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

July 22rd - July 25th 2013

Prepared by

The Governor's Commission on Disabilities

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Adopted on November 18, 2013

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

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Letter of Transmittal

November 18, 2013

His Excellency, Lincoln D. Chafee
Governor of the State of Rhode Island and Providence Plantations
State House
Providence, RI 02903

The Honorable Gordon Fox
Speaker of the House of Representatives
State House
Providence, RI 02903

The Honorable M. Teresa Paiva Weed
President of the Senate
State House
Providence, RI 02903

Dear Governor Chafee, Speaker Fox, and President Paiva Weed:

It is my pleasure to transmit to you the concerns and recommendations of Rhode Islanders with Disabilities and their Families, compiles from the testimony at six public forums held through-out during the last week of July.

There were 25 concerns raised at the forums, including the lack of: accessibility to recreational areas; IEP compliance; accuracy in Supports Intensity Scale evaluations; access to universally designed affordable housing; and RIde supports.

The public forum twenty sponsoring agencies reviewed the concerns and recommended action to address each. Most of the recommendations call for improved enforcement and awareness of current laws, regulations, policies and standards. Fewer than half a dozen require legislative action mostly adequate resources to meet current needs.

Sincerely,

RTF

R. Timothy Flynn,
Chairperson

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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 week-long 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 22, 2013, 4 - 6 PM
Woonsocket Harris Public Library, 303 Clinton Street, Woonsocket
Hosted by RI Department of Health

Tuesday, July 23, 2013, 4 - 6 PM
South Kingstown Public Library. 1057 Kingstown Road, Peace Dale
Hosted by Perspectives Corporation

Tuesday July 23, 2013 4-6 PM
Middletown Public Library's Community Room, 700 West Main Road, Middletown
Hosted by Opportunities Unlimited

Wednesday July 24, 2013, 2 - 4 PM
East Providence Senior Center, 610 Waterman Avenue, East Providence, RI
Hosted by National Multiple Sclerosis Society Rhode Island Chapter

Wednesday, July 24, 2013, 4 - 6 PM
Warwick Public Library's Community Room, 600 Sandy Lane, Warwick
Hosted by the Ocean State Center for Independent Living

Thursday, July 25, 2013, 5 - 7 PM
South Providence Library, 441 Prairie Avenue, Providence
Hosted by Bridgemark Addiction Recovery Services

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 8th 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.

Lincoln D. Chafee, Governor

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 & Brain Injury Resource Center,
Sharon Brinkworth, Executive Director

Bridgemark Addition Recovery Services, Christine Harkins, Executive Director

In-Sight, Christopher Butler, Executive Director

Keystone Group, Thomas P. Kane, President/CEO

Meeting Street, John M. Kelly, President

Multiple Sclerosis Societly, RI Chapter, Kathy Mechnig, Chapter President

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

Neighborhood Health Plan of RI,James A. Hooley President/CEO

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

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

Paul V. Sherlock Center on Disabilities @ RI College, Anthony Antosh, Executive Director

Perspectives Corporation, David Ruppell, Executive Director

Rhode Island Parents Information Network, Matthew Cox, Executive Director

RI Commission on 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, Associate Director

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

RI Public Transit Authority, Ray Studley, CEO

Seven Hills Foundation, David A. Jordan, President/CEO

United Healthcare of New England, Rhode Island Community Plan,
Patrice Cooper, Executive Director

Part One: Executive Summary

This year, twenty agencies sponsored a series of public forums across the state of Rhode Island to hear the concerns of people with disabilities and their families. The forums took place from July 22rd to July 25th 2012 in honor of the anniversary of the Americans with Disabilities Act (signed on July 26, 1990). The forums were hosted by the Woonsocket Harris Library on the 22rd, Middletown Public Form, South Kingstown Library on the 23rd, East Providence Senior Center, Warwick Library on the 24th, South Providence on the 25th.

The public forums serve as a chance for citizens of Rhode Island to voice their personal concerns for themselves and their families. The main concerns found at the 2013 public forums were accessibility, education, employment, healthcare/support, housing, and transportation.

The first topic of concerns addressed at the forums was that of accessibility. Concerns covered in this section included access to recreational establishments.

In regards to education, the concerns included IEP services and the compliance of the IEP documents. Caregivers were also concerned about students' screenings and their transitions to adult services.

The third category of concerns that was discussed was employment. The main concern was lack of funding and miscalculations on how much funding needed for each individual. There were concerns about the transition from education to adult services, especially regarding employment and post-secondary education. Concerns were raised about maintaining non-competitive employment options.

The next category of concerns related to healthcare and supports. The main concerns of the forums regarded reevaluating using the Supports Intensity Scales as an assessment tool. There were also concerns with the lack of funding of disability services. The lack of funding is resulting in untrained staff and high turnover and the lack of knowledge on autism by health care providers. There is a need for clarification on the eligibility of Medicaid and Sherlock services.

On the topic of housing, accessible affordable housing during transition stage and the year's long waiting lists into these establishments were a concern. Concerns were raised about accessibility to funding for home modifications.

The final topic of discussion at the forums was transportation. Concerns were raised about the price of Ride fare. Comments were also raised about mandating a sliding scale for users with disabilities. Concerns were raised about taking away accessibility to RIde when people fail to be at the scheduled pick up. Also concerns were raised about individuals needing more supports from the Ride bus.

Part Two: Community Concerns and Recommendations

Accessibility

Concern: Public events not having enforced accessible parking & seating 85
Recommendation: GCD legislation committee should propose legislation requiring those holding public events have the ADA required parking and seats as well as a way to enforce it (i.e. police)

Concern: Non-accessibility of state college campuses when construction is being done 65
Recommendation: GCD legislation committee should propose legislation requiring the state colleges ensure accessibility to all buildings. Walkways, etc., as well as the ratio of handicapped parking spaces, whenever a construction project is undertaken.

Concern: Transportation
Recommendation: GCD should propose a task force that develops a multi-faceted plan to expand transportation resources (such as using school buses top assist transporting people with disabilities)

Education

Concern: The increase in the number of students being dropped from IEPs (individual education plans). 65

Concern: Lack of screening in the early school years to pick up language based learning disabilities. 47

Concern: Lack of information on the transition from school to adult services/career supports for parents and students in high school. 101

Concern: Lack of information on the range of services that should be included in an IEP46

Employment

Concern: Lack of funding and miscalculations on how much funding needed for each individual. 35, 45, 51, 63
Recommendations: GCD legislative committee should review the eligibility category under Medicaid and the Sherlock Plan to better access the Education Plans for individuals with disabilities.

Concern: Supports Intensity Scale evaluations attempting to fit all individuals into one category because one size does not fit all 31, 32
Recommendation: GCD legislative committee should review a different assessment product for Employment First or modify the Supports Intensity Scale evaluation.

Concern: The lack of training for staff working with individuals on employment opportunities 84

Recommendation: GCD legislative committee should look into increasing training for staff of Developmental Disability employment.

Concern: Support Intensity Scale inaccurate Support Intensity Scale inaccurate rate structure and tier packages 56
Recommendation: GCD legislative committee should review how Supports Intensity Scale is determined and look into different tools. Funds are needed to provide different types of assessments for different needs. Funds are needed to provide different types of assessments for different needs.

Concern: With the cuts in shelter workshops, there are uncertainties about what individuals will do without them. 26, 28, 31
Recommendation: GCD legislative committee should develop a plan for Developmentally Disabled and older individuals that cannot work into competitive employment. There needs to be an alternative to the shelter workshops.

Healthcare/ Supports

Concern: Inadequacy in SIS Evaluations to reflect medical needs and supports. 14, 43, 46, 57, 59, 98, 99, 101, 103
Recommendations: GCD should encourage BHDDH reevaluate using the SIS as an assessment tool. GCD recommends BHDDAs and DHS LTC address medical/ nursing integration.

Concern: Lack of funding for providers resulting in untrained staff and high turnover. 32, 43, 49, 63, 66, 80, 105, 106, 107, 108
Recommendations: GCD should support a sustainable funding mechanism for DD services.

Concern: Lack of accessible housing for individuals who are trying to stay in their homes for as long as possible 87
Recommendations: GCD and the Legislative Commission should look into existing laws and initiatives for rebalancing, such as “Perry Sullivan.” GCD should support affordable housing initiatives that maintain people independently.

Concern: The lack of knowledge on autism by health care providers. 30, 32, 42
Recommendations: GCD Legislation committee should recommend collaboration and training between health services, families, medical providers and patients/consumers.

Concern: The lack of supports and funding for children transitioning into adult services. 23, 58, 82, 96
Recommendations: GCD should recommend state agencies stream line the transition process in eligibility and services.

Housing

Concern: Accessible affordable housing during transition stage and the years long waiting lists into these establishments 83
Recommendation: GCD legislative committee should review this information to check for discrimination.

Concern: The barriers for people with disabilities and trying to obtain affordable housing 64
Recommendation: GCD legislative committee should explore the idea of having a separate list of affordable housing for people with disabilities.

Concern: Accessibility to funding for home modifications for families of individuals in wheelchairs 81
Recommendation: GCD legislative committee should review housing accessibility funding and make sure the money is being distributed properly.

Concern: Affordable housing is accessible for all individuals 83
Recommendation: GCD legislative committee should look into making legislation for all new public housing should use universally (accessible) design.

Transportation

Concern: Taking away accessibility to Ride when people fail to be at the scheduled pick up. 50
Recommendations: GCD Legislation committee should look at another solution such as levying a fine

Concern: Access to an accessible minivan 81
Recommendation: GCD should refer the person to OSCIL.

Concern: High cost of RIde106
Recommendation: GCD legislation committee should consider submitting legislation that implements a sliding scale

Concern: Person (son) needing an assistant while taking Ride 85
Recommendation: GCD should follow up with family to let them know they can RIde the bus with them.

Part Three: Public Forum Testimony

Monday, July 22, 2013- Woonsocket Harris Public Library

DEBORAH GARNEAU: I think we're going to get started. Hi everyone, thank you for coming. We are going to get started. This is the first of the public forums. I just wanted to go over some of the information about the forum, and then we can hear your testimony. The purpose of these forums is to identify the concerns of people with disabilities and their families in order to assist the state develop programs to improve the quality of 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 be posted on the website by the end of November. The recommendations and the transcripts will be printed and sent to state agencies 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 Disability Law Center's panelist will be available to register anyone to vote, to register anyone who is a citizen and not currently registered to vote where they live to vote at the end -- of the testimony. People can also file a change of address if they have moved since the last election. So, at this time I am going to ask the panelists to introduce themselves. My name is Deborah Garneau, I am here from the Health Department. And I organize the special needs office at the Health Department.

ARTHUR PLITT: I'm Arthur Plitt, Commissioner with the Governor's Commission on Disabilities.

JOE MURPHY: Joe Murphy, supervisor for the Office of Rehab Services, northern part of the state.

KATE BOWDEN: Kate Bowden, staff attorney at the Rhode Island Disability Law Center, and I invite you to grab some materials we have brought. I have some, and they are also in the back, which gives you information about what we do at the law center, and also some voter education information and I am happy to answer questions about that, as well.

DEBORAH GARNEAU: I wanted to remind people that if you do need a sign language interpreter, we have interpreter services available, and so please let me know. Also, we have assistive listening devices that are available if someone needs them. We can get them available to you. And then I wanted to ask each speaker to identify themselves and to spell out their names for the captioner. All of these recordings, everything said today will be recorded and reviewed by the Governor's Commission on Disabilities, and so we want to be sure we are reflecting it properly. And also as you give your testimony if you can provide the city or town in which you live in. So, we have people that have signed up to speak. All are welcome to speak. And we'll have folks sign up during the course, or just raise your hand and let me know. But our first signed speaker is Anthony.

Healthcare/ Supports: Smoking Cessation Program

ANTHONY FRANCO: Thank you. Hello everyone. My name is Anthony Franco from the ABLE (Active Behaviors for Living Empowered) program, I work in the Behavioral and Preventive Medicine Department at Miriam and what we're doing, and it’s a smoking cessation program specifically for people with mobility impairments. Now you don't have to want to quit smoking in order to be part of the program. The reason we are doing is this seems counter intuitive why be in the program if I don't want to quit, the reason we want to see how well our program works. We developed the program in conjunction with scientists and people with mobility impairments and professors at Brown and we want to see how well

our program works or doesn't so even if you didn't want to quit smoking at the beginning of the program -- at the end of the program, did you cutback, did you quit. So the program is for smokers, regardless of motivation to quit. Specifically with mobility impairment, could be any kind, wheel chair, cane, leg brace, back brace, as long as it's a mobility impairment and age has to be 18 or over. You will be financially compensated for your time, up to $150 and all treatments are done in home (sounds like). One thing we found during our pilot, a lot of times patients want to quit smoking but don't have the necessary tools to get out of their home and seek treatment so we, I personally would come out to their home to do the interventions and treatments at their home so negate transportation issues. If they are interested in quitting smoking we provide two months supply of in this case teen patches at no cost to them. And so that's the program. I left some brochures on the back table, they look like this and anyone here who has family members or friends who are smokers and have mobility impairments, feel more than free to give them our brochure, if anyone here would like to sign up, -- here until 6:00 to approach me. Any questions, concerns, questions about eligibility? No? Okay. 401-793-8168; also have an e-mail address ABLE@lifespan.org. Other questions?
DEBORAH GARNEAU: Thank you. We have another panelist that has come if you can just introduce yourself.
JUDI DREW: Judi Drew commissioner on the Governor's Commission.
DEBORAH GARNEAU: Second person signed up to speak, Trudy. You can stay in your seat wherever you're most comfortable.

Healthcare/ Supports: Supports Intensity Scale

TRUDY CHARTIER: I don't know if this is the right forum to be at but seeing the Governor's Commission on Disabilities was going to be here -- my name is Trudy Chartier, I am the mother of a severely disabled daughter who is (inaudible). Carrie has had the SIS[1] (Supports Intensity Scale) (sounds like) done just a couple weeks ago, I was present, my husband was present disabled daughter was present; staff member who is with her many hours was present. We were not pleased at the outcome of the SIS evaluation because I don't think that interviewer really listened to the people that were answering her questions and her program was severely cut. And to be honest with you, we shall not tolerate that cut. That's a big cut. She is very disabled. We've had a very long haul, I know she's my daughter, been in two group homes, four psychiatric hospitals, she really is 24/7 but she is not returning to a group home. And we can manage with the hours we have but my family, I have three daughters but to say this evaluation was correct, it was not. And I have asked, I have called -- I can't tell you how many people, and I know what, I hate to say this, but, employees at the state do not return our phone calls. I last week went down to Simpson Hall (sounds like) and I still couldn't reach -- person and there was no one there. I had my -- I want a review, and I had 9 addendums from everyone of Carrie's doctors current, and I could not find a person to leave that with so I left it on the chair, in a room, next to her desk. I am hoping to hear from someone. I have called many people today. I have -- many e-mails and unfortunately no one gets back to you. I would just like to know if they got my papers? When the review is going to take place? Is someone else coming to my home? I just want to know what's going on but I will not settle, I will not settle for what they did -- for the tier they've given Carrie, I don't know what I have to do but I will pursue the eves I can, I don't know if this is the right group to bring this to but I saw the Governor's Commission on Disabilities -- I did send an e-mail out today to that department, sent out several e-mails and made many phone calls so hopefully you will

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[1] **Supports Intensity Scale** (SIS) is a unique, scientific assessment tool specifically designed to measure the level of practical supports required by people with intellectual disabilities (i.e., mental retardation) to lead normal, independent, and quality lives in society.

get that e-mail. It wasn't addressed to anyone in particular because I don't know who to address it to. I hope I didn't take too much of your time and I have it's the proper -- I came to but I felt I had to voice my opinion. I think that -- I get a lot of e-mails not just from parents and people that call me and I think that, the SIS program unfortunately has been kind of unfair to many clients and their parents because this is supposed to be a choice thing and living in a community and now it looks as though we're going backwards. So thank you for your time. And I vented. Thank you.
DEBORAH GARNEAU: I do have a clarifying question. Thank you for sharing, I know this is difficult and this is a very appropriate group to share with so we're appreciative to have it recorded and to be able to, you know, I know your voice is that of many that we have heard from, as well. Just to clarify, is your daughter, was this a reevaluation or.
TRUDY CHARTIER: Reevaluation. I have been doing the plans all these years because I felt, as a mother, and I have very good contact with the psychiatrist and neurologist and have a lot of faith -- strict medicine regime as the doctor wrote in all of the letters you will see they feel I am very qualified, I only have an LPN (Licensed practical nurse) license but, you know, they know I know my daughter, I know how -- medication, she has (inaudible) she was in the hospital three times, two for falls, one forever choking has dysphasia[2] real bad (sounds like). All her problems, the home care -- not home care really has her own apartment, independent, down stairs but I live with a baby monitor in my ear all the time, no staff, I am on call all the time. And she's, like I said, severely disabled. And the doctor’s letters will prove this. Sometimes people come to your home and because a young lady is sitting in a chair well groomed, doesn't say anything and doesn't move, they think, what a wonderful picture but when my husband told her, come to my house and walk our shoes for one day. It's very hard. I know these people are supposed to be trained because they are social workers. But, you have to live with a severely disabled person to know their needs, including my 49 year-old girl being put on a bed pan. Sorry. It just define stated me when -- got that report.
DEBORAH GARNEAU: So, the clarification is that she had a SIS evaluation in the past and had a certain number of hours.
TRUDY CHARTIER: Was never a SIS (sounds like)
DEBORAH GARNEAU: So this is a first time --
TRUDY CHARTIER: I guess in progress three years but I think she's at the end of the totem pole because her program is until October 1st (sounds like)
KATE BOWDEN: The term SIS is S-I-S and it's a term used at the division of developmental disabilities for a way that they evaluate the needs of a person. So, if I am hearing you right.
DEBORAH GARNEAU: Supports intensity scale.
KATE BOWDEN: If I am hearing you correctly sounds like your daughter received a SIS and the outcome is that, you don't feel her needs will be met under the program --
TRUDY CHARTIER: They put her in Tier C and she belongs in Tier E and the psychiatrist has written a plan down, said if she was in the highest, that they want documentation, I gave them all documentation. I don't think it was even looked at. I think it wasn't looked at my house anyhow so I don't know what that documentation went to so I delivered a whole package to Carol Leach last week, she wasn't in I would have like today speak to her because I made about four phone calls to her and wasn't able to speak to her, I didn't want to send it by e-mail or mail I wanted to be sure I got it in her hands because I wanted those letters read, they don't a have to take mom's word they can take the professional's word, you know they don't take mom's word but professional's word, hopefully they will take. So I am very, very disappointed, devastated, I heard some people cut 25 percent but she was cut almost 50 percent. That's

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[2] **Dysphasia**: language disorder marked by deficiency in the generation of speech, and sometimes also in its comprehension, due to brain disease or damage.

ridiculous. We fought all these years to get there and a lot of people -- Jimmy Nolan used to come to my house, Joe Houle (sounds like), I knew all these people in the state, they knew Carrie, they got the stack of ISPs there, they were all okay cans and I wrote them. And they would call me, I would call Joe Gould (sounds like), Jimmy -- was the one that saw how bad she was but unfortunately no one knows Carrie anymore because it's all new people in the state although Jodi Merryman does.

JUDI DREW: You're saying 50 perils cut in services; practically what does that mean for you as far as how the care for your daughter will change.

TRUDY CHARTIER: Cut from 90 hours down to 50 hours. I was doing the rest. She goes to bed at 11:00, up at 5:00 on meds and -- she cannot do any unassisted, severe movement disorder which gives Dyskinesia[3] or disco kneesia (sounds like), I had an episode last night until 12:00, severe pain, and you have to give her a tranquilizer, a Sinemet[4] (sounds like) for muscle rigidity and have to give all these meds and some reason the meds don't kick into her system, the anxiety, they don't kick in so you give her more and you give more and you get side effects like she had hallucinations last night and I don't get much sleep and unfortunately 2 days before the SIS -- I had surgery for breast cancer and I wasn't in the mood to (inaudible) but I did. I don't like the things that she had to say or deny me if she got a four (sounds like). I had staff that lived with letter and she needed fours in almost everything. When you get on tier C those are not fours.

JUDI DREW: Can we talk after this meeting?

TRUDY CHARTIER: Sure, I'm sorry everybody.

JUDI DREW: I'd like to talk about follow up ideas with you about advocacy.

TRUDY CHARTIER: Again I'm sorry.

FEMALE AUDIENCE SPEAKER: Don't be sorry.

DEBORAH GARNEAU: The next person that is signed up to speak, Vinny.

Healthcare/ Supports:
Supports Intensity Scale

VINNIE WARD: I'll come over here, there is no one behind me. My name is Vinnie Ward. I live in Woonsocket; my business is home care services of Rhode Island Inc. in Woonsocket. I have never been to one of these forums before so I can appreciate you having this, and just coming here, this particular moment, seems like an opportune time especially after Trudy just spoke. I have two patients that are in BHDDH (Behavioral Healthcare, Developmental Disabilities and Hospitals) care. One of them is in a community day program. The other one is a 23 year-old that basically spends time on her hospital bed in her home and doesn't go anywhere. She can't go anywhere, she's on a ventilator. When she mentioned the SIS, I can tell you, the people that are being interviewed with that form are not happy. They're asking questions about their sex lives, they're asking questions about their work, what they're able to do for work, and they seem to have this point of getting to what can she do for work, what can they do for work? It's like this direction that the state is going in, that's all they're concerned with. Their socialization, their work history, but when I deal with these of patients, I don't deal with them like seven hills (sounds like), they're dealing with behavioral and some other issues, I deal with the medical part of it. The forms that they are using in the ISP questions have nothing to do with what we're doing. It's not even an appropriate form for what we're doing but that's what the state came up with because 18 other states use it, they use it in other states as a portion of the tool that is used to determine what care and what services

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[3] **Dyskinesia** is a movement disorder which consists of adverse effects including diminished voluntary movements and the presence of involuntary movements, similar to tics or chorea.

[4] Carbidopa/levodopa (sometimes referred to as levocarb) is the combination of carbidopa and levodopa and is used to treat Parkinson's disease and dopamine-responsive dystonia (DRD). It is sold under several brand names, including **Sinemet**, Pharmacopa, Atamet, and Apo-Levocarb.

they are going to need. In Rhode Island, it's the only form they use so they are not using it as a complete program of looking at everything. So, what they have done to these two patients in the past two months because now home care has only been involved in this this year. We got called to meetings in April. I have never dealt with this. Our system was, you fill out an HS3 form, you send it in to the people at DD, they send back the form, and it's the authorization is for the year. And there was never a dollar amount attached to it. It was this is how many hours a week we are authorizing. And, you know, when they ask that, they would ask, how many hours a week do they need? They don't ask that any more. Now it's how many -- this is how many dollars your tier is going to give you in services. So in both of these cases, they have now been put in tier D. Tier D does not authorize enough dollars, there is not enough in tier D to get those two young adults the services they need for their two parents in one case; single parent in the other case, to get enough hours to work. They are put in a position, one of them, I asked the mother if I could provide you with a picture of their daughter, she said it would be okay, I am not giving names anyway but basically, this is her daughter. Now, they ask questions of the mother, of her socialization, they ask questions of her sex life, they ask questions of her work, possible employment. These are all things, and I can tell you that Dave McMahon, when I went to that meeting he said that every one of those factors have to be filled out with something. What they are doing to these parents is they're putting them through hell with a form that has nothing to do with what -- it's not community program people. These are people that are nursing, skilled nursing, and the problem that we're having is now, both of them -- the single mother, they have told me, now she has to work full-time, like everyone else I know. And, they are telling me that under the tier D, the skilled nursing will provide 37 and ½ hours a week. Now she worked 40. She has to drive to work, she has to come home from work and I know you're not going to believe it but she has to do grocery shopping, has to get out of her house sometime to go to a movie to get away from minus her 40 hours of work to do something to help this woman and the state has said under BHDDH (Behavioral Healthcare, Developmental Disabilities and Hospitals) -- again it wasn't your 37 and a half hours a week it was you are 9, -- so many dollars. All re-involved around dollars, this is the dollars you get in tier D, you can use it for community -- for respite -- but that's the total you got. The other case, husband and wife, they have to work. Almost 32 hours a week -- by the way the 35 (sounds like) hours a week has been for years. The other one that's what she was getting. The other 32 hours a week, for years, I've been taking care of her 15 years plus, it's been 32 hours a week. Now they're in their 60s and they're being told its 24 now. That includes the time in the morning to get them up, get them ready to go to a day program and come home at the end of the day so the parents can work. It's not enough hours but that doesn't matter because it's how many dollars it costs now. And I am telling you that's all they are concerned with, how many dollars is available to your child, daughter, son, whatever, is in this program, nothing to do with how much help you need, it's how many dollars is it going to cost to do it, if you go over that what they've now told me fill out a form for DHS (Department of Human Services) and we'll see if we can get an authorization for DHS but for a portion of that. The problem with doing that and I can appreciate that. I understand the state doesn't have a lot of money, also, I do know that. But, they are putting it, putting the parents in a position, one of them loses her job, she happens to work for the city of Woonsocket. She will lose her job after August 1st because she can't work full-time any more. I sent in the paperwork, I went to a hearing for this in April, middle of April. I had my, my paperwork in by May 10th, whole form filled out and that's when I could get an appointment with the social worker, the parent, myself, director of nurses -- you have to meet everybody, all the people have to be there. So, we got this May 10th. It was shipped off to them. I got a message back. Sorry, you're over hours -- you spent too much money. So because I spent too much money we need to apply to DHS. May 13th I sent a new set of four more pages -- actually more than that to DHS, May 13th. I sent them to the caseworker. June 29th I am on the phone, this ends July 1st. June 29th on the phone with four or five people from BHDDH and one of the fiscal people and they're all very nice people to talk to if you can get them on the phone, they are very nice. But it became, well, you have to get that form into us. I said what are you talking about? The fiscal people hadn't gotten the form from the caseworker. So it was like...I didn't think that was my fault. I sent it in May 13th. This is June 29th and you haven't given me an authorization for July 1st. This woman can't work in two days. So they said I'm going to authorize it for two more weeks, ended up authorizing it for a month. During that month they said to me, about, I waited until -- I didn't want to harass them, waited until like the 14th of the month, actually 15th it was a Monday, July 15th, I come in, I said, can you tell me where we stand, it's expiring today and they told me, it's going until the end of the month but you need to send in an S109 form. I said that's nice, when was someone going to tell me that? When was someone going to tell me what an S109 form was? No one ever said anything to me -- that's BHDDH's form -- how am I supposed to know you needed that form. They didn't say that before, this is the first mention of it, the day this thing was going to expire so two more weeks. I sent -- actually, I could have crossed your path last week, I hand deliver it had into the office at BHDDH. Jodi was not in. Trying to think of who else I had to deal with, there were two other caseworkers not in, the finance person, fiscal person not in, other fiscal person, not in. So I am not doubting at all that they are really busy and they're going crazy, I believe that because I know when you call anywhere in state government you can't get anyone to answer the phones because they're overwhelmed with work, I understand that but that's what happened I couldn't get it to anybody. Just so happens, my brother works for BHDDH for a completely separate area but in the Simpson building so I took it to him and said can you get it to them so it would get to the right people but the system itself is not appropriate for the medically needy patients. It's okay for the community, the day program people but it is not correct for the medically -- at this point have I no knowledge whether or not in the next week they will do something to get DHS to give me the extra hours so mom can keep her job which pays her Blue Cross which pays most of the bills instead of Medicaid paying them. Do they want her to lose her job and go on Medicaid for everything? I don't think so but they're not helping the situation. I know they mean well, I know they're short of money but if you leave these people with no help and you force them out of work, it's not going -- it's hard enough finding jobs for people, they have jobs and they can't keep them because the state doesn't want to authorize -- there are no other care givers, also. This is not like, well, get one of the kids, get....the spouse...this is not possible with these two particular cases so it's not like they're not, that they're just trying to abuse it. As a matter of fact when they don't -- one of the two -- the one that has two parents, one of the parents was out of work, we did less hours during that whole year while he was out of work because he had a severance package, now that that's done he has to go back to work. So, now he needs the hours again. We didn't abuse it, we don't believe in doing that. If the person doesn't need them we tell DHS, we tell anyone, 23 they don't need the hours we try to take them away to save them for someone that really does. Have you a question?

DEBORAH GARNEAU: Yes one of the roles of the panelist is to clarify the issues to be sure to try and address it. When you said calling DHS, is that in application for long-term care?

Healthcare/ Supports: Home Care

VINNIE WARD: I don't know. Because they said hand it to us. We deliver it to DHS so I have no idea. A form for some additional, skilled nursing hours but I don't know who gets it, who looks at it, I don't know. The other thing I want to bring up from a personal point of view from a home care agency owner. I am running into more people now, last week, I am looking for some CNAs

(Certified Nursing Assistant) that are bilingual and hi had real good luck with sir jobs in progress (sounds like) Pawtucket, Warwick whatever, I called Joe Hahn (sounds like) last week said I need a couple CNAs, his response, I am Medicaid only not Medicare so I don't reimburse gas mileage, his response to me was I can't help you, you don't reimburse gas mileage because you don't get enough money, well I can't -- the CNAs can't do it because they can't afford to because the price of gas is 3.75 a gallon, can't afford to work as a home care. The reimbursement rates, the one I just told you about the two nursing issues I went looking back in my records only stopped at 2002, the reimbursement rate for the skilled nursing is the same rate as it was in 2002 and it goes back further than that I just don't know how far because I didn't keep looking but same rate, called LPN (Licensed Practical Nurse) rate, I can't even have an LPN a, a case with (inaudible) so I'm paying an RN (Registered Nurse) (sounds like) -- haven't changed the rate in over 12 years. At some point the state has to recognize that and BHDDH says that's not our fault DHS sets the rates so call them what do they say not our fault BHDDH pays the money out of their funds. Have I had nurses come into the office as soon as we tell them the rate which is higher than many agencies and we know that because we talk to different agencies, they will tell us, they will laugh at us and say I am not working for $25 an hour. They can go to a nursing hour and get 32, 34, 35; they can go to a hospital get 42/45. Why do they want to do home care for $25 an hour and I am getting reimbursed 31.
JUDI DREW: Can I ask a question, first thing that comes to mind who bears responsibility if that nurse make a mistake for that client that is on a vent, do you provide coverage?
VINNIE WARD: Absolutely.
JUDI DREW: So that's part of the cost of your doing business, too.
VINNIE WARD: I assure the prices of that have gone up year after year -- I have to have professional liability insurance.
JUDI DREW: Do you require they do.
VINNIE WARD: No I have enough to cover them, if they choose to have their own and we advise them of that.
JUDI DREW: Not a barrier to recruiting nurses.
VINNIE WARD: No that's not a barrier, the barrier is, I am just, they are getting paid so little, if I take $31 an hour today from 2002 -- today the rate would have to be 40.something cents to be equal in value as it was in 2002 and it's equal to right now a $21 reimbursement is what it's equal to in today's dollars. So it doesn't stop them, I can assure you if there is a nurse doing home care it's because they want to help out not because they are doing it for the money, but it's making it more and more difficult, I belong to Rhode Island Partnership for Home Care, state said we gave awe raise in 2008, I guess we're supposed to say thank you, thank you, they're forgetting in 2009 they took part of it back, they never bring that up, but they did. And the previous rate before that you have to go back into the 1990ses.
JUDI DREW: How will it impact your business going forward?
VINNIE WARD: Already impacts our business, I have, not my patient, a family that called me with a ventilator patient that is in their 20s, the mother used to work for me so-called me and said, hey, can you help me? I can't find work. A nurse, they'll say no, it's third shift, second shift, and it's on a vent. They are not going to take someone is not going to work for $25 an hour on second and third shift in a home so it already affects me and more than me it affects those parents and those are the ones I am mostly concerned about I am trying 20 stay? Business but they are the ones really hurting when they don't get the help.
JUDI DREW: Like yours facing these barriers what it means to families that's why I am asking business related questions because the Governor's Commission we can't provide services all we can do is connect you to people to talk to but we can support legislation. So, if there is

anything that we discover in this hearing that there may be a legislative remedy that could potentially be our role that's why I'm asking these questions.
VINNIE WARD: Well I'm glad you're here and sorry I kept on but I had to bring up -- at least to help those two patients out. It's not, I don't want to blame anybody it's just, because it's new to BHDDH, the home care aspect, the nursing part is new to them, too, so I just don't know where else we can turn when the fact is the SIS form is not the appropriate form and the ISP is not appropriate questions for this particular level of care for these patients. Thank you.
DEBORAH GARNEAU: Thank you. Do you have another sheet for me? At this time there is no one else that has asked to speak but certainly we are here and we would like to hear testimony if you have it.
RAYMOND COURNOYER: I have a 20 year-old boy.
DEBORAH GARNEAU: Have you to state your name for the recording and where you live please.

Healthcare/ Supports:
SIS Reevaluation

RAYMOND COURNOYER: Raymond Cournoyer, I live in Woonsocket. I have a 20 year-old boy. He is in Tier B (sounds like). From what I understand from my wife and the teachers from school he should go to a Tier C.
DEBORAH GARNEAU: So you're talking about the SIS again.
RAYMOND COURNOYER: Yes, yes. We did fill out some forms last week, and gave all of the information that we had to but we want to know how do we go about wanting to get into a next tier, Tier C because we know our son and we know what escapable of doing and not doing. And he...what they gave us for funds and what he needs, it's not enough.
DEBORAH GARNEAU: So he is currently in the Woonsocket school.
RAYMOND COURNOYER: Just graduated this year so he is going to be going into (inaudible) street. We are with Seven Hills, five days a week, four (sounds like) hours a day with them. And he's going to be leaving them, he'll be 21 in August, trying to get all of his paperwork in, and we're stuck with this one -- we got our funds, we want to appeal it -- is that the word?
DEBORAH GARNEAU: There is an appeal.
RAYMOND COURNOYER: Went through DD went through all that got the social worker but we want to know how do you go about appealing?
TRUDY CHARTIER: Form 109.
RAYMOND COURNOYER: No one told me about that form.
MALE SPEAKER: It's a written page form (sounds like) you can add addendums but that form basically says on it you are appealing the tier that you're at.
SPEAKER: Where do you get this form?
VINNIE WARD: You can get it online the BHDDH website, project sustainability. Even if you did a search on BHDDH, if you did one for BHDDH project sustainability you should be able to get into the web site and find a form even in the search look up form S109. Sustainability, but your caseworker should be doing that.
TRUDY CHARTIER: It's a review form. Do it yourself.
RAYMOND COURNOYER: ...She's really on top of everything -- I'm out of work.
TRUDY CHARTIER: S109 and you want a review; you want a review form of the SIS assessment. Another thing that's going to be difficult, I have trouble getting staff because of my daughter's (inaudible) and the big frustration with her is communication and that's -- a lot of behavior problems and I have trouble getting staff -- fortunate Corliss for years, some left that place and came -- but she can't communicate that's a big problem you start cutting down their hours, I'm going to lose them. I am going to lose those people, they will not work from reducing their hours and I can't find people. Like he said, you can't find people to begin with

and if you don't give them hours they are going to leave you. That's a big problem there, too by having reduced staff.
RAYMOND COURNOYER: My wife has to go and hire -- we're just starting this. This is new to us. My wife Pauline, she's find the answer she won't give up.
TRUDY CHARTIER: ...On those forms, they are for people with a high IQ and even the ISP, they're just -- my daughter couldn't -- no way. No way, I mean, talk about their future, their vocational, their work, it's just -- can they get their own legal advice, have you to be kidding me, can she call a lawyer, she can't help herself how is she going to -- the questions are just so farfetched.
DEBORAH GARNEAU: The SIS is a summarized form that everyone --
TRUDY CHARTIER: Before you used to write your own summary, where she is at, goals, it was like a history, now it's all these questions that are just, almost unrelated to the situation. And if you don't -- I used to fill my own out, I am so afraid to fill it out now because if it's not filled out right it will be sent back to you so now your plan is being cut, if you want to hire a plan writer to get it done right that's $500, that comes right out of their program and it's reduced already so I hate to hire a plan writer. For the first time I am thinking of it and I hate to pay $500 because no one knows my daughter better than me but if it's not written right for the Department of Health and behavior, they will send it right back to me. So....it's just.
DEBORAH GARNEAU: It's unfortunate we do not have a representative from Behavioral Health Disabilities.
TRUDY CHARTIER: That's why I went up and looked at all --
DEBORAH GARNEAU: However because its written transcript they will get the information and we will be able to bring the issues forward.
TRUDY CHARTIER: I am sure people have brought issues to them, there's so many parents... request for reviews, you know.... I mean I can see where they have to cut but some of these cuts, you know, these are needy people, they're not hurting me or my husband in a way, they're hurting the clients, they are hurting the clients. Luckily, some of these clients have parents but parents are getting older. I have been at this, my daughter -- when she was 4... 49. We are getting older and starting to breakdown a little bit. You get tired. You know, you get tired and you just wonder, you have one or two or three years that you can devote to these kids of yours and what's going to happen after so trying to pave that road, and now they're going backwards, all the years we tried to pave the road, you know, now you're going backwards.
VINNIE WARD: If I'm correct BHDDH.
DEBORAH GARNEAU: Behavioral Health Developmental Disabilities and Hospitals.
VINNIE WARD: Notice what's not in there, anything related to skilled nursing. That's why I'm saying it doesn't fit in, like the round peg trying to go into a square hole, they don't fit right.
DEBORAH GARNEAU: I think it's still managed under DHS.
VINNIE WARD: It's managed under it but.
DEBORAH GARNEAU: So it's a separate.
VINNIE WARD: It's separate, it's a different issue. The other thing since I'm here -- DHS what they need to do, we have skilled nursing grades that are varied. They have them for like day shift, evenings, nights, weekends and holidays. What they don't have which is what I brought up, the patients on ventilators, they need something that is above all of those grades for high tech, high skilled nurses, to do things like ventilators, because that may allow us -- I don't ask them for more money for my company, whenever I ask for raises, I'll direct pass it right to the people. I just want it so they can pay for gas, they can go to a movie, they can go do something instead of feeling like they're working -- they're all falling behind year after year, their pay is worth less and less and less and when you're a CNA, it's going to get worse than

minimum wage if you have to go driving around and I pay them enough, too, but it's crazy, the value their pay is going down every year. So, it's just something that, they need a rate that will attract someone to do ventilator work on second shift or third shift. If the highest rate for -- is usually the overnight shift of a weekend of the same rate, say that's $38 an hour for an RN well then maybe there should be a $44 rate, at least I can pay the nurse $31 an hour, now maybe 31 will get someone to work it, 25 doesn't.

JUDI CHARTIER: I want to ask a clarifying question, if you can't pay the rate or pay fund to -- the care, where does that person end up, in the hospital?

VINNIE WARD: Of course, but they don't look at that, they don't generally.

Healthcare/Supports: Medicaid. Medicare

JUDI CHARTIER: Let's see home health care rate, hospital rate.

DAWN WARDYGA: I'm Dawn Wardyga, commissioner on the Governor's Commission on Disabilities, for those of you at the meeting earlier today, this just spoke volumes for me. We have heard about (inaudible) for God knows how many years and absolutely support that; if those rates don't come up we will not have the staff we need to keep people where they're supposed to be. Earlier today there was a hearing, a hearing on the state's Medicaid waiver application to the federal government. There was also a hearing I believe on Friday, but I am not sure and I don't have the file with me but I know there is one more public hearing, if someone has that information, there is one more public hearing coming up and it has to do with the application being submitted to the feds for a five-year plan for the Medicaid program in the state of Rhode Island. Listening to this discussion, I am not sure -- the rest of my friends out here your blood is probably boiling just like mine, these kinds of discussions like today, I'm thinking today, where were these people today, they needed to be at that meeting, of course they probably didn't know it was happening. So, there is a third hearing related to the Medicaid waiver discussions. There is also a written comment period, and while I don't have the information off the top of my head. I think that the commission, we should find a way to get that information out to whoever is in this room. Again, you don't have to attend the meeting in person, but you can certainly send in written concerns about the Medicaid program the way you see it. I haven't read it, every single page and I probably won't as long as I live and I have been doing Medicaid for a long time. But, I bet my last dollar and I'm almost there but I bet my last dollar that there isn't anything in there about an increase in rates. So, I am making a suggestion --

JUDI CHARTIER: Dawn don't they have to put out a public notice for that.

DAWN WARDYGA: Absolutely there was a picture of it in the newspaper I saw if on the website. Again, for the record I happen to be a task force member for the global waiver task force so the previous waiver and I didn't know about these hearings. I missed the first one because I didn't know about it; I did show up at the one today. But again it was... write it down here -- leave it to Denise -- okay. The next public meeting is Thursday the 25th, that's this week. Anybody know what the location was on that one? No? I'm thinking probably in the northern part of the state but I could be wrong. Public comment period July 10 through August 10, I am going to give a website. It's www.eohhs.ri.gov/ri1115waiver/updates. What that will give you is it's going to give you the actual language in the application that goes to the feds, this is the application that has been written by the Medicare officials in the state (sounds like), it's going to the federal government to get approved for a five-year plan. The only reason I am stressing that right now is if you're not heard now, you might have to wait another five years, I can't say that for sure. It's here, July 25th, 4:00 to 6:00 p.m. -- sorry, Woonsocket City Hall, Harris Hall in Woonsocket. July 25th, 4:00 to 6:00 at Woonsocket City Hall.

TRUDY CHARTIER: I have one more question maybe this lady can help me, my daughter was so bad, they wanted her to go to a nursing home and reduced that so because of that they put her on a Medicare waiver -- maybe it's Medicaid, waiver, so because she's on that should her hours be reduced that much.

DAWN WARDYGA: No this is exactly what I was saying, obviously Medicaid is very complex, where he got into a sayings about rates which as far as I'm concerned.

TRUDY CHARTIER: I just have regular people that are -- I'm lucky they take the job for what I pay.

DAWN WARDYGA: Your daughter is probably what think call dual eligible which means she has Medicare and Medicaid.

TRUDY CHARTIER: Correct.

DAWN WARDYGA: What that means is anybody in the state that gets Medicaid benefits regardless of their age, will come under the parameters of the state's Medicaid program. So, again, it's complex, clearly, complex situation, but, we know rates have been a huge issue for a very long period of time. But I remember hearing (sounds like) anyone raise the issue on the hearings related to this waiver that's being submitted to the feds. As a matter of fact it's already been submitted once and the feds kicked it back so I am not aware of any rate changes in there and I think that's what needs to be heard, and coming from you, all of you, mean a heck of a lot more than coming from me.

TRUDY CHARTIER: Even in the letter I got from Mr. Marchtin which is no longer in that capacity, the letter I got from him says something about...after this has been approved by your medical waiver -- I mean why does it, have to be approved by -- she's been on this waiver.

TRUDY CHARTIER: Like I said.

DAWN WARDYGA: What I can tell you about Medicaid and then we can move on, just because it's been authorized for however long they do have to be recertified periodically.

TRUDY CHARTIER: I get something every year from Woonsocket and I have to fill out -- then they send back you're approved, you're approved that's why I don't know why this letter from Mr. Marchtin telling me I have to check that happen out.

DAWN WARDYGA: Systems changing rapidly and I personally am not convinced that the offer all system is prepared to handle those changes.

Healthcare/
Supports: Transition

RAYMOND COURNOYER: I have a question, my name is Ray Cournoyer. My question is, how can the Department of Health setup a person to help out us filling out paperwork for our children, beside, tried social worker, has no clue because it's new to him, he doesn't understand it all.

DEBORAH GARNEAU: I was specifically going to ask either Denise Achin (sounds like) here with the Rhode Island Department of Education or Deb Maslin from RIPIN if they had information they could share with -- since his son is in transition, RIPIN has a -- there is a workshop for families whose children are transitioning from youth services to adult services with specifically, your child's diagnosis and there are workshops pathways to adult services is the name of it, so they're being organized so maybe -- I was looking through your e-mail to see if you had -- so they could follow up and also Denise (sounds like), the transition academies provide some sort of resources or.

FEMALE SPEAKER: Each School Department has people who are SIS families (sounds like) with the transition process and the know -- teachers themselves have been part of the SIS process, I don't know if in terms of filling out the paperwork or appeals that might happen what the role or training has been for school personnel to assist families with that, so something we could bring back. There is a network of teachers that work with the population that typically will transfer into the adult DD system through BHDDH and (inaudible) within that system to look to see what could be done to assist with that process as Deb had said the SIS while it's been around two or three (sounds like) years I think this is the first full implementation which I

think is why your daughter just had hers -- who had been in the system for years just had that done so I think we have to take that into consideration that there is a new system.
DEBORAH GARNEAU: There is that Pathways to Adult Services Workshop does go through how to prepare for the SIS, what you should expect, how to, what kinds of documentations, what is the appeal process...so, Deb (sounds like) can probably give you the phone number.
FEMALE SPEAKER: If you have a point person with the School Department that you worked with while your son or your daughter -- your son?
RAYMOND COURNOYER: Son.
FEMALE SPEAKER: While your son was still in the system -- a person there that is more knowledgeable, I don't what work has been done between the departments.
RAYMOND COURNOYER: When we had the last IEP, (Individualized Education Plan) they had no idea how to fill out any of the paperwork, so, we had to look and get help through the department. But we need to be educated on how to fill out this paperwork.
TRUDY CHARTIER: Plan writers are very expensive, they have professional plan writers but they charge you $500.
FEMALE AUDIENCE MEMBER: My sister is in the process of doing the plan with someone from Seven Hills.
TRUDY CHARTIER: Yeah if you have someone to help.
FEMALE AUDIENCE MEMBER: Her, and I were trying to -- because we know what (inaudible) is capable of; we know what he wants to do.
TRUDY CHARTIER: You're the best one that knows.
FEMALE AUDIENCE MEMBER: Right but then -- has to hire somebody, too, who can do this so they're trying to setup a program for him, Seven Hills is working with my sister (sounds like) to try and setup a program for him (inaudible) so, once that program is...you know, once it's set...then he'll be.
DEBORAH GARNEAU: One of the things I wanted to do is to ask if there is other official testimony we can definitely stay and share amongst yourselves and even with the panelists but is there other official testimony that anyone would want to provide to the Governor's Commission on Disabilities?
FEMALE SPEAKER: Can I just ask you to speak up so that the CART reporter doesn't have to strain to hear.
DEBORAH GARNEAU: I am going to propose that we take a ten-minute break and, feel free to stay and we're here, as well. (5:02). ***********************************
DEBORAH GARNEAU: It sounds like there is a lot of conversation here. I don't know if anyone has any formal testimony, we can go on the record again, it is 5:45. Okay, we can stay the way we are. (FORUM CLOSED)

Tuesday, July 23, 2013- Middletown Public Forum

CHRIS DEGRAVE: We are going to go ahead and get started.
LINDA WARD: Good afternoon, everyone. I am Linda Ward from Opportunities Unlimited. We are the sponsor for this forum. A couple of things, I am laughing because it says I am supposed to show you, tell you where the public phone is. I don't believe there are any public phones in the library anymore. However, bathrooms are out there if you should need them. And I am going to -- you all have signed in. And if you did not indicate you want to speak, but after you hear what other people have to say and you have something to add, raise your hand. And I am going to read exactly a couple of statements. The purpose of these forums is to identify the concerns of people with disabilities and their families in order to assist the state to develop programs that improve the quality of life of people with disabilities. It's also to ensure everyone who wants to speak today gets a chance. Please keep your comments short and to the point. If you have a critical need that needs to be addressed, the panel members

will be available at the end of the hearing to direct you to the proper agency for help. After the public forums are completed, in early August the sponsoring agencies will review the testimony and prepare recommendations which will also be posted on the website by the end of November. The recommendations and the transcripts will be printed and sent to state and Congressional officials and to the members of the General Assembly. And recommendations will be used to develop policy and legislative initiatives for the next year or until they are accomplished. There is voting registration material over there, right, Chris? And if you have a mean to change an address or anything, that's there as well.

There's some stuff from the Disability Law Center. I am not exactly sure --

BRIAN ADAE: That's me.

LINDA WARD: There's something up there.

BRIAN ADAE: Yes there is

LINDA WARD: And something from the Department of Health. Afterwards feel free. We are not using the mic --

CHRIS DEGRAVE: We will not use the PA system unless someone requested assistive device. Because it has some feedback, I would rather not. If we have to it's completely fine. The Assistive Listening Device, we have them available. And we are good to go.

LINDA WARD: I am going to ask the panel to introduce them-selves and we will go from there.

CHRIS DEGRAVE: I am Chris DeGrave; I am a staff person at the Commission of Disabilities. I do all the federal and state accessibility for the state of Rhode Island.

JOSEPH CIRILLO: I am Joe Cirillo, member of the Governor’s Commission on Disabilities and the former state building commissioner and an architect. But I am retired.

BRIAN ADAE: My name is Brian Adae. I am a staff attorney with the Rhode Island Disability Law Center. For those who may not be familiar with the Disability Law Center is part of the national protective and advocacy system for folks with disabilities that was created by Congress about 35-40 years ago. Essentially what the Disability Law Center is, is for the state of Rhode Island. There is what's referred to in every state territory a P and A. We are the one for Rhode Island. And we operate independent of any providers, the state or virtually anybody else, essentially federally funded providing legal based advocacy under a number of different federal programs, doing a variety of things. And what was mentioned that there is a packet there from my director. A request for comments. Usually every year at this time we go through our annual priorities, which determine what things we pay attention to and try to address. Those annual priorities are contained in that packet. And this is a request for comments or changes that you think should be made to our annual priorities that we ask the consumers and the community at large. Our contact information is in there. I encourage you to pick it up. And if you would like, we also do voting rights. So there's information about voting rights as well as voter registration. I would be happy to assist anybody who needs to register to vote. Any other questions, I am happy to answer, probably afterwards. Other than that, we would like to hear your comments today.

COLLEEN POLSELLI: I am Colleen Polselli, from the Office of Special Healthcare Needs at the Rhode Island Department of Health. And we have Pediatric Specialty Services in our office. This is for children and youth with Special Healthcare Needs, any type of special need, also disability and health program. We have a CDC grant concentrating on health promotion for people with disabilities, emergency preparedness, and improving accessibility.

MIKE MONTANARO: Mike Montanaro supervisor with the Office of Rehabilitation Services. We are a state agency that assists individuals with disabilities in becoming employed. Not only gain employment but to maintain employment also.

LINDA WARD: Okay. I am going to probably butcher a lot of names. So the first name is Walter Jachna. Did I say it right?

Employment: Shelter Workshops

WALTER JACHNA: Jachna, yes. I am with the James Maher Center on the board of directors and my in-laws and my family has been connected with the Maher Center even before it actually was founded. And I just wanted to say about the sheltered workshops. I really would like to see them go away. Yet we have a population at the shelter workshops[5] who really would be -- if not impossible, very difficult to integrate into a public job. I know they don't make a lot of money because of 14 C but they get paid on what they are capable of doing. And these checks, though small are extremely important to our clients and individuals.

My sister-in-law lived with us until her Alzheimer's got so bad she had to live in a group home. Every two weeks no matter what the size of her check, before she would do anything with it, she would come home with it. And she was so proud of that check, whether it was for $10, $20, or $30. But it showed that she was doing what she could do and putting every effort that she could into her job.

If they lose that, they are going to lose a lot of pride that will be taken away from them. It will take away self-achievement, what they can achieve. To me it's very depressing that that could be eliminated if 14 C is eliminated. I don't think there are any agencies that have the ability to pay regular minimum wage to a client who maybe can process three or four sheets of paper through a shredder in an hour. But no matter how small the check is to that individual, it gives them a sense of pride and accomplishment. And I would just hate to see that go away, because it's going to have a devastating effect on our clients.

I know, in the Maher Center as I think has been one of the leaders for employment. We have clients now who make more money at our federal contracts than some of our staff members. So we have moved people and integrated them into the community in large numbers, dozens of them. But there are these groups who need a quieter place to work and who need more guidance. And I think if you take away that opportunity to make some money, it will be devastating to them. Thank you.

LINDA WARD: Okay. Just tell me. Geidy.

Healthcare/ Supports: Smoking Cessation Program

GEIDY NOLASCO: Hi, my name is Geidy Nolasco. I am the director of the ABLE (Active Behaviors for Living Empowered) Program, which is a program for individuals with mobility impairments who are smokers. And what we do is we help them in the process of quitting smoking by providing intervention, two months of nicotine patches for free, and also we pay them for their time. So, if anyone is interested or know anybody that might be interested, please come see me and I will talk to you more about it.

LINDA WARD: I am not sure.

IRIA: Iria is fine. I personally have two medical doctors who have succumbed to environmentally induced diseases, one with brain cancer, and the other with leukemia. They both well before retirement age has had to transfer their practices to other MDs. One is not expected to survive. It's time for -- it's time Rhode Island move beyond its toxicological myopia (nearsightedness) and step up to its public safety responsibility.

At the request of the Rhode Island Governor's Commission on Disability in previous annual forum, a comprehensive review of risks associated with RF radiation exposure being installed in Rhode Island multiunit residential fire code response to 2003 Station Night Club negligence

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[5] **Sheltered workshop:** refers to an organization or environment that employs people with disabilities separately from others. The term 'sheltered workshop' is considered outdated in the U.K. and the U.S., and increasingly in Australia.

was provided to both the Rhode Island Governor's Commission on Disabilities and the Rhode Island Disability Law Center.

Housing: Environmental Concerns

Carcinogenesis has been {inaudible} "treatment for a single case up to $1 million and resources to address this already in short supply and not universally available in either developing or developed countries." Wireless industry FCC (Federal Communications Commission) disclosure of financial risk for liability for "health effects of radiofrequency transmissions" states "may incur significant expenses in defending these lawsuits and may be required to pay significant awards or settlements."

With 60,000 pediatrician MD members, the American Academy of Pediatrics formally expressed concern on "radiation standards" for wireless products to FCC, cost effective fire safety, and asthma prevention improvements could have been simply implemented without financially crippling Rhode Island's already chronically deficient affordable housing stock with legislation of multiunit residential nonsmoking policy successfully implemented in residential complex in Rhode Island over a decade ago for incurrent -- insurance cost savings purposes. And subsequently advised by HUD (Housing and Urban Development) and successfully implemented in some Rhode Island low income housing.

Asthma management accepted 26 years ago by top medical and US National Institute of Health MDs and widely published advised avoidance of respiratory irritants of cigarette smoke, perfume, and strong odors. Today accepted asthma management as described by our own top medical school MD experts is "avoidant of respiratory irritants" including cigarette smoke and indoor and outdoor pollutants and irritants specifically "gas, smoke, fumes or vapors with irritant properties" conditions inherent to shared building envelopes with gas appliances.

Rhode Island Housing and Mortgage Finance Corporation according to its own official statement "a public corporation" and instrumentally and agency of the state of Rhode Island and Providence Plantations references $39,950,000 of bonds issued to "make funds available to purchase program loans to finance the ownership and improvement of single -- single family housing within the state by eligible low and moderate income families."

Yet federal SSDI (Social Security Disability Insurance) disabled in pursuit of disability homeownership monthly payment assistance detailed in Federal Registered statute for over a decade have not been able to get phone calls returned from Rhode Island Housing and Mortgage Finance Corporation and have been steered instead to Welfare to Work, family self-sufficiency, and land trust training for work force affordable housing for working families making 35 to $85,000 a year annual salary.

Federal Social Security disability income earned through mandatory employment deductions is likely not much over $20,000 a year with no or minimal annual cost of living adjustments. Life savings are decimated by medical expenses and basic survival needs.

The lifeline to self-sufficiency for this disability sector we are representing is simple and achievable. It begins with health stabilization in detached unit housing, accessible to their well-defined and well documented medical needs under well-defined and long accepted medical standards. This disability sector is primarily university educated. And prior to their adult onset Federal Social Security Disability Income, disability was not from socioeconomically deprived background. They do not need Welfare to Work, English as a Second Language, high school, smoking secession, or asthma prevention education. They do not need child care or family self-sufficiency or budgeting or credit repair training. They do not need substance abuse, crime, or gang prevention supported services.

Housing: Accessibility and Affordability

They need housing accessible to their medical disability needs for the health stabilization needed to begin their path back to self-sufficiency. Their path begins with housing accessible to their medical needs. The disability sector we are representing needs the homeownership monthly payment option for purchase of detached unit, accommodative housing, detailed in Federal Register statute for a decade as a reasonable accommodation for their well-defined medical needs under well-defined and long accepted medical standards.

They need motel vouchers for emergency shelter as a reasonable accommodation for their well-defined medical needs under well-defined and long accepted medical standards. Shared building envelope multiunit housing stock simply cannot meet their medical disability needs. Rhode Island has a long well documented history of discrimination against this disability sector. It's time that changed. Who is held accountable for this formal complaint?

LINDA WARD: Okay. Next person is Ray Heins? Did I say it right?

Employment:
Shelter Workshops

RAY HEINS: Hi. I am Ray Heins. I am a parent of a disabled son with Down Syndrome. Earlier this year, I think it may have been in June, a so-called scandal erupted over the operation of a sheltered workshop by the Birchwood School and the Training Through Placement Program in Providence and North Providence respectively. Shortly afterwards the director of the Rhode Island Department of Behavioral Healthcare Developmental Disabilities and Hospitals, Mr. Craig S. Stenning, issued a statement promising to close all sheltered workshops and segregated day centers. I don't know much or anything about the Birchwood School and I do know about sheltered workshops and could not agree with closing the ones I know. They provide exactly what they promise, shelter from the world. These vulnerable individuals cannot negotiate without assistance and necessary assistance with daily life.

My point is this. Disabled individuals are in no position to compete with the general public for employment. The need to have -- they need to have additional services and protections. The Maher Center, the one I am familiar with, has sought to employ as many clients as possible in publicly visible jobs. These jobs are in Naval buildings, municipal buildings, and publicly accessible portions of Maher Center itself and their garden center. But there are individuals who do not thrive in such exposure. For them there is employment in a laundry, employment at a shredding facility, employment in a jewelry making operation. For those without the dexterity to make jewelry or strength to work in the other areas, there's an artist studio where they can create their own master pieces, regardless of any potential market. And yes, at times there is contract work to be done filling envelopes.

Are these individuals paid minimum wage? Typically no, is there any chance on God's green earth they can go out, get a job earning a minimum wage? I think not. My son and many others have extreme difficulty being understood. He's willing and able to man a mop or a broom. And he does deliver sandwiches to individuals detained in courthouses around the state. His paycheck, seldom reaching $100 over a two-week periods, are a source of great pride to him. I know this is also true of many other clients, even if their check consists of only a few dollars, immensely proud of earning it.

When Mr. Stenning closes down the workshops, I fear the only thing left for my son and his peers will be unpaid warehousing. However, the state of Rhode Island won't have to pay for it.

LINDA WARD: Rick Costa.

Healthcare/ Supports:
Governor's Commission

RICK COSTA: That's me. Hi, my name is Rick Costa. I am the chair person for the Rhode Island Statewide Independent Living Council. Although today -- I don't come here with many concerns, I come here in appreciation of the Governor's Commission on Disabilities holding these public forums, and how important they are to the persons with disabilities in our state.

As far as our council is concerned, these public forums are very helpful to us because the information gathered from these forums is used to write our Independent Living State Plan, which is done on a three-year basis.

So, I'd like to just show my appreciation and thank the Governor's Commission on Disabilities for holding these public forums and enabling the families and persons with disabilities to voice their concerns. So thank you very much.

LINDA WARD: Annette --

Healthcare/ Supports: Accessibility

ANNETTE BOURBONNIERE: Don't -- Bourbonniere. What I would like to really talk about very briefly today is Accessible Healthcare Rhode Island, which is a project that is funded through the Department of Health Office of Special Healthcare Needs. And what we are doing is documenting what healthcare services are accessible. So we are using the standards published by the Access Board; and we are surveying healthcare facilities; and we are creating an on-line surgical database, so that a person with a disability can go on-line to this project and say, this -- say the City of Newport and you want to know where you can find a mammogram that is accessible. And essentially you should be able to get a list of whatever facilities are available that will provide you with that.

We have not surveyed everybody yet. And it's a little tough getting all the doctors on board. However, we are diligently working on it. And we are -- we do have a website that you can start going to, to look for these services. So, you know, the website is accessible www.healthcareri.org. And you know there is a wizard that will take you through the steps to search. If -- it may not be perfect yet. We are still kind of ironing out some bugs. But it is there, and it is live.

And if you have any questions, please feel free to contact me. I am hoping that this becomes a much bigger network so that people will be able to find an accessible exam table, a Hoyer lift in a practice, a scale they can get on with their wheelchair. So we are trying to document what is there. So thanks.

LINDA WARD: Anyone who did not sign up to speak who wants to speak now? Can you just identify your name? I don't think you signed in.

Employment: Accessibility

BARBARA BURNS: I am Barbara Burns. I did sign in. I am affiliated with the Maher Center and on the board, but I also have a sister who is a client there. This is my dad. And so -- I am speaking both as a family member and somebody who is involved and has some awareness of the business side of the operation.

I think we all -- I think all of us agree that we've come a long way from Ladd School and we never want to go back to anything like that. And I think all of our hearts are in the right place. The Maher Center I think is justifiably proud of the things that have been done and were begun many years ago. Before the current focus on employment, Maher Center was there and really looking at putting together businesses and jobs for people. And we are proud of that.

Are we flawless? Absolutely not, however, a concern that I have is that we are currently looking at the law of unintended consequences. The Department of Justice is quite rightly looking at all of the operations in the state. We certainly have evidence there have been have been serious problems and those need to be addressed, absolutely.

On the other hand, a very quick and knee jerk reaction that supplies a one-size-fits-all solution in my opinion is not necessarily the right way to go. I call it the law of unintended consequences because, of course, we do not wish to take advantage of our clients, underpaying them for work for which we are getting paid. No one wants to do that.

But to what Ray has commented on, what Walter has commented on, we have a variety of individuals who make up the Maher Center. We have 300 and some different individuals. One size does not fit all. We absolutely believe that we need to provide training. We need to provide opportunities.

My sister and dad's youngest daughter work in the garden center and have an opportunity to interact with the public when it isn't pouring rain, an opportunity to interact with the public and we are very proud.

We -- Mary doesn't make a lot of money. She is not -- she doesn't make minimum wage. She, again, is very, very proud. And she does not cash that check until everyone has had a chance to look at the numbers on it. It's not very much but there's a sense of personal pride. She is also proud of the fact she votes and pays taxes and she is an individual.

We have other individuals in this center who come and spend time with us every day. They are not able to interact with customers. They are not able to pick up a box of plants and put it in a customer's trunk. But they have the camaraderie of working with individuals there. And they do get a stipend. We don't pay the stipend because we don't want to pay somebody minimum wage. We want to give someone the dignity of feeling as though they earned something.

We have a shredding room in our Aquidneck workshop and through the benefit of very generous donors and refitting that building, we have a shredding operation there. We have adaptive equipment that allows someone in a wheelchair to do one sheet at a time, to pull right up to that equipment and be able to do that work.

I do not want to get to the point where in order to do a one-size-fits-all, I cannot employ one of my clients to work in that shredding operation because it is quote-unquote a sheltered piece of real estate. I could hire a nondisabled person to come in and work that equipment. I would like to be able to match the circumstances with the ability of that client. I think all of us do. I think BHDDH does. Everyone wants to. We want to be very careful that we are not doing a broad brush that does not reflect what is required by our individuals. That's my primary concern.

LINDA WARD: I noticed a couple other people came in. Do you wish to speak? And if so, just raise your hand. State your name.

Healthcare/ Supports: Autism

KAREN DOCKERY: Karen Dockery. I just speak whatever I want I guess? For the most part, okay, I am a mother of a four-year old daughter with autism. And I guess the first -- I want to start out with a compliment to the state. When she got off the waiting list for Katie Beckett[6], she has been getting 30 hours a week from Perspectives [7]and we have been very impressed with those services and she's definitely made progress. And insurance is picking up a certain amount of it -- it's probably my husband -- no, it's not -- is picking up a certain amount of it and I believe Katie Beckett picks up the rest. So that is fantastic for us. We are very happy with that. However, when she was diagnosed, she was 2, by Yale University, they said you have to get her into intensive treatment as fast as you can, as many hours as you can of ABA's, what they are recommending and I guess that is what the research shows too.

And at that time, all we had access to EI. And EI just provided I think two hours of speech and maybe an hour of OT, and they had no ABA services. So, we had to pay privately until she got off the waiting list for Katie Beckett, and that was a year and $50,000 of our own private money paying for services. And we felt we had no choice because Yale said you had to do it fast, intensively, and do it now.

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[6] **Katie Beckett** is an eligibility category that allows certain children under age 19 who have long term disabilities or complex medical needs to become eligible for Medical Assistance coverage.

[7] **Perspectives** is a multi-faceted, dynamic agency that provides support to people with disabilities.

That would be one of my concerns is EI[8] not having enough ABA [9]or any ABA, at least the ones we have access to.

And then also the schools, we have felt a lot of resistance in the school system that we originally were involved with. We actually moved to another school system now which is more open. But there seems to be resistance to ABA support at the -- we saw it at the school. We dealt with and we heard from other parents as well. So those are my --

BRIAN ADAE: If I may ask, when referring to EI, early intervention by -- you are talking about applied behavioral -- and using that particular modality?

AUDIENCE MEMBER: Yes.

LINDA WARD: Okay. And -- it doesn't appear to be anybody else who has signed up to speak or at least who -- check this off because it is there. So I will ask though, does anyone want to -- anything else they would like to say?

We will be here until 6:00. So --

BRIAN ADAE: May I ask?

LINDA WARD: Yes

Employment: Employment First

BRIAN ADAE: Folks from Maher, a variety of people there, I want to make sure that I am hearing that completely -- in two respects. One is I think you have been referring to the BHDDH, the director Craig Stenning, the Employment First Initiative[10]; is that correct?

And in looking Employment First is part of what I am hearing -- and I think in particular when you spoke at -- this question occurred in my mind, is a concern looking at it as a Work First Initiative we used to have for folks with welfare assistance that you had to perform work or a certain amount of work first or you would not receive the benefits or assistance or supports?

Employment: Shelter Workshops

WALTER JACHNA: What I am concerned about is the fact that one, we have to -- the way I understand it right now -- and I don't have all the details -- that we have to set up a resume for every client and schedule an interview within a designated period of time. And we don't -- I have a lot of people that just can't work outside the sheltered workshop. What -- the way I understand it, at all work with -- in both the workshops -- and I hate the name -- will be eliminated.

And what I am concerned about is these individuals that cannot work in with other individuals and in the public sphere won't have any work to perform and will lose what small income they have. And the 14 C goes away, we can't pay a percentage and we have to pay minimum wage. There's no way based on the volume of work an individual can do that we can afford to do that and survive.

And my concern is you are not leaving anything for these people to do. You are taking it away from them. And to me what that means is you are going to take away their pride, take away initiative, and take away opportunity, and the self-satisfaction and how they feel about themselves.

For lack of achievement, not only that I know, my sister-in-law developed Alzheimer's [11]and couldn't work as much and then stopped. Her Social Security went up. So the government in the long run to me will pay more. And we've taken dozens of clients out of the system who

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[8] **Early Intervention Program** promotes the growth and development of infants and toddlers who have a developmental disability or delay in one or more areas.

[9] **Applied behavior analysis** (**ABA**), previously known as behavior modification, is the application of behaviorism that modifies human behaviors, especially as part of a learning or treatment process.

[10] **Employment First** is a concept to facilitate the full inclusion of people with the most significant disabilities in the workplace and community.

[11] **Alzheimer's disease** is a neurological disorder in which the death of brain cells causes memory loss and cognitive decline. A neurodegenerative type of dementia, the disease starts mild and gets progressively worse.

literally can support themselves with rather good paying jobs. But not everybody is capable of something like that.

So I would just want to take care of the people who can't go out there in public, can't really work at a regular job and compete with an individual who isn't disabled. I want them to have some opportunity to make some money and contribute to the community.

BRIAN ADAE: Could you just reintroduce yourself for the record for --

WALTER JACHNA: My name is Walter Jachna with the James Maher Center and also on the board.

BRIAN ADAE: And I think we saw the director of the Maher raise his hand. I think he might want to add some comments.

Employment: Employment First

BILL MARAZITI: I am Bill Maraziti, executive director of the Maher Center. For comparative purposes what is causing the consternation is the message being put out to all the providers in the state and that message has come in through various outlets. Probably the most concerning was the articles that appeared about three weeks ago in which the director was quoted as making a blanket statement that the sheltered work centers are going to be gone. Without any reassurance to the audience that was reading that message that there was going to be something available for the very individuals that the other people have spoken are concerned with.

And so to reiterate a couple of the concerns that were expressed and the very real concerns is this whole one-size-fits-all approach to addressing the employment needs of the widely disparate population that we support is a mistake. There has to be some allowance made for the people on the periphery, for those that don't fit neatly into the box we are defining.

I don't say that in a disparaging way. We certainly support wholeheartedly the efforts of Employment First. We support the movement to get people to the maximum extent possible into fully integrated in the community, minimum wage jobs at a minimum of 20 hours a week, which is the standard that's been defined.

So, but what we are saying also is that there are individuals that are not going to fit neatly into that box. And certainly we can do the planning. We can do the evaluation, the assessment. We can determine their interests and their needs. But in the end, there has to be some ability to provide for the employment needs of those individuals. And I think that's the fear is that that's going to go away.

So I guess the plea is somewhere in this very right-minded process of advancing this whole service delivery system forward, let's not leave behind the people who don't fit neatly into a box.

LINDA WARD: Okay. Mike Freeman came in. You wish to speak.

Healthcare/ Supports: Autism

MIKE FREEMAN: Hi. I am going to reiterate what my wife already said. We have a daughter with autism. Just that we would like to see the school system across the state implement behavioral analysis for autistic kids, which most districts, almost all districts do. It's really the only research based treatment for autism and have demonstrated successful tract. That's all I have to say.

LINDA WARD: Okay. Going once, going twice. Anybody else want to speak? Otherwise we will just recess, I guess. We will be here if anyone decides they want to.

Barbara Burns: I just have a quick one.

Healthcare/ Supports: Funding

My name is Barbara Burns and just a quick one. I know in order to make sure that state funds are managed properly and that there is no malfeasance, the state obviously needs to be very careful about where the dollars are going. It's very difficult to manage a business when the funding can change wildly every 90 days.

So, what we have seen is that every 90 days, a decision can be made as to what specifically is going to be funded. So there's somewhat of a moving target. Absolutely understand that we need to have controls to make sure that those dollars are proper and no one's getting billed for anything they are not supplying. Absolutely agree.

But it's very tough to manage a significant sized business when your revenue stream is that changeable. But most of the businesses salaries and we can't change those every 90 days. So just as a point of concern, it's very difficult to do that. I know it's well intentioned. It's awful tough to have the rules change every 90 days.

BRIAN ADAE: If I may ask, please let me know if I am exceeding too much in trying to draw some of this information.

In looking at that, do you view that as an impediment or a barrier for Employment First? In other words, does that cause an issue for folks trying to establish supports or the necessary supports to work in more integrated environments?

BARBARA BURNS: It's difficult for me to answer precisely because I don't have specifics to give you. But I do think, again, most of our funding goes to the -- to staff salaries, mostly direct labor, performing jobs. We want to adapt. We want to bring new skills in. We want to be able to provide the kinds of things that are required, job coaching as well as job development and so on.

It's very difficult to make a commitment to bring somebody on to do work that would create new jobs, whatever, if, you know, you are not sure in 90 days from now if that revenue stream is going to be the same.

And our experience has been that it has mainly decreased. It has, as I understand -- again my level of knowledge is about yay. If I am saying something incorrect, it's from lack of knowledge. But I think most of the time when they change things, the number goes down or it's the same amount of money but put into different buckets.

I don't think you can run a business that way, be able to invest in the skills that you know you are going to need as you adapt your business when the amount of funding may be -- you want to hire somebody and then find out you don't have the money to be able to put that person to work developing new jobs, for example.

BRIAN ADAE: That makes sense. Thank you.

BILL MARAZITI: If I might just expand on that a little bit to give you some perspective. I have been with the Maher Center for 25 years, and it has provided services to individuals with disabilities for 60 years. What I can tell you is that up until 7 years, 8 years ago, the funding that was made available gave our organization the ability to provide annual increases, maybe a small pension contribution from year to year.

As I stand here right now I am telling you that we have been unable to give a pay increase to a single employee in 7 years. We have been unable to make a contribution to their pension in 8 years. This is not coincidental. This is a function of how the budgeting and the funding has been -- as Barbara aptly described -- either reduced or moved from one bucket to another. It's almost to get -- the shell game to be honest with you.

The basic underlying program with 300 employees is that to your question, how does this affect or does it affect our ability? Does it create an impediment to people becoming employed? When you can't hire new staff because all you can pay them is $9.20 an hour or $10 an hour to perform work that is some of the noblest work that we can do really, you bet that's going to create an impediment to employment.

And that has become the cyclical problem. It just chases itself. That as the budgets get cut more and more and more, and we are able to do less and less and less to recruit and retrain and retain qualified staff, you bet it's going to have an impact on our ability to develop the jobs.

BRIAN ADAE: Mr. Maraziti, when -- am I correct that when we look at consumers and supportive employment or workshops, that at least Maher they are in fact Maher employees?
BILL MARAZITI: In some instances.
BRIAN ADAE: When you mention that you are not able to give a pay raise or include benefits, would that include the consumers that are Maher employees?
BILL MARAZITI: Those who are employed on our agency pay roll working on one of our various contracts with exclusion of our federal contracts. And I don't really want it go too far into that because that's a whole different issue. But for those employees that are working in our garden center or in our laundry where they are making minimum wage. If the rest of the staff doesn't get an increase, they don't get an increase. I don't know if that answers.
BRIAN ADAE: They are employees just as the others?
BILL MARAZITI: They are employees, correct.
But then we have the other piece of this is the community based jobs where people are employed in their own position, who require supports. And we are providing job development services, job coaching services, and job retention services. Those are all of the rates that have been consistently and consecutively year after year reduced and reduced.
BRIAN ADAE: So, in trying to understand this, if we are looking at this 90-day funding or quarterly funding that goes on rather than on an annual basis that this causes degradation in the supports for the folks that you are trying to engage in employment and more integrative employment?
BILL MARAZITI: It affects the number of people we can employ theoretically.
BRIAN ADAE: Does it affect the quality?
BILL MARAZITI: The quality of the services, no. The ability to reach a wider audience, to promote the interest of the individuals that we are supporting, to do the job development work, that all is degraded certainly by the amount of resources.
BARBARA BURNS: If I can add to the extent that we have significant turnover in our staff, not our client staff but our support staff because of salaries. I think it does impact what we are able to do with those clients. We do everything we can; obviously, to make sure that does not happen. But it's just natural if you have a lot of turnover, everybody is on a learning curve again and again.
MIKE MONTANARO: It would be possible for you to have a job coach who is working with an individual who became employed in the community making less money than that individual.
BILL MARAZITI: We actually -- we actually have that exact situation with the people who work on our contracts, the federal government.
MIKE MONTANARO: Contracts, exactly.
AUDIENCE MEMBER: So yeah. I mean try recruiting competent staff when what you are able to offer them is less than the people that they are supporting or making.
MIKE MONTANARO: Absolutely.
BARBARA BURNS: Our staff people are wonderful. They do what they do for love. And as a family person I really appreciate it. And I know there are some folks here who do that. I thank you again.
WALTER JACHNA: I would like to see as far as the Maher Center goes for the ability to create new jobs or buy equipment, there's no opportunity for us to get money from the state. And we have been able to -- through donations from individuals, from different grants, et cetera, we were able to build a whole new greenhouse. I think you may have saw it on your tour today. We have been able to put two yard crews out on the road doing yard work and hedge work, all from the trucks and trailers, all from contributions and money raised by the board.

Our shredding business again was all funds that the board raised for individuals in different companies, and to put people with disabilities to work. But I don't see any way or any funds that are available to us from the state to help in these type of programs. And I think that would be a big help to help integrate clients.

I know our yard crews were out there working with people. In some cases we service people with disabilities. I know we had one case where a woman who was legally blind had "her yard cleaned" by a crew and then even with her lack of vision realized that they hadn't done anything for her because she paid the bill. When our crew came in and did her lawn at a much reduced rate, she actually broke down and cried because our clients did it. And this is a good way to integrate our clients into the community.

When funds aren't available but for equipment, it gets difficult raising money to, one, help maintain the facilities, and two, to create jobs for people with disabilities. And some funding in some way or from some direction from the state or even the federal government to get equipment and create jobs would be a big help.

Employment: Funding

BRIAN ADAE: Just to make it clear for the record, the reference to {inaudible} there is a team from the Disability Law Center[12], actually a variety of teams from the Disability Law Center that are presently engaged in reviewing, in meeting, and under our federal access authority with the Disability Law Center, taking a look at 14 C sheltered workshop[13]s. And I was part of the team that was at the Maher today, so reference was to me. And may explain why I was trying to understand a little bit better some of the remarks that were made.

LINDA WARD: We had a couple people come in. And I know a lot of you did not check that you wanted to speak. I am going to again ask if there's anybody -- you do?

Healthcare/ Supports: Medicare and Medicaid

RITA CLARKE: I am Rita Clarke. I work for NCCMHE[14], community support program. One of my functions there is also coordinating with the rest of the staff to help clients maintain their Medicaid benefits. And the Med Flex Program[15] is actually hindering clients going back to work, especially people with Medicare and Medicaid. Because once they hit about $900 a month, they become a flex and they go off of Medicaid. And then they have to try to negotiate the system, which has gotten horrendous to negotiate, since 2008. And it stops them from getting a lot of services, especially dental, okay.

And this is just outrageous. I mean we have someone who's been in so much pain and we had to wait to find a dentist, okay. Never mind waiting around with every six months they are on and off of Medicaid.

It's the actual office. DHS is losing people left and right. Applications get lost. Then it's this battle. And the clients themselves cannot negotiate this. And then it hinders their work as well because they make over a certain amount, and it takes away, increases their rent, everything

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[12] **Rhode Island Disability Law Center** (RIDLC) provides free legal assistance to persons with disabilities. Services include individual representation to protect rights or to secure benefits and services; self-help information; educational programs; and administrative and legislative advocacy.

[13] **Sheltered workshop:** refers to an organization or environment that employs people with disabilities separately from others. The term 'sheltered workshop' is considered outdated in the U.K. and the U.S., and increasingly in Australia.

[14] The Mission of **N**ewport **C**ounty **C**ommunity **M**ental **H**ealth **C**enter, Inc., is the provision of quality, comprehensive, professional behavioral health services to individuals, to families, and to the community that: incorporate the principles and values of recovery orientation in service delivery; that are culturally sensitive and competent in application; and that are in accordance with regulatory, licensing, and ethical standards.

[15] If an individual's income is at or above 100% of the Federal Poverty Level (FPL), they may still qualify for Medical Assistance if they have medical expenses. This is called "flex test" eligibility. An individual's medical expenses can be subtracted from a person's income over a six-month period. This may reduce their income to fall within Medical Assistance eligibility guidelines and make them eligible.

else. And now they have to pay all these other copays on top. That is I think something that needs to be looked into.

We have two people who newly got on SSDI [16]but because of the amount of their SSDI check, they weren't eligible for straight Medicaid. But they can't -- Medicare for two years. So now they have no insurance and they are trying to get their medications.

BRIAN ADAE: If I can ask -- I keep having questions. Is there training available on some of the work incentives for Social Security Disability, SSI or SSDI, in particular, 1693, being able to maintain 1693. Does that sound familiar?

RITA CLARKE: There have been the PASS (Personal Assistance Services and Supports) Program and things like that. But a lot of the clients just say 'Forget it. I am not going to go through this hassle.'

BRIAN ADAE: But as far as 1693, the ability to maintain the medical benefits in spite of work, even though they may be losing their cash benefit depending on work -- degree of work they are doing.

RITA CLARKE: But that doesn't affect the flex. That's a different --

BRIAN ADAE: Is there training available to you folks or for these people so they can be -- that can be explained to them how to do that?

RITA CLARKE: We had actual individual come in and talk with the individual clients around how it will affect their benefits and stuff. But it's still -- it doesn't stop it from happening. It's really, really a problem for the clients.

AUDIENCE MEMBER: I can --

ANNETTE BOURBONNIERE: Are any of these people eligible for the Sherlock Plan[17]?

RITA CLARKE: We had one person on that and they are paid $600 a month to maintain their Medicaid.

ANNETTE BOURBONNIERE: That shouldn't be. That's not supposed to go over $200 a month.

RITA CLARKE: It did.

ANNETTE BOURBONNIERE: It was changed a couple of years ago to eliminate that problem. So you might want it look at it again. I'm not saying it's perfect, not by a long shot. But at least it might help those that are doing this Med Flex thing, get them off that roller coaster.

RITA CLARKE: If they are working, it will help. If they are not working, the flex is still a problem.

ANNETTE BOURBONNIERE: Like I say, it's not perfect. But it can help some.

LINDA WARD: I saw another hand. Just identify yourself

PAUL LEMAIRE: My name is Paul LeMaire and I am a disabled person. She brought up a point that -- I was -- a very perplexing thing to me because when I have my medication -- well, I spent better part of ten years laying in bed looking at the ceiling until everybody figured out what was going on with me. I got the right medication. Now I am pretty functional when I am medicated. Am I making sense?

So -- the thing is if I get my medication, I can work. Then if I get my work, I can't afford the -- if I -- and I -- if I get my medication, I can work. And I can function. But then if I work in a job and the income is reported and things like that -- then the benefits get taken away. And then you have to spend all the money you are making or more on the medication or on -- choose

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[16] **Social Security Disability Insurance** (**SSD** or **SSDI**) is a payroll tax-funded, federal insurance program of the United States government.

[17] **Sherlock Act or Plan** allows qualified Rhode Islanders receiving SSI or SSDI payments to continue receiving government subsidized health coverage in the form of Medicaid even if they return to work and exceed the income threshold that currently exists for Medicaid eligibility.

between your medication and rent, medication and food, that kind of thing. And it's just like -- it's incredibly frustrating situation.

So there's -- somewhere some legislation drew a line. This is where the line is. And there's no -- not much room for overlap or -- and it's just -- it's a frustrating situation. And so -- I don't know. I guess that's probably as far as I can go with that.

There's kind of a threshold you hit, and when you -- you get a letter, okay. Your benefit this month is going to be this because the last six months you earned this much. And you go -- I still got to pay my rent. I still got to eat. So that's the story. What you do with that, I don't know.

LINDA WARD: Well, I will say it's one of those unintended consequences that hasn't been thought out of what happens when people go to work and all of these things begin to be affected. And yes, you can do 1693 or whatever -- that's been around forever. And you can do Sherlock.

But nobody speaks to each other. None of the departments speak to each other. And nobody is really coordinating what happens. And so, I have been doing this for 38 years. It changes all the time. There is --

PAUL LEMAIRE: It's a moving target

LINDA WARD: There's no consistency at the DHS offices. The person you used to talk to and get information is no longer there. It's a very frustrating experience.

And so, I think there has to be some way that there is a connection and a much smoother transition, safety net, you know, recognition that maybe you make $900 this month. But -- and that puts you $300 over. I'm just picking arbitrary numbers. But you still have all these other things you have to pay. And if you add the value of that Medicaid or whatever you are losing that covers those meds that are extremely expensive, there is a disincentive to work at this point because nobody thought about how we do help that person still get those things that they need to be successful.

PAUL LEMAIRE: And if you were to go ahead and work in an unreported job or something like that, then people say; well, now you are using the system or abusing the system or -- you get that kind of thing. And you have guilt about doing it because I try to be a law abiding person. But you are forced to commit fraud.

RITA CLARKE: If I can interject here. It's not just the medication though. It's 20 percent of the doctor’s bills that Medicaid picks up. It's actually getting an appointment and being able to keep that appointment or that operation or whatever because you have the Medicaid versus don't. We've had people that had to put off procedures because they knew they were flexing during that time and they wouldn't be able to pay the 20 percent. So, I mean, it's much bigger than that. And with the Medicaid comes the lower rates of the copays for the medication, the lower rates for the part D silver script or whatever they have, et cetera. So, it blossoms into much bigger situation.

PAUL LEMAIRE: Thank you. And don't get me wrong here. I am happy that I live in -- at a time when medication is available to help me and in a society that is compassionate enough to help me as much as it does. But at the same time, there's this kind of maddening little gray area that you get in that you just don't know what to do. I spent about ten years lying in bed looking at the ceiling when I wasn't being medicated. And -- because I barely had the strength to go out of my room and you know into the bathroom and then back to my room. And then over time, I've gotten medication. I've been able to function a little better.

And once I got one of these things where I earned a little too much, I had to pay for my medication, and it was difficult. So that's all. I thank you very much.

LINDA WARD: Thank you.

BRIAN ADAE: May I ask that you speak with me afterwards, if you like.

PAUL LEMAIRE: Sure.

LINDA WARD: If there's nobody else, we will just be here, hanging.

Tuesday, July 23, 2013- South Kingstown Library

CASEY GARTLAND: We're going to get started. Again, I know some of you've heard this, but if you're interested in speaking, you should register in the back. We're going to be using that as the guideline for the order of speakers. Just to give everyone a little bit of guidelines, we try to keep the speaking to 10 to 15 minutes. If we get through everybody, and there's time afterwards, you're more than welcome to speak again, we'll have you testify again. I want to welcome everybody. This is the second, I believe, this week of the Governor's Commission's Forums. My name is Casey Gartland. I'm a senior director for perspectives. I also serve on the commission. Restrooms are out the door to the room, down the hall a little bit. Is there a public Telephone?
ALYSSA SAURALT: I actually don't know. But just to note for the bathroom --
SPEAKER: Phone --
ALYSSA SAURALT: Just to note for the bathrooms, they lock behind you automatically. As you're leaving, if you can leave it propped a little bit, because if not, you would have to come get me and interrupt the forum to go unlock the Door.
CASEY GARTLAND: I'm going to read something that we read for every forum. The purpose of these public forums is to identify the concerns of people with disabilities and their families in order to assist the state developed programs to improve the quality of lives for 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 be posted on the website by the end of November. The recommendations and the transcripts will be printed and sent to the state and congressional officials, and members of the General Assembly. And the recommendations will be used to develop policy for legislative initiatives for next year, or until they're accomplished. The RI Disability Law Center's panelists will be available to register anyone who is a citizen and not currently registered to vote where there live to vote by the end of the testimony. People can also file a change of address if they've moved since the last election. Now I'm going have the members introduce themselves.
JOANN NANNIG: I'm Joann Nannig. I'm from the Office of Rehab Services. I'm a supervisor there. I coordinate the transition program and, also the RI Works program.
KATHERINE KUIPER: Hi. My name is Katherine Kuiper. I am representing the Office of Special Health Care Needs of the Department of Health. I also work with the community agency of RIPIN (Rhode Island Parent Information Network).
MATTHEW TIBERIO: My name is Matt Tiberio. I'm a staff attorney at Rhode Island Disability Law Center. Just to let you know, there's packets in the back which has information in them. First, there's a cover letter, which has the contact information for the law center where you would call if you have any questions. They would direct you to our intake department. Then, also, as the letter explains, we have different funding priorities each year, and we look for public input on what kind of issues might be a good way to use any resources we get. And that's -- and these are last years, the yellow sheet. But we generate them every year. They're pretty similar year to year, but there are changed based on your input. There's a voting rights flier in there, along with a registration form. So pick one up on the way out, and the contact information, and other information you need.
MAUREEN WHELAN: Hi. My name is Maureen Whelan. And I work for the Sherlock Center for Disabilities. In that Capacity, I provide technical assistance to the Early Intervention System. That's part C of IDEA.

CASEY GARTLAND: We also have Vicky Ferrara from The Sherlock Center.

VICKY FERRARA: I'm Vicky Ferrara. And I work for The Sherlock Center to promote access (inaudible) for Employment.

CASEY GARTLAND: Again, this is the -- we want to make sure if you need an Assisted Listening Device, Alyssa can help with that. When you start to give your testimony, identify yourself, spell out your name for the caption, it's important, and indicate the city and town you live in. Again, we talked about the fact we have the list. I'll get that in a minute and get started. To clarify the role of the panelists, they have this on the back of their tags, as well. Their job is to listen and ask questions to clarify your concerns and ideas. They're not necessarily here to respond quickly. If they don't have answers today, the idea is to clarify get it on the record and have a follow-up later on. If you were not aware of existing service, you can suggest to the speaker (inaudible) at the end of the testimony and get additional information.

SPEAKER: Should I check the air-conditioning?

SPEAKER: Is there any air-conditioning?

CASEY GARTLAND: Thank you everybody who registered. I know some people signed in and did indicate they want to speak, so I want to go through the people checked off first. And the first name is Nicole Bucka. You're the first person who said they want to speak, so. 5

NICOLE BUCKA: I had no idea how many people were going to be here, excuse me. A hundred dollars at staples doesn't take you very far. Does somebody have a written on one? That's actually my copy. Sorry.

VICKY FERRARA: That's all right. I can share.

NICOLE BUCKA: Unless you're going to talk.

VICKY FERRARA: I probably would not do as through a job.

NICOLE BUCKA: So who am I? My name is Nicole Bucka and my city and town, East Greenwich, Rhode Island. And a little bit about myself. I'm an Educational Consultant. I'm also a governor appointed parent rep on the ICC, interagency coordinating council for idea part C. Today I'm here as parents of two boys on the autism spectrum[18].

Healthcare/
Supports: Autism EI

SPEAKER: Did you say you had two children with --

NICOLE BUCKA: I do, two children with autism. I'm also representing 80 parents that responded on the survey. I wanted to thank Casey, Matt, Joann, Katherine, Maureen, Vicky, Alyssa, and Tammie for helping to make this forum possible. So I'm here basically to represent the needs of kids affected by autism spectrum disorders. While I recognize the stories I'm going to share are kids ages birth to five, I know the governor's council may say this is not the forum for that, there's forums for Early Childhood. I wanted to say a few things about that, why I'm here. First, it's the fastest growing developmental disability in the country. It's now 1 in 55 for boys, 1 in 88 for boys and girls together. And of all disabilities, after emotional disturbance, it's the least likely to hold employment, and the most likely to be underemployed. So when you look at this disability with a 1,148 percent growth rate, it is now grown 10 to 17 percent annually, and it costs us $60 billion annual costs 60 percent of those costs are adult services. So I'm here today to talk about how those adult costs can be cut by two thirds with proper early intervention in the early years. I'm here to share a story of a family that's trying to access Early Childhood Intervention and it's not going so well. That's why I'm here. I also shared this with the ICC[19], and things are moving a little slower than I would like to see. So I share with

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[18] **Autism** is a group of developmental brain disorders, collectively called autism spectrum disorder (ASD). The term "spectrum" refers to the wide range of symptoms, skills, and levels of impairment, or disability, that children with ASD can have.

[19] **Interagency Coordinating Council** of Rhode Island for Early Intervention Program for Infants and Toddlers with Disabilities and Their Families

you today this packet. I'm sorry, I didn't have an idea how many people were going to be here, or if it was just me talking to the panel which is making me nervous. I first wanted to share, and make it brief, my children's own time line of experience, that's the first page. Then you'll see I'm going to share over 80 family's feedback on the survey that also mimics the same patterns. As I share about my family, what I would like you to reflect on is the mission of this group is about access. I read on your mission, are all people afforded the opportunity to reach their maximum potential. Reflect on that. Do you see my children being afforded the opportunity to reach their maximum potential? And then for the Americans with Disabilities Act[20], have we broken down barriers, or are there barriers I'm sharing with you in this state that we have not broken down. So Ethan, he's age five. He was born June 4th, 2008. My husband and I are teachers. We have college degrees. We owned a home. We waited until we were ready to have children. We were going to do everything right. We wanted to give our kids every opportunity. First year and a half, normal and healthy, my child was doing well. Suddenly age one and a half we had odd things happen, chronic diarrhea, word loss. They were there. Suddenly they're gone, loss of a couple skills, like pointing. I expressed my concerns to doctors. Doctor's pretty much do-a wait and see approach. This was in California, in all fairness. What the doctors should have done, recommended by the American Academy of Pediatrics, is follow up with a MCAT, (Medium-chain ketoacyl-CoA) [21]a particular screening tool. I moved to Rhode Island at that point. Rhode Island doctors were no better. At that point, I lost my job, home. Had to move back here to Rhode Island, which is fine. I wanted to be here. We also had a second baby. Again, doctors wait and see. No MCAT I found out from a friend about Early Intervention. Doctors didn't mention it. It was not publicized. I didn't know the existed. A friend told me. I contacted EI[22], and they quickly got me some services. My child did, of course, he did qualify. And at that time, I wanted an evaluation for autism. As soon as EI did the evaluation, I cried immediately. I said this is it. I know it is. I could not even find where in the state to get an evaluation. I did a lot of research. They put me son immediately on a wait list. He was two and a half years old, two Standard Deviations below the norm, and on a wait list. Wait lists are supposed to be illegal. They are not. You'll see that (inaudible) percent of parents said they were on a list, as well, in addition, when I did finally get it by complaining and advocating for myself, very small improvements. They were not using evidence-based methods for autism. They didn't have a way to say the child wasn't responding. The wait list for the evaluation took over four months, and the way I finally got in was I called in a favor from a state level friend and said, explained my situation, and she got in. Here I am at the Brown Center for Children at Risk getting my son evaluated. This doctor says he should be getting more speech. I ask EI. They don't have the capacity. They have nothing to offer. In addition, I was researching and trying to find research based methods like ABA (Applied behavior analysis). Couldn't find any ABA in the state, I couldn't find a listing of BCBAS, couldn't find anything.

VICKY FERRARA: Could you do the acronym review.

NICOLE BUCKA: Applied behavioral analysis. I was looking for board certified behavior analysts in the state. I couldn't find any. Jokingly, I said at the state level, is there a gatekeeper? Yes, there is. Evidence says this should be happening as soon as we suspect autism. Not after we go through this long process. You'll see how long it took for me to get --

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[20] **Americans with Disabilities** Act is a wide-ranging civil rights law that prohibits, under certain circumstances, discrimination based on disability.

[21] **Medium-chain ketoacyl-CoA thiolase deficiency (MCAT**) is a condition in which the body is unable to break down certain fats.

[22] **Early Intervention Program** promotes the growth and development of infants and toddlers who have a developmental disability or delay in one or more areas.

VICKY FERRARA: You had two acronyms.
NICOLE BUCKA: BCBA, Board Certified Behavior Analyst. I forget it's not in everybody's world. Anyway, I was doing the research on my own. I got it through a friend and found out about it. I began paying for private ABA because I wasn't getting it in any of the places I needed, even though it's the first thing the research says I should be getting. I did finally get a diagnosis from the doctor. It took a while. My son is atypical. I applied immediately for Katie Beckett. And was connected with CEDARR Center, and transitioning to a school district. At the bottom I also was saying my son was not communicating well. He was struggling. I needed a picture exchange system, a called PES. I asked EI. They didn't have training. I called the doctor. Doctor, medical doctor didn't know where to find it. He said, why don't you call a behavioral facility in South County. I called them. They said we don't provide that, because it's specific types of issues. Try Gateway. Finally, I get across to Gateway. They can help me if I label my child Oppositional Defiant Disorder. I did. It was the only way I could get the help I needed. He could not communicate. He was tantruming. My life was not very good. They came, helped, and were amazing. Again, all when I'm researching in the middle of the night because I can't sleep providing my kids what they need. I'm stilling paying ABA privately out of pocket. I'm now on a wait list for ABA Therapy. (Inaudible) says ABA. CEDARR center said ABA. Wait list took ten months. The insurance mandate said that ABA would be provided through the insurance companies. It's good for access. But now we have new issues. Funding silos have created a change how ABA is received in my home. That's another story. It's created an issue of coordination, collaboration, and money. Now I'm paying for eating therapy privately because he can't hold down medicine when sick, throws it up because of a medical issue. He ends up hospitalized when ill because he can't take the medicine. He can't go to a birthday party or be at school. I am paying for this out of pocket. I have health insurance. My husband has held insurance, double coverage. We have Katie Beckett [23]medicate for both of our children and none of this is covered across what they present as issues. My second child, June 29th, 2010, healthy and typical, this was my second child. So, I was no fool. I was videotaping. I was monitoring him closely. He was doing great. Only issue was constipation, one year evaluation from a doctor. He's a sibling. So he has 20 times the risk. At one year he said no evidence of autism. By 15 months check up, he now has immature speech. He says; call EI, to be safe. We went crazy. We can't do this again. With EI we got speech. At first one a month, then twice a month, we got OT. We had groups. We did everything we could to support our child. His gap was getting wider. Even EI said it. I was concerned with their methods. I wanted to start using PES (picture exchange system). I wanted to start using some of the Autism evidence based methods. They didn't have any way to provide that. I had a friend who helped me do it myself. I sought out my own implementation. They connected me to the More Than Words program. He told me it was provided through Groden[24]. It was not. I asked for a referral. This time the referral took five months to get my child evaluated. Why? Because the two places in this state that do the evaluations do it on a (inaudible) basis, worst case scenario first? So because I was being proactive, my child was punished. It took longer and longer. That summer my husband and I did Joint Attention Parent Training at Brown, over 50 hours of our work. We also did the Groden, More Than Words Program, provided by our own hard work. At this point, our child is not responding. It seems like there's probably something wrong and we need more, right? Well, that's not what I got. I got a diagnosis. Thank God for the autism mandate. I got it started right away. I got Katie Beckett at that point.

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[23] **Katie Beckett** is an eligibility category that allows certain children under age 19 who have long term disabilities or complex medical needs to become eligible for Medical Assistance coverage.

[24] The **Groden** Center is recognized internationally for its pioneering work with individuals with autism.

Healthcare/ Supports: Educating Doctors on ASD

Healthcare/ Supports: Autism

Right now I have to go to Massachusetts to seek quality health care from Lurie Center[25], and I have to pay out of pocket for additional speech because there are other issues in addition to ABA. I would like to ask you to think about are we providing what we need for our kids. Does it sound like systems are affording all the opportunity, and have we broken down barriers. When we look at the survey, I'm sorry; I didn't bring enough handouts for everybody. I would like to look at commonalities across 80 families. They responded to my parent survey commonalities. First one, if you take a look at page two and page five, start with page two, generally the parents agree doctors in the state have a serious lack of knowledge around Autism Spectrum Disorders. If you look at the first graph, which I believe is -- I'm sorry, page two, you can tell from my story to you that I told you doctors were telling me wait and see. Oh, they're boys, they develop differently. Basically, telling me there was nothing wrong. They also did not refer me to EI. Myself and three of the five parents that created this survey were all referred ourselves. On page two you can see that the blue and the orange on the far right-hand side are where parents saying we disagree or we strongly disagree. What do they disagree to? My doctor conducted autism screenings. They are not conducting them as recommended. My doctor does not display posters, pamphlets, or information in waiting areas. And in addition, overall my doctor is not knowledgeable about spectrum disorders. First responders are not responding. I guess I'll have to make it quicker. In addition, by the time they get there, I got page five -- you can look at the survey on your own time, because I only have two minutes. Common themes, doctors and first responders are not responding. Wait lists occur everywhere. They occur in EI, through our evaluation process and the Brown Center for children at risk. They occur as we work with Katie Beckett. Three, lack of evidence based intervention. Autism has evidence based. The National Autism Center, The National PD (Professional Development) Models, these are available. I'm telling you it's not happening. There's a lack of interagency coordination and collaboration. Every agency that serves my kids gives me hours and hours of paperwork every year. I need a personal secretary to keep track of Katie Beckett's paperwork, EI's paperwork, the doctor's paperwork, ABA, and IEPs. And I have to attend all the meetings and be part of all of them. Is this access? Is this going to help my children achieve their potential solutions? What I would recommend is we act on this moral and economic imperative. Quite frankly, I've done this presentation or something like to several places. Nothing happened. I have (inaudible) not one agency came in and said we would like to change this. I'm asking the governor's council to think about it and do something about it.

One recommendation I would have is to make a low cost campaign to educate doctors, teachers, parents, and providers. Look at the mass contact for what we can do. They use modern technology, like social media, videos, Twitter, and Facebook, to make sure they educate people. If parents knew their kids were at risk, they would demand better services. I would like to see a task force, group of parents leading or having a key role exploring the systems or how they Work. Most people told me the survey is the first time anyone asked them how their families were getting care. I think this task force should be used to put political pressure on groups and agencies to create urgency that clearly isn't there. These kids, I don't have time today, but I can show You video of my son a year ago playing with sticks, ignoring his name, to now, where I had no idea the capability of this child. My kids are going to be okay, because I get them what they need. And

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[25] **Lurie Center** is a multidisciplinary program designed to evaluate and treat children, adolescents and adults with a wide variety of conditions including autism and autism spectrum disorders, Asperger syndrome and developmental delays.

I work, my kids will be okay. Access, equity, there's a lot of parents that don't know what they should be asking for, never mind demanding it. A lot of people don't have a job that provides flexibility, like mine, where I can work at midnight if I need to. That's all. (Applause)
CASEY GARTLAND: Nicole, you're welcome to come up again if there's time. Next on the list is Hermine. Hermine Sihay, do you have something you wanted to say?

Healthcare/ Supports: Qualified and Quality Staff

HERMINE SINAY: To Whom It May Concern, my sister (inaudible) Wakefield, Narragansett and a long time client of Perspectives [26]Corporation has a better life because she is the first to (inaudible). However, changes put in effect at the State level has (inaudible) and attention given to clients and residents with disabilities. (inaudible) is aware that sometimes something has changed though she does not -- she somehow realizes that it is not of her hand. The current way of billing in 15 minutes (inaudible) provide to (inaudible). It is not at all effective. (Inaudible) it actually takes away from the important issues spending time with clients, developing disability programs and goals. Other important issues considered, then, (inaudible) individuals do not tell the whole story as they need and can (inaudible). The state needs to allocate funds to support provides, such as Perspectives Corporation, so they can continue to give the best support and care to those very deserving citizens of Rhode Island. This is not just a financial issue. It's also a moral responsibility to take care of those (inaudible) as far as I and many others are concerned, the perspectives corporation falls into the category. Thank you for giving the letter the attention it deserves, respectfully, (inaudible), who is my sister who wrote the letter (applause).
CASEY GARTLAND: Can we take the letter? The letter, can you pass it to the panel?
HERMINE SINAY: Can you just tell us who the panel consists of?
CASEY GARTLAND: Sure. I have someone else. Would the panel mind reintroducing themselves?
TIM FLYNN: Sure, I would be happy to. I'm Tim Flynn. I'm chair of the Governor's Commission on Disabilities. Did you tell them what we're doing here, and what the purpose is?
CASEY GARTLAND: Yes, I did.
TIM FLYNN: So I don't need to say anything more. I want to thank you for coming. This is where we formulate our legislative agenda for next year. I appreciate you taking the time to help us out.
JOANN NANNIG: I'm Joann Nannig, Office of Rehab Services.
KATHERINE KUIPER: Katherine Kuiper, Office of Special Health Care Needs and RIPIN.
MAUREEN WHELAN: Maureen Whelan. I work at the Paul Sherlock Center of Disabilities and help oversee the Early Intervention System.
MATTHEW TIBERIO: I'm Matt Tiberio, from the Rhode Island Disability Law Center.
CASEY GARTLAND: One thing I failed to do for the panel is after people testified is allow people to ask questions. Would you like to ask questions of Nicole now? I didn't know if they had questions. How about Hermine's Testimony?
VICKY FERRARA: For clarification, I heard you, and thank you for your testimony. You had a lot of good points. What I heard you describe as issues are, one, staffing patterns have changed, and how agencies have to document how time is spent with people, and supports are given in 15-minute increments. That's an issue from your point of view?
CASEY GARTLAND: Does that sound right, Hermine?
HERMINE SINAY: That's what she said. It refers it takes lot of time to do the documentation.
VICKY FERRARA: Staff is spending time on paperwork and less time providing the supports and interventions to support good quality of life?

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[26] **Perspectives** is a multi-faceted, dynamic agency that provides support to people with disabilities.

HERMINE SINAY: That's correct. A greater proportion of time spent on the paperwork.
VICKY FERRARA: And that the new system they're using to assign the funding level, the tier system is not capturing all the support needs that somebody has?

Healthcare/ Supports: Supports Intensity Scale

HERMINE SINAY: That's correct. They're using the Supports Intensity Scale, and its being -- it's being adjusted all the time, because it was discovered that the questions being asked were really not getting the information about exactly how much time and what kinds of supports people needed. So many times people receiving supports, because they have good supports, appear to be far more self sufficient than they really are. And the questions were being, oh, yes, she can do that. But not taking into account every step that had to be -- every step that needed assistance along the way.
VICKY FERRARA: The initial interview wasn't capturing the accurate information to determine the person's real level of function?
HERMINE SINAY: Right.
VICKY FERRARA: Okay. Thank you.
HERMINE SINAY: (inaudible) My own job at Ocean State Community Resources, where I go every day, except Friday, And I do all different kinds of things.
VICKY FERRARA: Great.
CASEY GARTLAND: I know there's another sheet back There of people who signed up I have one person who said maybe they would like to speak.
GREG MRAZTH: That's me. I have two questions, really.
TIM FLYNN: Sir, would you mind introducing yourselves?

Healthcare/ Supports: Funding

GREG MRAZTH: My name is Greg Mrazth (phonetic). I have a son and a daughter who both live in group homes in Rhode Island that are administered by Perspectives. Zachary is 31, and Eliza is 29. I was wondering if somebody could give me an update on what the budget is going to look like this coming year. Wasn't July 1st the start of the new budget year for the state?
TIM FLYNN: Indeed, it was. I'd be happy to. We have a breakdown of the budget. I don't have it with me.
FEMALE SPEAKER: I have quarterly service package values effective the fourth quarter.
TIM FLYNN: That's not going to help me right now.
FEMALE SPEAKER: It tells him what the values of the tiers are.
VICKY FERRARA: That's specific to the developmental disability population. Is that what you're asking, what the current budget is for --
GREG MRAZTH: Right. Are there going to be more budget cuts, or what? And then my other question was an update, I'd like to get an update, if someone could give it on the -- The last one of these meetings that I attended somebody on the panel talked a lot about the Department of Justice coming to the state in January or February. And there was this whole business employment. And we would like to get an update on where things stand with that.
TIM FLYNN: Sir, I appreciate your asking questions. That's not what we're doing here. We're going to hear your input, and you tell us what to do. Please contact me at the commission, and I'd be happy to talk about it with you.
VICKY FERRARA: You're asking those questions, though, for, probably based on some life experience that you're having. And so, you know, your sons are getting services through the division of developmental disabilities?
GREG MRAZTH: Yes.
VICKY FERRARA: Are things going well? Are things -- are you having some issues? If you're having --

GREG MRAZTH: My kids are experiencing what everybody else that's receiving services in the state are.

VICKY FERRARA: We may not know that, so feel free to share.

Healthcare/ Supports: Staff Quality

GREG MRAZTH: Okay. Well, the -- I don't have The figure in front of me, but you guys probably know better Than I how much money was taken out of the budget in the last four years, and how much money has been put back into it and so all of the services that my kids receive have been diminished by the budget cuts. The level of staffing and the quality of staffing, it's very troubling to see everything happening since my kids have been in the system, which has been 12 years now, all in Rhode Island 21.

VICKY FERRARA: How is that impacting their daily life?

GREG MRAZTH: If the quality -- if there's fewer staff interacting with them, and I'm going to say that the quality of the staff is less because the hourly rate is less, That -- the direct care that they receive is less than the quality is deteriorating, so that's the (inaudible).

MATTHEW TIBERIO: In terms of the DOJ investigation, if you called the Disability Law Center, we can give you -- whoever you talk to can give an update on what's going on with that and what we're doing. We started to look into some of the providers who run the 14 c, which pays subminimum wage to people with disabilities, and starting to look into more of those places that weren't covered by the DOJ's Settlement. If you want more information, there's a packet with Disability Law Center information back there, and the contact information is on there. And you can call and speak to someone who could give you a little bit more of an official formal information about what happened with the DOJ settlement, and what we're working on now.

VICKY FERRARA: Do you have any suggestions for how to improve, other than reinstating money? We know that that would be a preference, assuming, but do you have other suggestions that you want the commission to consider?

GREG MRAZTH: No.

MATTHEW TIBERIO: Do your two kids, do they have -- do they work as part of their day programs, or?

Employment: Funding

GREG MRAZTH: No, when I heard what the Department of Justice was suggesting, it seemed to fly right in the face of the budget cuts. Because everything that was being talked about in terms of getting folks like my kids out in the community with supported employment, it just seems so obvious to me that that was a required resource, which is exactly what, you know, that money is being stripped down in the budget in the state. Just like I didn't understand how those two things were going to be reconciled.

TIM FLYNN: If I may ask, how does sort of -- how does sort of being -- how does working really improve their lives? Just from your standpoint, or from their standpoint.

GREG MRAZTH: I think for Zachary, I never seen him happier or more fulfilled than if you give me a task he's capable of doing. That is when he is most thrilled. I think it's a great thing for his self-esteem. And I think that -- he has had jobs in the past ten years that have kind of gone away, but I think there's a great learning opportunity for him to be in a, like, he worked at a company where he has to be on time. There's all kinds of social skills that go away with having a job in a workplace. One of the impacts, direct impacts at Perspectives of the budget cuts was they used to have the department that was, whose job it was, was to look for across the state employment for the people they serve, and that department had to be disbanded because of budget cuts. So it's like, if there was somebody from justice here now, it would be like, how can this, what they're talking about implementing and the impact to the budget cuts in the state are just butting heads.

MATTHEW TIBERIO: I don't know, because I'm not involved in the state budget process or the funding for this, just in terms of value for your kids, do you have an opinion on what you'd rather, like, if they had money to go towards providing more services, or those services being trying to find a job in the community, integrated employment, do you have a preference for your kids about what's more valuable for them? I have no idea; I don't think it's one or the other, like they have $5 it can either go one way or the other. I'm curious for your kids what you see more beneficial for services like you're talking about being cut.

GREG MRAZTH: Yeah, you're talking about a day program and you're talking about a residential program. They're both tremendously important. It's kind of like asking who would you rather get the services, your son or your daughter. It's, really, I can't really answer that question.

DONNA GILTON: I didn't sign up to talk. My twin brother --

TIM FLYNN: Could you introduce yourself?

DONNA GILTON: I'm sorry. My name is Donna Gilton (phonetic). My twin brother is also developmentally disabled. He goes to the Laplante Center[27]. Lives at heritage house with the budget cuts, Laplante Center had the sheltered workshop. He worked in that. Now they can't offer those services anymore, and very severe staff cutting, as well. So it makes it difficult for them. And they're not able to take people out into the community like they did in the past. They had to really cut back, both at the center and at the residence.

CASEY GARTLAND: Thank you any questions from the panel?

TIM FLYNN: I do, actually. I heard you say they cut back taking your brother out into the community. What's that impact like for him?

DONNA GILTON: If he can't go out into the community as much, that means he's at the center and he's not able to take advantage of what's going on in the community and have those learning opportunities.

TIM FLYNN: Such as, like what kind of learning opportunities?

Employment: Socializing

DONNA GILTON: Just interacting with other people, knowing what's there, being able to find your way around. My brother is non-verbal. He's not able to talk. But I think at least getting into the community and having him interact; he's more likely to talk a little bit more, things like that.

TIM FLYNN: Thanks.

MATTHEW TIBERIO: Did he like working at the sheltered workshop?

DONNA GILTON: He loves it.

CASEY GARTLAND: Any other questions from the panel?

Healthcare/ Support: Support Intensity Scale

ELLA WHALEY: Thank you. My name is Ella Whaley. This is my daughter, Margaret Whaley. I'm a teacher that taught for 34 years. I've been retired for two years have been an educational advocate for people with disabilities. Also served on the South Kingstown school committee for eight years, so heavily involved with the educational process, and currently finishing seven years as principal of the South Kingstown Town Council serving as town council president. So my capacity has expanded into the community with serving people with Disabilities a couple of issues that I just want to bring up. One of them is the new SIS[28], the support intensity scale. Just recently went through that with my daughter. I did not really have a lot of

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[27] The Adeline **LaPlante** Memorial **Center** (ALMC) provides persons with developmental disabilities with the necessary skills and supports that with the necessary skills and support that will enable them to realize their personal goals of becoming effective members of their community.

[28] **Supports Intensity Scale** (SIS) is a unique, scientific assessment tool specifically designed to measure the level of practical supports required by people with intellectual disabilities (i.e., mental retardation) to lead normal, independent, and quality lives in society.

information. I was not able to attend the forums. But I'm really fearful that some of her funding will get cut is what I'm hearing. I know that there are 14 states that adopted this. I did call Kate Sherlock at Disability Law Center before I went into the meeting. I talked to David Reis down at Options. The parents that I talked to, like 30 percent of the funding are getting cut. So I haven't got the information get, based on my daughter's funding, but I'm afraid that she will also be in a situation where there will be decision to be made, do I cut staff, or cut hours, do I reduce staff, and possibly lose some of the staff? That's a concern. I know there's one state, talking to Disability Law Center that already has a lawsuit that its support system was not set to be a funding stream based on that, and that's what it's being used for. I'm going to be very interested in following that court case. The second issue, based on my family, is transportation.

Transportation: Accessibility RIPTA

Recently at the town hall we had a presentation here in South Kingstown for RIPTA. And at the end of the presentation I asked for, you know, you have gone out and sought improvements based on people, some of your riders, but you haven't mentioned anything with any people with disabilities. We talked about RIDE. The RIDE van and other different, the Flex van, but for those people with disabilities that are not one mile from a bus line, there is no transportation. I'm getting up there in age. I'm worried about who's going to be transporting my daughter in 10 or 15 years when she's not able to get her driver's license. Also, looking at a lot of other youth and parents in my situation, my husband is 17 years older than I. Also, you know, we're not in that great health, we're not young and just worried about what's going to happen. Is she going to be stuck in a house not able to get out, similar to what your concerns are? I am going to make a presentation, hopefully that our senior van here in South Kingstown will be able to pick up some of the disabled population. Right now, as it stands, the senior van, we have two vans here in South Kingstown; the van will pick up anybody that's disabled. They don't have to be 65. It's not just for seniors. We'll bring them to the senior center and welcome to have lunch. They will pick up the seniors and take them to doctors, banking, and stuff like that. We would like to see that expanded to the youth that are disabled and not able to drive. I would hope maybe in the future there would be some funding for towns that have some vans that could expand to people with disabilities.

Education: Children IEPs Services

The other thing that, outside of my family, I also attend a lot of IEP [29](Individualized Education Program) meetings for children in South Kingstown, Barrington, Burrillville, word has spread. I'm alarmed at the amount of children that are being dropped from IEP, and the Parents don't realize really what's going on and are able to look at the testing. I know there's a 10th grader here at South Kingstown high school, obviously the testing shown there was definitely some things going on with language based learning disabilities, and requested more testing. The child is now getting a one-on-one program next year. That parent did not have me at that meeting that child would be exited as a 10th Grader from an IEP, and this girl has high goals and now being addressed at the school department. I think our school departments are exiting kids from IEPs. I see it. I'm seeing the praises of Kathy Sanford in that group that put two bills together for children with dyslexia, and I really thought there would have been more work done on those bills. I think that the committee was sent up. I think there was the second piece of the bill that I thought really should have gone further, so the schools would be able to recognize children with dyslexia are a disability. So tied in with that is the language based learning disability.

Education: Screenings

We really do need screenings from the early school years to pick up on language based learning disabilities, and we need to train

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[29] **IEP** defines the individualized objectives of a child who has been found with a disability, as defined by federal regulations.

our teachers. Right now the biggest person that has the most amount of knowledge with language based learning disability is speech language therapist, and they're not allowed in some school districts, and I will say South Kingstown is one of them, that they will not allow speech and language therapists who have reading backgrounds to work with children with reading disabilities. I think that that is a real loss. We're not capitalizing on the strengths of our speech language pathologists working with the reading teachers to get the gaps closed for children. The longer the gap exists, the wider it gets, and the more money it's going to cost the school districts and, lastly, is just the cuts with all of the agencies, representative options. I know cuts are not as significant this year. But last year was a big hit. And I'm hoping that, you know, something really gets turned around there. Thank you for your time. Thank you for having this forum.

CASEY GARTLAND: Thank you.

ELLA WHALEY: And I have to get over to Newport, so I will excuse myself, any questions?

TIM FLYNN: Do you guys want to go? This is an issue floating around my mind. I hear a lot about it, parents planning for their children's future after they die. I think, I'm sure there are lots of people in this room concerned about this, I'm considered in sort of what you might think about, what recommendations you might have? Is there any sort of step in the evaluation process as you get involved, or introduce yourself your daughter to state programs, I mean, is there -- do you ever talk about that? And is it something that you're thinking -- you're obviously thinking about it now, what sort of, if there is sort of a policy recommendation you might have that might address this issue?

Education: Recommendation

ELLA WHALEY: I really think education to parents; I know that when my daughter left the high school there was very little knowledge. I know there are a lot of parents that have kids involved in independent transition academy. I get the call, what's going to happen? When does DDD, or when does ORS[30] (Office of Rehabilitation Services) get involved? She graduated in 2007. They held her diploma until 21. She's 24. The school department said to me, we're going to go through this process together. We're going to learn. Even from that point on, what has been learned is not being implemented in the school department. My biggest concern for my daughter, you know, I have a large family, and after my husband and I are gone, we do have family members that will come in. But transportation is a big issue. She's the type of kid where she's got a hundred things on her agenda. She does a lot of volunteer work. (Laughter)

SPEAKER: She's leaving.

Transportation: Accessibility

ELLA WHALEY: Let me tell you, if all of that is taken away because she has no transportation, it's going to kill this kid. We take six runs back and forth to town. She Works at South County Hospital, she volunteers at a preschool 2 days a week, and she’s on a heart group for South County Hospital. She has surgery as a baby, she works with the elderly.

TIM FLYNN: For you its financial planning underlined once and transportation underlined three times.

ELLA WHALEY: Yeah. Transportation is huge. Thank you, any other questions?

CASEY GARTLAND: Thank you for your time next?

Healthcare/Supports: Qualified and Quality Staff

KEN SUNDBERG: My name is Ken Sundberg. I have a daughter who is -- a developmentally disabled daughter that's living in a residential program. We're all concerned about the cuts. But I think one aspect of the cuts that really (inaudible) very seriously to me is the allowance for the direct care staff for the residential folks, the DD folks,

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[30] The Office of Rehabilitation Services (**ORS**) provides a wide variety of services to Rhode Islanders with disabilities.

and the group homes. They can go work basically at McDonald's and do as well. Some of those folks actually act in the form of a CNA a lot of those duties of which none of us are going to even think of having to do.
TIM FLYNN: Job coaches are you talking about?
KEN SUNDBERG: No, I'm talking about direct care staff in the group homes.
MATTHEW TIBERIO: You mean the people who do the CNA stuff, that the group homes can do just as well?
KEN SUNDBERG: Yes. If you look at what the billing allowance is for those folks, it's shameful.
VICKY FERRARA: It's not supporting people to get compensated for the work they do?
KEN SUNDBERG: Well, that, but, you know, the way that the compensation level is set, they have to draw from a much lesser pool of folks that are not as qualified. And I've seen a difference. I've seen a difference in the -- in some of the staff people that they're able to hire. And I think that is A -- if we're going to do something, that was one thing I think you'll see much better results, more bang for your buck, if you put a little bit into hiring a more qualified direct care staff.
KATHERINE KUIPER: Have you seen a larger turnover since the budget cuts?
KEN SUNDBERG: Absolutely, yes.
TIM FLYNN: And so that impacts your son or daughter?
KEN SUNDBERG: My daughter.
TIM FLYNN: That impacts her how?
KEN SUNDBERG: Level of care.
KEN SUNDBERG: The level of care in instances is not what it used to be.
TIM FLYNN: You know, what we're doing here is sort of formulating legislation. We're going to go up and talk to the legislature. The legislature, you know, depending on your opinion, are there to listen. Also kind of like what we're doing. But you have to explain to them specifically what the impact is. So when I ask -- I'm asking you, you know, what does your daughter have to go through as a result of this turnover? And it's --
VICKY FERRARA: How many strangers would you want to wipe your butt in one week? That's what the turnover of staff gets you, a million different strangers doing your personal care.
TIM FLYNN: Yup.
VICKY FERRARA: And that makes a big difference.
TIM FLYNN: Not knowing you.
VICKY FERRARA: I'm sorry.

Healthcare/ Supports: Funding

KEN SUNDBERG: I need all the help I can get. I will say, too, the interaction between a lot of the staff now and the residents is, it's not as good as I'd like to see it. And over the years, there have been some people that come in and they are so dedicated. This is just another job, a quick stop on the road to something else for a lot of them. And if you -- to
If the wages were increased to a descent level, I think it would attract a higher level of employees. But I'll also say there's a lot of disparity in the system, too, because the RI class, or state run homes are getting, what, $8 an hour more than what they pay in the private ones.
VICKY FERRARA: $8 more?
KEN SUNDBERG: I can't believe they allow that.
VICKY FERRARA: Because you have to look at the benefit package, too, they get, which is much higher.
KEN SUNDBERG: That's another thing; too, with the RI class homes they're on the state payroll and doing much better. Something else, too, that I want to point out, I've worked in the

industry for 50 years. I'm a strong believer in accountability, but this 15-minute interval of accountability is -- its overkill. It's overkill. I've never in all those years seen anything like that. And I don't know whoever came up with that, but it's just -- it's taking away from other things.

GAIL AMARAL: I can give you an answer that I was told on that one when this all started when I talked to the --

TIM FLYNN: Could you identify yourself, please?

GAIL AMARAL: My name is Gail Amaral. I'm going to speak. I addressed this to the state and governor's office. The information I was given was the reason for the 15-minute interval billing was because you could have people out there in homes called group homes where they're not having somebody in there performing the work and are billing. Where now they have to have accountability to bill on the 15 minutes, my answer to them was, well, I'll go out and find the houses that are empty, because I don't believe they exist. That's the bottom line.

KEN SUNDBERG: Those are the two points that I wanted to make. The funding level that's attached to the -- the funding amounts that are attached to the different levels or tiers; I believe that that has been reduced.

GAIL AMARAL: Dramatically.

KEN SUNDBERG: That's not brought out. In effect, they're taking more and more money away from the care of these folks. So that's another issue that I think that, really, I'd Like to see some investigation put into.

CASEY GARTLAND: Any questions from the panel? Thank you, very much.

ALLISON TARZWELL: My name is Allison Tarzwell. I am 28 years old. I live independently. And I also, I live with my cat. I have a great family and great support. Because I take the RIPTA bus, and I have a great job scanning with my mom every single morning, and I wake up in the morning. I have. I have every single day I scan because I know what to do with my life. And I have a great life. Because I know I have a disability. I have a full, great life. I have a great -- I have great parents. I have a great sister. I have a great sister with my new brother-in-law. I have new brother now. Not brother-in-law, I have a brother now. Because I have great support because I know I have Down Syndrome, and that doesn't prove to me that I can't do things. I have -- I support network that comes to my mom's house that gives up their time to be with me because I have a super-duper great best friend who does everything for me because we travel. When my mom goes away, she's with my -- my best friend is right beside me. My sister and my brother does the same for me. Because my staff does things for me, as well sometimes I -- sometimes I don't give (inaudible), but I have to.

Housing: Section 8

GAYLE TARZWELL: I'm Gayle, Allison's mother. Gayle Tarzwell. Thank you, Allison. I'm from Wakefield, Rhode Island, as is Allison wanted to touch on a few points. Allison is very blessed to have great supports. She has a self directed adult service, so we are able to get a budget, which has been cut, will continue to be cut, unfortunately. But a couple of points she lives in Indian Run, which is right down the street here. She was able to get into that housing, section eight housing, while they were still accepting people with disabilities. I have understood from other families now, waiting lists, they are no longer taking children with disabilities on that waiting list, that you have to be an elder person. So it's discrimination. I heard that the Disability Law Center is looking into it, or has looked into it. Whether or not it's legal or not, I can't comment, but it's a shame, because it's local. Ella spoke about the transportation. Allison can walk to the grocery store, the CVS. It's a treacherous corner down here, but she can do it if she has to. That's one thing. As we're looking for housing, DDD, they're looking to get out of the business of housing. They don't want our children in group homes. You have to prove that everything else failed before you get into one. So I do want to make the panel aware of that kind of discrimination that's going on in our community. We were lucky. Allison is in there. I had the forethought to get on the waiting list. We waited four years. She got an apartment. And we're delighted. We hope every day she can keep it.

Transportation: Accessibility

She does take the RIPTA bus, which is excellent for her. She takes it to my office a half a mile away, independently, so that's wonderful. However, it's a flex bus. She has the pass and doesn't pay anything. But if she misses the bus three days -- she has to make an appointment to be there. If she's not there three times, she's told she's going to get knocked off. If she oversleeps, she has problems, the other day as she was coming down to the bus she fainted and they called 911. She missed the bus that day. RIPTA doesn't seem to be strict about this, but it is a rule, and one of these days we may get nailed on that. She mentioned having a support network. I am the treasurer of a nonprofit called Plan RI[31]. We, as an organization, are a group of parents with people with disabilities and our families. We're looking ahead, what do we answer to her when she says what's going to happen to me when you're not here anymore, mom. She worries about it. There are a lot of people with disabilities that have that concern. Our organization, nonprofit, we're trying to surround a person with disability with a support network, natural supports. We don't take any government money. If anyone wants information, it's Plan RI. We can be found on the internet. We're helping families to form support networks. Is my time up?

CASEY GARTLAND: Not yet.

Healthcare/ Supports: Guardianships

GAYLE TARZWELL: I'm also an attorney, and I do a lot of estate planning. I've seen a lot of unnecessary guardianships. As you make recommendations, you've got to educate other lawyers and a lot of the probate judges. We have 39 cities and towns in South Kingstown -- in Rhode Island, and they all have different judges, probate judges. They need to be informed because I see lots of people with disabilities going under unnecessary guardianships. The last thing I wanted to mention is the big push for DDD for natural supports. I understand they're even defining this, so watch out. Natural supports are another word for dumping on families. And I have gone to hearings in anticipation of helping, like, a sibling who couldn't -- taking care of an adult sibling; parents are out of the picture, keeping that person with disability in his home couldn't work until 6:30 at night because the supports were ending at 3:30. Trying to get from 3:30 to 6:30 major effort, shouldn't be that hard. When you make the argument, look at all the money you're saving, you're not putting her in a home. They don't care. Natural supports, this is the duty of the sibling. There's a lot out there that say it's not my duty. DDD is in crisis mode. I see it all the time. I get called in to help those situations. They react to the crisis. They aren't proactive in trying to head off the crisis. One parent's deceased, the other one's in the nursing home, the other one's got cancer. Then you might get to have some notice. Until then, they really don't want to do much planning. And we need that.

CASEY GARTLAND: Thank you, any questions?

FEMALE SPEAKER: I have a question, do you get paid for the work that you do at your mom's office?

ALLISON TARZWELL: Actually, it's business money. Actually, it's business money, and it's --

FEMALE SPEAKER: You charge so much a picture. Why don't you explain what you scan?

ALLISON TARZWELL: Is it, like, the pictures.

FEMALE SPEAKER: Photo albums.

ALLISON TARZWELL: Photo albums. I had to scan in and I had to press the button and it goes in the scanner. And I had to --

FEMALE SPEAKER: What do you give your customers at the end of the scan?

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[31] Personal Lifetime Advocacy Networks of Rhode Island (**PLAN RI**) is a non-profit organization of families who have relatives with disabilities.

ALLISON TARZWELL: A thumb drive.

KATHERINE KUIPER: Do you like it?

ALLISON TARZWELL: Oh, yeah. There's one more thing I want to add. I love my mom so much, and there's two things I love about my mom.

FEMALE SPEAKER: No, this is not appropriate. Thank you. (Laughter)

CASEY GARTLAND: Anymore questions? Now, we have Gail Amaral.

GAIL AMARAL: I want to kind of sum up a lot of what we've been talking about, because I'm your future. I have a 45-year-old Down Syndrome brother. He'll be 46 in October. We lost our parents ten years ago. Simultaneous, within a four-month period, they went into a nursing home and resided with each other for about a year and a half, two years, and then both passed very quickly. I was facing a situation with my handicapped brother, what was going to happen with him? So I basically lost my marriage, moved in with him, and started to take care of him, turn the house around. The house was then turned into a small group home for one of the local agencies. That ran as a group home for 5, 6 years. And there were some issues that were developing. Being close sibling and, also, I built a home close to him so I could be in contact, but I wanted him to be independent. I purchased my parent's home and paid it off so he would have a home to live in. I have done my parent financially and continue to do it every day. Now we have issues going on with the agencies. Some of them do a great job, some of them have problems. I believe they do try to work with the problems. You talk about quality of staffing, some are great, and some are poor. Unfortunately when you walk in and find things are not acceptable and bring it forward, then you're less favored. So that can be an issue with agencies. They decided when the state came up five years ago with two new plans you could do, one was self-directing, and two was shared living. I was informed by the agency that his current roommate was going into a shared living situation. I was skeptical. They wanted me to possibility have somebody come in and share (inaudible). He has enough, and all these individuals have enough with people who come into their lives, are with them 3, 4, 5 years, and then move on. It's constantly changing and bonding. Down syndrome, they are very loving people. All of them are. They connect and bond, and then that person is leaving. I felt if I put another person in his home then the chances are this (inaudible). I then presented it to the state and agency I was encouraged greatly to put him into self-directing, and assured the FIS would not be held reliable because they would become self-directed.

Healthcare/ Supports: Qualified Staff

TIM FLYNN: FIS?

Employment: Funding

GAIL AMARAL: Fiscal intermediary. He self directs his funds, but it's handled through an agency to make sure all the monies are going where it should, and not in someone's pocket, such as mine. Which is fine, I understand that. He's now been doing that for four years. In the beginning, I was told if I could succeed with this in a year on the current budget that was given to him of 94,000 for the year. Now, you have to understand this covering everything, from his transportation, to his staffing, to his activities, to everything, you know, that they would pay for, that would be amazing. Well, I succeeded. And then through the years, he got up to 98,000. Now, I stay in that line. I have support staff that has been with him for four years. A couple have moved on, and the other ones have stayed. I am now looking at I can only pay my support staff 10.25 an hour. I know the agencies pay them $14 an hour. I can't pay my staff benefits. My brother attends a day program. This is part of what's happening, the day programs are getting shut down. They close everything down. I get the letters to prove where they're trying to get the individuals substantially out working in the workforce. You're talking 10,000 people, approximately out in a functional job that's going to help them support their way. You have such a variety of needs. It's not just one high functioning. There's a variety so not everybody can be employable. But they have their network in their day programs. He loves his day program. He loves the work he does in there. Yes, there was something that happened in the state that was wrong and brought the feds in and brought you down. That's okay. That happened. Learn from that. But in the program he attends, he produces work and gets paid a minimum amount and doesn't complaint. That money is for him to do with what he wants. Now I'm faced with the state says you have to quarterly bill it, this whole day program. Now they put a six hour block on it. Only six hours are they allowed to go to the day program. But they're working to shut the day programs down. They'll be like houses, and put them out into the public. How is this going to work? Look at the state of Rhode Island as it is, as far as unemployment goes. What's going to happen with these individuals? They put him out in a workshop, in jewelry, piece work. He couldn't stay. He has some needs that have to be monitored all the time. So he's not acceptable. He goes out one day a week and does a job in a local restaurant. They take him in. He loves it and is proud of himself. My problem is at $98,001 I have now received a 20 thousand dollar cut. I ask anyone, can you sustain somebody in a program that you have running 20 thousand dollar cut? It's impossible.

Healthcare/ Supports: SIS Revaluation

It's the new SIS. Well, just know your new SIS, support intensity scale, that the state of Rhode Island ordered is based on 7 other nations. What other nation do we want to emulate, I ask you? And 16 other states, well, you know, you want to go back to 1994, when lad school was closed. Took him years, three governors before he got that closed. That was a hell hole. I have a story about it. If you want to find out some day, I'll give it to you. Just give me an address, and I'll mail it. They say we're not going back to that. I hope we're not. This is what I hope. The bottom line of that is, where are we going? We're declining. We got to be the state where a lot of states are modeling, their programs. I have a niece out in Virginia who is modeling their programs on what Rhode Island used to be. It's not anymore. She's horrified. She cannot believe what's happening to my brother. You say siblings should come forward. I'm forward. But I'm getting older. My husband is getting older. We're going to die. This is fact of life. What happens to him? Do I take him now that he's lived in his home for ten years, take him and go to him, and say you can no longer live here. We have to sell this home, and you have to live in a group home. Is this fair? The state put him in this position. They gave this to him. My answer is for all of you. Talk to your representatives. Get your support. Get out there. Talk, stand up for them. We have got to turn this around when I hear from my representative last week that when they were doing the budgeting, the fiscal budgeting was at the midnight hour at the state house this past time. As of midnight, they hadn't come to an agreement. There was funding placed to go into DDD, but there also was that 38 studios. At the midnight hour, slid in the 38 studios, and the increase to DDD went out the door. Who is leading them to think we can do this? Who is standing there saying this is doable? It's doable. Unfortunately, but fortunately, for his sake, my brother has just been diagnosed with dementia. He is going to be started on a medication. Now I have to jump through hoops and get all the doctor information and put in a form, f109, for -- it's an emergency life change to possibility get the more funding put back into the program. I am questioning his SIS. I have to put in another form, f106, to question a copy of his SIS. Now, the person who came and did his SIS, when she came, she had an attitude, very flashy person, had an attitude. She was upset with him, and it was clear by everybody that attended it, my husband, his staff person, and the director of the program, that she was snapping at him. He can't speak clearly. He's not as articulate with his words as this young man is. He has a thicker speech. You have to know him to understand him. She's a snob because he's not answering. I don't need this. The person who sat in was very kind she picked out nice jewelry pieces and brought them in and gave them to her, and we stroked her ego through the whole program of the scale. Sometimes I would let her, okay, you make the decision. She felt very good to be able to do this. When I ever got the results back that he is a new Level C, I have the current levels with me of the funding that's going to be available and how they can change. Now I'm taking different steps because unfortunately of what happened. And I'm hoping and praying that his funding level goes to where it was. But remember one thing. I can never, ever, offer the staff anymore than what I offer them because it's not (inaudible) he is a self-employed person. He has to follow all of the guidelines of a corporation. He has to go to pay the taxes. He has got to have the workman's comp. He has to have all these things. This all comes out of his budget. We pay the intermediary a monthly fee. It comes out of his budget. We live in West Greenwich. There's no transportation. How does he go back and forth? I can go on for hours. I think I summed up a lot, and you can think about the ideas.

Transportation: Accessibility

TIM FLYNN: What do you think specifically we should do?

Healthcare/ Supports: SIS Recommendation

GAIL AMARAL: Think you should not look at it -- I think the fact they came out with this one SIS, I think you have to go into it deeper. You have to look at each individual person. When the head of DDD says to me, or the next, well, this is so the person in Woonsocket who has this diagnosis is getting the same funding as the person in Narragansett. And we used to go by the agency's report, but now we don't trust them. Everybody needed to tighten up. I could tell you the waste that goes on. I can't run his house. But, anyway, what you need to go do is get out to the individual people and find out what their needs are.

TIM FLYNN: Are you saying the current system bunches everybody in one group?

GAIL AMARAL: Yes. Now I'm going to pray. I have to have this all in by August 15th, so it's ready for his new budget October 1st. If it's not ready by October 1st, if I'm $1 over the one they currently give me, the 80,000, 1 penny, they will reject it. I have to start over again. I have to pay somebody $350 because they have so many regulations. Papers are this thick. I read it. I'm a nurse. I can't understand a lot of what they're saying because a lot of it is nothing but saying nothing. If you can follow that, they say nothing that makes any sense. They go on and on. I think they have to make it simple so people can understand, so families know what's happening. They don't know what's happening. I went to my agency, and they said funding is funding is funding. When I called the social worker we talked personally, but we talked a little bit about maybe this is what you can do. Then I called the Disability Law Center. I haven't received a call back for that. I am sorry about that. Then I called the governor's office, and they told me, well, he's not in the office, call the head, Craig Stenning. He's not going to talk me. He doesn't take to anybody. I used to talk to (inaudible). He jumped ship. The other gentleman left last week. They have another open spot. I don't know why these people are jumping, but I can imagine why. When I called Craig's office, they asked who I was, who I was calling for. I said, well, the governor's office told he to call you and talk to him. Oh, I'm sorry; he's not in this office right now. We'll have him get back to you. Somebody will get back to you. Call Dave. My husband already called him. No response. Okay. Within in a day, I got a response from him. Nice gentleman very direct. He could only say what he could say. He can only say what the laws are, only say what's there. He's the one that told me based on, fortunately, and I said unfortunately, that he's had a change in diagnosis in the last 30 days. I thank god for that one that was (inaudible) used to be followed by Dr. Brachell (sounds like), who was one of the first children to be followed. He was the one who actually diagnosed him at the beginning of dementia. That's the good thing that will help with all the funding. Isn't that a sad thing?

MALE SPEAKER: Maybe.

GAIL AMARAL: Maybe. It's sad he's not going up.
TIM FLYNN: If I may ask a fast question, you said you got a call back from someone in Craig's office?
GAIL AMARAL: David McMann, yes.
TIM FLYNN: You said he described the laws that were in effect at the time. I just want to know what the impacts of those laws, and how might you change those laws?
GAIL AMARAL: Well, I'm saying in talking with him I know he can't say how he personally feels. He can only say -- he can repeat to me what he told us three years ago, that the SIS is based on seven other nations in so many other states. This is the fairest way to evaluate people. I can say to him, I don't agree with that, because you can't group, especially these individuals with various needs as the same intensity scale, by the questioning that a computer is going to put together, and the computer is going to decide, okay, they fit into this group.
TIM FLYNN: I don't think that scale is part of the law, per se. I think that's an agency.
GAIL AMARAL: It's a policy that the state of Rhode Island Department of Developmental Disability bought, purchased this policy, and this is what we're doing.
VICKY FERRARA: Chose that process to determine eligibility?
GAIL AMARAL: Yeah.
VICKY FERRARA: Not eligibility, but determine funding?

Healthcare/ Supports: SIS Evaluations

GAIL AMARAL: Funding. If you look at -- I'd be glad to pass these to you. You have copies of the quality service (inaudible) that are effective for the fiscal year 2014 quarter 1. And it does give the tiers. If anybody wants a copy, it gives you the tiers. You can follow along with that.
TIM FLYNN: We can put those in the record.
GAIL AMARAL: For the record, you can pass them down. It gives you the tiers, tier C, 20 hours community supports, 6,229. 30 hours of the day support, 3500, 128 trips 64 days, 3 proofs of hours. First of all that buying units' proof of hours, it's crazy, I'm not buying a commodity. I'm dealing with a person's life. That's a -- that should be looked at. Absolutely, it was during that period of time that I actually was told by the governor's office that the reason for this was that because they felt that there were agencies out there, or buildings out there as agencies that were not performing, actually didn't have anybody in it. I said I'd like that job just to find those people and see what I can get. I'm just going to let go at that, because I think I put enough out there for you to consider and think about. And, you know, I just pray that I can (inaudible) get things taken care of.
CASEY GARTLAND: Deb Harbin?

Healthcare/ Supports: SIS Process

DEB HARBIN: I'm here as a parent. I work in the field. I have eight children. My oldest has some significant challenges. Because of the listens we learned from her, my husband and I went on to adopt four children through the state of Rhode Island with special needs. I'm trying to make my list here as short as possible, but I have to say, over the years my oldest daughter is 31, youngest is 15. And the services used to be we did have the best, and it's really challenge these days to say that. I'll talk a little bit about Vanessa. She's had a plan. She is somebody who can't use her hands, does not speak, is in a wheelchair, has seizures, and is g tube fed[32]. She's aware, and people who know her can kind of communicate with her. I've been lucky to kind of keep staff with her for years and years. But I got a funding -- I put my funding plan in through a self-directed, I will say, the regular plan, and put it through, and it got approved. Then I received a letter in the mail saying that they, she hasn't had an SIS yet,

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[32] **Feeding tube** is a medical device used to provide nutrition to patients who cannot obtain nutrition by mouth, are unable to swallow safely, or need nutritional supplementation

but they were increasing her tier by a couple thousand dollars. She's a Tier D, that's probably what she is. However, if I wanted the money, I had to resubmit the plan with a new 13 question eight page ISP form; they wouldn't just give it to me. And I had to have a medical care plan, because she's in medical care. I'm an RN (Registered Nurse). My husband's an RN. I went to URI. I paid licenses that have gone up a lot every year to the state of Rhode Island for my RN license. I've been a foster parent, my husband and I. And we have adopted through the state, through DCYF(Department of Children Youth and Families). We've been vetted through the state of Rhode Island about every way you can be. I was told it was a conflict of interest for me to write my own daughter's medical care plan. At my job, I'm responsible for overseeing every medical care plan that goes out the agency door. I did challenge this. And they said, well, they were going to think about it. I'm like, this is crazy. I live with my daughter. I told them if it's a conflict of interest maybe you should exam my house because maybe she shouldn't be living with me. It's crazy. I am pretty intelligent, but I struggled with the ISP. They didn't do any directions for self-directed. My daughter, I am her guardian. I have two sons I would like to be self-directed. I work with them, what do you need from your staff? They could never in a million years, they do have special needs, negotiate the regulations, or the things you need to do for the ISP. They only changed the ISP form I think four times since January, not sure having trouble. And you can't just download it on a PDF. You have to use their form. Its craziness and nuts, working for an agency, it costs us a lot more money to do that, that whole process was absolutely nuts. The medical care plan I couldn't write that I write professionally, I did write it, and it has been accepted, to my knowledge. I have not really gotten any confirmation one way or the other. So that was just nuts. The funding formula, now, I've been going to all these forums at this project sustainability. Sounds like a great idea going forward. How do you do this? Now, this all kind of started when the budget really hit the fan. And they assured us, no, this wasn't about budget cuts. It was really a separate movement to go on in a better way, and determine eligibility, and level playing field. But at the same time, and it was at independent square meeting, they did say, but they did have to back into the budget the legislature gave them. I really want some explanation. If you're doing a funding level with a SIS, you really should know what it costs for that level. Not what money you have to dole out. They've done it all ass backwards. They're saying it's not funding, but it is. If you're telling me Tier E costs this, but, I'm sorry, I only have this to give you, and then can't marry the two unless you're going to be true to what the tool is telling you. A little small thing about working, I'm going to say I have my oldest daughter; we've done a lot of things with her. But you have to separate her hands to get her to work. She doesn't like it. What I love about her is she has a true self -- she's one of the most self-assured people I know. She does not need to work for value. She just is. And that's the listen I learned. I've been told I have to have an employment goal for her. In three years, I have to have -- of my four goals, half of them have to be employment. I want to say, gee, social security deemed her totally disabled and unable to work. And how does that – how does that jive? I don't get how I'm going to have somebody work who can't walk, talk, or use her hands. And she's not being valued as a person if she doesn't have a job. My other two kids -- I've been working 21 years with them for them to be motivated to work. That will be one of my goals. So and so will learn to be motivated to work for a living. I get it there. But you can't have one size fits all.

Employment: Appropriateness

Thank you. (Applause)

DEB HARBIN: And the sheltered workshops are what they are. And some people are appropriate there. And you're not going to get them to be paid minimum wage for the ability they're able to do, which can be limited for some people. I have one more thing, money planning. We had several budget cuts over the years. And as a family, I always have to live within my budget. And I accommodate that. What I've seen from the state is that, and I would say at work we've gone through restructuring, we've gone through layoffs. Two years ago everybody at our agency got a five percent cut across-the-board, period. Everybody, from the top to the bottom, I don't see anything on the state doing the same restructuring, like cutting out the middle management, going to electronic system. They have now, but it took them a long time. There are no budget cuts up there. In fact, they keep getting raises. I get there's only so much money to go around, but you can do more with a, what you have. It's crazy not to say agency A, B, and C, you have to cut your overhead. You're paying your director too much. Then they get raises, and don't do any of the same work. They haven't done any restructuring. There are no efficiency models being followed up there. I think, the only other thing I have to say is the appeal, the SIS process in all of it, I'm an intelligent person. I can draw upon people at the agency to ask questions, but I don't really -- I have not yet understood how the funding formula comes out and how we appeal. When I talked to my social worker, because I thought, oh, this is as simple as -- I called my social worker and asked for the SIS results. Oh, no. It's an act of God to get that. I have to contact Tom Martin, who doesn't work there anymore. I haven't gotten any information on whom to contact for SIS appeals or results. Both boys got the same tier, but they are really very different, just not the same. One final thing, the SIS process for kids and IEP’s, everybody's been to an IEP. You do not write on negatives. You write on positives. This woman only wanted the behavior plan, all the negative documentation. Well, do you actually call the police? No, we -- he does have behaviors. Do you have a plan? No, we're a family. We don't have a written plan for behaviors. We deal with it. She goes on and on about it, I'm like, this one's a handful. We have considered calling the police, but we haven't. I said we're almost a therapeutic home here, but we don't call the police. We don't call the police on our children. We deal with it. It’s a lot of energy. We don't always write that stuff down. The point was I didn't have any documentation for this kid I took out of a group home at the age of 15, and the six years of sometimes rocky path we've had. I didn't write it down. I don't have a behavioral. And I'm not a master's level psychologist, so I wouldn't be able to write that behavioral plan anyway. I'd have to pay someone. There's a lot that Rhode Island did right, but boy have we gone downhill. And the way we're heading is not the way to be proud of our services, any questions? (Applause)

MALE SPEAKER: Could you say your name?

DEB HARBIN: Deb Harbin.

FEMALE SPEAKER: I just have one question for you. When you say about working, do you mean, like, if someone works, like, overtime, like over working and doing the budget, and stuff.

DEB HARBIN: Yes. If somebody is doing a job, and they're expected to do a job, and they work over the hours, they should be reimbursed appropriately.

FEMALE SPEAKER: Like, it was (inaudible), or being in the bank, or doing office work?

DEB HARBIN: Any kind of job they do they should be reimbursed appropriately for the work they put out. And I don't -- that's kind of across-the-board.

FEMALE SPEAKER: Do you hear that? (Laughter)

MALE SPEAKER: You better fire her right now.

Healthcare/ Supports: SIS Paperwork

JULIE ROMERO: Can I say one more thing about the medical care plan that it would be important for you to know. My name is Julie Romero. (Inaudible) is 23 years old. This spring, when we were doing his plan, all of a success I needed a written medical care plan for him and nobody could tell me what had to be in the medical care plan. I think I talked to Tom Martin. I talked to the social worker. I asked. Nobody knew. He does get therapy at home, and one of

the therapists wrote out with me what we thought should be in there, and we never heard back. And he's been getting his money. So I guess it's all good. That's a problem, when we want to do things correctly, and we can't get the basic information to do the work we have to do.
TIM FLYNN: No paperwork supports?
JULIE ROMERO: Nothing. No verbal direction, Nothing.
FEMALE SPEAKER: One of the medical forms doesn't have a space for the doctor's name. They're asking for all these codes, all this, but it doesn't say leave a space for the doctor to put the name or specialty. I'm like, hello.
JULIE ROMERO: There will be no change.
MALE SPEAKER: Just one thing I wanted to add briefly. You asked a couple of times what we could suggest that you could do to help us out. I've tried to get ahold of everybody, from the governor on down. I've never been successful in any kind of a meaningful meeting with any of them. The best I could do as far as the governor goes was to get to an assistant policy director, who sat and talked with us a few minutes. I don't know whether anything came out of that or not. But every year the people, his secretaries, and all the directors up there at the state level, advise the governor on what to do and advise the legislature on what to do. I'm not aware they have any kind of a meaningful parent group to represent this population to have their input and listen to their side of the story. If you could arrange or somehow direct us how we could get through to them in a meaningful way, I would be very happy to participate in that.
CASEY GARTLAND: Thank you. Anne Peters?

Healthcare/ Supports:
Supports Intensity Scale

ANNE PETERS: I'm Ann Peters. My daughter just turned 21 almost a year ago today. What strikes me as odd is how little communication there is. I think people are just so thrilled to be here today because there’s somebody to ask questions, and seem to be paying attention, and all these wonderful things. I followed all the forms. Filling out all the forms, and all that, met all the deadlines, and she didn't start receiving services until mid-October for an August 5th Birthday. We still have not been able to organize respite care because of the problems with TTP. It turns out the forms are filled out incorrectly by Perspectives. I think the rules changed so many times. Whether it's she's coming into the system as it's going through an earth quake in regulations, or what, but she's gone through three different tiers. The forms were filled out wrong. We did two reviews of the forms all at the same time. And, yet, I'm sitting there asking questions. She's shy. She has cerebral palsy. What employment would be appropriate for her? For years I arranged when she was getting past services through Trudeau. She's working through a library. That's the only job assistance she's able to do because Perspectives has no money for this type of outreach to get out into the community and look for these types of jobs. It's important for her. It's important for her to be out of -- I'm uncomfortable, she seems to be dealing with it just fine, with my 21-year-old daughter in a huge agency with people 28 to 55, little supervision, and an attractive young woman. These are all the things. There's no place -- the parent’s agency perhaps will address it, but it's hard -- it's going through mush to get answers to anything. I found a sympathetic social worker who has dealt with some issues. Everything is crisis mode. There are different answers from everybody. The fact that in less than a year I have gone through three different levels of funding, we over requested it. Then told we under requested it. It's the classic mad hatter. The rules change constantly, and there doesn't seem to be a way of communicating. You know e-mails, you know, the bulletins say, you know, the services, that you'll be assigned a caseworker within 30 days. Oh, how about six months. The few things that are written down are totally inaccurate. They still have the director listed as someone who's been gone for six months. I tried to deal with Trudeau for arranging respite care that no longer is the case. It's one thing after another. And where do you go for clear answers and, you know, what these different levels mean. I mean, I'm probably more confused than the average parent here because I'm so new to it. Her funds have changed so many times. Like so many others, I worry about what will happen. I became a mom at 40. I'm not going to be around forever. She's an only child. Is there some plan to help me look at the transition for her to a group home? You don't have time to look at those significant questions in an intelligent way because we're going from one crisis created by these 15-minute increments, and these changes in plans, and all that, for you to get any meaningful answers for what's important in your child's life.

Healthcare/ Supports: Transition

CASEY GARTLAND: Do you want to add to that?
GENE AMARAL: No. I had a quick comment.
CASEY GARTLAND: Make sure the panel doesn't have any questions of your testimony, first.
KATHERINE KUIPER: Have you ever been connected with Office of Rehabilitation Services with your daughter? Have they done an eval?

Employment: Transition Barriers

ANNE PETERS: We worked with them in high school. One of the other work things we've done, this being Rhode Island, the woman working with her at the school saw we were having her work at a gym. She went to the director of the gym and said she couldn't work there unless she was getting paid. So the gym said she couldn't work there. Okay, now that you butted in and ruined something my daughter liked. This was almost a year after being involved with this agency. Perspectives don’t really seem eager to work with ORS. My impression is because financial reasons. As I said, I've been pretty creative in finding useful things. As I said, I cannot do (inaudible). It's Rhode Island, so you can make connections and findings. But it's one of those things that scares you. There should be a system that helps create these, that the parents and siblings who I applaud for stepping in, the resources aren't always there, and the answers aren't always there.
TIM FLYNN: There should be a system that creates --
ANNE PETERS: Helps get placement in the community. The fact that, you know, I gather the money is not there for the agencies, like perspectives, to invest in creating job opportunities, whether they're supported or independent. Realistically, you know, I'm looking at several of her cousins that are college honors graduates who are not employed, so I'm really not thinking job opportunities are going to be really fast. For her, working in the supported volunteer opportunities, job opportunities, whatever you want to call them, is appropriate. But, again, there seems to be -- the state is putting a lot of money into assisting people, but we've got to be smarter about it to make sure the money is being used in an intelligent way to really help her get what she needs. I'm sorry. I have to go get her.
CASEY GARTLAND: Go ahead.
GENE AMARAL: I just wanted to say, I'm listening to some of the concerns you've had with the state. I wanted to tell you a story. Gene Amaral. They live in tents, and pop belly stoves and outdoor toilets. So the woman came up from the state to inspect it with her $200 suit, her high heels and a BMW. She said you got to get rid of the outdoor toilets. It's terrible for the children. The children loved them. Now you got to go out and buy Porter Johns. You can't put a heater in it, because it will melt. In the wintertime, they would freeze. In the summertime, they would (inaudible). She comes back two years later, she says, you got to go out and get trailers with air-conditioning, and heat, and I think a massage parlor. I wasn't sure. (Laughter) But there's no electricity down there. Now you got to get poles and plumbing. So they cut out

the program for the state. I left. I saw the gentlemen who worked there. How did it go? They couldn't use it because the pipes froze.

FEMALE SPEAKER: I just, if I may, I have the most recent letter that came from Craig Stenning in regards to what they're looking for in the employment. I only have one copy. I'll read it, and it go down in the record, or I can give it to you.

TIM FLYNN: Just give it to us.

FEMALE SPEAKER: I'll read it for the people to understand, is that acceptable? And then I'll give it to you.

TIM FLYNN: I don't think it is right now. It's a letter he wrote. I don't think he expected it to be broadcasted in a public forum.

FEMALE SPEAKER: It's the same letter he sent to everybody.

FEMALE SPEAKER: It's not personally to me. We're questioning what they're looking to do. And they are looking to get all the individuals employed.

FEMALE SPEAKER: I was going to say, there's only ten minutes remaining, I would love to represent the survey of the other 80 families if I could speak again.

CASEY GARTLAND: Anyone else testifying?

Healthcare/Supports: Supports Intensity Scale

AMANDA: My name is Amanda. I'm Allison's sister, I'm also an attorney. And I see not necessarily right now through Allison's system, but other families who are trying to appeal the SIS process, that as an attorney there's not a lot of written guidance on that, and, also, on certain issues related to funding for outside programs that the state doesn't have a proper suitable situation for a certain disorder. We have a client with a child that there's no home in the state of Rhode Island that can meet his level of need. And there is one in Massachusetts, but there's no process by which to request that. So I think you give out legislation going forward. I don't know if it's more appropriate for regs. It probably is, but then you're leading up (inaudible) in their timetable. But maybe saying something along the lines of there needs to be an answer. We have – there are rights for people with disabilities in the legislation right now. Maybe something amended to that to include an appeal process or a discussion of rights about communication within the system. I'm sorry I didn't really get that through more. But hearing it today about people having difficulty getting through and communicating with agency, it seems like there needs to be something in there. Thank you.

CASEY GARTLAND: You have the last eight minutes.

Healthcare/ Supports: EI Autism

NICOLE BUCKA: So I'd like to kind of be the outlier here back to the early childhood, if I could. I shared with you all my story, but we didn't get much to the survey of the 80 families that have had similar experiences. What I would like to do is recap. The first thing was a serious lack of knowledge from doctors. Not posting information. You can remember that I referred you to graph two. So I would just like to point out the blue and the orange, again, doctors are not conducting autism screenings; they're not displaying posters or pamphlets. Overall, when kids are diagnosed, doctors are not knowledgeable and not keeping abreast. Research is brand-new in autism daily. People are not keeping up. The next one issue is wait lists. Between full evals, takes months to be seen. EI [33]having wait lists. Katie Beckett [34]having wait lists. I referred to both my sons had a lot of experiences with that. I'm very aggressive, if you can't tell. So if I'm hitting these roadblocks, I know there are people pushing less that aren't getting it. Graph 3, this is out of 80 families, did you experience service delays, wait lists in EI. The

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[33] **Early Intervention Program** promotes the growth and development of infants and toddlers who have a developmental disability or delay in one or more areas.

[34] **Katie Beckett** is an eligibility category that allows certain children under age 19 who have long term disabilities or complex medical needs to become eligible for Medical Assistance coverage.

orange, about one-fifth, or so, said yes. The blue is no. The purple are People never in EI. Means doctors didn't screen. They didn't know kids were behind, didn't refer them to EI. No intervention before the age of three. Graph four, did you experience wait lists when you were working with the CEDARR families? About one third, if you put together the orange and the blue, had either after delay in connecting with CEDARR, because they needed to get Katie Beckett first, or a delay in their particular service, let's say ABA or Respite[35]. There was a delay in a service. Evidence based treatments for the spectrum; again, EI can be quick to give you services. It's not intense enough. It's not the right kinds of treatments. They don't have a protocol for intensifying when the child is not responding. Training is not there. Not enough specialists. Many treatments have few or none available in Rhode Island, and agencies are not aware of what others can provide to fill in gaps. ABA is required for a mandate, but you need a diagnosis. Doctors are screening, not referring. There's wait lists; therefore, no diagnosis. So, again, that's not happening, just wanted to show you that. Sorry, let me know when I'm done. Slide five, which is the next one, did your child qualify? Again, just wanted to point out about a third are too old, didn't know about EI. Then slide seven, asking about your EI -- I'm sorry, actually, six, asking about your EI experience. I would argue this data, notice most of the numbers are NA, brown, not applicable. Most of the feedback says parents were relatively happy except for adjusting the amount of therapy and intensity. I would tell you parents don't know what they don't know. The evidence based was not happening in my home, or the other option is providers vary greatly on what they're providing, which, again, is an access and equity issue. Next point is a serious lack of interagency coordination and child centeredness. When I told the ICP no one is supporting families, like no one is supporting these families. They said, that's supposed to be CEDARRR. I said okay, they're not supporting me. I don't know what they're supposed to do. I thought they were gatekeepers, to be honest. The first one is page four. I want to point out; again, over half of these families do not have CEDARR supports. So out of 80 very extreme families, over half of them had no CEDARR support at all. And three quarters of them experience a serious delay in getting that CEDARR support. On page eight, sorry to keep bopping you around, you'll notice here this is asking parents and families what affects their families most, what is stressing them, killing them. You'll notice here that the most -- sorry, no. I'm talking too fast. Page eight is an overall how does CEDARR support you. Notice brown is N/A; CEDARRR is not in my role at all, like most families and if you look across-the-board, and these questions came from the CEDARRR mission. CEDARR was created with these things in mind. When you look across the feedback, you have an equal amount of people saying this isn't happening at all, to saying its okay. I would question the set up and how it works. For my family, it is no use. If I had a choice for my money where I need it, CEDARR would be pulled out all together. They're doing nothing.

FEMALE SPEAKER: I don't agree with you, because we just went into adult services last year.

TIM FLYNN: Let me ask you a question. Are there other people that would disagree with you?

NICOLE BUCKA: I don't know. I think if you're a parent who knows nothing, maybe they support you. But I'm not finding -- they write in their plans they're coordinating. I'm coordinating. They're not doing anything. They're connecting Perspectives with my provider to the school system. They're not visiting my kids. They know nothing going on. Only put more paperwork on my plate and show up once a year, here, sign here. I get furious. I'm like, what are you talking about, and what are you coordinating. My husband won't let me talk to them. They'll say you're a very pragmatic parent. We don't really need to do much. I said, I wrote on

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[35] **Respite care** is the provision of short-term, temporary relief to those who are caring for family members who might otherwise require permanent placement in a facility outside the home.

this rating I have no time for myself. Our marriage is like; we have no moment, whatsoever, that isn’t about caseworker stuff. You don't think I have some needs? I think I have some needs. I don't think this money is well spent. I think over 80 parents at least half would agree. Almost done and then the last slide was the parents, what do parents say are the most common stressors from the whole family perspective. And you notice orange is number one. Blue is number two. Orange, number one is the need for counseling and support and education for extended family. Grandparents who think the kid is normal, and you slap him around and he'll be found. Or number two is spouses that need counseling and support. I tell people this all the time. Men and women deal very differently. Women want to kick some autism butt and do a good job for their kids. Men kind of hide denial, workaholic, depression, withdrawal. It puts a lot of stress on the family. What happens is the parent, or the caregiver, is focused on the children. They let all that go. We have substance abuse, divorce, neglect. This is ripe for destruction. I say this all the time to my husband, disabled kids do not need divorced parents. They have enough in their life that's not right. My solutions, low cost campaign to educate everyone like mass act early. We can do that, social media. And a task force, like that gentleman in the back said, something led by parents. No one is listening to the parents. I'm done.

Healthcare/ Supports: Knowledge of Service

FEMALE SPEAKER: I'd just like to say maybe more to what you want to hear, with can the state do? And in addition to what you said, I think navigating the bureaucracy is so difficult. There's nobody you can call to give you a clear answer on how to navigate the bureaucracy. Whether you have a son and my son became disabled right after he was ineligible for EI. It's been many years I've been doing this, but not since his birth and the paperwork. There is paperwork from so many different agencies. It's so confusing. Many of us are lucky enough that we've been to college. We have some knowledge of how to navigate things. I work as an OT[36] assistant in a school department. I see so many children not getting services from the state and the towns because their parents have no idea of what the child's needs might be. Nobody in a position of authority is being very helpful. There are certain individuals that are helpful, but there's no coordination. We had services at home before there was CEDARR. I dealt with the agency down the road from my house. I helped choose who would come to my house. And it was very simple.

NICOLE BUCKA: I want to say to that I left Rhode Island for 12 years. This is what I love and hate about Rhode Island. It's who you know, and the connections you make. It's strength of Rhode Island, because when I make connections it's good. But we need a system.

TIM FLYNN: We're past 6:00.

CASEY GARTLAND: I'm sorry. At this point, we can't take more comments.

MALE SPEAKER: Next time we do anything; please don't substantially block the fire exit. 70

CASEY GARTLAND: Okay, thank you, everybody.

Wednesday July 24, 2013- East Providence Senior Center

MEREDITH SHEEHAN: Good afternoon, everyone. I want to welcome you to the public forum sponsored by the Governor's Commission on Disabilities, I participate most years and it's always a really interesting forum and really generates a lot of new issues or old issues and gives the commission guidance in order to go forth dealing with the legislature or congressional, our congress, in trying to resolve some of these outstanding issues. My name is Meredith Sheehan manager of programs and advocacy for the National Multiple Sclerosis Society here in Rhode Island. So my primary job is to deal with people living with MS in

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[36] **Occupational therapy**, often called **OT**, is the use of treatments to develop, recover, or maintain the daily living and work skills of people with a physical, mental or developmental condition.

Rhode Island providing services through our chapter, educational programming and working with our health care professionals mostly neurologists and treating people with MS. So I would like to mention that right outside this door here just to the right are the public restrooms should you need them throughout the afternoon. For the purpose of these public forum social security 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 living with disabilities. To ensure everyone who wants to speak gets the 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 congressional offices 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. I just wanted to point out -- from the Rhode Island Disability Law Center, he will be available to register people to vote if you're not already registered or if you changed address since the last election or have questions about registering to vote you can talk to Brian. I am going to go down the line and have our panelists introduce themselves and where they are from and then we can open it up to audience questions. Monica.
MONICA DZIALO: Monica Dzialo business -- supervisor with Office of Rehabilitation Services, I develop recruitment and hiring partnerships with businesses so when they are looking for qualified job applicants they there is contact made to help fill their job announcements openings.
CHRISTY RAPOSO: Christy Raposo from the Office of Marketing Communications at RIPTA.
BRIAN ADAE: My name is Brian Adae staff attorney with Disability Law Center part of the national protective and advocacy system for folks with disabilities, disability related issues. We are the PNA (sounds like) as it's called for the state of Rhode Island although we are not associated with the state providers or anybody else, completely independent, essentially federally funded, we operate under 8 or 9 federally funded programs. I would ask or point out, on the back table there is a folded set of papers that is actually a request for comments for our agency, we give an annual survey, usually, to adjust and modify our annual priorities, the types of cases we look at and pay attention to. We are not doing a survey this year we are just handing this out and asking for comments and in addition to that as pointed out I am happy to assist or answer any questions regarding voting and voting rights or voter registration while we are here today.
SHARON BRINKWORTH: Sharon Brinkworth executive director of brain injury association of Rhode Island located on Park Avenue in Cranston and we also have a resource center there, people can come in, we help families who have someone in the hospital who have had a brain injury and don't know where to turn and also co-sponsor four different support groups throughout the state.
CARMEN BOUCHER: Good afternoon I am Carmen Boucher Rhode Island Department of Health at the Office of Special Health Care Needs.
CLAIRE ROSENBAUM: Claire Rosenbaum, I work at the Sherlock Center on Disabilities, which is the university center for excellence on developmental disabilities in Rhode Island.
DAWN WARDYGA: Dawn Wardyga, advocate and advocate for people of all ages with all types of disabilities and chronic illnesses and currently serve as a commissioner on the Governor's Commission on Disabilities.
MEREDITH SHEEHAN: Thank you. Elizabeth is our interpreter for today so if anyone is in need of sign language interpretation Elizabeth would be happy to do that. Okay, great. So we

do have a couple of people who did sign up to speak. So I will just go down the list in order. Anthony actually signed up first. You can stay where you are or.

Healthcare/ Supports: Smoking Cessation Program

ANTHONY FRANCO: Anthony Franco and I am a senior research assistant from the able program, the able program is part of the Miriam hospital -- preventive -- smoking cessation specifically for people with mobility -- average population smokes about 19 percent of the average population smokes and people with severe mobility impairments, up to 50 percent of people smoke due to various reasons, boredom, pain management, things of that nature. And so this program specifically for people with mobility impairments and what we do is we do home based treatments. That's another thing we discovered during our pilot study is a lot of time people with mobility impairments want to seek help but do not have the means or transportation to go to the hospital to go to these agencies to help them quit and so our program is home based intervention program, they can earn up to $150 compensation and if they are interested in quitting we provide two months supply of in this case teen patches at no cost to them. They receive monthly phone calls from me or someone else on staff to see how they are doing with their program and the only requirements, base requirements is that they have a motilities impairment and therefore use some kind of assistive equipment, prosthetic leg, wheelchair, cane, and that they smoke. Those are the basic requirements. Currently we are enrolling patients for this year only so it's a limited time program and we are seeking help from the community and other agencies and co-recruiting into the program. So does anyone have any questions? No? Okay. So, I will be here until the end of the forum if anyone has questions or wants to sign up feel free to come up to me.

FEMALE SPEAKER: I have quite a few people with MS (Multiple sclerosis) who have participated in the smoking cessation program and it's definitely worthwhile if you know anyone interested I encourage you to speak to Anthony afterwards.

MARY ANNE MACIEL: Mary Anne from Spurwink -- located in Cranston work with a large number of people with developmental disabilities and quite a few of them are residents of the city of East Providence a lot of former students from East Providence High School we currently service and actually has a group that comes here on Tuesdays and does some volunteer work helps upsetting the tables (sounds like) for the lunch program, cleaning, serving, and also facilitating bowling (sounds like) with the seniors as well but that's an aside. My main concern on behalf of the people we service is the overall lack of funding. Especially in light of the Department of Justice coming to the state and doing their investigation, which, I believe is still ongoing. I know some findings have come out. Others are still ongoing and as a provider of supported employment for people with developmental disabilities, just speaking on behalf of my agency we are no longer taking any new clients and it's due to the overall lack of funding of the population we service. We have had to cut salaries significantly over the last two years. There is a big push for community based integrated employment and mileage is a huge issue and it's fairly underfunded. The entire program is severely underfunded. We are losing staff, we have lost benefits, lost salaries and it has a direct impact on the population we service. I know there are people graduating from high schools and unfortunately they are sitting at home. I know, supposedly there is no waiting list...that...you know, is a huge question in my mind, that there is no waiting list when I know there are kids that have graduated and staying home because they don't have a provider. And all of the providers are severely underfunded. The cuts came across a couple years ago; last year was a significant cut. And until funding is restored, I don't see things improving for people we service, this particular population.

Healthcare/ Supports: Funding

DAWN WARDYGA: Can I ask a clarifying question what is the case load now, current case load.
MARY ANNE MACIEL: Depends on the individual, depending on the severity of the disability may require one-on-one staffing. Other people may have a one to two, one to three, one to five; it really varies based on the individual so I can't really give a blanket statement.
DAWN WARDYGA: Can you say how many people you are serving.
MARY ANNE MACIEL: We serve approximately a hundred people (sounds like). And we have a large program, we provide residential services, day program, I happen to be the director of the day program. My program just in day services, there is 50. Any other questions or -- I don't know if there are any families here that have experience in this?
MEREDITH SHEEHAN: Children or --
MARY ANNE MACIEL: No it's not children -- we have a school, Spurwink School is in Lincoln but I am talking about adults that are the population I work with adult developmentally disabled population so kids finishing up high school, anywhere between 18 and 21 and coming into adult services. Just to clarify.
DAWN WARDYGA: I can assure you, I was at a hearing earlier this week in Woonsocket and there were in fact family members who testified at that hearing so we have heard the issue from that perspective, as well. And there are more hearings going on so I imagine it will come up in a lot of places.
MARY ANNE MACIEL: I would think so.
FEMALE SPEAKER: Those were the two people I
MALE SPEAKER: I haven't had anybody officially checked off they want to speak I guess we can just open it.
FEMALE SPEAKER: So again the CART reporter is, obviously taking it word for word what is said here today so if you didn't sign up to speak but had any thoughts or concerns or issues that you wanted to bring up and make sure it gets officially recorded. Like I said we have a meeting after and it translates into legislation at time so obviously funding is a huge issue across the board statewide. Obviously I am hoping it can be addressed and level funding at least back to a couple years ago before the drastic cut. Anyone else wants to --

Housing: Barriers

ELLEN PARKINSON: My name is Ellen Parkinson, Community Research Specialist -- health care help with children disabled (sounds like) and adults with disabilities and the biggest issue we face is trying to find affordable housing for adults -- limited income. There are wait lists for housing years long in the community. This particular population of adults with disabilities that are single, that have no family, have no supports, without additional access to low income housing, a voucher or some sort of a way to supersede a waiting list, if someone is viewed as disabled there should be a separate list and maybe there is that I haven't found but I am pretty good at finding those things. Some of these members end up in emergency rooms, homeless, living out of cars and just as an example. If someone went to an emergency room for something that, if they had their basic needs met and we were able to case manage and help them navigate the system, ER visits, hospitalizations could be avoided, SNIF (sounds like), nursing home placements could be avoided. Big push is state wants people transitioned out of nursing homes but there is nowhere to transition them even if they are physically able to do that. I have actually sent a -- I'm not very political but sent an e-mail to the senate chair, I can't remember his name but he did respond they were looking into trying to do something but it's very, very important to allow that, it would save the state a lot of money for medical care, ER visits and that sort of thing if a disabled person could have stable housing. Food is not an issue because the state does take care of them, there are a lot of food banks, utilities would not be an issue because subsidized housing, and it’s included. But anything anybody on the committee could (inaudible) that's a big, big -- we deal with every day.

Education: IEP Compliance

MARY LOPRESTI: I just actually got notice I got an e-mail just the other night so this is very last minute I don't have anything prepared. I am a mom of a 6 and a half year-old little boy with a mitochondrial disorder, he receives various services from the state now in school in our town so there is some crossover there. I often tell people who don't live in the state, I think we are very fortunate we do live here because he is just provided with a very good quality of life which in turn translates for a better quality of life for our family because we have four other children. You probably hear and I am sure there are areas where there could be more funding but for the most part I don't know -- I don't know if because we just more efficiently utilize our services and try to make the most of it but I do think, at least for our family there is a good quality of life and we are fortunate to live here in Rhode Island so it was basically to say thank you. We are not really looking for more at this point. I think as with anyplace child of a -- handicapped or parent, do I (inaudible) is half the battle. For the most part in our town we get good services but we just went through this experience where my son's IEP[37] one of his services was not addressed and we said what about this? And it was sort of, oh yeah, what about that? Hoping you would ignore that. So I don't know how much there is over sight on the city or town level. I often feel and my husband and I are fortunate because we are college educated, professionals, I have a sister who is a special needs teacher, I worry about those parents who don't know that and I sometimes see and I don't think it's just in my town because I have talked to parents in other towns, is it just what they don't know they don't know and we'll just try to move things along so that is a little bit of a frustration and I would like to see that more equitably distributed. My son will be entering kindergarten, even developmentally he is not even near preschooler and it happens the school he is attending has no handicapped accessible playground and I thought this is interesting if it's -- he'll never be able to walk but if we can get a swing so that's been promised, hopefully it will go through. If there was something at a level maybe if the town was held accountable and I know there are budget constraints so for me maybe this is more of advice and maybe this isn't the forum.

Accessibility: Recreational

The other thing I wanted to share just a little -- we don't take family vacations but stay-cations -- took son to the -- because warm water he can tolerate to get to a pool, it's a series of steps, crossover and go back down. The night we got there, the young URI student said I am not sure if you will be able to get here they are doing construction and they had actually of courses this is a state funded college, blocked off access. My husband was able to carry my son, he is 42 pounds, I carry the stroller, we had to go upstairs across and down stairs to the pool so we made it happen but I thought what if there were an adult and there was an emergency and that person had to get out and I thought, can somebody just attribute it to the fact there is temporary construction or shouldn't there be more accountability that, no, we need to really consider the possibility that handicapped person may need to exit the building. And again, these are just like little anecdotal things but they are little frustrations and I know it's not just me I talk with other parents with handicapped kids and it's like we are willing to speak up but what about those people that don't. Thank you for listening.

BRIAN ADAE: Excuse me ma'am would you be willing to speak with me after wards about these issues.

MARY LOPRESTI: I have to get out at ten of 3:00 but I can jot down my phone number or on the list here.

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[37] **IEP** defines the individualized objectives of a child who has been found with a disability, as defined by federal regulations.

BRIAN ADAE: Whatever is easiest for you?

Healthcare/ Supports: Service/ Funding

MARY LOPRESTI: Can I just follow up on that a little bit, I do a hundred percent agree with you that the city of East Providence has a lot of nice services for kids especially and also they have a nice adult program through the city of East Providence for people with special needs which I think is wonderful and a lot of the young adults in my program take advantage of that. I think sometimes what parents run into sometimes is once you make the leap from school age to adult programming there is a huge gap in services and a huge gap in funding. I am a special ed. indicator, as well, and coming from that background, I know that work not guilty a school system or working in a private school when working with a young person with whatever type of disability, you're required to have a certified special ed. teacher. All of a sudden you get into adult programming, once they turn 18 or 21 or any time within that time frame and it's no longer a requirement. Therefore, the salary and the expectations follow. One of the things that contribute to that huge discrepancy is the funding is so inadequate and I want to point out further we as a provider as an agency providing services for adults with developmental disabilities, when you are in a school, you get a per pupil amount of money per year for that student. When you go into adult services, we get what they call quarterly allocations so every quarter we are told how much money we have for that young adult. If, this is something that totally doesn't make sense right now in the state, if that young adult is sick or takes vacation time with a family, we don't get paid. We lose the funding for that individual for that -- so we might be given a particular allocation but unfortunately we can't even take advantage of that allocation to its fullest extent because of those issues that I just pointed out. I mean that doesn't even make sense when you think about it, kid is sick or takes a week vacation with his family, am I supposed to say to my staff sorry can't pay you, stay home? Of course not but that's kind of what we are up against so I am just using that as.

DAWN WARDYGA: I would add too and it's such a contradiction, it's about a while since I had kids in day care but when they were in day care whether they were there or not I had to pay their tuition so it's very similar and age in my opinion should be irrelevant, sounds like it's based on dollars versus need.

MARY LOPRESTI: Exactly.

MEREDITH SHEEHAN: Speak up all you want, anybody else? That's everything for now? Sure.

Healthcare/ Supports: Funding

MALE SPEAKER: Comment and question. Also about funding, our grandparent with a granddaughter who is about to turn 21 she is going to now be applying for funding for whatever services she is going to be eligible for, one of the thing that is my daughter is considering is a self-directed support program. But she has found out that there has been some funding cuts this year, maybe as much as 25 percent in that program. And my question for the panel is, is this a fact, is there actually going to be a decrease in the self-directed support program, and if so, where would that funding, supposed to be coming from originally and why was it cut?

BRIAN ADAE: Actually we are not here -- our role here is not to respond to questions like that, that question would more appropriately go, could I ask are you speaking about the PARI waiver? Are you speaking about a particular provider you have been in contact with for example Options? Where did that information come from?

BRIAN ADAE: I don't think we have -- do we have anybody from the state.

CLAIRE ROSENBAUM: I'm not from the state but if you want after I can kind of explain, things are slightly different for people entering the system than for people already in the system in terms, they use the same instrument, support intensity scale or the SIS[38], people already in the system may get a funding cut based on the assessment, people new to the system don't have anything to compare it to, it's not a cut to the program, it's a cut to the individual's budget compared to what they were funded.

MALE SPEAKER: Level of funding overall would be whatever the current level is right now.

CLAIRE ROSENBAUM: but your daughter, if she is new to the system won't have a funding assignment or allocation until she engages with the assessment.

MALE SPEAKER: I see. Okay.

CLAIRE ROSENBAUM: We can talk after.

MALE SPEAKER: All right. Thank you.

MEREDITH SHEEHAN: Anyone else? Well, we, the panel, we are require today stay until 4:00 to if anyone has, nothing else to say or hear, they can feel free to leave whenever you like, you don't have to stay until 4:00 or you can take a break, you guys could talk, if you want to take maybe a five or ten-minute break to see if other people come, maybe Brian could connect with the woman in the back and you guys could connect just for a few minutes and then we can just re-gather. Does that sound okay to everybody? Okay, great, let's do that.

MONICA DZIALO: **************************************.

MEREDITH SHEEHAN: Okay. That was a nice little break I am glad some people were able to connect. We did have a couple people walk in and we'll -- well, we had Laurie walk in, who, I know on a personal basis so I would be happy to have her voice her concerns and we can address them as needed.

Accessibility: Recreational

LAURIE JOHNSON: Can I stay sitting down? That works for me so I'm Laurie Johnson; I'm from Warwick Rhode Island. As far as company, et cetera, I belong to many organizations but I wouldn't say any official capacity. So, today, the important thing for me is, as I asked last year, I would like for there to be two accessible egresses to places, especially if they have large capacities. I belong to the Kent County YMCA, they have one ramp. I am constantly waiting for a child or being run into by a child and having the mom go whoa to a child or one walker leading another walker, I said I should ask for a comment card every time I have to wait or someone has to wait for me, they have a space they could have a ramp up but they don't have a ramp, I said they should make one with a racing stripe for the kids, they would enjoy it. But I would love for there to be two ramps. The Warwick Mall Cinema, there is only one ramp. I don't know how many places there are, but if there is ever a fire or any disaster, I used to come from West Warwick, it bothers me. So, other than that, I was told that I should speak on some things that I have spoken for, most especially medically necessary food.

Healthcare/ Supports: Nutrition

I am on a gluten free diet, I have Celiac Disease[39]. The SNAP [40]program does not take this into account, I am not eligible for it anyway, any more, but I still only get, I haven't actually gotten a loaf of bread in a very long time, so whether or not I would be eligible for it if they took medically necessary food into account, I don't know, I just know that they don't. But it would be wonderful if they did. And if you had the same problem, you probably would, too, because somebody is holding the food away from you. When they say you have to decide between

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[38] **Supports Intensity Scale** (SIS) is a unique, scientific assessment tool specifically designed to measure the level of practical supports required by people with intellectual disabilities (i.e., mental retardation) to lead normal, independent, and quality lives in society.

[39] **Celiac disease** -- also known as celiac sprue or gluten-sensitive enteropathy -- is a digestive and autoimmune disorder that results in damage to the lining of the small intestine when foods with gluten are eaten.

[40] **SNAP** offers nutrition assistance to millions of eligible, low-income individuals and families and provides economic benefits to communities.

your food and your prescriptions, they are not kidding. I have one prescription right now that I am only taking half of what I am supposed to. You look like you want to say something.
BRIAN ADAE: I was going to ask just to clarify, medically necessary food, if you're talking about gluten free, some of the other aspects.
LAURIE JOHNSON: Yes, a loaf of bread cost a lot nor if it's gluten free.
BRIAN ADAE: I would imagine money spent on food or -- but if being supplemented by Medicaid Medicare, is that what you're suggesting.
LAURIE JOHNSON: The SNAP program actually food stamps should look at whether or not a person has to purchase food -- my loaf of bread would runaround $6.
BRIAN ADAE: You're saying if someone has a medically necessary diet that's more expensive there should be a supplement, is that what you're suggesting?
LAURIE JOHNSON: That would be nice. I know one other thing I brought up a while ago -- and I guess these forums, medical personnel don't exactly run to these, or maybe they're too busy, I don't know. But I have told a few doctors in the past they really should go to these because they tell me in Rhode Island pay aren't very good for doctors. Many medical people don't want to work here. I need doctors. Even my physical therapist, with the education she has to get is pretty close to being a doctor. She doesn't make very much money because she works in Rhode Island. Personally, I would like to see her get some kind of break, or any medical professional get some kind of break on -- their student loans or something, in order to, in compensation for working here. Some kind of incentives to stay would be nice. I think that's about it.
MONICA DZIALO: Am I allowed to say something to that? My husband is a doctor that's why I can say it, it's the insurance companies, and it's where their difficult issue is. They are not reimbursing at the cost, it is in fact -- the medical to run an office so they are significantly undercutting.
LAURIE JOHNSON: Last year when I brought it up I mentioned calling my insurance company and getting a vendor on the phone. It wasn't a good moment for me, I was rather upset, I was like, excuse me, but I called here why are you answering the phone and they said for prior authorization this is where you go to. And I am going, that makes no sense to me. To me that's -- can you spell corruption? It just sounded wrong. Why doesn't your husband come to one of these--
MONICA DZIALO: Because he's working.
LAURIE JOHNSON: And how long does he get with each one? How much time?
MONICA DZIALO: Depends what the procedure is, he's a dentist, he's drilling and filling. But they all, they did take -- they do, the insurance companies, very much do, and they say this is what we are going to reimburse that procedure at, and I do know many people have expressed concern about that.

Healthcare/ Supports: Governor's Commission

LAURIE: I thank you for your time and I thank you for pushing forward the fragrance thing I asked about three years ago now, maybe more.
MEREDITH SHEEHAN: Anything else?
LAURIE JOHNSON: I'm good.
MEREDITH SHEEHAN: Anybody have any follow up to that or any issues you have thought of in the past hour? We have a whole hour you can talk for 55 minutes. All right, great. We obviously still have an hour. Last time I did this and we had a little bit of a lull in the action, I just kind of asked people to maybe tell us a little bit more about their organization and exactly what they do. I know I am always referring people to the disability law center and I don't know if I'm even knowing everything they do so maybe Brian can tell us a little bit more even for my

own knowledge about what you guys address, I'm always sending people there for divorce lawyers and I don't think you have any.
BRIAN ADAE: We don't actually. I know where divorce court is..
MEREDITH SHEEHAN: For my clients family law is always such a huge issue and I never exactly know where to send people.
BRIAN ADAE: This gets to be a little tricky and it's a good question. I think even our friend Claire from the Sherlock Center[41] knows us fairly well, wonders what we do sometimes. We do an awful lot. I mentioned at the outset, I was introducing us that we actually operate under 8/9 separate federally funded programs. The concept of the PNA (Protective and Advocacy System) was something created by Congress 35 to 40 years ago, coincident with the beginning of the deinstitutionalization movement harking back to a time when anybody who is essentially different in some shape or fashion was most likely put away somewhere. That is back when we had the Ladd school, a number of other institutions, and often times if not always when you place people in large congregate settings like that it seems to be almost inevitable that there comes about neglect and abuse. There is a very famous documentary done by a very young Geraldo Riviera at the time, I think Willowbrook Hospital in New York state, and he went in there and found a number of individuals and did the documentary around that and the system around the kinds of abuse and neglect she were subjected to including one particular individual who had among another things a speech aphasia[42] (sounds like) so his ability to expressively communicate was -- a lot of really un-pretty abuse. I saw a later follow up to the documentary where this fellow who was sort of the poster child for that sort of thing turns out was a very, very bright guy when got the necessary supports and integrated into the community went on to get his Ph.D. and taught a number of things, very, very interesting. So out of that, congress -- I could go on about history since we're -- Senator Jacob Javitz (sounds like) -- New York at the time, system at New York state essentially the model, although certainly not the model now for a national system put through congress. So we actually operate under all of these different programs referred to as PNA programs, initially it was PAML -- advocacy for the physically disabled now we have PAVA (sounds like) voting rights, a tremendous amount of work based on the rights of the disabled and their families. The main thrust of it was originally to look at abuse and neglect issues but it's gone beyond that to what we call homestead issues to integration into the community, to be able to follow up and see that people get access to services or they can exercise their rights so we do a certain amount of employment discrimination issues, housing discrimination issues. We look at equal access issues, some of it might have to do with, we have gentleman from the Governor's Commission on Disabilities who was talking a little bit I think with some of the individuals about accessibility, accessibility to buildings and facilities, we do a certain amount of work in that area, too. We do special education, IEP issues, or combinations of schools and testing as well as post-secondary accommodations, I've had the opportunity to represent doctor who is needed accommodations for taking USMDs, National licensing -- learning disabilities, as well as folks that needed elementary parts just to be able to participate in society. So, what is it that we do? All sorts of stuff, we would like to do more. How we look at it, I mention the priorities, we have annual priorities by regulation, federal regulations, we have to do priorities because we have a limited amount of resources that get spread very thin so we try to prioritize what we do and that's why we ask for public input on the sheets in the back so if you do have the opportunity please take one with you, it has the contact information

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[41] Paul V. **Sherlock Center** on Disabilities promotes the community membership of individuals with disabilities in school, work and society.

[42] **Aphasia** is a disturbance of the comprehension and formulation of language caused by dysfunction in specific brain regions.

you can ask us to look at some of these issues and see if we can't get them into our priorities for the coming fiscal year. The -- what was I going to say? Sharon knows us fairly well there is a lot more. Maybe a way to look at it, you mentioned family court, no we don't do divorce court, we don't do, the fact that somebody may be disabled and have a legal issue doesn't mean that we are able to do it. Our mandate basically says that we are supposed to be looking at systemic issues, policy issues, but we do, do individual casework. We are not going to do a divorce. But there have been times when there may have been an individual with a disability who was potentially being discriminated in the process of their divorce or custody issues in family court and that's something where we may venture in not to do the divorce but to advocate for their rights on that particular issue. Sometimes it's been in the realm of, we do not do criminal law. If somebody is disabled it doesn't mean that we are going to, and we can't do criminal defense. However there have been times we have been providing technical assistance or advocating for certain kinds of things to occur in the context of a criminal case for somebody that has a disability, really tricky. One of the things we did, we don't have a lot happening at this point in time but we had an initiative at one point to utilize our federal access authority, which is pretty remarkable, for institutions, to go into the prison, the ACI and find, identify folks with disabilities and see what issues they might have that they could use some assistance with. So it really runs the gamut, hard to pin it down, sometimes I wonder myself. Is that clear? Claire knows us pretty well.
CLAIRE ROSENBAUM: Each year I know there has been occasion I might have helped somebody come to you on an issue, but, you pretty much pay attention to the issues, priorities. So just knowing what they are and contributing commentary to --
BRIAN ADAE: Can do a little bit of hand off here, too, unless you feel like it's picking on you to maybe explain a little bit about the Sherlock Center and how that fits into the picture.
CLAIRE ROSENBAUM: We are sister agencies with the Rhode Island Disability Law Center and the Developmental Disabilities Council so the three of us are sort of sister agencies funded by the same federal entity, the administration (sounds like) developmental disabilities. The Sherlock Center as the (inaudible) for Rhode Island has the mission to provide training and technical assistance to -- service folks, teachers, social workers...people trained around disability (pre-service) and post service so training type of assistance. We are kind of charged to do research pertinent to the population of people with developmental disabilities and training and technical assistance to people with families of people with disabilities as well and have been have housed division services for school age and educational advocates for children in DCYF custody, when the parents are not involved in their lives. (inaudible) and we also house the, again, school age, dual sensory impairment project and do a lot of training around early intervention, as well, so a lot of those aspects. My particular position is around adult issues. So, if you're an adult you will -- to me at the Sherlock Center and I can help as I can. But we have folks that really span the developmental disability world from birth to death.
MEREDITH SHEEHAN: Audience questions? Anything you have thought of? Anybody else want to talk about their organization, or just inform us a little about what you do on a daily basis?
CARMEN BOUCHER: So everyone must have heard of the Department of Health, Office of Special Health Care Needs we are basically located in the division of community, family, health and equity. Basically we ensure family centered community based integrated system service for children and youth with special health care needs through inn from a structure building, -- technical assistance and collaboration with family’s agencies. Sounds, most likely you have heard it, the same thing. Basically I will speak about the program I am working right now on is disability and health and what basically we're doing, we are working on health promotion accessibility and emergency preparedness so we have different programs, -- I am

talking about one that we have a 3 year grant on and basically what we are doing is integrating through policies and at the department of health, from all programs, how they're working with people with disabilities, making sure they are integrating them within their own programs and with that also doing a lot of health promotion throughout the community and as well as making sure that if written materials go out how they are integrating person with a disability in that program and how they are outreaching to them. Accessibility, we are looking at medical accessibility and we actually had a company that is going out and basically assessing health facilities and putting that in a web site so people can go up and looking for a cardiologist in this particular area that is handicapped accessible so that will show up and the person can go there. We are going to be -- in Phase 2 also doing the recreational service -- unfortunately the experience the lady has gone through but as well that we are going to be working on that as well, doing checking recreational activities, health programs that are ADA (Americans with Disabilities Act) accommodating for everyone. -- Emergency preparedness so we are doing a lot of work making sure that people have everything that they need. Having an emergency plan, what their emergency plan looks like. And so helping them develop that, as well. So, those are some of the things that we are working on in our office. We also have other programs (inaudible) partnership with Rhode Island Parent Information Network and we have a resource specialist at doctor's offices and they are helping families navigate the special education system, or the health care system. So, they have different outreach that they do, to meet with families. So we are doing a lot of work on policy. Again, making sure that everyone is included.
MEREDITH SHEEHAN: Do you guys work with the -- back to the emergency registry.
CARMEN BOUCHER: Yes, we are working together. Definitely, right now we are just kind of looking into the future, we are planning a conference for the end of March/beginning of April, and it is basically going to go for all of the regions to look at region-wise and we are going to be working, inviting individuals with disabilities and the caretaker to come in and hopefully, although in planning right now, everyone will be leaving basically with their own emergency plan so within the conference they will be given tips as well as helping people develop that themselves so they can -- that with them.
MEREDITH SHEEHAN: Christy, what do you do?
CHRISTY RAPOSO: Marketing coordinator public relations graphic design, social media there. The retirement of our ADA coordinator I inherited the advisory transportation -- accessible transportation advisory committee for rip taxer we meet once a month and they pretty much give feedback on our para-transit services and any issues they have I can take to personnel -- resolution and report back to the committee.
MEREDITH SHEEHAN: You gather feedback so consumers call with complaints or anything you assemble those.
FEMALE SPEAKER: Solve it. I'm a problem.
MEREDITH SHEEHAN: Do you know how the accessible -- are going.
CHRISTY RAPOSO: People love them and we need more funding so we can get more -- (inaudible) ride to a (inaudible)
MONICA DZIALO: I am the work force development supervisor so what I do is I develop hiring and partner, recruiting partnerships with businesses in the community. ORS (Office of Rehabilitation Services) is the state federal funded rehabilitation program and we are on an order of selection right now because there are so many in needs of services. What in a means are you no longer needed to have a disability that impedes your ability to do a job but also impacts three of your seven life skilled areas? So, we work with the most significantly disabled in order to help them secure employment. I developed some new programs at ORS. One is called on the job evaluation instead of on the job training. This is where I pay the

employer to actually assess a person's ability to do the job and that has really worked out well because this helps individuals with skills; real employment opportunities to hire a skilled individual. Basically help people go to work who want to work. Then we also have benefits counselors to talk to, so people understand how their SSI or SSDI (Social Security Disability Insurance) may be impacted based on work, and your medical benefits and we are all concerned about affordable health care... (Inaudible) helping a person understand dollar for dollar, sit we'll sit down and show you how working, this is what it will do, this is what will be impacted. And we also partner with many other community resources like (inaudible) does, called disability law center, they call us, come over, review our case. And things like this. And things like this.

MEREDITH SHEEHAN: Sharon.

SHARON BRINKWORTH: Unfortunately, brain injuries just keep happening. In 2009, there were, through the registry of the Traumatic Brain Injury Registry the Department of Health has, they recorded 6585 brain injuries in the state of Rhode Island and that is all the way from being diagnosed with a concussion all the way up to a severe brain injury. And they get these from the statistics from the people who have entered the hospital or were just seen in the emergency room and sent home. That was 2009. We learned a few weeks ago that in 2010 the amount has gone up to 8340. So, our doors hopefully will be open for a while. We are located at 935 (sounds like) Park Avenue in Cranston Rhode Island and we are nonprofit 501C3 organization, started in 1983. Started by families who have sort of been together, been a support group setting but have had or needed more information about brain injuries, had someone a loved one in the hospital with a brain injury and it's kind of a wait and see thing, sometimes doctors are not sure when a person first comes in how injured they are and how it's going to be and there has been a lot of advances of course since 1983 but also a lot of advances in the area of saving people. 15/20 years ago people used to die in a lot of the accidents and now because of all of the advances with medical equipment and so forth people are being kept alive. And they have -- after they are able to leave the hospital, they are able to go to acute rehabilitation. If they have insurance they are allowed to stay a little longer than those without insurance but after the acute rehabilitation and maybe someday rehab there is not a lot for people with brain injuries so they are looking for work if they can work and looking for activities if they are not able to work. So, housing is also a problem for people with brain injuries and transportation. So, all of the things that have been mentioned, like persons with brain injuries will fall into that category, also. Some of the programs that we are involved with and have created are, we co-sponsored four (sounds like) support groups throughout the state and we also have one of them at our location in Cranston and we have a second one at our location for care givers only because it's, a lot of times they want to have their own group because it's sort of 24 hour care with people, for families. We also have an annual educational conference on brain injuries every year, we sponsor an annual 5K run and 2 mile walk with a family picnic so it's sort of that time to get together for all of the families to enjoy that and that's going to be October the 5th, on a Saturday at Slater Park in Pawtucket. Also through a state grant through the executive office of health and human services, we have been able to operate a brain injury resource center at our office so we have a large amount of books (sounds like), CDs and information about brain injury and it's also, it's for family members, of people with brain injuries and also different providers who work to help them. And, we do many trainings in the community, too. Elizabeth who is our program coordinator has been out maybe in some of your areas; she has come with us and done training about how to work with people with brain injuries. Also we have been working with (inaudible) consortium in the Rhode Island interscholastic league to do pretesting for Rhode Island school athletes for the concussions. There has been, it's a computer program and it takes

about 20 minutes or so and each of the athletes will go in and take this test and it measures things like their reaction times and their memory and things like that and those tests are then sent into a central place. If the coach that thinks they have had a concussion they can go back in, they can go to their doctor and their doctor then can access that person's test. And they can do, have him take, him or her, excuse me, take the test again and prepare them and that helps for them to diagnose if that child needs to stay out of play for a little longer. The other thing is, in the next month or so, we have been awarded a grant through the office of highway safety and this will be to help promote and educate how important seatbelt use is among the 18 to 34 age group of young men in the inner cities so we are looking forward to working on that, now that we have the seatbelt law. That's about it, any questions?
MEREDITH SHEEHAN: Any questions for any panelists or Dawn can tell us what she advocates for.
DAWN WARDYGA: I have done work with the health department and a year's worth of advocacy work primarily for kids with special health care needs but have expanded beyond that. And I really have a question for the group and I am real curious, this is the second forum that I have participated in, and I haven't heard a whole lot about Medicaid. And I throw that out there simply because I know that it's a very active area right now in the state. And I don't know, maybe it's, maybe the folks that are concerned about Medicaid might be at different forums, I don't know, but I just find it odd, other than, I mean we heard testimony today and we also heard testimony when I was in Woonsocket about provider reimbursement rates which I don't think people necessarily connect that with Medicaid necessarily because sometimes it's commercial insurance, sometimes it's Medicaid. But Medicaid is going through some pretty significant changes. And I don't know if anybody has any feedback on that, because it's, I mean its happening as we speak. We're on a pretty tight time line.
GAIL DAVIS: ...Neighborhood Health one of the -- for Medicaid in the state -- Neighborhood, I believe, is, we are, we hope, is being awarded the contract for the dually eligible -- 2014 and this year for LTSS, the long-term support services and I don't know, some of the people that spoke, I am, right now, in -- child health -- case manager, population is pregnant women and parents of children with disabilities, adoption, people who (inaudible) adoption, foster care children, a lot of foster parents I deal with and I am very well versed in that population but I know we have applied for that contract, we had put in the RFP (request for proposal) for that contract for the long-term support services and the dually eligible which I worked for 15 years for Hewlett-Packard previously EDS which is the fee for service side of Medicaid so I know about people trying to get it over on the system and know about -- for dollars there. Also heard daily from providers who were sorely underpaid especially in the dental arena, I was the dental diva for 15 years according to DHS and the dentists have not had a raise since, well we started there in 1993 and I know home care (sounds like), listening to Vinny Ward on Monday, I was there, as well, they haven't had a raise either and that requires legislation, legislative changes to give them raises. I know that some of the other agency that is work for the state, that work -- take Medicaid have been getting -- raises, have gotten increases for their fees but most of the providers have not. I know that with neighborhood we pay, we are paid a CAP (sounds like) rate by the state and given a bucket of money to provide services for them and looking at some of the claims, we reimburse a little better than fee for service but it is Medicaid -- there are changes coming down the road, the state has put in for another five-year time frame for a global waiver, as well, so that will probably impact other services but we are doing, Steve is a colleague and we are all providing services, not providing directly but helping people network to get services, networking with agencies, whether home services or an appointment or transportation, finding an appointment we do all of that, help our members find services and find providers that will accept Neighborhood -- oh you have Medicaid, forget

it. Its managed care so a little different reimbursement. Even with the School Department I have a client that, she had to take her disabled child in a wheelchair to Bradley to take part of their day program with her other son because the LEA (Local Educational Agency) program didn't have a one to one for him that day. So, I was like, how did you get in there? And her four year-old daughter, as well, so there are other issues that we all encounter daily and we try to find networking and try to find the right people to call and we all have a list of people to call to find out certain things and looking for more people to contact to say. Okay, I need this who do you know what can you help me with.

Healthcare/ Supports: Service Barriers

GAIL DAVIS: I worked with -- over ten years started children special health care needs been a social worker more years than I can -- explain for pediatrics and I am not (inaudible) Neighborhood's -- they do allow us to do what we do for our members we do take care of them go above and beyond at every moment to take care of them. I think it's also why the state is -- the general disabled Medicare Medicaid population towards us because we do take care of people. I just mentioned to Dawn we have a tiny pilot program of under 40 members that utilize the hospital extensively and are disabled and a nurse took care of them, social worker took care of them and a behavioral health person took care of them over a 6 month period we saved -- dollars in cost taking care of that -- housing, making sure they had medication, getting to the doctors, healthy food in the house, you name it so it is a proven fact of case management so say we're an insurance company we're really not, health maintenance organization and health includes social needs, basic needs, behavioral needs. Obviously if we cannot solve their basic needs, housing, clothing, they don't take care of their health and it costs the state millions of dollars (inaudible)

BRIAN ADAE: If I might ask as part of the managed care, the part of case management include DME durable medical equipment.

GAIL DAVIS: On speed dial -- took her son to the hospital in a wheelchair, -- he's a big 11, no hospital bed, on a -- mattress on the floor and I hounded a particular had thing until he got the equipment he needed and it was a matter of, the mother does not speak English and the child does not speak at all so it's a miracle of getting we have a (inaudible) service for bilingual or not English speaking members and their family (inaudible) and dads don't speak English and I work with (inaudible) got her beds for her and her other children and got them the hospital bed and now working on a shower chair for her but she had to sign a paper, she got it in the mail it was in English so I worked with her and another nurse across the aisle who is bilingual and wrote a note for them to send to me the form the mother had to sign and I asked (inaudible) to help me write a note in Spanish to tell her I am highlighting the line you need to sign I have read this you need to sign this to get him his wheelchair and hospital bed, she did, I said send back to me, included self addressed envelope to neighborhood to me and I faxed it to the DME and they said I never got the letter the mother said I sent it, I said you get it, I have a fax confirmation, I don't play games you don't mess with me. So, we do go above and beyond. We make home visits when we need to. Steve has visited -- I had a member who was my member because he was under 21, turned 21 aged out, Steve took over, we collaborated and worked together and now Steve is taking care of his needs for community and social.

BRIAN ADAE: When you look at this, when you get certain situations you are involved in, home level, when you look at housing and affordable housing but also folks that may have mobility issues and start getting into perhaps a youngster, not an adult, so they may not be eligible for the usual disabled elderly assistance or subsides but families with kids that have severe -- affordable housing that is accessible. Have you run into that?

GAIL DAVIS: Same family working with now getting the landlord to agree to let the DME Company do an evaluation, doctor has to write an order. Mother is on a first floor but so she doesn't have to carry down the few stairs -- we managed to get him home care services but that particular home health agency -- would not carry down the stairs I don't blame her, it's not safe but mom -- has to do this now working the landlord speaking English and Chinese mother only speaks Spanish so -- I've been working on that since, I think November. But we are going to get it. I am not stopping until I do. But we do work on that all the time.
CLAIRE ROSENBAUM: Premature but you mentioned the contract for long-term, the LTSS, eligible, do you know if, and that's for anybody who needs long-term care within Medicaid who has Medicare and Medicaid.
GAIL DAVIS: Not necessarily old people can be young people determined.
CLAIRE ROSENBAUM: That would be physical disability as well as folks in BHDDH.
GAIL DAVIS: Phase 2 (sounds like) which is another year.
CLAIRE ROSENBAUM: That's not right.
GAIL DAVIS: Not right now. This is all (inaudible)

Healthcare/ Supports: Medicaid

DAWN WARDYGA: I raised this issue because it is so complex and it's ever changing. What's true today may not be true tomorrow and I raise this issue because we are smack dab in the middle of a reapplication on Rhode Island's five-year Medicaid plan and as I say that, well within that five years assuming they get approved which my guess is they will eventually but so far, have I to say so far the feds have been pretty stringent if you will because they submitted their first, they submitted the first round back in March, and the feds actually came back and said, they determined that the application was incomplete. So, we are in round 2 right now. And Medicaid is currently holding public hearings for feedback on this Medicaid application. So, often times in this discussion, you talk about what the unmet needs are and where the gaps are and that kind of thing but people don't often put together how that's all funded and so my concern is that we have this one train running along this track that is dealing with the approval for the five-year plan, granted within that five years my guess is they have some wiggle room to move things around if it's not working out, but still, like now is the time, if there are urgent things that need to be included and I said it the other day in Woonsocket, this issue about provider reimbursement. I have been doing this work for 25 years in this state and provider reimbursement has been an issue for 25-plus years because it was an issue when I came in the door and while we have this Medicaid work going forward and then we also have these initiatives around trying to keep people in their homes regardless of the severity of their needs, the question becomes where does it connect and in fact, I mean, home care for anybody who is eligible for it, I am like 200 percent behind that initiative, but do we have the supports in place and have we thought that through enough to be sure that we can make that a reality? So as I say often times people and for good reason because its complicated stuff, often times people don't connect those dots. So, what I will do and you can call it a PSA if you will and I don't work for Medicaid but I believe it's very important for the populations that we are talking about. They have one public hearing left. But there is also an opportunity to provide written feedback to the state before this round 2 application goes in. The final public hearing is scheduled for tomorrow, July 25, 4:00 to 6:00 p.m. at Woonsocket Town Hall, 169 Main Street in Woonsocket. And if you have any interest whatsoever I strongly advise that you go to the website and take a look at the documents that they have prepared to submit to the feds. Be sure you look at the March document. Don't assume that that one is taken care of because it's my understanding, there is the March document that got kicked back. But what the state is submitting now is a supplement or an addendum I think is the word they used, to the March document so you almost have to do a cross-reference to make sure. The web site

is www.eohhs.ri.gov -- and there should be -- I would tell you that there is probably something right there on that page that says 1115 waiver[43] but just in case it doesn't -- you have gone there and it does have a direct link off that web site? Okay, so then that will work. And again they have on that; posted the March application and they also have posted the addendum that they were currently getting feedback on. I can't tell you whether or not there is information on there on provider reimbursement rates. I can't tell you what plans they might have incorporated into that plan because believe me I have to do a last read myself because it changes all the time. So, those of us that work with these communities, where we see the dots not connecting, that is serious stuff and the feds need to hear about that and you can either, again, attend that hearing in Woonsocket. Or there is a mechanism to commit comments through the web site we just talked about, written comments we just talked about through the web site we just talked about and once this addendum gets submitted to the feds, once the feds approve that addendum, and I'm assuming they have to approve both documents because the first one hasn't been approved so far. Once those documents are approved there will yet be another public input process but it won't be here in Rhode Island. You will have to submit your comments to the federal government. So, like what you are looking at now is like a draft of what it might look like. When the feds give it the green light then there is that other public input process. Right through CMS centers for Medicare and Medicaid services I think is what that stands for so through the federal government that manages Medicaid so there are a couple of levels you can still weigh in. Again, I personally have not done an analysis. I have a headache just thinking about it. But for those of you, especially those of you with specialty area that is knowing that, you can say you're going to do this, this and this but how have you planned to be able to accomplish that from a fiscal standpoint. Those are critical questions.
GAIL DAVIS: From Neighborhood's perspective we work closely with Beacon Health Strategies, in our building and I believe they are part of the plan ???? going when that comes to as far as mental health issue and external providers. We do what's called warm transfers, if we are talk to go a member who has a need immediately or we suspect they may not admit to immediate but we may suspect it ask for permission to put them on hold briefly, call the network to one of the people in Beacon they will them the member ID so they can pull it up and tell them the issue quickly and we introduce them and get off the phone to network to -- in their areas to specialists, psychiatrist, mental health counselor, they can do that, they don't provide the services but they will get them a name and number to get there.
DAWN WARDYGA: That is a classic example in my opinion of how you guys are doing the best you can possibly do to make sure you are lining up all of your ducks, worst thing in the world is for me to be that patient or individual and finally get to the place I need to be and oh I'm sorry we don't take Medicaid.
GAIL DAVIS: But they know, we have the provider book and know who takes and who doesn't, they'll refer them, where do you live, where can you get transportation to if it's an issue and they will find providers that accept neighborhood for this person to get there and we have a transportation hot line they call and we can hook them up with transportation if they're not on a bus line or eligible for RIDE, if they are medically eligible, we get them taxi -- to get them to and from their appointments.
DAWN WARDYGA: Neighborhood only in this particular situation. We can't speak for those who are covered through managed care through United Health Care.
GAIL DAVIS: Or fee for service.

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[43] Rhode Island Global Consumer Choice Compact **1115 Waiver** Demonstration (*Global Waiver*) establishes a new Federal-State agreement that provides the State with substantially greater flexibility than is available under existing program guidelines.

DAWN WARDYGA: Or those still in fee for service who are really (inaudible)

Healthcare/ Supports: Coordination of Services

GAIL DAVIS: Let me address -- this is all theoretical. I think the biggest concern right off for this population we are about to take on, long-term supports and services. So, obviously on both sides of the coin we have had Rhody Health Partners[44] and that's particulate of the job I do is to -- for waivers through the state. The other part, only for certain individuals that are SSI (Supplemental Security Income) approved disabilities get those (inaudible) services so we have a whole other population that gets those services that we paid for directly and that we are the piece that gets the approval, the orders and hires the agencies and you name it, that's what we do. And so I think what's going to happen is...again just a theory. Normally someone makes a referral for me -- waiver and I call the state, the town, whatever is associated with and they dot eligibility piece and send out 7,050 forms to be signed and if that's not dotted...sometimes it take a year. That's not going to happen at neighborhood, we have 14 days to do that and we do that because it's a person that needs -- or in some cases it's a child that needs help so I think the role will reverse. They still approve the eligibility for the waiver, again, this is just my (inaudible) from reviewing thousands of pages of stuff and then we will be responsible to make the contact, make the home visits, make the evaluations and hire the staff and oversee that. So I just see that the process is going to be a lot better, maybe I am naive but I think we will be able to do the best job possible. And I'll go back to the first hundred phone calls I made to people when they came onto Rhody Health Partners and they asked me you're really asking if I need this, you'll really help me, you really care I don't have food and they were really surprised. And so I think, and that's probably 10,000 members later, -- if they had to roll off in two years if they were on Medicaid and rolled off and went on Medicare they cried, please don't we can't pay the co-pays we don't have money for this, nobody will take care of me like you guys do. Not trying to (inaudible) but that's what we do.

CARMEN BOUCHER: Just a comment obviously (inaudible) and presentation from your company and I was totally impressed. There were two people and I have done a lot of outreach in my years of experience and there were two people from your company there and I noticed that one was asking questions and then they would take turns and they would go to the other person. Some people were going aside and she was calling to get answers.

GAIL DAVIS: Absolutely.

CARMEN BOUCHER: It's funny because she was like moving them to the side and you know keeping track of.

GAIL DAVIS: Stay right there I'll get an answer, absolutely.

CARMEN BOUCHER: And with this being a public affair, the confidentiality, so it was very interesting how working as a team they were able to -- so of course I had to ask, you know who, are you calling? And it was really interesting that they were trying to get answers for some of the consumers like right there.

GAIL DAVIS: Happens all the time. You have a table and I'll get called from a marketing rep, family doesn't have food on and on and on.

GAIL DAVIS: That's because our marketing reps go out.

CARMEN BOUCHER: I was very impressed.

Healthcare/ Supports: Medicaid

FEMALE SPEAKER: And we -- in Providence -- we network, we know everybody, -- and I have known each other for 20 years. If I have an issue she knows who to call.

GAIL DAVIS: We share numbers, we get all the back line numbers, and we do.

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[44] **Rhody Health Partners** (RHP) Case Management Program can help adults with disabilities improve their health and wellness.

DAWN WARDYGA: I am going to make I think a final point on this Medicaid piece aside from the fact I think more people need to get involved than are involved. Anybody who knows me knows this; I am an absolutely huge advocate for equality in terms of access to services. And what you just heard I think is a great model and has worked very well over the years. I mean there have been bumps along the road but for the most part they have been managed and that type of thing. I am deeply concerned about the rest of the Medicaid population, those who happen to fall into this system, they're kind of embraced, if you will, and I mean, that's all well and good. And I know that Neighborhood has the lion's share of the managed care population in the state so that's a good thing (sounds like) but having said that, there are still those other two populations. I am going to assume that United Health Care has to live by the same rules that Neighborhood does. How they implement may be very different and so it might not look the same. So there is that piece. But then again you keep -- we keep going back to these people whose Medicaid is fee for service only and they are groping in the dark. They have no one to assist them. Don't even try to get through on the phone to the state agency that -- and even if you do you're lucky if anyone knows what you're talking about the second you mention special needs they're like, whoa, I'm not qualified to take that call. So my concern, big picture going forward with all of this work with Medicaid is that we are making sure we are taking care of every individual using Medicaid regardless of who is responsible for delivering their care that is one of my biggest concerns, it's an equality issue.
GAIL DAVIS: I think in the next year or so they are going to (inaudible) to Rite Care and the Medicaid expansion so they will take on, it doesn't have to be family related just income related and also increase the poverty level to join Neighborhood.
DAWN WARDYGA: Also I have heard through health care reform that Neighborhood Health Plan will be a plan that people can buy.
GAIL DAVIS: Yes, that's our plan.
DAWN WARDYGA: Something a lot of us have been asking for, for a long time.
GAIL DAVIS: Like an insurance company like a Blue Cross.
MEREDITH SHEEHAN: Under health benefits exchange it's you (inaudible) are the three providers. I mean I talked to Christine (inaudible) director of the medical exchange (sounds like) and she definitely indicated that the outreach would be strong in terms of making people aware of the changes to the Medicaid eligibility guidelines I think it will definitely make it easier for some people to access, to be eligible.
GAIL DAVIS: I understand the application will be much shorter.
MEREDITH SHEEHAN: She indicated there will be webinars and town meetings, it's great. Well, that's amazing. Gail, thank you so much. That was great. I appreciate everyone coming out today and taking the time to -- two hours is a lot of time in the middle of the day and I appreciate that and occupier panelists did a great job. Thank you to everyone. (FORUM CLOSED)

Wednesday July 24, 2013- Warwick Library

LORNA RICCI: We're getting started soon. If you make sure you have this brochure from the back, which gives more Information on all of the panelists, other supporters of the Governor's Commission on Disability. It's very nice. It also has information on all the different agencies, so it becomes a little bit of a mini resource for you. I think its right in the middle, several pages, stapled. And, also, if you wish to testify today, you need to sign up. We're actually asking everyone to sign up, please, so we can have an attendance list to be able to give the Governor's Commission.
Okay. Welcome to the Governor's Commission on Disabilities. Can you hear me? Okay. This is one of six forums being held statewide. We're hoping that you'll testify today, and you may hear something that kind of spurs you to want to also agree with the testimony that you hear.

And feel free to sign in that you are going to testify, or raise your hand and we'll be able to take your testimony, too. If you're a little bit shy and wish to put your testimony in writing, you can do that and submit it to the Governor's Commission before August 8th. They take all written testimony, and that is really why I wanted all of you to have that printout, because the information of where to send it is right on the front. It says the Governor's Commission on Disability. You can do it online, send it snail mail, any way you'd like to make sure your testimony is seen and heard. I'd like to go a little bit -- read, first, the purpose of today. The purpose of the public forums is to identify the concerns of people with disabilities and their families in order to assist the state to develop programs that will improve the quality of life of people with disabilities. After the public forums are completed in early August, the sponsoring agencies will review the testimony and make recommendations, which will also be posted in November on the Governor's Commission website. Transcripts and recommendations, everything that's recorded today, that is, that's the transcript, will be printed and sent to the state and congressional offices and to members of the general assembly. So everything that is said today, and at all six public forums, is actually going to be seen by our legislators. It's a wonderful way to get your concern to the eyes and hopefully ears of people that might make a difference. So everything that is said here is going -- is not going to stop here. It's continuing on. Kate Bowden is here from the Governor's Commission on Disability. If you're a citizen and not registered to vote, she can assist you at the end of testimony today, after the end of the forum, or if we have a break. For those that have recently moved from one address to another and need a change in their voting registrations, she can help you with that, too. Little commercial break to make sure everybody votes, our panelists today, our distinguished panelists are here to just hear the testimony, clarify if you use an acronym or initials that people aren't sure what they are. But other than that, this isn't a debate. You're not going to have people debating anything you're saying. And I say that because sometimes people are a little nervous to testify. They may be afraid someone might ask a question of them they're not prepared to answer. This is not that kind of forum. It really is to hear your concerns. We're going to be taking notes. All the panelists are going to be listening. One thing that might happen, if something is mentioned that a panelist really knows they can help you with, they may say, please, I'd like to talk to you later after the forum. This is also a way to help with resources and maybe get some answers to someone. It's not it's going to happen every time. It's just if a panelist in their work situation knows the answer to a concern that's mentioned. So that kind of conversation is taking place separately from the forum, after the forum. Our panelists today are Barbara Mulligan, from the Office of Rehab Services. Can you raise your hand? No. Tim Flynn is not here. Lisa Onorato from Brain Injury Association of Rhode Island is here and Kate Bowden, as I said, from the Governor's Commission on Disability.
KATE BOWDEN: Disability Law Center.
LORNA RICCI: Disability Law Center. She's also on the commission.
MITZI JOHNSON: From the Sherlock Center at Rhode Island College.
COLLEEN POLSELLI: From the Rhode Island Department of Health.
RORY CARMODY: From access point, and also representing the commission, correct?
RORY CARMODY: Yes.
LORNA RICCI: I thank you for your participation. They're here to listen to your concerns. I would like to thank the staff person, Alyssa Sauralt. She's back here. If you have any questions on the Governor's Commission itself, please seek her later for any answers. I always like to thank our interpreters, just what I do. And I'd like to thank Curtiss James and Jon Henry. Thank you. And our cart interpreter, Tammi Burnham, always working to make sure communication access is clear for everyone. I'd like to get started.
FEMALE SPEAKER: Rest rooms?

LORNA RICCI: Important news. Sorry. I jumped over some important things. Should you need the rest rooms, they're right out the door to the right. Very close here. Right on the right, and should you need telephones, they're down as you came in through the door on the right, going out on the right.
KEN PARISEAU: Two more people.
JANET IOVINO: Janet Iovino, Sherlock Center on Disabilities at Rhode Island College.
KEN PARISEAU: Ken Pariseau, from Neighborhood Health of Rhode Island. I snuck in.
LORNA RICCI: You snuck in. That's great. Just the process, I'm going to be calling out the names to testify. Please clearly state your name and the town that you live in. Remember that I had said this is going to legislators, and they'd like to know the concerns of their own constituents. So if you could say your name, your town, and briefly state the concern that you have, if you have several, that's okay. If you'd like to do it 1, 2, 3, I have these 3 or 4 things to talk about, that's fine. Do we have everyone here testifying, just- for an idea of time, Leslie?
LESLIE: We have six, right now.
LORNA RICCI: We have a little time for each, but we do have a limit on how long you can talk, so that we can hear everyone. The first person is Melissa Rosenberg.

Healthcare/ Supports: Funding

MELISSA ROSENBERG: My name is Melissa Rosenberg. I am the assistive technology specialist at Ocean State Center for Independent Living, located in Warwick. Our commission at OSCIL is to help elderly and disabled people remain in their own homes and own communities as long as possible. Agencies like us are important because so many people live alone and are at risk of falls and injuries, due to the lack of strength or endurance that it takes to take even a basic shower, things we take for granted during our daily activities. I would like to give you an example of what we can do for a consumer. The consumer I would like to tell you about is a 76-year-old male. He recently suffered a massive heart attack, leaving him very week throughout his upper and lower extremities. He was hoping to get back to showering independently and doing other activities on his own. And going into the basement, where he spent most of his time watching television and hanging out by himself down there. He felt comfortable down there, and it was important for him to get back down there because he had been doing it for over 40 years. His wife would appreciate, as well, because they had separate --
LORNA RICCI: Sounds like a man cave.
MELISSA ROSENBERG: Yes. It was very important for him. So it was important for us to help him do that? We were able to have two grab bars installed in the shower and provide him with a shower chair to assist him in transferring safely and more independently. We also added railings to both sides of the basement stairs so he could continue to go down there independently and safely. They reported that he can move throughout the home and more independently. He still requires assistance from his family, but because of the funding that OSCIL receives, he was able to do these activities more independently. He can continue to do the things he was doing before his heart attack, he's just doing them in a safer way.
LORNA RICCI: Next is Darlene Landi.

Healthcare/ Supports: Service Providers Communication

DARLENE LANDI: My name is Darlene Landi. That is my son, Ryan. I'm from North Providence. One of the concerns I have is the lack of communication between service providers, and consumers, and their families. Ryan just recently switched day programs, and we also use self directed supports. And the communication between the fiscal intermediaries and the day programs, it seems as though no one is on the same page. A lot of my questions go unanswered. My concerns sometimes seem to be swept under the rug. And

I often feel as though I'm being ignored. So I would like to see communication between service providers and consumers and their families improved.

LORNA RICCI: Thank you, very much. Next is it Geidy?

Healthcare/ Supports: Smoking Cessation Program

GEIDY NOLASCO: It's Geidy Nolasco. I'm the project director of the ABLE program at the Miriam Hospital. It's a program for smokers with mobility impairment. And what we do is we help the participants in the program in the process of quitting smoking, we provide with two months of nicotine patches for free. And we also pay the participant for their time. They can earn up to $150. So if you know anyone that has mobility impairment and is a smoker, please see me after the forum and I'll be able to give you more information about it. Thank you.

LORNA RICCI: Thank you. Next is Tara Townsend.

Healthcare/ Supports: Workforce Development

TARA TOWNSEND: Good afternoon. I live in Warwick, but I work for the Rhode Island Parent Information Network for Family Voices supporting families with children with Special Health Care Needs. We actually have only a few concerns tonight. We've had a very successful legislative year, so we are; our major concerns now are really with workforce development, especially with the special needs community, nursing. We're looking; we're trying to find some way to maybe possibly put some legislation in place about CNAs, having them have a certificate program, so that not just RNs are qualified to work with kids that are g tube feeds, and issues such as that. Not as intense as trach-vented[45] kids. But somebody who has a g tube and needs feeds, they have to have an RN. It would be nice if we could free up some of those RNs to work with the more medically fragile people, and CNAs have some type of certificate program so they are under the supervision of an RN, but able to work with children or adults that have g tubes, and are able to flush them, and do the minor things that are needed with the g tube feed. That's one of the things that we're looking at working on over the next year. Then, also, we've been, in my personal life, we're been working on some accessibility issues. I have a five-year-old who’s trach-vented, g-tube, pretty much immobile, and he's now 50 pounds.

Transportation: Accessibility

His -- he's switching from a stroller to a wheelchair, and we're having a really hard time with trying to get him in and out of the car. I have a minivan, but I don't have an accessible minivan. As of right now, we can take his stroller apart and put it in the car, but that's only going to last so long because we should have the wheelchair within a month or so. How I'm going to get that into the car when I transport him is an issue we're concerned about, also the accessibility with home modifications. There's not a lot of help with Rhode Island, besides through grants and things like that, for people to modify their homes, to make them more handicapped accessible. I would like to see something like that put in place in Rhode Island, as well.

LORNA RICCI: Thank you, very much. I'd like to. Welcome Barbara Mulligan to join our panel. Has she done that? Thank you for coming, the next person to testify, Susan Shapiro.

Housing: Accessibility and Affordability

SUSAN SHAPIRO: Hi, my name is Susan Shapiro. I live in the city of Warwick. I recently took on a new position as an options counselor for folks who are currently living in nursing homes but have an interest in exploring options outside of the nursing homes. And in the short period of time that I've been doing this, I've already found a number of issues that are barriers to the success of somebody moving from inside a nursing home to the community. The major one is

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[45] A tracheostomy is a surgically made hole that goes through the front of your neck and into your **trachea**, or windpipe.

housing. We have an insufficient supply of affordable housing, and particularly housing that is accessible. So folks have to wait sometimes years to be able to get into an accessible home that will meet their needs. Another issue has to do with assisted living facilities. For a number of reasons, many of them will not consider somebody who uses a wheelchair, issues around fire safety, getting a person out of the building, the amount of help that somebody needs, because you need to be somewhat, extremely independent in terms of those facilities. One of the things I was thinking about that doesn't exist right now, to my knowledge, is transitional housing.

Housing: Recommendation
Transitional Housing

We've talked about transitional housing for a number of years, and I think that that might be some kind of solution for people who are waiting for a suitable apartment to become available. So we would like some consideration for that. Another issue I discovered is the capacity of the social service agencies that are in our community.

Healthcare/Supports:
Transition

Because of cuts in funds, whether state or federal, there are waiting lists that are being developed for what I look at as poor services.

Healthcare/Supports:
Accessibility

Meals on Wheels have a waiting list. Friendly Visitor, who's working with volunteers for the most part, is developing a waiting list, because of anticipated cuts and real cuts. So these are items, if somebody is going to leave a nursing home and go to the community, they are going to need supports. It's important for the supports to be there when they leave. It's not enough for them to be in place two weeks, Or 6 weeks, or 9 months later. Those are some of the issues we've come up against already. The other thing, personal focus, the access to services, there seems to be a disparity based on income. Folks who are low income qualify for benefits that are government benefits. Those who are upper levels of income can afford to pay for services. But folks in that middle income sections are really struggling to get their needs met. And what happens is their safety is jeopardized as a result of that. They may have a little bit of money in the bank. They may have $5 or $10,000. If they have more than 4-, they can't qualify for medical assistance. Many of them are, as you know, older folks, who have struggled for a lot of years to be able to put that money aside, and are fearful about spending their dollars. And so oftentimes they go without so they have that little cushion, or that money is there to pay for their funeral, or things of that nature. And so those folks can't afford the safety issues that the home health aides, the devices that might be able to help them. What I recently learned was that insurers are no longer paying for bathroom modifications, whether it's a toilet seat, or a tub bench. Those are simple, inexpensive items that can help somebody and keep them independent in their home; However, they're not deemed as worthy of payment by these insurers. And so, as a result, people are putting themselves at risk. I think, what happens is once they fall, depending on the injury they experience; they may end up in a nursing home. And eventually they'll use up the little bit of money they might have, and then it becomes a burden to our state and federal government to pay for those services, when an initial small expenditure could have prevented that. I wanted to bring that to folk’s attention. Thank you.

LORNA RICCI: Thank you, Susan. Next is Mitzi Johnson.

MITZIE JOHNSON: I'm sorry. I put my name there. I'm sitting on the panel. I just checked it off by accident.

LORNA RICCI: It's okay. Did you have something to say?

MITZIE JOHNSON: No, not at this time.

Housing: Accessibility and
Affordability

LORNA RICCI: Okay. Anyone else? Anyone else? Leslie? Linda Bradley?

LINDA BRADLEY: Good afternoon. My name is Linda Bradley. I work at OSCIL (Ocean State Center for Independent Living) as the home access coordinator. I wanted to say to Sue, I worked in rehab for over 20 years, and as far as I know, most insurance don't cover bathroom equipment. They never have. Sometimes if someone is on the core waiver, they might cover it. And that's always been something that therapists shook our heads at, that with a simple device you could make prevent someone from having to come into the facility. And we never understood that. It's a very long-running problem. I've been fortunate to work at OSCIL for ten years now. I just love what I do. I get to help people stay in their homes. I've met so many wonderful people. I work with lots of different disabilities. And I just wanted to share something. When I was in school that always stuck with me, they told us a person may have a disability. It becomes a handicap when they encounter a barrier. What I do at OSCIL is I try to help lessen the barriers, break down the barriers. Examples of this would be often folks are in a wheelchair, or might be using a walker; they have stairs to enter their home. They can't go up and down the stairs any longer. A common solution we will do is perhaps around. And when I do my assessments, I'll go to the home and look at the front door, back door, side door, and determine what the safest entrance is, and actually put, usually, an aluminum modular ramp on the home for them. It's something we can reuse when the day comes when they have to leave their home. They have the option to donate it back to us. We can reuse it again, refurbish it, make sure it's safe, and can reuse them. We also sometimes for the interior of the home, again, if they're using a walker or wheelchair, we may be able to install a stair lift. A lot of older homes may have one bathroom. If it's on the second floor, they may not be able to take a shower. Imagine, like, with a summer like this, not being able to take a shower. That would be quite awful. There's also exterior stair lifts that we sometimes will do. Not as often, but, you know, more the interior ones we do. Bathrooms are another common problem for people. Often they are very narrow. People can't get into the room. We may widen the door by adding an offset hinge, which enlarges the space a bit. We might recommend they change the door swinging out of the bathroom. We might replace the door with a sliding pocket door. We'll put grab bars up in bathrooms. We will sometimes modify a tub by cutting a piece out of the side, turning it into more of a step in style shower. We sometimes will move a vanity. Instead of having a big thing sticking out into the room, we'll change it into a smaller wall hung sink. Now they can get into the space, and they can also pull under the sink. I mentioned grab bars. We put them up. When I do the assessment, I determine where the safest place is for people to have the grab bars. All of the things I'm mentioning are relatively low cost. We're trying to help as many as we can. I just want to say, please, please, please, keep the funding coming, so we can help folks stay in their homes.

LORNA RICCI: Thank you. Is there anyone else? Leslie?

LESLIE: No, that's it.

LORNA RICCI: That's it. Does anyone, after what you heard, is there anything that you'd like to add? Is there anyone that would like to go on record as agreeing with anything that's been said? I guess we can take a break and wait for -- we will be here. But we need to just stay here to make sure, maybe some other people are coming in a little bit later to testify. Please feel free to stay here, talk to the panelists. There may be some sharing of information that's valuable that can take place.

SUSAN SHAPIRO: Can I add one thing to what I was saying?

LORNA RICCI: Sure. Forget what I just said.

Housing: Accessibility and Affordability

SUSAN SHAPIRO: You can take a break, too. It's just a quick point I forgot to mention. One of the other recommendations I have is that all new subsidized developments in public housing use universal design, so that it is easy for somebody who needs an accessible unit to be able to move into them. There are so few now. It seems that that would be a way to ensure that there is enough. And if you look at our population in Rhode Island, certainly there are plenty of folks that need more and more accessible units. So thank you.

LORNA RICCI: Thank you, Sue, Anyone else? Okay. Now you can all talk among yourselves. I'll just give notice if we have other people that wish to testify. We'll stop and make sure everyone can hear their testimony.

(Break)

LORNA RICCI: I have a couple of people that would like to testify. You can carry on your conversation later, for sure. A couple of people would like to testify. Lori Thurber, come on up. Lori Thurber.

Employment: Barriers

Healthcare/ Supports: Services

LORI THURBER: This is just on the side we were talking. I'm from the Corliss Center, and we were just concerned the new employment issues with the state that everybody wants to, and needs a job, wants to work. And a lot of our members do want to work, but there are some that have behavior problems, and there's some that just cannot tolerate going to a job, or job training. And the way the state is pushing it now, they want everybody out into the community working, which a lot of the members, you know, they do want to work, but like I said, some cannot tolerate it. And I write the ISP plans, and it's very hard. I have one gentleman now. He's about 30 years old. And he's not interested in working. He's autistic. He does at will is drawing throughout the day. We try to get him into some of the activities. But he's not motivated to do a lot of different activities. It's like, I don't know, don't have any idea what to put down for employment. We're going to try to see, like, simple steps. If he'll look at the laptop computer looking for some jobs, maybe something, like that. But it's very hard when some of them are just not motivated, or not interested, or cannot tolerate even looking for an employment, or going out to a job. So that's a real concern, because not everybody fits in that box. Then we have some higher functioning members who worked before. And they want a job, but some of them their behavior, they have a lot of behavior problems. And they might just say one day, I don't want to go to my job, or just a melt down at the job. And they are very willing to work. So it's very concerning to us.

KATE BOWDEN: Could you say your name, again, sorry?

LORI THURBER: Lori Thurber, from Corliss.

LORNA RICCI: Go ahead. Judy May.

Housing: Accessibility

JUDY MAY: My name is Judy May. I'm from North Kingstown. And currently I'm a benefit specialist at the Point, the aging disable research center, and newly board member of OSCIL, which I'm proud to be a member of. I wanted to actually reiterate some of the things that Susan was talking about. Particularly what I deal with on a daily basis, it's almost in my, housing, housing, transportation, housing, transportation, housing. I don't mean to sound repetitive, but I can't tell you how many phone calls I received about this issue. The other issue that we have in relation to that is the population that are not young are not seniors, but that age right in between 40 and 50, placement for housing. Some of them have been put into places where they should not really be living, a nursing, per se, but there's a 25-year-old woman who nobody else knows where to put. Assisted living facilities sometimes turn down people in these situations, because of mental health reasons. Not knowing how appropriately someone might be when you're in the senior community. We have a lot of people that are in limbo, and in this waiting period, that have no families, that have no place to go, that are getting really frustrated. That really want to be independent and really want to do the right thing, and I'm having more and more problems finding even someone to listen or someone to help. I've actually had a particular person that unfortunately was resorted to kind of shutting himself out until his neighbors had brought to our attention how fearful he was. He was paraplegic, 45 years old. And he thought by hiding they wouldn't come in and put him in a facility where he knew he didn't belong, due to an accident and brain trauma and decided to hide in his home. Fortunately enough, we were able to get authorities there and help him on his way. But this is just one of the incidences that happened that we know of that people are so fearful and have no choices or no options where to go, a population that really needs to be addressed, not only in that aspect, but also accessibility. Some of these places that they're living that were accessible at one time, and then fallen on injury at a young age, or even older, and not able to return there, or to be easily exited from these facilities, have nowhere else to go. I recently just got off vacation, and I found a little accessibility problem myself. I went to one of our beautiful beaches here in East Matunuck, dying to take a plunge in the water, because I had this beautiful week off that we just had. Dying to get into the water, only to find out, to my disappointment, there was no surf wheelchair at the beach. Totally bummed I was. I dragged myself to that water shore got two lifeguards, cute by the way. (Laughter) to help me in that water, because there was no way in heck I wasn't going in. and me, being me, spoke to the person from the DEM (Department of Environmental Management) before I left and asked why. She said the state told us they have no money, really? And all of the other beaches excuse me, Misquamicut Beach has most of the other surf chairs, and they're all in disrepair. And they need to be fixed. Now, we're at the end of July. And she said on the 4th of July, to my embarrassment, I had to sit there and watch eight people car row a tourist from the parking lot to the beach so he could enjoy the lights of the festivities from the fireworks going on, because we had no surf wheelchair. I was blown away. Here we're looking for tourists. There's no surf wheelchair. The ocean state, they're broken. It blew my mind. So I had to do some investigating. Lifeguard told me there were not even body boards at this beach. I don't know if you're familiar with that. Piping plovers they preserve an area over there. They didn't have a body board. I called around. The person from -- I got switched from the Department of Environmental Management and then the Department of Health. And then on both websites one said that East Beach was a beach that should have one. There are ten. They listed the amount of chairs available. The other site had six chairs. East Beach wasn't one of the ones that were on there. They said they had a few that were put out and were waiting to get ordered. I just want that on record, as well, another accessibility issue, surf chairs. One more thing, on my vacation, I went to a Sunset Concert in Newport. Pulled into the parking lot, and was told, did I research a handicapped parking spot for the festivity. I said, sorry, I have a plaque. I never knew I had to call in advance. Well, for this you do. We don't have any parking. You might go further down the wharf and find a spot. But, again, I'd have to walk to where I bought an accessible handicapped seat ticket to see an event, luckily someone was pulling out. We got to pull in. I again did my trusty follow up work and asked, is this possible that you reserve a handicap parking spot for an event? Is it just because it's this venue, and right side by side, or is Newport like this? I've lived here 30 something years. Is this what we do in Newport? She told me that usually with the venues, they reserve spots. I then asked her, when I purchased the tickets and I directly had to speak with someone because I had to purchase an accessible ticket, I couldn't just do this online, why was I not informed at that moment, do you know you're getting accessibility seating, you might want to reserve a spot. That wasn't told to me. She then informed me, not everybody who buys an accessible seat uses handicapped parking. I said, well, thanks for your time, and I'll be talking to you later. Hopefully you'll see me at another event. I just wanted that on the record, as well. Thank you.

LORNA RICCI: Thank you, Judy. Anybody say I need to agree with that, I have another issue of concern close to that regarding access. This is your chance. I know we have service

providers. Did I see a hand? Yes. No. I know there are service providers and folks representing different agencies. You better than anyone know the different concerns that your consumers have. You hear it probably every day. Do I see a hand? I'm sorry.
MITZIE JOHNSON: Joann has something to say. She wants me to help her just to get her point on the record.
JOANN PLANT: Joann Plant, from Warwick.
LORNA RICCI: Do you want me to hold it?
MITZIE JOHNSON: Spin around a little.
LORNA RICCI: Great.
MITZIE JOHNSON: Do you want to start off? Come on now, you can do this.
JOANN PLANT: About ten years ago I had a stroke and I didn't know what to do about it. I didn't know that there was anybody for helping people, you know. And I went into the hospital, Kent County. They didn't tell me who to contact to get some help at home. But I found it in the paper, in the newspaper and the phonebook, I found who to get ahold of. So I got ahold of them. And they set me up with food stamps, and all that kind of stuff. Then I got -- they gave me a place where I could get somebody to clean my house, and all stuff like that.
MITZIE JOHNSON: Home health aide.

Healthcare/ Supports: Workforce Accountability

JOANN PLANT: Well, I hired two of them, and they both stole things from me, you know, like really expensive things. And then after that I cancelled. I cancelled that. And ever since then, I've been -- I had two other strokes besides that one. And I have Social Security right now, but my Social Security doesn't want to, like, really help. My husband works, so my Social Security is real low. So because he works so many hours a week, my Social Security is cut back so much money a month, you know. And so it's hard enough to pay the mortgage and the, you know, all the bills without -- with my Social Security. Because when I bought that house, I was working. I was working. I was all set. I had, you know, money put away. And, you know, and then you get to the point when you have -- when you have the stroke that your needs are not being met because you have to wait to kick into Social Security. So you burn through all of the finances that you had in the bank. Those are all gone. And then you sit there with your relatives, and your friends, saying, oh, I want to bum a dollar from you so I can get some bread, or something. It was really lousy time for us. Now my husband is still working. We're paying for everything that we have. But I got to find another job. Now who's going to give me, I ask them who's going to give me a job with my handicap? I can't get off Social Security, because that will take away all my medical. And I can't lose my medical, because then I'm screwed. I need that. And so I can't work full time, because I will lose that. But yet I got to make money, enough money, to help my husband out. And, you know, pay whatever else bills we need. So that's all I'm saying, is that you need more money for the people who cannot earn it, because they can't even afford apartments anymore. Prices of an apartment are ridiculous nowadays.
MITZIE JOHNSON: You got your point, but I just wanted to go over a couple things you might have missed, and then you can correct me if you didn't want to say this. So the first point I think I just want to summarize it, when you talked about the home health aide person, because you said that you went to the agency, and they found a home health aide person for you. And you wish you had a say in who was chosen to work with you. And you wish you could have had the ability to hire who you wanted, because you have a lot of friends and family members that would love to work with you and help you, but they just can't afford to just help you without the extra finances, and --

JOANN PLANT: Not only that, they could take me out, too. Because, you know, I'm stuck in Warwick. So once in a while I like to go see Coventry some day. Go see the Wal-Mart over there, whatever.

MITZIE JOHNSON: That was one point you wanted to make. And then the other point that you were making about employment, you didn't know that there was some agency that could help you find employment even though you were disabled. So you were sitting right over, you came right over to the right person over there, and we introduced you to someone from ORS, but you're interested in finding employment to supplement your income.

JOANN PLANT: Yup.

MITZIE JOHNSON: And the last point you wanted to make was the transportation issue, right?

Transportation: Accessibility

JOANN PLANT: Oh, yeah, the RIDE bus. Now, the RIDE bus could take me to a workplace, but it charges $4 per ride. So it charges $8 a day taking that, so that adds up to about $50 a week $35, $50 a week.

MITZIE JOHNSON: It's expensive.

JOANN PLANT: Now, if I'm only earning $150, then, well, there goes that money, you know., because now I only have a hundred dollars for my whole family for groceries for the week. You know what I'm saying? It's crazy. You can't get by.

MITZIE JOHNSON: Another thing Joann mentioned is that she is also a parent that has a child with a disability.

JOANN PLANT: My daughter has Asperger's Syndrome, and she's on Social Security, too, right now. Asperger Syndrome is, they, they're very smart, they are so smart.

THE SPEAKER: Yes, they are. We know.

FEMALE SPEAKER: Some of us know that personally.

JOANN PLANT: But that's a kind of autism where they have really strong fears about things. My daughter is afraid of toilets. So she won't go in any other bathroom but ours, unless I go with her. Now, my daughter is 18 years old. I really don't like walking in the toilet with her. But I have to, because she's terrified. She won't drive a car because she's afraid she's going to hit a child. She loves children. She's hoping to be a teacher some day.

MITZIE JOHNSON: That's great. So you shared that your daughter is the person that helped you since you're not getting any help, home health aide. I thought that was something that people should know about. Did I miss anything?

JOANN PLANT: No.

MITZIE JOHNSON: Okay, Joann. Thank you.

LORNA RICCI: Thank you, so much, Joann. Thank you. Jack, did you want to say anything? Jack Ringland.

Healthcare/ Supports:
Independent Living Survey

JACK RINGLAND: Thank you. My name is Jack Ringland. I am from Barrington. I am currently the secretary of the Rhode Island Statewide Independent Living Council, for those of you that don't know of the independent living council, we promote independent living for all persons with disabilities. We used to say advocate, but we can't say advocate anymore. Anyhow, that's what we do. We do have what is called a needs assessment committee that is very, very active. And the needs assessment committee has devised a survey. Now, this survey can be taken online and when we are out and about we do have some paper copies. You can find out about the survey by going to risilc.org. There you'll find it in just about every format you can think of. Maybe there's a couple we missed. But, anyway, it's there. The survey right now is set up, and it will remain that way, to determine the unmet needs of Rhode Islanders with disabilities. And you can go on and you can check off the boxes, and so on and so forth, and all of the demographics and you can even leave a few comments, and so on. And at the end if you want to enter for a gift card at target, you can do that, too, just a little incentive to get you to fill it out. It is designed for people 18 and over, either with disabilities, themselves, or their caregivers, PCAS, whatever, that are filling it out for them. The idea is that it's their thoughts.

Healthcare/ Supports: Accessibility

Now, some of the things that I've heard already, which are, you know, right up there on a first assessment, which was -- first results, rather, which were only four months in length, because we did them the last four months of last year. We're, you know, the good old transportation, housing, all of that sort of thing, education, jobs, you name it. Everything that we've been talking here today is right up on that list, and soon we're going to be sharing that online, some of those results, so that people will get the ideas there. Also, if anybody wants to contact the SILC directly, we can share some of those results, if you think it's going to help out with your own programs, and so forth. And we are in the midst of conducting the survey again this year. At the end of this year, we will be revising it based upon what we have found. And we have found a few little glitches, and everything. But you just can't revise it all the time. Now to the main part of the thing, we have long felt, and I have been a big proponent of it, because I was in this situation, that there are a great many Rhode Islanders that get trusted into a situation where they suddenly become disabled, and they got no idea what's available. I had a yard sale once, earlier this spring, and, for instance, a gentleman came up and noticed that I was in a wheelchair, and so forth. And we got to talking, and everything. He just has been diagnosed with MS. He had no idea what to do, where to go, or however. And he acted very, very anxious, short of saying terrified. I gave him a few ideas that I could think of, and hopefully he's been able to follow up on them. Anyhow, along this whole line of not knowing, or people, or me realizing and several of our committee realizing there are probably a will the of people in Rhode Island that know nothing about what's available to them, the needs assessment committee of the Rhode Island Statewide Independent Living Counsel has undertaken going to a number of public venues. The first public venue that we attended was the summer festival in Cumberland. The second was a marathon because it involves 13 days of concerts was the Bristol, Rhode Island, Fourth of July Celebration. And at those, we offered information. And, again, we're offering information. We're talking to people. We're getting them to sign our guest books, so we can contact them, if need be. And we're offering information, such as the brochures. Primarily on the two independent living centers that we copartner with, PARI and OSCIL, although we do have some things from ORS, which is also a partner of ours. So it's there for people to take on, and, also, there's information there for people to do the independent living survey, our needs assessment survey. Our next big undertaking is the second, third, and fourth of August, when we will be at the Charlestown Seafood Festival for all three days, with a booth, just inside the admissions gate. If anyone happens to be going by, stop and say hi. Send your friends, and so forth. Anybody that would like to fill out the survey, we will give them the information to do so, and we will have some paper surveys there to fill out if somebody has no access to computers. Stop by and say hi. We'd love to hear from you and love to get your thoughts. Thank you.

LORNA RICCI: Thank you, anyone else? Anyone else on our panel like to speak about services? We have a few more minutes. It's always a good opportunity to talk about your services, anybody?

KATE BOWDEN: Hi, everyone. My name is Kate Bowden, and I'm a staff attorney at the Rhode Island Disability Law Center. I have a packet of materials that we brought which outlines what we do. So if you do have questions about what we do, there are materials here

that will help you. And I'm happy to answer questions. I forgot your name. Joann, I want to talk to you, because I have some information that I think will be helpful to you. Okay. Thank you.
LORNA RICCI: Thanks, Kate, anyone else? Anyone else on our panel? Okay. I guess we're going to have time to talk among ourselves. We might get last minute people coming in.

Thursday, July 25, 2013 South Providence Library

CHRISTINE HARKINS: Testing, testing 1, 2, 3. Welcome, everyone to the state of Rhode Island and Providence Plantations public forums to identify the concerns of people with disabilities and their families and their fellow Rhode Islanders. This committee is very, very involved and very interested in hearing your concerns, what you think, so that we can make this a better community, a better state and a better country. The purpose of these public forums is to identify the concerns of people as I said with their families and other Rhode Islanders to develop programs to improve the quality of the life of people with disabilities. Also 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 and your family, or associates, to the proper resource. 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. That will be done before the beginning of November. The recommendations and the transcripts will be printed and sent to state and congressional officials. And to all members of the General Assembly, and the recommendations will be used to develop policy and legislative initiatives for the next year, or until these concerns are accomplished and addressed. The Rhode Island Disability Law Center's panelist will be available to register anyone who is a center and not currently registered to vote wherever they live to vote at the end of the testimony so you can stay here and register to vote. People can also file a change of address if they moved since the last election. If you are planning on speaking, and you have not signed up on this list, please sign up at a list on the table back there. If you need sign language interpreting, we have two top people in the western hemisphere right over here, sitting here, and they will be able to help you or family members. And another group of top folks that are willing to take your concerns and bring them to the law makers are the folks that I will now ask to introduce themselves. Panelists, can we start here?
KAREN DAVIS: Sure, my name is Karen Davis with the Office of Rehabilitation Services and I am a supervisor, I supervisor the deaf and hard of hearing region in addition to south county.
CASEY GARTLAND: Senior director with the agency are in Rhode Island that provides service to adults and children with disabilities and also a commissioner on the Governor's Commission on Disabilities.
ALEXANDER SPIGELMAN: Alexander Spigelman attorney with the Rhode Island Disability Law Center.
CARMEN BOUCHER: Carmen Boucher, I work at the Department of Health.
DAVID MCMAHON: David McMahon BHDDH administrator.
TIM FLYNN: Tim Flynn, Chairman of the Governor's Commission on Disabilities, I want to thank all of you for being here today, braving the weather but we are anxious to hear what you have to say and to take what you say and use it to formulate policy in the coming year so we want to thank you all for coming.
CHRISTINE HARKINS: I am Christine Harkins president and CEO of Bridgemark Addiction and Recovery Services, comprehensive treatment center for services relating to anything to do with addictions or alcoholism, gambling and other disorders of the -- so now we will start with Maria Orega (sounds like) -- and I understand you have brought an interpreter with you so you will testify and your interpreter will help.

FEMALE SPEAKER: She doesn't want to speak, she just came here for help, you said at the end of --

CHRISTINE HARKINS: At the end of all testimony you can speak to whomever you would like on the panel.

FEMALE SPEAKER: That's what she wants.

CHRISTINE HARKINS: Very good. Then the next would be Carmen --

Housing: Accessibility

CARMEN ARSEDO: I came because I need help because I have my apartment but it's not handicapped because I wasn't handicapped when I moved there. And getting in the shower and coming out of the shower is a problem. Now, when I applied at another place, and they were going to give me a handicapped but I need proof because when they check my records all of a sudden I have houses in Miami and cars and credit cards, and I've never been there, identity theft, and they need like a paper stating that. I came to see somebody to help me with that so that's why I came because in the other apartment that I am going to get, I don't have to get in the shower that is my problem. It's like I have the chair, I'll sit in it, walk in my walker and the water goes through the floor. But they need proof that -- all them things in Florida. For me to see somebody that will help me with that, that they'll write me a paper stating that I already said it and, what can they do for me because on the hottest days of the last two weeks, they have us running around and --

FEMALE SPEAKER: .(inaudible) sympathy, she is on oxygen, we had to go to (inaudible) they sent us somewhere downtown that she got lost and almost fell off the bus because I could not go. They sent her to see governor -- I don't know, downtown, and she couldn't go, she took her fingerprint and that's still not good enough for them so we don't know what to do.

CARMEN ARSEDO: Back and forth, back and forth, they need the paper, they'll give me the apartment but they need a paper I said I didn't do all those things in Florida, the closest I've been to Florida is watching it on TV. So, I don't know what else to do, and I want that apartments.

CHRISTINE HARKINS: Can you identify yourself again, your name please?

CARMEN ARSEDO: Carmen Arsedo (sounds like) you want me to show you my papers?

CHRISTINE HARKINS: No, that's fine I wanted you to say your name so we could get it on the transcript and at the end of the session we will have resources for you, some of the people we can pinpoint but we also want this for the broader use of this testimony.

CARMEN ARSEDO: Thank you.

CHRISTINE HARKINS: You're very welcome. Vivian Dinn (sounds like).

VIVIAN DINN: I just, I came with my mom -- I thought I had to sign in so I signed.

CHRISTINE HARKINS: Yes, we wanted you to, that's fine. Some people will testify and some people will not. Ms. Nolasco (sounds like).

GEIDY NOLASCO: My name is Geidy Nolasco from the Miriam hospital and I am actually here to offer a. --

FEMALE SPEAKER: That's my favorite hospital.

Healthcare/ Supports: Smoking Cessation Program

GEIDY NOLASCO: Great. So, I am actually here to offer a program that is available for individuals with mobility impairments that are smokers. And -- great -- so, , so the program is a health program that includes smoking cessation and if the person is eligible they will receive the program, they also receive 8 weeks of nicotine patches for free.

FEMALE SPEAKER: What do they do for over eaters?

GEIDY NOLASCO: And also they get paid for up to $150. So if you know anyone that has a mobility impairment and is a smoker I'll be here, I can give you more information about it and I will be more than glad to help out. Thank you.

CARMEN BOUCHER: Can you please explain that in Spanish? You are bilingual, correct?

GEIDY NOLASCO: The problem is the program is for English speaking only, for now.

CARMEN BOUCHER: So it's good to say that. Thank you.

CHRISTINE HARKINS: Thank you very much. Karen, did you want to testify, as well?

KAREN DAVIS: No, no.

CHRISTINE HARKINS: Ms. Davis? Okay and, Carmen. You're here as a panelist. Those are the folks that we have right now that have signed up. So, we are here until 7:00, however. Perhaps I will use this lull in the testimony to testify myself in a different role, my role as CEO of Bridgemark. I would like to say that, of course, you would expect me to talk about funding and to mention that behavioral health care and recovery services are essential to a healthy society. And quite often, could help greatly with other issues if we were indeed to go upstream and to solve the problems of sobriety and recovery and to assist people staying sober and healthy in those ways, we would perhaps relieve ourselves of some of the fiscal burdens that we need to fund further downstream. Emergency room visits, et cetera, et cetera. Rhode Island has really done a marvelous job with the money that its had, to help, but everyone needs to really continue to support that cause in order to keep Rhode Islanders as healthy in this issue as we are making great strides in other issues like all of the programs at Miriam hospital, it's phenomenal -- hospital. And yet behavioral health still seems to be the poor country cousin of health care. I will say at Bridgemark among other special programs that we have, we have a program that focuses on the deaf anyone coming and wanting to use American Sign Language as their primary language. We give all of our services in English, Spanish and American Sign Language. The difference is that when someone is having an emergency with a health care problem, they can go to an emergency room or they can get to see a doctor. If you need an interpreter, that put a little glitch in the process. So we would like to say that we feel as though there is a lack of funding for that purpose. If someone is having a heart issue, they can go to an emergency room if they feel as though they are going to have a heart attack. If someone has a behavioral health issue they often need to get to either a counselor or a 12 step program. The 12 step program existing in the community is like the emergency room in the hospital and it would be marvelous to have a line item that could assist with this.

TIM FLYNN: Specifically you're looking for interpreters?

Healthcare/ Supports: Interpreters

CHRISTINE HARKINS: Interpreters, we have some of the best interpreters I think on the planet, we need more but for funding, if someone wants to go to an AA meeting there is no funding for that.

TIM FLYNN: Certain meetings that are assigned or --

CHRISTINE HARKINS: Certain meetings are assigned and Bridgemark sponsors that right now but our funds are limited, we are very happy to do that. And I am very happy to volunteer my services by -- I am also a sign language interpreter.

TIM FLYNN: Probably hundreds of meetings around the state every day I would imagine, what percentage of those meetings.

CHRISTINE HARKINS: A fraction.

TIM FLYNN: I think I know the answer but any hard numbers.

CHRISTINE HARKINS: Two a week.

TIM FLYNN: Two are signed per week.

Healthcare/ Supports: Gamblers Anonymous

CHRISTINE HARKINS: And those are sponsored by Bridgemark at Bridgemark. Monday night at Bridgemark is an AA meeting and Friday night is a GA, gamblers anonymous, elm wood avenue in Warwick and they are well attended and we are very proud to do that but when you think about all of the meetings and it's marvelous, if

you have this horrible disease -- the good news is that on almost every block, there is a 12 step meeting. You can get to a meeting if you're hearing and if you speak Spanish. You can get to a meeting; you can walk to a meeting. If you're deaf, there could be a meeting in your own apartment building and you couldn't get there because you don't hear.
TIM FLYNN: Do you get requests often times?
CHRISTINE HARKINS: Yes, yes.
TIM FLYNN: How many requests do you get per month?
CHRISTINE HARKINS: Four or five.
TIM FLYNN: (inaudible) 15 years (sounds like)
CHRISTINE HARKINS: So it's not a fund breaker, doesn't have to be expensive, it's one of those things that are greatly important and it can change lives. And I thank you.
TIM FLYNN: If I may...I'm sorry, ma'am, I forget your name, you were testifying before, in the back row.
CHRISTINE HARKINS: Carmen.
CARMEN ARSEDO: Me?
TIM FLYNN: Yeah. This identity theft, sort of, can you sort of walk us through how it happened?

Housing: Barriers

CARMEN ARSEDO: I went to make an application where I want to get the apartment now. I became handicapped like about ten years ago, because when I got my apartment, my apartment, you know I could walk and everything then slowly I started getting sicker and sicker and they want to move me to their handicapped but I asked them, are the showers going to be lower so I can get in or are they going to be the same? They said no they're going to be the same so I applied someplace else and I am still waiting. But they sent for my reference and how long I lived there and there, in the building where I live this never came up. But when I applied about, let's say, 3 months ago, and like I had to go here, had to go there, so I went where they told me to go. And then, when I told, can I lease (sounds like) the apartment she said no because all this came out and I said what came out and she said you have houses in Miami, you have cars. I said how can that be?
TIM FLYNN: That was the first you heard of it, three months ago?
CARMEN ARSEDO: No I heard about it because I applied in Olneyville but the lady there was very, she yelled and through the paper to tell her my identity, I said shove it up your, you know what, I don't have to go through this, excuse the word (inaudible), but then when I applied over here, same thing came out again but the thing is, all the bills with paid up to date. My credit cards and everything, is paid up to date.
TIM FLYNN: Right, yeah.
CARMEN ARSEDO: So they are working now with her, with my social security and there is another lady's name on it, too. I don't know who that person is either. They (inaudible) I've never been to Florida and I haven't worked since what?' 99 or ' 02, I said it wasn't me but had to go there, had to go there, that's the first I heard about it. I have houses, cars, things in the back; I have all the proof here if you want to see it.
FEMALE SPEAKER: I want to be your friend.
CARMEN ARSEDO: And I have $51,000 in the bank.
CARMEN ARSEDO: 3 loans to 3 cars -- bank cards, everything.
CHRISTINE HARKINS: I have this information for you which is not the only information for you to look at but this is also a start. It's the Rhode Island Disability Law Center Ocean State Center for independent living, they're located in different parts of the state but that is just added information.
CARMEN ARSEDO:

Transportation: Accessibility

Well that's a problem for me, I can't go here, can't go there just like that because -- go on a trip but I can't do all this alone, when I get on the bus I fall off the bus (sounds like)

FEMALE SPEAKER: On hot days with the oxygen she was traveling they want the paper and want it on certain days, they don't understand.

CARMEN ARSEDO: I have to do it on bus on RIPTA, that's another problem. Not because of the $4 because I'll pay but sometimes they say they'll come and they don't come so there goes my appointment.

CARMEN BOUCHER: I would like to you clarify issues with the transportation (speaking in Spanish).

CARMEN ARSEDO: When I call for the bus sometimes for transportation it takes two days, two days now if I'm sick I can't go, if they don't come I can't go.

CARMEN BOUCHER: Are you talking about --

CARMEN ARSEDO: The RIPTA, the RIDE service, sometimes it takes me two days and then when they come, then I can't go because I don't feel good, it's not every day that I feel good.

CARMEN BOUCHER: So when you contact RIDE you try to make an appointment for the next day or whatever the -- period is.

CARMEN ARSEDO: No it doesn't happen that way it's always busy, the (inaudible) is always busy but there are a lot of other people I use -- so sometimes I call at 3:00/4:00 when I start since 8:00 (sounds like) so what I do is, I go on the RIPTA, the city --

FEMALE SPEAKER: And then the thing is if she has a doctor's appointment they want the exact time to pick them up, she tells the doctor, the.er doesn't take her as soon as she comes in the door so she tells them 3:00 -- our doctor is in east Greenwich so we don't know exactly what time he's going to be done with her so she'll tell them a half hour more so if her appointment is at 3:00 she'll tell them 4:00 and then they leave.

CARMEN ARSEDO: Then I have to have the doctor's secretary call them again so whoever is working around there is who picks me up to take me home. I am not going through an easy street here. I have to go here, go there, do this, and do that then when -- the proof, -- well you weren't supposed to (inaudible), well, how the hell do I know? And it's hard for me.

FEMALE SPEAKER: The information on RIDE is important so we shall provide it to RIPTA so they can use the information to improve their services.

CHRISTINE HARKINS: And I gave Carmen the telephone number of OSCIL, as well, OSCIL and PARI (A Resource Center for Independent Living), as well.

FEMALE SPEAKER: Believe me...

CHRISTINE HARKINS: We have a gentleman who just arrived, (sounds like), he would like to testify. Carmen, can you assist if he needs some assistance with English. He asked if there was anyone here who could assist.

CARMEN BOUCHER: I could listen to his testimony in Spanish, definitely.

CHRISTINE HARKINS: If you would like to testify in Spanish.

Employment: Accessibility

CARMEN BOUCHER: I would like him to try -- (speaking in Spanish) -- Erwin is his name. He had an accident in February, and they did a back surgery. He is talking about his -- sorry -- he is identifying his surgery, the part of his back L5-S1. He has been disabled since that time. The doctor said that he might not be able to do any kind of work that requires a lot of strain. I asked him what his concern is, it's like he is having problems with depression, and he is taking pills for sleeping. He is having financial issues. I have tried to find any help. I am here to see what the purpose of this forum is. I am going to explain what that is -- (speaking in Spanish) -- medical services, I have found. Financial situation, the only thing that I am getting is food stamps for financial.

TIM FLYNN: Say that again.

CARMEN BOUCHER: Financially the only thing he is getting help with is food stamps so he is having a hard time financially....To pay for my housing; my family has been helping me until now.

TIM FLYNN: Would it be okay if I ask a question? What kind of work did you do before you got hurt?

CARMEN BOUCHER: Before the accident I used to be self-employed and they use today pay me and I use today pay for some kind of insurance but the insurance is not paying (inaudible)...The insurance is only paying me 30 percent of what I used to earn.

TIM FLYNN: Is it your desire to go back to work?

CARMEN BOUCHER: I would like to, but I can't do the work that I used to do.

TIM FLYNN: There are other kinds of work.

ERWIN GARVEL: I would like to.

TIM FLYNN: Have you had any sort of vocational assessment, to identify your strengths and weaknesses?

CARMEN BOUCHER: I haven't translated in a while so it just takes a little bit. I used to be good at it but I haven't translated in years.

Healthcare/ Supports: Services

ERWIN GARVEL: No. Evaluation...psychiatrist...

CARMEN BOUCHER: His psychologist did an evaluation and her name is Anna Browns (sounds like)

CARMEN BOUCHER: I just asked to clarify if he had said it's a psychologist that had evaluated him and he said yes.

TIM FLYNN: Have you tried to contact the Department of Human Services in the state of Rhode Island?

CARMEN: Anna the psychologist directed him to different services.

FEMALE SPEAKER: ORS?

CARMEN BOUCHER: He is talking about services for electricity, for gas. I called all the places that they gave me but they said they were not available at the time and that they would call me back.

CARMEN BOUCHER: I am going to clarify the question and go back to the question that you had, if he had an evaluation...he just again would like to know what we are doing here...how can I get more (inaudible). So, I basically just asked him about clarifying again if he had had a job evaluation and he said no, and I asked him basically about that, just, for a job -- for job evaluation. I just basically told him there is an agency to help him do an evaluation to see what kind of work he could do

KAREN DAVIS: I would be more than happy to meet with you after wards and I can give I information about how to contact the office of rehabilitation services if you want some assistance helping to look for a new job.

CARMEN BOUCHER: Okay? So just basically I translated what she had said.

TIM FLYNN: Is there anything else that he wants to --

CARMEN BOUCHER: That will help me

FEMALE SPEAKER: Once he is done working with ORS or through the process with ORS there is a new federal program that's out through the DOT, Department of Labor and Training, it's called the DEI, disability employment initiative. And they can also help you.

CARMEN BOUCHER: Hold on -- He said that he applied for some programs, some work programs and they told him he did not qualify because he used to be self-employed

FEMALE SPEAKER: Where did you apply for the programs? I don't know enough details about that but you go through ORS and they can refer you over to the DEI program and they can help you locate work. They can work with you to get work.

ERWIN GARVEL: Okay.
CHRISTINE HARKINS: Thank you, sir. Our next speaker is Maria Orega (sounds like).

Housing: Utilities

FEMALE SPEAKER: She doesn’t speak in English but she says that her lights, she called to make an agreement so she could pay for her light but the amount was too high for her. And she kept trying to call to get an agreement and they didn't want to do it. So, in that process they shut her lights off so then she called, the lights, the utilities company and they told her if she paid $192 that they would shut her lights back on and then to call to make the agreement. Her lights were off for one day and she stayed with me. When we went in the morning around 9:00/10:00, the lights in the house were on. So she called them and said my lights are on, I want to make an agreement now. And they say, no, her lights are still shut off. To them, her lights are shut off but she has light which we don't get but when she calls to get the agreement they say they don't want to put lights in her name any more because she shows $3 --. To them she has lights; we don't know who put it on. They say they're off, our lights are on but the thing is they send letters and say she is not able to put lights on her name they don't want to and she can't make an agreement either so she left it like that but she doesn't want to get in trouble because she doesn't know what to do about that situation. And she needs lights on because she has open heart surgery, mechanical devices, she uses insulin. We are not going to call and say our lights are on, they are arguing the lights are off, the lights are on so we left it like that, we don't know the mystery. The lights are on but she calls and they say they're off. So she left it like that because we don't know what's going on. And she doesn't want any problems. She doesn't want them to come and take the whole meter (sounds like) when it's an argument they don't want to hear it. She calls, I want to make an agreement, no, you're lights are shut off we're not putting it on and she says oh well, leaving it like that because the lights are on anyways, they're on so we don't know and the bill is only -- she has the receipt she paid the 192 because they told her by phone to pay 192 -- oh, 194. So she paid it and the lights were on in the morning so we don't know. I don't know what she wants to do she just don't want to get in trouble for it but she's not going to argue with them, they say they're off and she knows they're on, so, I don't know.
CHRISTINE HARKINS: Again, have you, has she contacted any other resource other than the company itself?
FEMALE SPEAKER: Just the company.
MALE SPEAKER: Who owns the building?
FEMALE SPEAKER: Its housing, its OMNI point. We don't know what happened with that, we know they shut it off (sounds like), because we knew it, she was calling and the reason she didn't make the agreement because on a bill that was 392 they want her to pay...they didn't want to tell her for the agreement, that they're not going to do her no agreement.
MALE SPEAKER: Subsidized housing?
FEMALE SPEAKER: Yeah she gets section 8, it's section 8 that she gets but she's afraid, too, if she goes through the section 8 if she calls and tells them it will go against her. The lights are on so she's not saying anything. She knows there is a problem somewhere.
CHRISTINE HARKINS: The Providence Community Action Program may have a representative that deals with that and only that and there might be federal funding to assist people with that. Providence communication action program, CAP, another organization she could call to acquire again is the number that I gave you, the ocean state center for independent living that has a housing coordinator working there.
FEMALE SPEAKER: She went to pro-CAP and when she -- what other program did you say?
CHRISTINE HARKINS: Ocean State Center for Independent Living, OSCIL, 738-1013, I wrote that on a piece of paper for your mother.

FEMALE SPEAKER: So she calls and they'll help her.

CHRISTINE HARKINS: If she calls them to explain the situation they can either help or refer her to someone that can help. Sometimes the folks that you call are not the solution but they will tell you who the solution is. And the other is an independent living program in Pawtucket which is close to Providence, once again, they serve people in Providence, not just in Pawtucket and its PARI, people actively reaching independence and that's 725-1056. Again the person answering the phone, or the social worker there might not know the issue or the issue in their organization but they can let you know who in the community can help you with that because they are advocates as well as social workers and those are two independent living programs as well as pro-CAP but those two independent living programs will be able to help you research that.

FEMALE SPEAKER: They even told her to sign -- the doctor, to sign a letter that they can't cut her lights off because of her condition and they still cut it anyway, said they didn't care and she sent them the letter from the doctor because she uses insulin and has lifeline, the telephone.

CHRISTINE HARKINS: Well the independent living programs have advocates that will help that communication gap that will help you communicate with the company. It might be somebody you're talking to in the company that doesn't know that law or that policy exists.

FEMALE SPEAKER: They told her to send the paper so they wouldn't cut it. What they were supposed to do was give her a plan payment and they don't want to give it to her. They sent her the letter and say they are not going to put lights on, not going to put in her service no more but she has the lights and it's on.

CHRISTINE HARKINS: So those other two programs instead of who she is talking to, those other two programs may be the way to the solution.

FEMALE SPEAKER: She has the paper there that when she called, they said send 194 and we put the lights on and the lights were on but they say it's off.

CHRISTINE HARKINS: My directions were also to remind folks that the men and the women's rooms out here, they are accessible by the way, are to the right. So if anyone needs to.... Head to the.

CARMEN BOUCHER: (speaking Spanish).

CHRISTINE HARKINS: And is it time to ask our CART professional if it's time for a break? An issue raised by an interpreter who can feel every minute as it goes by and we thank you for that.

TIM FLYNN: Adjourn for ten minutes.

CHRISTINE HARKINS: We have a suggestion to adjourn for ten minutes, take a ten-minute break. (5:57). *********************************** (6:38)

CHRISTINE HARKINS: We have been joined by Elizabeth Santana; will testify when you're ready. You can sit or stand.

ELIZABETH SANTANA: I can stand. Start?

CHRISTINE HARKINS: Go right ahead.

Healthcare/ Supports: Transition

ELIZABETH SANTANA: I just wanted to point out; I have a special needs child. She is currently going to be 20 years old in October (sounds like). She used to know on the Katy Beckett program and it was fabulous, everything was good and well but unfortunately I guess when she turns 19, that program ends for her so she has to either choose -- I have to choose for her either Neighborhood or United Health, I believe it is. So I picked neighborhood because I was told it was better than united health. But, unfortunately, since that change occurred, it's been not such a good process. I have had quite a bit of problems with neighborhood insurance, with the Katy Beckett program. Whatever doctor I wanted my daughter to see which is in Boston, she sees doctors over there (sounds like). She was able to, I didn't need referrals and it was pretty easy for me to deal with her medical condition. But, unfortunately, with neighborhood insurance, I have to get approval for everything. And I can't now see some doctors she used to see in Boston because they just don't allow it. She sees one doctor in Boston which is her neurologist because she deals with her ketogenic (sounds like) diet[46], she follows it, that's why they allow me to go there. Also, before when I used to -- she goes to the regular school schedule, September to May. But once the summer starts, I have issues since I have the neighborhood insurance because I have to get approvals and they give me a hard time to get extra hours because also, the school schedule used to be Monday through Friday for summer program. And a couple of years ago has been cut for only 3 days a week and then 3 days of the week plus less hours so I have to find somebody to be there for my daughter. Unfortunately, she needs somebody with her for all of her ADLs, repositioning, she is in a wheelchair, she has a seizure disorder, developmental delay so she can't do anything for herself. And unfortunately like I said, with the insurance, just now, I had a very hard time trying to get -- it was a approved a few days ago but it is a struggle to get that help that she needs, if I put her in a nursing home it will cost more money, she's not going in a nursing home, but -- and last year, I wish I had the letter with me, but, they literally wrote in the letter they don't provide babysitting services, from a nurse that came. Seeing the diagnosis of her and all of the medical issues she has, all of the medications she takes, she comes out saying they don't provide babysitting, which makes no sense to me, coming from a professional. So, that's been the battles that I have been having and not long ago another nurse that, my agency that gets me the services for her, had a battle with that person, questioning some personal thing that is go on in my house that, why I need those services which I don't think she should be asking so much personal questions like where is your husband, what does he do, where does he go, what do I do? Like, read her diagnosis. She needs somebody there; I do work and have other kids I need to split myself for there is no need for personal questioning. So that is something I really do not appreciate it. Anybody is welcome to come to my house can see how my daughter is, all the facilities and she is well taken care of and there is really no need for all of this. That's just what I have to say.

TIM FLYNN: Thank you.

ELIZABETH SANTANA: Questions?

TIM FLYNN: Sure. Part of what we do is we want to make recommendations. -- services, if you put your thinking cap on, we have heard the problems. Do you have solutions in mind? Have you thought about those? Have you thought of what you would like to see happen specifically?

Healthcare/ Supports: Recommendations

ELIZABETH SANTANA Well, I don't know why, if it come from a professional standpoint like nurses that evaluate these approvals and whatnot, I don't know why they, the thinking is that way, that questioning. I wish -- I don't know. I honestly don't know because if they're professionals, you know what I'm saying...treating people like this, I don't know. I don't know. I think they should be more supervised or something.

TIM FLYNN: The social workers who deal with you, the people at neighborhood health, I just don't know who we're talking about --

ELIZABETH SANTANA: Actually I spoke with, let me see, she's, supervisor – nurse supervisor, and has to do with the scheduling for the nursing. Her name -- can I say her name?

TIM FLYNN: This person is at Neighborhood health?

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[46] The **ketogenic diet** is a high-fat, adequate-protein, low-carbohydrate diet that in medicine is used primarily to treat difficult-to-control (refractory) epilepsy in children.

FEMALE SPEAKER: Her name is Patricia, she's awesome, five stars. But then this other lady that has to do with reviewing of the hours was the one that was being very rude. And I don't know why also there are two people -- I don't know how the system works. But why there is two people dealing with, so there's too many -- you know what I'm saying, there's two people dealing with the case and two ways of thinking trying to get something approved. Make sense? It's like, why doesn't one person, you know, I don't know. And like I say, with the program she had was so awesome, no problems, makes my life easier. But unfortunately, since she got into neighborhood, it hasn't.
TIM FLYNN: Thank you, I appreciate you taking the time to come and talk to us.
FEMALE SPEAKER: Thank you for listening.
CHRISTINE HARKINS: Thank you very much.
(FORUM CLOSED)

Email and Mailed Testimony

From: LeeAnn Brigido
To: "disabilities@gcd.ri.gov" <disabilities@gcd.ri.gov>
Date: 7/24/2013 2:27 PM
Subject: Zachery Smith
Attachments: Request for review.doc
Governor,

Healthcare/ Supports: SIS Funding Cuts

I am reaching out to you because my son has an Individualized Service Plan (ISP) through the Department of BHDDH. This is the 3rd year we have participated in the plan. For plan 7/12-6/13 we did have a small decrease in the budget, and for the month of June I had to cut back on nursing and CNA hours because I was running out of funds. Then I received the 7/13- 6/14 budget in the mail at the end of June 2013. They decreased Zachery's budget by $29,918.00! This is more than a 25% cut.
That's removing 16 hours per week of nursing for my son that cannot do anything for himself and medically fragile. How will I support my family if I can't be at work for 16 hours a week they are taking away? How is this helping the economy if I have to cut a nurse 16 hours per week? Keeping my son at home has always been a goal of mine, and this also saves money by doing so.
Please take a look at the attached letter I sent to David McMahon and Craig Stenning at the Department of BHDDH last week along with Zach's medical plan and the form for a request for review.
The Department has taken on a "SIS Tier Service Package" derived from a test that was done in my home, and frankly it’s horrible!
The test questions that they asked me about my son were non-applicable, but she forced me to answer, actually lie, because Zach cannot work or go to school, and I had to answer questions that pertained to him being employed and educated. Zach is like a 3 month old!
I am looking for support on this very important issue.
Sincerely,
LeeAnn Brigido
Lincoln RI

From: Celest Martin
To: <disabilities@gcd.ri.gov>
Date: 7/24/2013 12:03 PM
Subject: SIS results for those using self-directed supports

To whom it may concern,

Healthcare/ Supports: Supports Intensity Scale

Unfortunately, I am not able to get to any of the public hearings this particular week due to various mishaps at home. However, I would like to express my dismay at the number of self-directed supports users whose community activities, including their jobs, have been negatively impacted by the SIS and its results. I will use my own son as an example.

Under the old PCI, Andrew was a Tier 3, and receives approximately $35,000/year (he is still under that until Oct.1), that has allowed him 35 hours a week of support. For three years, Andrew used an agency for day services, and had community supports in the evening. Every year at his ISP, everyone would say how capable Andrew was of holding a job in the community, but it never happened. Frustrated, we switched to self-directed supports beginning Oct 1, 2011.

Employment: Supports

Within six months, Andrew had two-part time jobs--one at Marshall's Department Store and the other cleaning the Mt. Hope Learning Center in Providence. He has maintained these jobs, received raises and positive evaluations. However, although he can do all the work himself, he needs a job coach to keep him on task, and, especially at Marshall's. Where his job is not the same every day In addition, he needs independent living skills, as he is about to move to his own apartment, most likely in September.

Housing: Independent Living Skills

The SIS was administered on June 10th, and we got the results in earl July. He was placed as a Tier A, Living with Family. This means he would receive approximately $12,000/year, almost a 2/3 cut. A cut such as that will force him to choose between working in the community, and having some support when he is living alone. He will initially need quite a bit of support as he gets into the routine of doing laundry, meal-planning, cooking, budgeting, and banking. Andrew also volunteers in the community-- for Water fire, and for a Hunger Program. With this very low amount of support money, Andrew's life would change drastically, and his ability to thrive in the community will be curtailed. He is only one example. Parent after parent is experiencing the same kind of community limitations after their adult child is switched over from the PCI allotment to the SIS support package. The whole idea behind the SIS (so we were told) was to allow MORE community involvement, not less. For most of us, it is becoming just the opposite.

Thank you for the opportunity to express my concerns. I have great regard for the Commission. Every year, Chris Rancourt Bruzzi comes to my disability studies class to speak about the ADA, and does a spectacular job. I hope you will take our concerns seriously, and work with BHDDH to remedy what is happening to our young adults using self-directed supports.

Cumberland, RI

July 25, 2014
RI Governor’s Commission on Disabilities
To Whom It May Concern:

Healthcare/ Supports: Supports Intensity Scale

My 30 year old daughter has multiple developmental and intellectual disabilities and receives support through BHDDH Division of Developmental Disabilities. She is one of approximately 325 individuals who “self-direct” their supports through the Division. I also facilitate the Self-Directed Supports Users Network, a network of individuals and families who like my daughter and our family self-direct their BHDDH-DDD supports. The network provides information, resources and supports to those who already self-director who want to find out more about this model (www.sdsri.net).

Although my daughter currently has a well-supported, full life of work and recreation integrated in the community, I have grave concern for others who are experiencing serious delays to start up, temporary disruptions in, and/or permanent cuts to their long term supports through the BHDDH system. I also worry about whether my daughter's quality of life will suffer after her support needs are reassessed later this year by BHDDH.

As you may know, in July of 2011, The Division of Developmental Disability (BHDDH-DDD) instituted a set of reforms under the name of "project sustainability." All newly eligible individuals as well as those already served by the Division are receiving an assessment called a Supports Intensity Scale (or SIS) to determine their level of support need and associated funding level (currently called a Tier Service Package). At the same time, there was a restructuring of the rates of reimbursement for BHDDH-DDD services. According to the BHDDH-DDD website, the intent of these reforms was to "develop a system that supports individual choice and self-direction, provides equitable assessment and transparent rate methodology, and above all, is sustainable."

I want to register concern, based on the experience of many of the individuals and families I support through the self-directed supports network, that this system currently is stifling individual choice by requiring rigid compliance to regulations intended for licensing provider agencies, not for individuals who self-direct their supports; its assessment system is being administered by interviewers who do not understand the population and often administer SIS's that produce inaccurate results – when appealed these SISs need to be re-administered, but most individuals and families are unaware that they can appeal; individuals and families cannot get clear and accurate information regarding their assigned dollar amounts in any timely manner in order to develop and submit plans and budgets in the required time frames, resulting in delayed authorization of the start-up or annual reauthorization of services; individuals and families are not informed by BHDDH about how to appeal any of the BHDDH decisions and frequently calls and emails to staff at the Division go unanswered.

In early June of this year, an informal survey of the self-directed supports network (approximately 150 individuals / families who use self-directed supports) showed that 31.5% of respondents reported experiencing delays in start-up or disruption of services because of untimely communication or response from BHDDH – DDD. 62.5 % experienced a decrease in their BHDDH-DDD funding as a result of a SIS (some by as much as 25% or more) resulting in decreased access to community integrated activities and a risk to health and safety in some cases. 70% were never informed by anyone of a process for appealing BHDDH decisions. Those who became aware of an appeal process found out about it from sources other than BHDDH.

NO ONE who had been assigned a Tier E service package was informed of the (internal and unwritten) BHDDH-DDD guideline that all Tier E plans must include a detailed behavior plan written by a licensed psychologist who will commit to monitor the plan throughout the plan year, yet these plans were being returned to be rewritten and authorization or re-authorization of services withheld until such a behavior plan was submitted and approved. Despite repeated requests for a list of qualified psychologists who can develop and monitor such behavior plans, BHDDH-DDD has refused to supply self-directed supports users with such a list. Even when behavior plans are submitted, they are often repeatedly returned for minor corrections in what seem like either bureaucratic inflexibility or perhaps stalling tactics (e.g. rejecting plans because a signature was missing a date, or requiring approval by a "human rights committee" when a human rights committee is a structure set up within a provider agency and is not typically available to individuals who self-direct their services). Whenever an ISP is sent back for correction, the start of service is delayed for new clients or disrupted for clients already in the system.

There are major difficulties for individuals entering the BHDDH-DDD system as young adults transitioning from high school. Although by statute BHDDH-DDD must accept applications from anyone over eighteen, the intake unit at BHDDH will not review eligibility until a person reaches age 20. Often a SIS which determines funding levels is not conducted until three months before a person's 21st birthday (when they must exit school supports). Then BHDDH can take up to six weeks to inform the individual of the Tier level (in incomprehensible language – see attachment). One cannot tell from this letter what the accurate total funding amount is without also consulting confusing rate charts that change every quarter and are not included with the Tier letter. Only at this point is the person assigned a social case worker who (in theory) can guide them to plan for their services. This BHDDH timeframe clearly does not allow individuals or their families adequate time to interview and visit various provider agencies or to decide whether to self-direct their supports and to make other informed decisions about the best array of long term supports. BHDDH requires that Individual Support Plans and their related budgets and purchase orders be submitted 45 days before expected start of service. Given that plans take at least a month to be thoughtfully developed and a family may take several months of research to decide on where and how they want supports to happen, the individual entering the system needs to know his / her Tier level at least nine months before the expected start date, not a mere month or two.

Education: Transition

Remember the people eligible for support through BHDDH-DDD, by definition, have cognitive and often multiple disabilities and their families are frequently responsible for the day to day details of their care as well as for planning their supports within this new and confusing system. In spite of applying to BHDDH-DDD in a timely manner, many transitioning students never get to the planning stage with BHDDH -DDD before finishing school (which had been their major support system) and so never get connected to services. We have met many 24 and 25 year olds who have been sitting at home, with only the tenuous support that their stressed and often misinformed families can muster, who got lost in this transition gap in spite of having applied to BHDDH well before exiting school. The result for some of these young adults is loss of hard won skills, sometimes loss of employment due to lack of necessary employment supports, increasing isolations and sometimes the onset of depression. BHDDH makes no effort to find or identify these individuals who have applied, and maybe even been assessed, but have not accessed service. Many others have begun and continue the process of planning, but experience a gap of months to even years after exiting school while they continue through BHDDH bureaucratic maze trying to get their ISPs approved and services authorized to start.

In Massachusetts, Chapter 688 requires school districts to make referrals of students with severe disabilities to their DMR (Mass. Equivalent to our BHDDH-DDD) a full two years before exiting school and requires DMR to accept those referrals and assign a social worker to assist with timely joint transition planning. The RI legislature could consider some similar legislation so that BHDDH-DDD is required to review and set into a planning process all applications of people over eighteen and that school districts make referrals of all students over 18 with significant support needs.

Beyond difficulties of transition, those already served by the BHDDH system are also experiencing problems. This year, as anniversary dates of the annual ISPs approach all individuals in the BHDDH-DDD system are receiving a SIS. Many are experiencing cuts to their individual funding as a result of a SIS by as much as 25%. Families and individuals are SOMETIMES informed of this change in funding approximately one month before the due date for their renewal ISP (sometimes even later or not at all. Providers who try to inform individuals and families of changes to their funding in the absence of communication from BHDDH-DDD have been reprimanded by Department administrators). Sometimes these cuts are reasonable and individuals and families can manage to continue supports with the new lower levels. However, there have been numerous instances that have come to my attention where the person receiving supports has very high medical and or behavioral support needs, and has been re-assigned to a very low level of funding.

Healthcare/ Supports: Supports Intensity Scale

When individuals and families are able to discover what the appeal process is and submit an appeal, sometimes a SIS is redone and funding restored, but not before causing major upset to the individual and family, sometimes a disruption of service while the appeal is in process. When the appeal is not decided in the individual's favor, some have been left in very risky living situations with inadequate supports, requiring family members to take leave from work or quit jobs entirely in order to keep providing needed care for their loved ones. On some occasions, individuals are forced to consider nursing homes or other congregate residential settings, when supports in their family home had been successful prior to the SIS-driven cuts to their individual budget.

Employment: Barriers

When families experience such concerns, they may call on their social workers. These workers report that they are powerless to change the rules of operation at BHDDH-DDD and often upper level administrators will not respond to consumers' emails or phone calls. There is not a clear and well-publicized process for appealing any BHDDH decision. Without accurate information or answers to questions necessary in order to pursue developing renewal ISPs, time ticks by and individuals do not receive a renewal authorization – that also means disruption in service. Many of these concerns would be resolved with clear, early and timely communication between BHDDH-DDD and the individuals and families they serve, as well as a more functional communication within BHDDH- DDD between social workers and administrators. A "stay put" rule – mandating that current level of services remain in place while individuals are in the process of appeal or waiting for re-authorization would also help reduce the disruption of necessary supports that is currently a reality for many in this system.

In spite of the intention of providing a "transparent rate methodology," there is no clear transparency about the relation of the SIS to the resulting funding level or Tier Service Package. Individuals are not allowed to see the recorded responses to their SIS or the formula that resulted in the Tier Package. As a result of waiting lists for residential supports within BHDDH-DDD, an ever increasing number of adults with intellectual and developmental disabilities live with their families. BHDDH-DDD funding assignments appear to make assumptions that the natural support available for individuals "living with family" are all the same. Yet a 90 year old parent with their own health issues cannot provide the same support as a healthy middle-aged set of parents with extended family around to support. A slightly built single mom with a bad back cannot provide the necessary lifting and transferring support for her family member that could be provided by a strapping cousin or brother-in-law. There is no mechanism in the SIS to assess this variance – and no flexibility in the funding system and rate structure to provide for exceptions or adjustments based on family capacity. BHDDH-DDD needs to look at and consider not only the person's individual support needs, but the support-providing capacity of the "family" they are living with. Prior to project sustainability, BHDDH-DDD used a "situational assessment" to evaluate family living circumstances, but this no longer happens, resulting in some very strained and inadequately supported family living situations.

The recent and ongoing investigation by the Department of Justice Office of Civil Rights has resulted in a new focus on community integrated employment and other kinds of community integration within the BHDDH-DDD system. This is certainly a worthwhile goal. Toward that end BHDDH has promulgated an “employment first[47]” policy which mandates that plans for working age individuals include employment goals and support services. However, the rate structure and Tier packages still require individuals to “substitute” these relatively expensive employment services for less expensive, but necessary, direct support within their service package. So, if individuals try to comply with the employment first policy (which they must according to the new policy) they are forced to forfeit many hours and sometimes days per week of other support that may be necessary for their health and safety in order to purchase the mandated employment supports. This just clearly does not make sense. If an “employment first policy” is going to be truly implemented and not merely given lip service to satisfy the Department of Justice, appropriate funding will need to be allocated to both build the capacity of providers to identify and appropriately support integrated work in the community, and for individuals to purchase that support.

Healthcare/Supports: Supports Intensity Scale

Project sustainability may be reaching its goal of saving money, but it has done so by delaying start-up of supports for new individuals and renewal of plans for those already in the system and developing a rate structure that does not adequately fund the real support needs of people. Haphazardly administered SIS assessments have resulted in cuts to existing plans that have put people at risk in some cases. At the same time, project sustainability has not provided any transparency or promoted choice and self-direction. In fact, many individuals and families who have been self-directing may be forced to move toward more center-based day supports that do not allow for as much individualization, flexibility and access to community integrated activities because of drastic cuts to the budgets for their plans and other arbitrary bureaucratic decisions.

Healthcare/ Supports: Governor’s Commission Recommendations

Some of the problems at BHDDH-DDD that I have pointed to can be attributed to poor communication, some to incompetence, some to inadequate funding, and some to bad policy and unnecessarily cumbersome bureaucracy. They are not occasional glitches, but larger systemic problems that are having real and dangerous effects on the lives of real people. I speak for many of those who are too overwhelmed with those real life consequences to tell their individual stories to this forum. I recommend that a legislative committee take a close look at the internal policies and operation of the BHDDH-DDD and the effects on the lives of Rhode Island’s most vulnerable adults and their families, with specific attention to

1. Possible legislation outlining the parameters of a smooth and timely transition from school and other children’s supports into the BHDDH-DDD system of adult supports (such as MA Chapter 688)
2. Mandates for timely and clear communication to individuals and families regarding the funding for their supports and services in language that the typical layperson can understand.
3. Mandates that decisions about individuals supports be communicated to them in writing in a timely fashion and accompanied by clear information for individuals and families regarding the appeal process for any BHDDH-DDD decisions along with appropriate contact information.

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[47] **Employment First** is a concept to facilitate the full inclusion of people with the most significant disabilities in the workplace and community.

4. Requirement of a “stay-put” policy (guarantee of current level of service while appeal is pending or waiting for an annual reauthorization of an ISP submitted on time) for anyone engaged in an appeal of a BHDDH-DDD decision or re-authorization process so that existing services are not disrupted because of clerical error, bureaucratic incompetence or red tape, or an individual challenge to a BHDDH-DDD decision.
5. A close, honest and practical look at what it will take from both a provider capacity and individual funding standpoint to implement the “employment first” policy that has been held up to the Department of Justice as reality when, in fact, there are little funds and current expertise within the provider system to implement this policy.

Thank you for your time and consideration.
Sincerely,
Claire Rosenbaum

From: Robin Giacomini
To: "bcooper@gcd.ri.gov" <bcooper@gcd.ri.gov>
Date: 7/26/2013 10:09 AM
Subject: the GCD needs to become visible in RI.. your poor turn reflects on your efforts
CC: "crancourt@gcd.ri.gov" <crancourt@gcd.ri.gov>, "disabilities@gcd.ri.gov"...

Healthcare/Supports: Governor’s Commission

How can we help you? :
I would be nice if you could be more effective.. how can you expect the public to turn out to speak at your forums
IF THEY HAVE NO IDEA THEY ARE OCCURRING!!!!
forget the flyers, the emails.. you are not a household name.. your not visible enough.. NO ONE I KNOW IN DD knows who the GCD is??
Your outreach efforts to inform the public community associated with people living with disabilities.. especially intellectual disabilities who are serviced through providers or transitioning from secondary to adult supports is weak, are nearly nonexistent, turn out at the public forums is poor because no one knows
a) who the GCD is..
b) that you even exist
c) especially parents who are new citizens to the USA and primarily live in Prov, they really have no idea about the GCD,
You have nearly a million dollar budget... use a larger portion to self promote, hire a promoter, get on radio. Get addresses of families in DD services, mail them with postcards, get you name involved in Local family centers, do some local paper advertising, get in the schools, get on face book, twitter, go to orientations, meet the parents in transition, do something!!! Otherwise how are out really helping?
Because what you’re doing currently is not reaching or helping the population out here who need you most. People are getting very frustrated with State DD and now the ADA settlement is in play.. some of the high school population are already with DD providers.. who is monitoring for compliance? we know who is monitoring birch and TTP, but what about the other providers? I have not seen anyone holding their feet to the fire..who is spot checking, doing drop in inspections without warning.. talking to all consumers not just handpicked ones by the providers? how do we know how they are implementing employment first as prescribed? who checking on the providers? **How can a family file a complaint with the GCD if they don't know WHO YOU ARE!!!** Please don't tell me you on the web or your name is on rights pamphlets.. no one checks on how the providers implement rights instruction so they

may never show it or mention you.. yes you email, and your number is posted on line or you leave pamphlets..BUT is that enough???

what are you doing to make yourself a household name.?? you get almost a million a year?? how are you spending that to reach the public? czu I can't see the fruits of your labor anywhere except on you website... whatever good you think you do.. is not translating at large, break out of your inner circle.. go beyond those in the know, those like me who understand DD services.. we don't need you ... they do.

Robin Giacomini

From: Nancy Thomas
To: <RhodeIsland1115Waiver@ohhs.ri.gov>
Date: 7/27/2013 4:56 PM
Subject: 1115 Waiver testimony
CC: bcooper@gcd.ri.gov

Healthcare/ Supports: Institutional Care

I would ask that RI's leadership remove any further steps to put in place difficult obstacles to those of us who are, or who have family members who are facing community based care over institutional care.

With 30 years in healthcare, some of which were spent in the developmental disabilities arena and over 20 in the cardiovascular care and stroke care arena, I find it revolting that these vital support programs will be cut and curtailed. In addition to community based care cuts, we are looking at cuts to respite care, which often is the only thing preventing families who are overwhelmed with care of a disabled family member at home from giving up and institutionalizing their loved one.

We simply must revisit this action regarding the 1115 waiver extension. With leadership above that of many states in the area of care to our aged, chronically ill and disabled, how can we let the state of this care disintegrate into what could be compared to the state of disrepair of our roads, bridges and infrastructure. As we recognize these as priorities, may we also recognize our brothers and sisters, too. People first. Always first. Those in need and those of us who care for them.

Thank you for hearing my plea.

Nancy Thomas
President, Tapestry Communications
former, VP Communications Landmark Medical Center
former, Director of News Media Relations, American Heart Association
co-founder, Mended Hearts of RI, Landmark & South County Hospital
past member, RI Governor's Commission on Disabilities (2006-2011)
former Executive Director, RI Society for Autistic Children and Adults
Cranston, RI

Herc < 07/30/13 18:02 >>>

Healthcare/ Supports: Funding

To whom it may concern,

My name is Herculano and am the brother of Celia Figueiredo who has muscular dystrophy. I am writing you today on behalf of my family and sister to express my concerns in recent budget cuts and support which is negatively impacting my sisters core support needs. Over the past two years my sisters approved support hours has dramatically declined and has resulted in an extreme hardship on the required care

necessary for Celia. We are working with the agency and state representatives however there is no clear solution in sight. We are officially requesting my sister have an SIS done ASAP to asses her needs and as well as increase the approved hours per quarter in ensuring the quality of life support required for Celia
Thank you for your consideration
Herculano Figueiredo

Thomas and Linda Armstrong
Riverside, RI
August 5, 2013

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

Healthcare Supports: Funding

We are parents of a thirty year old man whose disability can be very challenging for him and our family. He needs consistency in the support that he receives as well as a lot of direct support. The agency that he receives services from has been very negatively impacted by the cuts in funding. In the past, their staff turnover was low. They had well trained staff who had salaries that were not high, but were a living wage. The conditions created by the cuts in funding, as well as the reimbursement formula for individuals with disabilities served by the agency (for instance, no reimbursement if a client is sick or absent for other reasons) have created shortages in staff. Many staff are leaving for other jobs that pay more with a lot less stressful working conditions. Many of the individuals they support have complex challenges. Paying direct support staff $10 an hour is not close to a proper compensation for the responsibilities they have. It will be more difficult to attract qualified staff at that compensation level. Moreover, agencies are beginning to hire part-time employees without benefits, which makes the job even less attractive.

When my son's assigned staff are sick, sometimes there is no one to fill in, so he loses services. This is very difficult for him as well as my husband and I, as he has better behavioral control when with staff. If coverage is arranged, it sometimes is such that his access to the community is lost. If he was supposed to exercise at the YMCA, something very important to his health, he cannot go.

Transportation: Accessibility

There is greater reliance on the RIDE bus program since the cut in reimbursement for transportation. My son cannot independently use the RIDE bus, so my husband or I often end up having to transport him to a volunteer job or to a meeting site in the community on days when the RIDE bus would be used.

Healthcare/ Supports: Quality and Qualified Staff

: My son has developed a chronic pain condition that causes him to get extremely upset and deregulated on days that he is in pain. My husband and I are finding it very challenging to support him through these behavioral episodes. The system of care is so compromised at this time that we feel like we have no where to turn for help during these challenging times. We worry about our ability to have him at home with us, but know that residential possibilities are non-existent due to cuts in funding. We worry about what will become of our son. He is thirty years old and we have worked so hard to support his development and progress through the years. It is heart wrenching to think of him regressing due to lack of adequate support. He has years ahead of him, but we worry that those years will not be fufilling and could actually lead to him wasting away due to lack of adequate support to participate in the community or even be safe due to behavioral regression brought on by inadequate support by those who are underpaid and not adequately trained. The staff turnover is so high, it almost does not pay to provide staff with the level of training they need to work with people with high support needs.

We urge the Governor, State Department heads, and the General Assembly to closely examine the impact of cuts and reimbursement to agencies, whose survival is at stake, and it's subsequent impact on the individuals to whom they provide services. Where will the system of care and support be if these agencies go under? Support in the state-operated services is much more costly to the system.

Thank you for your

From: Wiss Andrews

To: "disabilities@gcd.ri.gov" <disabilities@gcd.ri.gov>
CC: Wiss Andrews
Date: 8/6/2013 8:59 AM
Subject: A cry to stop cutting our programs

Healthcare/
Supports: Funding

I am writing this letter pleading with you to hear our cries to stop cutting money to the special needs program's. This is my son's first year in adult services and the more I learn the more concerned I am about my son's future. His program is running on a skeleton crew, financial cuts are forcing these fine men and women to look for work elsewhere. These people are the ones we NEED so desperately as they are the ones who have a heart and love to work with this special population. But I cannot fault them for looking for work elsewhere they will be paid what they are worth.

If you personally had to deal with a special needs child that will AWAYS need you to watch over them I believe you would have a different view about where to make budget cuts. I trust you will make the right decisions. A VERY concerned parent, Karen Andrews Sent from my iPhone

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From: "Gina Macris"
To: <bcooper@gcd.ri.gov>
Date: 8/7/2013 9:19 PM
Subject: Public Comment on State funding and services for the developmentally disabled

Healthcare/
Supports: Funding

To the Governor's Commission on Disabilities Comments on State funding and services for the developmentally disabled 8-7-13:

I speak as the mother of a 30 year-old man with developmental disabilities, significant mental health issues, and chronic medical conditions who is in the care of Spurwink RI. My son, Michael Smith, lived with me until he was 27 years old.

Housing: Employees

Then, a suitable residential opening became available with Spurwink, an agency recognized nationally for its psychology-first approach to teaching clients to be as independent as possible in the community. Spurwink's approach suits Michael perfectly.

It is now clear that Michael's needs are too much for any one person to handle, and yet I fear that should Spurwink be forced to close its doors, Michael would be back living with me. I would be thrust into the role of full-time case manager, employer of part-time staff, and driver to appointments with about ten different doctors. Over the past few years, I have watched the State squeeze private non-profit agencies serving people with disabilities to the point where Spurwink can only pay direct care workers about $11 an hour -slightly more than they could make as dog walkers. Meanwhile, State workers who provide the same category of services as Spurwink employees make an average of $18.00 an hour, with generous benefits. Health insurance for Spurwink employees is becoming increasingly expensive as a result of budget cuts to private providers. When Spurwink staff resign, the agency now can only hire part-time replacements with no health benefits.

I care about these issues because they affect continuity of care, which is critical to Michael's well-being and his ability to function in the community. His physical and emotional health is built on stable relationships with his caregivers, who should be treated with dignity and respect commensurate with the human lives they hold in their hands. A revolving door of part-time staff paid like dog-walkers would, over time, threaten Michael's emotional stability, his safety, and the safety of others. These are subtle, but important, dynamics that public officials do not notice until the number of psychiatric hospitalizations skyrocket or a tragedy occurs, and the Governor orders an investigation.

For some ill-conceived reason, the State seems determined to drive Spurwink and other private, nonprofit providers out of business, with the disabled just pawns in this scheme. This is a dangerous and foolhardy path. If Spurwink and others must shutter their doors, how will the State absorb all the people with disabilities who need 24-hour care? In a warehouse? A new Ladd School? Surely there would be lawsuits, yet I fear that the State is headed in that direction. No one really wins in a lawsuit.

The pattern of state funding in the last several years encourages the kind of cost-cutting possible in a sheltered workshop[48], where one worker may supervise as many as 15 or 16 people with disabilities in a segregated setting. Yet recently, the U.S. Office of Civil Rights cited the State for violating the civil rights of people with disabilities in just such a setting in North Providence, and OCR continues to investigate other similar situations. In North Providence, OCR ruled that the sheltered workshop in question does not afford people with disabilities the opportunity to live integrated lives in accordance with the Americans with Disabilities Act. Meanwhile, Spurwink's day program strives to live up to the spirit and the letter of the ADA, but it struggles to survive amid the constraints of state funding. The day program, called Voc Links, provides one-on-one job coaching to my son Michael at job sites in the community, and it deploys multiple staff members to supervise groups of disabled people in community activities.

The trend in State funding for agencies like Spurwink is penny-wise and pound-foolish, if not downright immoral. Something must be done to reverse it, or the gains Rhode Island has seen in the last 30 years in its treatment of people with disabilities quickly will be quickly eroded. Once gone, they cannot be quickly recovered.

Gina Macris

Barrington

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[48] **Sheltered workshop:** refers to an organization or environment that employs people with disabilities separately from others. The term 'sheltered workshop' is considered outdated in the U.K. and the U.S., and increasingly in Australia.

Joan Petteruti
Ronald Rampone

August 7, 2013

Bob Cooper
c/o Governor's Comission

Healthcare/ Supports: Funding

Dear Mr. Cooper:

I am voicing my concerns due to the budget cuts for the disabled. As a mother with a son with developmental disabilities I am very concerned with the state budget.

My son has been attending Spurwink and the Fogarty Center for many years. I have seen in the past how these cuts have affected my son along with the staff that cares for him. These cuts have had definite impact on the services provided.

Many of the dedicated staff has had to find other full time employment and I feel the replacements are less qualified. The dedicated staff that has chosen to stay has had to assume more responsibly due to the staff to consumer ratio becoming worst. Also, this ratio puts more responsibility on the staff that at times I feel it is definitely a safety issue. I feel this is not fair to the employees and more importantly to the consumers.

Spurwink and the Fogarty center have helped with my son's development and independence. I fear that everything that we have worked hard to accomplish will be lost.

Please listen …

It is imperative that the state reinstates these cuts.

Thank you

From: Laure Manning
To: disabilities@gcd.ri.gov
Date: 8/6/2013 12:56 PM
Subject: comments

Transportation: Accessibility

I have a major concern with access to transportation. Because I am too far from a regular bus stop, Wakefield, I cannot request the RIDE Bus, unless for a medical appointment or test.
I have not been able to attend my local MS support group or other activities.
There are many other people in neighboring towns, who are in the same situation.
We need more extensive bus service in this part of the state.

Thank you,
Laure Manning, individual with a disability
Wakefield

Maria Kerker
Cranston, RI 02831

July 17, 2013

Healthcare/Supports:
Department of Human Services

My mother, Maria Kerker, is 85 years old and a severely disabled person. She suffers from Parkinson's disorder in advanced stage, severe form of osteoporosis, which caused her spinal cord failure, anemia to name a few. In 2007, she fell, broke her hip and had a hip replacement surgery, All these factors made her totally disabled. She cannot get up from her bed on her own; she cannot get dressed or undressed by herself; she cannot walk, even with a walker; she cannot eat by herself, she needs to be fed. Her mental ability deteriorated significantly, showing signs of dementia.

I applied on her behalf to the Department of Human Services to place her into a nursing home due to her medical conditions in 2012. However, DHS denied her application on the grounds that she hadn't been living in the United States for five years; her five years anniversary would be on 8/15/2013. My mother is not a U.S. citizen, but she is a legal resident. We appealed the decision by bringing to the DHS attention the fact that my mother is a disabled person and. therefore, is not a subject to a five year rule. Our appeal was denied. and the reason for the denial was that we did not submit a proof to my mother's disability. That was not true because her application was accompanied by a physician assessment. and based on that assessment. DHS should be able to determine that my mother was disabled, or if they needed more documentation or forms, they should ask for them. After all, they are the Department of Human Services, and supposed to provide services to the public. Unfortunately, my mother didn't receive much of a service from that department.

In 2013 I applied again, this time we provided all the forms DHS requested, with a proof of disability included. The case was denied again, this time because MART deemed my mother not disabled. My understanding: MART stands for Medical Assessment Team; however, it's not clear whether it calls Medical because it deals with medical issues or because it has a medical personal on their team. We were given no explanation as to, why the case was denied, contrary to my mother's physician assessment. All our attempts to find out a reason for a denial failed.

Nobody at OHS would talk to me; they were giving me runaround referring me from one person to another without any result. All of a sudden, they could not talk about the case; they could not provide any information like OHS was not a state agency but some kind of organization akin to CIA.

We asked other people to interfere on my mother's behalf: Senator Frank Lombardi and Congressman Langevin, however, OHS would reply to them that they have hundreds of other people waiting before my mother, and she should wait her tum.

The truth is, however, that her application and appeal already went through the process and were denied under false reason. To say that my mother is not disabled is preposterous. Her disabilities are obvious and visible; anyone can see them, one doesn't have to be a doctor.

What OHS is doing to my mother constitutes an elder person abuse. Abuse is abuse regardless whether it was committed by a person or a state agency. The result is the same: inflicting an unnecessary pain and suffering upon an elder person.

I would like the Commission to interfere on my mother's behalf and put a stop to OHS abuse of power, stop to denial my mother's disability status. I ask the Commission to help to place my mother into a nursing home, where she belonged due to her medical condition.

I would like to meet with the Commission representative at his/her earliest convenience to discuss the situation; answer any questions, which may arise, and provide all available documentation to support this complaint.

Sincerely,
Yuri Alexander P.O.A for Maria Kerker.

Healthcare/
Support: Services

I am writing this letter with hope it will be read.
I am 57 years old I grew up in the time you took care of family. I left school at 16 to care for my mom and help with a disabled brother and sister. In those years I had two children of my own. Still went to my mom's to help out, If any of them took ill I was there even more. Then my aunt (my mom's sister) needed care as well and her daughter also needed care. At times it get to me. I never got or asked for anything. They are family. Lately I have been trying to get my brother in a group home. I myself have a disabled daughter who needs me at this time.
I just can't figure how the state can see that people who have healthy and normal kids are taken care of. They pay people to care for others but nothing for a family member. My brother and I are living on what he gets a month. My own bills are so behind I'll never get caught up. I see to it that my brother eats, go to doctors, bath's dresses and I just get pushed down. They just don't realize there are a lot of people like myself caring and getting nothing. When you work and have to call out because someone else is sick gets in the way of work. Even companies aren't how they use to be when it come to family. I use to be able to just explain to my boss and it was okay by them. Now a day's they use it for excuse to let you go or have you fill out a bunch of forms and then just tell you no. I just can't see how they can over look someone who is a care giver as if they (me) just don't count. When a family member is cared for by family they also get loved. As only family can give. I guess what I am trying to say is the state needs to help the family member who gives the care. Not making it as if we need to beg for it.
It has not been easy over the years but I would do it all again. Please try to get social workers for these people get the help needed all around. I think more people would care for family if it didn't get us in such a rut and depressed state.

Thank you for reading my letter
Marie Loven