



**State of Rhode Island and Providence Plantations**

**Public Forums**

**To identify the concerns of people with disabilities and their families**

**Monday July 23, 2007 3:30 – 5:30 pm**

Independence Square II,

Independence Way, Kingston, RI

**Governor's Commission on Disabilities**

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

**Transcript**

>>>ELAINA GOLDSTEIN: Rhodes to Independence has been involved with a grant from the federal government and we've been involved, very actively for the last four years and I must tell you that it's from these forums that when we resubmit our grant to talk about the barriers for people with disabilities to become competitively employed, a lot of what issues come out of these forums that highlight what we will be doing and working on the following years. So a lot of the comments that you'll be making, not only my organization but many of the organizations that are represented up here, hear what you're saying and try to figure out how to improve the delivery of services, improve the systems so that your concerns can be addressed, you know, as soon as possible. And sometimes those concerns turn into actual legislation that the Commission is top-notch on getting legislative initiatives passed in the state house. And then implemented. Sometimes it doesn't need that legislation, sometimes what we need is that an agency, let's say the Department of Health needs to hear that one of their programs is kind of not operating exactly as they want it to operate. Well, what do they need to do administratively to make their program operate better. So there's many things that can happen in response to the concerns that you bring up. Now, this is a little, well, I'm going to read what it says, don't laugh. To ensure that everyone here gets a chance to speak, there will be a time limit of five minutes each. When the timekeeper announces your time is up, please finish your sense. I don't think we'll be so strict. If there is time after everyone has spoken and someone wants to speak again, they may. Now, hopefully, anyone who did want to speak for sure, for sure put their name down. I have that, we don't have a slough of people here but I'm hoping we can have a bit of a dialogue with everyone here in the audience today. When you do speak -- what I'm having everyone do here is everyone on the panel will introduce themselves to you and give you a little bit about what their organization does and so maybe when you ask questions you can tell us who you are and if you're representing just you or maybe representing an organization, let us know who that organization is. The panelists may ask questions to help understand your concerns better. And that's really a case where you're not quite getting what you're talking about, we can do that. But our job here today is not to solve your problem today, that's a tough thing to do. Our job here really is to listen and to hear. Concerns of everybody out there in the community. So now what I would like to do is to ask each of the panelists, we'll start down to my right over there, to introduce themselves and tell a little about your organization.

>>>HAROLD FAYERWEATHER: My name is Harold Fayerweather, Ocean State Center for Independent Living. OSCIL has been in business since 1988 to help people become more independent. And for a person to be involved with us, it's just a question if they want to be involved and to be involved -- and the service -- a question of housing, some are in the area of information referral, we have information referral specialists that handle all calls. Basically, we have a staff of eleven. And once again, as I mentioned, we've been in business since 1988. We're one of two independent living centers in the state, the other being PARI out in Pawtucket. Our executive director is Lorna Ricci. And the board of director social security made up of a staff, many people

on the staff are people who have been disabled in one form or another so they're familiar with what the people need and request for services. Other than that, I'll just say once again, we're just people helping people become more independent.

>>>ELAINA GOLDSTEIN: Okay, thank you.

>>>STEVE BRUNERO: My name is Steve Brunero. I work at the Office of Rehabilitation Services. I would like to thank the attendees for attending the public forum today and also my future and current panelists before, some people I've seen here before. Any questions have you about the office rehabilitation services, I'd be happy to answer after wards. ORS is more commonly referred to as three separate divisions, the one most commonly known is the vocational program, assists people with disabilities become successfully employed. Other programs are services for blind and visually impaired. A number of services run, some programs are children's services where they do children screening in schools for blindness and visual impairments also services for elderly with the and D. D. S. Determination of Disability Services, 100 percent federal which adjudicates. So if there are any specific questions, I'd be happy to answer after wards.

>>>DEB GOLDING: I am Deb Golding, I work for the Rhode Island Parent Information Network better known as RIPIN, and they have put me at the Department of Health, Disability and Health. And my focus is on adolescent health transition. Some of the things that the disability and health team that I work with at the department of health are working on for people with disabilities are health promotion, emergency preparedness, traumatic brain injury, adolescent transition and data surveillance. I know a little about what's going on with those things but adolescent health transition is sort of what I'm doing. I have three children, my youngest son has autism and that's how I got into the school.

>>>ELAINA GOLDSTEIN: Janet Spinelli is probably caught in traffic. She is hopefully going to get here and will be representing the department of mental health retardation and hospice.

>>>CHRISTINE MARINELLA: My name is Christine Marinella, staff attorney at the Rhode Island Disability Law Center, nonprofit law firm that provides legal services to people with disabilities we have a staff of approximately ten lawyers, and the executive director, and one paralegal. And Alexandra is here today if anybody wants to register to vote, we're getting involved with more and more so we certainly have forms here if anybody is interested in doing that. We provide services both on an individual level as well as systemically and we really appreciate this opportunity to hear from you about what you think are major issues impacting you bus that helps us to formulate every year, we have to kind of narrow down the cases and projects we can take on because of funding limits really and resource. So what we have with us today is, if you would like at the present end, we have a survey asking you to kind of check off the areas that you would like to see some focus on and we do use these, we set our priorities for the up coming fiscal year which begins in October. And we rely heavily on these forums to see which kind of cases we take for the up coming year. So you have a moment to look over this and fill it out. You can mail it in or hand it in to us, we really appreciate that. And we do systemic work on larger issues, not on individual, but larger issues and these forums are a great way to here what those issues are for a give year.

>>>ELAINA GOLDSTEIN: As I said Janet would be here and here she is. If you could just give a little bit about who we are and the organization we represent.

>>>JANET SPINELLI: Janet Spinelli, MHRH, division of behavioral health care, people with disabilities, mental health issues, substance abuse issues.

>>>ELAINA GOLDSTEIN: And I'm Elaina Goldstein, project director for Rhodes to Independence, which started as a grant to help people with disabilities become competitively employed and our job to look at all of the barriers that people with disabilities have and actually go into work. So, not only do we look at the issues of actual employment but the issues of health care and -- did you bring the Sherlock Center stuff.

>>>MATTHEW IRVING: Mr. Cooper said you had it.

>>>ELAINA GOLDSTEIN: Oh, no. It's unbelievable. Anyway, well at all the other ones get outreach materials on the Sherlock plan and also on the work incentive that is social security has, both 1619 A and B. What I did was I gave all of the copies for all of the forums to Bob Cooper at the Commission and I didn't think of just bringing

extra ones for my own little thing here. In anyplace event, we operate out of the University of Rhode Island which is one of the reasons we're having the event here. And within of the things that I like to try to do is as I meet people at these different forums, anyone who is interested in participating in our advisory board, as a consumer, we're more than welcome to have you and our advisory board meets now every other month and actually our next meeting is going to be in September and we're going to be working with Raytheon. Raytheon came to our Social Security Summit and offered up, they have this rate six stigma which is a problem solving technique they use to actually save money in their company, many companies evidently foreign 500 all use something similar to this and they wanted to come and help see what they could do to help solve this problem that we have with the federal government's programs and state government programs and how we could help facilitate more of an integration of getting these programs working together better to help people with disabilities back to work oh so that's going to be in September. I think this in this booklet here we have our contact information, how you get in touch with us, and we have a web site so we hope that people would like to continue [TO/] advocate on your own behalf or on behalf of whatever organization you have, we would love to have you participate what is the association with the pharmacy school, any with the Rhodes to Independence.

>>>ELAINA GOLDSTEIN: That's where we are, it's independence, like Independence Square. That's irrelevant, but the College of Pharmacy, because we do a lot with health care issues we are ear under the College of Pharmacy and Anne LeClerc with RIPTA, we administer the RIdE system and TIKs system and some of the drivers with the RIdE. As a planner work more with the RIdE program and fix service. Also a member of the state rehab council and a former member of the statewide independent living council.

>>>BARBARA MCCRAE: My name is Barbara McCrae and I work for PAL, an organization started by parents and friends who were looking for alternate living, and that's how we came up with the name PAL. All people on our Board of Directors are parents of children with disabilities, helping families navigate the system which can be challenging. I work in the quality of life initiative, we visit 400 people each year who receive support services from the division of developmental disabilities. And we get some feedback from our visit to the person, their agencies and their social workers and we do some follow up about issue that is might arise that a pothunters or needs and we do some follow up on those. Some of the data is also sent blind without any names attached to the human services research institute where they do a comparison on how Rhode Islanders are feeling about their support services compared to, I think about 25 other states are in the project. So, we also have another, a couple of initiatives that run out of our organization. One is the employment information network and part of that is a mentoring, kind of a support peer to peer, people call others who are looking for jobs and help them with ideas on how to find jobs. Weapon don't actually find people jobs, it's just more of a motivation to keep looking and some new ways to try and to keep talk being what you want because the more people that hear I speak up, the better chance that somebody will be there to listen. And we have a resource library, so, we just kind of, we're doing a lot of community belonging and kind of helping to promote relationship development and community friendships and relationships and really trying to look at the community so that people are not only out there doing things but also engaging and feeling that they belong in their own community.

>>>JEANNE BEHIE: I'm Jeanne Behie, representing the Governor's Commission on Disabilities today. I work for Washington County as a service coordinator working with children with behavioral and emotional issues helping them access information and resources and help advocate force their child, but more importantly, personally I'm here because I'm the mother of a son, a young adult son who was born with disabilities and I found it very important to find out the resources that were out in the community that would help him so over the years I've gotten involved in many of the offerings here, I've gotten on different boards just so I could find out what would be good for him and then later in life, both of my parents developed disability, they developed brain injuries and suffered vision impairment and my father was paralyzed so beside trying to get services for my son, I tried to find out what was available for my parents, too. So, if I'm not sitting on the panel for one of these public forums, I'm always in the audience then asking questions and talking about the concerns I have.

So, if anybody has any questions about any of the things about Washington County CAS (phonetic) and many of the other organizations, I'd be happy to talk with anyone afterwards.

>>>ELAINA GOLDSTEIN: Great, thank you. Is there anybody else who signed up that came in that wanted to speak? No, okay. Would you like to I'm going to have everybody speak, big surprise.

>>>GAIL LUSSIER: I can speak to problem with my daughter. So, I certainly am limited.

>>>ELAINA GOLDSTEIN: That's not limited, that's quite a lot of information, trust me. I just want to be sure that -- who here on the list would actually like to speak? I have a maybe and a question mark.

>>>BRIAN MONTEIRO: I didn't realize I was on the panel until I walked in here. The maybe was me.

>>>ELAINA GOLDSTEIN: Maybe was you. Okay, who is Laurie?

>>>LAURIE BOYERT: I'm the question mark.

>>>ELAINA GOLDSTEIN: Who is Ernestine? You know what we'll do, we'll make this pretty informal. All of you who came today are here hopefully because you wanted to, hopefully you wanted to voice a concern or you wanted, because that is the purpose of these forums. So, yes, sir.

>>>JEANNE BEHIE: Are we going to go around the audience and have them introduce them selves?

>>>ELAINA GOLDSTEIN: If they're comfortable, but first we'll here from Brian who I never met before, so, we're all meeting Brian for the first time.

>>>BRIAN MONTEIRO: Brian Monteiro from the Office of the Lieutenant Governor. I do some work on long-term care. I'm just getting my hands into all this stuff so I'm not as versed as some of you may be that's why I was shocked to see my name on this panel.

>>>ELAINA GOLDSTEIN: You were shocked, okay. Hopefully you will take back a lot of this to the Lieutenant Governor. For those of who do not know, the Lieutenant Governor runs the Long-Term Care Coordinating Council.

>>>BRIAN MONTEIRO: Once a month and I think resume meetings in September, if I'm not mistaken, I can get a definitive answer on that at the office, it's on my calendar but I know the legislature is not in session so we're kind of on a break right now.

>>>JEANNE BEHIE: What do you do about long-term care?

>>>BRIAN MONTEIRO: Basically discuss legislation, bills that come before the General Assembly. It's almost like a, this is, there's a committee and almost like we have here, people come and ask questions and things like that, different lobbyists come and we just basically monitor the long-term care in Rhode Island and monitor all of the bills that come through the General Assembly.

>>>JEANNE BEHIE: Is that private residences and group homes?

>>>BRIAN MONTEIRO: Yes.

>>>JEANNE BEHIE: Community based care only?

>>>BRIAN MONTEIRO: No, assisted living, nursing homes.

>>>GAIL LUSSIER LUSSIER: What about somebody in a private home by them selves who still live with their parents?

>>>BRIAN MONTEIRO: Are you guys getting visits from, say, a nursing placement, are you familiar with nursing placements?

>>>GAIL LUSSIER LUSSIER: On and off.

>>>BRIAN MONTEIRO: Then you're more than welcome to come. It basically covers the whole gamut.

>>>ELAINA GOLDSTEIN: Okay. How about, Laurie, why don't we start with you?

>>>LAURIE BOYERT: I just saw this in the newspaper, it said for people who have family members or who are disabled. I have a son who is 26 who was diagnosed at age 20 with bipolar disorder and that has changed him from what he was before because he was hospitalized. So, it's been like, I'll tell you it's been a nightmare. For me, not having this illness earlier in his life, not knowing where to go, having been hospitalized in another state and it's just been so frustrating and I applied for medical assistance from the state of Rhode Island thinking his meds cost him 600 a month, he must be eligible for that. He has a menial job, 7.50 an hour at Burger King, used to work at wall mart, but got fired for pushing a cart into a car my certain is I'm 60 if I die first, who takes care of this kid who can't balance a checkbook, he

did get a high school degree because he wasn't sick -- but he's definitely limit until then what he can do and chronologically is about a 14 year-old so I feel like, one of those agencies, North Kingston, it wasn't you -- we had a private doctor so we missed out on the services South Shore had to offer because I don't know that South Shore is where I should go, I wept once and was very unhappy with a doctor, but now I'm back there just to get the service that is are there and that's been really helpful. If only I knew that's where I should be going but when there's a doctor there you disagree with have you to leave, anyway I'm just really frustrated and I've applied for MHRH, your department, we have paperwork in there but we were denied medical assistance through the North Kingstown, whatever, through the state of Rhode Island because he works. Well, I want my son to work.

>>>ELAINA GOLDSTEIN: That's a good thing. There is a -- when I said the Sherlock - - I can't believe we don't have the things here. The Sherlock Plan is a program that was created just for people who are working who can get into the medical assistance program, Sherlock plan is a kind of a medical assistance but it has different rules than the other medical assistance programs. One of the rule social security, you have to be working, the other rule is that you need to have a disability determination. Now, have you ever applied for social security?

>>>LAURIE BOYERT: No, and I'm college educated but I'm overwhelmed by this. I went to social security and they said, don't even bother, he has a job. This was like three years ago.

>>>ELAINA GOLDSTEIN: Would you bold that, please?

>>>LAURIE BOYERT: I'm just telling you what's happening to me. It's like people slam their head against a concrete wall and I have, you know, I don't know what to do.

>>>ELAINA GOLDSTEIN: All right. Well, you're here, and there are a lot people here at the table. You actually, there's a gentleman sitting behind you who actually works for the Department of medical assistance here, Brian, who knows a lot more than pretty much anybody in the department.

>>>LAURIE BOYERT: I'll be sure to talk to him.

>>>ELAINA GOLDSTEIN: But, there is a program in medical assistance called the March program, so even if you've been before or your son has never been on social security disability before they can go through and make the determination that he is disabled in accordance to be eligible for the Sherlock plan, that's the medical assistance department. But you need to .

>>>LAURIE BOYERT: I have that format home.

>>>ELAINA GOLDSTEIN: The department of ORS also has counselors.

>>>LAURIE BOYERT: He's had ORS services.

>>>ELAINA GOLDSTEIN: Roberta Green and Steve Brunero, but Roberta Green and staff do benefits counseling for people who want to work so that's for sure a place, that's two great people and I'm sorry to --

>>>LAURIE BOYERT: This is just what really truly happened to me and I became overwhelmed and I shut down. I was denied medical assistance, he was denied and when I saw he was denied, I started crying, threw out paper in a pile in my living room and didn't look at it for a month and when I did it said, you have 307 days to appeal it and it was too late and that was my fault because I as a parent couldn't deal with it because I'm going to work I have other people in the house and it was just overwhelming. So I'm glad you have this forum.

>>>ELAINA GOLDSTEIN: We're going to hook you up, we're hooking you up. Also, you go, give your name and address, I will send Sherlock in the mail, our brochures South Shore Mental Health --

>>>JEANNE BEHIE: I work in the children's department but I would be happy to meet with you after wards and talk to you about some of the adult services that perhaps you're not aware of yet.

>>>LAURIE BOYERT: I was really happy, we just started back there and the psychiatrist told me about a medical program that I've never heard of called Cmap or something like that, somebody with a mental impairment is eligible to get psychiatric drugs with no co-pay if going to South Shore Mental Health and have no insurance.

>>>JEANNE BEHIE: You said he's been hospitalized because there's also case management services we don't have that.

>>>JEANNE BEHIE: I'll talk with you afterward about some of the programs.

>>>LAURIE BOYERT: Thank you. That's all, I'm just frustrated, that's it.

>>>DEB GOLDING: I would like to give my number, too, if you have the paperwork with your office. when I started working at the department of health, adolescent transition and figuring out what was had a and made the mistake of saying, isn't there an easy to read health brochure that tells you how to move around in the system and I said there should be one and they said, okay, there's your job, make one. So I've been working for about six months on this to actually put in, like this chronological order of date and age and then how you enter the health care system, whether public or private insurance and what happens as you move along in your age, whether you're in a military family, whether you're on social security, whether you're in the mental health piece of it, DHS to get their pieces of it and I'm trying to get MHRH and I've gone to the military so we're trying to map out this whole thing and everybody is really excited about it, so hopefully it will be this tool where people can say, okay, I fit here so this is where I have to go that would be really helpful. So, anybody here who wants to get in on that with me, I would appreciate that. That's something that we're getting a loft good feedback and I know trying to figure out the whole system myself, it's on a link from one thing to a next and you ask a question to somebody who picks up a phone and they may not even know the answer and put you right off and you think it's a dead end where it's really not a dead end.

>>>BARBARA MCCRAE: I would just like to you know that you're not alone, either. Because the amount of time it takes people to get to the right person to find out the information is too long for Rhode Island. So, I just want to you know that you're not alone. The frustrations that you have, I think many have, really. So, I don't know if that helps you.

>>>LAURIE BOYERT: Yeah, I guess so.

>>>BARBARA MCCRAE: But it's sad in some ways.

>>>ELAINA GOLDSTEIN: Ernestine, would you like to --

>>>ERNESTINE SWANLUND: No, I just really came to sit in on this.

>>>ELAINA GOLDSTEIN: Would you like to say something?

>>>SABOURIN LUSSIER: I'm her daughter, so, I find that transportation to work is still a problem even with the -- they quit at four or five o'clock, and if you can find a job where somebody works two to six or something, you have no way or eleven to seven.

>>>ANNE LECLERC: What town are you in?

>>>SABOURIN LUSSIER: I'm in Wakefield and another person in North Kingstown works eleven to seven.

>>>ELAINA GOLDSTEIN: And the RIdE program won't do it after a certain time?

>>>SABOURIN LUSSIER: We've looked around it, there's no RIdE on Sundays when people go someplace, there's no RIdE after seven o'clock on Saturday nights. Also we've had trouble with medical appointments when I have work and she has -- Westerly seems to be off limits.

>>>ELAINA GOLDSTEIN: What is your name by the way Gail Johnston? But I think that's been fixed with the medical, RIdE is separate from the RIdE program?

>>>GAIL LUSSIER LUSSIER: No, you still can't get from South Kingstown --

>>>ANNE LECLERC: You're in Westerly?

>>>GAIL LUSSIER LUSSIER: We're in Wakefield, but sometimes she has to go to clinics at the Westerly Hospital.

>>>ANNE LECLERC: RIdE is an umbrella program, there are a number of different ones under it. the department of elderly affairs pays for a number of services for medical appointments for seniors. For certain people receiving medical assistance, we call them special medicals, dialysis, chemotherapy, those type of services. For people under 60, the only option really for anyone under 60, MHRH, the Arc pay for some trips.

>>>GAIL LUSSIER LUSSIER: We always pay for all our trips with the trip particulars like anybody.

>>>ANNE LECLERC: The only program for someone under 60, and not in the Arc is the American with disability programs they, the to provide the RIdE type service for people's whose disability provide -- a fixed routed system.

>>>ELAINA GOLDSTEIN: Do you know what that is the regular bus.

>>>ANNE LECLERC: Right. So it operates at the same time and the same location as the regular bus so if there is no public transit in general there's knock un the identify RIdE program. If the program closes at seven, the ADA closes -- a person's

eligibility depends on their disability and how it affects use of the fixed routed system. But to get the trip there's now second level, when someone is deemed eligible needs to end within a quarter mile so, there are people eligible who don't live near a fixed route who don't live --

>>>GAIL LUSSIER LUSSIER: That's why we live where we live.

>>>GAIL LUSSIER JOHNSTON: And on the weekends, the bus route changes and it's more than three quarters of a mile because my son has the same problem on the weekends, bus does not go that close on the weekends.

>>>ANNE LECLERC: Sundays and Saturdays are different, weekdays are one, Saturdays less service and Sundays even less. So it is equivalent to the fixed route service. So if there is no fixed route service, there's no other service approximates.

>>>GAIL LUSSIER LUSSIER: Is that online?

>>>ANNE LECLERC: Yes.

>>>JEANNE BEHIE: If someone is receiving Medicaid, they're eligible through DHS like RITE care, but we're talking about adults on Medicaid, Frank do you have.

>>>FRANK SPINELLI: You're he will -- if you're eligible for medical assistance and have no other mines for transportation, there is a transportation hot line that will make arrangements to pick you up pick you up and take you back usually when 24 hour notice, same day is difficult.

>>>FRANK SPINELLI: I do not have that number but if you give me your number later, if you know somebody on medical assistance -- particularly from Wakefield to Westerly Pain Clinic.

>>>ANNE LECLERC: We have a general public service between wake field -- Westerly has flex service which is a combination between our fixed service and the RIDE program. Anyone can use it for any reason and it's the same fair as the bus. But because none of the services for Westerly are really in Westerly, there's no fixed route service down there. Westerly has a bus that stays in the area all day and then one bus that comes, Westerly to wake field three time a day. But people can go back in the wake field area, around nine a.m., to 11:15 and 2:15, so we call it bus stop at the end of your driveway, same type of vehicle as the RIDE vehicle but painted like RIPTA. But other than that, works just like the RIDE program buses. It's mainly by reservation and has some bus stop where is people can get on without reservation but goes into neighborhoods. So if you would like more information with that, I can give you that information.

>>>JEANNE BEHIE: One last thing, you mentioned the wound clinics and you probably know South county hospital has a wound clinic and they provide transportation. I've been there a number of times in the last few weeks with someone and the services were excellent.

>>>GAIL LUSSIER LUSSIER: The other thing, which this lady might be interested in, what really services, like, I'm old, my husband lives in Texas, and I'm having trouble staying with her and having a husband in Texas without really feeling there's any support medically. Right now she's on IV antibiotics and pumps don't work and this kind of stuff. Is there a service for -- I'm sorry, talking about long-term care to have a nurse come in every week and check skin or check to be sure they've got food or check, that type of thing or a service to check their checkbook.

>>>ELAINA GOLDSTEIN: What health insurance TRICARE for Life Medicaid Medicare and TRICARE for Life military retiree. Three types, pending on the insurance that you have, are services available to you. Now Medicare for sure pays for -- they pay for home health care and so does Medicaid, I'm not sure about TRICARE same as Medicare. Most should have some sort of a skilled nurse, if you need a skilled nurse, most of them all pay for skilled nursing care does medical assistance pay for skilled nursing.

>>>STEVE BRUNERO: Not usually an ongoing private duty for instance just to check in to make sure someone does not have a burn, that they burned their hand cooking and couldn't --

>>>FRANK SPINELLI: The medical assistance skilled nursing is usually time limited, for example, someone may need ten units of nursing services that would be covered but having an R. N. would be every week is normally not a conferred service. But there may be other option that is we can talk about. Where will people in wheel chairs, wound care where they don't see.

>>>STEVE BRUNERO: I understand the need that's why I said there may be other options.

>>>ELAINA GOLDSTEIN: I think you have to look into it.

>>>FRANK SPINELLI: I welcome the conversation.

>>>ELAINA GOLDSTEIN: Also I would contact, she's military also, they also have benefits.

>>>FRANK SPINELLI: Most like Medicare and TRICARE like medical skilled nursing, intermittent crisis or acute episode, time specific, or, I fall and break my hip, we'll have someone come out that's what I find is available.

>>>STEVE BRUNERO: There are some shared coordination programs that are being developed that they fit nicely, too, so, I'll talk with you guys after.

>>>JEANNE BEHIE: And Gail, there's somebody who works at RIPIN who is very involved in TRICARE, Geri Elmer, and I'm sure she would be happy to talk with you about services.

>>>ELAINA GOLDSTEIN: Do you know what RIPIN is?

>>>GAIL LUSSIER LUSSIER: Yes.

>>>JEANNE BEHIE: Rhode Island Parent Information Network, 1-800-464 -- is it 3399, Deb?

>>>DEB GOLDING: I don't have my --

>>>JEANNE BEHIE: I think that's it but they're also online.

>>>GAIL LUSSIER: I was talking to Geri Elmer the other day because of a project I was working on and she was saying, between TRICARE and medical assistance, which is the first one and it seems to be always be -- Geri said Jerry sometimes doesn't think so there's often problems in that way. I'm not sure about that.

>>>ELAINA GOLDSTEIN: Isn't Medicaid always last? There may be a question who's primary between TRICARE and Medicare because Medicaid is always lost by TRICARE and Medicare would be I was told because I didn't realize TRICARE for Life was almost the same as Medicare and when we were going to Children's, we would give Medicare letters and started getting fliers saying TRICARE for Life was the primary instead of Medicare and secondary, or, would be Medicaid.

>>>STEVE BRUNERO: There's a citizen in the room with three coverages who still can't --

>>>ELAINA GOLDSTEIN: Right. And the other issue, is the service available to get, that's the other problem.

>>>GAIL LUSSIER LUSSIER: The kind of service I would like for checkup on regular basis isn't available from RITEcare or Medicare and I didn't think it was available from Medicaid.

>>>ELAINA GOLDSTEIN: That's the other problem.

>>>GAIL LUSSIER LUSSIER: Not somebody to pay for it, but we tried privately to find somebody who would come every week and I'm just not in those circles, every nurse, would you like an extra job just to come once a week and check -- everyone is busy. And another thing I have is what happens when kids, or young adults meet young adults and want to get married and live on their own -- is there support for two disabled that.

>>>JEANNE BEHIE: What kind of support are you looking for, kind of case management?

>>>GAIL LUSSIER LUSSIER: Case management. It's hard because they don't make a lot of money. Are we as parents always going to support them. Are they eligible for food stamp it is, fuel assistance, that type of thing.

>>>JEANNE BEHIE: Yeah, they are eligible if they have their own household. They don't need to be married for those kinds of things.

>>>GAIL LUSSIER LUSSIER: What if they're living in the house you own and you pay -- I mean --

>>>JEANNE BEHIE: If they're living in your house then your income would be a part of the consideration what if you're not living in that house with them or you're only living there because or you're there three weeks, or ten days out of a month.

>>>ELAINA GOLDSTEIN: You're actually on Medicaid.

>>>SABOURIN LUSSIER: Yes.

>>>ELAINA GOLDSTEIN: So she's already reached the criteria of income eligibility so there's, the different programs, food stamps and she needed housing all have their own specific income eligibility requirements but if you've made it to be on Medicaid, my guess is some of the other programs you would also be eligible for.

>>>JEANNE BEHIE: No, no, no.

>>>ELAINA GOLDSTEIN: You say you work also --

>>>JEANNE BEHIE: Just because you're on Medicaid doesn't mean you're eligible for food stamps.

>>>ELAINA GOLDSTEIN: I didn't say that but, but --

>>>JEANNE BEHIE: There's somebody at the Jonnie cake center twice a week to answer questions, could you call and see what hours they're going to be there and either call them or make an appointment to spike with them about it but I do believe they will real estate look at your income too unless it's a separate household, and it could be a separate apartment with a different number. And also what supports do you receive from Waves?

>>>ELAINA GOLDSTEIN: What is Waves.

>>>JEANNE BEHIE: Adult service provider local evaluation services.

>>>JEANNE BEHIE: It's an adult service provider have I to say I'm disappointed there doesn't seem to be any urge to find everyone a job or get them working for a couple hours a day.

>>>ELAINA GOLDSTEIN: You need to be hooked up with rehab services, Steve Brunero, I love him, we have a known each other for many, many years. Why do you think I sat directly in front of him?

>>>JEANNE BEHIE: Gail, what you just said is a very valid point that there isn't much of a move to thing adults working when you look at adult service providers it's a lot less expensive for them to provide recreational services to people rather than do the job training, job exploration and job placement that people want and that's something I think that's not just indigenous to Rhode Island, it's a problem for every state that has adult service providers, it's more economically feasible for them.

>>>GAIL LUSSIER LUSSIER: Put them in a housing area.

>>>ELAINA GOLDSTEIN: I'm going to time out here because I have to say, I think that depending on the different type of disability group you're talking about is very, very different. And that is the, what we've been doing is working on this. There's agencies in this state that work on helping people with disabilities get employed. There's many people with disabilities getting employed so when talking about providers, one of the big problems is the provider in the community and what their own internal biases are for certain things. One of the things we hope to do next year is go out and train providers on the fact that there are, there is a huge, ticket to work act that passed in what was it 98 that it passed and congress, it's making a big thing, one of the big problems that came out of our social security summit, social security is kind of schizophrenic in this area. They have people once on disability and you go to a field office -- which one of you said this, we don't have anything to do with getting people back to work. Well, yes, they are supposed to have something to do with getting people back to work. That's one of the problems, if you go to social security office and they don't tell you about going back to work, that's been part of the social security program believe it or not since the beginning of social security in 1965 and it really isn't something they do, they will say the people there will at ORS, you were at the summit, the people at ORS, voc. rehab. Like you said, this is overwhelming to find out about all of the information. But there is a big push, there has been a push. I think it's matter of getting the right information to people in the right time to be able to note about all this. I don't know how many people have heard of the Point, they're not represented up here but they're another entity in the state that has been developed.

>>>STEVE BRUNERO: Two one one, too.

>>>ELAINA GOLDSTEIN: Two one one, we're giving information out about the kinds of service that is are available for you. But if you didn't know about the Point, the Point has a telephone number and can call them and tell them about your specific situation and they will look up for you. There's another thing out there called ask Rhody, I think there was one big push for it. It was a program that you key in where you live and you say the kinds of services you want and it was part of taking that, basically the crossroads database and putting it into online and adding in other additional information and services and organization that is provide services. So this issue really the issue is getting the information, people knowing that the information is there and where to get it. That continues to be a huge problem.

>>>JEANNE BEHIE: And Elaina, let me just say one thing, too, you work -- how many hours a week do you work?

>>>SABOURIN LUSSIER: The max, I think 20 hours.

>>>JEANNE BEHIE: Well that's pretty good.

>>>GAIL LUSSIER: And that's doing piecework, she's working. Two hours are doing customer at the office of Waves. So they're sort of employing her in house for two hours a week and the rest is, she used to come home and say, I did 874 pieces I'm so excited, okay, and she'll get 4.07 at the LaPlante Center.

>>>JEANNE BEHIE: And my son works four hours a week. Steve, with ORS, he's considered gainfully employed. He's considered a success with ORS because he has worked four hours a week for a number of years at the same location. He would like to work a lot more than that. So we may say, it's not getting the information out there but ORS does look at her as successfully employed, and my son as successfully employed. But they probably don't make enough money to support themselves.

>>>STEVE BRUNERO: ORS people are unemployed and under employed. Many people in the community are working a minimal number of hours but not enough to be independent. Many of those folks who I know very well, I feel are under employed if doing piecework. I don't want to get into specifics, but if someone is under employed and you feel they have the potential or capacity to work more hours, different job, I invite you to contact me individually so I can refer to you a counselor to work with Waves or planned center who get funding from ORS or MHRH but you need to call and let us know. It's true if you go out, it's competitive wages. And if it's ten or fifteen or twenty hours a week, it's successful. But if they don't come back and tell us, I'm looking for another job or more money, we don't know that. Sounds like she can use more vocational services. And when you talk to LaPlante or Waves, they keep promising you, we'll work on it, but a year will go by.

>>>BARBARA MCCRAE: Absolutely.

>>>STEVE BRUNERO: Sounds like she needs a rehabilitation counselor.

>>>BARBARA MCCRAE: I would like to know if you called, you know, some of these places, who would they, other than the LaPlante Center and Waves -- would Ask Rhody, or 211 -- what other places in this area might help her get a job.

>>>ELAINA GOLDSTEIN: First of all, there's Network Rhode Island.

>>>GAIL LUSSIER: I found Sabourin a job like at the new movie theater. She took on a job there, but Safes said we don't provide transportation. And sometimes it's support to get them to learn the job.

>>>BARBARA MCCRAE: Inflexibility sometimes of the agency to provide, I don't know, the nine to five kind of thing.

>>>GAIL LUSSIER: Not nine to five, like 8:30 to 4:30.

>>>BARBARA MCCRAE: You're right.

>>>ANNE LECLERC: We should talk about the flex program. South county commons you're talking about. They operate until 6:30 with weekends possible.

>>>GAIL LUSSIER: That was the other thing, the job was six or seven at night and getting out at eleven, so there was just no way anyone could.

>>>ELAINA GOLDSTEIN: There might be other kinds of work -- what Steve is talking about, ticket to work is all about that, getting additional training to be able to work. You seem like a very bright lady. You don't have to be working through Waves, right?

>>>GAIL LUSSIER: That's our service provider.

>>>ELAINA GOLDSTEIN: You don't have --

>>>GAIL LUSSIER: It would be a service provider. We don't have to have a service provider?

>>>ELAINA GOLDSTEIN: No.

>>>STEVE BRUNERO: Why don't we talk after so I can give you more information about providers out there, job coaching, training. There are a lot of services we can provide you with.

>>>GAIL LUSSIER: I thought LaPlante, and Waves, and Perspectives were supposed to

--

>>>STEVE BRUNERO: They need funding to do that. So you need a state agency to do that. I see what they get every year and sometimes I'm tempted to say, I could do a lot better than that with the money.

>>>ELAINA GOLDSTEIN: One interesting thing I think you're bringing up, unless I'm, you know, what exactly are these agencies actually providing the types of services that the client needs for the money that they're getting. It's like day care, isn't

that what you're asking. There's things called outcome measures that different providers don't get paid unless they are showing you guys -- unless you're showing outcomes. What is that called, it's all written up, looks wonderful, but never actually .

>>>GAIL LUSSIER: Whenever we have a meeting and we discuss the things we want, they put it in the.

>>>ELAINA GOLDSTEIN: In the plan.

>>>GAIL LUSSIER: And never follow through.

>>>BARBARA MCCRAE: Absolutely, I agree with that.

>>>GAIL LUSSIER: And the previous program I was in. --

>>>BARBARA MCCRAE: I think job development.

>>>JEANNE BEHIE: It's a problem.

>>>BARBARA MCCRAE: I think it's a big problem.

>>>STEVE BRUNERO: As a consumer, you have choices. Don't need to go to one particular vendor. In particular job coaching. We found in a survey a few years ago, there's a shortage of qualified job coaches in Rhode Island. So we started a grant for an agency to hire three or four job coaches educated and will stay on board because they're getting the proper salary. One problem with the vendors, job coaches and employment specialists are making ten or eleven dollars an hour and don't stay. So this grant is established to have people with a higher education and salary stay with folks. So there are choices out there, you just need to sit and talk with me after wards.

>>>CHRISTINE MARINELLA: We have a client assistance program at the Disability Law Center.

>>>GAIL LUSSIER: We've used the Rhode Island disability .

>>>GAIL LUSSIER: With the previous program because -- it was not a good outcome. I mean, the lawyer wouldn't even talk to me about anything that we wanted for Sabourin.

>>>CHRISTINE MARINELLA: Were you over or under 18?

>>>GAIL LUSSIER: Probably over, but she's not her own best advocate, and nothing was done.

>>>CHRISTINE MARINELLA: I'm sorry that you had a not great experience, but the law says, when a person reaches the age of 18, they are the person that makes the decision for their education. So as the lawyer, you would be the client, so I'm not able, putting myself in the position that the lawyer, and I know it's frustrating for parents, but we're not able to discuss it with you unless the client says, let's sit down --

>>>GAIL LUSSIER: She said it all the time.

>>>GAIL LUSSIER: I said it every single time, I want my mother here because she knows me very well, and there's some questions that I can't exactly get out there and she can. And the lawyer wouldn't even answer her. I was disappointed.

>>>CHRISTINE MARINELLA: I would be happy to talk to you.

>>>GAIL LUSSIER: Well it's over and done.

>>>CHRISTINE MARINELLA: that's okay. If there's something we could do to address what your concerns were, and use these forums to say, that's what happened in that situation because we see her as the client. But kind of starting off fresh, this is a different program, client assistance program, and again, you would be the client. But I just generally, if there's a family member, they would like to come in, we'll discuss that. But there are some issues of attorney-client privilege once you're in the room that doesn't always apply. So there are real reasons why.

>>>GAIL LUSSIER: I was up front with that person that I wanted my mother there the whole time. We didn't understand that.

>>>CHRISTINE MARINELLA: So we have this program that helps with not just educational issues but, as well as, vocational counseling program, and feels like you're not coming to an agreement of what the services are supposed to be. You tried to work that out and don't feel the agreement is being honored. We have a presence at ORS, Alex LaPlante is over there and has a good relationship with ORS and trying to make sure clients know their rights. And unfortunately, there are those instances where you can't negotiate, and we can advocate and become that, act as a lawyer for the person seeking services to try to get services.

>>>BARBARA MCCRAE: Do you have that social worker from DDD, the division of, I believe Peter --

>>>BARBARA MCCRAE: Do you know how much money is in your support plan?

>>>GAIL LUSSIER: About \$24,000.

>>>BARBARA MCCRAE: There's a program that runs out of, well out of East Providence, but throughout the state called Options and you can take your money, and you hire your own staff and you use the money.

>>>GAIL LUSSIER: I heard that DD would just fight that like crazy.

>>>JEANNE BEHIE: No, no. And we can meet with you afterwards and tell you about it.

>>>GAIL LUSSIER: I spoke to another lady who tried that and they were trying to take her child away from her.

>>>BARBARA MCCRAE: If you need help advocating for that, you can contact PAL, and I'll give you information afterwards because the Options program is running, and it would be nice if there are more people using it because it is a way to use your individual support money. If you can find the support yourself, you don't have an agency overseeing it, it's very difficult.

>>>JEANNE BEHIE: And supervise them.

>>>ELAINA GOLDSTEIN: Is she talking about Personal Choices, is this the Medicaid program?

>>>JEANNE BEHIE: No, this is DDD, funding for adults with --

>>>ELAINA GOLDSTEIN: Right, but that's not --

>>>JEANNE BEHIE: This is using this funding.

>>>ELAINA GOLDSTEIN: This is that --

>>>JEANNE BEHIE: It's hiring somebody to work.

>>>ELAINA GOLDSTEIN: Sort of like Personal Choices.

>>>FRANK SPINELLI: Through that program?

>>>GAIL LUSSIER: We're in the DD.

>>>ELAINA GOLDSTEIN: The DD waiver, that's probably it.

>>>FRANK SPINELLI: We'll talk later.

>>>ELAINA GOLDSTEIN: So we have it clear.

>>>FRANK SPINELLI: There's 154 slots within the DD waiver that people --

>>>ELAINA GOLDSTEIN: It's called consumer directed services.

>>>JEANNE BEHIE: That's a different program. You're talking about the one run out of PARI or something.

>>>FRANK SPINELLI: No, the DD waiver, 3800 people on the waiver. About 154 families were chosen to self direct services, to go through agencies like Options.

>>>JEANNE BEHIE: Okay.

>>>FRANK SPINELLI: Not the Personal Choice.

>>>JEANNE BEHIE: But the personal choice program?

>>>FRANK SPINELLI: If she's DD, she's already qualified. In all honesty, there isn't much, if you're having difficulty getting access to services through the DD waiver, you'll have difficulty with services.

>>>GAIL LUSSIER: So, you're saying that I probably would have a hard time doing the Personal Options if I with the DD waiver already?

>>>FRANK SPINELLI: No, I'm not sure who their network of providers are. They have a network of agencies that provide an array of services. You should probably talk to the case manager.

>>>ELAINA GOLDSTEIN: What Frank is explaining, if she's qualified to be on the Medicaid program through the DD waiver, there's like two components. The regular DD waiver, which is, you basically go through the agencies and sort of what you're doing it sounds like. Then there's another option that you have that if you want, you can sort of, as Frank -- it's called consumer directed care. So you're part of this DD waiver, but you can be directing your own care, or services. Hiring your own --

>>>GAIL LUSSIER: Like job coaches?

>>>ELAINA GOLDSTEIN: Yes. He said there's 154 people who are within the DD waiver who have chosen to do this but is there's a max, how many people can choose --

>>>FRANK SPINELLI: No, but there's limits on the services. There's a number of coaches, or --

>>>ELAINA GOLDSTEIN: That gives you another choice that is available to you now.

>>>CHRISTINE MARINELLA: Speaking of the division, you were raising earlier a question of home health care aid. I understand that in the past, they have done that

if it's appropriate, that's the sort of service they can approve and provide if it's part of your plan.

>>>GAIL LUSSIER: The DD, you mean?

>>>ELAINA GOLDSTEIN: Yes. You have this chunk of money now, so I could hire a nurse to come every week to check her, from that money.

>>>CHRISTINE MARINELLA: We're talking about two separate programs. But under DD, if you're eligible for services and you have a caseworker, I'm not as familiar with self directed care, but the other, someone to make a request for whatever particular service you're asking for. And if your funding level wouldn't be able to fund for that, that can be put into the plan and DD will actually arrange for a particular -- for example, nursing service to come in periodically. The situation I'm thinking about is very similar to the one you had posed so it has been done.

>>>BARBARA MCCRAE: You go through Peter and he puts in a request to services. You can get residential, you can get day, and then you can get family support if someone lives with their family.

>>>ELAINA GOLDSTEIN: Maybe even transportation could get added.

>>>GAIL LUSSIER: We have trouble with transportation for some reason.

>>>BARBARA MCCRAE: You're not alone on that one, not at all.

>>>GAIL LUSSIER: Especially if you need a wheelchair lift. We have a van that takes her around and actually, I should talk to you because it does say that she could drive the van herself. However she went to the hospital for about a year after she started driving and was going back to the hospital for month's time, so since then, we didn't know how to get her back to having driving lessons and get the van back.

>>>STEVE BRUNERO: South County Hospital is a new provider of drive evaluations. We can help with modifications with the van that's done.

>>>ELAINA GOLDSTEIN: Had your van been modified?

>>>GAIL LUSSIER: Yeah.

>>>ELAINA GOLDSTEIN: Well that will be a big help.

>>>GAIL LUSSIER: She needs to feel more comfortable driving. She thinks it's me, but --

>>>ELAINA GOLDSTEIN: Steve is going to be --

>>>GAIL LUSSIER: Steve has known me for how many years now, Steve, eight years?

>>>ELAINA GOLDSTEIN: See how the world works. There's one lady that has been sitting over here very nice in her peach shirt, we haven't heard from you at all.

>>>GAIL LUSSIER: I came just to listen and sit in. Thank you all for what you do. I just came to listen.

>>>ELAINA GOLDSTEIN: No questions for anybody?

>>>JEANNE BEHIE: No problems, everything is great.

>>>GAIL LUSSIER: I've been to a couple different states because my husband doesn't live in this state, and there are no places I've been that has the support that the state of Rhode Island has all the way around.

>>>ELAINA GOLDSTEIN: In spite of what you said, oh, my goodness.

>>>GAIL LUSSIER: If you find the right places to go --

>>>ELAINA GOLDSTEIN: one of the major issues you both brought up, not only knowing how to find out about everything, how do you find out and knowing how to find out about everything. That is really one major critical issues we have been working on and working on and have not solved.

>>>LAURIE BOYERT: First thing that surprised me, when I went to my son's medical director, he would say, this is where you go.

>>>ELAINA GOLDSTEIN: For my project perspectives, that is our focus next year, to do provider -- medical doctors. People talk about providers, they're talking about like job coaches, that's a different game. When talking about like physical therapists, occupational therapists, nursing, physicians, a lot of those people, all they know about when somebody has a disability, what they will do is encourage you to go on social security disability. They don't realize that all of these laws have been passed, that all of these other services are available. A lot of them do not know that, so that becomes one of those things that we are going to try to get throughout to the different societies, the medical associates to be able to start to educate those who are really your first line. I'm assuming you, too. And even the mental health employers to understand systems. There have been a lot of changes but if nobody knows about the changes to the system, nothing has changed.

>>>JEANNE BEHIE: When parents with kids with disabilities are asked who is the most helpful with sharing information, it's not the physicians, it's not the teachers, it's other parents. And I'll just give you an example of one of my experiences with a doctor. My son was born, and the next day, he was born with bilateral club foot, the next day, I noticed something wrong with his eye, and an ophthalmologist told me he was blind in that eye. Three months later, the ophthalmologist said to me, he's visually impaired in the other eye, too. And he walked out of the room. And I stood there with tears coming down my face, and I walked out, and I said, I know that there's some sort of organization like services for the blind in the state, shouldn't I be given, can't you give me that phone number? And that's how I got a number. But I was told nothing. So it's very unfortunate and physicians and nurses do need to be educated. And there's many initiatives in the state to do that. There's parent coordinators and advocates being put in physician offices to work with families. But it is other families that really are sources of information. And some of those phone number that is Elaina just shared about 211 and -- what's the other place?

>>>JEANNE BEHIE: The Point and Ask Rhody.

>>>JEANNE BEHIE: So we are working at trying to change it.

>>>GAIL LUSSIER: And I'm a nurse and I can't tell you how many things I did wrong that hurt her. You have, you know, everyone has different fields but they stick to that field and don't venture out to find out what's around.

>>>BARBARA MCCRAE: That's why it's important that you came because so often parents feel so isolated at home and they are not getting the information they need to get help. When we visit, it's amazing how many parents don't know the services that are really available to their children, you know. And it's like, you can't believe that they don't know it. So you try to provide them with information and contacts, but, so, it's really great because and I think there's a tendency for parents to try and contact everyone. I think they're so overwhelmed most of the time that they just want to stay in their house.

>>>LAURIE BOYERT: I'm only here because I don't work in the summer. If this was the school year, I couldn't come

>>>ELAINA GOLDSTEIN: Even at five o'clock, you wouldn't have been able to come?

>>>LAURIE BOYERT: Maybe not, I'm tired, I'm pooped out. And have I to concentrate when I listen. I have a cadre of people here all saying different things. So you have to focus. I'm glad you're down here in South County because usually these meetings are in Warwick or Cranston. I didn't grow up here, I don't know how to get half the places. Butler Hospital has a lot of great programs but they're a long way away at night in the dark in the winter. I can't go up there. I won't go up there in the dark.

>>>ELAINA GOLDSTEIN: The Commission is really good about that. They try to have a forum in all different parts of the state, I must say, and they did a really good job this year.

>>>LAURIE BOYERT: Luckily I take the local paper so I saw it.

>>>ELAINA GOLDSTEIN: Too bad -- last year, I think we had maybe another four or five people. We're going to be here -- I don't know if there's anybody else that would like to share or ask any questions, we're here until 5:30 because there could be someone walking in at 5:25 because they did work.

>>>LAURIE BOYERT: That's what it sounded like, could you drop in any where in between?

>>>ELAINA GOLDSTEIN: We have to stay here until 5:30. So, you know --

>>>ANNE LECLERC: And if you think of anything later, you can send in written comments, as well.

>>>ELAINA GOLDSTEIN: If you would like to, I'd like to get your -- there's certain things as we're trying to find out, I find out mostly what is really going on through people like you. This issue about the DD, you know, the different, the providers, one of the things that I do, Gene over there works with me, we have, developing a Medicare/Medicaid link database. And we've been working on this report, it seems like forever, but this report from 1995 to 2001 looking at people that are on both the Medicare and the Medicaid program. And when we did this report, did these different reports, you find out that when you're looking at the cost of care from the Medicare program and the Medicaid program and you look at people with disabilities as oppose today people that are senior citizens as opposed to people that are really, really old senior citizens and the total bout of expenditures being spent. A lot of senior

citizen would say people with disabilities get all this money and services that are provided to disability, senior citizens want the same thing if I take out the DD waiver population from people with disability and take out the costs affiliated with the DD waiver, people with disabilities actually get less money. I mean, less services respect spent on people with disabilities and are spent on senior citizens. So the -- now you could say, like Frank said, all of the service that are available to someone who is in the DD waiver surpasses, I think, any other program that's in the Medicaid program, isn't it, pretty much any program as far as the actual services available?

>>>FRANK SPINELLI: In terms of community supports?

>>>ELAINA GOLDSTEIN: For the term of community supports, which is all of the waivers, the point of a waiver versus the traditional Medicaid program, you're waiving what, you have to be someone that would be eligible to be in a nursing home. But, instead of being in a nursing home, you're going to get your services through this waiver. And the services will be home and community based services, so they're home and community based waivers. So when the waivers are developed, they have to make sure that they're going to be cost effective and each of the waivers, and there's what --

>>>FRANK SPINELLI: Six.

>>>ELAINA GOLDSTEIN: Six waivers. Each has different services available to it. And the DD waiver has been around probably, was probably one of the first waivers, right? And it does provide more services and -- so my first question was, interesting she would say this, my first question and I haven't met with Ellen Ellison (phonetic) yet to share with her this information to say, what are we doing -- because I've heard people in the past talk about frustration in being able to get people that want to be employed in higher paying jobs seem not to be able to get into the higher paying jobs because of the providers they're with under the DD waiver. And I could never really figure out what they're talking about. And over the last couple years, it's become really clear, I mean, job developers and all this terminology, I'm basically a health care person. So DD is very different than for me and the health population and very different for the physically disabled population. It's like, you know, different worlds. PARI and OSCIL predominantly deal with people that are physically disabled. And as far as the work environment goes, it's very different than these job developer people, isn't it?

>>>HAROLD FAYERWEATHER: Yes. You can refer them to the Office of Rehab Services, and in turn, ORS has also referred clients back to us based on what those needs are, whether for housing, you know, whatever it be. Basically an independent living center.

>>>STEVE BRUNERO: I and R is basically information and referral, so if we have a referral given from ORS. Basically, you would take, all that information may be able to be handled, everything from that call to making other referrals to other agencies. Like I say, we're all networking all the time. From the standpoint of direct services, we get involved with that depending on what those direct services are, what the needs are, and we advocate on behalf -- we want them to advocate on behalf of them selves. And then, basically, peer support. But you mentioned earlier about your daughter, I thought I was understanding like IEP plans, she's in school to 21. I'm saying even before 18, in the school system she was involved in, did they have IEPs for Special Ed. for certain equipment and everything else? You had to be involved with IEPs as a parent.

>>>GAIL LUSSIER: She was.

>>>STEVE BRUNERO: So, were there short comings then that turned you in the direction of Rhode Island Disability Law Center. So in some cases, what I hear about children in the hospital, well the physician may not give you the information you need, but even the social service department within South County Hospital, or social director there, I forget her name, but she's been very, very good over the years and made even direct referrals for peep toll OSCIL. Depending on the issues. And being involved with Steve for years. I'm pretty sure if Steve was involved with training, that also paid for your transportation to go to the training. That's part of ORS, too. So, it's a question of what do you want, what do you need and then being hooked up to the proper.

>>>ELAINA GOLDSTEIN: Did you know anything about the two independent living centers that are in Rhode Island?

>>>GAIL LUSSIER: We know PARI, OSCIL is --

>>>HAROLD FAYERWEATHER: And PARI in regards to the waivers, they've come up with the personal choice waiver. You or your daughter would run it yourself, you're the administrator. But PARI would have staff assisting you, so much money in the transportation, so much money is in to a nurse you want on a weekly basis to check the burns or whatever. And this gentleman, like he said, will get together and talk to you about the six different waivers. But that's just one option. Depends on what your needs are.

>>>GAIL LUSSIER: As a parent, sometimes you're not sure.

>>>ELAINA GOLDSTEIN: Right.

>>>GAIL LUSSIER: And you get so much stuff coming in.

>>>HAROLD FAYERWEATHER: That's true.

>>>GAIL LUSSIER: Confusing because we're not used to the terminology and the different, all the agencies sound the same. But they're different.

>>>ELAINA GOLDSTEIN: I want to you give your name and address, too. One of the things, at least from our, again, I've been involved in this now for seven years, working and trying to, every time we seem to sit down in other places, I look at it like an onion, you keep on uncovering the onion skin and it's one thing after a next. There's loads of material out there. A lot of times the materials tend to be what I call governmentalize, it's probably all very accurate, but it's like, what we try to do is put ourselves, and it's easy for me because a lot of these programs I didn't know anything about. Listen, I have a law degree and when they start, I don't understand it. And how in the world does somebody going through a crisis going to be able to get through all of this. So what we're trying to do, and I think we have our first outreach, this, you know, back to work, how to get back to work and had people at ORS look at it and see if it's something that's easier to read than a typical kind of material -- doesn't look like a government thing. It's really hard for, I think, people that are so involved in the actual law and implementing the program to find of get out of their talk. Medicaid, my gosh, you want to talk about a language all to its own. Medicaid -- code, 1619 A and B, you're supposed to know what that is, 1619 A and B of what? And there's terminology that gets thrown out there. And when you're so involved in running the programs, you sometimes forget the people that are coming for help, you know, have no -- and I think that's a sensitivity that needs to be reinforced, especially with the field offices where you would go and talk to people from Medicaid and other social services. You go to a field office, are those people really more sensitive to know, how do you interpret this. People don't know the services they want. How do we provide people information without inundating them with information about all of the possible service that is are available. So I think it's really important that when you have an opportunity to call somebody and the point is supposed to be very good at this that when you call, they have a sensitivity to be able to know to maybe ask you some questions that will help you describe some more information that then they could say from that, you know, there's other services available that you may not have known about that, might be useful. Very similar to what a lot of the people did up here, but that person that you call should be able to sort of ask you some leading questions that will provide them with some information that they can provide you back with additional information.

>>>GAIL LUSSIER: It would be hard on my end to take all of that. I know -- well we started with Perspectives, and because she was in the hospital for a year, they fired us, because I was working for them. And they also kicked me out of their .

>>>GAIL LUSSIER: And wouldn't let her back.

>>>GAIL LUSSIER: I supposedly didn't follow what they want, which I did.

>>>GAIL LUSSIER: Once you get someplace and you think you're fairly contractible and have a six-hour plan for the day that keeps a regimen and keeps your child busy, you really don't go any farther. You stay there because -- and the change is taking a chance of not having something as compatible for your child.

>>>ELAINA GOLDSTEIN: Do they have revaluations of any of these programs? You know how social security does their revaluation to find out if you're still eligible for social security.

>>>STEVE BRUNERO: As I said earlier, once someone is closed to ORS, they can come back at any time.

>>>ELAINA GOLDSTEIN: But it would be up to them?

>>>STEVE BRUNERO: They would come back to us because they lost their job or they're under employed, not working enough hours, maybe they've improved in their physical disability, whatever they have. People can come back. The question of transportation is a good one.

>>>GAIL LUSSIER: I called Cora .

>>>STEVE BRUNERO: Cora just came back last week, she's back as a rehab counselor.

>>>GAIL LUSSIER: I want you back.

>>>JANET SPINELLI: If you want to leave your number with me, I could have someone from MHRH --

>>>GAIL LUSSIER: Does that mean consumer choice.

>>>ELAINA GOLDSTEIN: Consumer directed plan, right.

>>>BARBARA MCCRAE: And how much money is in the plan, and then if you want additional residential support like you were talking about or if you wanted those to go into managing your own plan.

>>>ELAINA GOLDSTEIN: Any of the advocacy groups up here actually help a consumer through at no time consume I remember directed.

>>>BARBARA MCCRAE: We're learning more and more about options. We work with families to try to help them through it but I don't know how much success Dorian has had to have parents actually take the chance to move because it is scary to move and it's usually individuals who are just tired of trying to do it.

>>>GAIL LUSSIER: And also, your significant other there knows people around and doesn't want to leave because they have friends and they're afraid.

>>>JEANNE BEHIE: And that's a big deterrent from moving out because they have friends, they do recreational activities, and this will terminate that part of it.

>>>GAIL LUSSIER: And it's so hard to get any kind of friends when have you any kind of problem.

>>>BARBARA MCCRAE: You can call Dorian because she's really involved at looking at and sitting with families and going to agencies and really supporting families and people who are looking for changes in the services that they have. But we usually work with people from the DDD service, not usually people all the time in that kind of physical disabilities.

>>>ELAINA GOLDSTEIN: I think she is.

>>>GAIL LUSSIER: Is there an agency, we were talking about it being so hard to help, is there an agency that has, in the state that -- we were talking about, job coaches that were trained and they have a list of those people, or is that --

>>>JEANNE BEHIE: And are they in southern Rhode Island?

>>>STEVE BRUNERO: The expansion contract I was talking about earlier was with Goodwill Industries, they do not have -- they used to have a satellite here in this building at one time, but they opened up an office in East Bay, but job coaches can go statewide. So if you chose a waiver program or if you came back to ORS and Sabourin needed a job coach, we would pay for that. And that person would come down.

>>>GAIL LUSSIER: But you have a list of people.

>>>STEVE BRUNERO: There's three or four new job coaches through that grant. So, there are some other options.

>>>GAIL LUSSIER: This sounds like a personal one-on-one.

>>>ANNE LECLERC: Life Inc.

>>>STEVE BRUNERO: That's East Bay and they have -- Rhode Island people hate to come across the bridges, but there are a number of job coaches that are available for Sabourin. And when we meet we can talk about different options. I'm glad you and Laurie came here today. I'm hearing about programs and services and I've been in the system for over 30 years, that I'm un aware of. So I can imagine how difficult it is for you guys. But we're a small state and it shouldn't be as difficult to navigate as it is.

>>>GAIL LUSSIER: A lot better than other states. They wanted to put her in a nursing home.

>>>STEVE BRUNERO: What I wanted to say, I'm glad we came here today to talk about concerns and issues you have. And being a small state, you have a face and a name, and you can pick up the phone and talk to a Jeanne Behie or Steve Brunell .

>>>GAIL LUSSIER: We're running a job fair through Rhodes to Independence, and it will be publicized through local newspapers and on TV. We've have resources and training personnel on hand to help, that you might need to get another physician, and

this will be some time in October. We haven't confirmed the date yet but more than likely it will be at the Sheraton on Post Road is where we're hoping to have it.

>>>GAIL LUSSIER: Just a short story, even with things in place -- my son had a job lined up to be a dishwasher at the Brighting Commons, and they were all, this looks great. But he had to take a drug test. He takes six medications so he got freaked out and couldn't pass the urine, so went back to the guy and said, I couldn't do it. And the man said, it's okay, take another one. Very nice. My son goes back, walking. Doesn't drive, so he has to go back to this agency in Wakefield, he has over diluted his urine sample now, and it's not valid. This is the second urine test, and then he goes back. And by then, he's completely not functional, can't do it, so he loses the job. And that's the story of his life. And so those are the kinds of things he goes through. We just put our hands up, and like, oh well, that job is done. And that's a job he could have done. He probably could have succeeded with that, but it's closed to him now because he couldn't urinate on command.

>>>ANNE LECLERC: They couldn't come up with an accommodation?

>>>GAIL LUSSIER: By then, no. They did, they accommodated him three times, but the second test he over diluted the sample, so that didn't -- the whole thing, it's just to show you the kind of things that happen that don't happen to anybody else it doesn't seem like. My son was walking to South Kingstown High School, I think you were in his class, because I was irate with him one morning, and an animal bit him in the leg, he didn't look, but as a result of that, he had to go through rabies treatments because he didn't even look. So it's just, it's like another world. And it makes us crazy.

>>>BARBARA MCCRAE: Something else you mentioned earlier, too, is as you get older, this comes up a lot on our visits. As parents get older and children are still living with them, finding housing and places where they get the support that people need is really tough. That's another issue, first I need medical.

>>>GAIL LUSSIER: I think there's a housing authority, my daughter was on a list for about three years, and she was eligible, and then she was sick and in the hospital for a long time. Then they put her back on the list and it's been eight years for her to get out and get her own apartment. But I think I've given, she's just going to stay in our house and I'll move out.

>>>BARBARA MCCRAE: Housing is a big problem.

>>>JEANNE BEHIE: Just not enough low income housing, especially in South County.

>>>ELAINA GOLDSTEIN: Anybody know about -- can you talk about the housing bond?

>>>HAROLD FAYERWEATHER: I can't give too much about the bond.

>>>ELAINA GOLDSTEIN: Rhode Island housing works, the Rhode Island foundation, sort of the organization that ran this, it's called Rhode Island housing works. And they ran a campaign, you probably voted for it this last election about the housing bond that was available. One of the things we were very involved in I'm sure a number of the organizations here were very involved in getting that passed was, we wanted to be sure there was housing being developed for people with disabilities. What we did was when the regulation, it was time to write the regulations, we worked with the Commission and we worked with, actually the senior agenda to make sure there was going to be housing developed, and the ability to have the, the terminology is not accessible, it's -- I wanted universal designs, maybe it is accessible, but ways you build a facility in case she needs grab bars, things like that. The actual building itself would be able to hold on to them. And it doesn't cost as much money as if you have like a house that doesn't have sturdy enough walls. In any event, this was all put into the housing bond legislation so that anybody that will be building new apartments or homes has to meet these standards that are out there. So, I believe -- I'm not sure how soon the housing, you know, bond money is going to go out to the developers, but I'm sure they're in that process now. Do you use the computer at all? Housing -- RI Housing Works, a lot of information. They just put out another fact book. The other thing is that Rhode Island Housing, and I want to you contact Rhode Island Housing, they have, we were just working with them with different programs that are available to actually do home modifications.

>>>GAIL LUSSIER: I've already worked with them.

>>>ELAINA GOLDSTEIN: Because Rhode Island Housing is going to be very involved with the implementation of the bond program, so there might be somebody there that can talk to you. We're going to be working with them and helping fund something called the

housing locator. Once this comes up, it should be unbelievable. Because right now, unfortunately, what someone has to do to get into affordable housing is go to each one of the specific housing authorities, which there's a whole bunch of them throughout the state. This housing locator is something that you would go onto and you would be able to find all of the different housing, apartments. And in, not only apartments, but also homes which doesn't seem to be your problem, but apartments available through the state. It's a software program that has been developed and works in many other states. So that's what we're purchasing, and Rhode Island Housing would be the one that is the keeper of the locator. It's not here yet, but we're right in the process now of going through all of the governmental work that has to go through. I just want to give them money to buy it already. You would think I have the money, why can't I just give it to you now, buy it already. Talk about being frustrated. But we are very, very close now to coming up and providing something for people in housing, at least, that is going to be wonderful. So not here yet, but it's coming.

>>>ANNE LECLERC: I urge people if looking at housing and don't drive, pay attention to the new housing developments that come out with the bond issue. They're often located away from existing services including fixed route bus services, which means no transportation. This is an issue we keep pointing out, affordable housing often has people included in it that happen don't drive and if it's located away from bus routes, we don't have money to expand, unless you're going to be giving us money to expand services. Not all housing authorities are on bus routes so that's something to pay attention to.

>>>GAIL LUSSIER: Rhode Island Housing helped me. I sold a raised ranch, a child with a wheelchair, and there were only two lots I could find, it was within three-quarters of a mile.

>>>ANNE LECLERC: So if anyone needs to check -- it's not driving distance, so, no one can check it for you. We had an unfortunate incident where someone told them they were not and she quit her job which was across the street from the Kent County Court house that has tons of service. Please check RIPTA or RIDE . We have people over the corridor, over the bay, you wouldn't think. Highways don't count. 95, any where a bus can't stop. You can't stop along the highway. But we'll check it for you if you have any questions, if you're looking for housing or someone is looking for housing and we'll rely on the ADA corridor. But please check and don't assume because we had an unfortunate circumstance where people were out who thought they were in.

>>>CHRISTINE MARINELLA: I would just like to go back to the surveys. And I'm going to ask, these will be out at the front. And even ask the panelists if they could go over it and --

>>>ELAINA GOLDSTEIN: We can do that now unless anybody else --

>>>CHRISTINE MARINELLA: Don't feel compelled. If you don't want to fill it out, you don't have to. And the back is optional if you want to identify yourself.

>>>ELAINA GOLDSTEIN: If anyone would like to speak individually up here, please feel free to do that. We'll be here until 5:30.