side is there's been recent legislative change that enables you to complete a mail-in ballot with no reason. If any of you have completed them in the past, there's a section that says other, and you can do that without ID, which is kind of a curious thing.

MALE SPEAKER: You have to apply for that?

DONNA MARTIN: Go to your local Board of Canvassers. Pick up a local form. You need a form of ID, but you don't need an out-of-state reason to demonstrate why you're out of state at the time of the election.

BRIAN ADAE: Talking about ID, not familiar with that, somebody else in my office works on that. Expired state ID, expired driver's license, expired state identification, do not have a license, but one that is expired, more than five years old, will that work or not?

CHRIS DeGRAVE: Negative. It has to be a current and valid ID. So, technically, if it was a two-day old, expired license, they don't have to accept it. The way it's written in the legislature it says it has to be a valid photo ID. So, for the 2014 mark. In the back, start seeing these posters around, this poster explains exactly what's accepted in this election, and explains exactly what's accepted in the 2014 election. My recommendation is this: If you don't have something with your face on it or with your name on it, I suggest you go get one. If you can't afford it for whatever circumstances that exist, the Secretary of State's Office will provide you with a free photo ID. It has your face, your name, and birth day, not date. It can only be used for elections, and cannot be used to get another form of ID. So, they will only give you that if you don't have one of these things, which would be: A driver's license, US passport, ID card issued by the United States Educational Facility, United States military identification card, State of Rhode Island or US Government issued ID card, or a government issued medical card. If you have one of those, you don't need it, but if you don't -- and this year, you can use non-photo Social Security, Medicare, or birth certificate. And these are on the back. This, obviously, there's a couple to be hung, but if you have questions, and there are some questions and answers on this form explaining exactly what is and is not required, and those are in the back in a pile.

SHARON BRINKWORTH: Thank you. I received in the mail, a green card, I think that came out in the state a week or so ago. Did everyone get those?

BRIAN ADAE: Just Barrington.

SHARON BRINKWORTH: I don't know. Anyway, it tells you where you vote.

PAT RYHERD: It will notify you of, if any, change, who you need to contact.

SHARON BRINKWORTH: I thought that came out from the state.

PAT RYHERD: Apparently not.

SHARON BRINKWORTH: It's a green post card.

CHRIS DeGRAVE: It's usually from the Board of Canvassers.

SHARON BRINKWORTH: Oh, okay.

BRIAN ADAE: I received something when I lived in Barrington. It indicated my post had recently changed.

SHARON BRINKWORTH: Is that considered an ID?

CHRIS DeGRAVE: Negative. And actually, I have a question for change of address. If you don't mind asking it that comes up quite often. We're talking about ID, but what do you need to register for a new address, what would you need to provide? Obviously, people go to different group homes, facilities, what would they need to provide?

DONNA MARTIN: I think either a driver's license, or in this case, a utility bill, something that shows their name and address. And I have a correction, I'm sorry, the phone number that I gave for the Family Advocacy Network is 773-7774. Sorry.

SHARON BRINKWORTH: Chris, would you like to find out if that lady who just came in is wanting to speak?

CHRIS DeGRAVE: Absolutely. As they said, we're here until five no matter what, so take up some of our time. State your name, and if you haven't signed in, in the back, when you have a chance, sign in so we have your name on record.

CLAUDIA GORDON: I wanted to apologize for being late, so I'm not sure what has been discovered or covered and what hasn't. My name is Claudia Gordon. One of the reasons I came is was I was hoping to hear about disabilities and how it relates specifically to services that are generally either for the elderly or those over 60, particularly resources like Meals on Wheels and services that would typically be covered if you have no assets at all, or if you're over 60 or 65. That's been a major problem for some of us who have not been able to get out of the house, that are house-bound. Although it's been stated you qualify for services, when push comes to shove and you go through the process, it turns out there's, it's not there, and there's a denial.

BRIAN ADAE: Maybe to clarify it a little bit, when I'm looking at this, maybe clarify a little bit -- You're talking about services and eligibility and denial. You're talking about services for the elderly and disabled through DHS, Department of Human Services for long-term care; is that right?

CLAUDIA GORDON: I'm not sure if it's long-term care through the blue book and point programs such as Meals on Wheels comes to mind because that was the most recent one, but it may be long-term care, but...

BRIAN ADAE: I'm going to try to lean on some of our friends from the state here, because I know that Dave is from Behavioral Health Developmental Disabilities Hospitals, which is a part of the Executive Office of Health and Human Services. If you're talking about point, and for those of you who may not be familiar, there's a blue book for services for the elderly. When we look at Medicaid, and a lot of them are, if you're looking at single source where you get this information, there's something called the blue book. Please correct me if I'm wrong, even though I know you're essentially from a different agency, through long-term care, which would apply to the elderly or folks that are disabled long-term on the basis. It's very interesting when we look at eligibility because we look at the agency, for example, that Dave works with, that deals with folks with developmental disabilities, but also folks who have mental illnesses and various programs, and it all comes in under the gamut of the global waiver where there's one point where we can get the information we need in one application, even though we're looking at a bunch of different factors. May be dealing with somebody who is 35 years old who has Autism, nonverbal, or somebody who is 65 years old and has a variety of orthopedic issues.

DAVID McMAHON: Contact us or any agency. We try to take the application and shift people to the appropriate place. The idea is one point of entry, so it's a little bit simpler to folks if you contact us directly.

CLAUDIA GORDON: I think I was referred to somebody through you guys, and then I was told there was, that the eligibility criteria was met and they would help facilitate whatever the services were, but then those individual providers, for lack of a better word, they said actually you have to be either over 60 or 65, even though it's clearly stating that if you have long-term disability you may qualify, so...

DAVID McMAHON: I can't speak with specific cases, but, in general, an application comes to us, we go through the eligibility process, once we get to a point that it goes to a different department, we facilitate that. So, it's not just folks who are over 65, it's for folks all the way up, it's for all sorts of programs, that's why we're trying to develop the point to be a little bit more efficient. Maybe that's what you're describing. It came to a department, got to a point, and got shipped to the other?

BRIAN ADAE: That's one of the questions on an individual basis. Maybe if you want to talk afterwards, we might be able to sort it out. I think that there are a whole bunch of services out there, and it gets to be very complicated. I've been working in this business as a lawyer for a number of years now, and I'm looking at it from the outside with an overview, and I get confused a lot. So, for the average person who is trying to obtain necessary services for what they need can be incredibly difficult and confusing. They're trying to simplify it, so that's a good point about the point. Generally speaking, if you're having difficulties navigating, go back to the point. The other point is, if there's eligibility and then denial, it might be helpful to speak to the Disability Law Center, which has nothing to do with the state. Somebody can look at it and say on a legal basis, we think you're eligible or not. It's a matter of confusion of which door to go through. If you got stuck behind one door and should go through another door. We can talk about that afterwards.

CLAUDIA GORDON: My question is if it's happening to me, then it's probably more widespread.

BRIAN ADAE: I think we've heard this in previous years, too, sitting on these panels at these forums where the complaint is confusion about what services for who, where, when? Which door do we go through? And they've tried to simplify that. That's the whole point of the point: To have one entry and get directed to one place. If you go down to the Registry of Motor Vehicles, it can be very confusing. You do more there than just renew your driver's license or register your vehicles. They're going to point you to the right place so you don't get this far down the line and find out you're in the wrong place and you need to be somewhere else, as opposed to let me get you to the right place. It is a good point to keep making.

CLAUDIA GORDON: Professionally, my background is mental health and social work, so I thought I would have an easier time navigating the system and helping a couple of other people but that hadn't been the case.

CAROL ARAUJO: Not happening.

CLAUDIA GORDON: Unfortunately. If I could ask a question: How does one get another application?

DAVID McMAHON: Probably the best thing to do is see me after. Find out what happened. It's a matter of what happened. If you've hit a dead end, you could go the legal route.

CAROL ARAUJO: Where do you live?

CLAUDIA GORDON: I live in Barrington.

CAROL ARAUJO: Have you been referred with the Barrington Senior Center?

CLAUDIA GORDON: They referred me to the different resources and said there are people that can make a difference because certain disabilities would qualify just as an age requirement would, which is what I, my understanding of it has been, but then, that's really not happening for some of us.

CAROL ARAUJO: David will help. If not, Brian will.

SHARON BRINKWORTH: Sometimes you have to just keep going back. Get the right person, I guess. I think you could make a shortcut here between these two.

CLAUDIA GORDON: Thank you very much.

SHARON BRINKWORTH: Don't forget to sign in before you leave. I know you just came in.

CLAUDIA GORDON: I do apologize.

CHRIS DeGRAVE: It's fine. We're here.

CLAUDIA GORDON: Thank you.

SHARON BRINKWORTH: Anybody who hasn't spoken change their minds? Did something spark a thought? Don't everybody look down at their papers.

DAVID McMAHON: Jokes? Amusing stories? Anything?

TOM DaPONTE: I've got one. I was on the Bristol-Warren School Committee years back.

Education: Accommodations	John was mainstreamed there in class, and I thought I had my eye on what was going on with John in his classroom. And I went for a parents conference and went in and found out things were a mess in that room, so I went a little haywire, hear it from my wife who was a special needs teacher, and this was not going to happen to me. So, eventually, I called the Department of Education ranting and raving. And I'm sure I identified myself. And after going on and on, he turned to me and said, "Have you called your school committee," and I said, "I'm on the school committee." So, these are things we all go through, but there are people there trying to help, and sooner or later you find your way through it.
------------------------------	---

3. Wednesday, July 24, 2012 – South Providence Public Library

DEBORAH GARNEAU: Hi everyone. Thank you for coming. My name is Deb Garneau. I'm from the Health Department Office of Special Health Care Needs. We're hosting the forum tonight. We're hoping that we can hear a lot of input. I have a few formal things to say, and then we can introduce our panel that's here. And then we can start in with some of the comments. The purpose for the public forum is to identify the concerns of people with disabilities and their families in order to assist the state to develop programs to improve the quality of life of people with disabilities, to ensure everyone who wants to speak to get a chance. Please, keep your comments short and to the point. Although we don't have a huge crowd tonight, so if you wanted to talk a little further, then that's more than welcome. If you have a critical problem that needs to be addressed, the panel members will be available at the end of the hearing to direct you to the proper agency for help. After the public forums are completed in early August, we have them all throughout this week, then the agency will review the testimony and prepare the recommendations, which will also be posted on the website by the end of November. The recommendations, and the transcripts will be printed and sent to state and congressional officials and the members of the general assembly, and the recommendations will be used to develop policy and legislative initiatives for the next year, or until they are accomplished. In the back there's information on the Rhode Island disability vote project. The materials are there. Also, if you want to change your address before the next voting comes up, you can do that through those forms, as well. We're going to ask the panel to introduce themselves.

GREG MROCZEK: Does this happen every year?

DEBORAH GARNEAU: Yes.

GREG MROCZEK: Do things that come out of this actually get enacted? Is there a track record; is there anything you can say about how it actually plays out?

DEBORAH GARNEAU: Yes.

TIM FLYNN: My name's Tim Flynn. For years I headed up the legislation committee, as well. To answer your question, yes, we go all around the state; they really are a blueprint for the legislative initiatives that we derive every year. We got successful taxicabs in the state of Rhode Island, a person with disability can call up and show up and a cab will go. We enacted what is known as a crisis intervention bill, which meant that if there is a person with a disability who is

being abused by a caregiver, and a lot of problems usually, because they don't want to pick up the phone, because if the caregiver gets arrested, the person is left with no one there to take care of them. It's a disincentive. We've got people with disabilities included in, I think it's EDE, I what's the acronym? Bureau --

DEBORAH GARNEAU: Behavioral Health Developmental Disabilities and Hospitals.

TIM FLYNN: Thank you. They have a unit that goes out. And if there's a problem, there's a 311 number, a hotline people can call. And they will have a social worker come and show up and provide, make sure that you get to a hospital.

GREG MROCZEK: Is there a relationship --

TIM FLYNN: To answer your question, yes, everything that happens at these meetings does get enacted.

GREG MROCZEK: How do you think about what goes on here relative to the budgeting?

TIM FLYNN: I think, why don't we go through the process of introducing yourself and get started. I think we can go q and a later.

ANNE LECLERC: Anne Leclerc, from the Rhode Island public transit authority.

TOM MARTIN: Tom Martin, Rhode Island department of behavioral healthcare, developmental disabilities and hospitals.

KAREN DAVIS: Karen Davis, office of rehabilitation services.

CHARLES MESSINA: Charles Messina, Rhode Island Disability Law Center.

CONNALLON CONNALLON: Elizabeth Connallon, brain injury association.

VINCENT DeJESUS: Vincent DeJesus, Rhode Island independent statewide living center council.

JACK RINGLAND: Jack Ringland, Rhode Island statewide independent living council.

DEBORAH GARNEAU: Great. So we have our panelists. I have the sign-in sheet. And then for people who wish to speak, if you want to check off, either, by your name on the new sheet. So far there hasn't been anyone that has checked to speak, but maybe there is on this sheet. As Tim was saying, we want to hear feedback about the system and about what is happening. There's -- definitely, looking at this materials, everything is transcribed, and gone over, and looked at for particular trends and common themes that are coming up, and then legislation and teams are worked on around some of the overriding issues. Any comments? I didn't want to interrupt your conversation. If you have any other comments for us.

GREG MROCZEK: I've never been to this before. My name's Greg. My son Jeffery is 31. He

Housing:
Group Home

lives in (inaudible). My daughter is 28. She lives in Pont (sounds like) house, which is in North Smithfield, and they're both administered by Perspectives. I'm just an interested parent that had been, you know, watching with dismay as the -- with the whole budget crisis that's been happening year after year. So I'm just here to listen and learn.

TIM FLYNN: If I might ask you a question, you're probably an expert on this, I guess you sort of -- you say you worry about the budget, what specifically are you worried about?

GREG MROCZEK: My kids are really young, and hopefully life is long for them. And so with the trends that's been happening in the state in terms of the impact of the budget crisis, it's just very troubling for me to think, all right, what's going to -- if the trend conditions, what does five years look like? What does ten years look like? I mean, they can be alive for 30, 40 more years. That, to me, is the most troubling part of the whole -- so I've seen the impact of the cuts on the quality of the services that are provided for both of my kids, and looked at the quality of the direct care staff, and the impact that the budget crisis has had. It's very troubling.

TIM FLYNN: If you could, I'd like you to be more specific. Like, what specific cutbacks? You said they experienced cutbacks. I just want to know. I just want to know. Cutbacks in transportation, or -- what specifically can't they do now?

Housing: Group Home Staff
GREG MROCZEK: I think in terms of Aliza, the staff turnover, and the kind of staff they're able to get. Because there's less money for professional training, it looks to me, any ways, like it's less of a -- it can't really be a career choice for somebody who's even -- if you can't make a living wage, there's not going to be ongoing training available, it attracts people that see it as just another job. and if it's your child that's on the receiving end of the direct care staff, that makes a big difference.

TIM FLYNN: You've noticed the past, say, two years?

GREG MROCZEK: Yeah, it's tough. I want to answer your question, because it's also hard, because you're talking about people here, that I don't want to be blunt.

TIM FLYNN: Be blunt. Nothing happens if you're not blunt. You don't have to name names, but.

GREG MROCZEK: No, I think that the quality of the people that I interact with that are the direct care staff has deteriorated. It's not surprising.

TIM FLYNN: You think that's because of less hourly wages?

GREG MROCZEK: Yes. It's just less hourly wages, less training involved. A current path that may be more of a dead end in terms of what we're -- where somebody can go if they want to stay in the system. And, I mean, the hourly rate. It's like when I went to the state house, whenever it was, between \$10 and \$11 an hour. It's not a living wage. A lot of the folks that are doing that direct care staff it sounds like have other jobs. So they're working with my kids, and they're also at other jobs, which makes sense given the amount of money they get.

DEBORAH GARNEAU: I don't know if any of the panelists have a response?

GREG MROCZEK: Let me just say, here's one example: My kids don't have any balance. They have a genetic disorder. They're mostly in wheelchairs, but they have to do transfers. She has fallen like four times in the last month at her group home. To me, in terms of cause and effect, a year ago that didn't happen. Not that she didn't -- it's always challenging doing transfers with someone who has no balance. But the number of falls has increased. To me, that's a direct result of the training that the staff has gotten and not gotten that would equip them to have her not fall when she's transferred from the wheelchair to the toilet, from the wheelchair to the van. All of them.

TIM FLYNN: Our mission here is sort of, we're not here to answer questions, but we want to clarify your issues.

TOM MARTIN: Can we respond back? I'm from the Department of Developmental Disabilities. And, yes, we took a big cut in 2011. This last year budget, they did put 9 million back in the budget. And the department is using that money to maintain the present hourly wage. So we're not making a cutback as previous years.

GREG MROCZEK: Just as an example, it would be like taking somebody's salary and saying you were making \$20 an hour, now you're making \$10.50 an hour. We're not going to cut it anymore. Still, the bar is here, now it's here. It's better than continually going down, but it's clearly not the outcome that I was hoping for.

TIM FLYNN: We may approach that as a budget item, for instance. We're going to testify. Every year they come out with a budget, and we go through. And we look at, you know, whoever, whatever agency is responsible for that, we can say, in our forum, someone expressed a concern over the hourly wage and high turnover in the homes, perhaps it might make more sense if you raise the hourly wage and get better, you know, more continuity. We all know the time we're

living in. It's a tough balance. But we're up there talking about it. So you never know. Also, you know, you can also testify on this stuff. It's very powerful for, I mean, I'm sitting here watching you, and, you know, you make a very strong case. If you have a finance committee sitting around listening to you, they'll understand exactly what you mean. You might just put that in the back of your head.

GREG MROCZEK: Yeah, I heard people say much better than I did. The senior managers of the Perspectives of the state did a much better case of being able to really quantify the stuff that I'm just kind of referencing.

TIM FLYNN: Can I make a quick point, though, with all due respect to the panelists; representative agencies are professionals in this stuff. When you're a legislator sitting around the table and have an agency, you will with a great deal of respect, but if you're a parent, somebody on the ground doing it, I think it has greater impact.

GREG MROCZEK: One other thing that occurred to me. Aliza is 28, and there's like seven residents at her group home. and six of them, they're all in the age range from 30 to 40, but then, like, a 67-year-old woman moved in. The reason she did, who's more involved in terms of her disability, the reason she did was that Perspectives was put in a position where, and I'm not going to be able to say it in a way that really does justice to it, but that the budget crisis sort of forced their hand in terms of how much funding there is available, and the places that they are able then to put people that need services. And so it's not really an appropriate placement for this woman, but the way --to hear Perspectives, for me to say that to Perspectives, really, this doesn't seem to make sense, and listen to their response, to me, it was all about dollars and cents, and less dollars and cents, and the fact that they have fewer options.

TIM FLYNN: Thank you.

DEBORAH GARNEAU: Thank you. Are there others that would --

Education:

Learning Disability

JENNIFER NEUQUITZ: Is there anyone on the board that can answer questions about education? I'm here, my school notified me of this meeting. My son has a learning disability, and I have complete confusion about all of it.

TIM FLYNN: Why don't you talk it through? What's your name?

JENNIFER NEUQUITZ: Jennifer. And my son goes to Waldorf school, which is a private school. He's dyslexic, and he uses public funding to support his needs of three days a week, and

Education: Private
School Support

four days a week speech. I've been fighting for. He's going in 5th grade. I fight every year for his services. Every year the battle is new, and every year it costs me money to hire lawyers to fight it. I'm at my breaking point.

So I don't know. I don't know where I take my questions.

DEBORAH GARNEAU: The Rhode Island Department of Education funds family members who provide resources and information through the Rhode Island Parent Information Network.

JENNIFER NEUQUITZ: I've done that. They won't take me, because I'm not enough of a case.

DEBORAH GARNEAU: The Parent Support Network, as well, does that kind of navigation and systems with families. the RIDE Special Education Office has a person on staff that fields concerns and, you know, navigates, like, due process, and some of the --

JENNIFER NEUQUITZ: It's Glenda, right?

DEBORAH GARNEAU: Yes.

JENNIFER NEUQUITZ: I spoke to her a lot. I feel like there's no place to go that -- I called for a lawyer, and said, I don't know what to do. I don't know who answers these questions.

Because my child has needs, and they need to be met. That's the law. But I feel like every year there's a new loophole. Do I continue on that path and every year be ready to fight the fight?

DEBORAH GARNEAU: Well, does the Disability Law Center have any input?

CHARLES MESSINA: The -- I have to confess, I'm not the expert in special education. I'm the guy that does the social security cases in the office. I'm the exception to the rule. But I will try and answer questions as best as I can. The federal law and state law require that a child be provided free appropriate public education, FAPE, as it's called. The question becomes what services and what equipment goes into FAPE, and is the school providing enough. There have been lawsuits, some have gone all the way up to the Supreme Court of the United States. I am not suggesting that you start there. Basically, saying that the school does not have to provide an entire variety of goods and services as long as the child is getting free appropriate public education. The twist in your case is that your child goes to a private school. Up until changes in IDEA, which I think is in 2005, 2006, somewhere. 2006, I think it was. Now, because of the way the law has changed, those services are pretty much on the year by year basis. It's like, do we do it, do we do it, do we do it? I don't have the answer to that without looking at a ton of information. And I probably would be talking to another lawyer in my office anyway. What I can tell you, we do have a free publication on special education. I believe it's on our website.

JENNIFER NEUQUITZ: I have it.

CHARLES MESSINA: It's about as up to date as you're going to get. I don't know if you've ever spoken to us. The problem is we don't handle every special education case when we get requests for assistance. We have priorities. I will pause here, our priorities questionnaires are in the back of the room. I'm asking everyone to take one. Fill it out. Underneath it there's an envelope, stamped and addressed, take one of those and mail it back to us. You're free to call us and see if there's something we can do for you.

JENNIFER NEUQUITZ: Is that number back there?

CHARLES MESSINA: Yes. I can tell you. I would rattle off the 800 number, but I never remember it. It's 831-3150. We're open 9:00 to 5:00, daily. You can also look at our website, which is www.ridlc.org. If you prefer, we have -- you can leave a question on our website. We do answer all the e-mailed questions. We just ask that you don't put any personal identifying information -- name, age, social security number. And you're get a call back. If you don't call us, we'll call you.

TIM FLYNN: If I might summarize, your child goes to private school. If the legislation committee is going to look at this issue, the real issue is you want to see similar funding that is available to public school students?

JENNIFER NEUQUITZ: That's a law in Rhode Island.

TIM FLYNN: Even for private school students.

JENNIFER NEUQUITZ: In Rhode Island, which is one of two states in the country, which allow public funding to be used for private education. Like you said, it doesn't flow seamlessly.

TIM FLYNN: I can we can certainly--

JENNIFER NEUQUITZ: It's really a squeaky wheel. I just need to get rallied again to do it.

TIM FLYNN: You can do it.

JENNIFER NEUQUITZ: Thank you.

DEBORAH GARNEAU: Are there other speakers? No.

MARY JANE DeANGELIS: Can someone hold up my paper?

DEBORAH GARNEAU: What is it? You want to hold up a paper? Maybe if you can come closer, so we can make sure we record.

MARY JANE DeANGELIS: My name is Mary Jane DeAngelis. Yes. First of all, I'd like to tell you a little bit about myself. (inaudible) I went to Smith College and studied

Education:
Funding

physics. And I went to University of Connecticut Health Center, why I majored in physiology. After that I went to law school. I left for financial reasons. Now, my

Human Services: Office of
Rehabilitation Services

first exposure to the state disability system was to the Office of Rehab Services. Before I went to law school, I asked for funding. And they lied to me. They said, we don't do that. despite the fact I had a piece of paper in front of me, the counselor that was telling me, that lied to me, said, you know, (inaudible) the counselor that lied to me didn't want to look at and

lied in her answer, because it said clearly on there that under the Rehab Act, the federal government funded and directed states to fund, especially persons with disabilities, to go to law school. After that incident, I felt frustrated. I didn't bother. I went to law school. The problem that I knew I was going to come into I came into. And I had to drop out of law school for that reason. Next, I went back to the Office of Rehab Services. They took medical information from me in order for me to become a (inaudible), become a client of the agency. They abused the privilege. They tried to use medical information for years to determine what services I should get, and what my goals would be. And for the 20 years that I was with them, I found jobs on my own, but they never once, despite my excellent academic background, tried to help me get a job. And despite the fact that I understand they get close to \$30 million a year in federal funding. To me, this is completely outrageous, and, you know, totally (inaudible). And they completely ignore the directives of the Rehab Act. It clearly says in the rehab act that a person is supposed to choose their own goals, own services, and own technology. And yet they keep with this constant policy deciding the fate of their clients. I believe it's to eliminate (inaudible) make sure that they are keeping the money to themselves, and deciding what their money goes to, instead of letting the person do that. I think that the law should be changed. I think that the state law should prevent a lot of us from pressing medical information from the client more than once. I think that the law should preventers from delaying choice of goal and (inaudible) of services and technology, because that was a constant kind of policy, unofficial policy, to find their goals by delaying. I think they should be fined somehow for not keeping - not allowing a person to get back into the workforce, because it's outrageous to keep someone from working because they're spending years deciding, for instance, what kind of cell phone you want to get someone. Believe it or not, they did that to me. One of the things they did to me, also, was they promised to get me an interior track that's vital, it's a lift system. You know, it's vital for me to transfer to ambulate, to maintain my health. They promised me that. And they spent over a year with architects

Housing: Home
Modifications

designing a system, and so forth, and yet despite all that, 12 years have gone by and it's never been installed. DHS, Centers for Independent Living

Advocacy Groups, like the Disability Law Center, have a conflict of interest, because they take funds from the state with (inaudible), or they have otherwise some other contractual relationship. For this reason, they violate the ADA, they tell people they don't have to advocate what the person wants. And this is clearly, clearly, in violation of

Human Services:
OSCIL

the independent living section of the rehab act. This goes on all the time. In fact, I had a big tussle with one of the groups about this. I wanted

something (inaudible) on my behalf, something, I don't remember exactly what it was. And because I insisted that they do that, they dropped me from their services, and I had to sue them. I won the lawsuit, by the way. The point is that this was seven years ago, and it still goes on. OSCIL, for instance, they perform what's called assessments for the consumer. They have no business doing assessments. If you look at the law very carefully, it says in the

independent living section of the rehab act that they're supposed to advocate. They're just advocates. They're not supposed to be objective evaluators. That's not their job. They don't have medical personnel to do that. They don't have the right to do that. In fact, the state lets them do that. They encourage it. One of the things OSCIL said to me last year when I asked why they were doing the assessment, instead of, you know, advocating for my needs as an independent living center is supposed to, they said, because we're going to give the state what they pay for, and we're going to tell them what they want to hear. This is incredibly -- this is -- I can't believe this stuff is going on. Why are they still going, I mean, why aren't-- they should be shut down. They're not-- that's not an independent living center. They're not advocacy groups anymore. They're acting as home health care agencies. That's what a home health care agency does. That's not what they're setup to do. The whole -- the main reason why the federal government put them into existence was so that they can stand up before them, (inaudible) the consumer and say, this, that the other thing, here's the state with all their power and money, we're going the person that's going to stand up for the little guy and tell the state that, you know, the doctor said she needs to start another thing, she believes she needs to start another thing. That's what she should get. For these reasons, because of the conflicts of interest, independent living centers have distain because they're unwilling to advocate. One of my social workers, her name is Michelle Simon (sounds like) violated another law, a community choice option. I understand that the state has (inaudible) to comply with. She violated my rights, preventing me from getting

Housing: Home Modifications

this track. Telling me because there is supposedly a state policy that you can't have a new exterior lift, a new interior lift within four years, \$208,000, you have to wait for four years, 5 years until I can get an interior lift. Now, from what I read from the Community Care Act, (inaudible) options, and so forth. She is supposed to

Human Services: Abuse and Neglect

be --first of all, she's not supposed to be using state law, she's supposed to know that. She's supposed to know that federal law takes precedence overstate law, number one. Number two, she's supposed to know that she's supposed to be helping the state to change the law to make it comply with the federal mandates. They're not doing that. I don't know when this is going to happen. For years social workers also violated my privacy. They misreported my experiences from one agency to another, always making me look like the bad guy. So a new agency will come along and knew, quote/unquote, my history, and didn't want to take my case. This is not (inaudible). They let aides assault me with (inaudible). They let aides fail to show up, and commit abandonment and commit other infractions. When I complained about these things, I got mischaracterized as the bad guy. The state at one point gave me a device called Lifeline, which frequently calls the EMTs and the cops, because it's a huge switch button. I would just touch it, and sometimes it activates. A lot of times it activates. Even when I used to tell people, these people that come over, speaker, you hit the button, even when I used to tell the people that used to answer, ring a bell, so to speak, used to come over the speaker from lifeline, I used to call the monitors and used to tell them that I didn't want EMTs to be called, or cops to be called. They used to call them anyways. So it was a judgment call on my part. I used to tell the police, I used to tell the EMTs, I used to tell the social worker, I told everybody, okay, that this was not my fault. Admittedly, the EMTs and cops were upset that they were being called 20 times a year. I understand that. I didn't design the system, and I didn't even want it. It's not the system I asked for. Everything I have to say, by the way, I can verify. Despite that, the state has started talking to the cops, EMTs, my home health care agencies, they talked and they violated my privacy. And they -- one day they got together and decided that I should be sent to a nursing home. I didn't know about this. This is how they did it. They violated my fourth amendment rights, no hearing, no mental health advocate, on an

assumption, there was no diagnosis of mental illness, against my will they forced me into a psych ward in order to get me into a nursing home. I was in and out of there, because when I looked that doctor in the face, I could meet them with reason. I told them they violated my fourth amendment rights. I have no idea this was going on. I completed about it. And then Lifeline was there to back me up to tell them I did complain and was wondering why I was there. My current social worker seems to have the same plan. She doesn't seem in any hurry to make me independent. She's not trying to put the track in my house so I can be independent and not worry about(inaudible). I have reason to suspect her of having (inaudible) for reasons I'm going to go into right now. The bottom line was that subsequent to that hotline, I went to a neuro psychologist, and I had myself diagnosed to prevent this from happening again. And guess what, I have high anxiety. There's no reason for years that there's abuse on the part of the state. with. The next thing I'm out raged about. DHS does not require ethical enforcement of Medicaid laws. What I mean by that is there's a lot of, for instance, physical therapy agencies or rehab centers that don't want to take Medicaid because it pays them very poorly. It pays them a very small percentage of what they would get, say, in comparison to blue cross, or Medicare. Now, DHS knows this. They know this, and recommended to go to a rehab facility by a doctor, sometimes several doctors. They don't care. If the rehab facility comes up with a bogus reason, oh, we don't treat your disorder there, they'll just accept it. Many times, the reason is very easily reputable. You can just look up on their website to find that they're lying. Why do they let this go on? I don't know. But a lot of this stuff smacks me of corruption, of payoff. I hear aides telling me they hear nurses talking in nursing homes about how social workers are getting paid off to let one person get abused by a system, to let people in nursing homes stay there when they want to go home, in order to --actually, let them go home so they can die and seize the property. I had social workers ask me if I owned my house, and lawyer friends tell me they're after it. Look, nothing's going to happen here, you know why, because I got a big mouth, because I'm smart. This whole state, whole country is going to know something if anybody ever tries to do anything to me. But I'm really sad and upset that this system is so corrupted, and then it failed, it fails us, day after day. I'm sure that if there's somebody like me that they have the nerve to try to abuse in this way, that there's tons of people, lots and lots of people, that don't know as much as I know, or don't know how to defend themselves that are out there being victimized. Now, by the way, I got a job as a professor in physiology, and I have reason to believe that my social worker said something about my health in order to try to get me to lose that job. This is outrageous. This is outrageous. You know, sometimes I feel like I'm living in like a totalitarian state, when the state wants to do somebody in, they can use all kinds of means to put you down and keep you from getting ahead, instead of doing what they're supposed to do, what they're getting paid to do, which is to promote your well-being. The system is supposed to want people like me. I keep trying, because I'm smart. I know it. And the other thing is I believe that my condition can be better. I know it can. In fact, I know they let it get this bad because they didn't want to give me rehab when I needed it. I had doctors tell me as much. This --

DEBORAH GARNEAU: Thank you, Mary Jane.

MARY JANE DeANGELIS: One other thing, I expect this whole thing, when it gets reported, that first of all, who is the federal regulators for the funding for the state, do you know?

DEBORAH GARNEAU: No.

MARY JANE DeANGELIS: I don't know.

DEBORAH GARNEAU: What is the question? I didn't know the question, sorry.

MARY JANE DeANGELIS: Who are the federal regulators of the funding for the state?

Housing: Nursing Homes

TIM FLYNN: I don't think that's a question we can answer

right now.

MARY JANE DeANGELIS: I want to find out.

DEBORAH GARNEAU: All of these comments recorded here will be looked at by the governor's commission on disabilities, and looking for different trends, and different information, and specifics around some of the areas that can be addressed. So we thank you for sharing. I didn't know if the panelists had any comments, or? Thank you for living us so much information. is there anyone else that wanted to speak?

TIM FLYNN: If you want, we can adjourn and reconvene in 15 minutes and see if anyone else shows up.

DEBORAH GARNEAU: Anyone want to speak at this point? I think we might just adjourn for 15 minutes, so we don't have to record, we can have other conversations. But then if somebody else comes, we will go back on the record. (adjourned)

DEBORAH GARNEAU: I just wanted to open it up again if anyone wanted to speak. No. All right. I think we will stay until -- sorry.

JACK RINGLAND: I didn't know whether you wanted us to talk about the Independent Living Council, the people that don't know.

DEBORAH GARNEAU: Sure.

JACK RINGLAND: My name is Jack Ringland. I am a member of the Rhode Island Statewide Independent Living Council, and currently the secretary. This is Vincent DeJesus, he's also a member of the statewide independent living council. We're here this everything to tell you want something we've been working on for the last year and a half. The statewide independent living council, along with ORS, develops every three years the statewide plan for independent living. And we try and address people's needs, and so on and so forth. So it gets into the thing, and then funds come back from the federal government through title seven, you know, the rehab act, and get administered that way. And we file with courts, and monitor what's going on, and so on and so forth. Getting back to the last year and a half, we decided that this time, this go around, we would try and come up with a Needs Assessment Survey. Now, we work very hard on it. It is available in several formats. Now, up on the front here, I have some flyers if anybody would like to take one. It tells you how to fill out the survey. And, also, we have buttons here. The buttons are called My Voice Matters. And very definitely for a disabled person your voice matters. If you've not filled out the survey, we encourage you to do so. How do you go about doing so? The best way is to go on to our website, which is www.risilc.org. And right there on the page you will see, like, right to the survey. You'll see it right there. It's very easy to find. We have it in -- we have put it up there in just about every way we can think of, in the most common languages - English, Spanish, and Portuguese. We have it in sign, for people that need to have things in sign. We have it in large print if you're visually challenged. And we have it in graphic form, also. Now, if you don't have a computer, or whatever, you can -- uncertain as to how to get in touch, on this sheet of paper, there is a telephone number available. If you were to call into that telephone number and say you would like to take the survey, they will either take your information anonymously over the telephone, and so forth, and record it that way, or they can send you a paper survey for you to fill out and return. A little incentive that we're trying to do is that everybody that fills out a survey, by the way, this survey is for people 18 and older that have, either have the disability, or their caregiver that can fill out the survey for them if they're not able to do so themselves. As an added extra incentive, every three months we are drawing for a target gift card. We already had one drawing, and so forth. So that lucky individual will get his gift card in the mail, his or her, rather, gift card many the mail, and hopefully spend it wisely.

Let's see. I don't know what else I can say. I could go into the whole story of the SILC. Vin, go ahead.

VINCENT DeJESUS: I wanted to add, I can take it, I believe it also works with jaws, we try to incorporate every disability. Doing the paper survey, I wanted to clarify, you can't print it out, well, you can print it out of the computer. They won't count it. If you call the organization and have them mailed to you. We want to keep it more as – more legit as possible, that way the information gathered is more accurate as possible.

JACK RINGLAND: Yeah, we don't want anybody stuffing the ballot.

THE SPEAKER: What is JAWS?

VINCENT DeJESUS: That's for people visually impaired.

THE SPEAKER: How do you spell that?

VINCENT DeJESUS: JAWS.

THE SPEAKER: I couldn't understand what you were saying.

VINCENT DeJESUS: That's okay. I do tend to mumble.

THE SPEAKER: That's okay.

JACK RINGLAND: This survey, I might add, is a never ending survey. There are places that you can make comments, and so forth, and those comments are taken into consideration when we combine all the results for our own internal use. If we find that somebody is suggesting that we add such and such an item into the survey, then we're going to look at it and add it to the survey. This thing will change probably every three years, or more often as necessary. And we want it to be something that will be able to be used, and everything. if you take it now, and a year from now it comes up again, there are probably going to be some changes to it. And those changes will go into the next three-year cycle. When we come up for our -- plan comes up in 2013, so right now, actually, we're starting to think about what we've got to do for meetings, and, you know, negotiations, and so on and so forth, to get the plan drawn up.

VINCENT DeJESUS: Also, this, the survey, it's not, like, 20 minutes long. It's straight to the point. It's about 5, 10 minutes. It pretty much asks you all various types of questions that – what needs are not being met, that way we can help, you know, and we can try to be --because this is a survey for people with disabilities, written people with disabilities, like all of us on the council, we all have different disabilities, whether it be visual, stability, whatever. Basically – and also it's -- SILC is part of the national organization, but it's a nonprofit organization, so.

JACK RINGLAND: The federal government mandates that each state has a statewide independent living center, or an independent living council, excuse me. and that is what we are. The reason is that we come up with a plan, and so on. and the funds get distributed that way, without getting into a lot of explanation. So we -- each state has one. They have varying responsibilities, and so forth, but we are responsible to the federal government. And what we set up for a plan that goes to the federal government gets approved through RSA, can't remember the name, can't remember the wording. It's the Rehabilitation Services Administration, I think it is.

VINCENT DeJESUS: Ors?

JACK RINGLAND: Not ORS. RSA. So it goes to them, they review it, and then it comes back to us. And they may ask us to make some changes, but usually the plan is pretty well thought out. And then we go on from there. And we file what is called a 704 report periodically that kind of keeps things up. We did so many of this and so many of that. This is one of the things that's going into the 704 Report, that we finished this survey, it's posted to the website, we received so many to date, and things like that. It puts another feather in the cap.

DEBORAH GARNEAU: great. Thank you. We have the disability law priority list, and then there's also the voter registration formats in the back. is there anyone else that would like to enter a comment? Okay. I think we're going to end then.

4. Wednesday, July 25, 2012 – South Kingstown Public Library

MEREDITH SHEEHAN: Welcome everyone. Thank you so much for coming out today and attending the Governor's Commission on Disabilities Public Forum. My name is Meredith Sheehan. And I'm the program and services coordinator for the national multiple sclerosis society in Warwick. We're a lot chapter of a national organization. If there are going to be questions about my organization, in general, I'll be happy to talk to you after. Just to let you know, the rest rooms, if you need them during this session, are right out the hall and to the right. The purpose of these public forums is to identify the concerns of people with disabilities and their families in order to assist the state in developing programs to improve the quality of life of people with disabilities. To ensure everyone who wants to speak gets a chance, please keep your comments short and to the point. If you have a critical problem that needs to be addressed, the panel members will be available at the end of the hearing to direct you to the proper agency for help. After the public forums are completed in early August, the sponsoring agencies will review the testimony and prepare recommendations, which will also be posted on the website by the end of November. The recommendations and the transcripts will be printed and sent to the state and be used to develop policy and legislative initiatives for the next year, or until they are accomplished. Just to let you know, the Rhode Island disability vote project is here today. And they're available to register anyone who's a citizen of Rhode Island and is not a registered voter. You're easily able to register to vote here today. And, also, just to let you know, you've probably heard in the news, this is the first year that they're requiring a photo ID to actually vote. So if you have any questions about that, there's some information on the back table, as well. I'm going to start with the panel, and have everyone please go down the line and introduce yourself and what agency you're with.

MATTHEW TIBERIO: I'm Matthew Tiberio. I'm a staff attorney at the Rhode Island Disability Law Center. We provide free legal services to people with physical and mental disabilities. Each year they come up with a list of seven priority areas for which we focus our services. For example, there was an emphasis last year on dealing with the disability, the disability cuts in the budgets. But I wanted to raise that because on the table over there we have a flier that allows a survey that we give out at these meetings to try to get public input as to what our priorities should be, so that the voice of the community is heard in making that decision. It's a survey. It's over on the table. If you can fill it out, you can either give it back to me at the end of the session, or we have self-addressed stamped envelopes over there. You can send it in when you want. It gives you a chance to use five different priorities that you think our office should be focused on, and those surveys will become part of the decision making process. The voting rights, we also on the table have our voting rights flier that we put out from our office, which also has a voter registration form, and gives you some pretty straightforward information about the voting process, and what your rights are when you go to vote. You can pick one of those up and take it. Hopefully, it's useful information for you.

BARBARA MULLIGAN: My name is Barbara Mulligan, from the Office of Rehab Services. We provide vocational services for individuals to get back into work.

DAWN WARDYGA: My name is Dawn Wardyga, and I'm a consumer representative on the commission. I founded family voices. And my primary area of interest is children with special health care needs.

ANN LEAMY: My name is Ann Leamy, and I'm the BHDDH, and group homes that need assistance.

CASEY GARTLAND: My name is Casey Gartland. I'm a Senior Director of Perspectives Corporation. We're an agency that contracts with the state of Rhode Island to provide services to people with developmental disabilities. I also serve on the Governor's Commission for the Election Access Committee, to ensure that we increase access and opportunities for people with disabilities to vote.

COLLEEN POLSELLI: I'm Colleen Polselli from the Office Of Special Health Care Needs at the Rhode Island Department of Health. And we have the Disability and Health Program in our office. So we have received policy for the State of Rhode Island.

MEREDITH SHEEHAN: Thank you. I wanted to remind everyone, if you do need an assistive listening device, there's some on the back table over here. There's a sign-up sheet that went around. I'm not sure if you all had a chance to sign up, but if you could, before you leave, that would be wonderful. We're going to open it up. No one really checked that they have anything to say, but it's an open forum, if you do want to say anything, no pressure, just kind of speak from your heart. And if we can try to answer it as best we can, or try to guide you to the right agency you might want to be speaking with, whatever your issue or concern might be. Last year I was at a few of the public forums, and, obviously, the cuts made to the developmentally disabled community were hard on people. And certain public group homes that came out. It was really impact full. I think it really made a difference, the lobbying efforts to reinstate the funding. It does make a difference when we can take some issues back with us. Does anybody want to start? Anybody have any questions, or concerns, or knowledge they want to gain, or?

BETTY MERNER: I don't know if it's the right forum for this, at all, now that I'm here. Since I'm here, I'll bring it up any way. I'm the resource coordinator at the Meadowbrook

Education: Private School Funding

Waldorf School, which is a small private school. We do have children with IEPs and disabilities in the school. We do receive, which we're very grateful for, IDEA money that is filtered through the lea to our children.

My concern is, however, I mean, our system works for a lot of children, because we're a small school. It's a multisensory approach to education. It's a real practical arts portion to it, and it works for a lot of children with disabilities. My concern is that the idea money that comes into us, we don't, although it comes to us, we don't have the freedom to use it in the way we feel it would work best with our curriculum to assist our students that are there with Special Ed needs. I'm not sure who addresses that problem. I'm trying to find the right people to address that problem with us. I don't feel we're getting, maximizing the use of our money. It has to be dictated through the public schools, the lea that we're under.

MEREDITH SHEEHAN: What does the IDEA stand for?

BETTY MERNER: IDEA.

DAWN WARDYGA: Let me provide a little clarification. IDEA is the Individuals with Disabilities Education Act. It's a federal law that provides children with disabilities a free appropriate public education. The issue raised that's being raised here has to do with the fact that the funding flows to the public school districts, and it's the public school districts who determine how that money is utilized. And we're hearing from private schools who has kids from within that public school district, and they basically have no say in -- what's working in the public school systems may or may not be working in the private school system. It sounds like we're looking for a voice here from the private schools, in terms of how they might better utilize that funding. I can't solve the problem, but I think, for clarification purposes, that's the federal law. And just, it wasn't -- I don't think it was mentioned earlier. For those of you who are here for

the first time, basically, this information all comes back. As you can see, we have a stenographer here. This information all comes back to the commission. And every single word, verbatim, gets considered by the commission and goes into a process that we have that helps us identify priority areas around legislation and policy in the state. So regardless of how large or small you think your issue is, I just want to throw it out there that this is the place where you tell us, because we can't consider it if we don't know what's happening.

MARY DRAKE: I have a question about the transportation. My daughter is in Langworthy Group Home in Westerly. It said in the letter from Julie Sacks that there was a three percent increase from the transportation. And some of the transportation has been cut, such as her ride home from church. And I wonder if you can give me any input as to where the three percent to transportation went, if it did go to individual group homes, or what?

CASEY GARTLAND: I can speak somewhat to that, actually. The transportation line in the budgets provided by BHDDH pertaining primarily, if not entirely, to the day program. It's not separated out for residential use, such as you're talking about, a weekend activity. It is part of the general residential support services. When it comes to the transportation line that you're speaking of there, that's primarily for rides to and from day program or a job, and it has to be billed accordingly.

MARY DRAKE: I don't think I quite understand.

CASEY GARTLAND: The piece I think you're speaking about is that, and I can't speak to this, although your daughter is in one of the homes we support, it has to do with overall sense that resources were cut across-the-board. I believe what some of the homes did in terms of addressing those was prioritize certain activities over the others. I can't speak to your individual situation, but I do know, in my own home, for example, they had to prioritize activities, family visits. They sometimes had to ask families for assistance to go to church back and forth, because the resources were just so that the staffing was no longer available, let alone access to a vehicle.

MARY DRAKE: Would it go according to, perhaps, the amount in use, certain ones used, like, some might have more activities than others?

CASEY GARTLAND: We try very hard. Sorry, I didn't mean to cut you off.

MARY DRAKE: No. I'm thinking.

CASEY GARTLAND: Yes. I would say overall it's a very democratic approach, which is that everybody who lives in the homes needs to be part of the community, and we try to plan ISPS accordingly.

MARY DRAKE: We do provide a lot of assistance in transportation, a lot of assistance. Since this is very important, I could look into it some more.

CASEY GARTLAND: Sure. I'd be glad to speak with you afterwards, if you'd like.

MATTHEW TIBERIO: I will say, that's a good example of something you can bring to our office that's an issue that you want. I know each year we seem to get a lot of cuts to RIdE. I know this isn't RIdE, but when there's cuts to transportation, it's something we look at it. I don't know how much we can do when it's placement at Perspectives. If you fill out the survey, maybe it's something we can look into on a general level.

MARY DRAKE: Thank you, very much.

MEREDITH SHEEHAN: We just had another panelist join us. I'll have him introduce himself and where he's from.

BILL INLOW: I apologize for being late. My name is Bill Inlow, and I'm a member of the Governor's Commission on Disabilities. Having being appointed by Governor Carcieri, and going

Housing: Group Home
Transportation

Transportation: RIdE

primarily to my state senator, June Gibbs, the late June Gibbs, a wonderful state senator and a close friend of the governors. I'm a member of the legislation committee of the commission. I'm a vice chair. I retired on February 1st of this year from a position at RIPTA, where I worked with the ride program. Transportation for persons with disabilities and for elders is always a topic of good concern, and it should be. And I'll be glad to participate on the panel, and listen to the comments that you folks have. And as appropriate, depending on who's chairing this panel, I'll try to respond to any questions or comments that you might have. Just as an aside, again, I don't work for RIPTA anymore, and I'll take the blame for everything that's wrong with RIPTA and ride, as long as you give me credit for everything that's right. That's not a way to excuse complaints, or criticisms, or suggestions, but it's the knowledge that I, like most of the people, most, not all, of the people at RIPTA, acknowledge that we make mistakes every day. But we also do a lot right. It doesn't take away from the criticism. Thank you, very much, for your attention. I'll be glad to participate in any way, shape, or form that the chairperson of this group decides. Thank you.

JEAN CADORETTE: I live in Westerly, and I use RIPTA four times a week, sometimes five, I never had a problem, but if they ever put me on Ride, I never had anything go right. And I

Transportation: Ride recommend RIPTA to anybody.

BILL INLOW: Thank you.

JEAN CADORETTE: You're welcome. Thank you.

BILL INLOW: It's unusual, because usually we hear from people who have things to complain about, most of which are valid. It's nice to hear, not just for me, I'm no longer a part of RIPTA, but it's nice to hear good things, too.

JEAN CADORETTE: It's wonderful for me.

BILL INLOW: Thank you, very much.

LESLIE CHOUINARD: My name is Leslie Chouinard and I'm advocating for my sister who **Healthcare: Medicaid** has MS. I brought her up from Florida recently. She had Medicaid in Florida, and it has been a nightmare trying to get Medicaid here. Not so much on the Rhode Island state level, but working with Florida to get a letter of closure. I've been working with a really nice woman at the Department of Health and Human Services, but they can't process anything that I sent for them until they get the letter of closure. And I now have a lawyer working with me to try to get the letter of closure. We may have to go through Sheldon Whitehouse's office. But my question is, and I think turned new Affordable Health Care Act, and I'm not sure about that, that at some point it will be just like Medicare at some point. Or why isn't it like Medicare that goes from state to state, instead of going through this. Again, I'm not questioning Rhode Island, but it's been a nightmare, so -- and her bills are piling up, which isn't covered. So does anybody have any suggestions, or is there anything pending that would make this transition less despicable?

Healthcare: Affordable Care Act DAWN WARDYGA: I just want to respond by saying that the complications of transferring Medicaid from state to state, it doesn't matter what the state is, whether it's Florida, or any other state for that matter, yes, it should be a much simpler process. In terms of what may change in terms of health care reform, we haven't gotten to that level of discussion yet about how that might play out. In terms of recommendations for how you handle it now, I think the best advice I can throw out there is that do not pay a bill out of your own pocket, because Medicaid will not reimburse you. What you have to do is be in touch with those providers and let them know what the situation is, and why you can't pay, so it doesn't look delinquent.

LESLIE CHOUINARD: We've been doing that.

DAWN WARDYGA: That's important. Again, if you pay out of pocket, you won't get the money back. You really have to go back. In terms of your suggestion recommendation about, and I'm less familiar with Medicare than I am with Medicaid, if that is a seamless process at the federal level, and it has been prepared in health care reform discussions, that has been talked about, why isn't Medicaid running along the parallel path that Medicare is. It's on the table is what I can say. Bringing it up here, I think, again, brings that to a different level where the commission can consider that as we go forward with next year's priorities, next legislative session's priorities.

LESLIE CHOUINARD: When you say next legislative session, are you talking about Rhode Island?

DAWN WARDYGA: Yes.

LESLIE CHOUINARD: And you would do what?

DAWN WARDYGA: Basically, what happens is, I don't know if you were here when I mentioned it. I mentioned the feedback that comes from these hearings goes back to the Governor's Commission on Disabilities. We review it all. We have someone taking notes back there. And we use this to determine what the legislative priority will be for the upcoming legislative year. So the topics, the issues that all of you raise are what come back to the commission to take into consideration. So, and as you may know, this is one of, what, five, this is one of five public forums across the state. The last one is tomorrow, I believe. All of that information is brought together. That's what we work from. It's important to raise issues like that, especially those specific examples like how your sister is personally impacted by the current system.

LESLIE CHOUINARD: If you don't have an advocate and you don't have somebody who can help through the system, these people are out of luck. She happens to be lucky, but there are a lot of people who aren't. When you say legislative, I understand exactly what you're saying, what I know right now Medicaid is state to state. And I know some governors and some states are a little tenuous about the Medicaid at this point.

DAWN WARDYGA: Absolutely right. But Medicaid is a state and federally funded program. So the feds have some say in that. 50 percent of Rhode Island, as a matter of fact.

LESLIE CHOUINARD: Again, my problem hasn't been with Rhode Island. It just we're going to now have to go to appeal because we've been held up so much. Thank you so much.

SHIRLEY WRIGHT: My problem is with Rhode Island. I have a 57-year-old son. And three years, well, four years ago, he was told he had chronic Pancreatitis. If anybody has ever known anybody with that, you know you're in pain most of the time. Well, a year ago he had an aneurysm of the artery between his pancreas and his spleen. And we got it just in time. He almost died. He was in surgery for 30 hours. Not really all 30 hours. They couldn't close him up because Healthcare: Medicaid he kept spurting out in different places. He has applied and been turned down by the state of Rhode Island, so far, five times. We have gone to every agency in the state of Rhode Island, and gotten nowhere. He gets \$150 a month in food stamps. That's all this guy gets. They're about ready to throw him out of his apartment. I can't afford to pay his rent anymore, because I'm a widow. Now he has an aneurysm of the aorta in his heart. There's four places where you can have it. His is in the worst spot it could be in. And we can't find a doctor who will operate on him because he has no insurance. Now, there's got to be some help in this state for him, somewhere. This guy is going to die if that thing bursts. The aorta is supposed to be 2.5, whatever. His is already a little over five. He doesn't have much more time. But we've got a lawyer working on it. He's not getting anywhere. I'm going crazy. I don't know what else to do for him. Let's bring up people are coming in here and going to college, and

everything else, from other places. But all I'm asking is save this kid's life. And we're not getting any help from the state. He always paid his taxes. He always worked. But there's absolutely no help in this state for him.

DAWN WARDYGA: Is he considered disabled under social security law?

SHIRLEY WRIGHT: He's gone through all that, they still rejected him. New London, he was going to new London, because he lives in Westerly, and they said, oh, you're all set. We can go back six years and get you all that social security and stuff. And then at the last minute they said, sorry, you don't qualify. Now, why doesn't he qualify? Who can tell me?

DAWN WARDYGA: Any discrimination is required to be provided in writing. In that written notification, it should define an appeals process.

SHIRLEY WRIGHT: He's gone through that. Right now, we're waiting for them to set up a time for an appeal hearing. But that was four months ago. And we're still waiting.

DAWN WARDYGA: Are you still working with New London.

SHIRLEY WRIGHT: No, they turned him over to somewhere in Providence, or Wickford. He's really not well enough to do anything.

DAWN WARDYGA: Right. This comes back to a question earlier about health care reform. As health care reform rolls out, there will be opportunities for coverage for folks in that situation. Currently, unfortunately, there is no -- unless you're a parent with children at home, there's no way for single adults to qualify for Medicaid in Rhode Island.

SHIRLEY WRIGHT: Is this humanly right?

DAWN WARDYGA: Not if you ask me.

SHIRLEY WRIGHT: This guy is going to die. Everybody says, oh, I'm sorry, there's nothing I can do.

DAWN WARDYGA: I just want to throw out there, not only for this issue, for any issue that is raised here, your congressional delegation has a responsibility to respond to constituents about these kinds of problems that aren't easily solved. That doesn't mean they can fix everything. What that means is they can put some pressure on some points in the system in order to get this stuff moving along.

SHIRLEY WRIGHT: 17 doctors have signed letters sent to Providence, or whatever.

DAWN WARDYGA: My recommendation is, again, in this case, and any other case you're running into problems, if you haven't notified both senators, Whitehouse and Reed, and your congressmen, which I think in this area of the state is Langevin. Sorry, I live on the other side of the bay.

SHIRLEY WRIGHT: Nothing happens down in Westerly. You know we're the forgotten part of the state.

DAWN WARDYGA: Exactly. Those three legislators have workers in their office. They're constituent representatives.

SHIRLEY WRIGHT: Letters have been sent. Nothing is being done.

DAWN WARDYGA: Don't do with letters. Nag them to death on the phone. Do whatever you have to do, just keep at it. That's all you can do in terms of -- because system change doesn't happen overnight. I understand this has been going on for a longtime. But SSI is very difficult to get through that process and time consuming. And, unfortunately, we look at paper, and we don't look at people. And so when you have a situation like this, we're not looking at a gentleman who's -- who may lose his life. We're looking at paper in a file. Do I believe that's the way we should do things, not necessarily. The only way you can push things along is advocate, and get your congressional legislation around.

SHIRLEY WRIGHT: We told them. They know it. Nothing was being -- I'm at my wits.

DAWN WARDYGA: I bet you are.

SHIRLEY WRIGHT: I just lost my husband, plus the fact that Mr. Garland is my next problem. My sister and I have a niece in a group home down here in Narragansett. We live in

Housing: Group Home

 Westerly, and I live in Ashaway. They tell me there's no place out of 14 places in Westerly that they can put her. She's been with them for, well, she went in '91, '92, 10 years. She has gone from this level, down to this level. Because she's

Housing: Group Home
Transportation

 in a group home that -- they like having her because at least she communicates with them. She can do things. But on that budget cut that you were talking about, she was at Olean Center in Westerly.

Now, because of that transportation deal, they won't bring her to Westerly. She sits in that house seven days a week, because there's nothing else for her to do. We went to her Christmas party. They gave us a new -- I don't know if advocate is the right word. They assigned somebody to take care of her needs. That was it. October. We went to the Christmas party. We take her out to eat and she eats like you and I do. At that Christmas party, because there was three other people at our table that belonged to her group home, were eating with their fingers, she ate with her fingers. We asked to have her haircut, go down and take her out. We can't. If she doesn't want her haircut, she's 56 years old. Her mother never taught her to do anything. When she died, we got this dumped in our lap, not knowing anything. And all we seen her do is go downhill. And this lady that was assigned to her hasn't even met with her since the Christmas party in December. I don't understand. They assigned her 7 o'clock every Sunday night either to call my sister or call me, because we're the only family she has left.

JEAN CADORETTE: She never calls us.

SHIRLEY WRIGHT: She has not called us yet. We get along with her fine. But they say if she doesn't want to it, don't push it. That's not why we sent her to Olean Center. We thought she was going to be taught something. Nothing. I'm upset about that.

CASEY GARTLAND: Sure. I can't speak to your specific situation. Have you talked to the people, I'm assuming you have, who oversee the home and do the service coordination?

SHIRLEY WRIGHT: We talked to everybody. Now we've got this other problem. I don't know what else to do.

CASEY GARTLAND: I'll be glad to review that.

SHIRLEY WRIGHT: That's all I got to say today.

BILL INLOW: Many of us are taking notes and making note of your concerns just because we don't have a clear response and answer.

SHIRLEY WRIGHT: I realize that.

BILL INLOW: We are taking notes. I don't blame you at all, ma'am.

ANN LEAMY: Do you know the name of the group home?

SHIRLEY WRIGHT: Yeah, Rodman street.

JEAN CADORETTE: Rodman House.

DAWN WARDYGA: Narragansett, is that what you said, Narragansett?

SHIRLEY WRIGHT: I don't know what's going to happen to her other than nothing when we go. I'm not going to be here much longer.

JEAN CADORETTE: It was terrible to see her eating with her fingers, because the others do. She eats fine when we take her out, or have her at your house.

SHIRLEY WRIGHT: Yup.

MEREDITH SHEEHAN: Anything else?

SHIRLEY WRIGHT: Nobody has even called to say how she is. They must know that we have been in touch with her, because we said, you call us, we're not going to call you.

CASEY GARTLAND: I'm surprised to hear that, because we have an expectation of them keeping in contact with the family at minimum monthly, and with the case managers.

SHIRLEY WRIGHT: Maybe I expected too much from Perspectives and the state. I don't know.

MARY DRAKE: I have to say our dealings with Perspectives have been wonderful. Maybe there's some little piece that's missing that can be corrected.

VICTORIA LETOURNEAU: My name's Victoria Letourneau. I was at Rhode Island hospital yesterday. I want to congratulate the state for having handicapped transportation now available for those in wheelchairs. Unfortunately, the driver of one of those vans was not educated on how to handle an individual in a wheelchair. I went into my appointment. He came out an hour later. That gentleman was still there, trying to get that wheelchair and that individual into the van.

Transportation:
Accessible Taxis

MEREDITH SHEEHAN: This was in a taxicab?

VICTORIA LETOURNEAU: This was the new handicapped transport van. And it was a very sad sight in a hundred degree weather.

DAWN WARDYGA: You didn't use the van, you witnessed it.

VICTORIA LETOURNEAU: I witnessed it. It was an hour. And when I left, they were still trying to figure it out. It was a very long press.

BILL INLOW: This was a cab that had an accessible feature for a wheelchair. That should not happen, number one, obviously, that's obvious. I can report that, myself, but can also give you the phone number to call to make a report. We'll try to make sure that doesn't happen again. There's no excuse for it happening. We apologize. The number to report it is 781-9400. And they will look into it and they will get back to you. There's no execute. Local cab companies actually they are required to have all their drivers go through training. And they should have known how to do that. But if you call 781-9400, that's RIPTA. We're ultimately responsible. Not we, RIPTA is ultimately responsible for the performance of that program. And --

VICTORIA LETOURNEAU: There were three phone calls made from the parking attendant staff while I was waiting for them to park my car. They were frantically trying to get somebody to get help, because this individual was suffering in the heat.

BILL INLOW: And they were unable to get it in or secure it properly.

VICTORIA LETOURNEAU: They couldn't get it in and secure it properly in order to get it into the van. And he readily admitted out loud that he just didn't know how to do it. Being a disabled individual, it was very disturbing.

BILL INLOW: I'll bet.

VICTORIA LETOURNEAU: I recommend people using the disability services in the state.

BILL INLOW: Right.

VICTORIA LETOURNEAU: Although I was very happy to hear that there are 12 handicapped vans to transport people, if you can't get people in and out of those pieces, it's kind of a waste.

BILL INLOW: If you call that number I gave you and ask to speak to the general manager's office, I would go to the top, and make that complaint; they made a big slash in the newspaper when those wheelchair accessible taxicabs were put in place. And as a consequence, RIPTA and everybody else associated with that should meet the quality of standards, or standards of quality that people deserve and respect. Sorry that happened. The way to try to do something about it is to call the general manager. And make sure that doesn't happen again. And accept our apology.

VICTORIA LETOURNEAU: I will follow up with the valets at the hospital to see how long it took, as well.

BILL INLOW: Just the fact that you were unsatisfied you should follow up. And I'll report that back the legislative committee, as well. Ultimately, the government is responsible to provide quality services. And that's a poor example. Thank you for speaking up.

DIANA GORDON: My name is Diana Gordon. And I have two issues, one of which I think I would like to speak to someone from the Department of Health afterwards, it has to do with the drug halfway houses that are springing up around Rhode Island, especially in my area. And the other thing does have to do exactly with what we're talking about. Several years back they put in Pontiac, the road, Pontiac Avenue. And when they did so, they have ramps that are to be used for the handicapped, or the people that, you know, are in wheelchairs, it's for wheelchair access, on to the sidewalks. It seems they didn't plan it out very well. And they have telephone poles right in the middle of the ramps. You cannot get your wheelchairs around there. And it is really, it's all the way up and down Pontiac, from one end to the other. And I -- a friend of mine pointed that out to me, a Dolores Eslor (sounds like) and I saw a thing she did on it. Since we're here, I thought this was appropriate to bring up. And who would I speak to after the meeting about?

Human Services:
Halfway Houses

Accessibility:
Sidewalks

CASEY GARTLAND: I'm not sure we have someone from the Department of Health.

DAWN WARDYGA: We do, actually.

DIANA GORDON: Would that be her department that I would speak to about the halfway houses?

DAWN WARDYGA: If it's the Department of Health she can bring it back. She can get specific information from you and bring it back.

MARY DRAKE: Okay. Thank you, very much.

THE SPEAKER: One more thing, and, actually, bathroom accessibility, I know that most new places they have the bathroom accessibility. But sometimes they say handicap bathroom may be used, but you can't get your chair into the handicapped stall. That, to me, I was never made aware of this until I brought my sister up and she had a mobilized chair. It looks big enough for somebody with a walker, and even in some of the older buildings, if they would knock the stall down, or something, and then you can get the wheelchair in. My thing when you're talking about legislation, whether the restaurants are older, the newer ones aren't as much of an issue, I don't think. I don't know.

Accessibility:
Bathrooms

VICTORIA LETOURNEAU: They are. They should really put a wheelchair in there when they build it.

THE SPEAKER: I would ask you to take this back legislatively and make these people knock down the stall so you can get a chair in, or a mobilized chair, because I'm sure when you transfer you can't get there.

VICTORIA LETOURNEAU: You may be able to get the chair in, but you can't transfer.

THE SPEAKER: Here's a woman speaking from experience, that definitely has been a problem throughout. I would like to see something done about that. You prompted me when you were talking --

BILL INLOW: Are you talking about the door to the rest room, or the door to the stall?

THE SPEAKER: The door to the stall.

VICTORIA LETOURNEAU: The stall, itself, is not large enough for you to transfer from a chair to the toilet. A lot of them you can get in, but you can barely get in. And then you have no way to close the door behind you, because there's not enough room to move.

BILL INLOW: The Governor's Commission on Disability has a committee on accessibility. And there are standards that businesses, public facilities are required to adhere to. The issue is monitoring and enforcing. I'll report that.

THE SPEAKER: Yes, they think they're doing what you should. When it comes to putting in the chair, and as this woman said, you're not bringing in the chair. So if some of these things look big enough for you and I or with a walker, someone like this it doesn't work. It should be mandated that even with the older buildings that people take down the stall or doing something so these people can comply.

BILL INLOW: So it rarely works.

THE SPEAKER: It looks like it will work, but it doesn't work when somebody's trying to get in.

BILL INLOW: We'll report that to the committee, they'll look at the standards, as well.

THE SPEAKER: They're supposed to be ADA compliant. And I really think that they're not fully following the measurements that the ADA has put out there. Because if you go into an ADA compliant bathroom stall, you can turn your chair in the stall. You can actually get in and move. Which is the way it should be. I shouldn't have to fight to use the rest room.

BILL INLOW: I'll certainly take that up with the committee and if it requires legislative action, we'll look into it. Sometimes if it's ignorance, they just don't realize, even though they tried to make it accessible, it's truly not. We'll look into it.

THE SPEAKER: It wouldn't cost a person much to do that. It's a matter of moving the wall of another stall. It wouldn't be like it would cost a lot of money to do this.

DIANA GORDON: Is there a way they can change the sidewalk arrangements on Pontiac so it is wheelchair accessible, since they do have the ramps with the telephone poles in the way.

THE SPEAKER: I think that's the department of transportation, right, they're the ones who

--

DAWN WARDYGA: If it's an ADA compliance issue, I think it involves more than one agency. We'll bring that back.

MEREDITH SHEEHAN: There was just a -- I was just asking, there was an accessible curb cut law that was passed, either last year or the year before. But, of course, it was only written to apply to new roads, or if they're repairing and had to make them.

DIANA GORDON: But they never had ramps until they did that particular -- when they changed the road. There was never ramps there. And they said they wanted to make it handicap accessible. It is not. I mean, even a bicycle has trouble.

BILL INLOW: We will report that. We have it in the notes. Again, this, the material that we're taking notes, we have transcripts, every word is written down. Pontiac Avenue, certainly there are -- there are others. There will be a process of incentive. You have to put one in, in order to work. Thank you.

MEREDITH SHEEHAN: Cranston, right?

BILL INLOW: Yeah. I guess the other thing is on the commission there are a number of people who know intimately, the challenges of being in a wheelchair, because they use a wheelchair themselves. The chairperson of our commission, Tim Flynn, uses a wheelchair. There are several other members. It's not an academic thing to them or to the commission. We do take that will seriously and try to do the best we can.

DAWN WARDYGA: I don't know if others have information they want to share? But I guess I'm going to ask a somewhat self serving question in that we haven't heard any issues come up about children with disabilities. And that's not to say I'm telling you there are any, but often time when is we have these hearings you hear a majority of things about adults with

disabilities, and that type of thing. I want to make it clear that this is definitely the venue for people of all ages with all types of disabilities. So if there are issues that you're hearing in the comment or experiencing with family members, then the commission needs to know that.

MEREDITH SHEEHAN: We need to stay until 5:00, we do, but don't feel like you need to sit here in silence until 5:00 if you've already voiced your concern and have some resolution to it. I know somebody wanted to talk to somebody privately. I actually want to talk to you for a second. Maybe we can take a quick break. If other people come in we can resume the format. Does that sound good? (adjourned)

MEREDITH SHEEHAN: We're going to come back together and reconvene for a couple of minutes. We have another lovely Rhode Island resident who I know very well. I'll give Laurie a chance to express her concerns and have the panel respond, if we can, or certainly take back the information.

LAURIE JOHNSON: Do we want me in any particular spot, or can you talk from here?

MEREDITH SHEEHAN: She needs to record your name. She already did, good.

LAURIE JOHNSON: I am a voter from Warwick, actually. Unfortunately, I could not make it to the public forum on Monday. I have four points I would like you to address.

Accessibility: Ramps

The first one is I would like two ramps, two accessible entrances, exits, in some places. Make you can figure out by the number of people normally in a place. I lived in West Warwick for many years, and I know the importance of having exits actually go to the Kent county YMCA, and because of the population shall we call it, I have to wait for the ramp, because of strollers and children going down them. I have written comment cards like crazy to them asking, please, you know. They already have an entrance on one side of the building that could be used if they just had a person there to check you in.

DAWN WARDYGA: You're asking for two ramps per facility, is that what you're asking for?

LAURIE JOHNSON: If there are facilities that have larger amounts of people in them, I have no idea what you would call the cut offline, but in places where there are bigger amounts of people it would be nice if there were two accessible entrances and exits.

BILL INLOW: Can I ask a follow up on that? I would assume that in most public places there's a requirement for at least two ways to exit a building or a facility.

LAURIE JOHNSON: Yes.

BILL INLOW: In an urgent situation.

LAURIE JOHNSON: Yes.

BILL INLOW: So if you think about it, you probably can meet the federal law by having one accessible entryway and exit, right? But if you think about the ADA, equal treatment under the law for people with disabilities, then you wonder, wait a minute, if it's so important to have at least two, or more, exits from a building for safety for people in general, most of whom don't have disabilities that affect their ability to ambulate, to move, then maybe -- I don't know if anybody ever thought about that. To respond to your point, to have more than one way to get in, the person with limited mobility wheelchair, walker, whatever, it's also as important to have another way to get out. Again, ADA, equal rights under the law, right, the civil rights law.

LAURIE JOHNSON: And some of these places actually have another spot that you could get in and out, but normally they're locked. You can't use them, normally. Now, I don't know about you, but when an emergency happens, who goes running to that spot to lock the door, because I don't see it happening.

BILL INLOW: I just -- it peaked my interest and I will take a look at that issue. We have an accessibility committee on the commission, and it's in the transcript. So we'll take a look at that. Thank you for raising that point.

LAURIE JOHNSON: Thank you. My next point. Recently dealing with one of my

Healthcare: Medicare
Healthcare: Blue
Cross/Blue Shield

medications I ran into the issue of what's called prior authorization. Apparently for one of my drugs I must have prior authorization that says I have to be 20 percent after using this drug. Now, if you want to check me the first year, I completely understand that, but to continue

to check me year after year after year, I asked them, did you expect me to get 20 percent better every year, in which case, I can throw away the cane, start dancing around, yell. Hello, they left me without my medication for a week. It took me over a month to recover. I still say that I am not quite back to where I was. The drug actually made me walk better. and if they take it away again, I will probably wind up in a wheelchair.

DAWN WARDYGA: Is this Medicaid, is this Medicare, who's the insurance?

LAURIE JOHNSON: I have both Medicare and Blue Cross/Blue Shield. And my husband is the only worker at his place of employment, so I believe Medicare comes first.

DAWN WARDYGA: You have Blue Cross/Blue Shield through.

LAURIE JOHNSON: His employment.

THE SPEAKER: So Medicare is the primary?

DAWN WARDYGA: I'm not sure about that rule in terms of the one employee in the agency, is that what you're talking about.

LAURIE JOHNSON: Usually, after a hundred employees for an agency in order to be the first health insurance.

DAWN WARDYGA: The prior authorization is really the Medicare concern?

LAURIE JOHNSON: I'm pretty sure. Although, I'm not confident.

CASEY GARTLAND: This is recent, is this very recent?

LAURIE JOHNSON: After they got through all the red tape, which took a week, I'm covered for May to May. So I'd say it happened in May.

CASEY GARTLAND: It happened in May, and it was the first time you came across it.

LAURIE JOHNSON: I believe so, yeah, it happened once before, but it happened fast enough I wasn't without this drug for a week. That's why I said this time we already did this. You already said I'm good enough to have this drug, why do we have to do this again? And how long before I have to do it again? They said every year you will have to do it again. I'm going, this makes no sense. Do you really expect me to get 20 percent better every year.

CASEY GARTLAND: I was asking because earlier I was telling people we run group homes for people with disabilities. It was something we found since the end of the Bush Administration. We have a wonderful nurse who codes those things, and have a wonderful pharmacy, who has to constantly be on the phone to get prior authorizations, otherwise people won't get the medications or they're only filled for a finite amount of time. We found it for four years now. That's why I was curious about your time frame.

LAURIE JOHNSON: I'm not going to ask where you're from. Next, same situation I would say, repeatedly having to call my insurance company. I called the number for my insurance company on my medical card, and a major pharmaceutical company answered the phone.

Healthcare:
Insurance

THE SPEAKER: Is that Blue Cross you're talking about?

LAURIE JOHNSON: Yeah, I'm trying not to name, name, I called them and a major pharmacy answered the phone. I said excuse me, but I called my insurance. They said, oh, yes, we know. But you are -- and they're going, yes. I'm going, this does not sound right. I was very happy to have an independent company survey me not long after that, and I ranted and raved. To me,

it's like the vendors answering the phone for the, I don't know what you call insurance, but it's wrong. Very wrong. Lastly --

BILL INLOW: The fox is answering the phone.

LAURIE JOHNSON: Yes, exactly. That's a good one to put in it.

BILL INLOW: I'm glad you're writing that down.

DAWN WARDYGA: That's her job.

LAURIE JOHNSON: That's okay, last point, different time, different situation, I had a physical therapist very upset, told me that she -- other doctors are having a very tough time making it in the state of Rhode Island. I'm sure any disabled person, and I am way up there, needs their doctors, their physical therapists, et cetera, to stay in this state. But she is saying that the insurance companies are giving them such a low amount.

THE SPEAKER: Reimbursement.

LAURIE JOHNSON: Yeah, that they're having a tough time making it. Doctors don't want to stay here, doctors who are just coming out of school are wanting to go elsewhere. I started taking a survey, and every doctor, dentist, et cetera, that I asked this question has agreed.

DAWN WARDYGA: You're talking about all insurers, right, whether it be commercial, or Medicaid, or whatever?

LAURIE JOHNSON: Actually, I didn't name, but I think one of them did, and one of them said Blue Cross/Blue Shield of Rhode Island. I think that was the physical therapist.

DAWN WARDYGA: It's across insurers, that's the impression you're getting, right?

LAURIE JOHNSON: I'd say check it out.

DAWN WARDYGA: Thank you.

LAURIE JOHNSON: Thank you. I am done.

BILL INLOW: Ms. Johnson, you testified before. Do you recall anything that you raised or talked about that got some response?

LAURIE JOHNSON: In the past, I -- there's two major ones that I can think of that I brought up. One was the allergies to aroma or scents. Sand that point --

BILL INLOW: Environmental issues people response to environmental.

LAURIE JOHNSON: That one's gotten quite the response. The other one is I have a gluten allergy, and my food costs more than the average food. And that one has gotten no response. Because my big gripe at the time was that nobody takes the medically necessary food into account when doing food stamps. As I said then, I buy one loaf of bread a month, and I still only buy one loaf of bread a month. It does, it costs pretty much \$8.

BILL INLOW: So food items do have printed on them gluten free, but that's more of a marketing type of thing?

LAURIE JOHNSON: No, those item when is they're in the grocery store and are gluten free, I will buy because they're cheaper. Hot dogs, I can get those in the grocery store, but my loaf of bread is still much more expensive than the regular bread. My bread, my pizza. It's pretty much \$6 for a pizza this big.

BILL INLOW: And your point being that even though that's not a medication, obviously, descent food is important to the quality of life.

DAWN WARDYGA: When you think about it, if you're not eating the proper food, you're going to wind up in a medical situation, yes?

LAURIE JOHNSON: Yes.

DAWN WARDYGA: Do you know what that is, it's all about prevention.

LAURIE JOHNSON: I'd like to thank you for listening.

Human Services: Allergies

DAWN WARDYGA: Thank you for sharing.

LAURIE JOHNSON: You're welcome.

COURTNEY BLOOD: My name is Courtney Blood. I came here just to observe, but I do have one issue. I have a 7-year-old who has Asperger's, which is a form of autism. I have five -- applied

Healthcare: Autism

for Katie Beckett, and he did not qualify, twice. I applied for SSI for him.

He qualified medically, but unfortunately, my husband and I make too much money. He was not able to get that. He requires several therapies that cost a ton of money, and I would like to see more coverage for these children with autism because, again, it's a prevention, not a prevention, but the more therapies I can give my son at an early age, he was diagnosed as the age of five, but we have known since he was about three, and the more therapies I can give him, the better off he's going to be. And he can hopefully live independently. But these are the things that need to be covered, and they're not. And they -- I'm sure that you guys have all heard it. It costs a ton of money to get my son the therapies he requires.

Healthcare/Supports:
Supplemental Security Income

DAWN WARDYGA: I just want to throw out that the last legislative session, legislation was introduced to allow for a Medicaid buy in for those very kids you're talking about. And not only so that everybody is clear, not only those with an Asperger's diagnosis, but any child who meets the disability definition under social security rules, child with disability social security rules, whose family might be over income for SSI, but the child does not meet the, quote/unquote, institutional level of care criteria, and these are families that are primarily middle class families, for the most part, they have commercial insurance and pay for commercial insurance. And what winds up happening is because with their child's special needs, they wound up with extraordinary out-of-pocket expenses. Legislation was introduced in both the house and the senate, they got hearings in both sides, but they were held for further studies. This is an area, if you didn't know already, is near and dear to my heart. One of things I vowed to do a year ago, is that, I mean, I didn't anticipate in the first year it was going to fly any way, especially in the fiscal climate, but I intend to be sure that that legislation gets reintroduced on an annual basis until I die or someone takes over, whichever comes first. I'm throwing that out there because we need families like you that are willing to provide either written testimony or come with me to the state house. I will take you to the state house, and support you in any way you need to be supported. Because I can talk about this from an advocates perspective. My child with disabilities passed away a long time ago. We need families who are living this nightmare right now to be able to come and to support this and to make those legislators know how very important this is, because these families are being forced into poverty so that their kids can get what they need. So, clearly, bring your friends. And Katie, send them by way. I have a new e-mail address, Katie.

COURTNEY BLOOD: I would like to get that.

DAWN WARDYGA: Absolutely, I would be happy to give it to you. I appreciate you bringing it to the table.

COURTNEY BLOOD: It's a big issue, there are a lot of families like ours.

DAWN WARDYGA: You'd be better off if your child was totally eligible for Medicaid and did not qualify for commercial insurance, which is nuts.

COURTNEY BLOOD: Exactly.

MEREDITH SHEEHAN: What is the nature of autism overall? Didn't they just last year or the year before --

DAWN WARDYGA: Last year there was a legislative mandate, a commercial insurance mandate to provide treatment for kids with autism. I can tell you that if you pick up the phone today and you call the health insurance commissioner's office and you ask where the

implementation is on that, you're going to be extremely disappointed. That wouldn't even get at some of the stuff that we're talking about. It might get at some of it, not all of it.

MEREDITH SHEEHAN: It sounds like it's on the radar, finally.

DAWN WARDYGA: That's only one example. Again, that legislation is specific to autism. Whereas my philosophy is that every child, I don't care what their disability is, if they fall into that category where if their family were making less money and they met the definition of disability under social security, they would automatically qualify, they would automatically get Medicaid, they're being disqualified for Medicaid. Personally, I consider that to be a discrimination issue.

MEREDITH SHEEHAN: Thank you.

DAWN WARDYGA: Can I ask you where you live?

COURTNEY BLOOD: Cumberland.

MEREDITH SHEEHAN: This legislation, as well?

DAWN WARDYGA: No, on the house side it was introduced by Eileen Naughton and Lou DiPalma. There was some good preliminary support for something very new.

MEREDITH SHEEHAN: That legislation would have addressed Courtney's issue.

DAWN WARDYGA: No question. It allows for a buy in to those families, after buy in for Medicaid.

MEREDITH SHEEHAN: Right now this is a state to state issue, and not --

DAWN WARDYGA: Yes, because there is a federal law, it's called Family Opportunity Act, that allows states to offer a buy in program, and there's certain criteria, as with any other federal

Healthcare: Family Opportunity Act

 law, there's a minimum, but states have the option to go higher, for instance, the federal poverty level. I think the FAO, Family Opportunity Act, I think that the number is 300 percent of FPL. But states can go higher on that and charge families, you know, prorated, basically, based on income. That was how we intended to go forward with this. This wasn't a so-called free ride, which some people thought it was. Come to my world some days. We'll talk about a free ride. So this was an attempt for those families to buy supplemental wrap around. And a lot of the thought behind is for a lot of you familiar with cedar family centers, we know they're disabled, they immediate the SSI criteria for disability, but unless they're eligible for Medicaid, they can't access services to the Cedar Centers. You're going to be my new best friend. And I'm looking for some new best friends.

MEREDITH SHEEHAN: Did you want to say anything else?

VICTORIA LETOURNEAU: Actually, I did. In speaking with Dawn, she had told me that this may be the forum for me to present another issue that I've come against. And it's the medical gap

Healthcare: Donut Hole

 otherwise known as the donut. I don't know how familiar you are with that, but do you have a dollar amount attached to your Medicare. This year it's \$6,350. Once the insurance company hits that mark, it comes out of your pocket to pay the next \$6,350, or January 1st, which ever comes from. And for those of us that fall into that medical gap, we can't afford it. We can't afford to keep the, you know, the roof over our heads or the food in our bellies. We have to make a decision between whether or not we buy groceries or medications. I have a medication that I have to have that's \$16,000 a month. And without my insurance, I could never afford it. I could never, ever have it. And that's what makes me function every day. What was part of or was optioned to be a part of the medical reform was to have it flat across-the-board every month you pay the same rate for your insurance, and you have medical coverage for 12 full months. And I need to see that stay in place for people like myself that fall into that medical gap. Because that's -- it's so detrimental. And it can happen to anybody. And you don't have any idea when it happens. You go to the pharmacy to pick up your medication and

they tell you, okay, you owe me \$6,000 today. I owe you what. It's not going to happen. But you also then have to suffer for 5, 6, 7, 8 months, whenever you fall into the gap. Because you can fall into the gap any time as long as you hit that \$6,350.

THE SPEAKER: For medication?

VICTORIA LETOURNEAU: For medication.

DAWN WARDYGA: This has been discussed at the, I'm a member of the Rhode Island Health Reform Commission. And this issue has come up a number of times. You hear people talk about the donut hole, basically. And what I can say in terms of the health care reform law Rhode Island is moving forward probably, I feel as if, and I hear it from other states, that Rhode Island is much more progressive in moving forward in implementation in health care reform. And I'm very glad that we're a state that is on the other hand, there are, like, rolling implementation dates for certain components of the reform law. While this is already on the radar screen, I think it's really important that it's shared here, because the commission is aware of it, and the commission, quite frankly, can network with the Lieutenant Governor's office who is responsible for the Health Care Reform Initiative. Again, just more information that it's coming up in other settings, basically, which pushing the agenda a little bit harder. Thank you for your comments.

MEREDITH SHEEHAN: Any last thoughts? Anybody?

BILL INLOW: I, personally, think that, I'm out of line here, but I don't care, throwing you off. That's an example of how the Healthcare Reform Act, otherwise known as Obama care, and I think he should be proud. In the process of solving that ridiculous problem. And people should be reminded and realize that there are a will the of really good things in the health care reform act, which is monitored on a state program in Massachusetts. It's pretty obvious the state of Massachusetts has them falling off the face of the earth because of the universal health care program very similar to the health care reform act. The governor's commission is somewhat limited to its official role in terms of partisan politics, but a lot of things happen at the federal level that have a dramatic impact on individual citizens of the state of Rhode Island and other states, people really need to pay attention. Things are not perfect. They can get a hell of a lot worse, and will if people don't stick together and affirm good descent social policies. Throwing you off.

DAWN WARDYGA: That a boy, Bill.

BILL INLOW: Thank you. Thank you for speaking up. Reminding us that some things are getting better, we just hope they continue.

VICTORIA LETOURNEAU: There was an article in the Providence journal, I think it was last week, that Senator Whitehouse had actually initiated some steps for the reform. and to try and close some of that gap. The problem is it doesn't trickle down to those of us that suffer with it right now. And it's going to take a lot for it to all get implemented.

BILL INLOW: Sure.

VICTORIA LETOURNEAU: And we don't have time. If you had to go without food for six months, you wouldn't be here. But you're asking those of us that need our medications to go without our medications for six months. And we won't be here either.

BILL INLOW: Thanks for speaking up.

DAWN WARDYGA: You will be my friend, too. I'm just racking them up.

VICTORIA LETOURNEAU: I'm proud to be your friend.

DAWN WARDYGA: Likewise.

MEREDITH SHEEHAN: Thank you to everyone here who came out today and all those who left. And our panelists, thank you so much for taking the time out of the day. I know I'm going to

the one in Middletown on Friday as a panelist, and Casey is doing the one tomorrow night in Woonsocket. Hopefully, we'll see you all again soon.

5. Thursday, July 26, 2012 – Woonsocket Public Library

CASEY GARTLAND: I think we'll get started and bring this to order. Good afternoon. My name is Casey Gartland. As I was saying, my name is Casey Gartland, I'm a senior director with Perspectives Corporation, we're an agency that for 35 years has provided services to adults and, not to mention, children with disabilities. I also serve on the governor's election access committee. So am also with a group of very dedicated people to make sure there's good access to the voting areas, as well as awareness about registration, things like that. In just a moment, we're going to have the panel introduce themselves. And then we'll start with the order in which people registered when they came in. Before we do, I do need to read from here. The purpose of these public forums is to identify the concerns of people with disabilities and their families in order to assist the state in developing programs to improve the quality of lives of people with disabilities. To ensure everyone who wants to speak gets a chance, please keep your comments short and to the point. If you have a critical problem that needs to be addressed, the panel members will be available at the end of the hearing to direct you to the proper agency for help. After the public forums are completed in early August, the sponsoring agencies will review the testimony and prepare recommendations, which will also be posted on the website by the end of November. The recommendations and transcripts will be printed and sent to the state and congressional officials and to the members of the general assembly, and the recommendations will be used to develop policy and legislative initiatives for the next year, or until they are accomplished. The Rhode Island disability vote projects voter registrars are available here. Are they here? The disability vote project's here, as well, the representative?

CHRISTINE RANCOURT-BRUZZI: Yes, Casey.

THE SPEAKER: We're not exactly, but, yes, we're here.

CASEY GARTLAND: There's here to register anybody who is a citizen not currently registered to vote where they live to vote. People can file a change of address if they moved since the last election. At this point, I'm going to have the panel introduce themselves and identify their organization, and say what they have to say. We can start at the end.

LINDA MAHONEY: Hi. My name is Linda Mahoney. I'm from the behavioral health developmental disabilities and hospitals.

KATHLEEN SHERLOCK: Hi. My name is Kate Sherlock. I'm from the Rhode Island Disability Law Center, but we have a relationship with the Rhode Island Disability Vote Project. So I tried to leaflet all of you, and there are voter registration forms. They are also available in the back. If anybody needs help with registration, they can see me after, as I can help with that. In addition, the Disability Law Center needs to seek public input annually on its priorities. So we have developed a survey, which I attempted to give to all of you as you walked in. There are some available in the back. If you would be so kind as to complete the survey and give it to us, but the other thing is you could also take an extra copy and make copies and give them to whoever you know who might want to do one. If you can't give it to me today, I have some self-addressed pre-metered envelopes so that you could fill it out and send it to us in the mail. But soon, because we need to develop our new priorities before October 1st. Thank you.

JUDI DREW: I'm going to be brief. I'm Judi Drew. I'm a commissioner on the Governor's Commission on Disabilities.

JOE MURPHY: I'm Joe Murphy. I'm a supervisor for the Office of Rehab Services.

SHERRI PROVENCAL: I'm Sherri Provencal. I'm a nurse, a private practice in Lincoln, but I'm here today for the brain injury association.

CARMEN BOUCHER: I'm Carmen Boucher. I work at the office of special health care needs.

CASEY GARTLAND: As of right now, I believe we have two people to speak. We're going to go in order of how they registered. We do have a couple of people with question marks. That means later on we will open up the room. The first person registered is Brenda Pafundi. Why don't you go ahead.

BRENDA PAFUNDI: I have MS, newly diagnosed. I came here when my father passed away. And he left me the house, and he left me over \$2,000. Which this guy paid for me. We didn't know I had MS. I was going through all these tests, had to be four years, and so he paid for everything. He's retired. So now I'm getting liens on the house, liens on the cars. I have no medical. I had a lawyer. And the judge gave me one year back pay, 2010, I guess, 2011. \$7,000. The lawyer took 5,000. That's not even enough to pay the taxes on the house. What do they want me to do? I don't get it. I don't understand. So now I called the MS people, and they referred me to a couple of lawyers. And they said the same thing, as long as you have money in the bank, he said, spend it, spend it, get rid of it. I'm like, come on, I don't have that mentality, number one. Number two, I don't have the strength to run here and there. I canceled a lot of things. That was one of my doctors. I see 3 or 4 doctors a week. I got to pay for them. I don't get it. I don't understand. I worked up until 2003. I also had other problems, depression, bi-polar, insomniac. Didn't know it for years. Only knew I never could sleep. I have that, too. Finally, they gave me these seroquel. They knock me for a loop. They're not narcotic. It's just crazy. I don't know.

JUDI DREW: Could you clarify something for me. Are you receiving any support from social security?

BRENDA PAFUNDI: They denied me. They paid me, judge best gave me one year back pay.

Healthcare:
Social Security

He's a real nice guy. He is. Everybody, my lawyer, oh, don't say nothing. And he came out, and he said, I don't think your attorney likes you too much, because she told everything. And the judge said, did I ask you for that? He was

funny.

JUDI DREW: Why don't you and I talk after the meeting. Okay?

BRENDA PAFUNDI: Okay.

CASEY GARTLAND: Anything else to do with that? Okay.

BRENDA PAFUNDI: Thank you.

CASEY GARTLAND: Thank you, very much. The next person that we have registered to speak, and I'm sorry, I can't read the last name, Maryanne.

MARYANNE NOLIN: I just walked in, Nolin. Hi, I've been a resident of Rhode Island for four years, and I was at Crossroads for a couple of weeks and couldn't endure it for much. I just left in the middle of the night. They told me at the clinic there, listen, if you ever need to leave, just go to the emergency room. The emergency room said there's nothing else to go to, go back to cross roads. It wasn't an option. My 28-year-old son who's well employed. I've been on SSI

Employment:
Accommodations

before, raised him while I was on that, got off. Worked, had a ten-year work history for 10, 12 years, at the most. Moved here from out of state, because I lost a position in which I was -- I had been a public schoolteacher for three years. It was impossible for me with my condition. (inaudible) to be a teachers aid. I was receiving disability services in the state of Virginia, and I had to bring in a counselor twice to explain to the teacher why I needed accommodations. She chose not to do that. Lost that job.

Health Care: Social
Security Disability Income

Didn't choose to stay. My family invited me up to live with them because she was bit by a dog and lost her job. Did that, and now the

family, now had to make other arguments. That's when I went to Crossroads. From there I got on the SSDI program. I'm on rehab services, I've been on rehab services since they sent me to a person who evaluates another condition. And I can't get that agency to really work for me. I have been through Goodwill's Training Program. They put me on a position that wasn't proper for me. And since then, I can't get my counselor to call me back. They're swamped. They are swamped. They have caseloads of over 60 people. They say they're hiring for people. I was put for job developer. We just got my resume together. What I ended up doing was accepting a thing called foster grant parents. Did that for a year. I just came out of a program at Butler. And there aftercare program, good experience, the best I've had. So I have a good report on that. I just don't know what to do. I have called my counselor and they were going to terminate my case, because they couldn't find it. And then Butler advocated for me. I don't know how to develop a relationship with my counselor where you can actually sit down and have a discussion and say this is what's worked for me, this is what hasn't worked for me. They did say in the paperwork I could go through capital and they can try to call me back. That's only when I thought the case got completely dismissed. I think what I need is an attorney to really look at what my skills are, transferable skills. I wouldn't mind being in the AmeriCorps program. Part of my recovery involves work. I want to work. I have a good work history. I was misdiagnosed at a local clinic that treats a lot of people that have disorders. They cut me off from all their state programs two years ago while I was pending. I had the SSDI, but not the Medicare. It takes two years to get on Medicaid, I'm sure you know, Medicare, rather. I'm not eligible for Medicaid. I don't know, I would just like to see our rehab services be more responsive to people. I wouldn't mind being on a board to work with that. But I'm a little fed up. It's been three years, and it hasn't really be enough for me. The other thing is they had the job developer, and he relocated. His phone number was no good. He e-mail wasn't accurate. And I've been floating around since then. I would like to see a little more of, I know they're overwhelmed, I get it, I get the budget cuts are extreme. That's not helping the people. I'm not asking for special privileges, I'm just asking for a little more expediency. Thank you.

CASEY GARTLAND: We might have a couple questions for you. You're welcome to sit down.

MARYANNE NOLIN: Do you want me to stand up still?

CASEY GARTLAND: If it's easier for you, because we want to make sure it's entered into the record.

JOE MURPHY: After this forum is over, I can speak to you. I work at the Office of Rehab Services, maybe explore what's going on with you.

MARYANNE NOLIN: Okay. Like everybody, also, you know, I'm putting it out there for other people that might have the same issue.

CASEY GARTLAND: Thank you, very much, for your time.

MARYANNE NOLIN: You're welcome.

CASEY GARTLAND: At this point, we don't have any registered speakers, but we'd like to open up to anybody who has spoken or not spoken yet. Anybody here in terms of the disability services of Rhode Island? If you can state your name clearly for the record.

DEBBIE CARROLL: Do you want me to stand up?

CASEY GARTLAND: That would be great.

DEBBIE CARROLL: It's hard for them to see. My name is Debbie Carroll. I live in North Smithfield.

Healthcare/Supports
Social Security

I'm not sure how to put this together. But my diagnosis is a mental health diagnosis. I was only diagnosed about 12 years ago. And all my life it had been very difficult with work and living. And I've had good

jobs, but it was hard to keep them. And I think, like, for the past four years, you know, my doctors have all, my therapists, you know, you've got to get up, thanks John, SSDI, you got to apply. But I

Employment:
Discrimination

never wanted to apply, because I just wanted to work. I wanted to be successful. And I got a job back in 2007, I think it was seven, actually, at an independent living center where they hired, you know, I don't know, what's the percentage, 75 percent, 80 percent of people with disabilities. But I never told them I had the disability when I got hired, but it's hard to do that, especially with the mental health diagnosis, because it's something that you can't see. And I didn't want them to know my story. But I felt very comfortable with my director who was my immediate supervisor, and I was a coordinator in a little department. And my meds had to be adjusted. It happens, you know, diagnosis with mental health illness, and I have sleep apnea. There was a combination of things that, in my mind, was not in an organized state for a little bit of time, but then I struggled. And we had a supervision meeting. And at this supervision meeting, I, which I have weekly with her, we were just talking about, you know, disabilities. And I said, no, I understand that, because I have one myself. And she said, do you, really? She said, do you feel comfortable? And I didn't have to say anything. That's the law. But I felt comfortable, and I have one. This was an agency that dealt with it. So I told her what I had. And she sat back in her seat, and she said, I never dealt with that before. And when she did that, I knew I did make a big mistake by saying anything to her. Within one week, I was let go from my job. That was the thing that was bad for me. And they don't need a reason to let you go, they can give you any reason that they want. They can. And you can't, you can't let a person go with a disability, probably, on the books. But it doesn't matter what's on the books, because they do what they want to do. That did it for me, I landed up in a hospital, at Butler, because I could not believe what happened. And all my life I never wanted to tell anybody I had a disability. There I was saying, and it was the end of my job. So I got on unemployment, and still I got, you got to apply for SSDI. I'm like, I don't really want to do that. And they said you really should, because it's a lifelong condition, all this stuff, you don't know how long, and if it's going to get worse, and you're getting older. And I don't want to hear that, but that's what they said. So I did. That happened two years ago. So I got on in, I think it was December, or January, something. So I have that now. And it's really not a lot to live on. It isn't. Not when you have a job and go on that, it's like unbelievable. And I never understood when people talked about being on disability and how they have to work under the table to make ends meet. And I'm not working under the table. I'm not. I can't do it. I just don't feel comfortable doing that, because it's just not right. But it puts people in a very awkward position because you don't make enough to live on. You have to get on Medicaid, which is another story in itself, how it makes you feel to go into a human service agency that's supposed to be there for people but that make you feel like you're

Healthcare/Supports:
Medicaid

just a piece of cattle, or something, coming in. And they make you feel like you're doing them a disservice by being there to get services, to be honest with you. And unless you're assertive, which I am, you really fall through the cracks. People do. It's horrible. Being on is one thing, but how do you get when you like lose your dignity, you lose yourself respect. There's a lot of people like that. I wait in that room, I see the faces of people. It's sad, it's really sad. So I got on Medicaid. And SSDI. Well, now, I just finished this big training program for this new innovative thing, peer specialists, diagnosis and recovery, recovery coaching. You have to have an illness to do it, which is a good thing, I guess. Because you don't have to hide behind I don't have a problem. Which is nice. I also had an issue with gambling. So the recovery coaching is right up my alley, because I understand. Which is great, because I have to have an addiction to do this, to have gotten the training. So we got training from Yale University, which was outstanding. Now I do a lot of volunteering to get my

foot in the door. It's not pressure when you volunteer. I volunteer quite a lot of hours. I don't know, maybe over 30 hours a week. I also do help line for, you know, sexual assault and trauma, and I'm at the anchor, and RRI, just started an internship there for 15 hours. Okay, here's the deal, well, when you make minimum money, so right now, an internship is minimum money. And so the deal is, is that off Medicaid. Now, I got off Medicaid, my medications are over \$600 a month. They are. If I don't take my medications, I'll end up in a hospital. I need them to live. I couldn't afford them on my own. It's just the way that it is. It's my life, it's my life. This is how it goes. So I'm faced with earning so much money, what is it, I don't even know, \$1,010, something like that, gross, which is gross, to live on. Then you cut off of food stamps, cut off of Medicaid, you have to pay the extra medical insurance for the, you know, what you have to pay. Well, I did the math. And I did the math for getting hired at the center as a coach, and I went even higher, because I know what my hourly wage can be worth. I did it like that. And I did it two ways I did it, one, with what I receive right now with state help and all of the health assistance I get, which is less, I -- I hope that it stays. I did the math without the services that I had and what I earned. And at the end of the day, it would only be 2,700 more per year for me to live. Now, when you think of all of that, it looks, you know, you do the math, you can honestly see how people work under the table and stay on all their benefits, because there is no incentive to get off. There isn't. It's really tough. And you want to have your dignity, you want to work. I want to work, I don't know about anybody else. People get on for everything else on SSDI, I don't know how they do it, but they do, get on for minimum things, they do. You know that. But there's not an incentive. It's not help, \$1,010 is no -- it's nothing. You know, I mean, you know, what I have to live on per month to pay my medical, I don't want to live in section eight housing. Nothing against people that do. I don't want to. I don't. I don't want to move from where I've I am. I love where I live. I've been there a long time. I want to live a normal life. That's my choice. But it doesn't give me the option to do that. And I'm stuck. I really am. I don't know what to do. I don't know how things can change. I don't see them changing, I don't. And it really puts me in a situation I don't want to be in, but I'm faced to live in. You know what I'm saying? And then while I was -- while I had applied, two years, right, and I had been working, they give you the -- they give you the seven-month, what is it, nine-month trial for work period. Well, because I worked and there were times I didn't work a lot, they used, I have no more trial period. That's scary, terribly scary. And although they say you can be expedited to be back on, I don't know that for sure. I don't know. I've never done this. There's all these questions I have. And it's sad to think that you got to stay on SSDI, live with Medicaid, which is, just, it's just the whole thing. I never knew what this was like until I was faced with it. I think that's a different, it's a different spin on it, you know what I mean? I don't know what can be done. I hope that something can be done. I hope there's a fight for helping people to increase the amount of money that you can earn, to gradually get you off. It shouldn't be. This is - - if you earn \$1 over \$1,010 you are off. That's it. You're off. So what does that give you? When you're making so much with food stamps, which you don't really want, but you have to do it. You're getting your Medicaid which pays for your medical benefits, copays, everything, basically, medications are that high, I pay \$30 or \$35, which is great. But I don't want to bill the state, I don't want to bill the federal government. I don't have an option, because I couldn't make my medications, which would be better preventative health care, because I will wind up in a

Employment: Opportunities	hospital. And it will cost the state a lot of money for me to stay in a place like that. And I probably could have been in a lot more, but I fought to stay out of it, because I don't want to go that route, but that's debilitating in itself. That's where my skill is. I hope I made sense with everybody. I just really hope that there can be a fight for something that can help because. Because I know, I work with the aides, I volunteer there,
------------------------------	--

and I here all the stories. They're all the same stories. It's sad. Because there is no incentive. When you got to earn \$2,500 a year extra, what does that say to a person? I'm going to work under the table, and I earn whatever it is. And people do all the time. I hear it all the time. And they make better than, probably, you do. You know, really, truly. I'm not kidding you when I say that. You wouldn't believe some of the jobs people get, they help with framing, they do what they do, they make really good money. Because it's all clear, they don't pay taxes. They walk home with their cash.

JUDI DREW: I have a couple of questions for you. I work -- I've been in this field for a long time, and I work with people on a regular basis who are on disability to help them get their benefits and help them decide what they can do for careers once they receive their benefits. Some of the information you're sharing with us is not accurate based on my knowledge. So the first thing I wanted to do is ask you have you ever met with a benefit specialist?

DEBBIE CARROLL: I'm in -- I'm getting rehab services.

JUDI DREW: You are, from the Office of Rehab Services?

DEBBIE CARROLL: That's what I was told. As a matter of fact, I made another appointment to meet a person in another week.

JUDI DREW: I would encourage you to talk to the benefit specialist again, because if you earn over that 1100, you're not immediately cut off.

DEBBIE CARROLL: You are. I've been dealt -- I'm not telling you your job by any means, but I've been down to the welfare office and DHS.

JUDI DREW: That's the only thing I'm confused about, because if you're on SSDI, you qualify for Medicare, not Medicaid.

DEBBIE CARROLL: No, Medicaid.

THE SPEAKER: Two-year wait for Medicare.

DEBBIE CARROLL: Two-year wait, yeah. Medication.

JUDI DREW: That's probably why you're receiving, because it's determined on medical needs.

DEBBIE CARROLL: For Medicaid or Medicare?

JUDI DREW: SSDI has Medicare. SSI has Medicaid. And the benefit specialist should be talking with you about those differences, what you can reserve, what some of the set asides are. Because there are set asides, depending, um, to not fully count what your earnings are against what your check is if you have certain expenses that are high, and you can't work without those things being part of your life. That's why I really feel that you need to talk to a benefits specialist again, maybe get more in writing.

DEBBIE CARROLL: He's the one that sat down with me and figured this whole thing out. I told him everything.

JUDI DREW: It's not making sense to me based on what I know. I don't know what John knows. I work with people with mental health issues all the times. We're colleagues. Are you hooked up with a community mental health center?

DEBBIE CARROLL: No, no. I'm doing an internship right now, but I have a private therapist.

JUDI DREW: That's different. The community mental health centers here in the state, as you know, because this peer wellness program is part of the new Rhode Island health homes initiative. So the community mental health centers have case managers that can help support you, they have.

DEBBIE CARROLL: I used to be a case manager. I know all that.

JUDI DREW: You know what I'm talking about. They have employment specialists who can help you locate employment, help you make decisions about better career options. So I just feel you're kind of out there hanging out there by yourself, and you're not getting access and don't understand all the resources, apparently you do. If you want to talk to me afterwards, I'd be glad to talk to you about it. Maybe name people you can call, if that would be good for you.

DEBBIE CARROLL: Thank you, very much.

LINDA MAHONEY: I want to thank you for being involved as a peer specialist. You're exactly the type of person we want. We want someone who's going to work with the facilities to make it more respectful and to be able to have a voice. When we developed the peer specialist program itself we looked at the benefits. Because the last thing we wanted to do was have anybody volunteer and have it where they couldn't eat. That wouldn't be profitable for you to participate in the program. So there might be more information you can get from the peer specialists. I know we've had a lot of good people, a lot of education for the benefits, itself, we looked at that before we designed the program. Maybe we can get you more information on that.

JOE MURPHY: I also work at the Office of Rehab Services. If you're having difficulty with your benefit specialist, we can talk to you afterwards, and I can get your name. Judi said there are things like IWRH. You don't have to know what it is. It's a set aside if you need certain things.

MARY GOLOUSKI: I'm sorry, Joe.

JOE MURPHY: It allows you to put -- social security wouldn't count those things as income you get on earned income. So you can set aside that money to pay for those things you need to work. And social security doesn't penalize you. There's the Sherlock plan, too.

JUDI DREW: That's why the Medicare Medicaid issue is so important. Because it's a very complex thing, as you know. You have to have a law degree to understand it.

DEBBIE CARROLL: Well, he mentioned that, as well.

JUDI DREW: Sherlock has what's called a Medicaid by in, where if you continue to work. We don't need to get into that. I want to make sure you're connected with the right people to walk you through this to help you understand. You really can do this. The other thing I'd like to ask you to do, and everybody else that you talk to about this, is to call your congressman and say to them, you've got to change the SSDI system to the SSI system. The ticket to work is my dissertation for my doctorate. So I know why it's not working. One of the biggest areas we hear as many years as I've been in this field, why aren't there more incentives for people who have worked and qualify for DI, we're more likely to get folks like you back to work with the two for one like SSI, then penalizing you for going over a certain dollar limit. They try to do things differently and make changes. The only thing going to change is if congress changes the law.

DEBBIE CARROLL: How many people say it, one voice. You know what I mean. You know what I'm saying.

JUDI DREW: You're not the only voice, trust me, there are hundreds of thousands people across the United States asking for this change and we don't understand why it's not happening. Only political pressure is going to make the difference. You've got to be active and really advocate to have this change come out. More people would be working with disabilities if that were possible. I want to encourage you to be an advocate.

CASEY GARTLAND: In the future, I know this is a little bit like closing the barn door after the horse left, but if you do have an issue with a job based on a disability, you have a right to access the ADA to find out.

DEBBIE CARROLL I did. I had a good case against them. But when it came down to the wire of actually getting to the final thing, because they had an attorney, I had an attorney through the Disability Law Center, awesome, but

Healthcare: Confidentiality

I had to share my records, all of my mental health records, with the agency, with that lawyer. That would have been brought up in court. And you know what, I shouldn't have to have done that. That's my own personal life story. That's my business, nobody else. I have a lot in there. I don't want it all put out there. I have to decide, do I want to go through with this. I don't want my job back, how do you work like that. And maybe get money as compensation, or let all of your records be out in the open. So that was a choice that I made. I'm not sorry for it, but it shouldn't have to have been that way, either.

CASEY GARTLAND: Thank you for elaborating. Okay. We have a couple of more people who have registered to speak. Laurie Archambault.

LAURIE ARCHAMBAULT: Is anybody reading that?

CASEY GARTLAND: I think most of the speakers are reading it as they're speaking.

LAURIE ARCHAMBAULT: I'd like to sit here and address everybody. My name is Laurie, and I'm here today to represent my oldest son, Jared, who was born with multiple disabilities and a rare medical condition. He is completely blind. He has a seizure disorder, and severe osteoporosis, he's autistic, with multiple sensory deficits. He's not verbal. He gets anxious when taken out of his comfort zone, and displays his frustration in fears, kicking, biting, pinching, hitting, flipping furniture, and breaking glass windows on occasion. There's a long adjustment period when he's presented with new people and new environments. He has a severe intellectual disability. His rare medical condition left him small for his age. He's on several medications that he has to take daily, which require constant monitoring and adjustment.

Human Services:
Developmentally
Disabled

One of those medications sustains his life. Although he's 32 years old, his limitations are so significant that he functions at the level of a toddler. He's a elopement risk, and has a history of wandering off looking for someone or something. I think it's obvious that he will always need someone else to take care of him. He will always need someone else who has his best interest in mind to speak for him, to make all of his decisions, and to protect him. My concern about the current services for the developmentally disabled is that they're incomplete. The primary focus of the current system is the development of job skills and fostering independence. While this may be appropriate for most, it's not appropriate for Jared. There is no alternative program that will provide him with the opportunity for maximum growth and development.

Human Services:
Transition

Jared's quality of life has greatly diminished since entering the adult service system in 2002. His health has declined and suffered numerous injuries of unknown origin. The most important

Healthcare:
Physicians

things for me are his health and safety. His medical needs are not being addressed appropriately. In addition to a general lack of communication and coordination, there is a lack of knowledge and training about his diagnosis, the purpose of his medications, as well as the signs and symptoms of the adverse effects of those medications. It's been hard to find and keep doctors with knowledge about his rare medical condition. It took eight months to get an appointment with a potential primary care physician. We had to wait a little over an hour to see the doctor, not a pleasant experience for Jared. He was outside his comfort zone. He did not allow the doctor to examine him. It took me three days to get in touch with that doctor to follow up on paperwork needed for an upcoming surgical procedure. He had missed doctor appointments, been late, gone for appointments on the wrong day, and has gone to appointments that needed rescheduling, because the premeds were insufficient. The most recent visit to the dentist shows his teeth are not getting brushed adequately, if at all. He requires visits to the operating room under general anesthesia to perform any medical procedures. We won't know the extent of restoration until he's there. Due to the poor oral hygiene he received he has to have a sealant to be applied to his teeth. I learned it's not

covered by his insurance. He's too old for that. Where is he supposed to get the money to pay for this? Wouldn't be it be more cost effective to provide care to save his teeth rather than multiple visits to the operating room under general anesthesia to extract them. Since 2002, he has had three primary care physicians. The first made an unnecessary medication change without talking to me. What he read to be a low test result was normal for him. The second lost his license to practice. He has had three endocrinologist since 2002, the first left his practice, and left us without a referral. The second didn't appear to have enough experience with his rare condition. His safety needs are not being addressed appropriately. The lack of supervision has resulted in numerous injuries of unknown origin, including a broken finger and multiple large bruises. Frequently, he uses the bathroom unsupervised. He has bowel movements, and wipes himself with his hands and clothes. He will not wash his hands without cues and assistance from his caretaker after using the bathroom. Just the other day I went to see him at 9:30 in the morning, he smelled of feces again. It was all over his clothes and under his nails. He is completely blind. He explores his world and eats his food with those hands. He is an elopement risk and currently lives in a group home with the policy is to not lock the doors. In fact, when he was placed in his current living situation, he had an exit door in his bedroom. He is required to climb over the side of the tub and scale the walls to get into the position for the shower. They say this is safe for him, despite the fact he is completely blind, has a seizure disorder and severe osteoporosis. My request for a walk-in shower was denied. This is an accident waiting to happen. The group home provides one overnight staff. There are six people living in that home. In the event of an emergency, not one of them is capable of getting themselves out of that home safely without physical assistance. His socialization needs are not being addressed appropriately. He does not have the opportunity to participate in recreational activities that are meaningful to him. The people that live in the group home do not interact with each other, too often, the staff are on the other side of the house watching television. His physical needs are not being addressed. He gets absolutely no exercise, which is leading to lethargy and rapid weight gain. His sensory deficits are not being addressed. This has led to difficulties with behavior, communication, eating, hygiene. There is no outside monitoring within the current service system. Monitoring based on the honor system. My suggestion for improving services and expanding opportunities is to design and implement an alternative therapeutic program for those individuals with developmental disabilities who are completely incapable of developing job skills and attaining independence. A complete comprehensive system of services would and should provide an array of residential and support service options ranging from the least restrictive to the most protective. For those who require the most care and cost the most to care for, it would be beneficial and cost effective to provide their services in one location. There are many states that provide an all-inclusive program within a residential developmental center, whereby providing consistent programming throughout the entire day. Northern Virginia, my personal favorite, Maryland, Delaware, Ohio, and Illinois are a few states who have these. He has severe cognitive and physical impairments. He is incapable of self advocacy, self direction, and self preservation. He cannot protect himself from abuse, neglect, mistreatment, or exploitation. He cannot use the telephone. He cannot monitor his health or his medication. He cannot begin to understand or exercise his rights. Again, there is no outside monitoring, just the honor system. He functions best within a highly structured consistent and predictable environment. He likes to swim, listen to his favorite music, and he enjoys being outdoors on his sensory swing. When he received the types of services he needed when he needed them and in the amount he needed, he was happy, smiling and giggling often, and he had more energy and he ate a much healthier variety of foods. He was more focused and less

Human Services:
Transition

behavioral. I have not seen that Jared since he left the under 21 services and entered the adult service system in 2002. He has regressed and lost many of the skills that he had learned. By not providing the appropriate types of services when he needs them his health care costs have and will continue to rise due to illness and injuries that could have been prevented. It's very frustrating to see that the system that was originally designed to care for people like my son has failed him. Jared has been in five different placements since entering the adult service system in 2002. Three of those have been within the past three years. The types of services that he needs are not available to him in the current service system. I would like to inform this committee that I did not learn about these meetings from the group home where my son lives. Staff were not aware of the week long forums. I did not receive any mailing on Jared's behalf. I'm his mother, his advocate, and his legal guardian. He currently lives in Cranston in a state run group home within the RIDE class program. Finally, since it is the anniversary of the signing of the Americans with Disabilities Act, I would like to emphasize that nothing in the ADA or its regulations condones termination of institutional settings for persons unable to handle or benefit from community settings, nor is there any federal requirement that community based treatment be imposed on individuals who do not desire it. Thank you. And I'll be sitting right there. So if anybody wants my number, talk to me, anything, I'm available. Thank you.

CASEY GARTLAND: One question. (applause)

CASEY GARTLAND: Can we also ask you questions, though, right now, because we want to enter it into the record, as well.

LAURIE ARCHAMBAULT: Sure. I'm available for questions.

CASEY GARTLAND: Is there anybody with questions?

LAURIE ARCHAMBAULT: I think it's a lot to digest, really. But it's a true story.

CASEY GARTLAND: I'd be curious to know, in the past, when you were advocating for him, did you utilize the social services that was assigned to him?

LAURIE ARCHAMBAULT: I went everywhere. I was at the Disability Law Center. I testified at the general assembly. I went to my own legislators, who ignored the situation. In 2010, I ran for representative, and I'm doing that again this year, so that I can get in and play in the same ball field as the people who make the decisions.

CASEY GARTLAND: So you did talk with the DHS social worker along the lines?

LAURIE ARCHAMBAULT: Everyone.

CASEY GARTLAND: Are you aware of an office that was called quality services, now quality improvement?

LAURIE ARCHAMBAULT: We dealt with them in the very beginning in his first placement the group home. Naturally, he can't tell us. Nobody knows. Everything goes undocumented, because nobody can explain it. That's not the way it should be. If he's getting injuries, people should know how he's getting them so we can avoid it in the future.

CASEY GARTLAND: Sorry for your experience.

LAURIE ARCHAMBAULT: It's been a long hard road, but I need to bring the message to the people who, hopefully, can make some changes and advocate for these people who are unrecognized in the current system.

CARMEN BOUCHER: Have you filled (inaudible)

LAURIE ARCHAMBAULT: I did go through an appeals process, and made our way all the way up to the top in front of the department, the directors. And the ultimate thing was they couldn't deal with the issue on the placement of not getting the services that he needed, and our next recourse would be superior court. Who has money for that? Jared certainly doesn't. He's on

SSI every month. How do we access the court system? There's no fair access. So we kind of have the brakes put on and hit a brick wall.

CASEY GARTLAND: Thank you, very much. I appreciate it.

LAURIE ARCHAMBAULT: Thank you.

CASEY GARTLAND: Next is Gail, Gail Campbell. She registered, but I don't have her name, Chris.

GAIL CAMPBELL: My name's Gail Campbell. My testimony is similar to Laurie's. Community-based services, a blessing for some and a curse for others. My handsome older son who will turn 33 later this year, he has severe autism, severe mental retardation, and full blown Tourette syndrome, complete with all the bells and whistles. He takes medication to help control involuntary motor tics associated with this disorder. His favorite activities include watching another person sift his pony beads while his wiggles his fingers and makes odd hissing sounds. He also enjoys watching his sesame street and Disney sing along music videos. He has been watching some of these same old videos for more than 20 years. Jason has been a toe walker ever since he started walking. He usually can be found pacing about on his toes while engaging in Echolalia or Coprolalia, which involuntary cursing. He frequently bangs on the walls with the back of his right hand and sometimes bites the same hand, wrist, or forearm. He has put his hand through windows many times and be cut by the broken glass. Jason, like Jared, is completely incapable of self advocacy, self direct, self preservation. He cannot use a telephone, or even communicate if he is sick, injured, or in pain. He cannot report abuse, neglect, or mistreatment. He cannot sign a document, or even begin to understand his rights. Household chemicals must be kept in a locked area because he engages in pica, eating inedible substances. He also engages in rectal digging, which is most likely due to his chronic constipation. He, on many occasions, ingests small amounts of fecal matter that get on his fingers. He then touches his uncircumcised penis with dirty hands. I only mention because it has resulted in numerous urinary tract infections, about eight times since last year, which are rare in young men. Unaddressed sensory impairments lead to problem behavior, which all too often leads to injuries. Sometimes they are quite serious, needs a trip to the ER. As a result of accidental injuries occurring within the past seven years, Jason has received multiple staples to the head on at least four separate occasions. This type of serious injury most recently occurred in March of this year. Somehow, even when no problem behavior is noted, Jason receives far too many injuries of unknown origin, which most

often are evidenced as facial bruising around his eyes. At one point, he had dark bruising around both eyes, and a large egg under his left eye. The frequency of this type of injury is alarming. It is extremely and increasingly difficult to keep him safe and injury free in any setting. Jason resides in a privately operated group home and attends a day program for adults with developmental disabilities, both are run by the same agency. Although it is a good program for many higher functioning

individuals, Jason still requires the same services he received as a child while attending an excellent program which specializes in autism treatment. He also still needs a 1 to 1 staffing ratio, although this is no longer offered to him. Sadly, there are no special autism services offered to adults in Rhode Island, no matter what the experts may lead one to believe. Jason has always been an elopement risk. He is fearful of unpredictable, unstructured activities in unfamiliar crowded settings, and, therefore, does not enjoy going out into the community. Consequently, transitions and outings are difficult and dangerous for Jason. He cannot go on camping trips, go to the movies, attend dances, go to an amusement park, go to the beach, or go swimming at the YMCA, even though he loves the water. He's terrified of all dogs and will attempt to run away if he sees one. He is not and will never be appropriate for

Housing:
Group Home

Housing: Autism
Program

vocational training. So why, then, does the state insist upon his participation in this activity? It seems totally senseless and impractical to me, because both his self injurious and outwardly aggressive behaviors are exacerbated by forced situations and non-preferred activities. What's the point? Jason needs an alternative program which focuses on his health, safety, and sense of well-being. If Jason had a diagnosis of Alzheimer's or other form of dementia, my thoughts and wishes regarding his care would be understood and respected. It is my sincere opinion that his service needs are in many ways similar to those of the aforementioned population. Since any movement towards independence is unsafe and undesired, I truly believe that Jason would be best served in a large, protective, predictable, controlled environment, where all services could be provided consistently and under one roof. I suggest a structured, therapeutic, recreational,

Human Services:
Programming

physical educational program where Jason, and others like him, would not simply survive, but also flourish. Gail Campbell, mother, advocate, and legal guardian of Jason Campbell. (applause)

CASEY GARTLAND: I'll ask that in the past have you advocated with any social worker and gone through similar --

GAIL CAMPBELL: Not as much as Laurie. She's younger and has more endurance. I've been through a few things. Enough to know this is it. And, actually, Jason gets better services than a lot of other people. The agency, it is a good agency. It just does not have what he needs. In fact, it's probably the best placement you could get in Rhode Island. We need more. The system is incomplete. It really is incomplete. Thank you, very much.

JUDI DREW: Have you seen a change, you know, the fiscal environment is tough right now, as you know, there have been many cuts in services with individuals with disabilities, developmental disability programs have taken a severe cut, also, other programs, have you seen a change in the quality of care that he's received since these cuts, are there fewer on staff?

GAIL CAMPBELL: He no longer receives the 1 to 1 staffing, which he needs. Not to go out into the community, because I don't care about that. All I care about is his health and safety. He needs it because you blink and he's into something. He could be in the closets.

JUDI DREW: Since the reduction of funding you've seen a change in the staffing support for him?

GAIL CAMPBELL: Yes. Absolutely, yes. With that said, I want to say that all, you can throw all the money you want at these agencies. They do not have what these kids

Housing: Group
Home Staff

need, what Jason or Jared need. They have needs beyond what can be offered in the community, as I mentioned, he can't even go swimming at the YMCA,

because he has so many sensory issues, like Jared. He's distracted. Even though he may have the right to be in the community, he doesn't have the desire to be there. He has behaviors that infringe on others. He'll go up to people and want to touch their toes, and things. It's one of his --

CASEY GARTLAND: I know a few people like that.

GAIL CAMPBELL: I'm all set. Thank you, very much. I have several copies of this, if anybody wants some.

CARMEN BOUCHER: Can I ask a question? You guys did such a great job explaining, definitely, I see that. Did you have an idea of what the perfect program would look like for your loved one?

GAIL CAMPBELL: Go online and look up the Northern New England Training Center, and what it is. It's a large institution. And not all institutions are bad.

CARMEN BOUCHER: Northern Virginia?

GAIL CAMPBELL: It's how they are run, how they are monitored. I think they should be federally monitored. It's what you make it, like any other program. There are so many different

agencies, some are great, some are not so great. What I mentioned, my son also has been with another agency, which is how I met Laurie, because her son is also being serviced by the same agency, if you can call it that. The name of the agency, which I think is probably worse in Rhode Island, is called Gateways to Change Incorporated. And the executive director is Catherine McGillivray.

CASEY GARTLAND: Thank you, very much. We do have another person? Finally I've got your name here. Sorry about the wait.

MARY GOLOUSKI: Mary Golouski. I'm 54 years old. I've been a nurse for 30 years. I married my husband in 1985. We didn't have children for a long time, then I did get pregnant. And right after that pregnancy, I had a daughter first and right away I got pregnant again and had my son. And he was born with orthopedic issues. And he's had a number of surgeries. When he was eight days old, he went to a specialist, and, because his bone wasn't forming correctly in his lower leg. Dr. Damato said we often have to do an amputation, either that or a whole bunch of surgeries, a

Employment: Back to Work Program

leg lengthening procedure. So rather than doing the amputation, his dad and I decided to go through, like, every three years he was having some kind of surgery. Things were okay. My husband working. I was working. Then in 2001, my husband got laid off from his job. And depression runs in his family, and his disappeared. And it happened to be in September. So September of '01 he killed himself. So while everybody else was, you know, upset about New York, I was, like, in my own private hell. But, eventually, I took a little time off from work, went back part time, then full time. I have to work hard for my two kids. Then, my son also needed another surgery. And, like you, I was brought up with a good work ethic. I'm a nurse. I was working 40 or more hours. What happened, I'm not sure if you're familiar, but my 13-year-old daughter hung herself in her room. And I came home from work and found her hanging in her room. I said, that's it. I had enough.

Healthcare/Supports:

And I, you know, obviously had to deal with that whole business. And I went to a psychiatrist, and the same one I saw after my husband had died, and decided that I couldn't work, post-traumatic stress, anxiety, depression. That whole process of applying, I got a lawyer. Of course, they take a lot of it when you do it get it. Enough time -- she died in July, July 1st of '09. So I am on Medicare now. And I could get social security.

Healthcare/Supports: Supplemental Security Income

The thing is, it's kind of relating to expenses, I'm over income to get, I guess it's called Rite Care for my son. And when I left work, I did have a package, like, a cobra for, probably, 18 months. And I still had to pay for that. But then I got on Medicare. So now that leaves my son with like no insurance. So I've been paying \$520 per month for Blue Cross/Blue Shield. I'm afraid to

Healthcare/Supports: Insurance

let it lapse. He has to go to appointments. My daughter died in July of '09. In September of that year, he had to have that length lengthening procedure. He missed a year of school, because he had that on his leg. It was hell, but it distracted me from losing my daughter. We've gotten close. Like I said, I did go to the, I don't know, the welfare office, just to see if I would qualify. And I had been to the social security office, because his dad had died, he gets social security income. But he -- if he didn't get that, he probably could have gotten a disability income, but then he could have gotten insurance. But they have to take the higher amount. So I just didn't know if there was some way he could get insurance that's not going to break the bank, 520 a month, plus, when he has x-rays I'm getting bills in the mail, copays, deductibles, specialist, \$40. I have a pension from work, and I already went in it like \$20,000 a year. I am thinking about selling the house, I have to get a new septic. That costs money. Let me see if there's anything else I wrote down here. Then I thought, you know, I've been doing better emotionally, except now, just talking about it. I thought maybe I should try to go back to work. And I know there is that back to work program. But now I need, I actually need a total hip replacement. I'm scheduled for next month. And I don't know what the deductibles are going to be for that to be in the hospital. Any ways, just some ideas. If my son, he is not mentally disable and can go to school. Even though he had that leg lengthening procedure, he still toe touches on the right. He has scoliosis so bad he needs a surgery. He has a brace, one for the day, one for the night. Being a teenager, he'd take it off any opportunity he had. I'm just still dealing with -- oh, and then, I'm paying so much money for this Blue Cross, the doctor, his

orthopedic doctor, and he's, like, the chief of orthopedic medicine in Providence, and he wanted to give him a Botox injection in his calf to relax the muscle. They denied that. It makes you upset because you're spending all this money and you still can't get something he needs. That's it.

CASEY GARTLAND: I want to see if there's comments, because it sounds like one of your issues, if not all of them, has to do with navigating the system?

MARY GOLOUSKI: Then part of me, I was, like, almost tempted to be, okay, after his next appointment, maybe I'll drop his insurance and see what. I don't know where we are with Obama care. You can hardly live on social security, and I had to go into my pension.

CASEY GARTLAND: I can't speak very well to this. The person on the panel that I attended yesterday could. But supposedly Rhode Island is very aggressive. I don't know where that leaves people, but, supposedly, it was Dawn, she had said that Rhode Island was one of the more aggressive states in implementing some of the aspects.

CARMEN BOUCHER: I would like to give you her number to contact and follow up.

MARY GOLOUSKI: Should I see you after, then?

CARMEN BOUCHER: Yeah. Definitely, we could definitely -- I can give you my card. 270-0101, and ask for the resource center. And they will help you. It's actually the same person, the same agency where that person --

CASEY GARTLAND: Okay.

CARMEN BOUCHER: So they will be able to guide you through that, because it sounds like there are different avenues. There's five different avenues for insurance that you could go with. So there might be a navigation system issue.

MARY GOLOUSKI: I'm thinking, too, when he reaches 18 --

CARMEN BOUCHER: How old is the child?

MARY GOLOUSKI: 15 and a half.

CARMEN BOUCHER: You're fine. They are other -- as your child continues on, there are other services and transition services that they will actually help you navigate the system, too.

Employment:
Transition

MARY GOLOUSKI: I have to have surgery. Hopefully, I can do well, with all the bad luck that I had. If I do want to go back to work as a nurse, I can always work part time. Should I contact someone before I attempt that?

CARMEN BOUCHER: Well, I could just speak on the health insurance of the child, and, definitely, someone would be able to help you with navigating that system.

MARY GOLOUSKI: See Joe about that?

JOE MURPHY: We have services, transition services for kids to transition into, vocational. We also have services for adults who have disabilities, to help them with employment. We also have specialists that work in our office.

MARY GOLOUSKI: And you have a card, as well?

JOE MURPHY: I have a card, sure. Where do you live?

MARY GOLOUSKI: North Smithfield.

JUDI DREW: If you're going to go back to work, it's good that you talk with a benefits specialist so you understand all the issues around returning to work, and what your options are, and get good advice.

MARYANNE NOLIN: I can comment and say something. People it might be a little known fact that hospitals do offer financial assistance. You can apply, even if you have insurance, or whatnot. And, also, on the back of your insurance card get on the phone and talk to them until they are tired of hearing from you. There are specialists. These plans get so much money to administer our Medicare advantage plans. I didn't even know there was a difference between advantage plan and a supplemental plan. Part D, do you have to have it? You know, because then

you're penalized if you don't keep it. I'm all over with that non-sense, really. It's becoming unbelievable.

JOE MURPHY: One of the other numbers available to anyone if you call 211. It's like 411 and 911. It's information resource you can actually call, and they will give you some information, call any kind of human service agency.

MARY GOLOUSKI: I'm always afraid to call a number, figuring you get put on hold.

JOE MURPHY: This is administered by the United Way. And they have -- they're not state agencies, but they have resources available and phone numbers, and who to contact at the agencies.

MARY GOLOUSKI: I was going to mention, too, that I had -- before I went and got the Blue Cross plan, like, the name, you feel it's reliability. I'm not happy with what's happening over in Woonsocket with the hospital. I had been on the internet. And you can sign up with insurance through people on the internet. You see the plan, it looks good. I don't know if I trust going with this plan that says, oh, yeah, we'll pay for that, we'll pay for that. Then I might actually use it, and then, you know, be in trouble and find it's not covered.

JOE MURPHY: Every hospital has financial assistance. So if your income is low enough, you can be put on a sliding scale. If your income is below 18 or 20,000, you can have zero copays any time you go to the hospital, any kind of services. There's a lot of paperwork. It's a lot of work.

JUDI DREW: Medicaid has a category called medically needy, too. So if you have assets, but your expenses exceed your assets, you can talk to them about it and see if you qualify.

MARY GOLOUSKI: Yeah, because I'm sure I spent more than ten grand on insurance related or medical for myself and my son.

JUDI DREW: The payment for the insurance wouldn't be covered, but the cost for medical benefits would be considered, so. You've been given some good resources. There's also another organization, for those of you with kids, called the Rhode Island parent information network. They're great. Lots of great resource, lots of good connections to professionals in a variety of disciplines. You might want to look them up.

CARMEN BOUCHER: That's what I gave them.

CASEY GARTLAND: That's the information she gave them.

JUDI DREW: I thought it sounded familiar.

CARMEN BOUCHER: Definitely once you contact them, give me call, if you can.

MARY GOLOUSKI: Also, the point, does counseling for people with disabilities and seniors on plans.

CASEY GARTLAND: Before I ask if there's anyone else that wants to speak, are you sitting on the panel? Would you like to introduce yourself? I apologize.

ANNE LECLERC: I'm Anne Leclerc, from the Rhode Island public transit authority.

MARY GOLOUSKI: Maybe I can ask one quick question. Let's say, maybe the resources isn't in here, let's say I let my son's insurance lapse, because I just can't pay that 500, and then I try to get insurance. I know this is why Obama care comes in, I would be afraid that I wouldn't be able to get insurance because he has this extensive health history. Is there any comment on that?

MARYANNE NOLIN: It's preexisting. So that has already been implemented in Obama care, from what I understand.

MARY GOLOUSKI: If he missing a month and they disqualify him, then he would be without insurance. If I reapply, I would be afraid that --

CARMEN BOUCHER: They will answer a lot of that information for you. Like I said, call that number, first. And, definitely, I gave you my card. That's my name in there, and in the

Healthcare: Pre-existing conditions

pamphlet. Call me up and give me an update. I like to follow up, just making sure that you're satisfied with the services that you received.

CASEY GARTLAND: Thank you.

MARY GOLOUSKI: Thank you.

CASEY GARTLAND: At this time, I have no one registered to speak. Is there anybody who would like to speak now, ask questions, bring anything to the committee? Okay. Well, we are obligated to stay here until 5:00. So we can take a small break, but we will be here until 5:00, and we'll reopen the record for more questions, if you'd like. (adjourned)

CASEY GARTLAND: We're just going to reopen the forum for the last ten minutes, make sure if anybody came in they have the opportunity to make comments or speak if they'd like. Or reopen for anybody that's already here. Has anyone come in since then?

Healthcare/Supports:
Social Security
Disability Income

MARY GOLOUSKI: I had a question about, I've been dating a guy, actually, probably stop dating soon. Anyway, he applied for social security disability, I don't know, maybe at least ten years ago. The reason being is he had injured himself, hurt his back, ended up having back surgery. Did well, was married at the time. One of the screws came out, or something, he had to go back for another surgery procedure, and it was botched. I don't know why, he could have had a lawsuit, or whatever, but, you know, he ended up in more pain than prior to the surgery. And he ended up with a condition called Arachnoiditis, which is inflammation of the spinal cord. And applied for social security disability, had a lawyer, had doctors vouching for him. He did not get social security disability. And now a whole bunch of time has gone by. He learned to live with his condition. Had to live under the radar, does work under the table, just to survive, having friends here and there to help him. Now it's like he probably can't reapply for social security disability, because now he doesn't have enough, too much time has gone by, is thousand how it works.

JUDI DREW: It's 40 quarters, it's have to be --

MARY GOLOUSKI: He hasn't worked in the system for over ten years.

JUDI DREW: That would be a problem.

MARY GOLOUSKI: He needs current quarters before he can apply for social security. He might find a job, say, as a bus driver, or something, and work for two years and then apply for social security disability. It's like, why, you've been working. It's a catch-22. I just didn't know if there was anything. He doesn't have any health insurance. And he's too proud to apply for food stamps. But I know he would be eligible, a friend of mine said, well, he lived in Rhode Island now for a while, with me, but I'm just getting tired of being the one supporting him, because I have nothing to support him with.

CASEY GARTLAND: Sure. So your question is how would he go about reapplying, if he's eligible?

MARY GOLOUSKI: Right, and what other things could he get besides food stamps, could he get medical.

CARMEN BOUCHER: You can definitely call, and they'll be able to help you.

MARY GOLOUSKI: The social security department, or just go to the office?

CARMEN BOUCHER: Call the 270 number, the one I gave you, and discuss that. But, also, do know that someone mentioned in here for medical care, you know, there's the health centers will also, the hospitals, they have free care that you can definitely apply for.

MARY GOLOUSKI: I think he's just also depressed and not motivated to do this. I've always been a caregiver, and now I'm just --

CASEY GARTLAND: Sure.

MARYANNE NOLIN: They have social workers at the hospital to do everything. You have to be denied Medicaid sometimes for the programs. Every hospital is different, but.

MARY GOLOUSKI: That means having to go into the hospital. I just wonder if you walk to the social security --

MARYANNE NOLIN: The networks, like, Lifespan, you're covered under the Lifespan facilities. The copay is picked up. He doesn't have insurance.

MARY GOLOUSKI: We're living under the radar.

MARYANNE NOLIN: That's who to talk to. They have people right in the hospital in financial aid.

CARMEN BOUCHER: The health center, as well, they have social workers on staff for all that paperwork, as well. But, unfortunately, they have to apply, themselves.

MARYANNE NOLIN: Can they take it over the phone, applications over the phone?

CARMEN BOUCHER: Actually, DHS and all that, there's a lot of forms that are now by internet that you could fill out, as well.

MARYANNE NOLIN: Medication companies, and apply companies for medications, and get, you know, the actual company. You don't get generic, the real thing. The pharmacy will tell you what companies.

JUDI DREW: If you can see me afterwards, I have additional information I can share with you.

CASEY GARTLAND: Any other comments?

THE SPEAKER: How do we be informed of these -- is this every year you do the forums?

CASEY GARTLAND: Every year, actually, it's always the month of July. One thing that you might want to do, I'm not sure, Chris can help me with this, is it possible to be on the mailing list that Bob sends out?

CHRISTINE RANCOURT-BRUZZI: To get the --

CASEY GARTLAND: Anything coming out of the GCD.

CHRISTINE RANCOURT-BRUZZI: Look at the website.

CASEY GARTLAND: The Governor's Commission on Disabilities website.

THE SPEAKER: They haven't had that job fair in a few years, Rhodes, they had their own job fair for disabled people.

CHRISTINE RANCOURT-BRUZZI: I believe that grant has expired, so -- there was a job fair that Network Rhode Island is holding, October, Disability Awareness. So there is going to be a job fair coming up in October. I would contact Network Rhode Island to find out the details.

THE SPEAKER: Did they close the Pawtucket office?

JUDI DREW: Yes.

CASEY GARTLAND: We're all set. Thank you, very much, again, for those of you who did come in and speak. Thank you.

6. Friday, July 27, 2012 – Middletown Public Library

TIM FLYNN: I really want to thank everybody for coming. I really want to welcome you all. My name is Tim Flynn. We hold these forums so that our legislation committee can address and hopefully provide policy for the legislature and the governor to make policies for folks with disabilities to have better policies. Do you know where the rest rooms are? Men's room right here, and lady's room right there. There are really far away. (laughter) is there a public phone? No public phone. Sorry, you can't make any calls. I'm going to ask you to turn your phones off and put them on buzz so we don't interrupt the meeting. So, I'm going to read my preamble here, and then we'll get going. The purpose of these forums is to identify the concerns of people and their

families. In order to assist the state in developing programs to improve the quality of life for folks with disabilities. To ensure everyone who wants to speak gets a chance, keep your comments short and to the point. If you have a critical problem, the panel members will be available to you at the end of the meeting to direct you to the proper agency. After the forums are completed in early August, the sponsoring agencies will review testimony and prepare recommendations which will also be posted on our website by the end of November. The recommendations of the transcripts will be sent to the members of the General Assembly, and will help with issues for the next year or until they're accomplished. Voter registrars are available for anyone who is a citizen and not currently registered to vote where they live. People can file a change of address. You can, also try out the voting equipment. I don't know what that means, but I'm told I have to say that. I'd like to, now, if the panelists could introduce themselves.

MIKE MONTANARO: Mike Montanaro, Office of Rehab Services. And I'm the supervisor for the East Bay region.

JODI MERRYMAN: Jodi Merryman, I'm from the Division of Behavioral Health Care, and supervisor in the Behavior Management Unit.

ANNE MULREADY: Anne Mulready from the Rhode Island Disability Law Center, and I'm going to leave on the table over to the side, our own survey, which we do. We use this information, and also information from the public about what our priorities should be for legal work in the next year. If you feel like filling it out today, or taking it with you, thank you.

COLLEEN POLSELLI: Colleen Polselli, I'm from the Office of Special Health Care Needs at the Rhode Island Department of Health. And within our office is special needs for children and youth and the disability and health program. We oversee policy for the state.

MARY BETH STARRS: Mary Beth Starrs, and I'm the survivor of a traumatic brain injury, and representing the Brain injury Association.

JACK RINGLAND: Jack Ringland from the Rhode Island Statewide independent Living Counsel. We are kind of like a think tank in developing a state plan for independent living. We're developing a Needs Assessment Survey, which we took about a year and a half to fine tune. We're starting to get out the results of the survey. When adults with disabilities take it, it will be cleaned out and used to formulate, or help formulate the next state plan. I also have some giveaways out here, too, some buttons. The campaign we're promoting is called My Voice Counts, or My Voice Matters, so if you want to take a look at that, you may.

TIM FLYNN: Feel free to take whatever you need. I'd also like to introduce some staffers up at the committee. We have

CHRIS RANCOURT-BRUZZI: James, what's your last name?

JAMES LINCOLN: Lincoln.

TIM FLYNN: The legislative fellow for this summer. He's done a spectacular job. Fellow of the future is back there, Gabrielle. Welcome. Thanks for coming. So, what I'd like to do now is I'd like to, people have come in to sign in, and there are two people who want to speak. Senator Christopher Ottiavo.

SENATOR CHRISTOPHER OTTIAVO: Just don't call me late for dinner. I just want to say thank you very much for coming down. You did a great job advertising this through e-mails and the legislature to promote this. Thank you for your time. It's obviously very helpful to us in getting the information. Thank you for your time.

TIM FLYNN: You represent this district? If you have a problem in this area, that's your man right there. So what I'd like to do. The next person is Cheryl.

Accessibility: Chemical and/or Electromagnetic Sensitivities

CHERYL CROW: First, I'll take a moment to thank you and the panel and the MS Society for their mailed notice of this forum.

Housing: Chemical and/or Electromagnetic Sensitivities

This is helpful to persons without newspapers and internet. Secondly, kindly consider replacing your statement "please realize that what may seem to you may be a mild fragrance can be..." With a statement such as, "For the health and safety of all participants...", as the awareness of Asthma mainstreams. In Canada, where not a fragranced bathroom was found, kudos for their efforts. Where here with in-room Purell dispensers and electromagnetic triggers in the hospital. This, despite expert advisement seven years ago from the July 15th, 2005 indoor environmental quality report funded by the Access Board, "According to the Americans with Disability Act and other disability laws, public and commercial buildings are required to provide reasonable accommodations for those disabled by chemical and/or electromagnetic sensitivities. These experts explain that persons with chemical or electromagnetic sensitivities can experience reactions from exposure to extremely low levels of common chemicals, electromagnetic fields emitted by computers, cell phones, and other electrical equipment. They advise, "Measures taken to improve indoor environmental quality, such as reducing air pollution, noise, and electromagnetic fields in buildings will increase accessibility for people with Asthma and chemical and/or electromagnetic sensitivities, and provide a more healthful environment. The EPA notes there is a growing concern that standards by the Green Building Movement are not sufficiently protected for health. Finally, we have yet to see housing for this growing disabled community despite the National Council on Independent Living 2009, for requiring, at a minimum, two percent of all housing constructed or substantially renovated with federal funds to be fully accessible to persons with chemical and electromagnetic sensitivities. As a point of reference, they also call for two percent for sensory disabilities, and ten percent for mobility. The National Council for Independent Living called for homeless shelters to be accessible for persons with disabilities regardless of their disabilities. And persons with chemical and electromagnetic triggered disabilities tend to be chronic homeless due to this lack of housing for their disability. And who are the contact persons for the reasonable accommodation of motel vouchers until housing accessible to this disability is secured? Thank you.

TIM FLYNN: Thank you, Cheryl. I appreciate it. Any comments from the panel? I really have a question for you. You really have done a spectacular job in, sort of, the legislative solutions.

CHERYL CROW: You gave me my coaching to speak up and stand, and that was a long time ago, 2004.

TIM FLYNN: I think we could be doing a better job.

CHERYL CROW: The fellow secondhand smoke causing my problems through the walls of the duplex died of cancer. So, I was validated in my concerns I brought to you.

TIM FLYNN: I think what I'd like to ask you is, sort of, what are the impacts of, sort of, of chemicals on your day-to-day life? How are you affected in terms of -- I want to put a human face on this and understand, exactly. So, how does this disability affect your life?

CHERYL CROW: With botanical fragrances, I have no problem; however, today's fragrances are derived from petra chemicals. For example, from the hospital, from the sheets that they claim they're chemical free, the environmental committee said they're chemical free, this was a couple of weeks ago, I, my airway, my larynx and trachea poured out mucus and got inflamed. Obviously, if they close on you, you don't breathe. Because I have such difficulties with chemicals, the drugs they provide to the average person aren't available to me because they cause life threatening reactions. Just to use the example of the hospital bed, it was one big electromagnetic field. It had the power thing for something every time you moved, something shifted in the bed, it blew up some air or something so that you didn't get bed sores. It had the speakers for the television right there at your ears. It was all on a big power generation thing

right underneath my head. I got excruciating headaches. I spent the four days in the hospital trying to get as far away from that bed as I could. On a day-to-day basis, obviously I'm not going to isolate. I had a very significant fortune 500 career, which I miss terribly, but I like people, so I go out and get exposed to the common day fragrances and electromagnetic fields and have to spend several days in bed after exposure like that. I have no energy, no stamina, and I'm prone to getting irritant induced bronchitis, which can be threatening. So, it's not an easy disability to manage. Primarily because of the ignorance of the common person. If I could get somebody in this state to hear me after this decade that I've been crowing my words, we would have accessible housing for the handful of disabled people who can't function in the average housing situation. Something from the legislative aspect, this reactive fire law that came down as a result of the station fire, and they went in and they added an addendum to it saying that they could allow for wireless construction in the fire safety alarms makes all of the multi-unit housing that was barely accessible before completely inaccessible to me now. As a matter of fact, I fled under force. I was injured by the landlord who was trying to force me to get the wireless unit in the fire safety, in the fire alarm system in an apartment I was in for four years. The fire marshal was there, watched her injure me, and then I got "evicted" because I wouldn't comply. Even though the police officer that was there on several occasions said that you have to accommodate her disability and do a hard wired solution. So bottom line, there isn't anything that couldn't be accessible to me if people would stop being so damn stupid and arrogant and start listening.

TIM FLYNN: Any comments? Questions? I got more.

CHERYL CROW: I know, you always do, Tim. But thank you for not interrupting me and letting me talk.

TIM FLYNN: We want to address all issues surrounding MCS.

CHERYL CROW: First of all, I prefer you not call it that because of all the bias associated with it. I think the sources call it chemical sensitivities and electromagnetic sensitivities. The multiple is scientifically invalid, and brings it as not being truly a physical disability.

TIM FLYNN: But my question really is if we were to create a legislative initiative, and I mean we understand that total environment is important to address, but within the total environment are there priorities that you think are more or less important than others? Is it housing? Would that be more important.

CHERYL CROW: Housing is critical. That's the only place that you have to go and restore and repair. And it needs to be informed by the people like myself that are well, well versed on this. Not only from their personal experience, but because of their executive background.

Housing: Chemical and/or
Electromagnetic Sensitivities

TIM FLYNN: So you're an expert in this?

CHERYL CROW: I'd have to be, or I wouldn't be alive today.

TIM FLYNN: What are the numbers in terms of population in terms of folks, do we know or?

CHERYL CROW: I would say that now that articles are appearing regularly in the women's magazine, that the numbers are huge. They're really, really large. As far as people that are disabled by it, that have to truly manage their circumstances as myself, those are less, and those should be the priority for people who have the appropriate accessible housing.

TIM FLYNN: Questions anybody? Comments?

MARY BETH STARRS: Comment, I think. We really don't know how many people are affected, just in their private life, right? I've had, I, personally, had a severe adverse chemical reaction to chemicals in a school. I was a teacher in Middletown, and permanent markers, you

know, they're extremely toxic, and we had been using, we were supposed to have been using just the green cleaning products, and somebody used 401 or Fantastic, I had no idea I was going to have anything like that. It just happened all of a sudden. That was a -- it got so bad I'd break out in hives, couldn't breathe, I had to leave the building. But that was dealt with kind of in-house. Permanent markers were banned from the school, and so that was dealt with. So, are you thinking that this effects everybody in our public buildings, also?

CHERYL CROW: Absolutely. There's no question about it. I mean, I can go into bed and bath, which I don't normally do because there are so many candles and products. And I had the conversation with the sales rep and said I don't shop here because of the chemicals and he said you know, I get such a headache from them, too. So, I think it's a matter of information. People are evolving and learning more about it. You are fortunate where you have people who were intelligent enough to accommodate you, versus my former landlord who injured me. I have now a permanent back and neck and sciatic injury from her doing this to me. Well, I think the quote that I gave on, from the access board funded report according to the Americans with Disability Act and other laws, public and commercial buildings are required by law to provide reasonable accommodations for those disabled by chemical and electromagnetic sensitivities. That was written in 2005. Obviously, you were fortunate. Two weeks ago I was in the hospital. I had to be released two days before I was supposed to be released because it wasn't accessible to me. And they claimed that their environmental, whomever it is, committee, whatever it is, claim there was no chemicals in that laundry. Give me a break. My airways don't inflame like that in a matter of seconds if there's no irritants involved.

TIM FLYNN: Thank you very much.

CHERYL CROW: No more questions, Tim? Disappointment.

TIM FLYNN: Thank you so much. Once again. Well, that's sort of. No one else has signed up to speak, and so what I'd like to do is, does anybody have anything to say in the audience at all now that we have time? Well, no. Rhode Islanders are silent? Come on, guys. Please. That would be fine. Great. Turn it over from here.

JACK RINGLAND: I'm Jack Ringland from Rhode Island State Independent Living Counsel. As I kind of briefly said before, we have a subcommittee called the KAC that has been for over a year and a half that developed a Needs Assessment Survey, and we realize we don't address everything, and it's ever changing, so as we see new concerns pop up, we'll add it to the survey. The survey is designed to be taken by people with disabilities or their caregivers in instances that maybe they cannot communicate fully or need help or whatever. We do allow that, but we're trying as much as possible to make sure we get just the people with the disabilities. The best way that I can say as far as taking the survey is that you could go onto our website, or you can telephone us. If you go onto our website, you'll find the survey. And please take a copy and even a button or two. I have buttons that I keep with me all the time, and when I see somebody that's obviously disabled, I will pass them a button or something like that and say if you'd like your disability issues to be addressed, please go on and take this survey. Anyhow, if you go onto the Rhode Island Statewide Independent Living, which is the www.RISILC.org, immediately what pops up is the Needs Assessment Survey. And it pops up in several different venues, you can take it in English or Spanish or Portuguese. You can take it in sign. You can do it in, we have large print, we have what else, what did I miss? Graphic. So --

TIM FLYNN: I'm hearing universal accessibility.

JACK RINGLAND: We've taken a lot of time to address individuals to get it up. When you take the survey the results are confidential. And I should add that if you don't have computer access, you can telephone. You can either do the whole survey over the phone, or we'd be happy

to send it to you, along with a stamped, self-addressed envelope, and there's actually two in there. One you put the survey in and mail it back to us. The second envelope, you record your name and contact information and so forth, and return it in an envelope, and that envelope, the name gets entered in a drawing which every quarter we draw, one lucky individual gets a gift card, so it's a little extra incentive to take the survey. The results get compiled, and beginning later on this year and next year we will be using them to add into the state plan. So, by all means, please fill out the information. We know that we haven't addressed everything, but we did the best that we could. By the way, this is a survey that is developed by people with disabilities, and again, it's for people with disabilities. The Independent Living Counsel is made up of between 13 and 25 individuals of which more than half have to be with disabilities, and we do a pretty good job. We have a pretty good cross-section. We have traumatic brain injury, we have MS, we have CP, physical, I have a spinal cord injury myself. Blind. We have hearing impaired. Mental health issues. Those are just the ones that I know of that people have shared their information. You're not obligated to share information as to what your disability is, and by the way, we're looking for a few good individuals, so if you're interested in becoming a member of the counsel, please, by all means, same sort of thing, take one of these, you'll see the website, you can contact us by telephone.

TIM FLYNN: If you know someone who might be interested.

JACK RINGLAND: Yes.

TIM FLYNN: I'd just like to add, the Statewide Independent Living Counsel is responsible for the Statewide Independent Living Plan. Maybe you want to talk about what that is?

JACK RINGLAND: It's kind of a blueprint, and sets goals and standards and so forth for the independent living centers. ORS is involved with us, of course, us. And then when this plan gets compiled and agreed upon by all parties involved, it gets submitted to the RSA.

TIM FLYNN: Rehab Services Administration.

JACK RINGLAND: And they look it over and tell us whether we're on the right track or have to go back to the drawing board. Then the monies get released and so forth, and they're administered by ORS, and that's how the independent living centers operate and we get our budget from that. And then we go back and work on the surveys again. We're also, besides the disabled venues and so forth, we're trying to work some public venues. So far, as I live in the East Bay, I have a few public venues that will probably be coming up next year, what is it, the Road to Recovery, the one in September?

FEMALE SPEAKER: Rally for Recovery.

JACK RINGLAND: Rally for Recovery. That's Waterfire up in Providence, we're going to have a group there. I have a couple places, you know, in Warren just got done having their Quahog fest. We're pretty positive we can setup there. Bristol, Rhode Island just got done with their independence, two weeks, next year we can setup there. My feeling, and the feeling shared by a number of people, there are an unknown number of people in Rhode Island that don't have any idea where they can go for some of the services, and where to even start, so we're hoping to give a start. We're also leaving it open, and at this point I don't really see a problem with it, if somebody were to want to join with us at some of these things.

DIANA KRINER: You must have been channeling me. Diana, I work with youth age 14 to 27, I'd love to have a conversation with you as to how we can get that information.

JACK RINGLAND: Certainly. And also, I might add that people that are here that are representing organizations, we are more than willing to come out and do a presentation. We've done a presentation for the MS Society and a couple of other places, and we're more than willing

to come out and do them. We have a nice little Power Point presentation, and so forth that goes with it and explains a lot more. So I guess if you have questions –

CHERYL CROW: I have a question for you. Since the GCD did a special forum in 2005 for

Human Services: Chemical and/or Electromagnetic Sensitivities

persons effected by chemicals, by household chemicals, and the forum was filled to capacity, and I know Chris was the chairperson of that, it was at the American Lung Association, so obviously the people's needs were being very, very vocalized since 2005, at least.

I haven't heard anything that's happened in the state to address this disability population's very serious needs. Have you had any experience or –

JACK RINGLAND: I have not, personally. We do have a person that is a member of the counsel that, I believe, has the concerns of the environmental –

CHERYL CROW: Are you able to share that person's name?

JACK RINGLAND: I don't know. I don't know whether, you know, she was, she's been around for quite some time. She was a member of the disability vote project, stuff like that, and that's all that I really can say without her permission. I'm sorry, but I wish I could do more, you know.

LISEL ROCKWOOD: I believe we have two or three at different levels.

JACK RINGLAND: Lisel here is the program assistant.

TIM FLYNN: Would there be somewhere that she could follow up, could they follow up with you guys? You could probably follow up later on at some point next week, maybe.

CHERYL CROW: Do you have a card? Okay. Thank you.

ANNETTE BOURBONNIERE: Something different. I know there was legislation.

TIM FLYNN: Always something different with you.

Accessibility: State Buildings

ANNETTE BOURBONNIERE: No, but we had legislation that was introduced last year, and I don't know what the status was but that state buildings it was to have state buildings to become accessible. One of the reasons I'm especially concerned about this is CCRI in Newport, brand new building, built way after the ADA was enacted. The bathrooms are not accessible, they call them accessible, but you can't turn the wheelchair in the bathrooms. This is the State of Rhode Island. I don't know about the other buildings, I know there is certainly a lot of access problems at URI.

Accessibility: Bathrooms

TIM FLYNN: I think it's fair to say we've done a statewide assessment of all state facilities and the access problems that exist there we could probably list, we've actually had architects working on several different solutions. I think the grand total came out to somewhere in the area of about \$28 million. The total cost is even greater. So your question is what happened last year?

ANNETTE BOURBONNIERE: What happened to the legislation?

TIM FLYNN: Budget happened. What we can do is we can compile a list of where the problems exist: State buildings, universities, colleges, recreational facilities, the DEM. So the list is there. We know where the problems are. And you know, what we do is we can submit them to the governor for his budget, and you know, in tight times like these, stuff doesn't get done.

ANNETTE BOURBONNIERE: Who is making sure that they don't continue to create such problems? There's really no reason that that should be inaccessible.

TIM FLYNN: That surprises me. We usually review plans for all public buildings.

ANNETTE BOURBONNIERE: It surprised me, too.

TIM FLYNN: Maybe we could talk about it after.

JACK RINGLAND: Tim, I have one. I don't know how many organizations of you use the Crown Plaza for events. We were there at the conference this spring, and you

Accessibility: Bathrooms

Accessibility: Parking Lot

know their bathrooms aren't very accessible? I got into one, could not turn around, but fortunately I transfer easily, so I was able to use the bathroom. One of our, at least one of our people went to use the bathroom, and she couldn't get into the "handicapped" stall with her chair, ended up by struggling to transfer herself and had to leave the door open with the chair in the door. We, as a counsel, wrote a letter to Crown Plaza, made it nice and so forth. We had some other issues. Can't get a Ride bus under some of the canopies for instance, so they would have to leave people out in the parking lot and negotiate across the parking lot and road ways where people are driving. And some people have no idea about a wheelchair. The other thing was the closest parking spaces to the entrance were for able bodied people and the fourth thing we had was one of our girls in a power chair almost had a disaster. She went out the door and everything. She didn't realize that there was a curb straight ahead. The cut was offset, and she almost went over. In fact, I guess she nearly went over, and there happened to be a couple workers outside, saw her, and helped her back up. For the number of things that Crown Plaza does, you would think the place would be accessible.

ANNETTE BOURBONNIERE: This is state buildings. URI just recently extended a sidewalk in front of the building that I'm in, and they extended the sidewalk to the curb. So the only way on and off this sidewalk is this one place so if you're going any place, you're rolling in the street. Again, they extended the sidewalk, and you think they would have put a curb cut there so people could get on and off, but you try and you have that same disaster. These are state buildings where it's going to cost money to fix, so why don't they do it right in the first place.

Accessibility:
Sidewalk

JACK RINGLAND: Something about state.

ANNETTE BOURBONNIERE: Go ahead.

TIM FLYNN: I think you should go in the audience.

JACK RINGLAND: It's state, it's probably well known that Hope Street in Bristol is undergoing construction by the State of Rhode Island, new curb cuts and so on. Since they have done this, and everything, I frequent the downtown and some areas quite frequently, I have been flipped in my chair from going off a curb cut and then coming to a screeching halt by something being uneven. I consider myself being a person who gets around very well in my manual chair, and I have fallen at least three times.

Accessibility:
Curb Cuts

TIM FLYNN: Last year in the legislative session, the legislature in its wisdom.

ANNETTE BOURBONNIERE: Is that in quotes?

TIM FLYNN: Since Senator Christopher Ottiavo is here we're going to say it's not in quotes. There was a big influx of construction happening. If you're fixing any sort of road way, building, any new sidewalks, what happened was we got a lot of complaints about new projects that would be beautiful, accessible, fix a road, and at the point when the project stops, they put a nice curb cut and crosswalk, didn't put a curb cut on the other side. So we got legislation passed saying putting in a curb cut you have to make sure there's a curb cut on the other side so that folks can get off the street. You would think it's -

ANNETTE BOURBONNIERE: You would think it would be logical.

TIM FLYNN: Planners and architects all say, "I know how to do it. We'll take care of it," and when push comes to shove, need a foot here and foot there in the plans, who gets the shaft, or who gets compromised? And it would be that extra foot in the handicapped stall to be able to turn all the way around, that's sometimes what happens, I'm not excusing it.

ANNETTE BOURBONNIERE: It's downright illegal. And then they will turn around and play the budget game as far as fixing what they messed up, which is not right. That's what they

do to us all along. Have unrealistic policies that cost a lot of money, and then they cut services instead of looking at policy. It makes no sense. But I don't know how to get that changed. Do you?

TIM FLYNN: You know –

ANNETTE BOURBONNIERE: I want the answer from you.

TIM FLYNN: I've been Chairman of the Commission for three -- I'm still figuring it out. It's difficult. A lot of times priorities shift and certainly, recently budget roles are a serious issue. Sometimes we'd like to get on top of the priority list, we're just not there.

ANNETTE BOURBONNIERE: If they were more realistic in their policies, their costs wouldn't be so high and they could continue to provide the services and provide a better quality of life.

TIM FLYNN: You're absolutely right, it's better to get it right the first time. We make that point all the time. Sometimes it gets listened to, sometimes it doesn't.

ANNETTE BOURBONNIERE: Maybe our senator here is hearing us.

TIM FLYNN: I think so.

ANNE MULREADY: I don't think cost is a defense to new construction.

TIM FLYNN: And that's coming from the Rhode Island Disability Law Center, so don't mess with them. Anybody else like to speak or comment? I think what I will do now is I will adjourn this for about 15 minutes, we'll see if anybody else comes in and wants to testify. But I really, before we go I want to thank you all for coming. These forums are really, you know, one of the reasons we exist and do what we do, and they are very hopeful in helping formulate policy. I want to thank our panelists coming down here on Friday. Might have had other things to do. I appreciate you coming down and I appreciate your dedication to our cause and this cause. With that, why don't we take a break for about 15 minutes. Thank you.

TIM FLYNN: Call the meeting back to order. Thank you very much. We had a new arrival. Who showed up recently? All eyes on you. You didn't want to testify?

AUDIENCE MEMBER: No.

TIM FLYNN: You sure?

AUDIENCE MEMBER: Positive.

FEMALE SPEAKER: We'd like to hear from you.

TIM FLYNN: We've had 15 minutes. I'm wondering if anybody has had any brain storms, ideas of anything they want to speak about. Any of the panelists have anything they want to talk about, address? Thanks folks. We are back in -- what am I calling this? Recess.

JACK RINGLAND: Recess or adjournment?

TIM FLYNN: We are not adjourning. We have to stay here until five to five. So we will probably, we will adjourn at quarter of.

CHERYL CROW: Could we use the time constructively to hear some more about what the different organizations do or are doing or have done or progress?

TIM FLYNN: That's generally not the protocol we follow. I certainly don't have any objection if anybody would like to speak briefly.

MARY BETH STARRS: I could speak about some of the things that have happened at the Brain injury Association of Rhode Island from a participants point of view. We have a support group that meets once a month. It's wonderful, and we also, I was a member of the, a participant of the first photo voice project that occurred, and that's a wonderful way for somebody who has a brain injury to express to people who don't have a brain injury what it's like. And they have other groups doing it. I think it's like once a year they do it. And they've also had the same type of thing happen for Veterans coming back from overseas. It really is a photo journey of -- like I had a ruptured brain aneurysm and three other brain aneurysms that had to be clipped. I had to get

permission from Channel 10 news because I wanted to -- I don't know what the words are now, I wanted to use the blowing up of the Jamestown bridge to -- like an analogy, does that make sense.

JACK RINGLAND: A metaphor? An example?

MARY BETH STARRS: Because it ruptured. I used all those photos and did a narrative, and it was so healing to me. We put them on display at the -- there was a library in which, it was in the Warwick library. It's just a really good place to be. If you know anybody with a brain injury, there's loads of resources. The people who work there Elizabeth and Lisa and I forgot the other woman's name, they're really nice, and there's really a lot of information that people could use whether you have a brain injury or not. There, I took up some time, right.

TIM FLYNN: The Brain Injury Association.

MARY BETH STARRS: In Cranston.

TIM FLYNN: Are you thinking about Sharon?

MARY BETH STARRS: Sharon's one of them.

TIM FLYNN: Anybody else?

MIKE MONTANARO: I could talk a little bit about ORS. We are an agency that focuses strictly on employment. We work with individuals with disabilities on helping them to obtain or maintain employment. We don't have any age limit or requirement as far as you know who works with our program. We actually have counselors that cover every high school throughout the state, also, so we do a lot of work with high school students in helping them to research their interests and abilities and getting them to look at post, after high school. Try to kind of have a service plan setup for them so when they get out of school, they know the direction to head into. We don't have restrictions on how many times you can come through the program, which is something I like to mention. Sometimes a lot of programs, they give you that one shot and that's it. Our program it's very common for people to come into the program, and then maybe something, you know they might be hospitalized, something happens, put things on cold, might even close the case out, and when they're ready, when things are better they can come back and reapply. We have an eligibility process that a counselor would have to go through who applies for our services. We need to get releases and obtain information regarding the disability, and the counselor has, you know, steps they have to go through to determine a person's eligibility. We have an order of selection right now, which is a fancy word for waiting list. However, we've been able to recently start pulling off of that waiting list, so it's -- it is but it isn't -- we have been widdling away at the list. It's almost nonexistent. We have three categories we break it down to when we talk about eligibility. Category one, most severe disability; category two, most disabilities; and category three, everybody else. At one time we were taking a lot of referrals and we were only servicing category one. If you were category two, you would be put on that waiting list. You would be notified from the counselor assigned. You're still an open case, still found eligibility, just we weren't able to work with you immediately. Like I said, we've been taking people off of that list pretty consistently. We're almost off of it now. Not too much of an issue, we have to make people aware of it because it is a possibility. Like I said earlier, employment is the main focus. A person that wants to work. A person has to be able to benefit from the services at the time we're working with them. And a person has a right to choose their goals, the services they get, and the providers they work with. How that happens is a counselor and the customer would get together and after some evaluation or assessment, we get together and together we develop an unemployment plan, and the plan isn't signed or in process until both parties agree, so both people have to agree it, be happy with it, sign off on it, and then we'd move forward in getting the services. When I say you have the ability to choose the goal, service, and providers,

you do, and that's something worked out together with the counselor. We're regionalized. I'm the supervisor of the east bay region, East Providence all the way to Newport, but we're throughout the state. We have supervisors in regions that cover the whole state. Depending on where you live, your application will be sent to the supervisor of the appropriate region and assign it to the counselor who is up for that rotation. A lot of people, transportation is an issue. Especially now with RIPTA, I know Tiverton has one bus route, and it's a dialysis route. We're not going to expect somebody in Tiverton to get to Providence for services day after day. What we've been doing, our region, we've been try to go get more service providers, options, choices, and agencies we've had success with. One example is called work opportunities unlimited. We've been able to get them to assign some of the worker toss the east bay area. It's been working out pretty well we take into account transportation. Like I said, our counselors are very mobile. Our home base, basically if you want to call it, our home office is Providence. Every counselor, no matter what area is Providence, doesn't mean we require people to have to go to Providence. We utilize the community. We have an office at the Newport hospital. A counselor is there two sometimes three times a week. We really do try to be community based. Places like the libraries or anywhere else we can find that we can have a confidential place to sit and talk to people so they're not going to go down to Providence and waste half the way for an hour meeting. We're also trying, we're going to start up, we're try to go identify a place. Believe it or not we've had a little bit of a lull in referrals, so we're trying to increase that. We're trying to identify areas or places in the community, especially Bristol-Warren and go twice a year and give an orientation for anybody who wants to hear about the program and get information. So we're try to go do that to get the word out there. Especially in that area it seems to have slowed down. We have a very strong connection with the network in Warren, which was great. A lot of referrals, it was a meeting place, a really good place for us. When they closed that office, it almost seems like the people there thought we closed down because it really kind of dried up as far as that area for the adults. Students we have somebody who goes to the high schools, plenty of referrals for them, but the adult population, there's a very minimal compared to what we used to get. We're trying to do that. Hopefully we're going to be able to identify an office, building, somewhere, like I said at least twice a year. Because we do have orientations we run now, but for this year, the Network RI, the ones that are left, we'll do them there. We have an orientation once a month we hold in our office in Providence. Usually the first Tuesday of every month at ten a.m. We're trying to get that out into the community so it's a little bit more convenient for people to get to. The easiest way to explain our program is employment. Look at goals, we do assessments and evaluations to help identify interest, abilities, areas of difficulty and try to find the job that matches that person's area of interest and ability. And look at are there accommodations on a jobsite or a person's job that they could use. To help them keep the job, sometimes we work with individuals who have jobs and it's causing disability and go to the jobsite and provide accommodations to help with that. We have training which include short-term training programs, furthering your education. Again, that's something that's discussed and determines between the assigned counselor and customer. And if they agree, it's something we put on a plan. We would always, we're subject to financial aid, so a person would have to complete financial aid requirements. We go past. If you're eligibility, we have to take it into account and look at what is left, what remaining portion is left to go to school and there's a possibility -- we can't go above and beyond financial aid. If a person is eligibility, they have to utilize that, too. Our program is a little under 80 percent funded. As a matter of fact we, not too long ago, had the federal government came on a week-long visit to go over what they liked, what they didn't. They'll pick random files and audit them and say we need to change this, this is good. There's a process when you talk about sending

someone to school, or we call it training, there's a process we have to go through before that can be approved. It has to be on the plan, the goal, the financial aid has to be completed. We have a form we send to the financial aid office of the school you'll go to and they'll itemize expenses and show us award money, grants, scholarships, whatever, and we have to subtract that award money from the cost and look at what portion is left over. That's something a counselor, if that's something that is part of the plan, the counselor would definitely sit down with the person and go over that step by step and show you what you need to do to achieve that. We have incentives for employees, too. We have on the job training, or OJT, which is something that we offer if an employer really seems interested in hiring someone but has a concern that there's a part of the job that they think that person may need extra training on, we can offer them OJT which we pay for the first month or two, half their salary, and a lot of times that's just an incentive to hire that person, rather than hiring somebody else and giving them the full salary, that way they're more willing to give that extra time at the beginning. Where as they were paying full salary, they may not want to spend that extra salary. If they know they have to pay half, they may be more willing to work with you more at the beginning. A lot of services are time limited. OJT is usually a first month or two. We also, sometimes we're almost a bridge to get involved with someone younger, kind of assess the situation, setup the services. Like job coaching, we can also do that. But it's time limited. Sometimes we'll have a situation where a person has eligibility for Jodi's program, we may start out, and they pick it up on a long-term basis. We have a lot of mutual -- we meet together with the client so they know what we've been doing, so they know what's ahead of them and set it up. One thing I like to also mention is it's a very flexible individualized program. It's not, we don't have set plans where you know we have three set plans and try to fit you in the one that best fits you. Every plan is custom to the person's needs. Like I said, people always want to say give me a list of services you offer and what I say is not really, I can tell you the most common services and the basic ones we do offer, but a lot of times we'll sit down and something will come up, and if it's related obtaining or maintaining that job, we have to look at it and see if it's something we can do. So, someone's plan could be the only person who has that service, because it's particular to their situation. So it is a very flexible, like I said individualized program. It makes it a little difficult to explain because it's not set in black and white. We do have a lot of situations where a counselor might feel very strongly about a particular service or accommodation or something for a client and come to a supervisor and convince the supervisor that something needs to be done and they need to go to the deputy administrator of the program and in a sense argue their case. We can get administrative approvals for certain things. It's very flexible, individualized, and you work very closely with the counselor assigned to you to work on those things and figure out the best course of services for you to reach that goal. The plan can be amended also, and that's the other positive feature of the program. You can write a plan, have it, something happens in the middle of working towards the plan and there could be circumstances to cause to you want to change the goal, we have the ability to amend plans when we need to. You get together with the counselor, go over the change so you have the new plan that would have the new goal with the new services to help you reach that goal. It would be like starting over again. So, that's another kind of flexible part of that program. That's about it.

TIM FLYNN: Thanks, Mike.

COLLEEN POLSELLI: Do you work with all ages?

MIKE MONTANARO: I've noticed, I don't know if other supervisors have, I noticed that there's definitely an increase in age of applicants. I think there's a lot of individuals who maybe have retired and are finding out they can't survive and want work and have a disability. Or very limited income or fixed income and feel like they need more, not making it, so they're applying

and want to go back to work. We don't have an age limit. If somebody comes in and 65, we don't say no.

COLLEEN POLSELLI: Under 18?

MIKE MONTANARO: We do. Ideally we like to start with a student, we usually don't like to start before tenth grade. They're changing their minds so much, we would be doing it every year. We have a benchmark of a person's, junior year, do all the assessment in that year so when senior year comes, we have a good idea of what they're looking at and have a plan in place. What we do with the students is, the plan is more of a research evaluation, try to increase work experience through summer work programs and what we call situational assessments, trial work, try a job out for five or ten days to see if you look it, how you do and we get reports back on how you did or how we can help you. Students more focused at researching interest, really seeing what the physical requirements of that job are.

TIM FLYNN: I want to. We have, I think it's safe to say that if we have a lot of agencies here who deal with clients from east bay. Mike's the guy you want to deal with. I've worked with him before, he's excellent. I guess, Gloria Johnson has arrived. We are all ears.

GLORIA JOHNSON: Is this formal?

TIM FLYNN: Just get up and state your name, and we can proceed.

GLORIA JOHNSON: My name is Gloria Johnson. I'm a disabled Rhode Island resident. I'm here on behalf of myself and my children. We were not disabled prior to going through family

Human Services:
Family Court

court. There's this thing that in the family courts that they're doing is Parental Alienation Syndrome. And I'll just read you, and it's not billable, parental -- it's not a syndrome, it's for pedophile -- the doctors say -- like

Penn State -- and all of the officials that hid these people making kids and women disabled. I was court ordered into this -- it's called PAS -- by Judge Shorecross in Wakefield. First, I had a restraining order. My ex-husband had to be taken out of the house because he was going to kill us. He had to turn in his weapons. We had to go out of the house, and he had to turn his weapons into the South Kingstown Police Department. Shortly thereafter, I went, and was granted a restraining order. I guess my husband, my ex-husband had enough money, he was the one that sexually assaulted my children. I just want to read you something first. This was a report that was drafted by the Major Crimes Squad of Connecticut. (READING)

TIM FLYNN: We are under time constraints. We have to be out of this room in five minutes.

GLORIA JOHNSON: Well, the logistics are I was sexually assaulted, my kids were. The major crime squad in Connecticut did a report. State of Rhode Island wouldn't look at it. This is a major crimes squad in Connecticut. They put us into these court ordered reunification visits with our sex offender, and if we did not attend those sessions, I was going to be sanctioned. They're putting women in jail. I have PTSD, complex form. My daughter was institutionalized. She was a National Honor Society student. She came out of Bradley on Seraquil, liquid Valium, and they continued and continued to torment us. \$225 thousand later, I, all three of us have post-traumatic stress. The Office of Rehabilitation for the State of Rhode Island is now paying to rehabilitate us. I lost two jobs because of this. Peter Kosseff, the doctor that practices this type of therapy. I have an audio recording with my daughter 48 times begs -- the major crimes said if they don't believe you, you have to put a tape recorder on her -- she begged 48 times in that recording. The next day, Dr. Murray said you have to go to the hospital. It was like she had a traumatic brain injury. All of us are now disabled. There would have been many women here this evening, but they're too afraid to come forward.

TIM FLYNN: The problem is that it's the visits with the abusive husband.

GLORIA JOHNSON: He sexually assaulted all of us.

TIM FLYNN: What is, from a rules or a legislate –

GLORIA JOHNSON: We were not disabled prior to this.

TIM FLYNN: I get that, but what can we do as a –

GLORIA JOHNSON: Obviously nothing now, it's already been done. I go to the community college right now. My daughter, because I had to take her out of South Kingstown High School because of all the trauma, police showing up, drugs, alcohol, and chairs flying in public school, the quick jerks and movements, she was a D and F student. I took it upon myself to put her into CCRI her senior year in high school. She graduated four weeks ago with 27 college credits and a high school diploma. But I'm saying this should have never happened. The State of Rhode Island, the family courts are making people disabled.

TIM FLYNN: Because they –

GLORIA JOHNSON: We didn't have any ADA advocates there.

TIM FLYNN: What was -- I'm just trying to get a grip on what caused the disability. The visits with your ex-husband; is that the problem?

GLORIA JOHNSON: With the kids and I, yes.

TIM FLYNN: So, the Rhode Island court system making you and your children visit, contact your ex-husband, and because that happened, disability arose.

GLORIA JOHNSON: Post-traumatic Stress is an invisible disability.

TIM FLYNN: It's still a disability. So you would like to see –

GLORIA JOHNSON: It stopped.

TIM FLYNN: If the required visits with a former abuser, with an abuser, you don't think that they need to be.

GLORIA JOHNSON: No. Not only that, but –

TIM FLYNN: They should be discontinued. Now, would this be in all cases or in some cases or -- I'm just trying to understand what the best approach here is and what you think.

GLORIA JOHNSON: This type of threat therapy is like going from the trauma in their house right to the trauma again, and the State of Rhode Island Bar Association is trained in it. The Department of Health and Human Services, social services has been trained in it. Lawyers advocating for that. And the number one thing is I'm a medical biller and coder by back background. This is not a billable code. They're taking my son, diagnosing him with anxiety, shooting it off to Blue Cross, getting paid \$120 on a visit, but doing this. It's like operating on one arm and doing another procedure on the other, so it's fraud.

TIM FLYNN: Do the panelists have any questions?

ANNE MULREADY: What did you say the name of the therapy was that you were concerned about?

GLORIA JOHNSON: Well, I can give it to you. Can I come up?

COLLEEN POLSELLI: Parental Alienation Syndrome.

GLORIA JOHNSON: It's like saying to the Penn State victims, let's reunify you now. Family therapy, Parental Alienation Syndrome.

AUDIENCE MEMBER: Are they still making you go to this?

GLORIA JOHNSON: No. People who have left the state because of it.

TIM FLYNN: Any other questions?

ANNE MULREADY: No. That was it.

AUDIENCE MEMBER: I was just wondering with the sexual assault, were the children evaluated? Was it proven?

GLORIA JOHNSON: Yes, it was. She disclosed many times, and what the doctor didn't show to the judge and perjured himself were the medical records.

TIM FLYNN: I really want to thank you. It took a lot of courage to come here and talk about this.

GLORIA JOHNSON: I speak for the people who don't have a voice.

TIM FLYNN: We have full admiration for you doing that. Any other questions? Well, thank you very much. With that, I'm going to close this session. We are adjourned. I really want to thank everybody for coming and participating. I want to thank our panelists. I want to thank the court reporter.

7. Correspondence



Cross Disability Coalition
AN INITIATIVE OF THE RHODE ISLAND DEVELOPMENTAL DISABILITIES COUNCIL

Testimony For Governor's Commission On Disabilities Public Forum

On behalf of the Cross Disability Coalition, we Christina Battista and Tanja Blicher-Ucran, co-coordinators, would like to express some of the concerns of our members.

The Coalition is for individuals with all disabilities to connect and talk about what is important in our lives and what we can do together to improve quality for all people! It is also an opportunity to become familiar with different services available from agencies in Rhode Island and learn what these agencies can do to support and meet the needs of individuals. Our priority issues are: **safe affordable housing, employment, transportation, and budget cuts**. These issues have been identified by our members and they would like to see some of these issues resolved.

Due to the lack of Section 8 vouchers, individuals have come up with a possible solution to reduce the waiting lists. Many abandoned properties along with old mill buildings could be renovated into low income housing. The result would be more safe, affordable housing for people with disabilities, the waiting lists for Section 8 would decrease, and Rhode Island will profit by rehabbing vacant housing and with property taxes..

Housing:
Affordable

Our next area of concern is employment. People with disabilities are just as valuable as anyone else in society, and unfortunately these people are not being utilized to their fullest potential. Employers should be aware of the number of people that could fit into the many positions that they are trying to fill, if only they would consider people with disabilities. Our members understand the fears that employers may have, but maybe individuals with disabilities could conduct a training for employers on hiring people with disabilities. Therefore, employers could hear directly from potential employees with disabilities. Our members want to be able to advance in either their current job or change to a

Employment:
Opportunities

better paying job. Also, a recommendation made by our members is to have resources that are in simple language accompanied by attractive graphics.

Transportation has always been a barrier for people with disabilities. Our members are very pleased that Rhode Island now has accessible taxi cabs. Despite this

Transportation:
Accessible Taxis

accomplishment, we still have a long way to go. Fares for the use of accessible taxi cabs and the use of the RIdE Program should be revised in order for individuals to continue with the use of these services. A possible solution to this issue is setting up bulk passes or creating some sort of billing system that would allow for people to pay for the service at a later time. Thus, allowing individuals to still use the services and have the flexibility to go where they want and not worry how they are going to pay for it at that time.

Transportation:
RIdE

Rhode Island continues to face budget difficulties that impacts the lives of people with disabilities. Members are afraid of losing their staff, the place where they live, and fear of the unknown. It would be beneficial if Rhode Island would consider establishing an Individual Development Account (IDA) program so people with disabilities can improve their financial futures.

Thank you for allowing us to express our concerns on the issues we feel very strongly about.

Respectfully Submitted,

Christina Battista
Co-Coordinator

Tanja Blicher-Ucran
Co-Coordinator

cc: Executive Committee
Mary Okero

Sheldon Whitehouse
170 Westminster Street
Providence, RI 02908

Dear Senator ,

I write today, as a follow up, to a meeting I had with Mr. Toni Simon. At his request I have compiled these issues for your review. It is my hopes to prevent another tragedy from occurring in our immigration system. It came to my attention, you were working on this legislation, so please consider my position.

I also have to fit this last 8 years of my life into a one page statement, so forgive me if it is rather rushed.

The poorest of the poor, are the wickedest of men. Desperate for a place to sleep and food to eat, they will say and do **ANYTHING** they can, if they see a way out. But the problem is that, once they learn it, they tell others, and form groups from their own country, and help each other with loop holes in our immigration ,and legal system, that permanently damage our law abiding American citizens. It is this hope to protect our citizens from harm that I offer this information to you.

In order to commit this act, one needs a willing participant...namely, an American Citizen. And usually the person fits the profile. Honest, God fearing, forgiving, Christian (or very religious) usually they have traveled to the country of the immigrant, and have a giving heart, and always

lives on the up and up. Law abiding citizens who have done good their whole life, are used, abused, and reused. People who follow the law and even help change it, to make it better, are being ignored over the rights of the immigrant. Every tiniest of lies are believed to be truth. They form these groups, and use each other as witnesses in court. They have no problem lying to police, filing false police reports, using falsified documents as entered into a court of law, or worse.

They are predators who study the American and find the one thing to accuse them of that will cause the most damage. They play off those fears and then use them against the citizen to get whatever they want. It is so easy to accuse the American of being crazy, after all, if they don't research correctly, they will find the thing that makes the American have the most damage mentally, and use it.

Whenever they get away with it, they rejoice. It adds an element of entitlement, and strengthens their circle, to be able to con other Americans, and advise others immigrants here, how to do the same.

Mine had me committed, and investigated for sexually abusing a child, I lost my ability to work with children, I now have a record. I was found guilty on Friday, of spitting at him, and now I must go to domestic violence classes. It's not bad enough to be abused for over 8 years, but to have overwhelming evidence against the immigrant isn't enough. All they have to do is cry abuse. The children are handed over to DCYF. The state takes financial care of the entire event. The biological father wants nothing to do with the child after years of planning with the citizen to bring his child here, to live like a family "like he always wanted to", when in fact he uses the child as a deal breaker to attract other potential victims.

You know, it is rather brilliant. As an immigrant in this particular situation did, he did exactly what his friends, that he secretly lived with for over 3 years, instructed him to do. How do I know this? It is rather simple. Take a man who cannot read or write English. Suddenly he is making accusations to proper authorities saying exactly whatever he needs to, to get the job done. Utilizing the exact branch of our judicial system, to support his claims of abuse.

The citizen is duped into thinking they would live as a family. Instead, only days after his child arrives with a green card, he gets his green card final notice, he comes with the police to have the child placed in long term DCYF custody as he makes outrageous accusations against the American of sexual abuse.

Methodically he plans, with his friends assistance. If you file abuse charges with immigration, then your entire file gets sent to NH and a special closed door court occurs. A motion under the 1969 VAWA act allows the immigrant access to our entire legal system FOR FREE, while the American is left to pay for everything. The immigrant can say and do whatever he pleases. The more disgraceful and humiliating the better. They study the American to see what will do the most damage and help them the most, and then they methodically act on it. Usually they obtain an attorney that is so taken by the lies and deceit and fully prosecutes the American for no reason at all.

The result, is a list of people, who don't matter to the American Immigration system. Americans who are rapped over and over without prosecution or reprimand. Instead they are rewarded and allowed to lead totally new lives without supporting their children they leave behind.

What's worse, they then, later use the children they abandon in our DCYF system as a way of remaining here permanently. This is another loop hole that needs to be closed.

There are only 3 ways to remain here once you over stay your visa, or come here on a K-2 or Visitor Visa. One is to marry an American here on US soil. The next is to have a blood child

residing here in US, because the law "try to unite families" allows them to remain. Then of course there is asylum. I'm not speaking about asylum at all. Just the first two.

Help to understand this please...How is it possible that for 8 years of grueling visits back and forth to Ghana to get my "husband" and his daughter here, I can be referred by him as nothing more than a babysitter? How is it possible, that I lose my job in medicine, over getting her a visa to come here and be a family, and then be totally ignored as a responsible guardian? Why is it all about the American citizen for over the entire process and as soon as they get here, we no longer matter, legally. Isn't it MY citizenship that brought them here? Why am I now nothing in the eyes of the law. And now why am I being told by immigration I will be forced to support them and also pay all bills relating to them. I had to submit so many personnel documents and perform so many duties, and PROVE I was able to take care of them. Now, he can go to the police, and accuse me of atrocities that even lifelong criminals don't commit. How did this happen! I am so outraged that there is no end, to this nightmare I live on a daily basis. But no one really cares. No one listens, and certainly no one will do anything about it.

Then as soon as his child gets here, finally, the immigrant gets a job. They realize they will need to support the child and spouse so they get together with their friends. Usually in a house with multiple "single males" who defraud the city and state and government, by making up lies to stall our legal system, abuse our law abiding citizens, and move on to get employment, a new car, and a new life. While the citizen is left beaten rapped, completely financially broke due to overwhelming costs of legal fees to try to just survive the process they put us through.

When I found documented proof, that the immigrant was sending money to another woman for quite a while, from a secret place, that he lived in with other people from his country. He presently works in a nursing home, with patients. Lord knows how he will con them into his many ways. He has caused me to have SEVERE, SEVERE PTSD. I have flash backs of the police removing my daughter dragging her down the stairs, TWICE and refusing to even look at documentation I had to show I had custody.

After an investigation by the FBI for civil rights violations, I finally learned the extent of the lies he told. Evidently, he claimed her life was in dire danger. he threatened the police with a law suit if they didn't give him his child. He also told them the men with him, had also seen his daughter and I sleeping together. She was handed over to him and his 3 friends and she was kidnapped, and beaten for 3 days. I have a video of the abduction that she made for DCYF, and also the 911 call she made to be rescued.

I spent over 2 thousand dollars getting her room ready for her to be in. It's kind of stupid to do that and plan to sleep with her, especially when I was on TDI with a broken leg in 4 places. I used my life's saving to bring them here and give them a safe and loving environment, and I never got a thank you, only abuse.

After attempting suicide in DCYF custody for 3 months my daughter was transferred to a long term facility. I never saw her again. His allegations had far reaching effects. I was being harassed for sleeping with my child over and over(I have the recordings to prove) he took her from the police without a shred of documentation that he even knew her. Surely if he WAS her father, why did he have no documentation to prove it. Especially, if I was just babysitting. They were all black I was white. He and his friends moved her across the state line several times. She even called me while I was at ICE, and I gave the phone to them so they could hear she was being beaten. She even had a recently diagnosed medical condition that needed medical attention that I was given custody for, and as soon as he got her, he never ever took her to the doctor.

When I was given custody, Instead of getting my daughter, he went back to the police had her dragged out again, in front of all my neighbors, I was accused of being a child molester. 3 men I

didn't know claimed they saw me when the immigrant was in my apartment They told the police they saw me rape and sleep with her. She was then, placed with 3 men in an SUV, and was beaten for 3 days. She jumped through a window and called 911. He was arrested for 3rd degree child assault. The police never got the information to the court, his case was dropped. Because he doesn't have to pay child support, even the divorce judge I asked said as long as she is in DCYF custody he doesn't have to pay support. As long as he doesn't pay support, he is free to travel around the world. I can't even go to Wal-Mart down the street and be across the state line, I have never done anything, and tried to do a good thing bringing them here to a better life. I used to build hospitals and set up the lab aspects. I have worked in medicine for over 32 years. I have started 3 501(C)3 organizations, and have traveled all my life. I have never had a record for ANYTHING my whole life. Not even a speeding ticket. Somehow with the assistance of the US government I am left in shambles and he is free to earn money and live in a house with others like himself, and never support his daughter.

Friday, the judge said "just because I say I have PTSD doesn't mean I have it" She wanted paperwork, which I had with me, and she refused to look at after the reading. I asked my lawyer to use it and she said it was hearsay. I needed the Dr to come in and "there was no money for that".

So I guess I am not worth it now. Everything I have done, gone in an instant. To go through domestic violence classes will cause me to have major flash backs of abuse. He is allowed to abuse me further. I have spent my life savings over 25 thousand dollars alone this past year. I lost my job, now I have a record and I will never get one. In 3 weeks my unemployment runs out. I'll be homeless.

I don't know any famous lawyers. the money I wasted was a joke. I even spent my last 3 thousand for a lawyer who "forgot" to show up for court. I filed an appeal, but I'm sure no matter what I do or say no one will listen...except to the immigrant. Somehow he gets all the rights and I get zero!

My suggestion is this:

As soon as fraud is suspected with the immigrant, the sponsor should be able to prevent them from turning over their file to NH for a free ride. No matter what the fraud they commit, it should be seen as illegal and they should be deported for it. Look at Terri Mc Millian. she wrote the book waiting to exhale. She learned only weeks after her immigrant got his green card, that he was gay. he had been having unprotected sex with men and then sleeping with her. how much fraud can that be? But yet he is free to remain here, and destroyed her life. Our tax dollars are used for everything. Food shelter, job, education and most of all legal fees. They bring other people into their circle and then to court with them to swear to the abuse. They swear to each other's lies, and usually this occurs within a very short period of time after getting their final green card interview. Then the government comes after the American, for fees associated with the immigrant ,or his family. Even if you don't know to file a I174 Form to withdraw support from the immigrant. They would have to find another one to sponsor them, or risk deportation Usually they just marry some other American victim to use. Then, the immigrant gets to start the application process to bring the rest of their family here. To further brutalize Americans while living off our tax dollars and leaving death and destruction in their path.

The very, very worst thing though, is they tell each other how to do it to another American and they become predators for the next immigrant to use, abuse ,and reuse us. I have a 50 pound box of documents relating to my case. Nothing I say is not backup with MULTIPLE documents. I hired a retired immigration (ICE) agent to investigate, I used 7 different branches of our court system, 10 different lawyers. I was accused of having a drug problem, then my negative urine

tests were "doctored" because I was a lab tech. then "I was crazy". Even though for over 8 years I was ok and woke up one morning "crazy". I had to be admitted to Butler for evaluation. and pay for it all! I had to prove I wasn't crazy., just to clear my name and possibly see my step daughter again.

I was released with a diagnosis on PTSD and I was not crazy. The lead Physic Dr for the state did a 4 hour additional evaluation at 2 thousand dollars, and also said I have PTSD. His report went on to say I could never had done any of the atrocities I was accused of and this immigrant is a con man with a lot of support to allow his lies to be brought into several branches of our legal system. Immigrants should be barred from using "witnesses" who have only known the immigrant who is claiming abuse. They should also be barred from using these "witnesses" from their own country. If my husband was unable to produce an American to back his lies, then most likely, they are not acting in good faith to learn English, and participate in our society. They only keep to their kind, and that's how they form these circles to support each other's agenda, they are too busy making "friends" to go to classes and learn English. it's because they have no interest in our society, and usually HATE this country. it's clear.

Please Senator, can't you do something? Change our laws, stop us from being abused. The ICE agent John Sampson will be in Boston soon. Look him up, or check out his web site out of Colorado where he works to change immigration laws thorough his own branches of government. Americans are falsely accused, imprisoned ,humiliated ,abused , rapped and then thrown away like a piece of trash. Immigration only investigates "rings" of marriage fraud. This only further proves my point that Americans are "worthless" in the governments eyes. We only matter if numerous immigrant swill be charged. Is it because they want more bang for their buck? So, because it is individuals who suffer in many of these fraud cases, it is not cost effective to investigate. This attitude, facilitates the immigrant's abuse of the American, and with the assistance of the US government and our tax dollars hard at work.

The immigrant is rewarded for his deceit, by allowing our legal system to be used to his advantage. these lie s they creates are stories easily disproved with documentation, but they get gag orders and restraining orders to prevent travel back to their countries to tell their families at home what is REALLY going on. But, usually the families are involved as well, with a promise of American travel. Then the immigrant leaves the state, to pick up the tab, while they work several jobs, reside together and destroy the American's dreams of living as a family. All the while living here without contributing to society. But the absolute **worst** thing, is that they form groups to tell each other how to abuse us and the system, how to get away with it and even have the state pick up the tab. It is this life, that I freely give to my country I love so much, to be sure this never happens again to someone else. I was just tiring to do a good thing, bringing them here, to help the world, but no one steps up to help us when we are abused. Please consider the marriage loophole and allow sponsors to report abuse no matter the time frame. If we can prove the immigrant is committing fraud in any way, during the green card process they were here under, they should be subjected to an investigation, with the assistance of the sponsor to be sure what they claiming, is really true. Look at the McMillan case. If you are gay, you don't just wake up one day and you are gay. It is fraud in his announcement of being gay. He hid this aspect, of his life, until 2 weeks after getting his green card. he exposed her to dieses, of other male partners he had hidden. he should be deported for fraud, but he is not. Stop giving them a time frame to abide by. There should be no end to the waiting period. Presently they have to wait here for 2 years, in order to qualify for a green card. You should tact on a clause that orders them deported when ever fraud is discovered, no matter how long it takes to find out the immigrant was lying.

This would eliminate the immigrant from skipping out on the relationship, usually within a short time frame from getting their green card.

Sincerely
Phyllis Stafford
150 Juniper Street
East Providence, RI
401-419-8431

Testimony about Discrimination in the RI Judiciary
A Pattern of Practice
by Patrice Livingston
August 1, 2012

Human Services:
Family Court
Accommodations

The RI Governor's Commission on Disabilities attempted to "mediate" a harmful and menacing denial of access and equal protection abuse of due process scheme on me by the RI Judiciary in the context of my two invisible disabilities over two years ago. It was a complete failure and only brought judicial retaliation on me once the "ruse" of a proposed settlement was coerced on me that the state would "train" the Family Courts on the needs of people under the ADA and make access and requests for any type of accommodations a more definitive and clear process - instead of one that further burdens and causes more trauma, pain, humiliation on the exploited individual (*and works against expedited litigation per what best practices and the code of conduct call for*).

The RI Judiciary has a pattern of practice that is codified in their rules and procedures, physical facilities and judicial practice manuals for attorneys, GALs, judges, and social workers which intends to menace and intimidate, discriminate and punish - people with disabilities. The pattern of practice occurs on individuals whether their disability is temporary, physical, emotional, mental, psychological, permanent, neurological, invisible or a terminal medical condition that causes the impairment. In fact, the court process itself has been known to cause temporary disability through trauma impact on people. It exploits vulnerable and unsuspecting families and the public trust.

They do this both administratively and judicially. The administrative discrimination is done by abuse of due process, deceit of procedure, and failure to accommodate. Also it happens when the court routinely thwarts a reliable calendar process when people need to schedule advocates to be with them, and in the court's whiplash to insist some accommodations are part of an "administrative" process and others are a "judicial" process. This is confusing, and completely inconsistent and causes harm to the litigants - despite the so called state wide training. NOTHING CHANGED.

As far at the pattern of practice to discriminate judicially against vulnerable litigants, especially those with PTSD or traumatic events in their lives, this is seen routinely by the abuse of their OWN civil rules and procedures and in their rulings which are NOT based on findings of fact or rulings of law - instead on ex parte, maliciously prosecution absent evidentiary hearings or due process. The courts also have as a pattern of practice, as codified in their Guardian ad litem manuals, and trained by the Bar Association and Judicial conferences, an abusive scheme to

judicially discriminate, harm, intimidate, menace and punish by exploitation and abuse of the mental health community and the use of psychological evaluations (by court paid professionals) to skew judicial rulings. In fact, this falls under the category of what the FBI terms public corruption:

“Public corruption poses a fundamental threat to our national security and way of life. It impacts everything from how well our borders are secured and our neighborhoods protected...to verdicts handed down in courts...to the quality of our roads, schools, and other government services. And it takes a significant toll on our pocketbooks, wasting billions in tax dollars every year.”

source: <http://www.fbi.gov/about-us/investigate/corruption>

In fact the FBI goes on to say in their article “Public Corruption Why It’s Our #1 Criminal Priority” 03/26/10, the following:

“Public corruption is a breach of trust by federal, state, or local officials—often with the help of private sector accomplices. It’s also the FBI’s top criminal investigative priority. To explain why the Bureau takes public corruption so seriously and how we investigate, we talked with Special Agent Patrick Bohrer, assistant section chief of our Public Corruption/Civil Rights program at FBI Headquarters.”

source: http://www.fbi.gov/news/stories/2010/march/corruption_032610

It is clear to me, that officials in the judiciary, to include members of the various Disciplinary Boards for attorneys, and social workers, attorneys and psychologists, meet the definition above for breach of public trust, **often with the help of private accomplices**. The private accomplices here are the attorneys and psychologists, PAID by the judiciary as state contractors or from federal grant pools, who corrupt the judicial outcomes. They then claim to be immune from being penalized or sanctioned for their many hateful, discriminatory, unethical and even unlawful activities. Actions taken - often for private gain and to keep the referral doors and fees swinging round and round. In fact, the additional private accomplices are found at the disciplinary board (*are they considered the private or the public sector ...?? we never get a straight answer*) to cover-up and in turn, corrupt the entire legitimate grievance process! So how do we get the Disciplinary Board itself held accountable?

Healthcare: Confidentiality

The Boards’ failures to intervene, early on, and actually sanction the pattern of practice, unleashes these individuals to continue to act with increasing frequency and intensity of harmful abuses using the legal system, and their direct line access to judges, to exert undue power and harm people. For example, attorneys were allowed to subpoena my private medical and mental health records, in a civil proceeding, absent any criminal or public interest and against two state confidentiality laws by intimidating my provider and threatening sanctions and manipulating the judge into ordering the release of my records. My side of the house was so intimidated and threatened, so that the records were provided ostensibly ONLY for the judge to review and return - and instead the judge handed over copies of my records to the opposing counsel !!! - **the judge** made copies of my records and put them in the case file and handed OUT copies instead of giving them back to the provider as asked.

This is abject judicial discrimination, in civil proceedings, absent any statute state or federal and against HIPAA laws that are explicit about not violating privacy or records absent any CRIMINAL

or PUBLIC INTEREST in the balance that weighs against protecting the confidential records of an individual. The release of records are not to be obtained by abuse of judicial power, or abuse of subpoena by attorneys or other individuals whose only purpose is to maliciously prosecute, harm, humiliate or degrade an individual. I did not raise my disability in any criminal defense. I was ATTACKED in the context of my two invisible disabilities from the very beginning as being an unfit parent -from which I had to allow my own brain to be used against me, or face contempt of court.

It was a fishing expedition - that should not even be allowed to go on, since even IF a mental illness is found, there is no statute to allow it to be used to take custody. AT ALL. So fishing for it and Testimony about Discrimination in the RI Judiciary A Pattern of Practice by Patrice Livingston August 1, 2012 coming up with one (by paying your own court contracted mercenary third party to write it up as such) still does not justify a 100% black out of custody under the law!! So why waste time, money, protract litigation, allow the harm, humiliation, fees to mount and more in what is clearly malicious prosecution bordering on hate crimes (under "disability" hate) ... when judges are not to rule based on that anyway!? These activities and malicious/hateful intentions are also against RI Bar Association Code of Professional Conduct and Judicial Canons for Judges and against any ethical or competent standard. Yet, once again - where does a traumatized individual with invisible disabilities turn to get ANY OF IT held accountable and punished. Will the RIGCD go to bat for disabled litigants who are discriminated against by judges and file at the judicial tenure board to STOP The harmful pattern of practice? This judge needs to be sanctioned. Here is the section out of HIPAA:

SEE in the attached HIPAA Privacy Summary PDF this:

(5) Public Interest and Benefit Activities. *The Privacy Rule permits use and disclosure of protected health information, without an individual's authorization or permission, for 12 national priority purposes.²⁸ These disclosures are permitted, although not required, by the Rule in recognition of the important uses made of health information outside of the health care context. Specific conditions or limitations apply to each public interest purpose, striking the balance between the individual privacy interest and the public interest need for this information.*

THERE WAS NO NATIONAL PRIORITY for my records to be released like that.

p. 7 Judicial and Administrative Proceedings. *Covered entities may disclose protected health information in a judicial or administrative proceeding if the request for the information is through an order from a court or administrative tribunal. Such information may also be disclosed in response to a subpoena or other lawful process if certain assurances regarding notice to the individual or a protective order are provided.³³*

I was NEVER provided notice of a subpoena on my records by Atty Gifford NOT was a protective order provided for me. Covered entities MAY - not SHALL - the language is clear: MAY. I said no.

p.10 Minimum Necessary. A central aspect of the Privacy Rule is the principle of "minimum necessary" use and disclosure. A covered entity must make reasonable efforts to use, disclose, and request only the minimum amount of protected health information needed to accomplish the intended purpose of the use, disclosure, or request.⁵⁰ A covered entity must develop and implement policies and procedures to reasonably limit uses and disclosures to the minimum

necessary. When the minimum necessary standard applies to a use or disclosure, a covered entity may not use, disclose, or request the entire medical record for a particular purpose, unless it can specifically justify the whole record as the amount reasonably needed for the purpose. See OCR "Minimum Necessary" Guidance.

Giving over copies of my raw answers and private evaluation notes was WAY BEYOND any minimum use necessary to make a custody and visitation determination especially when there was ALREADY a finding of fact, and ruling of law and evidentiary hearings that I was not mentally ill and posed no harm to my teenage daughter by the prior judge: it was already res judicata.

AND:

p.18 Criminal Penalties. A person who knowingly obtains or discloses individually identifiable health information in violation of HIPAA faces a fine of \$50,000 and up to one-year imprisonment.⁸⁹ The criminal penalties increase to \$100,000 and up to five years imprisonment if the wrongful conduct involves false pretenses, and to \$250,000 and up to ten years imprisonment if the wrongful conduct involves the intent to sell, transfer, or use individually identifiable health information for commercial advantage, personal gain, or malicious harm. Criminal sanctions will be enforced by the Department of Justice.

The judge intimidated my provider into giving the records and gave her no written order. Further, the judge then made copies contrary to the request and denial of release by me and the two quashes we filed. There was nothing in writing AND the only reason, the only reason at all, that my records were obtained, willfully and in violation of state and federal privacy laws by Attorney Gifford was under false pretense. She did it because she needed to coverup her initial fraudulent pleadings of PAS as codified in the practice manual (*deliberate harm by targeting one parent as mentally unstable and then traumatizing and punishing them with sanctions, extreme court orders, loss of custody, property or money and/or jail time - as a menacing means of achieving trauma based control over people*). This was done by her for commercial advantage to rack up her legal fees, and personal gain to coverup her initial and subsequent false filings in the court, and in malicious harm on me to conduct TRAUMA BASED retaliation on me for my attempts to get grievance and relief and remedy; and also for my complaints on individuals like her and on the court system. She acted so unethically by fomenting hostilities that she has also caused harm to her own client's child.

Without the help of the RIGCD to call in the DOJ and enforce the **page 18 criminal** penalties section for violating me, (and many others) and to enforce the definition of the FBI's public corruption (with the help of private accomplices), and without a full audit by the US Atty via a grand jury investigation of the federal monies that are racketeered through the RI Judiciary, then vulnerable people will continue to be exploited by the courts. In fact, the Family Court in particular, with its codified pattern of practice and refusal to accommodate the needs of people who are hurting and in life transition or who suffer job loss, and other life difficulties, actually causes people to become temporarily disabled. If you take a baseball bat to both my legs - I will become disabled until they heal. If you have battered me sufficient to cause complex trauma and nerve damage, I might walk with a limp for the rest of my life! The court BATTERS people this way - and pretends they did no such thing, when in fact, the system, in actions by individuals, CAUSES emotional upset, mental duress, and even PTSD in litigants through the legal abuse,

through the abuse of due process, through the suppression of evidence, ex parte hearings, failure to prosecute false filings and this sort of malicious harm by using psychological evaluations as a means to menace people. I have also been denied proper accommodations in the Superior Court. The two courts are not at all trained or consistent - even though under Title 8 the Family Court is supposedly a horizontal "specialty court" of the Superior Court with jurisdiction solely and only over Title 14 and Title 15 issues. CIVIL.

So even IF a mental disorder (temporary like depression or grief or job loss, or what have you) is found, there are NO STATUTES that allow a temporary (or invisible or permanent) kind of disability broken leg, back surgery, car accident, clinical depression, whatever ...to be used as fodder for TAKING CUSTODY or PROPERTY or JAILING SOMEONE or invading their privacy or for sanctioning them to the point of economic impoverishment! These actions are very psychologically violent on the part of the court system, and by the private actors in it, and the rules and procedures and written practice manuals which call for such INHUMANE treatment of people. It is debilitating.

If someone is suffering emotional upset that is not a crime. If someone is struggling in the bad economy with lack of steady work, they don't deserve to have severe fines. If someone is angry at being mistreated and has an outburst, they need to be heard and the underlying mistreatment addressed - they don't need to be "brought into line" by *trauma based* control mechanisms like 100% blackout from their children absent any nexus of harm or reason to justify the state sanctioned abduction. Life events and the emotional turmoil which accompanies them ARE NOT CRIMES. Speaking out about being mistreated or at having one's rights violated, or false representations is not a crime. Having a disability - does not make someone "dangerous". It requires a humane approach of inclusion and accommodation, respect for privacy and dignity NOT more trauma and HARM.

The court system engages in psychological violence per the CDC definition of such here:

"Psychological/emotional violence involves trauma to the victim caused by acts, threats of acts, or coercive tactics. Psychological/emotional abuse can include, but is not limited to, humiliating the victim, controlling what the victim can and cannot do, withholding information from the victim, deliberately doing something to make the victim feel diminished or embarrassed, isolating the victim from friends and family, and denying the victim access to money or other basic resources" (CDC, 2007).

Source: United States Department of Health and Human Services. Centers for Disease Control and Prevention. Intimate partner violence: Overview. Retrieved on June 28, 2007, from: <http://www.cdc.gov/VioencePrevention/intimatepartnerviolence/index.htm>

Human Services: Governor's
Commission on Disabilities

If the RIGCD wants to help - then ENFORCEMENT of HIPAA, ADA, Title 9 penalties for false filings and a written request for a grand jury investigation and audit of the courts is in order. Not only was I exploited to begin with and it took two years to even get to the so called RIGCD mediated process - the result of the so called solution was a farce, and no disciplinary measures were taken, and the people responsible were not at all penalized, suspended or sanctioned, and the Disciplinary Board was allowed to dismiss me as a mere disgruntled litigant, The Board of Health

engaged in mail tampering and coverup of the pattern of practice that the courts use to cause disability and dysfunction in people, then exploit them in their post traumatic state, then fail to accommodate them, and then say they are either unfit, disabled or dangerous (*due to the symptoms they display from being mistreated BY the court!!*) as the reason to justify TYRANNIZING litigants by a loss of custody, visitation, psych evals or medical treatment or institutionalized against their will, or simply jailed or put into the RONCO system as a danger to society under maximum penalty.

Then I spent a third year filing DOJ complaints, trying to file in superior and federal court for my Title II rights. I was denied access to the courts to petition for visitation the entire year 2011 over my insistence on ADA accommodations! Then I was paced through legal battering, complete humiliation about the medical records and total emotional and psychological violence as we PROVE the filings were false, the affidavit false, the transcripts altered, the other side commits perjury and the court's OWN rules for filing DR6 are not followed. By every single statute, case law, testimony, evidence, and disbarable offenses by the other side, I should have had full custody restored to me, the money due me for 2/3 costs associated with raping my privacy (*while wrongfully ordered by the court under threat of contempt*) and also damages. Instead I was denied custody, denied meaningful visitation (*they picked 4 two hour visits twice a month over two months on days where my daughter already had a full schedule*) and left to remain in the statewide RONCO systems which carries criminal penalties ON **ME** - under threat of more legal entrapment and outside of court harassment, hate crimes, discrimination and abuse, because the private actors who did this to me - were NOT DISBARRED - they were REWARDED for abusing me in the form of more fees, earning a GAL position to practice the scheme on another child, and by having their license to bully and carry on the pattern of practice kept in tact. They were publicly praised by the judge making a final ruling that was pretty much a verbatim reading of their final argument and ignoring all evidence presented for six months in abject legal abuse, civil and constitutional rights violations. It was a very profound fourth and final round of TRAUMA BASED control on me, that has caused me to leave the state because my fundamental liberty was taken from me short of being jailed. Here's how it went:

April 2008 - false filings, ex parte, the PAS script initiated and they start to run down it
May 2008 - a PAS Guardian ad litem is assigned; I am charged thousands in fees - more ex parte
June 2008 - the PAS psychologist is pulled into the next act, again more fees and she is the master of pretend and deceit; claims to understand; really works for the state
Sept 2008 - more ex parte - court documents are altered, new judge, PAS script continues
Oct thru Jan 2009 - more legal abuse, discovery abuse, manufactured allegations that I am a danger might abduct, am mentally ill, should be supervised (more extortion - pay to see your kid, program ... while the state gets federal funds the more # of people served)

All of 2009 is a fight for my civil rights, and humane treatment while everyone has the script but me. abuse of psychological evaluation, instead of mediating the issues - I am accused of being unfit by the court psychologist, who UNBEKNOWNST TO ME was on state payroll while charging private. All kinds of legal abuse goes on - I finally file for ADA accommodations as I am being constantly exploited, provoked, traumatized, lied to, manipulated and abused by the system - where one set of rules exists (unwritten) for them; and one set for me (also unwritten, yet I am constantly accused of not following the unwritten rules). If I file motions, the dates are changed, if they file them - its an "emergency" - always an emergency, I am not notified, accommodated,

served, or included and then orders are written and I endure more trauma based punishment from the court, Its a bad economy, I have lost my job, my home, and now my kid. The COURT HAS HARMED ME.

Then. all of 2010 are evidentiary hearings and an attempt to get the LEGAL ABUSE of my TITLE II civil rights addressed. I disclose my second invisible disability - even though I am not obligated to do so. The RIGCD mediations end up being a ruse, and a total failure, since as soon as its done - I am retaliated on in the fall of 2010 and sent back to supervised visitation, extortion to pay, and more, the way it was *prior to the start of the RIGCD grievance process in Mar/April 2010 to begin with!!*. I WAS TOTALLY EXPLOITED and DECEIVED in that process.

Then, all of 2011 I am denied access to the court, to plead to see my daughter. I was told to file a MOTION for ADA accommodations that were supposedly in place for 18 months from summer 2009 to winter of 2010-2011, only I asked for an update to do recent events surrounding the falsely filed Dec 2010 RONCO thing. I was maximum defaulted into the RONCO system in Dec 2010 as a danger, because I refused to appear in court without proper summons and without accommodations and because I was extremely symptomatic and upset about what was happening and at having been deceived from July 2010 to Dec 2010 and NOT REMEDIED at all.

After the so-called mediations, instead I was severely and traumatically retaliated upon. STILL - I can get NO HELP from RIGCD or DOJ or any proper disciplinary process in the state. Not Board of Health, not AG, not State Police for my Hate Crimes complaint as a disabled person, not the FBI on public corruption, not the General Assembly and not the RIGCD who has washed their hands of responsibility for the EXECUTIVE BRANCH to hold the JUDICIAL BRANCH accountable and put a check and balance on them. By the time 2012 has rolled around - its four years of abject legal abuse, exploitation of my invisible disability, no chance of rightful grievance process working - those organizations are also corrupted and its three full years now of 100% no contact with my daughter, which has altered ~ irrevocably and forever ~ both of our lives, and our relationship and which has profoundly damaged us both. We are still not in contact as of this writing, because ONCE AGAIN - I was denied access to the court as recent as June 27, 2012 having been told that court simply cannot "accommodate me" with telephonic access, even though I was 1500 miles away and filed a motion requesting it a month in advance - because they don't have a phone with a speaker on it. Really?

Human Services: Family Court Accommodations

So the judge said "no" and they proceeded to hold the hearing without me - on reviewing my ability to talk to my daughter on the phone long distance and ONCE AGAIN - the malicious, hateful filings of the attorney are allowed to be filed trying to hold me in contempt of court, while I am 1500 miles away for the summer. My daughter and I now do not talk. We had reconnected briefly and that even that very very little bit of positive reunification has been allowed to be damaged by the same attorney who has menaced me without discipline - FOR FOUR YEARS. The judges indulge her. I am now not returning to the State of Rhode Island. I remain falsely filed in the statewide RONCO system. The fraud on the court was proven and the abuse order on me was not vacated even though I obeyed the falsely filed affidavit for 18 months without a single peep by living a severely curtailed life, looking over my shoulder, being upset constantly and having my civil rights violated and my disability symptoms exacerbated the entire time. Instead of vacating it as evidentiary hearings had proven was warranted - the judge EXTENDED it on me, to the maximum default.

Instead of remedy and FIXING things - she criminalized me for no justifiable reason. I am not welcome in the State of Rhode Island. I am vulnerable to harassment outside of court by those attorneys, their PI's, their buddies in law enforcement and any judge they might go to with lies about me. I can be picked up and arrested on any manufactured "violation" of the RONCO registry - after all, if it was allowed to be filed falsely, also extended to Jan 2014 falsely and I remain registered falsely, then they can very easily manufacture a pretend violation on me and arrest me falsely, and jail me falsely, and stamp a felony on my record falsely (*which would no doubt make an already difficult and protracted job search - nearly impossible*). Who can live under such fear and tyranny every single day?

That is how you treat people with disabilities in Rhode Island - you violate their rights? And when they have the strength, fortitude, courage, and facts to PROVE the violation - you just traumatize and abuse them further? Or just have the cops beat them into having heart attacks like in the news, or drive someone like me into complete neurological dysfunction, that is so painful, with pins and needles in my arms and legs, and breaking out in red splotches all over my body, and temperature dysregulation and more - that the attorneys and judges are rewarded by humiliating me and driving me out of town by falsely registering me as a danger to society? really? That's what you do with the information you RAPED out of my medical records? And I committed no crime; even in the criminal proceedings - the statutes PRESERVE confidentiality.

ATTACHED DOCUMENTS:

- * HIPAA SUMMARY
- * INVISIBLE DISABILITIES legal article
- * McElroy Amicus - Spells out the TWO RI Confidentiality laws
- * Harmful DeProgramming Practice by Courts and Private Actors
- * PTSD Chart and Review - the courts CAUSE this in litigants

*NOTE: the PAS script is NOT condoned by ANY standards body: AMA, ABA, APA, etc... **yet** the State of RI codifies it as a pattern of practice and spells out the deliberate harmful and harsh actions that the judge, attorney and psychologist should conspire to take - to bring "PAS" parents in line. There are also NO STATUTES in RI for "supervised visitation" -its just a money making racketeering program the state uses to get federal funds OR to line the pockets of private actors and kickback referral agents who exist in the cottage industry around the courts.... in the pay-to-see-your-kid, no accountability, or tracking, - cash-only supervised visit EXTORTION activity.*

Dear Sir or Madam,

Transportation:
RIPTA & Ride

One major issue I have, has to do with bus service in my area. There is none. The closest service from my house is Wakefield Mall. This is too far to request the RIDE bus. The only appts I leave the house is for medical appts.

I have heard of others in the area (Matunuck and Charlestown) with no bus services either. I'm sure there are probably more than three parties who could use bus service in this area.

Sincerely,
Laurie Manning
104 Green Hill Beach Rd
S.K. 02879



*A Citizen Advisory Group
on Transportation Issues*

Karen Salvatore
Founder & Consultant

Winston Stadig
Co-Founder

To: Rhode Island Governors Office on Disabilities
From: Bob Votava, Executive Director
Re: July 26th and 27th Public Hearings For the Disabled
Date: July 26, 2012

Due to the fact that Rowena Fayerweather is physically impaired and does not have transportation facilities to attend these hearings, she would appreciate if they are read into the minutes of the hearing.

**Accessibility:
Curb Cuts**

She is one of many who live very close to Tower Hill Road in Wakefield, their main shopping locality. Unfortunately, the sidewalks are riddled with curb cuts for the business's. If Ms. Fayerweather rides her electric scooter on the sidewalk, she turns over when crossing a curb cut due to the extreme drop in the sidewalk. Therefore she and others have to ride in the street. This Road has been submitted by the Town of South Kingstown for ADA funding for correction of these sidewalk violations. Please prioritize this project in the RIDOT ADA program.

Our organization thanks you for holding these hearings and and working with the physically impaired to improve their quality of life.

CC: Susan Sosnowski, State Senator
Teresa Tanzi, State Representative
Michael Lewis, DOT Director
Myrna George, President South County Tourism Council
Steven Alfred, South Kingstown Town Manager
Rowena Fayerweather, Co-Chairman Citizens For A Walkable Wakefield

DOT Watch, Inc.
Dol-Walch
481 Post Road
Wakefield, AI 02879
(401) 783-8886

CITIZENS FOR A WALKABLE WAKEFIELD
681 Kingstown Road, apt. 109 WAKEFIELD, R.I.
02879

January 27, 2012

Michael Lewis. Director
R.I. Department of Transportation 2 Capital Hill
Providence. R.I. 02903

Dear Mr. Lewis,

As we read our local newspapers, the articles frequently inform us of local happenings. This includes businesses that are coming or going, buildings that are being proposed and street projects that are being considered or scheduled for reconstruction. Unfortunately, we never see articles about the reconstruction of Tower Hill Rd., going from the Dale Carlia intersection up to Rt.1.

Accessibility:
Curb Cuts

The citizens of our community were informed that Tower Hill Rd. was submitted by our Town to the state DOT for reconstruction. The reason being due to many ADA violations in conjunction with the dangerous conditions for citizens to cross Tower Hill Rd. to shop at our local stores. Many citizens of our neighborhoods include seniors and those who are physically impaired.

Our organization would appreciate an update on the progress of this project. Thank you.

Sincerely,
Rowena Fayerweather, Co-Chairmen

CC: Steven Alfred, Town Manager
Susan Sosnowski, State Senator
Teresa Tanzi, State Representative

Michael P. Lewis
Director

Department of Transportation
OFFICE OF THE DIRECTOR
Two Capitol Hill
Providence, R.I. 02903-1124

OFFICE (401)222-2481
FAX (401)222-2086
TDD (401)222-4971

March 15, 2012

Rowena Fayerweather, Co-Chairman
Citizens For A Walkable Wakefield
681 Kingstown Road, Apt. 109
Wakefield, RI02879

Dear Ms. Fayerweather:

Thank you for your January 27, 2012, letter concerning proposed improvements to Tower Hill Road in Wakefield.

The project that you are referring to was submitted by the Town of South Kingstown for consideration in the upcoming Transportation Improvement Program (TIP), and has been included in a draft version of the TIP. Developed over the past six months by staff from Statewide Planning and the RI. Department of Transportation, in conjunction with the Transportation Advisory Committee, the TIP is a Federally required plan for transportation funding that specifically lists the projects a state intends to implement over a four-year period.

The Statewide Planning Council will hold public hearings on the 2013-2016 TIP on Thursday, April 26, at 2 p.m. and 6:30 p.m. in Conference Room A at the Department of Administration, One Capitol Hill, Providence. Final adoption is scheduled for July. For a copy of the draft or more information on the process, please visit www.planning.ti.gov/transportation.

It is important to note, however, that inclusion in the TIP indicates that the project is a priority, but it does not guarantee funding. Plans can be accelerated or delayed based on the availability of both State and Federal funds. Congress is currently debating a new surface transportation bill, and the results of that debate will affect the breadth of what can be accomplished here in Rhode Island over the next four years.

You may be interested to learn that the Department of Transportation is working on several other nearby improvements that will aid pedestrians in Wakefield. There is a project under development that will reduce Kingstown Road to three lanes from School Street to the Route 1 interchange. Instead of two lanes in each direction, there will be one lane each way and a center turning lane. Commonly called a "road diet," this type of change has proven to reduce speeds and traffic accidents.

Rowena Fayerweather
March 15, 2012
Page 2

The Department also will be updating the traffic signals at Dale Carlia Comer, Charles Street and MacArthur Drive, and repairing some of the sidewalks along Kingstown Road. Pending funding, we anticipate the work to begin this fall.

Should you need any additional information, please contact our Customer Service office at 222-2450. Thank you.

Sincerely,

Michael P. Lewis
Director

From: Myrna George mgeorge@southcountyri.com
Subject: **FW: SAFE PASSAGE FOR ALL**
Date: June 28, 2012 2:44:36 PM EDT
To: 'Bob Votava' bobvotava@me.com
2 attachments, 49.1 KB

June 28, 2012

Dear South County Caucus Senators and Representatives:

I write in support of the BIKE WALK HEALTHY COMMUNITIES committee that has been meeting over the past months. As recently as Saturday, June 21, they met to examine Tower Hill Rd., going from the Dale Carlia intersection up to Route 1 and the neighboring properties.

Since the Town of South Kingstown had previously requested monies for removal of ADA violations on the Tower Hill sidewalks, the project was submitted to the Transportation Advisory Committee for review. They placed the project in the TIP under Highway Program. Appendix C as the WAKEFIELD TOWER HILL ROAD project within a category for ADA projects.

**Accessibility:
Curb Cuts**

The attached photo illustrates one example of ADA violation on Tower Hill Road. The large neighboring community of Indian Run Village, which includes the physically impaired, who cannot ride their electric scooters on the sidewalk because they turn over at the abrupt drop into the curb cuts located on the road. Therefore, they must ride in the street. Recently a member of this community was killed on Tower Hill Road at Dale Carlia intersection.

Please help South County resolve this tragically dangerous situation, as illustrated in the attached photograph.

Thank you for your attention to this pressing issue.

Sincerely,
Myrna George
President & CEO

South County Tourism Council
4808 Tower Hill Road, Ste. 101
Wakefield, RI 02879
800.548.4662 401.789.4422
401.789.4437 fax
www.southcountyri.com

**DOT WATCH INC. 481 POST ROAD,
WAKEFIELD, R.I. 02879 401-783-8886
email bobvotava@mac.com**

Kevin Flynn, Secretary
R.I. State Planning Council
One Capital Hill
Providence, R.I. 02908

July 2,2012

Dear Mr. Flynn,

Now that South Kingstown has been selected by the R.I. Department of Health (DOH) to partake in the HEATHY PLACES BY DESIGN project, which includes walking and biking, many old problems are again being revisited. Mark Fenton, the consultant hired by DOH has worked and walked with us to reiterate problems that need to be addressed. One of the most critical is the Wakefield Tower Hill Road ADA project.

**Accessibility:
Curb Cuts**

Due to the serious safety issues that plague this Road, we ask you to prioritize the ADA funding for this project. Surely there are other ADA needs in our state but I doubt that they require physically impaired citizens to ride their electric scooters in the street to avoid being over turned by the abrupt drop of the many sidewalk curb cuts. Refer to attached photograph.

Also it is important to put in perspective that this capital project listed in the TIP was not just initiated. The request from the town was years ago. How long do citizens have to inured such dangerous conditions to shop for daily needs along this state speedway?

It was only due to the recent death of a senior citizen who was killed on this road when walking across adjacent to the Dale Carlia intersection, that traffic lights were reconfigured to help minimize such events. Will it take another fatality on Tower Hill Rd. to bring this ADA project to the top of the list?

Please help the members of our community who are unable to be car dependent to safely shop at this major commercial hub in Wakefield.

Sincerely,

Bob Votava, Executive Director

CC: Lincoln Chafee, Governor
Leonard Green, Director, R.I. Department of Health
Steven Alfred, South Kingstown Town Manager
Kathi Crowe, Executive Director, South Kingstown YMCA



**DOT WATCH INC. 481 POST ROAD,
WAKEFIELD, R.I. 02879 401-783-8886
email bobvotava@mac.com**

To: Susan Sosnowski, State Senator
Teresa Tanzi, State Representatives
Michael Lewis, DOT Director
Raymond Cooper, Governors Committee on Disabilities
From: Bob Votava, Executive Director
Re: Wakefield Tower Hill Rd. ADA project
Date: July 2, 2012

Now that South Kingstown has been selected by the RI. Department of Health (DOH) to partake in the WALK BIKE HEALTHY COMMUNITIES project, many old problems are again being revisited. Mark Fenton, the consultant hired by DOH has worked and walked with us to reiterate problems that need to be addressed. One of the most critical is the Wakefield Tower Hill Road ADA project.

Undoubtedly you are being asked by many to prioritize the ADA funding for this project. Surely there are other ADA needs in our state but I doubt that they require physically impaired citizens to ride their electric scooters in the street to avoid being over turned by the abrupt drop of the many sidewalk curb cuts. Refer to attached photograph.

Also it is important to put in perspective that this capital project listed in the TIP was not just initiated. The request from the town was years ago. How long do citizens have to inured such dangerous conditions to shop for daily needs along this state speedway?

It was only due to the recent death of a senior citizen who was killed on this road when walking across adjacent to the Dale Carlia intersection, that traffic lights were reconfigured to help minimize such events. Will it take another fatality on Tower Hill Rd. to bring this ADA project to the top of the list?

Please help the members of our community who are unable to be car dependent to safely shop at this major commercial hub in Wakefield.

CC: Lincoln Chafee, Governor
Leonard Green, Director, R.I. Department of Health
Steven Alfred, South Kingstown Town Manager
Kathi Crowe, Executive Director, South Kingstown YMCA