



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

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

Tuesday October 4, 2011 1 - 3 PM
Alliance for Better Long Term Care,
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meeting graphic

Attendees: Kathleen Heren, Convener; Angelina Stabile; & Linda Ward; Deb G.;
Absentees: Jeanne Behie; Sharon Brinkworth; Donna Martin; Arthur Plitt;
Staff: Bob Cooper

	Agenda Topics	Moderator/Leader	Time
 meeting graphic	<p>Public Forums on the Concerns of People with Disabilities:</p> <ul style="list-style-type: none"> ➤ Review the Human Services Related Testimony; ➤ Identify the Concerns; and <p>Recommend Solutions</p>	<p>Kathleen Heren, Convener</p>	<p>1:00 PM</p>
<p>Purpose/Goal: To identify the human services concerns and recommend solutions addressing those concerns.</p> <hr/> <p>Discussion: In developing solutions take into consideration the following: infrastructure & resourcing; guidance & coordination; quality control; information & referral; professional development & credentialing; & quality of life.</p>			

Affordable Care Act Related Testimony:

Starting on page 42 Cumberland Forum:

DAWN WARDYGA: There is another group and Jim can probably speak better to it, another group through his department that have applied to be recognized as health homes to be able to pull in the extra Federal Medicaid reimbursement. **Human Services** I'm not sure what the Governor's Commission role has been in the past with the Healthcare Reform Commission that's run by the Lieutenant Governor, but I can tell you as one who has been involved in that process from the get-go, one of the things that I advocate very strongly for in that setting is that as we go forward in the development of the health insurance exchange that we're required to under healthcare reform, I continually talk about the fact that this should not just be about the fact of commercial insurance, it should be about all kinds of insurance including Medicaid. If those discussions aren't happening right now at the ground level, then what we're going to do is simply have another tower we're going to have to work with outside of Medicaid. So the integration piece with what's happening with healthcare reform and the integration of commercial and public insurance I think is critical and now is when it needs to happen because it's at the ground floor level. I'm sure you're all aware the lieutenant Governor chairs that group. It's a very open and inclusive group. I would encourage you to visit her website and get background information and send an email and say send me the information. Even if you don't attend the many meetings they have you have access to the meetings notes and all the information. As we talk about people with disabilities and healthcare reform we don't want them out here and everyone else out here which is typically what happens.

Autism Related Testimony

Page 12, Barrington Forum

TOM ARMSTRONG: My name is Tom Armstrong, and I have a 28 year-old son with autism that lives at home with us And this is an overriding concern that builds upon what other folks have said, that with the budget that was passed by the legislation got passed and signed by the Governor, a concern that with these budget cuts the effect that that has on the community-based system that we've built where we've gone over a number of years over a lot of years from an institutional system to a good, community-based system, and what effect these budget cuts are going to have on this

community-based system. Human Services The provider networks basically, the choices that you have are to cut services, to cut for instance staff paying benefits, which, in the long-run is not good at retaining and attracting the best staff that you can get. So, it's an overriding concern as to how those cuts are going to effect the community-based system that we've built over time. And a concern, too, actually, that the DD budget is 3% of the State budget and 15% of the cuts that were made actually came out of DD. Any consistency in terms of that are much larger percentage of cuts out of DD than out of other concerns. So, a real concern as to how the agencies can continue to provide and build on good community-based services to people with developmental disabilities. And I just actually wanted to add on another issue on the transportation issue that has come up with a few folks, there actually is a group, transportation comprehensive transportation group, that actually has been looking at other funding strategies for RIPTA because the gasoline tax is actually decreasing over time as fuel economy gets better on vehicles, actually the money that's being collected by the gas tax has actually been decreasing over time and probably will continue to decrease, so that there is a need for another funding strategy to fund RIPTA. Transportation And this group has been looking at other strategies and actually vehicles, miles travelled was one of the funding strategies that has been looked at. And actually, a couple of weeks ago when some of the stories with RIPTA cuts came out, there was actually an article in the Providence Journal that addressed this issue, and this transportation group has been looking at other strategies for funding because the gas tax is not sustainable over time. Thank you.

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Susan Donovan, and I think I signed in under my work name but I would like to speak as a parent. I wasn't going to speak but my friend, Leah inspired me because I've known her since she was this big. Human Services My name is Sue Donovan and I have a 16 year-old with autism and seeing Leah today brought me back many years, brought me back and I wanted to share with the Council and say publicly that with the State budget cuts and the new evaluation system that's being rolled out with BHDDH, the scales intensity evaluation, my concerns, as I look at my 16 year-old, who up to this point has had some wonderful opportunities, and I think I spend a lot of time with families who have younger kids and to hear you speak about your son being at home and to see Leah today and think about my 16 year-old, I just hope as we move forward as a state, that we can work through our, you know, financial issues, but that we can maintain the creativity and community-based opportunities for the young people coming through now that we've had in the past, because I hate to see us slip backwards. I do worry about going back to institutions and I do worry about you know, putting everyone in sheltered workshops again and I do worry about that. Because it really doesn't save money and it doesn't improve lives and just recently, you talk about disability from a youth perspective. Human Services My daughter recently lost her Katie Beckett waiver so she no longer receives Medicaid support. That Medicaid support paid for services that helped her become involved in the community and unfortunately, the past ten months we're seeing regression. You hate to lose the gains. We've made so many gains over the past five or ten years, I hate to see that lost. So that's all. That's all I want to share. Thank you.

Page 45, Cumberland Forum

LISA REGO: Lisa Rego. Human Services That's DCYF's I don't know if you want to call it a new policy, even at Groden no matter what the age whether they're 14 or old, they go in with a 90 day contract because DCYF's new thing is reunification. They go in with a 90 day thing, in 90 days if they're all better they can go back to their families which in our children's cases isn't really what's going to work.

Page 105, Providence Forum

LISA REGO: I'm Lisa Rego I'm here on behalf of my daughter, Chelsea, who is 19, she is severely autistic, mental retardation and a social disorder. Human Services She attends the Groden center. I'm very concerned about the cuts that DCYF is putting into place. The Groden center has just cut the extending day program and a portion of they are they are put in a day program. Like I said, she's 19 so she's going to be an adult soon and there is DD cuts right now that are \$24 million I really don't know how that's going to effect anything. And Chelsea has lived in a group home for four years. She does very well there. She comes home for weekend visits and I'm still able to work because the reason she had to go into a group home is I have two younger children. Both me and my husband work full-time and she used to try to climb out of the house, beat everyone up if she wasn't happy. She couldn't control herself. And her living in a group home, she can control herself. She can come home and have very nice visits at home with the family. And she's still very much part of our lives. I wish I could get the state legislatures to understand this. I've been at the house committee, the Finance Committee, I've been wanting to see the Governor and am still waiting. I'm speaking on behalf of a few Groden parents. Chris is another parent. There are other parents but because of their children, they couldn't be here. We're all very concerned. We're very involved parents and our children need these services and I don't know what else to do to get the legislators to understand that I didn't wake up one day and say let me put Chelsea in a group home, isn't that a great idea? It took a lot of work. She's had respite services and in-home services and it wasn't enough. It's not easy for me to say I couldn't take care of her but I couldn't. And now she has very good services and I'm very worried what's going to happen if the state keeps making all of these cuts.

DEB GARNEAU: Informing from the panel?

LISA REGO: I've still been write to go my legislators. We all do. We're a strong advocate group at Groden and we feel the services are important and we need to keep letting our legislators know that.

TIM FLYNN: That's it.

LISA REGO: Unfortunately they don't listen to us, but we're going to keep trying.

DEB GARNEAU: Thank you.

RORY CARMODY: What I think is interesting with legislators is having multiple discussions with them, too. I don't think they understood the unintended consequences of their actions. We had 38 new members between senate and house, that's almost 40 percent when you think of the general assembly. So Tim is right, if we don't pick up the phone every day and call the legislators, the only ones they'll get information from is the number crunches who think human services is eating up the state budget. I know it's time intensive and we shouldn't have to fight.

LISA REGO: It's very frustrating, I took time out of work to testify at the House Finance Committee and there were four people there. Some people sat in and some leave. The Senate Finance Committee, there were two people there. One of them was on their blackberry and I wanted to go, "hello! I'm talking to you." I want to explain how important it is and they don't even want to listen to you. So that's why I tell people, I still write to them all the time. I'm still here, we're not going away. Just because you go there, I mean, I left letters. I left enough with the person and said can you please distribute them to everybody? But I just feel like they should be there if they're supposed to be listening to testimony. We've elected them to be there. They should be there.

Page 46, Cumberland Forum:

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

Just one other comment, you had said that you know, some people like can live independently with the extra services and so forth, and we actually tried that with my son when he was first living in his regular apartment by himself or with the

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

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

SANDY LABOTTA: It's very frustrating.

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

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

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

have to spend all of my time with him while he's there, every second watching. I take him home because I love him, but it's not an easy situation. He really needs the specialized group homes and those are threatened right now. So that's my big concern.

PATTY DAVIS: At the PAL meetings they did talk about getting the providers all on the same level and also evaluating the services Human Services.

JUDITH DREW: Right, but don't equate one with the other. Because one is assessing the needs of the individual while the other is they're in negotiation with the providers across the state to get the providers to accept an X rate and everyone has the same rate. Rather than different contracts at different amounts.

PATTY DAVIS: The reason they started to do the whole evaluation system is money, is to get it down and not because they feel that there are a lot of people who don't need the services. It's all to get the money down, which is fine but it's a long process and we don't know what's going to happen with our children. And we don't even know how qualified these evaluators are. They're training them and my son was diagnosed by a neurologist, a psychologist and I can't understand somebody else that's being trained today, evaluate him is going to be able to know more about it than the people that have already evaluated him.

JUDITH DREW: They will have access to the records. The records will tell the story.

PATTY DAVIS: It just seems like a lot of work for something that's already been done. More money, more time. Right now my son doesn't have a social worker because the SIS hasn't come up for him yet and they don't know when it's going to come up. So he's in the loophole. Who do they evaluate first? They should evaluate the people who are transitioning, I would think. But they don't even know that.

JUDITH DREW: I don't know what the criteria is for who they're evaluating first. There is a negative side which you're expressing but there could be a positive side to this. Call me Pollyanna there could be people who they discover who are underserved. There's something to providing services -- it's going to cost the state more in the long run if the services are taken away and that person ends up in the hospital. What's the risk of the person ending up re-hospitalized offer whatever? I hope they're taking that into consideration.

PATTY DAVIS: But they want to get away from group homes and do shared living more. In some of our cases, shared living won't work. It will have to be a group home. And when Ryan turns 21 he can't be put in any group home. He needs specialized care for autism and I'm worried about that.

JUDITH DREW: You certainly have a legitimate right to ask who the evaluators are and how long the process will take and how they're being trained.

JAMES DEALY: There is another issue, too, I'm assuming there's some oversight or appeals process that backs up this?

PATTY DAVIS: Yes.

JAMES DEALY: So you wouldn't be taking one evaluator's opinion.

PATTY DAVIS: Well, I did hear it was going to take three years to evaluate everybody at one of the PAL meetings also. It's a long process when my son has already been evaluated and I don't know what's going to happen when he turns 21.

MONICA TAVARES: I don't know much about this either, is there a plan in place for the folks coming off the services, like what happens next?

JUDITH DREW: Well, everybody is going to be reevaluated for what services they require as adults. She's right. He's transitioning from the children's services you get whatever you need, mostly, to the adult services where at this point you really have to fight for what you need. To their credit what they're trying to do is evaluate who needs what services so the money that's being spent is being spent appropriately.

MONICA TAVARES: So if they're told you don't need these services anymore, but this is what you need or this is where you can access other supports?

JUDITH DREW: Well, the hope is that what we've been told is that the hope is that they'll properly evaluate people so that services can be appropriately matched so that again, money is well spent rather than you know, here you are you're in this group home of course you get all of these services whether you need them or not. That's a waste of money. If they're told they don't need a particular service, what happens then is that the parent or legal guardian can appeal, go through the appeals process and have a reevaluation process done.

LEO CANUEL: I think we need to move on. We do have some other testimony and we have only about a half hour left.

ANGEL MADERA: If I may say, Housing I'm leaving some information concerning housing on the desk and if anyone would like to use it, you may do so.

LEO CANUEL: Thank you, Angel. Thank you, Patty. Our next person who signed up to testify is Jill and I'm sorry I can't read your last name.

JILL HANKINSON: I understand that, I just don't write well, Hankinson. Human Services And I, too, have a son, seriously disabled with autism. He is going to be 27. He is luckily in a group home that is a wonderful group home. He is

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

Behavioral Healthcare Related Testimony

Page 38, Cumberland Forum:

PHYLLIS DOBBINS: Hello. I've never done this I'm Phyllis Dobbins [Human Services] I'm representing SOS. I volunteer with NAMI and a volunteer at the harbor house an independent clubhouse. Working with those suffering from mental illness. The four areas of concern and very quickly, the first is the community medication assistance program, the CMAP. This is as I understand it where those suffering from mental illness can get help if they cannot afford it or through their own insurance. And the rule change means that they must have been in the hospital or in the emergency recently to qualify for coverage and that they will not be able to keep that coverage after they've been stable. And those of you familiar with mental illness, know that that's not easy. My family member has been hospitalized four times along with several emergency visits and he's not been back in the hospital for five years. And this is due to his help he's getting from CMAP for his medication. Those who volunteer work in the community but usually they don't have coverage and this coverage that CMAP provides is an important part of their path to recovery and contribution. It The second point is the certified peer specialist program, this is a new program recently funded and the request here is that the actual peer organizations be involved in delivering those services. seems, it's proven that those who have experienced themselves, a mental illness, can use this experience to effectively work with their peers in ways that the mental health professionals often cannot. Professionals are doing a good job, but sometimes peer to peer is far more effective and we urge that the actual peers be involved in this new program. Thirdly, he will nor Slater hospital needs sufficient funding. The ACI is inappropriate and expensive option in many cases.

JAMES DEALY: I do have a question, Miss Dobbins. I should probably know this but I don't. What's your understanding of setting up the peer specialist program?

PHYLLIS DOBBINS: [Human Services] I understand the community mental health centers that currently provide the professional medical model treatment are being asked to conduct the new certified peer specialist program. And we're advocating that some of the community peer groups that are non-medical be allowed to also participate because they can be as effective sometimes more effective, than the medical model in actually running the program, yes.

JUDITH DREW: Are you suggesting the training piece or actually providing services.

PHYLLIS DOBBINS: Training and providing services. In other states it's actually the peers doing the servicing and it's wonderful because then of course, they are trained and they are in many cases able to reach those and pull the right strings and be much more effective than the professionals. No offense.

JUDITH DREW: I'm an advocate of a program and an educator in the field.

PHYLLIS DOBBINS: Often times with the stigma of mental illness you don't want to be going to the doctor's office. It would be nice to not always have that. That's what we've done at Harbor House.

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JOHN GALLAGHER: Hi, [Transportation] I'll ditto my concerns about the RIPTA cuts also for everybody. And like I said, I have schedules of hearings if people want to take it. Also, what I've observed a few years ago, I don't know if it's the same true for today, but I [Human Services] had a friend of mine and he is the nicest guy, he is bipolar and he's the nicest guy when his medication is corrected and everything is okay, he's the most pleasant guy in the world. But one time he was hospitalized and then it seemed like, it's like a revolving door he goes home and it seems there wasn't really adequate, the agencies weren't really adequately checking in on him. And he seemed to be often in a manic state for a straight two years. He's fine today. But it just seems like there wasn't adequate checking in on him, really, after he got out

of the hospital. You know, I would like to see some improvement in that field. Human Services Uhm -- and the only other concern I have really, well, you know, things that I've noticed from my perspective, I'd like to see more like libraries when they get, you know, or such places to have handicapped access. You know, one that I can think of is the Elmwood Avenue Library; they have the long stairs, if you have to use the stairs to go to the bathroom. And like the Mount Pleasant Library that's basically, they say democracy starts in libraries and builds like that I think they should be more handicapped accessible. That's all I can think of for now.

LEO CANUEL: Any questions or comments.

ROGER HARRIS: Just one, John, you said inadequacy of the agencies?

JOHN GALLAGHER: Yeah, like the mental health agencies. Human Services This particular individual lived in Central Falls and I guess he went through the, I guess it was formerly called Arrow Way, I don't know if it's still called Arrow Way that agency. I had to call up a few times and say, you know, check in on him, you know. But it took about two years for him to finally get the right medication. I've known him for like 20 years and I know when he's different. So.

JUDITH DREW: So what you're saying John is you feel there is a lack of adequate community supports sometimes for people transitioning from the hospital back into the community.

JOHN GALLAGHER: Right, that's what I'm saying, you know?

JUDITH DREW: Right.

JOHN GALLAGHER: I'm not try to go throw the blame game at anyone.

JUDITH DREW: That was your observation.

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CHRISTOPHER REEDY: My name is Christopher Reedy. I'm the administrator of Newport Community Health. I'm here to talk about the Community Assistance Program. Currently the Newport County Mental Health Center participates in the Community Assistance Program through the state. Human Services We provide services under this program to about 160 individuals who have different degrees of mental illness or substance abuse problems. The C-MAP program, as it is called, is open to individuals who are uninsured and who have low incomes. Often times, having access to subsidized medications is what keeps people out of hospitals and able to function in the community. As I understand it, the proposal is to restrict the C-MAP program, reduce the eligibility to only people who have recently come out of a hospital, a psychiatric hospital. Currently that's not the way it works. People can be on the C-MAP program long-term, as long as they meet the criteria. Often times we work with individuals who are uninsured if they are eligible for long-term insurance through Medicaid program or eligible for SSI benefits. We work to help people get those benefits. Until they do it they often times don't have any income supports and don't have any way to pay for medications that would keep them functioning at basic levels, enable them to improve their lives and to keep them out of the hospital. Mental illness affects people in many, many ways, but when it interferes with a person to hold a job, limits their income and disrupts their ability to function, keep a job, keep insurance, keep housing, and often times in addition to people with mental illnesses, we work with people with substance abuse issues who also have no income. In order for them to get on top of their substance and dependence issues, they will need to have treatment. Medication is often times a helpful part of substance abuse treatment. These people often times need to be part of the C-MAP program. We work with a number of people coming out of prison, who also, often times have mental illness, substance abuse or dependence issue or both and have no income. They are not employable because they have a record and there's discrimination in employment because they are convicts.

That's another group that is proposed to be cut off of the C-MAP program. My suggestion to the disabilities council is that the Department of Behavioral Health, Developmental Disabilities and Hospitals and the Department of Health actually manage the C-MAP program. This program can be run effectively and in a cost efficient way without cuts to major groups of people. I ask one thing. If major groups of people are cut out, people who are stable in the community with the assistance of the CMAP program, or you have people being cut off. Where is the savings if they deteriorate to the point where they have to go back into the hospital or get incarcerated again? There's no savings there and the cost would be greater. Emergency room visits and psychiatric hospitalizations can run as much as \$1,000 a day. Incarceration is probably \$30,000 to \$40,000 a year for individuals. The stability that is provided through the C-MAP program is nowhere near that cost.

I think the Department of Behavioral Health can achieve cost effectiveness by working with the community providers who are the C-MAP providers to make sure that it is run efficiently and medications that are covered under the C-MAP program are used in the correct ways. They've already begun to make efforts in that direction. So, my suggestion is to spare the cuts to the C-MAP program and work with the Department of Behavioral Health and make sure that they are running the program in the most efficient way.

ATTENDEE: May I ask a couple of questions?

CHRISTOPHER REEDY: Yes.

Have you had this conversation from others in the community?

CHRISTOPHER REEDY: I was not aware that the C-MAP program was on the chopping block until the last couple of days.

I would take it or I'm asking if you had an opportunity, obviously you know your population and you know your staff

when you've had an opportunity to be able to quantify the numbers that you may be talking about at this point in time.

I have not had a chance to do that yet.

Probably given that short notice, have you had an opportunity to address it? I understand that the Department of Behavioral Health --

I think BHDDH is a disrespectful name to the religion.

What use to be MRH has there been a suggestion there?

I have not. I don't know that we have as an agency yet.

It is not a departmental program. It is not a Department of Health Program it is a behavioral health.

I guess that is whether or not there has not been enough time to discuss it with the DOT and Department of Corrections?

Part of our local council, I know that the Department of Corrections has done, has really looked hard at the issue of inmates being released and making sure that vulnerable populations are being released with at least two weeks of medication. We work in the community to get those individuals into services quickly. So there are efforts, moving toward a good seamless system of care.

Are you suggesting that these folks that are re-entering into the community from prison and after their two weeks supply provided by the Department of Corrections upon discharge from the prison, the C-MAP, without the C-MAP for these individuals they would be on Medicaid. Would they be at risk for recidivism. That's easy for you to say. Also they need to be hooked up with a provider in the community who will write the scripts. The psychiatrist at the ACI write scripts for a certain amount. They need to be hooked up with a community provider. If a person has a low-cost medication and it has a \$4 script at Wal-Mart, that's fine. But sometimes people need other kinds of medications. Enrolling in the C-MAP program is something to do right away when somebody comes out. I would be interested in knowing what those numbers might look like particular, across the state.

Sure. We can work to try and get it to you.

I was at the hospital two years ago, Miriam Hospital was doing a study looking at doing a maintenance program in the prison before they are released or that sort of thing, even just from their history of addiction and having it implemented before they are released and continuing on. Miriam Hospital has something on that.

The hospital center is working with the psychiatry staff at the ACI. They work to make sure that the people get the right treatments. There's some medications that they will not use at the ACI but plenty that they do.

Some of the medications that they won't use, they are buying by contract?

I don't know.

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ATTENDEE: Is there any indication that this priority list, a list of priorities any indication of how they are prioritized. Human Services People who are in psych hospitalizations. People turning 21 in out of state schools. People turning 21 in DCF custody. I'm trying to think of the other priorities. Once in a while somebody has an elderly parent who is no longer in a position -- there are a lot of kids turning 21 that are out of state or in-state psychiatric placement and in DCYF care. That tends to be the priority. That's a very different and difficult process.

ATTENDEE: Are there individuals who are at risk of institutionalization?

ATTENDEE: In there are a psychiatric facility they are not leaving it. Somebody is paying for it, we are not sure who. I have no idea. That's a question to the Department. I do know that for providers, the challenge also is that now, resource allocations are authorized quarterly and quarterly we have to resubmit with a multiple of signatures and wait for the Department to approve it, so that we can continue to receive funding. I don't know how many of you work in business or home businesses that you budget on quarterly. It is a challenge. People who are self directed. Some of the organizations that do that are very concerned about the volume of those that they have to send in every quarter.

ATTENDEE: They are taking a risk -- someone like us. Not knowing if they will be paid for their time and energy to develop that plan.

ATTENDEE: I think it will get straightened out but I don't know how.

ATTENDEE: In defense of the Department and I do have to say that they have been so kind and full of information and trying to guide us through this process. They have relayed the same information. When I spoke with them last week they did say we have a flag on this record of the 21st birthday. I think there's some mechanism in place but it is not formal. When I hung up the phone I felt like somebody there really understood the urgency. I told them I'll call every six weeks, but there has to be a better way.

ATTENDEE: I'm going to be optimistic that there will be something at some point. Something that does not exist now. When you lay in this new model that is driven by the SIS assessment with cuts in funding, new licensing regs. And it just becomes an overwhelming entity to manage. In a department that has lost a lot of administrators and I'm not necessarily a fan of a lot of administrators, I think you need a certain number to process paper and plans and approval. It is hard to do that. I'm going to be optimistic that some of this makes no sense. Quarterly authorizations for people for whom their needs do not significantly change for whatever reason. It does not make a whole lot of sense.

ATTENDEE: I just don't understand why the government chose to do what it was not supposed to do. I just think it is unfair that the government cut our services and me and my friends, who still go out and do things. I think it is unfair that they did it in the first place. It should not have happened in the first place. I'm just saying it is really unfair for people like

me. They are cutting and we don't get. It is really, really a shame and not fair at all. (Applause).

Page 87, Kingston Forum

MARK VOSE: I want to express the need for interpreting services. Human Services Especially for substance abuse and often I'll go into a program or try to get treatment and it has to be postponed. I want access to programs at the state government level. I think that the state often is not aware of what needs to be done. There's a lack of awareness of who has to pay for that accommodation. They think that it is the Deaf person that needs to pay for that. I would like to see work done to clarify that and educate the state about who is responsible for paying for interpreting services. For substance abuse and AA and NA, so forth.

LAURA JONES: Thank you, Mark. We have the next person signed up to speak is James.

JAMES: Hi. Good afternoon, everyone. Ladies and gentlemen I wanted to share a similar sentiment as Mark. Human Services I go to the Bridgemark Treatment Center for treatment. I'm a Deaf person and I use sign language. I don't speak or use lipreading. I like to attend AA and NA meetings, often times three or four times a week. Often times there's trouble finding money for access to those meetings. There are many meetings in the state, but not many of them have access of interpreting services. I'm hoping that there can be advocacy work done to encourage insurance companies to provide access or pay for that access particularly for those treatment needs.

LAURA JONES: Thank you, James.

Can I get a clarification. This is for the NA meetings? And the AA meetings? Are you getting enough access to interpret the services at Bridgemark?

ATTENDEE: There is access, but when you go to outside NA or AA meetings outside of the Bridgemark facility there's not enough access.

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DEBBIE RAICHE: Human Services My name is Debbie Raiche. I'm a staff person at Bridgemark, formerly known as the Kent House. I've worked there for 15 years. I have my LCDP. I'm a Deaf counselor. These are two of my clients, I appreciate them coming and speaking about advocacy as far as providing interpreters. In the past when we had Deaf clients, they went to NA and AA meetings I was hoping that maybe GSO or other insurance companies might be willing to pay for the interpreters, now, they are not able to go to as many meetings as they would like to go to. It is frustrating. They don't have the access that other people have. They really require going to these meetings to help maintain their sobriety.

If interpreters are not being paid for and they are not able to go to the meetings then they do not have the access to maintain sobriety. Bridgemark pays a lot of money for interpreters and it is not fair for the Deaf community, I appreciate you listening. I wanted to share.

LAURA JONES: I didn't get your name Deb Raiche.

DEBBIE RAICHE: We are the only Deaf treatment center in Rhode Island for people with issues for substance abuse issues.

LAURA JONES: Deb, since you've been working for Bridgemark for 15 years, I have a question to ask: Has there been funding for interpreters in the past? Is this something new or is this something that has always been this way?

DEBBIE RAICHE: It has been the same. There's been a little bit of improvement, but not enough at this point.

TIM FLYNN: Thanks for testifying. My question would be, would you like to see a law in place that says that insurance companies have to be required to pay for interpreter services for their consumers?

DEBBIE RAICHE: Yes or any mental health issues, NA or AA meetings, any type of service that they need in order to provide accessibility. So we need to fight then for 2012, hopefully it will pass this time.

TIM FLYNN: Have you actually formulated legislation in the past and tried to get it through the legislature?

DEBBIE RAICHE: Yes.

TIM FLYNN: You have?

DEBBIE RAICHE: It was denied so we have to try again in 2012.

TIM FLYNN: Perhaps you would be interested in attending some of the Commission's legislation-committee meetings and work towards this. I'm familiar that substance abuse and disabilities -- substance abuse is more prevalent among folks with disabilities than they are among the general populous. Certainly it is swept under the rug in a lot of cases. So I think we need to bring it to the daylight and talk about it. I appreciate you bringing it up, all of you.

DEBBIE RAICHE: Thank you.

LAURA JONES: Once again, I'm going to open it up to the floor if you have testimony that you would like to share. If you have already spoken and you would like to speak again, on another concern we would love to hear that as well.

LAURA JONES: Okay, if nobody else wants to say anything else, further we can adjourn for a little while. If people have questions for the panelist you can come up at this time and ask your questions to the panelist off the record, then we can re-adjourn again if others come. Thank you.

LAURA JONES: We are going to reconvene. Thank you very much. We are going to reconvene. If we have any testimony from the floor. If you could state your name for the record.

MICHAEL CERULLO: Michael Cerullo. I'm a licensed clinical mental health counselor in private practice from Exeter,

Rhode Island. I live in Exeter, Rhode Island.

LAURA JONES: If you would like to talk about your concern, we would love to hear it.

MICHAEL CERULLO: First what I should say I come specifically with two voices today. Speaking from the perspective of two voices. Human Services One is that of a mental health professional who provides psychotherapy and counseling services to a wide range of brain-based illness and the rest of the psycho-stressors along with that. Sometimes, accompanying and contributing to it. I come as a man who has, since 1978 been aware that I'm living with and struggling with what we understand to be bipolar. In general, more or less successful at that. Although there's some times that people may suggest that I'm not as successful. I actually came to this field late in life after a career in business and have been in practice, primarily serving adolescents and males through all age ranges. I've been doing that for more than a dozen years now. Those are the voices with which I speak today. The particular cuts that I'm concerned about, the particular issues which I'm concerned have to do with the community-medication assistance program well as the SSI-match for assisted living.

I want to spend most of my time talking about medication. I think that from the perspective of a practitioner, I think that in the case of brain-based illnesses, the serious ones. I don't think there's any question that medication adherence is the single biggest barrier beyond having a place to live or in concert with having a place to live.

The biggest single barrier to success in managing a relationship with a brain-based illness, like bipolar or schizophrenia or depression or post traumatic stress disorder, many of the others we've come to understand is about brain science, it is not rocket science, we know that if we do not maintain consistent treatment, we have no scaffold upon which to build the relationship of an individual successfully, with his environment, with his -- the ways in which he manages, he or she manages the individual aspects of their relationship with the condition that they are living with.

It is absurd in my mind that we would invest the kind of money that we invest to help someone get stabilized in high-end residential or hospitalization settings or in the case of individuals who have been incarcerated. The kind of money we invest in stabilizing them and helping them build that scaffold and then pull the plug on them 30 days afterwards makes no sense at all. It will contribute to recidivism and in some cases death. We would not do it for someone with a physical situation, why would we do that with a brain-based illness like bipolar because one in six or one in nine individuals succumb to suicide. It does not fit with the requirements for parity in the current legislation and the laws that have been brought into existence.

I certainly would never have been able to struggle successfully, without medication, especially in times when I did have reasons to be hospitalized. And I cannot imagine anyone else being able to do it. With respect specifically, to the individuals who are incarcerated, research makes it very, clear, very clear that somewhere between 30-70% of our incarcerated population has some form of diagnosed or undiagnosed or untreated mood regulation issue. It is no secret, it makes perfect sense that they would find themselves incarcerated if they had no buffers to help them control their impulses. It does not excuse the behavior, but it certainly explains it. We have the individuals, we bring them into treatment in a facility, if they get the treatment there, we stabilize them, then we send them back out into the community and 30 days later the scaffold that they need to help them stay in control or have the opportunity to stay in control of their impulses, are taken away from them. That's absurd.

LAURA JONES: Just so that I'm clear, what happens after 30 days?

MICHAEL CERULLO: Well, that is going to depend on the individual. What generally happens is that for most conditions that are like cycling and mood disorders, you will find people self-medicating.

LAURA JONES: As for the funding ending for 30 days.

MICHAEL CERULLO: Yes that's what cutting the CMAP is all about.

TIM FLYNN: Is this a new phenomenon? Or was there a system in place to ensure these individuals?

MICHAEL CERULLO: I'm operating under the assumption that everybody knows what the cuts were. Community Medication Assistance Program has been cut, that means that people who were -- people without insurance, whether they were coming out of a hospital, whether their situation involved poverty or lapse of insurance policies or people coming out of prison who did not have coverage. These individuals at one time had their medication subsidized. They could receive their medications, now the way that the program has been cut, an individual after 30 days, discharged from a hospital, "stabilized" is no longer eligible for that support and that's what is creating -- that's what is going to create the problem.

TIM FLYNN: What are the numbers on that?

MICHAEL CERULLO: I don't have that. I see my world on a day-to-day basis on a microcosm. My colleagues on the Board of the Mental Health Association could give you more specific numbers at that specific level. I see things on a day-to-day basis. I know how hard it is, even when a family has insurance, to encourage medication adherence. Especially with young people when the condition first manifests. Often the most dangerous of the episodes. No one knows that the 18-25 year old whose behavior has destabilized. No one knows for certain that that's the condition they are living with. They get hospitalized and stabilized. Even with all sorts of insurance it is difficult to encourage that adherence to support it. Long enough, for example, to help them understand what their lifestyle changes can do in support of their controlling the condition. When you know you have someone who has no medication available to them, you lose the opportunity to persuade even the few who might, to do that.

TIM FLYNN: So you want the restoration of the CMAP funding?

TIM FLYNN: Who administers that?

MICHAEL CERULLO: That is BHDDH. They are on the list to cut, but in the current environment this is what the

legislature decided to make happen. Tough choices, but this one is an absurd choice. This does not make any sense at all. There's no way it will save anybody money, even in the short-term. It could start spiking costs within a three-month period, especially if it happens during seasonal and the manifestations of these conditions.

TIM FLYNN: Elaborate.

MICHAEL CERULLO: Take something like a cycle mood disorders, there are periods during the month, periods during the year in which the condition manifests more strongly. Even when it is contained or buffered by a medication, I have patients who will come in struggling to control the condition, say, in my experience, the spikes, this is supported pretty much by hospitalization studies of individuals with this particular condition, but it would be in any other. In any case what happens is that late -- midwinter through maybe the first week in summer there's a spike in hospitalizations, late August through Thanksgiving there's a spike in hospitalizations, if you have no medication it is going to make it that much more difficult. You will have an increase in it. If I have a patient who is medicated, if they are under a particular stress, they will manifest, more and report more experience with that condition. Without medications that could happen within a 3-6 month period. If you take someone off of medication for 30 days, that takes six weeks to titrate, at the very minimum, you will have nothing left of that medication's effect within six weeks. 45 days after -- 45-60 days after someone is discharged that individual is at risk especially if there's a serious stressor like homelessness to relapse. Very, very likely to happen. That would be the case whether or not you were talking about schizophrenia or bipolar or major depression or somebody working on PTSD and needing the support of a medication when they are trying to regain control of that aspect of their lives.

LAURA JONES: I have a question to ask: If some of these individuals that are uninsured were able to be insured, that would then allow them to have the means to get the medications correct?

MICHAEL CERULLO: That's correct.

LAURA JONES: Part of this could be an insurance issue. Lack of insurance.

RORY CARMODY: Lack of insurance is certainly the reason that the program was instituted to begin with. It was meant to support those who did not have it.

There's no guarantee that if the medications are available you will get adherence, you don't get at shot at it. You need the access to the therapy and the kinds of community supports that encourage adherence.

TIM FLYNN: I want to understand. These individuals who are on medication are they -- do they qualify for Medicaid?

ATTENDEE: If they did, they would have the medications.

TIM FLYNN: They probably make more than just about poverty level? I'm trying to narrow down who this population is?

MICHAEL CERULLO: The population with which I work mostly has the insurance. The ones that do not, but do not qualify or did not qualify to this were folks whose families had the resources, but the individuals would not qualify because they were still connected with the family in one way or another.

For instance, I can recall a 25-year-old, clearly, diagnosed with some form of either bipolar, schizophrenia or a combination of the two conditions, schizo affected. A well-educated, middle class family, they did not qualify for Medicaid, no way to support his therapy. No way to support his medication other than through the family. No way to get him even to the place where he would be willing to take the medication. But I mean the population that concerns me the most because I spent so much time in the juvenile justice system, especially the older adolescents when they leave incarceration they do not have the insurance. Within 30 days they are in trouble. That's -- that's complicated in a number of ways, but for adults no question very little if any medication available to prisoners returning to the community who do not have the kind of family supports that would get them back on to private insurance.

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NZINGA MISGANA: I am a caretaker of and relative of people with disabilities. What I wanted to speak mostly about tonight are people with psychiatric disabilities, but I do help care for my elderly parents who have mobility issues. Human Services My mom had a stroke many years ago and walks with a cane and a walker, and I just want to say what you probably already know but I find it outrageous this is not a physically accessible state. One of my favorite theaters has restrooms up a steep flight of stairs. I know they're probably grand mothered into something, but it's still not fair. In my neighborhood, curb cutouts are sometimes there and sometimes not. There is a crazy system there is a curb cutout and an island, and then another here (indicating). There is a curb cutout and then an island and then cutout again. What are you asking people to do? Stand in the street and pray no one comes by? I find over and over again that those of us who try to be sensitive to this, you notice it everywhere. I ask that existing laws be enforced. Where is the enforcement? Dedicate more money, please. And in general, just let's all try to walk in one another's shoes and let's make sure what's available to me is available to all of us. So I want to move on to psychiatric disabilities. There are two major issues I want to speak about and I'll be brief. But the first, I'm a caretaker for someone with a psychiatric disability, very young person, very smart person, very capable person, when he is well. But we sometimes have to go to the Rhode Island Hospital emergency room. And these folks are getting lots of Medicaid money, so it's, you know, the state should be interested in how folks are treated. I don't know how many of you have been to the psychiatric emergency room at Rhode Island Hospital. Anyone? The first thing you do is you get taken down to the dungeon. It is not an exaggeration. You walk down many, many corridors from the regular ER to the psychiatric unit, and the only way as a family member or a friend if somebody is already there, someone has to accompany you because there are several places where they have to swipe

the card. But I should back up for a minute. Because the first thing that happens is an intake process. You talk to very nice people, but sometimes you end up the way we did last spring in the overflow intake room. There were dozens of people who were in great pain, who were being told to sit. They couldn't stand, they couldn't walk. Some people were strapped to gunnies. Whatever was going on with this woman, everyone knew about. My person was asked three times while jumping out of his skin, three times for his intake information because they kept losing it. Eventually we got taken to the dungeon, where there is a cell in the center of it where the staff is with computers. The doors lock behind them in an octagonal arrangement so they can see into the rooms. I was with a friend who had unfortunately served time in prison, and he said, this is the ACI. You're almost treating people as though they've done something wrong and are stigmatized from something that feels therapeutic, but to something that feels like punishment. I'm talking about this experience for the moment. So, the only way to describe it is as a cell. And there is a permanent security guard that is guarding everyone, or depending on what your loved one is going through, if they seem more agitated than they should be, there is a security guard standing at the door, will go to the bathroom with him or her, take them back. It's very, very punitive. Uhm, and then there's the hours and hours of waiting. I've been there for more than 24 hours with my loved one, just leaving to grab a snack and come on back. It's just not okay. It's brutal, inhumane and you've got to fix it. You've got the power, you've got the influence, you've got the purse strings.

Page 108.

CHARLES FELDMAN: I grew up when things were a little bit better and so I'm doing pretty well now, just like John, I'm working part-time which is okay, you know, I'm doing all right, but what if I was a little younger. Now I have Medicare part D which is okay, but when I was younger, Human Services I was on the Community Medication Assistance Program, or C-MAP and that program, the eligibility requirements have been tightened so someone has to have been recently in the hospital or the emergency room before they can get their psychiatric medication on C-MAP. I wouldn't have been able to get my medication on that if I was still on that, I wouldn't have been here today or have recovered if that was the case. Fortunately I was never in prison, but people tell me the prisoners are able to get their medication in the prison, in the hospital, in the nursing homes but they're not able to get their medication in the community and as we know, a lot of people with mental illness if they're symptom attic they may end up in the criminal justice system but if they're on their medication and recovering they will be contributing to society and so this is totally backwards. And as a matter of fact I heard a couple of cases of people who were doing well and this situation happened that they could no longer get their medication and they ended up in the hospital. So that does not save money t costs the state money. So I think we ought to reverse those changes. Also, as Nat pointed out, when I first got sick the doctor had me live with my parents for six years. If that was not available, I would have been in assisted living and if that was the case, and the cuts happened back then and I was in assisted living, I could have been out on the streets and in a nursing home and I wouldn't have been able to recover the way I've been able to. And what Matt didn't say is they don't even allow them to have fans in their rooms now because they can't afford electricity. They cut down the TV watching, the air conditioning, they cut down the fans. So it's already starting to affect people. So that's another thing. Transportation And then RIPTA also, if I was younger and I stayed out later, now I go to bed early, so I'm not likely to be out after 10 o'clock, but if I was younger and staying out later, I might not have been able to get around where I wanted to go. Excuse me, and even as it is now, I didn't even think to look at this, when I go to my spiritual center in the evening and on Sunday evenings I don't even know if I can get back home by bus anymore if these cuts go through. And then I was in the hospital, I fortunately was never in the Eleanor Slater hospital, if that had not been there for me, I wouldn't have been able to recover and be here now. Fortunately I was able to get into the hospital and get the treatment I needed. It took a while to get the right treatment but I was able to get the treatment I needed. On a totally separate issue, the Behavioral Health and Developmental Disabilities or BHDDH, Human Services they're starting a peer specialist program. Those are people with mental illness and they can serve their peers and have a point of views others have not had because they're going through the same situation their peers have been through. This allows people to advance in their recovery who otherwise weren't able to relate to the regular mental health professionals. There is some resistance to this and also talk of trainings being held by the provider organization. And in most states around the country, peer specialist programs are run by the mental health consumer organizations such as mental health consumer advocates and NAMI has peer programs like peer to peer and NAMI connection. And I think that the peer specialist program in Rhode Island as much as possible, and there's no reason why it couldn't be, should be a peer run program. So let me say one more thing. I happen to be walking by the Rhode Island Disability Law Center office last night and I ran into someone who I used to go to school with, who said he was on his way to help a person with a developmental disability whose mother had died and this person was just stuck in his house, he was eating out of cans, not eating a decent diet, not paying his bills and the person I talked to said that BHDDH didn't even want to hear about it because of all the cuts. So I think we need a cross disability movement. All the people in this room from different disabilities need to get together and unit and you know, work with the Rhode Island Disability Vote Project. There already is the disability cross disability coalition which meets at the office in Cranston and we need to expand these efforts and work together and unit and become a voting block and an advocacy block just as much as the senior citizens and any other voting block, labor and any other voting block, so the politicians realize that's what they want is to be elected. And if we have a big coalition and we're able to advocate for our positions and we've heard many of these things today that people really need to recover and to get by in their lives, then I think the politicians will have to listen to us. Thank you.

Page 120, Written, Faxed, and Emailed Testimony:

Hello, my name is Max Zapata and I am representing the Save Our Mental Health Services Coalition, or SOS for short.

I am concerned about the following issues, and I would like the Governor's Commission on Disabilities to focus on these in the upcoming year:

The Human Services Community Medication Assistance Program, or CMAP, is the program by which people with major mental illness and no insurance can get their psychiatric medications covered. Now, the rule is that people have to have recently been in the hospital or the emergency room to qualify for CMAP. That means that people with major mental illness living in the community, will not be able to keep getting their medications after they have been stable for a while. It also means that people coming out of the prisons will not be able to get their medications, and may end up back in prison. We ask that all people who need psychiatric medications to stay in the community, have access to these medications.

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

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

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

We ask that Transportation RIPTA be expanded, rather than cut back, so that all people in Rhode Island who need buses or Rhode vans, can use public transportation to get to doctor's appointments, shopping, and even recreation, which people need to lift their spirits.

Just think about and realize how difficult is the daily struggle, hardness and limitations of many people and families dealing with a mental condition such as bipolar disorder, schizophrenia, depression, anxiety, OCD, PTSD, panic attack and the more than ninety phobias that are out there. Those people deserve our attention and support.

Frank Zapata {signature} August 31, 2011

Children's Services Related Testimony

Page 29, Warwick Forum

TARA TOWNSEND: Hi, my name is Tara I work for the Rhode Island Parent Information Network. I'm here on a professional and personal level. I have a 3 1/2 -year-old son who is trached on a ventilator full time and receives services through Medicaid and social service. As you know Human Services Medicaid is being severely threatened right now. Katie Beckett, if you know about that option. It is always being severely threatened. They are throwing out denials left and right nowadays. People are not accepting the -- it is the same application, but when you go to receive services, more people are being denied. There's different protocol going on. When you ask what the protocol is, they say nothing has changed. Obviously there's an issue going on behind the scenes that we are unaware of. We did put a staff member over at Katie Beckett and things seemed so have gotten better and denials are coming all of the time. Rhode Island Parent we are here and if you have any questions we can help you with that. Other things we've been hearing about is the DDD program issues. No new regulations out but the regulations are not being accepted. So people in the adult disabled population are not getting their applications approved or denied. It is in limbo. We do not know what is going on. The old regs are not being utilized and no regulations are in place. We are questioning what is going on in that area.

Page 40, Cumberland Forum:

DAWN WARDYGA: DAWN WARDYGA: My husband just retired and I'm thinking I don't want to retire ever. Maybe slow down, but retire, I don't know. So under the Medicaid, if you will umbrella there are several different issues that we are very much concerned with. The significant cuts to the adults with developmental disabilities population in this past budget session are draconian. How can we even begin to think we can implement those kinds of cuts without doing harm is beyond me. I can't even express that strongly enough. That I don't know where we go from here and I know that I'm a good friend of Craig Stenning and known Jim for 20 plus years basically and it's just as hard on the department as it is on the population that's being impacted by it. So you know, whatever it is, that we can all do collectively to implement what we need to implement but keep in mind in my opinion, the civil rights, maybe consult the Disability Law Center on this, the civil rights of this particular population as we begin the horrendous cutbacks that unfortunately our legislature approved and our Governor signed. So that's the first issue. Human Services Second issue, and again I don't want anyone to think that there's any priority order because they're all especially when we talk about Katie Beckett, for the last at least 7 years, 7 legislative sessions, there have been very deliberate threats to the Katie Beckett population. Fortunately, for 7 years, we've been able to cut them off at the knees and stop that process. I have to tell you, I'm getting pretty tired of it.

Again, I'll go back to potentially civil rights for these kids. That I understand that for Federal Medicaid purposes this is a population that is referred to as optional, as the mother of a child with significant disabilities, I will have that argument with you to the death as to how optional those services are and those populations are. So having said that, this has been a state specific threat. This is not anything that's coming from the Feds. This is something that's being initiated by the state. Who is throwing out the suggestion in the budget debate, I have no idea and I don't really care, to be honest with you. But it comes up every single year. It started off with basically a proposal to implement a cost-sharing component for kids who were eligible under Katie Beckett. It had nothing to do with; they weren't going to make any money. I mean they really were not going to make a dent. The principle behind it was if RICARE families have to pay a co-pay so should people on Medicaid by Katie Beckett. 90 percent of those kids are covered by commercial insurance and their parents are already paying for insurance. They're already cost-sharing. There is that component. This legislative session it really got ugly. With the proposal in place, even though they can't do it legally at this point in time anyway because of our global favor, there was a suggestion that we should eliminate the Katie Beckett eligibility population altogether. I can tell you that in, I've done a lot of work in the global waiver process and I can also tell you it's been one of the most frustrating things I've done in my career, but I will continue to participate in the process and bring others into that process or the kids don't even exist. They plain don't exist. If someone isn't there speaking for kids it's all about the elderly and the nursing home diversion and in the almost three years we've been into this process, it's all about the other populations. So, kids don't come into the mix. Having said that in terms of the threats to Katie Beckett currently through Federal Law they cannot eliminate populations. They cannot touch eligibility. They can touch services at this point in time that's the way it goes. But that doesn't mean two or three years from now and right now they're already having the early conversations about reapplying for this global waiver when the first one runs out. So now is when the ideas are going to come up basically. We need to be very careful about anything, any optional populations. Not just Katie Beckett kids but any options under Federal Medicaid law if we're to protect the people with disabilities in the state. This is also Medicaid-related and we do have a Medicaid buy-in we all know we have to show our man and that's fabulous T. Doesn't help families who have kids with disabilities who do not qualify for Medicaid through any mechanism whatsoever, including Katie Beckett. These are kids that clearly meet the Federal definition of disability under Social Security law whose families are over the very low income threshold for eligibility for SSI. So, these are kids that clearly have disabilities, we cannot debate whether or not they have disabilities, they have clearly established disabilities, who require medical care and support care above and beyond your typically developing child, basically. They don't meet or they're determined not to meet and I use those terms very deliberately because the eligibility process for Katie Beckett in the way it's being applied in particular, the level of care criteria document, the way that's being applied to determine eligibility is much more strict than it was even two or three years ago. I can tell you the number of eligible kids who have gone in the last three years, two years, from 1,500 kids in the state and we are now below 1,100 and I have been told the official word from the Department of Human Services is that there has been no change in policy. So, clearly, something is different. Uhm -- but they're not calling a change in policy. So these are all kids in addition to the ones who wouldn't qualify anyway because they wouldn't meet the level of care who have qualified for Medicaid, these are kids that have no access to the home and community-based services that many of us worked very hard to develop maybe ten, 15 years ago. They cannot access the family centers unless they're eligible for Medicaid. So what we've done now is we've created kind of sort of a safety net for kids with disabilities and now we're restricting who can actually access those. So we're kind of going backwards with that. I would love to explore the option of a Medicaid Buy-In for these families on a sliding scale fee. These are families, again, the child definitely is disabled, the family may be over income, they may be a dollar over income, or \$10,000 over income, whatever the case may be, I think we need to look at that as a potential way for those families to buy in so they can access the community-based services, because right now they can't. There's nothing out there for them. Many of you are aware under the Medicaid I'm sorry, under healthcare reform that the Medicaid agency has applied for the CEDARR family centers to be recognized as health homes. Those health homes assuming they get approved will be reimbursed at a 90% Federal Medicaid rate. In other words, it's a boost to the CEDARR family centers, which is a good thing in my opinion, because then of course, you can serve more people. But if people can't access that, what good is it? To be paying attention to what that really means and how it plays out. From what I've heard it sounds as if the feds are very interested in approving CEDARR family centers as health homes.

JUDITH DREW: I just want to thank you for touching on some very important issues because it's been my experience at one of the biggest barriers to returning people to employment who have disabilities are the health insurance issues. A lack of good access, they can't maintain their health because they don't have the coverage to buy the medication. So they remain at an unemployment status. I'm very impressed that on that little square of paper, you could give us everything you did. You're amazing, Dawn.

(LAUGHTER)

DAWN WARDYGA: Human Services Let me say the one thing around employment and if you think of it in a different context is one of the issues around those of us who are parents, who are caring for kids with special healthcare needs at home, many of our parents, especially with budget cuts, are being forced to refuse promotions, to not go to work at all because it's going to threaten their kid's benefits or for one parent to have to leave a job for lack of services. So there are employment and quality of life implications for those families as well, based on the special need of the child. So

you know, again it's a secondary, not the person with the disability, but as long as that person is in the care of those parents, that's going to have implications.

JUDITH DREW: We've been raising that argument on the Commission level for a while, especially this past year with all the budget cuts and so far, it's only anecdotal information. We can give them this example here and this example here. The only thing that's going to make a difference is if we have parents stepping forward contacting their legislators and saying if you do this, this is going to be the impact to me and my family. Or you get a group of people together and canvas and provide us with the documentation. Right now we're just telling them stories, it's not that they're not listening but --

DAWN WARDYGA: There is some research that's been done at a national level, don't know if it's been called out on a state level, but there is research available on a national level about employment implications of participates of kids with disabilities.

JUDITH DREW: Whatever you can do to provide that to us would be great. But our legislators want what's going to happen in Rhode Island.

DAWN WARDYGA: Absolutely, I totally agree.

JUDITH DREW: If you can reach out to your network of people and say you need to start calling and writing so they get the real world picture that would be enormously helpful.

DAWN WARDYGA: Who would be on my distribution list? I would be happy to add you.

JUDITH DREW: Please add me. Talk to me later.

DAWN WARDYGA: Later on basically, I keep a distribution list and it's not, I can't -- it's not a once a week thing or a digest it's not that sophisticated. I'm a firm believer and have been since the birth of my son that information is power. It does no good to sit in my E-mail box when people can take that information and run with it. If you're getting too much information or interested you're not interested in, that's why they have a junk box.

I have a comment I totally agree with you about contacting the legislators. However, we were very frustrated this year our children go to the Ruben Center in Providence, we testified in front of the Senate and House committees, we had people writing letters and calling, it's like they didn't hear anything we had to say. Not that we're going to stop. But it's just that we, I mean we wrote letters, I mean we called their offices. I was calling people, calling parents saying we have to keep calling them. We have to keep calling them. They're not voting until next week. We have to keep calling. We told them why our kids are in group homes and it's not that we woke up one day and said let's put them in a group home it's a great idea. They're doing well there because they're there. But they just obviously didn't want to hear us this year but it doesn't mean we're not going back. We're going back and we're still trying to get in with the Governor. I met with two of his policy advisors and I thanked them very much. I thank them every week for meeting with me but I still want to meet with the Governor and I will email every week until I get the meeting with him.

LEO CANUEL: Way in the back.

DEB O'DONNELL-LEE: Human Services I'm a foster participate and we just received a young lady who turned 18 in a group home and she has mental disabilities. And the thing is they changed the policy now that these kids can only stay there three months. And that they're losing the care that they need. That they're getting. You know, the instruction that they get in these group homes, the child we got, she was there for about a year and-a-half. But then they went and changed. So she had to get out of there. Cut and dry, get out. So they contacted us and said would you please take her? And so, I mean, she still has issues and stuff that we're trying to get you know, help with, but the thing is, now all these other kids that are sitting there, you're not going to get any help in just three months and to cut it down to three months isn't fair to these children.

LEO CANUEL: Can I just ask, your name, please.

DEB O'DONNELL-LEE: Deb O'Donnell-Lee.

ROGER HARRIS: And the name of the group home?

DEB O'DONNELL-LEE: This was Lincoln house.

JUDITH DREW: Do you know which organization this was part of?

DEB O'DONNELL-LEE: No, she was part of DCYF. A lot of the kids in there are from DCYF but family service took her on. I'm a member of family service foster parenting therapeutic care. And it's kind of like we're there all the time. So if she needs anything, we try to get it for her. But the thing is, like I said it's that three months now that these kids are really going to lose. They're not going to get the services that they really need to progress to move on into a regular home.

JAMES DEALY: I think first off, that Lincoln house I think is for adolescents with sort of behavior problems?

DEB O'DONNELL-LEE: Yes.

JAMES DEALY: I don't know what is the three-month policy you're talking about? Can you explain a little bit.

DEB O'DONNELL-LEE: They changed it. Kids used to be able to stay there and get all the counseling they needed.

JUDITH DREW: At Lincoln house?

DEB O'DONNELL-LEE: I understand it's at almost all of these group homes now. So, any child that comes into this with problems, once they do their three-month thing, they have to get out of that one. And if they can't find a placement, they go to another group home and then another group home and they keep getting moved around. These kids suffer so

much because of education and everything. You know? They never get a good education because they're floating from home to home to home. And three months is not enough time to have these kids get settled and really learn something.

JUDITH DREW: So are you saying that you think the rules have changed and the policies have changed somehow so that these kids who need therapeutic foster care placement.

DEB O'DONNELL-LEE: That is an organization I belong with.

JUDITH DREW: Okay, but these other programs you're saying there was a time when kids could stay there until it was felt they were ready to move into a normal quote-unquote normal foster home placement.

DEB O'DONNELL-LEE: Right.

JUDITH DREW: And now the rules have changed they can't do that and they have a maximum stay of three months.

DEB O'DONNELL-LEE: Exactly.

JUDITH DREW: As a result they moved out of there and moved into another type of foster placement.

DEB O'DONNELL-LEE: They're moved into another group home if they can't find foster placement.

JUDITH DREW: Does this have anything to do with the fact that they're turning 18.

DEB O'DONNELL-LEE: No, once they're there three months they have to move out and get another placement and most of the time it ends up another group home and another one and another one.

JUDITH DREW: You're stumping me because I've not heard about this.

LEO CANUEL: Maybe you can talk to her during the break so we can get more information.

JAMES DEALY: Can you get collar fiction from DCYF because I don't know how this policy works.

LEO CANUEL: And what was your name.

LISA REGO: Lisa Rego. Human Services That's DCYF's I don't know if you want to call it a new policy, even at Groden no matter what the age whether they're 14 or old, they go in with a 90 day contract because DCYF's new thing is reunification. They go in with a 90 day thing, in 90 days if they're all better they can go back to their families which in our children's cases isn't really what's going to work.

LEO CANUEL: Actually I want to get back to Dawn now if we could. You had brought up the Sherlock plan that's near and dear to my heart. We started it six years ago and they fixed it this year. When it was passed six years ago it was broken to begin with. We are working on the regulations for them. We have upcoming meetings to work on those regulations. My question to you is, because I can foresee and I've always been an advocate of the Medicaid buy-in for all people who are not able to have advocate insurance, so I think the Medicaid buy in for adults with disabilities who want to work is a place to begin. I just want to clarify with you that working with children under a Medicaid buy-in your thought is just to clarify is it would be only the children that would be covered under Medicaid and would not be the entire family unless the family financially is eligible for Medicaid in the other program.

DAWN WARDYGA: Human Services Exactly and there is a Federal Law that allows, it's called the family opportunity act that allows for a buy-in and uhm, I would extend that to say that because a lot of like pushback that I get from the Medicaid agency, believe me I've been on this one for a long time with them, is that even if the family were putting up the state share to get the Medicaid match, if you will, the actual cost of the care for the child is going to be way over and above so in fact is across the state. I can't argue with that. That certainly is a good point that they make. But I would say a Medicaid buy in is one step. I would also say and it's something that the CEDARR family centers were supposed to have done in the first place and DHS didn't support them through the process, there should also be a sliding scale fee at the centers so that for families who cannot buy into Medicaid or who don't meet the criteria to buy into Medicaid, can actually buy the services because those services are not available anywhere. If I'm a millionaire and I live in watch hill and have a kid with significant disabilities, I can't get services. I can't buy HBTS services because there's no mechanisms in place.

JUDITH DREW: But you can do it privately.

DAWN WARDYGA: I guess.

JUDITH DREW: You can do it privately outside the system.

All the efforts of Katie Beckett have been based on, talk about lack of data, based on the fact that certain kids have, honest to God, I'm not lying this is real, this is the story the state has used in the general assembly that certain kids on Katie Beckett live in certain zip codes. Don't even get me going on that one. They're making assumptions that some of these kids, the kids left on Katie Beckett which is a dwindling number, I just got a breakdown within the last two weeks of how many kids live in which communities and that kind of thing. How they ever came up with an assumption about that is beyond me. It makes no sense to me whatsoever. That's literally been used in testimony at the state house. So the whole thing about access, Medicaid buy in may be one option but there also needs to be and should be and was intended to be a mechanism in place so that I could go to the CEDARR family center and pay for those services based on a sliding scale fee if I had the means.

MARY WAMBACH: I will summarize my comments because I understand other people want to speak and have to leave. My comments are from my home address because I've not had time to go through all of this with my board. I'm very familiar and very involved in almost all of the agencies and groups that involve people with disabilities at State and local levels. Many of the people involved in these groups do so much work for very little recognition. Many of them without any kind of pay or reimbursement for any travel or other expenses. Human Services My general comments, Rhode Island is very behind most states in compliance with ADA and section 504 as well as other disability legislation has had its budget and staffing definite stated and as a result, there are very few people there to do anything except answer the phones and they do a lot of work to keep the public informed. They try to review and get out some works of legislation, upcoming meetings. But the Governor's Commission on Disabilities should be a leader. They should have enough staff to do a lot of training, to do a lot of public education, to do enforcements. There is supposed to be the enforcement for ADA, they don't have enough staff to do that. Unfortunately, in my view, the way that the Commission has been defunding and the staffing has been reduced, there is a statement about how Rhode Island views people with disorders. Rhode Island's human service agencies and programs are another demonstration of how ADA and 504 are regarded. The services and programs for the most part, are not accessible. People don't know that they have to get an interpreter applied for. The poor response system, seeing people with hearing loss and disabilities, they can't use the system, they're too fast and the language is too complicated. It's not accessible. Starting in 2008, the defunding of agencies and programs and services that help people with disabilities and others, has just, it's reduced the ability of so many people to be part of society. And I believe it's recreated the class system that Rhode Island had years ago, the haves and have notes. And most people with disabilities and seniors are in the have notes.

In the past, the DD programs were able to give a lot of attention to individual choice and need. Under the new funding regulations, and staffing ratios, we will not be able to pay nearly as much attention to individual aid. Adults who have mood, behavioral, medical communication needs, there's going to be very little time between staff to do a 15-minute head count to really pay attention to the consumers that most need support in order to be active in society. BHDDH (sounds like) and EOHHS, have said services won't change. Services are going to change a lot. Transportation Most of us have already cut our transportation budgets. We've reduced staffing. We can't do recreational stuff we used to do anymore. Human Services Most of us are not going to have anymore out of state trips, job training, supported employment, especially if we're not getting funded. We're not going to have that anymore because the new billing system will not pay for staff to do this. I think it's warehousing human beings and I think it's criminal. And I think that the state needs to stop try to go sell the program to families as if there were no changes. And my paper it suggests that maybe we can start a 12-step program for administrators and solutions. I just felt about the fact in my agency when we needed to make serious cuts, we started at the top, myself and my manager took significant pay cuts. That was last November, we're not getting them back now, and we don't expect to get them back this year or maybe ever. That's what this state needs to do. It's obscene that in Rhode Island, when the people up there make mistakes, even big ones, even year after year after year, the people up there are not the ones that take the hit, it's what they call the low-hanging crew, and I think that is criminal. And I think that we need to start seeing pay cuts for our top officials. We need to start seeing memos saying that there are no more leased vehicles, no more new office furniture and please, no legislative aides with almost no experience and no college degrees and a father who is a union official who is earning \$85,000 a year on a job. I have four people that could do that job for that amount of money. I hope that Rhode Island will stop pretending that the Newport jazz festival, the regatta the beaches aren't the most important things about Rhode Island. The most important things about Rhode Island are its people and many of us have disabilities or seniors or the poor and we're tired of being on the bottom. It's disgraceful. Thank you very much.

BRIAN ADAE: Ms. Wambach, I know we have many many other folks here to speak. I have one question. One question, I can't speak for the panel, but I certainly have, myself, the impression that what I'm hearing at risk here is certainly quality of life in a varying number of degrees. Are you aware of any specific individuals who may be at risk of institutionalization as a consequence of the funding reductions?

MARY WAMBACH: At my agency at this moment, there is no one. But the other programs have said they have to close programs and that those staffing and there's nowhere to put people except institutions. We don't have enough institutions. Rhode Island doesn't even have institutional care for adults with developmental disabilities. We stopped that years ago.

BRIAN ADAE: This, I understand. The Ladd center was closed some time ago for institutionalization. I'm saying being integrated to the highest degree possible. Perhaps we're looking at whether someone may end up either hospitalized, nursing home, that's my question.

MARY WAMBACH: It's very possible and it's awful to put someone in a nursing home. We're very worried because we measure dates and weeks when we don't have emergencies and hope that we never do. But when we do, we not only risk the health and safety of the people we serve, we risk our programs. If there were to be a lawsuit or something filed. We're very, very, very concerned.

ANGELINA STABILE: Do you have this information on your website?

MARY WAMBACH: Yes, we do, but I also recommend that you please consider going to CPN Community Provider Network Rhode Island. Because they've collected a lot of concerns about the regs and rights and this whole mess. Thank you for the opportunity to speak.

Page 87, Kingston Forum

MARK VOSE: I want to express the need for interpreting services. Human Services Especially for substance abuse and often I'll go into a program or try to get treatment and it has to be postponed. I want access to programs at the state government level. I think that the state often is not aware of what needs to be done. There's a lack of awareness of who has to pay for that accommodation. They think that it is the Deaf person that needs to pay for that. I would like to see work done to clarify that and educate the state about who is responsible for paying for interpreting services. For substance abuse and AA and NA, so forth.

LAURA JONES: Thank you, Mark. We have the next person signed up to speak is James.

JAMES: Hi. Good afternoon, everyone. Ladies and gentlemen I wanted to share a similar sentiment as Mark. Human Services I go to the Bridgemark Treatment Center for treatment. I'm a Deaf person and I use sign language. I don't speak or use lipreading. I like to attend AA and NA meetings, often times three or four times a week. Often times there's trouble finding money for access to those meetings. There are many meetings in the state, but not many of them have access of interpreting services. I'm hoping that there can be advocacy work done to encourage insurance companies to provide access or pay for that access particularly for those treatment needs.

LAURA JONES: Thank you, James.

Can I get a clarification. This is for the NA meetings? And the AA meetings? Are you getting enough access to interpret the services at Bridgemark?

ATTENDEE: There is access, but when you go to outside NA or AA meetings outside of the Bridgemark facility there's not enough access.

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DEBBIE RAICHE: Human Services My name is Debbie Raiche. I'm a staff person at Bridgemark, formerly known as the Kent House. I've worked there for 15 years. I have my LCDP. I'm a Deaf counselor. These are two of my clients, I appreciate them coming and speaking about advocacy as far as providing interpreters. In the past when we had Deaf clients, they went to NA and AA meetings I was hoping that maybe GSO or other insurance companies might be willing to pay for the interpreters, now, they are not able to go to as many meetings as they would like to go to. It is frustrating. They don't have the access that other people have. They really require going to these meetings to help maintain their sobriety.

If interpreters are not being paid for and they are not able to go to the meetings then they do not have the access to maintain sobriety. Bridgemark pays a lot of money for interpreters and it is not fair for the Deaf community, I appreciate you listening. I wanted to share.

LAURA JONES: I didn't get your name Deb Raiche.

DEBBIE RAICHE: We are the only Deaf treatment center in Rhode Island for people with issues for substance abuse issues.

LAURA JONES: Deb, since you've been working for Bridgemark for 15 years, I have a question to ask: Has there been funding for interpreters in the past? Is this something new or is this something that has always been this way?

DEBBIE RAICHE: It has been the same. There's been a little bit of improvement, but not enough at this point.

TIM FLYNN: Thanks for testifying. My question would be, would you like to see a law in place that says that insurance companies have to be required to pay for interpreter services for their consumers?

DEBBIE RAICHE: Yes or any mental health issues, NA or AA meetings, any type of service that they need in order to provide accessibility. So we need to fight then for 2012, hopefully it will pass this time.

TIM FLYNN: Have you actually formulated legislation in the past and tried to get it through the legislature?

DEBBIE RAICHE: Yes.

TIM FLYNN: You have?

DEBBIE RAICHE: It was denied so we have to try again in 2012.

TIM FLYNN: Perhaps you would be interested in attending some of the Commission's legislation-committee meetings and work towards this. I'm familiar that substance abuse and disabilities -- substance abuse is more prevalent among folks with disabilities than they are among the general populous. Certainly it is swept under the rug in a lot of cases. So I think we need to bring it to the daylight and talk about it. I appreciate you bringing it up, all of you.

DEBBIE RAICHE: Thank you.

Developmental Disabilities Related Testimony

Page 22, Warwick Forum

NOELLE: I'm going to introduce my son, Joseph and then I'm going to come up and testify. Thank you. Thank you, distinguished panel members. I do not object to be recorded. I'm not a newcomer to this. I've given testimony before the Governor's Commission up in Lincoln and I'm familiar with the Rhode Island Disability Law Center. My son Joe is 39

years old. Joe is a client of Gateways to Change in Warwick. He has been for two years. There are many issues that I want to address today. On behalf of all of the citizens here. I want you to know that those of us who can be advocates for you, need to step forward at this time because there are so many things going on that are really detrimental. Human Services The budgets cut, I've been to the Generally Assembly in both chambers and have spoken to various legislators. I got a message that there was a bamboozling going on. It seems that at the 11th hour the budget cut that was presented seemed to reflect a \$4 million budget cut. All of you know that \$4 million is nothing to sneeze at. If it was divided up among all of the agencies in the state, it would not have had such an impact as really the \$24 million that actually was cut from the budget which has a tremendous impact on the services that our citizens, who have disabilities are receiving.

So, if you stop and think for a minute, if all of the people in the state of Rhode Island, I hope I get these facts right because I have a lot of figures in my head. If those people who make \$250,000 a year or more were to pay 1% more in income tax, they would not have to take a cent away from the programs that benefit our citizens here. That's amazing. People who make \$250,000 a year or more pay 1% more income tax and there would be no more budget cuts for the people who have disabilities. Instead of taking the money from the wealthiest, they are taking the money away from the citizens who are the most vulnerable, who cannot always speak for themselves, and who are dependent upon the services of the so many wonderful staff people who are here today with their clients who are not making a fortune, they are earning a moderate or below moderate wage to do some of the most important work that anyone can do in their lives. They are taking care of the people who need them desperately to be able to survive day to day. You need to think about that. Transportation We talked about the RIPTA situation, Joe just got his first RIPTA pass. He was so excited about it. He can go all over the state. If he want to go to Narragansett to go to the beach, he can do that. To visit his sister in Tiverton, he can do that. He's not driving any more. It was a great thing for him to be able to do that. If the funds are cut from RIPTA, he's not going to be able to do that and many of you who go to work or appointments or visit family and friends will not be able to do that.

You know today the director of the agency that works with Joe had to leave and you know why she had to leave? She had to go to check in to the billing situation because now she's expected to provide documentation for every 15 minutes of day services provided to Joe. All of the people who run other agencies are going to have to do the same thing. Now, if you think about it, imagine have to account for every 15 minutes of time that is provided for one client and you have to do that for every client you have and your budget has been cut drastically, what are you going to do? You need more staff, obviously in the billing department. You will not even able to keep the staff you have.

Human Services Also if any of the agencies cut services to their clients, given the budget they have now. If they cut services their licenses can be pulled. That is really scary. Now, we are going to have the same amount of clients, the same amount of staff, we are going to pay them less and we can't provide any less services for the clients, but if they do, their license to operate an agency is going to be pulled.

So those are some of the things that I would like you to keep in mind. I'm going to continue to be at the statehouse. When Joe got his letter of approval for services, I was called by Mr. Stenning's office and told he would not have those services rescinding his letter. They were barking up the wrong tree. I went to the Governor's Office every day and when the governor pulled up in his SUV, and I greeted him and I went to his office to greet him every day. I continued to do that and call the Governor's Office. And I said after a week it was time to go to channel 10 and 12. Then they said "we'll not rescind his services" you know what? Not everyone has an advocate. Many of the clients don't have somebody that will be that forceful. When Joe was 2 1/2 years old he started in school, special ed in 1973. People at 2 1/2 were not going to school. He was going to school because the superintendent was tired of listening to me. I'm going to ask everyone who has the ability to join me; I want to start a program where there are 3 or 4 people every morning that go down to the statehouse and just talk for these people who cannot speak for themselves. To try to keep services before this October cut comes through -- they want another \$13 million taken off these services then. We have to stop that. We have to let this country know that they need to start tapping the wealthy people and people who are able to do everything and anything they want with their lives because many others cannot. We cannot have their services taken away from them. I'm sure if I asked there would be more people that have disabilities that raise their hands, ask them, they vote. You vote, too. That's great. That's your right under the constitution to be able to vote.

I may not know much, but at least I vote for people to help me. You can ask someone to help with the ballot and explain the situation. They allow me to go into the voting booth. He tells me what he wants to vote for and who and that's what we do. That's your right. You should do it if you can and speak up if you need help. God bless you all and I hope we can win this battle and continue to fight it so everybody gets a fair shake. You are all citizens of the United States of America and you all deserve fair treatment, thank you.

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BILL WALASKA: I signed up but I don't know who is before me. So many are signed up. Senator Bill Walaska.

BILL WALASKA: I'm pleased you are all here and you know I understand and appreciate the trials and tribulations. You know. Human Services I've been somewhat active over the years. I have served on the board of the Trudeau Center. I'm not sure how many of you are associated with the Trudeau Center, but tonight there's a meeting. Family members will be there also it would be a good idea to go there because the cuts as you all know have been dramatic this year.

We tried to, I know I did and others did, we tried to keep as much of the dollars in the Human Services Budget as possible, unfortunately, there's some issues on the other side that the -- I don't want to point fingers, but on the house side they felt that's where the dollars are and we need to cut. It was cut dramatically. What we need to do is get the message to your senators and representatives and council people, also, mayors, we cannot take any further cuts. Next year it will be another very difficult budget. Another difficult budget. A big chunk of that budget is Human Services. That's what they will look at. You really need, you are here today and the place is packed. That's good. You need to stay active and be vocal. I know many of you were at the Statehouse this past session expressing your concerns, you need to continue doing that. Even more than that, you need to contact your individual legislator, you are a constituent, you are a voter, political people listen to the voters. They listen to the voters. You want to get re-elected, you need to get the votes to come up as a group that's great, but you need to contact the individual legislator and let them know your concerns. If possible, I'm sure that some of the agencies have done so, they need to get a meeting with the senate president, with the speaker, with the finance chairs both the senate and house in order to ensure that there are no further cuts. I sat on finance for a couple of years. I don't sit on finance any longer, however, I do have some friends on the committee and certainly they will do what they can do to -- I'm not sure if too much money will be restored. What we have to concern ourselves with again is no more gets cut. That's really all I have to say. I'm here more to listen to what your comments are. If someone has any questions while I'm here I'll be glad to answer them, if not, I'll be glad to listen to your remarks.

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MARY JARRETTE: Good evening, my name is Mary Jarrette. I have a daughter that goes to Gateways to Change. She's in a group home there. As the other young man said he had meningitis at the age of 9 months. My daughter also took sick at the age of 9 months. She could not walk or talk or any of these things. They said she would never walk or talk as long as she lived. If you hear someone hollering out there that's her. She's been walking and walking and walking, but she has broken both of her feet. I think it is because of the lack of calcium.

Human Services I cannot take her home because she needs to be in a wheelchair. Gateways to Change has really taken care of her in Smithfield. I love it, I love it, she loves it. She was there for two months when she first got there and I brought her home and all night she kept on waking up and saying, this is a child that never talked. She said I want to go to my house, "this is not my home" I looked at her and this is strange. This child has never talked. And I said "you are at your house" no, no, my house. "All through the night she kept on doing this. The next morning, I took her back to Gateways and I said "look you keep her she loves it here" she's been happy there. I do not know what would happen if they cut the funding for that group home or for the programs or anything, she's just a child who needs a lot of attention and she needs it. I cannot give it all to her. My house is too small for a wheelchair. I pray to God that they will not cut the fundings for the handicapped children. They need it and we need our sanity, they need theirs, thank you. (Applause).

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LYNDA ARMSTRONG: Hello, I'm a mom of a 28-year-old with significant developmental disability Human Services. I'm here today to agree with the first person that spoke. I want to support what she said. We really need to advocate. I think the state and the politicians' kind of count of people not being registered to vote, people with disabilities. I think it is very important that people register to vote and also advocate for their needs.

The other thing that I wanted to talk about was that we have to look at how services are funded. I think what is happening in this country and happening in this state. Other politicians are not saying that it is true. You cannot just cut your way out of this problem. We need to look at revenues. Looking at the people that are quite wealthy that can afford to pay a little bit more. I don't know how much support there was for governor Chaffee's 's taxes. If you can afford to have your hair done, you can pay for a tax. And spread it out and maybe we would not have had the cuts. If those taxes were supported. We need to look at how services have funded. There's only so much money and we need to look at increasing that money in order to be able to have services, thank you. (Applause).

LORNA RICCI: I have only one person left who has signed up, if you wish to say something, but the room is a little bit tight and you may not be able to get over to where Leslie is seated. If you want her to come to you to sign you up, we could do that. It is a little tight over here. Does anyone wish to say something and have Leslie sign you up? Okay. Arthur Seal is next.

ARTHUR SEAL: Human Services Hi. I live in a group home, with my housemate. And I feel that it is wrong that the state is taking away my money without that, I won't be able to go to the movies, and out to eat. So, that's very important to me that I don't lose my money. And I don't want that to happen, thank you. (Applause).

LORNA RICCI: Thank you. Ted Siaviani.

TED SIAVIANI: Good afternoon, everybody. Human Services I'm the parent of a 49-year-old daughter, severely impaired with developmental disabilities. I've been very active supporting people with disabilities way back from early 1968, I've been president of the local RI ARC in my community and president of the State RI ARC twice. It seems to me that in the early days, I call them the early days we seem to have been more effective and advocating for the people that we represent. It seems to me today particularly, with these budget cuts, I think that people are enthralled with numbers only. I think there's an attitude here where there's a larger amount of money being spent in a certain area. This is where you have to cut. I think we have to change an attitude here in a country as wealthy as ours. And we have people in Washington, in gridlock who cannot even agree to manage a budget, but yet are willing to cut, Medicare and Medicaid, the

funding sources that support our people. There's something wrong with the way we may be advocating. We go to the statehouse year after year after year. We talk to our legislators, and the cuts remain. The cuts are deep. And the cuts are impending. They are coming more and more. Yet I heard a lady this afternoon, say that if 1% were increased on the wealthy of this country, we could pay off all of the cuts that are imposed on us. What is wrong with this country? Somehow we have to change an attitude. It is not only dollars and cents, it is for people who cannot help themselves in a nation where the wealthy don't pay the taxes. This is absurd. It seems to me that we have to have a way that we can convince our legislators, to actually go back to the sources in Washington, we used to have an ARC that was so good at advocating in Washington for people with developmental disabilities, it seems to me in this day and age it is ashamed that we don't have this source of advocacy any more.

I think it is up to the youth, I'm 81 years old. I'm advocating since 1968 we've done great things through the ARC agencies that the local ARC agencies that were involved in those early days. It seems we have to reactivate that kind of attitude and change the attitude from where there's a large amount of money being spent in the budget that this is where you cut without giving a thought to who is being supported with that money and where is that money coming from? And why are people that are wealthy -- escape taxes where they can just use a little punch of that money -- money that we need and stop these ridiculous cuts.

LORNA RICCI: Thank you.

NOELLE SIRAVO: I wanted to address, if I may, something about advocacy. I'm Noelle Siravo. I'm glad that you brought that up about the advocacy. There's a way that we can enlighten these people, the politicians, once again. Human Services As a matter of fact, I work at Women and Infants Hospital in the NICU. I'm sure that plenty of the babies in the NICU will be in this room in another few years. Many of them have developmental disabilities. I'm a member of 1199. The union that represents health care workers. Our union has taken it upon themselves as advocates with people with special needs to invite legislators to come with us to come to the homes that are being serviced through these funds. As you said they are looking at dollar signs and a lump sum of money and that will go to this group and go to the people with disabilities, but unless they are the parent of a child with a disability, or the sibling or the grandparent or the caregiver or the person who manages the agency, they have no idea what it is like to live in that situation. So therefore we've invited them on a state level to come to some of the homes and see for themselves, exactly where this money is going and what it is funding. The next step would be invite the people from Washington. The legislators from Rhode Island in Washington. Shame on them if they refuse the invitation. I don't intend to let that happen without putting up a good fight. In that way, I think it is one thing to talk about where the money is going, but it is another thing to see where the money is going. That may be the beginning of a different kind of advocacy program for these citizens, thank you.

LORNA RICCI: Thank you. Anyone else? Anyone else signed up? Would anyone else like to come up and speak in you just need to give me your name for the record.

REBECCA: I'm Rebecca and I live with three of my friends, I've been living on my own. (Applause).

LORNA RICCI: Thank you. Anyone else.

KATHLEEN: I'm sorry I'm back again. I'm Kathleen, I feel clueless like on how much on Medicare and Medicaid and how much are they taking it out on staff money and on ours and bus rides. What about the poor handicapped people that can't see, speak, nor move at all? I feel that they are hit the most and they are attacking handicapped people with money, but feel that they need to take more, out of us. I wish they stop cutting the money and the help -- the staff. We the people should wake up and be positive on us and all of us. Thank you. (Applause).

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LYNDA ARMSTRONG: I am a Lynda Armstrong. Okay, one thing I had not said before that I've thought about a lot is that I know the legislature this year talked about other states being able to provide services for a lot less money and I think that they don't know what those services in other states look like. I think we need to speak up and tell people in the legislature, you know what a service is doing for people in the state. Let them be aware of what will happen if the cuts are made so that they don't have this blanket idea that they can do it cheaper in other states so we can do it cheaper here. What does that mean for quality of life for people? We don't want to be warehousing people. We want people to have a life. We did that years ago. We don't want to go back there. (Applause).

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ATTENDEE: Bob Anderson I'm speaking for West Bay. I have a 31-year-old son, started at Meeting Street School he's come to West Bay for the last 14 years, for the last two years, I've been working at West Bay I'm getting older, my son is getting older, so I lost my job like everybody else in this state. Everything going to China. Nothing that our government has done for us. On behalf of my son, I came to West Bay to work because pretty soon he will be older and I may not be able to take care of him at home. He goes to the day program, he lives with me at night and on the weekend. I wanted to see what a group home was like. Obviously, Human Services the pay that these people work for is minimal. Most of the people a lot of them work second jobs to pay their bills, but they are willing to take this job because they love the people at work. They have a heart. I wanted to see this firsthand so when I started working there from the office people on down, people that go there they change, they pick people up, they feed people and medicate them, everything for these people. You would not believe what they get paid. I know I'm there. In the meantime, now, you want to cut and cut and cut. Are we going to go back to the way it used to be when it was Ladd School when there were 40 people on a floor. These

people live in homes that's the big thing. We are calling them homes because they are four and five people. Now, you've heard people say "they don't have family, where do they go? Where do they go? I have a 20-year-old daughter who says to me "my brother is never going to live in a group home because they keep on making cuts" is she going to give up her life to take care of my son even though it is her brother? It is not fair. I'm saying, where do we stop? Where does it end? When a foreign country has a disaster our government thinks nothing of sending billions and billions of dollars to foreign countries, why not start at home, take care of our people in need, our handicapped and our elderly. We have not discussed elderly but we are a third world country when it comes to taking care of our disabled. That's all I have to say. (applause).

LORNA RICCI: Anyone else that would like to come forward. This is wonderful, anyone else that would like to add something? What is your name?

RACHEL SAVISTONO: Rachel Savistono. I live in a house with my housemates and I feel bad for the one that has no family, like I do. I don't want no more budget cuts, sorry. (Applause).

LORNA RICCI: I think that's the word for the day from Rachel. No budget cuts. Sorry.

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DEB O'DONNELL-LEE: Human Services I'm a foster participate and we just received a young lady who turned 18 in a group home and she has mental disabilities. And the thing is they changed the policy now that these kids can only stay there three months. And that they're losing the care that they need. That they're getting. You know, the instruction that they get in these group homes, the child we got, she was there for about a year and-a-half. But then they went and changed. So she had to get out of there. Cut and dry, get out. So they contacted us and said would you please take her? And so, I mean, she still has issues and stuff that we're trying to get you know, help with, but the thing is, now all these other kids that are sitting there, you're not going to get any help in just three months and to cut it down to three months isn't fair to these children.

LEO CANUEL: Can I just ask, your name, please.

DEB O'DONNELL-LEE: Deb O'Donnell-Lee.

ROGER HARRIS: And the name of the group home?

DEB O'DONNELL-LEE: This was Lincoln house.

JUDITH DREW: Do you know which organization this was part of?

DEB O'DONNELL-LEE: No, she was part of DCYF. A lot of the kids in there are from DCYF but family service took her on. I'm a member of family service foster parenting therapeutic care. And it's kind of like we're there all the time. So if she needs anything, we try to get it for her. But the thing is, like I said it's that three months now that these kids are really going to lose. They're not going to get the services that they really need to progress to move on into a regular home.

JAMES DEALY: I think first off, that Lincoln house I think is for adolescents with sort of behavior problems?

DEB O'DONNELL-LEE: Yes.

JAMES DEALY: I don't know what is the three-month policy you're talking about? Can you explain a little bit.

DEB O'DONNELL-LEE: They changed it. Kids used to be able to stay there and get all the counseling they needed.

JUDITH DREW: At Lincoln house?

DEB O'DONNELL-LEE: I understand it's at almost all of these group homes now. So, any child that comes into this with problems, once they do their three-month thing, they have to get out of that one. And if they can't find a placement, they go to another group home and then another group home and they keep getting moved around. These kids suffer so much because of education and everything. You know? They never get a good education because they're floating from home to home to home. And three months is not enough time to have these kids get settled and really learn something.

JUDITH DREW: So are you saying that you think the rules have changed and the policies have changed somehow so that these kids who need therapeutic foster care placement.

DEB O'DONNELL-LEE: That is an organization I belong with.

JUDITH DREW: Okay, but these other programs you're saying there was a time when kids could stay there until it was felt they were ready to move into a normal quote-unquote normal foster home placement.

DEB O'DONNELL-LEE: Right.

JUDITH DREW: And now the rules have changed they can't do that and they have a maximum stay of three months.

DEB O'DONNELL-LEE: Exactly.

JUDITH DREW: As a result they moved out of there and moved into another type of foster placement.

DEB O'DONNELL-LEE: They're moved into another group home if they can't find foster placement.

JUDITH DREW: Does this have anything to do with the fact that they're turning 18.

DEB O'DONNELL-LEE: No, once they're there three months they have to move out and get another placement and most of the time it ends up another group home and another one and another one.

JUDITH DREW: You're stumping me because I've not heard about this.

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DIANE ROSS: Human Services The PAL meetings going on they're going on throughout the state, I think that all of us should be going to those to find out more about this evaluation system and how long it's going to take and who the people are. Because I didn't get that answer when I went, and it was something I was trying to find out. You know, they're still in the process of it. And the training so, they didn't give us much information.

DIANE ROSS: Hi, I'm Diane Ross I work for PAL and I know that yesterday, and that was the second one, there had been a forum on how to write a new plan because all the new regs came out and people are so concerned that these regulations that govern people with disabilities and the providers that they work with are so involved that no one is going to understand them. Before Dawn leaves, I wanted to also mention that Kevin was the only person with a developmental disability on the COBRA Waiver Task Force.

AUDIENCE MEMBER: Can you repeat that.

DIANE ROSS: This is Kevin he was the only person on the Global Waiver Task Force with developmental disabilities.

KEVIN: Human Services They wouldn't take that into account at all. The meetings were so unbelievably confusing people left. The first couple of meetings I went to, I had someone who said I have a PhD and I don't know what happened in that room. It was like it was so bad.

DAWN WARDYGA: I couldn't agree with you more. It's been such a dysfunctional process.

KEVIN: There was nobody taking me into account even though I was in the room. People with PhDs couldn't understand what was going on. How can someone with a cognitive disability even know what's happening. I'm pretty high functioning, and I had no clue.

DIANE ROSS: So when you said adults with developmental disabilities were not represented in the room it's because the people they asked to be in the room were not recognized and left out. And it's too bad.

DAWN WARDYGA: I would just respond by saying that it's been my and I've been involved in this from the get-go and I stay involved as painful as it is, but I can honestly tell you that the same principle applies across the board. It doesn't matter if you're a PhD or a person with a cognitive disability or you're somewhere in the middle. They're not listening to anybody is what it comes down to. So yes, it's been frustrating but again in order to be sure, you know, I show up, like that bad penny that just won't go away, and to make sure they know we're watching out for kids and watching out for families and there are some advocates in the room that advocate for adults with developmental disabilities. But having the population in the room to me, as long as they're supported and I'll be honest with you, I'll be the one nudging him saying open your mouth.

DIANE ROSS: Even that part was daunting because there were two of us with Kevin. Kevin and I work for Advocates In Action. We represent people all over Rhode Island but it was so painful.

KEVIN: It blew my mind. It was the most painful meeting I've been to.

DAWN WARDYGA: You have friends I'm with you.

ROGER HARRIS: What does PAL stand for.

DIANE ROSS: Parents and Advocates for Alternate Living. But the acronym is PAL.

FAYE MELLO: Human Services Did you talk about the 15-minute increment they have to do with the new law. Did they talk about it today?

LEO CANUEL: Can you identify yourself for the record?

FAYE MELLO: I'm Faye Mello. I wanted to know if you believe in that they have to do the 15 minute increment, mark down if they're late or in a workshop. You know with that new law they're going to be doing. Did they talk about it while I was gone?

JUDITH DREW: No, no one has brought it up.

DIANE ROSS: It's implemented.

FAYE MELLO: Do you think it's right? Can you stop it being done?

JUDITH DREW: No, you can stop doing it and you won't get funded. It's a managed care model. They're being required.

FAYE MELLO: But it's more paperwork than taking care of our clients.

JUDITH DREW: I don't disagree.

FAYE MELLO: There's no way to stop that?

JUDITH DREW: No it's been passed. It has to happen. If these organizations or providers want to get funding they will now have to identify what they do in 15-minute increments.

FAYE MELLO: Is it 7 categories they're going to put the clients in?

JUDITH DREW: I don't know about that part.

FAYE MELLO: heard about instead of four it's going to be 7.

JUDITH DREW: I don't know.

DIANE KRINER: I signed in as not sure, as an agency rep. I would like to speak as a parent. My name is Dianne Kriner. Right now my family is running on a Plan A and a Plan B. My daughter is 20 years old and she will turn 21 in April. Human Services We have an application in process with a new system in place. I have to go on record as saying that the Department of Developmental Disabilities have been so kind every time I call and inquire about the application. I guess my concern is, moving through this system, it could come down to the wire. We could go until her birthday and it hit me like a brick wall. I was talking to the service providers they reminded me on April 7th services will stop. It took my breath away. We have a window of time. My husband and I started talking about plan B with the budget cuts that's a very real situation. I'm wondering if I'm leaving a system that is full of mandates and timelines and regulations and into a whole new world, but it does not leave much time if you are not deemed eligible to appeal. I'm wondering if there would be a timeline put in place that would give the person the opportunity to not lose the program and support staff that they've had for six or seven years to appeal the decision if they are not deemed eligible. Services stop at 21. I guess I'm wondering as we navigate the system together as a family. We navigate with lots of other families, I thought is there a way? I know it is a long process and we are going through a lot of changes. I went to the support intensity forum. Again I have to say that the Department has been filled with empathy when I call, but that was just my thought, perhaps there could be a better way that would allow the youth that is going through this process the time to appeal and not lose services.

ATTENDEE: May I ask you a few questions and maybe help some folks that may not be familiar. What you are talking about if I'm not incorrect, somebody who has been in transition. They have the support of the school system and special education, IEP, perhaps ORS services and now, we are looking at for that 18-21-year-old range. Now, we are looking at the 21st birthday. The developmental disability eligible and if there's a timeline of application to in other words, that determination has to be made within X amount of time. Once there is the determination eligibility, the timeline to develop an ISP an Individual Service Plan. The funding of that plan are you putting that into consideration?

ATTENDEE: That's my panic button all of that time in between. For us, say we were looking at self-directed supports. That's a natural flow for a youth that has been accessing for home-based therapeutic services and the application was put in a while ago, with the system change there was a whole application process with the school, I guess the flag would be before they turn 21 would there be a way to set a time, I don't know what the appeal would take, three months would that give them an opportunity before their birthday. Going up to the 21st birthday and losing all services and go through the appeal process. That may or may not happen, but it is a weighing concern within our family. I wanted to share that with you. Navigating this process has been an eye-opening experience. The process changed on July 1st. So it is significantly different and under the -- I'm not a Commissioner at the moment but under the pretense of transparency we have created a system that is more bureaucratic and requires more signatures and jumping through more hoops than ever. I would suggest that we are working on eligibility now and there should be in theory a response that says as of a birthday for 21, yes she's eligible for services, but the system has gotten more complex. For those of house run agencies and provide services, trying to figure out what we are doing is crazy. We just -- I know there's another provider in the room. We spend hours at meetings figuring out what they are paying for and what they are not. There have been statements made no changes in services to folks, when you cut somebody's budget by \$40,000 it is hard to provide the same level of services. It is a trying time right now. It is not too soon to start whatever process.

ATTENDEE: We are in process that's what I've been told. I don't know if I answered your question.

ATTENDEE: If there is a determination of disability, found eligible for services, so, by the time of application, determination of eligibility, so you may have someone that is 21, achieved their 21st birthday and achieved eligibility. So the timeline at that point -- then there's also part of the process after that which is the developmental of the plan as well as the approval of that plan. The funding of that plan, I'm not sure. I'm not a provider. That's partly why I'm asking you what your experience may have been. The authorization so that the provider gets paid by the Commission. They are all steps.

DIANE KRINER: It would be perfect if it happened before the 21st birthday and you could keep the staff you had. This is uncharted territory for my family. Our plan B is to do whatever we could to keep the support staff she has. That would probably mean selling our house and I would have to leave my job and we would have to sell our house in order to do that to make sure she had what she needs.

ATTENDEE: You mentioned the SIS. What exactly is that?

ATTENDEE: The new evaluation tool that the Department will be using for evaluating. July 1st was the implementation.

ATTENDEE: It will determine not funding, we don't call it that any more "resource allocation" it is in terms of units in service.

ATTENDEE: What I do like about the new tool and I'm appreciative of it, they reinitiated the face-to-face interview. For our youth that tend to look good on paper, it is not until you sit down and have a conversation with them and that's the ah-hah moment where they see they may need that support. I did not hear a lot of talk about youth and I agree working together. Because our youth get older. Thanks for listening, I don't know if we could ever create a timeline. I think what I'm hearing at least is the suggestion that there has to be some sort of time frame or deadline in which to make the decision and I would assume.

ATTENDEE: That question was asked yesterday at a training. What was the timeline of responding to a denial of a plan? How long would it take for an approval of a plan? They have not figured that out. It is disconcerting, yesterday was the 25th or 26th that we don't have some of that figured out. Particularly for folks coming into the system and don't have supports in place to have not an answer to that, it is a problem. So, I don't think there are not well-defined timelines yet.

ATTENDEE: Is that something that should be in the regulations? The new regulations?

ATTENDEE: The Department is really the entity at this point. There's nothing in the regulations that goes into effect August 3rd that includes any timelines for the Department to respond to anything. That's a problem.

CARRIE MIRANDA: I just wanted to make a comment as a provider I'm from Looking Upwards. I think this -- in the past, as much anxiety families have had of their child transition Human Services. We've taken the leap together and landed with supports in tack. Sometimes the providers would go for it and would have assurances with a phone call. From July 1st the system did a big tank in terms of everything is in transition. Everything is up for grabs and nobody seems to really be talking to each other in a clear manner that helps us understand what that looks like. I have -- I know in our organization we've had conversations with families that children are turning 21 in August. There's no answer from the Department, the division who authorizes the funding. The answer and the solution lies in the Division of Disabilities and the Department's hands. It does not rely in the hands of the families and folks providing the services. Your suggestion is a good one. If there was a timeline that was more clear, then everybody would be able to be working on the same page. I'm Carrie Miranda from Looking Upwards. As the providers, I'll speak for myself. I'm aware of a memo sent out by the director that essentially indicated that they had been planning and trying to deal with the reductions or as they said savings proposed in the Governor's budget and handed a limit as to what the assembly's budget was implemented. My understanding is "please bear with us while we sort this out."

ATTENDEE: Okay, in that process, are there specific individuals or group of individuals whose birthdays or new eligibility is coming up prior to the end of this year? I assume.

ATTENDEE: Yeah, people are turning 21 every day. Eligibility is a question for families. I'm not joking. Some of these people are they without services?

ATTENDEE: I don't think we can answer that. We do know that the Department has a priority list for services that grows longer and longer every day. And why it grows longer I'm not totally sure.

Page 88, Kingston Forum

ROBERT ROMERO: My name is Robert Romero. My stepson had a traumatic brain injury before his fifth birthday. My wife has been working diligently and hard to get services for him since then.

From the consumer's perspective of getting help there are too many different agencies Human Services. Too many different entities to deal with. It seems inefficient and it is frustrating. It would be nice if it could be more streamlined. With the current economy and the fight for funding, I hope the public can become more educated that a little money to help families, keeps people working. If we cut enough, people will not be able to go to work because they will be caring for loved ones, that does not help the situation for society at large. And finally, I throw out a question that I don't know the answer to: How do we make a society that truly wants to care for the most vulnerable in society and not a society that is selfish and composed of self-serving people?

TIM FLYNN: Hi. I really want to thank you for raising this issue. Let me ask you a question, could you give us an example of sort of the many agencies to deal with. Just give me a, for instance.

ROBERT ROMERO: Okay. For Myles she was getting HBTS, I think it is called through OSCAR an agency that has an office in this building. About three years ago, she went from being directly dealing with OSCAR to having to go through another organization called CEDRR. There's another level of people to fill out forms for and talk with. He did not get more service, it was another step to have to go through. Myles is about to finish his high school. He's going to turn 21 next year. I don't know all of the agencies because Julie does most of the work. Julie is my wife, Myles' mom. The Department of Developmental Disabilities that we have to deal with, the Office of Rehabilitative Services is offering things and that's another office that you have to deal with. Then there's Social Security to deal with then there's, in Myles' case, Medicaid and Medicaid is dispensed through United Health and doctors and therapists have to submit applications to United Health to get appliances, to get equipment, to get tests, to get therapies and there are more. It is an awful lot of work. How come there has to be so much bureaucracy? How come it cannot be a more streamlined process. This may threaten peoples' jobs and it is not my point. But someone who is clearly in need of assistance, if you meet Myles he cannot stand up on his own, sometimes he has seizures, he has speech issues, he is a sweet, wonderful person, he does not have behavior issues, but it is clear he cannot be alone. More steps. It seems, from the consumers' point of view, it is frustrating to have to work so hard to get some help.

TIM FLYNN: Thank you.

TIM FLYNN: I can understand the frustration, certainly. Thank you.

LAURA JONES: There has been efforts made to help families and consumers, coordinate care better in our state and CEDRRS their role in the children's system is to help coordinate those services along with pediatricians who are suppose to be providing families with what they call a medical home. Where everything is coordinated out of their primary care office with the help of the CEDRR centers. That was the intention of CEDRRS and I think also it is really important for people to know that is part of the role of their primary care doctor and to ask that of them. So I'm just putting that out there. I'm not minimizing what you are saying about that. It does make it complicated and difficult and you made the statement about peoples' jobs and that kind of a thing, but really it is about the person who is being served. You know, if it does not work for the people being served, then it is not working. I appreciate you coming out and expressing that. It is really important.

ANNIE OLEAN: I'm Annie Olean.

I don't have anything prepared, so I just wanted to share with you some of the concerns that I have and I had asked

you what year we were talking about? We are talking about planning for next year, I'm more focused on the here and now. Maybe I misunderstood the intent of this forum. I have to talk about what is here and now. Human Services I'm here as a sibling, my brother is 53 years old with a developmental disability. My other brother is here who is his advocate and guardian as well. My concern of the here and now of the cut that has come down to the Development of -- -- Developmental Disabilities it was enacted 12% of the immediate cut -- it was placed upon the division of the residential and day program agency providers. I just want to kind of talk about what that cut does and how it is manifested in the everyday life of an individual. My brother lives in a home, 24-hour support with living arrangements with three other individuals with developmental disabilities. He also attends a day program.

With the cut in the funding that happens almost immediately, what that has happened is that he will be receiving two hours less a day of the state program services. The day program has to cut back on what the services that they can provide. The residential program and the agency that is providing services by is Bridges and it is a wonderful organization. I'm speaking very highly of them.

What is happening is Ladd Center closed, I do not have the exact dates. We started deinstitutionalization in the late 80s and everybody was living in community-based programs and the Ladd Center was completely empty by 1992 or everybody had the opportunity to live in a community-based program. My concern is with the cut that has been enacted and will continue to be enacted in the future. What we have done is have closed Ladd Center and merely now because of the restrictions in the funding, we are creating mini Ladd Centers. By that I mean when you cut the funding, you cut the staffing, when you cut the staffing hours, you cut the opportunity for individuals to access the community. Transportation Therefore, transportation, they won't be able to go in the vans and access -- especially in a rural community we don't have RIPTA or public transportation at a particular hour that maybe they were able to access their community after 6:30 p.m. or 7:00 p.m. in the evening. Human Services They will not be able to do that because the staffing patterns will be different or they will not have the gas in order to access their community. I'm finding that on the basic human rights of individuals with developmental disability they do have the right to respect and dignity in a safe and supportive environment. I don't believe we can continue to provide that and access to our communities, if we are going to continue to cut the budget. 12% is a significant amount of dollars to cut an agency to provide any types of services.

I think that the year 2011 and 2012 is important, but I'm much more concerned about August 6th, 7th and 4th and going forward. These cuts are in effect today. Therefore, I feel that my brother and many other people with developmental disabilities, who are living at home or receiving supports of a group home, are going to be denied access to your community.

You had mentioned of living a life where they are truly integrated to their fullest potential. I believe that the cuts that the legislature has done are denying them that opportunity now, not next year. Thank you. (Applause).

LAURA JONES: Thank you so much. Do any of our panelist want to speak to that?

TIM FLYNN: It may or may not be too soon to ask this question. Have you -- have you remarked--

ANNIE OLEAN: What is your question?

TIM FLYNN: I see.

ANNIE OLEAN: Because the cuts are happening and will be occurring I can tell you that we spend many hours with our brother on Sunday, but because the staff pattern will be changing we'll spend 9:00 a.m. in the morning until 7:00 p.m. at night with our brother in order to support him and access the community and spend time with us. Community activities will be affected because there will only be one staff person on 7:00 p.m. on in the evening. Based upon the diagnostic profiles who live in the home we need two staff on. So, yeah it will impact. Again the agency that we are involved with is outstanding and wonderful. This is not critical of the agency that administers the program. This is the restriction of the hours. What happens is that it is easier to monitor individuals when they are in a closed environment, we all know that, but that does not mean that is quality of life for people, how would any of us would like to be home by 7:00 p.m. at night. To know that we cannot access the community until the next morning when we have more coverage. Because if we want to access the community we have to make sure that all four of us want to go to the same place at the same time the same way. That's denying people making their own choices. The services will be affected starting in August.

LAURA JONES: Thank you, very much. We are opening it up to the floor if anybody would like to speak.

MATTHEW TIBERIO: Annie, in response to your question, I know you asked me about the timing and the sheets up here for our priorities next year, and I encourage you all to get one of these forms and fill them out. We are currently dealing with the issues related to those cuts. It is not that we are only here to hear out things for the future. That's just the purpose of the forum over here to fill out. We are currently dealing with these issues now. It is not that we don't do anything new.

ANNIE OLEAN: I would like to talk to you afterwards as to what the Rhode Island Disability Law Center is doing about those cuts.

MATTHEW TIBERIO: Okay.

LAURA JONES: Yes.

JANET NOKE: My name is Janet Noke. I'm in a similar situation where I am one of the guardians for my niece. Human Services We also take her out into the community. However there are others within the home who have no one else visiting, therefore their only way to get out is for staff people to take them.

So there's more than just our issue, there's also the issue of those who have no family members to help take them out and do things, fun things and community-active things with them. This is the second 12% cut that we are asked to take.

LAURA JONES: Thank you. There's a gentleman in the back there.

CASEY GARTLAND: I'm Casey Gartland. Human Services I want to echo what she just said. That would be one of my concerns. The second that compounds what she and with this woman said was the change in regulations. The current regulations that are proposed by the Behavioral Health and Hospitals would reduce the budget, but requires an inordinate amount of administrative paperwork for billing. If you take a day program is that modestly funded and take a percentage that they have for staff and administrative needs and have to record in 15 minute increments what type of service they have, whether or not they are in a community or at the center. It compounds and lessens the choices because it is requiring more administrative paperwork to achieve an end. The standard billing was achieving that purpose. Not only the reduction of money that is concerning but a change in regulations which makes it harder for the consumers to access more of their contract, doing administrative functions, and again, day programs specifically are modestly funded, even less so now.

LAURA JONES: Thank you.

TIM FLYNN: Can I ask a question?

LAURA JONES: Please.

TIM FLYNN: This funding has been on the horizon for a long time leading up to this legislative session, I'm sure you are really active. If you could describe what efforts you made leading up to the budget debate and the final decision. Did you talk to your legislators? Did you write letters? What happened?

CASEY GARTLAND: Yes to all. Many of the agencies and the families we had quite a significant e-mail letter writing and phone call campaign leading up to it, several, because there's been a series of reductions not just one. It does not seem to have made much of a difference. A few of my family members said, we are adopting what your own Department wants. That was concerning. That was some of the response. We had significant contact with our legislators and with people having to do with the budget.

They said that the Department of Behavioral Development and Disabilities and Hospitals wanted that.

ATTENDEE: A couple of legislators responded that we are adopting the budget that your own department has recommended.

ATTENDEE: Sounds like a politician.

LAURA JONES: Do we have any other comments from the panel, thank you very much.

JOAN GARDINER: Someone just came in. Joan Gardiner I'm with the Brain Injury Association. Sharon asked me to come down. She told me 3:30 p.m. to 5:30 p.m.

LAURA JONES: Come join us.

JOAN GARDINER: You are all sitting, I'm all set.

LAURA JONES: I just want to introduce Joan Gardiner from the Brain Injury Association of Rhode Island. She's also a panelist. If you could say what the Brain Injury Association does.

JOAN GARDINER: They have a resource center in Cranston that provide -- we have a library that provides materials for persons who are interested in brain injuries, traumatic brain injuries or minor brain injuries, whether there are people with them or family members of somebody that has one or medical people that are trying to learn more about them or even students. Then we advocate for persons with brain injuries to make sure that they get help in whatever they may need. That's about it.

Page 100, Providence Forum

HEIDI SHOWSDED: Couple of things I want to say, I'm Heidi Showsded, and typically I serve on about 8 subcommittees, on a handful of boards across the state. Today I'm collecting information for them, but I'm speaking for myself. And I have two major issues that I really want to work on. Human Services The first one being is that people with disabilities have enough things in their life that they need help with. And they have enough constraints put on them with, you know, what they can and can't do, the amount of money they're able to make without being penalized and as a person that uses personal choice services, I really think that it's important that when it comes to your personal care, you're able to do them how you see fit. That's the one level of, one of the major levels of control that you have in your life. I really don't want to see any cuts happen to the personal choice program, either hourly or financially. I also do not want to see any cuts happening to my friends that use DD services. Human Services It becomes a quality of life issue. And it becomes a sustainable life issue. If you're wondering, you know, if you're going to be able to keep people because the funding is low enough to begin with or if you're going to be able to do the things that you need to do day-to-day to live your life, it's really an uncomfortable emotional situation to put people in. And I think we need to work on improving service options and service availability and service hours for people with disabilities, as opposed to all the cuts that have been made.

Page 116, Written, Faxed and Emailed Testimony

July 27, 2011

Governor's Commission on Disabilities

John O. Pastore Center

41 Cherry Dale Court

Cranston, RI 02920-3049

To Whom It May Concern

I attended a meeting of the Governor's Commission on Disabilities on July 26 at the Warwick Public Library. I didn't know what to expect because I have never been to one before. I'm sure that you will remember me because I was the one that cried the whole time I was speaking. I was hoping that someone would hear what I was saying and point me in the right direction as to how I can beat this. I am running out of time here. I am going to write everything that has happened since 2004.

My son, Robert (Bobby) is a 21 year old who has Muscular Dystrophy. Human Services He is the best thing that has happened to my family. He is an angel on earth and he deserves only the best. He doesn't complain, much. He has such a bright outlook on life, or should I say, had such a bright outlook on life. He thinks nothing bad about anyone or anything. He takes life as it is and he is a very happy young man. What the state has done to my family is a disgrace. They are messing with his quality of life. In 2004, I was working for an agency and getting paid to care for my son. I was giving him the best care that he deserved.. He did not ask for this horrible disease to inflict him, but he has taught me more than anyone will ever know. I was working outside of the home at a nursing home and getting 35 hours a week with the agency. He was admitted to the hospital with respiratory distress and pneumonia. I had asked a social worker how I could get more hours due to his change in respiratory status. He was going from overnight on bipap to 24 hours a day.

In August, I received a letter from the Department of Human Services stating that I was not allowed to get paid to take care of my son. Also, how I could appeal his rights. I sent an appeal letter and received a letter from them stating when and where the hearing was. My hearing was on Monday October 31st. I received a call from my supervisor (Betty Blanchette) the week before the hearing was to take place telling me that I had been reinstated. I called Anne Roach and she confirmed that I had been reinstated and was allowed 56 hours a week. I also received a letter stating the same. I have been getting paid to take care of my son since October/2005. I have a fax from the Department of Human Service authorizing Coventry Home Care for 242 hours per month. Anne Roach knew that I was going to be the one caring for him. In December, 2010 Gerry Fox asked me what agencies were in my home and I told her Coventry Home Care. She said that they were not listed, and I told her that I have been doing it since 2005. Coventry Home Care was listed because I have the fax. The Department of Human services authorized me to continue from *12120/2010-3/5/2011*.

Gerry called me to set up a meeting for Feb. 24 or March 3rd. I told her March 3^d. She asked if I was bringing any legal help with me. I said, Do I need to and she said no, we just want everyone to get everything out on the table. I told her that my husband would be coming because he gets out of work early on Thursday's. Gerry called me on the 1st to tell me the meeting was on the 2nd, not the 3rd

On March 2nd, I went and met with Tom Martin, Gerry Fox, and another state worker. I showed them all of the paperwork from 2005, but because I do not have the letter reinstating me, it never happened. Tom Martin said that it was against regulations to allow a parent to get paid to care for their own child. I asked him to show me this in writing, but they couldn't. I also asked for a denial letter and Tom said what denial letter.

I said the same one that I received in 2004. I still have not received a denial letter so that I could appeal my case and it has been 4 months. I told them that the authorization was going to be up on the 5th, what was going to happen? Tom Martin said that he was not changing anything yet. This was my income, there is no way for me to go to work because they can't find me a full time nurse that is dependable, consistent, and some of them have no clue.

I have been taking care of Bobby through everything. We have a happy, healthy family considering his disease. For 6 years, I have been his main caregiver. The agencies can't even give me the nursing hours that I have requested for the past 6 years. I can't work outside of the home because I have not yet found an agency that has consistent and dependable nurses. I was working in 2004 outside of the home, but lost my job because the state could not find a nurse for me to continue to work. I would have pursued a different career 6 years ago, but I was allowed to do this.

I have called the town rep who referred me to Pat Serpa's office. I was speaking to Louis with the Speaker of the house office. He spoke to Craig Stennings who told him it was against the law for me to be getting paid to take care of my own child. I have called the Disability Law center who came to my home and had Bobby sign releases to all of the agencies and never sent them because she didn't think she would get any information. I thought that that was the reason for sending the releases. She cannot help me because this issue is not a priority in her office. I'm sorry to say that this is a priority for my family.

We have chosen to keep Bobby at home in order to give him the best life that he deserves. I have spoken to Brenda Pacheco with Senator Jack Reed's office and Craig Stenning wrote an e-mail to Brenda stating that DHS could come after the agency to recoup the funds.

Bobby applied for the Personal Choice Program and was approved for \$5600.00 a month. Gerry Fox told Barbara Sullivan from Pari, that DHS would deny him this program. She said because of the waiver that he is under he would not be able to go to RHD and be on the Personal Choice Program.

On July 27 2011, I received an e-mail from Barbara Petrarca at BHDDH, signed by Tom Martin. The letter states that he has been approved for nursing services through BHDDH nurses. I have one nurse that comes on Thursday evenings and every other Saturday. I have given the hours to them and when the start coming, they think that they can modify their hours to suit them. Beth from BHDDH called me last week to let me know about a nurse that could come Monday and Tuesday 5-8:30 pm. Beth called me back to ask if the nurse could do more than 3 1/2 hours and I explained why that was all

I needed. She decided not to come. I told Beth that Monday, Tuesday, Wednesday, Friday, every other Saturday and Sunday's were available. If I was not interested in anyone coming in the home other than me, why would I tell them that every day is available if I didn't want anyone else. It is not about what I want, it is about what Bobby wants.

Sincerely yours,

Beth Dennis
CNA

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Zackchange 8/4/2011 10:07 PM

Dear Sir or Madam; I am the single parent mom of a 16 yr old w/ CP who uses a w/c, and is severely affected by the CP. Human Services I also have a 12 yr old daughter who has MR, ADHD, and learning issues. I tried to come in person, but couldn't juggle work and where the forums were being held. My biggest concern has been the equipment I have gotten in the past few months. My son got a w/c that started falling apart 2 wks after getting it!! (No, I am really not kidding.) My ex husband had to hammer wooden blocks onto it to get the lateral supports to stay put. My son couldn't sit right in it because the cushion/seating was so poorly made. There is no protocol to follow to return something for poor quality, but there needs to be a way to hold these companies accountable. This one went out of business a month after we got the chair, and have now been bought out, but will not honor any sales from before the buyout. My son is in a loaner chair, but needs a new chair NOW. Similar issue w/ shower chair we just got. Seat is caving in the middle, so he can't sit right in it. Hard on my back as well as his. This has to be remade, and better not cost a thing!! I'm afraid to look at anything, as the demo always seems to look good, but quality is awful, probably because they know we're stuck with it!!!

Thanks for listening!!

Amey Morris, Zachary's mom

Financial Support Related Testimony

Page 15, Barrington Forum

JONATHON TRIANGELO: What I want to ask is, I work with money, I understand money. Basic requirements to go on disability. Human Services I can't get on, okay? I haven't worked enough so I can't go on SSDI that's a given. Now, the other requirement that I could go on is Medicaid. I live in a house that was left to me in Barrington, I have some cash, I have some antiques, but guess what? I know a ton of people who are on that Medicaid disability, or broke that may sit in an apartment or whatever, they can go on disability. I can't go on disability. The only way I can go on disability is whatever the State pays me, a lien will be put against all of my assets. This is bullshit, that's the only way to put it. I tell you right now I'm going to die before I give the state a penny. The way it should be is something like okay, if a person has assets, I have a clear disability. Do you think I can go out and get a job? Do you think anybody will hire me? No. Absolutely not. So what do I do? I struggle, I do odd jobs, junk picking little stuff like that and have some money coming in. In Rhode Island, 22% of people are on disability. Human Services Everybody I know who is on disability policemen, firemen, guess what? They're not disabled. They're playing golf every day. I have a clear disability, and I can not go on disability. What you should maybe have is if somebody like me has assets, I should still be able to go on disability, but I can't use my assets or spend my cash. Like I said, I will die, D-I-E, I'll put a bullet in my head before I give this state one penny. That is the number one big thing. And secondly, is there anyone here with MS or knows anyone with multiple sclerosis? Human Services What I want to say is that there is a cure for multiple sclerosis, and it's not a joke. And what the state needs to do is get all information out to disabled people that they help. For example a green leafy vegetable diet will reverse MS. It's not fun, it's 60 years old. I found out by friends down south and they bumped into people at Church who had done this. The husband was in a wheelchair and the wife would feed him. She would have him picked up with straps and put into a pool and move his legs after three or four years, they're in their high '70s, they walk around with no cane. The multiple sclerosis society continues and will never have anything about the green leafy vegetable diet. They're supposed to bring information sufferers. They don't. This is maybe where the state needs to just have, if it's just a one-page thing where people with new ideas can mail them in to you and it gets sent out to sufferers. I won't stay on this, but the best book that anyone could read is called The MS Recovery Diet and in that book, it consolidates everyone's findings for the past 60 or 70 years about the diet. The diet is not old, it's not fun. That's really it. Human Services But I'm really disgusted about requirements for getting on disability and I even tried to get on disability. I had an SSDI hearing. I was showing some income, which isn't good and what I'm getting to is, the state, what the state is saying is, you're not disabled. What the state is saying to get on disability, you have to be broke. It's determined by money, it's not determined by disability. Unbelievable. So I go for a disability hearing. And the judge is coming at me like I'm a complete farce, a complete joke. And guess what? At that disability hearing 7 or 8 years ago, no. Do you think anyone will hire me? No. I live in Barrington, heat with wood, oil lamps; I live like a house rat. That's it. You need to completely restructure the requirements to get on disability. And I just hope, you know, the people, you have State jobs you're probably making big fat salaries, big pensions all this stuff.

BRIAN ADAE: One observation that might be of assistance to you. I think that the disability eligibility requirements you're talking about are Federal in nature with the Social Security Administration and perhaps talking to your representatives in congress and senate, the legislators there might be one answer as well as please bear in mind that not all of us sitting here are employed by the state.

JONATHON TRIANGELO: Yeah, but you know what, to be honest with you, I wouldn't waste my time. I figure you're here, you're disability oriented, you could do something about it which you probably can't. To be on Medicaid you have to be dead broke to go on.

ANGELINA STABILE: May I see speak to you after we're done?

JONATHON TRIANGELO: I can't hear you.

ANGELINA STABILE: May I speak to you after we're done?

JONATHON TRIANGELO: Oh, yeah, sure. But I mean also, what you want to do is put in Roger McDougal in Google and read his story of recovery. Human Services But again the MS society continues to never breathe a word about this and even in the book they even talk about this. So the state needs to develop something where you know, they can send information to you and you can send it back out. Because the societies, they're not doing it, it's all money driven. So that's about it.

SHARON BRINKWORTH: Excuse me what was the name of the man --

JONATHON TRIANGELO: Roger MacDougal. It will say this is my personal story of recovery. He was in a wheelchair and couldn't move. What the really sad thing is about the MS society not mentioning this is I know one or two people now, who have died from being tube-fed, they were stiff as a board. I personally was in Memorial Hospital a year ago in a wheelchair, and I'm up walking around now. The diet -- they kept trying to tell me to get ready to be tube-fed in the future. We're admitting a lot of people now that are tube fed. A lot of doctors laugh at it. The MS Society, nothing. I went to the MS society and some other meetings put on by Pfizer, the people who get their drugs from Pfizer, and I approached 22 people over a period of time with the book and everything, and not one wanted to hear about it. Not one took it seriously, because the MS society doesn't endorse it. So there you go. That's it.

SHARON BRINKWORTH: Thank you.

JONATHON TRIANGELO: Yep.

SHARON BRINKWORTH: What was your first name?

JONATHON TRIANGELO: Jonathan Triangelo.

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MARY WAMBACH: Just, just a point of information. Human Services MacDougal was talking about a plan of Federal benefits. Correct me if I am wrong, but a year and-a-half ago when Rhode Island decided that payments would include state payments, Department of Human Services took over preliminary interviews, even for -- (inaudible) and if you go to Social Security website it will tell you. I know this because I have a family member that just applied and she had to go to DHS for everything.

BRIAN ADAE: If I may respond and maybe my colleague from DHS can assist, but I think what you're speaking to Mary and I know again we're not really in a position to respond to individual questions but maybe to assist in that, if you're talking about Social Security disability determination, at some point, the Federal Social Security disability determination and that is the Federal building et cetera, et cetera, whatever, however there is a DDS disability determination services or disability determination unit where it's actually state folks but those are Federal, it's Federally funded, okay? Even though they might actually meet with the state in doing, it's Federally funded. And they have to adhere to the exact standards for example medical eligibility they're looking at the medical listings provided by the Federal regulation under which Social Security operates as well as for purposes of the financial aspects when it comes to SSI as opposed to SSDI we're looking at the Federal rules and regulations. But the DDS or DDU even though they may be state employees are actually Federally funded and they're operating by Federal regulation law. Does that make sense?

Page 32, Warwick Forum

ARTHUR SEAL: Human Services Hi. I live in a group home, with my housemate. And I feel that it is wrong that the state is taking away my money without that, I won't be able to go to the movies, and out to eat. So, that's very important to me that I don't lose my money. And I don't want that to happen, thank you. (Applause).

Page 62, Middletown Forum

DARLENE THOMPSON: We are both members of the National Federation of the Blind. Two years ago I was before this Commission and issues that were brought up were housing, affordable, liveable, RIde cuts to programs and I sat back over the two years and I've seen nothing change. Now, with those cuts in place we are losing more services and we are being told "accept it." I'm sorry I cannot accept it. I depend on these services as does everybody else in this room or their family members. I can't give up my Transportation RIde program because I'm considered dangerous if I'm walking. I might walk into a street because the pavements and sidewalks are not accessible. As Annette mentioned two years ago,

Newport is not sidewalk friendly for wheelchairs and blind people. They like to put things on the side, and they are not consistent. There's a sidewalk across the street leading to Valley Road, I have walked into that wooden pole and hugged it so many times because Middletown will not take that pole out of the middle of the sidewalk. Sometimes I think it might be my mother, so, I'm hitting it and I grab it.

Now, I'm being told "accept your cuts to RIPTA" accept that you are not getting food stamps. Human Services I've been taken off the food stamp program because I did not read my mail that was sent to me in the mail. Darn, I'm blind I don't usually read written mail. I've ask them to e-mail me and call me or send it electronically on a tape, CD, however you need to do it that will help me. That's not their way.

I don't have food stamps, I've not had food this month except for the donations from my family. I've called representatives and I'm still waiting, but I bet none of you sitting on that panel and I'll bet none of my representatives and the Governor, have had to make a loaf of bread stretch the whole month. Where are my food stamps?

As the prices are going up and nothing goes down, Transportation they are asking me to pay more money for my RIde program. It was just increased last year. Okay, I would love to. It is a service I need. It is a service that I value, and it is worth it. I would pay millions for that service, if I had it. I don't have it. Always the government comes back to the people that can least afford it and ask for our money that we don't have. I was talking to one of the RIde drivers the other day and mentioned the \$5 increase. And I said that's not a bad idea, I would gladly pay it, but I can't. Thank you and I hope these issues do get resolved.

Page 79, Kingston Forum

MARGARET: Hi. Hello, I'm the owner of three assisted living homes. Two of them are in Pawtucket. Darlington Assistive Living Centers. The third one is in North Providence. We have different groups of people, elderly people, and a younger group of people. Human Services Most of our residents are on SSI, which means that we may get cut of \$206 a month. That means I will have to be sending out notices to all of those residents. Elderly residents will probably go to a nursing home. The state will have to pay \$6,000 a month instead of paying between, \$1,132 a month. Which is about five times more expensive. Some of them may end up homeless. Probably end up going to hospitals without proper medications. It is going to probably cost the state a lot of money in medical bills. The third building which is the North Providence location. The Darlington Memory Lane. We are dealing with dementia, Alzheimer's. We are the first in the state to take SSI and waiver people. There's nobody, no assistive living in the state of Rhode Island or Massachusetts that takes people who have no money. We are the first assisted living.

If we are going to give those people 30 days notice to move out? Again they will end up going to a nursing home. Again, the state will have to pay five times or six times more then they are paying us.

People will be heart broken. Some of the residents have been there from 8-10 years. How am I supposed to give them 30 days? Am I supposed to do like the other assisted livings? Like the biggest one that take only private pay people? That's what the state is trying for us to do or close down? That's not what I want to do. I want to take care of the people who are on welfare. Thank you. (Applause).

Health Care Related Testimony

Page 15, Barrington

JONATHON TRIANGELO: And secondly, is there anyone here with MS or knows anyone with multiple sclerosis? Human Services What I want to say is that there is a cure for multiple sclerosis, and it's not a joke. And what the state needs to do is get all information out to disabled people that they help. For example a green leafy vegetable diet will reverse MS. It's not fun, it's 60 years old. I found out by friends down south and they bumped into people at Church who had done this. The husband was in a wheelchair and the wife would feed him. She would have him picked up with straps and put into a pool and move his legs after three or four years, they're in their high '70s, they walks around with no cane. The multiple sclerosis society continues and will never have anything about the green leafy vegetable diet. They're supposed to bring information sufferers. They don't. This is maybe where the state needs to just have, if it's just a one-page thing where people with new ideas can mail them in to you and it gets sent out to sufferers. I won't stay on this, but the best book that anyone could read is called The MS Recovery Diet and in that book, it consolidates everyone's findings for the past 60 or 70 years about the diet. The diet is not old, it's not fun. That's really it.

BRIAN ADAE: One observation that might be of assistance to you. I think that the disability eligibility requirements you're talking about are Federal in nature with the Social Security Administration and perhaps talking to your representatives in congress and senate, the legislators there might be one answer as well as please bear in mind that not all of us sitting here are employed by the state.

JONATHON TRIANGELO: Yeah, but you know what, to be honest with you, I wouldn't waste my time. I figure you're here, you're disability oriented, you could do something about it which you probably can't. To be on Medicaid you have to be dead broke to go on.

ANGELINA STABILE: May I see speak to you after we're done?

JONATHON TRIANGELO: I can't hear you.

ANGELINA STABILE: May I speak to you after we're done?

JONATHON TRIANGELO: Oh, yeah, sure. But I mean also, what you want to do is put in Roger McDougal in Google and read his story of recovery. Human Services But again the MS Society continues to never breathe a word about this and even in the book they even talk about this. So the state needs to develop something where you know, they can send information to you and you can send it back out. Because the societies, they're not doing it, it's all money driven. So that's about it.

SHARON BRINKWORTH: Excuse me what was the name of the man --

JONATHON TRIANGELO: Roger MacDougal. It will say this is my personal story of recovery. He was in a wheelchair and couldn't move. What the really sad thing is about the MS society not mentioning this is I know one or two people now, who have died from being tube-fed, they were stiff as a board. I personally was in Memorial Hospital a year ago in a wheelchair, and I'm up walking around now. The diet -- they kept trying to tell me to get ready to be tube-fed in the future. We're admitting a lot of people now that are tube fed. A lot of doctors laugh at it. The MS Society, nothing. I went to the MS society and some other meetings put on by Pfizer, the people who get their drugs from Pfizer, and I approached 22 people over a period of time with the book and everything, and not one wanted to hear about it. Not one took it seriously, because the MS society doesn't endorse it. So there you go. That's it.

Page 23, Warwick Forum

BETH DENNIS: Can I sit down. Okay, I have a 21 -- I don't think I'm going to be able to do this.

ATTENDEE: You can do it.

RORY CARMODY: Where does he receive services?

BETH DENNIS: He's not getting much from anybody any more. Human Services In 2004 I was taking care of him. The state took my job away from him and then I appealed it, the day before my hearing they reinstated me. For the past six years I've been taking care of him. They took my job away from me, again.

RORY CARMODY: Who is providing services now, for your son?

He just turned 21. He went from DHS to DDE, I believe. And I have one nurse that comes four hours one week and six hours another week. I have to get a job because I'm going to lose my house. He's going to lose his house. I have been fighting this since December. Sorry.

RORY CARMODY: It is okay.

BETH DENNIS: I get doors slammed in my face from his social worker. Not a very good social worker. If she would, it would be in the best interest of him. She's not. I have to fight for everything for him. And I've been doing this since he was diagnosed when he was 6 years old with muscular dystrophy.

RORY CARMODY: Have you talked to the Rhode Island Disability Law Center?

BETH DENNIS: Yes, they've turned me away. Jack Reed's office has turned me away. I do not know what to do. I've been fighting since December. I've been fighting since he was 6 years old, actually. Everywhere I go, I get slapped in the face. His social worker tells stories and says one thing. She has like, I think five different supervisors, I have one supervisor, I don't need five supervisors to supervise me. That's my story. In another month I will be getting foreclosed on my home. Which me and my husband fought for 20 years to get. Now, the state is taking everything away from him. He has a wheelchair. It took me two years to get him a new one. The new one is sitting in his bedroom because the company will not give me a joystick for it. He cannot drive it without a joystick. He has two wheelchairs. His old one, I can barely get him in it. The company refuses to give me a joystick. We took him out and his joystick broke, it was freezing. I called the company on Monday and said "we are not giving you another joystick he cannot be in two chairs" and I said when the old wheelchair joystick broke, my husband took the one off the new one to drive his old one. Otherwise he would have sat in maybe for six weeks waiting for the parts. I called and they would not give me the parts. That's been since February. He's suppose to be in his new chair. I can't get a joystick. I have gone through the proper channels. I get the door slammed in my face. Either somebody is going to give me a full time nurse so I can go to work, -- I can't even get a full-time nurse. I cannot get a nurse that knows how to take him to the bathroom. They are paying these nurses \$30 an hour to sit there and do nothing with my son.

Then I take over and it is just ridiculous.

How old is he?

BETH DENNIS: 21, ever since he turned 21. His school carried him until 21. Now, he's 21. He can talk, but you cannot hear him. He's on trach.

RORY CARMODY Is this related to the budget cuts?

BETH DENNIS: I think so. In 2005 I was reinstated, I will not say her name she should not -- she reinstated me and gave me my job back. For the past six years, I have been doing it. That's my income. My husband works, too, but we cannot survive on one paycheck. For the past six years we've been doing it. I can show you my bill records for the past two years or more. We've been paying our bills. They have been paid. Now I'm late with my mortgage and all of my bills.

SUE ELEOFF: You were being paid to be his personal care attendant, and it cannot continue?

BETH DENNIS: They said it was against the law. Craig Stenning said I was breaking the law and I said put me in jail. I chose to keep him at home with me because I've worked in nursing homes. I see what happens in nursing homes. Some of these people that work in nursing homes are very mean to patients. I kept him home to give him the best

possible life. And everything I try and get him, I get the door slammed in my face, help. Channel 12 will not help me, the Rhode Island Disability Law Center will not help me. When I found out about this meeting, I have to fight for him because nobody else will. They said it is his fight. And I said it is not. It was my job taken away not his. So that's my story. (Applause).

You did a good job!

BETH DENNIS: Thank you.

Page 29.

TARA TOWNSEND: Hi, my name is Tara I work for the Rhode Island Parent Information Network. I'm here on a professional and personal level. I have a 3 1/2 -year-old son who is trached on a ventilator full time and receives services through Medicaid and social service. As you know Human Services Medicaid is being severely threatened right now. Katie Beckett, if you know about that option. It is always being severely threatened. They are throwing out denials left and right nowadays. People are not accepting the -- it is the same application, but when you go to receive services, more people are being denied. There's different protocol going on. When you ask what the protocol is, they say nothing has changed. Obviously there's an issue going on behind the scenes that we are unaware of. We did put a staff member over at Katie Beckett and things seemed so have gotten better and denials are coming all of the time. Rhode Island Parent we are here and if you have any questions we can help you with that. Other things we've been hearing about is the DDD program issues. No new regulations out but the regulations are not being accepted. So people in the adult disabled population are not getting their applications approved or denied. It is in limbo. We do not know what is going on. The old regs are not being utilized and no regulations are in place. We are questioning what is going on in that area.

The final thing I would want to talk about is more personal. My son, Andrew, has severe physical handicaps. Human Services With the insurance a lot of things are being denied. He needs certain things to maintain his health and maintain -- to be able to live and stay at home. Those things are not always being approved. They are being denied. He's denied for nutritional medications. If the doctor says he needs it, doesn't he need it? We've been waiting for over a year, for vitamins because he does not eat, he eats through a tube and the Pediasure is not enough. Supplies can be cut back. Since these things are happening, He's been sick. He came home from the NICU. Now, the past year and a half we've been denied supplies, things have been cut back and he's been sick three or four times. One time he ended up with pneumonia and had to be hospitalized. That's why we are here. We need to make sure that we put our voices together and stand up and show everybody that we have a voice and we need the support and we need everybody to help us. Thank you. (Applause).

Page 92. Kingston Forum

CHRISTINA WYSS: My name is Christina Wyss. My concern is because of the cuts in their personal care products, I don't want to tell everybody what it is. I have a sample of what is expected of him to wear at this time. It is very disturbing and it is very upsetting. And I would like to show you the sample after, what he is expected to wear. Human Services And I have been with the social worker. I called the Governor's Office last week because of the cuts. I called another agency, they will not accept United Health. It is a big run around. I have not had services for his personal care since June. I have had to buy the products myself for him. I know that more families will be going through this too. It is because they changed companies. The company they had prior was wonderful and the state would not give them a contract. We had to go through another agency. It has been problems and problems for two years now, because of the cuts.

LAURA JONES: So if I could just clarify, the product that he was previously using with the other company, he's not able to get with the new company. Their alternative is not to your satisfaction?

ATTENDEE: He was with Comprehensive Home Health Care and the state changed over to Vanguard. Now, nothing but problems. I have seven boxes sitting in my living room waiting to be picked up because he cannot wear them.

Page 110. Providence Forum

GWEN REEVE: I actually would. Can I do it. Hi, my name is Gwen Reeve with the National MS Society and one of the things brought to our attention this year and not too long ago was problems with some of the insurance policies that are being issued by Blue Cross blue shield and probably some of the other providers. Human Services Now in their co-payment structures have developed a tier 4 co-payment for some drugs, most of them biological drugs or drugs that are pretty expensive and they justify this by saying that they can offer cheaper insurance policies if they have higher deductibles higher premiums in this tier 4. The problem with tier 4 is that the co-payment is 25%-35% of the cost of the drug and for people who have MS, the drugs that slow the progression of the disease cost about a couple thousand a month and so if you have one of these insurance policies with the tier 4, you're going to be paying about \$700 a month for one drug. And these are people who work, they have an insurance policy, so they're not on any kind of assistance, but they still can't take their medications because the cost of medication with insurance is too high. And we see this becoming more and more of a problem, as some other insurance providers like United Healthcare and Tufts also start issues plans that have these tier 4 benefits. So this is a real concern with people not getting the kind of medications they need. Thank you.

"Christina Wyss" 8/1/2011 1:48 PM

Good afternoon,

My name is Christina Wyss. Human Services I have a 25 year old son with disabilities. My concern is the poor quality of pull-ups and liners that are being supplied to individuals with disabilities. I am planning on attending the meeting Wednesday the 3rd @ Independence Square. I am hearing impaired, that is why I am sending this e-mail to you. Hopefully this issue can be resolved in some way to give my child and others the dignity they deserve.

Thank you

Christina Wyss

Independent Living Related Testimony

Page 6, Barrington Forum

BETSY ROCKEFELLER: My name is Betsy Rockefeller. I work filing papers and I work in different parts of the (Corliss) center.

Human Services And things are move ago long well this summer, despite the weather. And I am very independent. I walk around the community. Warren is a small community, so I can walk up and down the sidewalks and see the shops. I shop for myself. It's a nice small community and I go to the restaurants in town. Sometimes they're closed for a little break mid-day, but I'm really independent and various shops have various operating hours. I get to the bank. I do all these things myself, budgeting and shopping and the bank. And sometimes staff takes me in the van or in a car. I go food shopping and staff goes with me for that. Members go with other staff. There is a guy named Brian, who helps me out. In the summer, I can get out more, but in the winter, I can't get out as much, so the staff has to help me for, for example like going food shopping. I was on vacation, and this is my first day back from vacation and there is a lot of people. I'm hearing about all this news that's happening. Warren is small, it's a great community. It's much better than New York City because it's just too crowded; there are a lot of people and a lot of cars. I use today live in New York when I was younger. And Warren is nice and small, there's not too many people. And when I got back from vacation, I heard about the budget cuts and I've been concerned about that, that's why I'm here. Sorry about that. I've gotten a lot of letters about the budget. I've gotten a lot of mailings in the mail about the budget crisis and I don't know what to do, it's a little overwhelming. I've gotten a lot of information. A triple A, an AARP, they've sent me things as well. Got a lot of information about it. The State of Rhode Island is cutting fund to go Corliss. The funding at Corliss is being cut and we have had to cut staffing because of that and that's how that effects me. That was the point to my whole story. I'm try to go show you how independent I am, thanks to having staff. But now I'm not going to be as independent if I don't have the staffing and the transportation. That was my point.

SHARON BRINKWORTH: Thank you. The next person is from Corliss, Karen Goodmacher. (Sounds like).

KAREN GOODMACHER: My name is Karen Goodmacher. Human Services I'm independent and I'm able to go shopping, go to restaurants go to the supermarket. I can go there often. I'm able to go out to Stop and Shop and when I need some food, that's where I go. I cook for myself. And I clean my apartment every week. I go to the bank every two weeks. They exchange money for me. Every month, I write my checks to pay my bills. I pay my utilities, my Chase Visa account, I have a credit card. My phone bill to Verizon. I pay my bills every month. I'm all done.

MARY WAMBACH: Does Corliss help you to be independent?

KAREN GOODMACHER: Yes, it does.

MARY WAMBACH: That's what they want to hear about.

KAREN GOODMACHER: I'm all set. Thank you.

MARY WAMBACH: Thank you, Karen.

SHARON BRINKWORTH: Thank you, Karen. The next person is, is it, Sue Mullen? Sue?

JILL MERLIN: I'm Jill.

SHARON BRINKWORTH: Jill? What's her last name? I'm reading handwriting that I can't quite understand.

JILL MERLIN: My last name is Merlin, M-E-R-L-I-N.

SHARON BRINKWORTH: That's Jill, yes.

JILL MERLIN: Hello, everyone, I'm Jill, Merlin, M-E-R-L-I-N, I have a dog. She is a Yorkshire Terrier. Her name is Muffin. Human Services And Muffin helps me when the doorbell rings, she let's me know I'm independent. I am an independent person and I have staff helping me and helping all the other members at Corliss. I don't have a car. My deaf friend, Gilbert Sanborne, he takes me around and staff takes me around. Sometimes it's not enough staff because they're busy and I'll call my friend and he'll come over and take me food shopping or we go out on the bicycle. I go to the movies, I go food shopping and Muffin lives with me, we have a really nice existence in our apartment. I have a television, I have Wii, I play hockey, I read books I do bowling. I love Wii bowling, that's the best! It's a lot of fun. The YMCA, we used to

go swimming there. And it used to be free, but then I had to start paying for it. I work at Employment CVS in Barrington, I worked at CVS in Barrington for five years. There was a staff member by the name of Greg, he used to coach me at work, and Lisa and Rob and I and Marco and Donald, we used to work in the recycling program. Mary Wombach set up the recycling program and I was able to work and earn some money and then I didn't make anymore money and the recycling program was shut down. I miss it. I have my own apartment. And my own bills that I pay. My parents taught me, I'm grateful for them for teaching me those life skills and I'm happy when I can work and earn some money. My father died, which is sad and my mother has been helping me out and she's been telling me about all the funding cuts in Rhode Island.

MARY WAMBACH: Remember, today we're talking about the budget cuts in Rhode Island that's what we're here to talk about today. Human Services The funding cuts. And how that effects the members of Corliss. We're not talking about your personal things, we're talking about the State funding cuts. And Corliss and the members and staff, that's what we're here about today.

JILL MERLIN: I was trying to explain that. My mom told me about the funding cuts in Rhode Island. And we're not going to have enough money to pay our bills.

MARY WAMBACH: Right, we're here to talk about the funding cuts. If there's less money for Corliss, there's less funds to help you.

JILL MERLIN: I've been a member of Corliss for a long time and it's important to have staff. I'm sorry that funding is being cut. I'm going to miss staff if they leave. Thank you. I really try to be independent and pay my bills and do everything myself.

MARY WAMBACH: You said you hope your dog Muffin feels better.

JILL MERLIN: I hope that Muffin feels better because Muffin is sick, I've had to clean up after her she's not feeling well.

MARY WAMBACH: We're not talking about Muffin anymore we're talking about the budget cuts in the state. Thank you, Jill.

JILL MERLIN: Thank you very much, have a nice day.

BRIAN ADAE: Ms. Brinkworth, may I pose a question?

SHARON BRINKWORTH: Yes.

BRIAN ADAE: To our friends from Corliss, we have an individual here sitting in the front row who has been assisting. I think we need to be clear for the record that's been assisting in voicing the issues that have been brought forth and if I may pose a question to that individual if you could, it might be of assistance if you could identify yourself, and if you could tell us.

MARY WAMBACH: My name is MARY WAMBACH. I'll be speaking as well.

BRIAN ADAE: Excellent. That's exactly what I was going to request. One of the things I was particularly wondering is if you could identify which specific cuts that you're, that folks from Corliss are speaking about. Thank you.

MARY WAMBACH: There are probably two more testimonies, but I will give all of you papers and give you specific examples of how the cuts will impact Corliss.

BRIAN ADAE: Can you identify for us where in the budget these particular cuts are that are effecting Corliss and our friends from Corliss?

MARY WAMBACH: Yes. I'm going to voice for myself and let the interpreter sign for me because it's easier for her to sign. We get an 11% cut across the board. It's very complicated because in the past, we had the ability to meet member interests. Under the new system with the cuts, each staff has to be with a specific number of consumers all day. Let me explain the change this will make. Let's say one member is doing training for a job, so one staff will work with that member, that's how we've done it in the past. Other members, consumers, we call members, other members will be participating in group activities, maybe play games, maybe do other trainings, maybe do arts and crafts. Under the new system, we cannot provide one-to-one services. So to other people or one other person we will have to be with that person that's getting specific job training or we can't bill for any staff during that time frame. So the two people that aren't applying for that job will have -- so they can't do what they need to do. Another example in the past, if one consumer had a medical appointment or dental appointment, they would be accompanied by one staff. Sometimes there is an interpreter at the doctor's office, sometimes there's not and our staff has to help. Under the new guidelines, if that staff has to cover three people and not one, two other people have to go to the doctor's appointment or they can't go. I don't know about you, but going with someone to a doctor's appointment, it's not my idea of productive time. Another change, staff now have to do a head count every 15 minutes. Now, if you're doing an activity, if you're having a discussion with a member and maybe their family, if you're helping members learn a new activity, you have to stop every 15 minutes so we can do a head count. That's not providing services. It's complicating papers and doing administrative work that removes services. It also removes consumer choice. And in my opinion, it's a violation of human rights. Human beings are not lab rats where you say, three over here, two over here, six over there, nine in the back. That's how we're going to have to do the programs according to the new model of billing. If each staff does not have the required number of consumers with them, at all times, for 15-minute intervals throughout the billable day, we can't bill for those services.

BRIAN ADAE: May I ask further, the source of the funding would be the Division of Developmental Disabilities within the BHDDH?

MARY WAMBACH: It's within BHDDH and this is a long, long story. There's been an ongoing and growing deficit. When we started planning for this year's budget we were told the deficit was about \$11 million. Somehow in the space of a few months, it grew to I think \$17.5 million. Nobody can explain where all this deficit is coming from.

BRIAN ADAE: If I'm not --

MARY WAMBACH: Part of the problem with this state is paying utilities and a lot of other -- group homes. That was part of the deficit. When the cost of utilities went up, but other than that, they didn't identify where all the expenses are and services to adults with disabilities. None of us is getting rich. What the funding allowed us to do is have enough staff so if someone had an unexpected behavioral or more problems, we could dedicate one staff to that person until they had calmed down, until they were ready to resume activities with the group. Under the new arrangement, we can't do that. We absolutely cannot do that. Because if one person is given one staff, that staff is not meeting the mandate of two or three staff requirement and therefore, we can't bill.

BRIAN ADAE: When you made reference to the new regs, the regulations are these the regulations recently promulgated and there were public hearings on, on the first of July, Friday, the first of July, those particular regulations?

MARY WAMBACH: Yes, it's the new system under what they're calling the project sustainability. And they're working. It's project sustainability that's been ongoing for a year now. And it's with Burns and company Consulting and it's with the new software called Solana. We still don't have all of the information, but we're told this new billing system and format is retroactive to July 1. And yes, this was under the most recent votes and the legislation.

BRIAN ADAE: Has Corliss as a provider been able to offer public comment on the regulations, the new regulations that were proposed and/or has Corliss, as a provider, been able to express what you are here today to the division of developmental disabilities directly to discuss it?

MARY WAMBACH: We've spoken with the division our nurse and other staff are commenting and responding to the draft regulations. I will happily send the division these comments. I've been to legislators to provide them input. We're a small agency. If I were to do all of the things that I should be doing and my staff were to do all of these things, there would be nobody in the office.

BRIAN ADAE: The next question I have, when you mention public legislators, as I understand it from reading the public media, that the division that is BHDDH has been handed a budget by the general assembly. There was a budget proposed by the Governor that was negotiated, and the general assembly went ahead and proposed a budget that required additional cuts from BHDDH. They may have been referred to as savings by DDH, but they are cuts. Are you able to identify these are the cuts that you're talking about that the legislature handed to BHDDH and required them to make?

MARY WAMBACH: We've gotten four funding cuts in the past three years. I don't know if anybody can tell you that anymore.

BRIAN ADAE: I may have misstated that, I think if I'm not mistaken that an amount of money was appropriated by the legislature to BHDDH that they have to act within. There is nothing specific they told them to cut, but it was up to them to figure out how to spread less money. Is that about right?

MARY WAMBACH: They left it up to BHDDH to figure out how the exact cut will be distributed. But we know that in the past, individuals who got 24/7 one-to-one, many of them will not get this anymore. So individuals who require 24-hour staffing, one-to-one basis, that will be reduced.

BRIAN ADAE: What will be the consequence, if any?

MARY WAMBACH: It means that in Corliss and other programs, where we would have had someone overnight, evenings and overnight one-to-one, they may now have to check on three or four different people during that time, if the regs allow. And we won't, hopefully we won't, have any emergencies during that time because there's no any emergency care or respite cares. If we have a consumer who in the middle of the night or any other time has a catastrophic or psychiatric event, we call 911 for physical help and we go to the ER and they find a police officer to sit with the person. If the person is deaf, they call an interpreter, and maybe there is an interpreter. But people have waited as long as two days to get emergency psychiatric services, there's nothing in Rhode Island. And now, with the new funding cuts and regs. it will be worse because you won't have enough staff to cover backup if there is an emergency. I just also want to say, I don't want to do this to preface my comments, nine of us in our agency voluntarily took significant pay cuts last November in the belief that we would get the funding restored. In July, we were told back then everything was better. We didn't get the money back and we're not going to get it back and we're still under the pay cuts. And it's okay, I led my agency in doing this. But we started from the top, we didn't start at the bottom. So I ask you to keep that in mind for when I make my other comments about Rhode Island as a state.

BRIAN ADAE: Thank you.

SHARON BRINKWORTH: Thank you. There was someone else from Corliss, Robert, who wanted to speak.

MARY WAMBACH: I haven't made my comments yet. I was answering question, I did not give my testimony.

SHARON BRINKWORTH: I thought you wanted to go last, Mary.

MARY WAMBACH: That's fine.

Page 14.

LEAH: Hi.

LEAH: Hi, my name is Leah and I do a lot of things. Like theatre, going to college, sometimes I do a lot of things, too like hang with friends. Sometimes I go to parties. I work.

AUDIENCE MEMBER: Leah, how are you able to do these things, do you have help?

LEAH: Transportation Oh, yeah, I also have, what is it called? Ride.

AUDIENCE MEMBER: And you have people from Looking Upwards to help you.

LEAH: Yes.

AUDIENCE MEMBER: And they helped you to learn how to work at CVS

LEAH: Employment. Yeah, at CVS and stuff.

AUDIENCE MEMBER: Do you work there alone and independently?

LEAH: Yes, I do.

AUDIENCE MEMBER: How long have you worked at CVS?

LEAH: A few years.

AUDIENCE MEMBER: A few years. And so now, you do it all on your own and you earn your own money.

LEAH: Yes, I do.

AUDIENCE MEMBER: Pretty cool, huh?

LEAH: Yeah.

AUDIENCE MEMBER: Human Services So if you didn't have the services from Looking Upwards, you wouldn't be able to earn money and wouldn't be able to be as independent, right?

LEAH: Yes.

AUDIENCE MEMBER: That's very important to keep that, right?

LEAH: That's really important.

AUDIENCE MEMBER: Do you want to say anything else?

LEAH: I think that's it.

Page 28, Warwick Forum

EDWARD GALIPEAU: Hi, how are you doing?

If you want to sit down I can put the mike in front of you.

EDWARD GALIPEAU: I'm just talking about what I went through. Where I just got here and I'm really, you know -- I began receiving assistance from Human Services Hal Fairweather over there. I was not receiving assistance from the Epilepsy Foundation at the time I needed it after brain surgery. Here are pictures of my brain surgery and what had happened. If anybody would like to see it.

You know, just after I became aware of everything that I needed to do in life after surgery, I finally found the gentleman over there, Hal, to give me assistance, the Epilepsy Foundation did not offer assistance to me. They removed two parts of my brain on the temple. They did not even offer any support or anything. I do not have any family, I have no family, okay. No family assistance, I have friends only. Mom has passed away, the father is alive, but not known, okay. Anyway, no support. I received assistance from Hal Fairweather he was offering everything to me and I enjoyed his company and support because I needed it and a place to live on my own and finally move in somewhere that I could live by myself and just it worked out really great that he offered, I have gotten back to being aware of everything around me.

So I just needed the support he had given me and I appreciated it very much.

LORNA RICCI: Is he with an agency, Hal?

EDWARD GALIPEAU: Yes. I just wanted to point that out. The Epilepsy Foundation was not offering anything.

LORNA RICCI: Did you make a phone call to the Brain Injury Association?

EDWARD GALIPEAU: I'm not aware of anything. I wanted to offer help to the Epilepsy Foundation at the time. They were not wanting to contact me or doing anything. It is just awful. I had spinal meningitis when I was nine months old. That gave me temple lobe epilepsy. The seizures worsened in 1991 when I moved out on my own because of stress. When the seizures began, you know, I was not receiving any support from the Epilepsy Foundation. My friends tried to get it for me, but Hal, helped me out after my brain surgery, I was able to speak to someone and he did it. He helped me get back on my own. That's where I needed the support.

Seven years ago, was when they removed the two parts, I'm just feeling a lot better and I wanted to relay that. He offered that help. That's where I want to begin and try and get help for people like myself that needed it at those times. You know, that's why I wanted to come here and talk. It is needed. I have no family and we need it. People like that.

Page 30.

JOE SIRAVO: My mom spoke earlier. I'm her son, Joseph. Human Services I would like to live on my own, enjoy my life, have a little money in my pocket to go out to sports event. I have diabetes and at one point it was at level 10. Now, my AO1C is excellent thanks to my support staff at Gateways. I play on three Olympic sports teams and I've lost almost 30 pounds and I like my independence. Thank you.

Page 33.

HEIDI SHOWSTEAD: I would like to speak. Thank you, very much, typically, I serve on multiple boards across the state and I'm here today on behalf of the Rhode Island Statewide Independent Living Council just so I can get the feedback for the state of Rhode Island. Right now I'm speaking as a private citizen. Human Services I support just about everything that has been said today, but I would like to make a couple of other points as quickly as possible, if I may, there's been a lot of support as there should be for developmental disabilities and those waivers being saved and kept up, but I would also like to speak on behalf of people that do self directed care. I think that people have a right to live their lives the way that they choose and if the system is not broken and it works for a lot of people like myself, don't break it. Don't come in and change it, don't make cuts that have not had to be made in the past. If people are not making waves and complaining about their services, that means that something is being done right. Rather than trying to take away from what is being done, right let's expand upon those opportunities. Let's also think about RIPTA. Somebody like myself, I personally, cannot work due to the way that the system is set up and how it currently works against people with disabilities who are trying to make a difference, but the way in which I make a difference in my life is through volunteerism and public speaking.

Page 39, Cumberland Forum

JOHN GALLAGHER: . Human Services Uhm -- and the only other concern I have really, well, you know, things that I've noticed from my perspective, I'd like to see more like libraries when they get, you know, or such places to have handicapped access. You know, one that I can think of is the Elmwood Avenue Library; they have the long stairs, if you have to use the stairs to go to the bathroom. And like the Mount Pleasant Library that's basically, they say democracy starts in libraries and builds like that I think they should be more handicapped accessible. That's all I can think of for now.

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

SANDY LABOTTA: I guess my concern is more adult reason related. I have a son that we adopted 35 years ago. Human Services And was always in the quote-unquote special ed classes and that type of thing. When he got to be an adult, he obviously stayed living with us for quite some time; probably about I want to say six years ago, he wanted to go out on his own. So we encouraged him to do that. He got an apartment. Actually had a girlfriend at the time. And so I think that kind of helped the transition where he was not living with us anymore, so he still kind of had somebody living with him. Because of his disabilities, and his disabilities are more, uhm -- like mental disabilities where he sometimes will get paranoid about you know, people saying things about him, doing things. Employment When he was in the workforce, he was constantly losing his job because he would either have outbursts at work that were like to the point where someone would say, you know, you need to leave, because you're working with the public here and he would just be like flipping out. He's never really in my estimation been diagnosed properly. Human Services He last has a lot of paranoia, he has a lot of, uhm, autism-type, things on the autism spectrum which to me has never been addressed with any of the doctors he's seen. If you were to meet him, he would probably appear to be a "normal kind of kid" he's one of those kids that for his whole life has fallen through the system. Housing He's borderline where he's not really eligible to live in a group home because they don't feel that his disabilities are anywhere near what he, you know, what the group home type of population is. I feel like there is no, uhm, housing or any kind of uhm, services for someone like him. And I've talked to several people who have you know, grown up kids now that they're dealing with and there is no place for these people to go. Right now, he's living in an uhm, housing for elderly and disabled. We just had a meeting last week with the person who runs the place and she said that he is one step away from being thrown out of the place. And that he had been warned like twice before. Of course, she never communicated that to us and I've always asked her to keep the lines of communication open because I know what my son is like, and he won't say anything that's going on in the place. And so there's been a couple of incidents where he said people are harassing him in the building, people are writing things on his door like foul things and stuff. That's part of his make-up. I don't know if it's bipolar we're dealing with maybe some schizophrenia, I really don't know, I don't know. I don't have a whole lot of background on his family so I have very little to go with as far as that. But he almost needs like a group home type of setting but not as restrictive, obviously, as the other type of setting. He needs to know, he doesn't take his medication. When he was at home, I would give it to him every day and make sure that he had it and his behavior and his you know, everything was kind of more like on keel. But without the medication, he can't function. He's not held a job, I want to say at least two years, possibly three. And you know, basically, because of that, he's not staying on his medication. There's nobody there to say you need to take this, you know? And he'll do it for a while, he'll do it for a week or two or even a couple of months and then he feels he doesn't need it anymore. He feels he's in control, but everyone else around him knows the difference between on medication and

off medication. You know, the only solution I have at this point is to bring him back into our house, which would be very disruptive. Human Services And I think almost kind of going backwards with him, where he's finally learned to kind of live on his own and he has his license, he has a car. But he doesn't know how to handle money. He doesn't get that he needs this medication. He doesn't get that you know, the car needs gas to run and so he's run out of gas like I can't tell you how many times. He screwed up his engine because of it, it's like, this kid is like totally dysfunctional. You know, as much as he feels he's functional, he's not. I've looked into some housing and there isn't anything for those kinds of kids. You're either down here or normal. But there's nothing. And even in the school system, he was always put into a special ed class that I felt was not geared to him, but there was nothing else. So they would kind of like appease me by saying we're going to mainstream him into this class and mainstream him into this class but I don't think anything has ever, ever worked and now he's 35 years old and we're not really sure what can be done or you know.

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

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

SANDY LABOTTA: It's very frustrating.

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

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LEO CANUEL: Human Services If I could indulge the group by stepping out of my role as host and provide my own testimony as the Executive Director of PARI Independent Living Center one of the programs that PARI runs is the Personal Choice or Personal Care Assistant program for Medicaid adults with disabilities that do not have a developmental disability. It's a program by which people are able to hire who they want to hire to come into their house to help them with their activities and daily living, bathing, dressing and so forth. And this past year, we found out one day that the state legislator with the swipe of a pen wiped out the whole program. Which meant that about 420 people in the state were basically not going to get -- well, what they wiped out was the administrative portion of the program. So people could still get services. However, none of the PCAs could get paid and none of the assessments could get done because all the administrative part was defunded. So as Roger was talking about, calling state legislators, we did that and it got refunded this year. My concern and what I want to testify about is support for next year because we keep hearing that the budget cuts for next year are going to be greater than they were for this year or the budget short falls are going to be greater than this year and it's going to be to be a bigger issue. And in this particular case, it seems that it was just randomly let's go through the budget and stop every other line or third line and wipe it out. Because there were things cut from this budget this year that absolutely make no sense. Because what I said to legislators was this was going to be defunded as of January 1st, it wasn't like on December 31st 420 people were going to die or move out of the state. They were still going to be here and need services which mean they needed services from home health aides or nursing homes. So it seems to be a random thing and my testimony is that the Governor's Commission needs to continue to stay on top of this as they always do and do so well because as an advocate getting this information from the Governor's Commission helped us to implement our forces and get our consumers involved and consumers, family members, PCAs called and saved the program. And also getting programs such as the Sherlock plan passed. But I'm concerned in the next coming year, what are they going to cut now? Where are they going to get the money from? And we need to be on top of this because I'd hate to see surprises like we had this year where suddenly two weeks before they were going to vote on a budget, they basically just decided, well, let's cut a million dollars here, a half a million dollars there and 20 million dollars

there. And some of that did not get put back into the budget. So we need to stay on top of this and make sure that the communication happens from the state house on down to folks like us so we can advocate more. And that's it. Politicians would do things without telling us? I thought we had an open government law. We are require today stay here for another 15 minutes by that clock back there until 12 o'clock. Thank you all for coming.

I was going to say, when I testified in front of the house finance committee, most of the Senators left the room except for one. Actually there was another one there but he was on his iPhone the whole time. So you know, I don't think they wanted to listen to us anyway.

LEO CANUEL: I've had that happen before, too.

AUDIENCE MEMBER: We have been still writing letters and I haven't had my representative call me back at all. And I've called a ton of times.

Page 58, Middletown Forum

NANCY CASWELL: I'm here representing those around the state that has the advanced SSI program for assisted living. Human Services This is a program which keeps individuals, both frail elderly and disabled individuals out of long-term care or nursing home placement and sustains them in assisted living in apartments where they have a much more independent and autonomous lifestyle that is much less restrictive. The program began in 1999 and was built on the premise that those individuals who have low income, could have SSI to supplement what they have in order to pay for their rent and meals.

The Medicaid waiver pays for the services of this program, so this program was built upon this funding mechanism.

This year, the amount of the cut which came through the Public Assistance Act Article number XXIII, section I in the budget, they took \$206 off of each of those residents SSI amounts, bringing it from \$1,232 to \$926 a month. That's to pay for rent and meals. It was cut from \$1,232. You know it is -- we are working so hard to sustain these individuals in our Assistive Living at Forest Farm, and we had already been on a limited budget because of the Medicaid waiver which pays \$42. \$16 a day to sustain somebody a day for assisted living. They receive three meals a day and transportation and housekeeping and laundry and if those individuals were in nursing homes, the cost would be \$200 a day. We are asking anyone here who can assist us with reinstating that \$206 to that SSI amount. We are hoping to have the Governor's ear regarding this, we are working with the Rhode Island Assistive Living Association. Where there are three developments in the state including ours on Forest Avenue in Middletown. Two others, Franklin Court in Bristol and one in Providence where these developments were built on, you know, the funding mechanism that we would have this SSI and Medicaid program. So, uhm, this is what we are still trying to get this reinstated before, this goes into effect in October. Thank you very much.

Page 74, Blackstone Valley Forum

NANCY LAUSIER: Housing I am actually an owner of the assisted living facility here in Pawtucket.

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

ROGER HARRIS: Nancy, the Alliance.

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

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

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

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

ROGER HARRIS: Do you do laundry?

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

through, maybe, if we don't close our doors and eventually be gainfully employed and out there, hopefully. The rest of my residents are permanent residents. They have psych issues that will not allow them to live independently. They do well, they are happy. And they love their home, don't you guys?

JOE: Yes.

NANCY LAUSIER: Terry used to live at a home that let him go out in temperatures of 90 degrees in a winter coat and he had heat stroke because he was not being taken care of. It has not happened since, right? Rickey was living in a home, a home with his sister who was not equipped to deal with four developmentally disabled adults with anger management problems. Rickey came to us from the community and he has been with me since the beginning, seven years. And a year at Ashbury Manor. Now, seven years. Something you want to say about your home?

TERRY: Well, my sister.

NANCY LAUSIER: No about where you live now.

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

NANCY LAUSIER: But it is okay.

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

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

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

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

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

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

Page 100, Providence Forum

HEIDI SHOWSDED: Couple of things I want to say, I'm Heidi Showsded, and typically I serve on about 8 subcommittees, on a handful of boards across the state. Today I'm collecting information for them, but I'm speaking for myself. And I have two major issues that I really want to work on. Human Services The first one being is that people with disabilities have enough things in their life that they need help with. And they have enough constraints put on them with, you know, what they can and can't do, the amount of money they're able to make without being penalized and as a person that uses personal choice services, I really think that it's important that when it comes to your personal care, you're able to do them how you see fit. That's the one level of, one of the major levels of control that you have in your life. I really don't want to see any cuts happen to the personal choice program, either hourly or financially. I also do not want to see any cuts happening to my friends that use DD services. Human Services It becomes a quality of life issue. And it becomes a sustainable life issue. If you're wondering, you know, if you're going to be able to keep people because the funding is low enough to begin with or if you're going to be able to do the things that you need to do day-to-day to live your life, it's really an uncomfortable emotional situation to put people in. And I think we need to work on improving service options and service availability and service hours for people with disabilities, as opposed to all the cuts that have been made.

HEIDI SHOWSDED: Be it DD services Human Services or self-directed services, people should be entitled to have the care in which they're most comfortable with and to not have the stresses of what's going to happen with the budget and what does that mean with how I live my life everyday. No matter what your care or funding source is, that should be available without question. And if there's a lot of money there and there's not problems with the way things are being run, then please don't make problems by trying to make cuts. Not you guys, I know I'm preach to go the choir, but the state in general. It's a scary state of affairs for people with challenges.

General Medicaid Related Testimony

Page 14, Barrington Forum

JONATHON TRIANGELO: What I want to ask is, I work with money, I understand money. Basic requirements to go on disability. Human Services I can't get on, okay? I haven't worked enough so I can't go on SSDI that's a given. Now, the other requirement that I could go on is Medicaid. I live in a house that was left to me in Barrington, I have some cash, I have some antiques, but guess what? I know a ton of people who are on that Medicaid disability, or broke that may sit in an apartment or whatever, they can go on disability. I can't go on disability. The only way I can go on disability is whatever the State pays me, a lien will be put against all of my assets. This is bullshit, that's the only way to put it. I tell

you right now I'm going to die before I give the state a penny. The way it should be is something like okay, if a person has assets, I have a clear disability. Do you think I can go out and get a job? Do you think anybody will hire me? No. Absolutely not. So what do I do? I struggle, I do odd jobs, junk picking little stuff like that and have some money coming in. In Rhode Island, 22% of people are on disability.

Page 57, Middletown Forum

ANNETTE BORBINAUER: No, really. Borbinauer. I want to talk a bit about how we are all being affected now by budget cuts. [Human Services] One of the things that happens is that we are all different groups of persons with disabilities. We have people who are blind, people who are receiving services maybe on the Katie Beckett Waiver. People with developmental disabilities and people on Personal Choice Waiver. One of the problems that is happening is that by being small groups like that, we are much more vulnerable to budget cuts because they think of us in terms of small groups.

We need to change that. We have disabled policy that really does not work any more. It was made for the way life was in the past and so, what happens is that in order to get some of the services that we need, we need to impoverish ourselves and then pull the rug out from under us and it is not what it should be. We need to be together as a group and try and fight that. The only way to fight it is if we are all doing it. If we are just protecting the Katie Beckett Waiver, that's under 300 families, if we are only talking about a Trust Waiver that's under 500 people. We need to be in larger groups and fighting all cuts to persons with disabilities until we can get disability policy changed to something that is a reflection of what life is like today. That's what I wanted to say.

Transition from Children to Adult Services testimony

Page 71, Middletown Forum

DIANE KRINER: I signed in as not sure, as an agency rep. I would like to speak as a parent. My name is Dianne Kriner. Right now my family is running on a Plan A and a Plan B. My daughter is 20 years old and she will turn 21 in April. [Human Services] We have an application in process with a new system in place. I have to go on record as saying that the Department of Developmental Disabilities have been so kind every time I call and inquire about the application. I guess my concern is, moving through this system, it could come down to the wire. We could go until her birthday and it hit me like a brick wall. I was talking to the service providers they reminded me on April 7th services will stop. It took my breath away. We have a window of time. My husband and I started talking about plan B with the budget cuts that's a very real situation. I'm wondering if I'm leaving a system that is full of mandates and timelines and regulations and into a whole new world, but it does not leave much time if you are not deemed eligible to appeal. I'm wondering if there would be a timeline put in place that would give the person the opportunity to not lose the program and support staff that they've had for six or seven years to appeal the decision if they are not deemed eligible. Services stop at 21. I guess I'm wondering as we navigate the system together as a family. We navigate with lots of other families, I thought is there a way? I know it is a long process and we are going through a lot of changes. I went to the support intensity forum. Again I have to say that the Department has been filled with empathy when I call, but that was just my thought, perhaps there could be a better way that would allow the youth that is going through this process the time to appeal and not lose services.

ATTENDEE: May I ask you a few questions and maybe help some folks that may not be familiar. What you are talking about if I'm not incorrect, somebody who has been in transition. They have the support of the school system and special education, IEP, perhaps ORS services and now, we are looking at for that 18-21-year-old range. Now, we are looking at the 21st birthday. The developmental disability eligible and if there's a timeline of application to in other words, that determination has to be made within X amount of time. Once there is the determination eligibility, the timeline to develop an ISP an Individual Service Plan. The funding of that plan are you putting that into consideration?

ATTENDEE: That's my panic button all of that time in between. For us, say we were looking at self-directed supports. That's a natural flow for a youth that has been accessing for home-based therapeutic services and the application was put in a while ago, with the system change there was a whole application process with the school, I guess the flag would be before they turn 21 would there be a way to set a time, I don't know what the appeal would take, three months would that give them an opportunity before their birthday. Going up to the 21st birthday and losing all services and go through the appeal process. That may or may not happen, but it is a weighing concern within our family. I wanted to share that with you. Navigating this process has been an eye-opening experience. The process changed on July 1st. So it is significantly different and under the -- I'm not a Commissioner at the moment but under the pretense of transparency we have created a system that is more bureaucratic and requires more signatures and jumping through more hoops than ever. I would suggest that we are working on eligibility now and there should be in theory a response that says as of a birthday for 21, yes she's eligible for services, but the system has gotten more complex. For those of house run agencies and provide services, trying to figure out what we are doing is crazy. We just -- I know there's another provider in the room. We spend hours at meetings figuring out what they are paying for and what they are not. There have been statements made no changes in services to folks, when you cut somebody's budget by \$40,000 it is hard to provide the same level of services. It is a trying time right now. It is not too soon to start whatever process.

ATTENDEE: We are in process that's what I've been told. I don't know if I answered your question.

ATTENDEE: If there is a determination of disability, found eligible for services, so, by the time of application, determination of eligibility, so you may have someone that is 21, achieved their 21st birthday and achieved eligibility. So

the timeline at that point -- then there's also part of the process after that which is the developmental of the plan as well as the approval of that plan. The funding of that plan, I'm not sure. I'm not a provider. That's partly why I'm asking you what your experience may have been. The authorization so that the provider gets paid by the Commission. They are all steps.

DIANE KRINER: It would be perfect if it happened before the 21st birthday and you could keep the staff you had. This is uncharted territory for my family. Our plan B is to do whatever we could to keep the support staff she has. That would probably mean selling our house and I would have to leave my job and we would have to sell our house in order to do that to make sure she had what she needs.

ATTENDEE: You mentioned the SIS. What exactly is that?

ATTENDEE: The new evaluation tool that the Department will be using for evaluating. July 1st was the implementation.

ATTENDEE: It will determine not funding, we don't call it that any more "resource allocation" it is in terms of units in service.

ATTENDEE: What I do like about the new tool and I'm appreciative of it, they reinitiated the face-to-face interview. For our youth that tend to look good on paper, it is not until you sit down and have a conversation with them and that's the ah-hah moment where they see they may need that support. I did not hear a lot of talk about youth and I agree working together. Because our youth get older. Thanks for listening, I don't know if we could ever create a timeline. I think what I'm hearing at least is the suggestion that there has to be some sort of time frame or deadline in which to make the decision and I would assume.

ATTENDEE: That question was asked yesterday at a training. What was the timeline of responding to a denial of a plan? How long would it take for an approval of a plan? They have not figured that out. It is disconcerting, yesterday was the 25th or 26th that we don't have some of that figured out. Particularly for folks coming into the system and don't have supports in place to have not an answer to that, it is a problem. So, I don't think there are not well-defined timelines yet.

ATTENDEE: Is that something that should be in the regulations? The new regulations?

ATTENDEE: The Department is really the entity at this point. There's nothing in the regulations that goes into effect August 3rd that includes any timelines for the Department to respond to anything. That's a problem.

CARRIE MIRANDA: I just wanted to make a comment as a provider I'm from Looking Upwards. I think this -- in the past, as much anxiety families have had of their child transition [Human Services]. We've taken the leap together and landed with supports in tack. Sometimes the providers would go for it and would have assurances with a phone call. From July 1st the system did a big tank in terms of everything is in transition. Everything is up for grabs and nobody seems to really be talking to each other in a clear manner that helps us understand what that looks like. I have -- I know in our organization we've had conversations with families that children are turning 21 in August. There's no answer from the Department, the division who authorizes the funding. The answer and the solution lies in the Division of Disabilities and the Department's hands. It does not rely in the hands of the families and folks providing the services. Your suggestion is a good one. If there was a timeline that was more clear, then everybody would be able to be working on the same page. I'm Carrie Miranda from Looking Upwards. As the providers, I'll speak for myself. I'm aware of a memo sent out by the director that essentially indicated that they had been planning and trying to deal with the reductions or as they said savings proposed in the Governor's budget and handed a limit as to what the assembly's budget was implemented. My understanding is "please bear with us while we sort this out."

ATTENDEE: Okay, in that process, are there specific individuals or group of individuals whose birthdays or new eligibility is coming up prior to the end of this year? I assume.

ATTENDEE: Yeah, people are turning 21 every day. Eligibility is a question for families. I'm not joking. Some of these people are they without services?

ATTENDEE: I don't think we can answer that. We do know that the Department has a priority list for services that grows longer and longer every day. And why it grows longer I'm not totally sure.

ATTENDEE: Is there any indication that this priority list, a list of priorities any indication of how they are prioritized. [Human Services] People who are in psych hospitalizations. People turning 21 in out of state schools. People turning 21 in DCF custody. I'm trying to think of the other priorities. Once in a while somebody has an elderly parent who is no longer in a position -- there are a lot of kids turning 21 that are out of state or in-state psychiatric placement and in DCYF care. That tends to be the priority. That's a very different and difficult process.

ATTENDEE: Are there individuals who are at risk of institutionalization?

ATTENDEE: In they are a psychiatric facility they are not leaving it. Somebody is paying for it, we are not sure who. I have no idea. That's a question to the Department. I do know that for providers, the challenge also is that now, resource allocations are authorized quarterly and quarterly we have to resubmit with a multiple of signatures and wait for the Department to approve it, so that we can continue to receive funding. I don't know how many of you work in business or home businesses that you budget on quarterly. It is a challenge. People who are self directed. Some of the organizations that do that are very concerned about the volume of those that they have to send in every quarter.

ATTENDEE: They are taking a risk -- someone like us. Not knowing if they will be paid for their time and energy to develop that plan.

ATTENDEE: I think it will get straightened out but I don't know how.

ATTENDEE: In defense of the Department and I do have to say that they have been so kind and full of information and trying to guide us through this process. They have relayed the same information. When I spoke with them last week they did say we have a flag on this record of the 21st birthday. I think there's some mechanism in place but it is not formal.

When I hung up the phone I felt like somebody there really understood the urgency. I told them I'll call every six weeks, but there has to be a better way.

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HEIDI SHOWSDED: I just want to speak up one more time because there is an issue that's always been dear to my heart that I haven't heard brought up today and I think it's crucial. And that is the opportunities for the youth in transition. Human Services I know that we're having a lot of budget cuts, I know that we're having a lot of issues, but I mean, there are people that are coming from high school to go to college, they kind of fall through the cracks of ORS, they don't know what their options, they don't have a realistic picture of what they can and cannot do and who they are as people. And I really think we need to have more programs for speaking out for the youth in Rhode Island, because they are the next generation. And we're having so many cuts threatened to Medicaid, to Medicare, to job services, to SSI, SSDI and there really needs to be a focus on rewarding the youth for the efforts that they've made. We live in America and we need to tell them what is possible and what the money is there for, as opposed to what is not possible and what used to be there that's not there anymore. So can we please think about you know, some people can't work full-time because it really impacts their benefits and they're not able to live independently. Can we please think about more advocacy programs for the youth to speak out for their needs and to learn who they are, as well as more stipend and part-time job opportunities for the youth and an increase of programs for youth and families to really get a realistic picture of what is available, what's possible, and what could be possible for them in the future. A little more youth involvement in development of policies.

TIM FLYNN: I think you just gave yourself a job, Heidi.

HEIDI SHOWSDED: I'd love to, sign me up!

Concerns	Recommendations	Testimony on Pages
Lack of accessible communication of government notices (SNAP), not written in understandable language.	Require notices to be written in understandable language and in multiple formats.	61,
Limited accessible communication of services (Substance Abuse)	Require services in accessible formats	87, 92,
Lack of transition planning from children's to adult services	Require implementation of the transition planning to be completed prior to exiting youth service	12, 17, 42, 50, 105
Traumatic transition between foster home and family	Need to get clarification from DCYF	44
Lack of Autism adult services - BHDDH eligibility criteria	Need to get clarification from BHDDH on support for "high" functioning adults with autism.	12, 45, 105, 46, 50, 53,
Fear of discontinue of Behavioral Health programs; i.e. CMAP, Club Housing models	Advocate support of multiple service delivery models.	38, 67, 92, 108, 120
DD services - funding and capacity	Advocate for enough funding for services	22, 24, 31,
Aging independent consumer with developmental disabilities, needing services later in life, difficulty locating system navigators for assistance	Support and assistance	34, 35, 70, 85, 100, 116, 121
Reassessment of Katie Beckett eligibility	Monitor application of the definition of eligibility	29,



voting check off graphic

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

 <small>alarm clock graphic</small>	Adjournment	Kathleen Heren	3:00 PM
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 <small>voting check off graphic</small>	Convener adjourns meeting at 2:30 PM
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