

## 2015 Public Forums on the Concerns of People with Disabilities and their Families

Governor's Commission on Disabilities, John O. Pastore Center, 41 Cherry Dale Court, Cranston, RI 02920  
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July 28, 2015 Warwick Public Library

BETH PINKHAM: Can everybody hear me okay? Good. My name is Beth Pinkham from Ocean State Center for Independent Living. We are hosting the forum here this afternoon. I want to welcome everybody. The purpose of the forums is to identify concerns that people with disabilities and their families have in the state of Rhode Island. So that the state can develop programs to improve the quality of lives that persons with disabilities can live. To ensure everyone has a chance to speak, please if you have comments, keep them short and to the point. If there's more information that we need to give, we will be able to meet with you afterwards. So please, you know, keep that in mind. After the forums are completed in August, they will be used to help develop the agenda for the year for the commission. That way moving forward, whether there's legislation that needs to be proposed or budget issues and so forth they will be able to do that. They will be on the website, posted on the governor's commission website probably by November. So you can keep checking for that. And also if anybody wishes to register to vote or change their voter registration, we do have a staff person from Rhode Island Disability Law Center here this afternoon to help you out with that. So I am going to pass the mic on down the line and let the other panelists introduce themselves and let you know where they are from.

JANE CANNATA: Hi. I am Jane Cannata from Office of Rehab Services.

BOB FRICKLAS: Welcome, everyone. I am Bob Fricklas. I am from Meeting Street.

DEB BELANGER: Hi my name is Deb Belanger I work at Rhode Island parent information network.

KATHY KUIPER: My name is Kathy Kuiper. I work at the office of special healthcare needs Department of Health.

MEREDITH SHEEHAN: I am Meredith Sheehan, communities program for the National Multiple Sclerosis Society.

KATE BOWDEN: I am Kate Bowden. I am a staff attorney with the Rhode Island Disability Law Center.

BETH PINKHAM: And just as a bit of housekeeping, if anybody needs restrooms or anything, if you go out the door you came in and go to the right, you should be all set there too. So again we are here to listen this afternoon. We will start with folks that checked in that they have a comment that they would like to make. The first person that we have is Barbara Henry. We will let you -- why don't we bring the mic down to you so everyone can hear.

BARBARA HENRY: Hi. I am Barbara Henry. I am -- my first concern is I am blind and I cannot drive and I take RIPTA, the bus. I take the bus and I take the RIDE program. Can you 

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 hear me? Okay. So my first concern is the RIPTA bus. It is not really accessible for someone who is blind. For instance, at Kennedy Plaza, when I wait for the bus, which is every day, multiple times, sometimes throughout the day. When the bus pulls up, I have no idea what bus it is. For anyone else here who is blind or legally blind or maybe elderly who is just their sight is a little off, it's stressful. There is no -- they do not announce the bus. And I feel that they really discriminate

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against anyone who is visually impaired or maybe if you are even print disabled or anything to that matter. So I have to go and just ask people what bus this is and I feel like it places my safety at risk. And now its summertime there's more people at Kennedy Plaza. And I have some people that appear to be just a little suspect that come up to me and say oh, I think that's the bus you want to get on. And I don't really appreciate that. I really feel that RIPTA does discriminate against people who are blind in terms of this. They renovated Kennedy Plaza. They put on the bus stops in Braille the bus stop letter. But they didn't put the number in Braille, which I don't understand for the life of me. That makes no sense. So I still don't know -- I have to ask a total stranger what bus stop I am at. So I really feel that I just feel every day when I take the bus, also when I get on the bus. Today, for example, I waited at a bus stop for years the bus stop was physically there. They removed the bus stop. I'm not aware of that. And so I'm standing there with the assumption that the bus stop was there. And they removed it. How am I supposed to know that? The bus driver stopped but who's to say the next bus driver wouldn't have stopped? These are some real concerns I have. I feel that RIPTA does discriminate against people who are blind. Thank you.

BETH PINKHAM: Thank you, Barbara. Next we have Heather Schey.

HEATHER SCHEY: I am Heather Schey. My biggest concern is transportation but it's Logistic Care. I have a twin who is also visually impaired. And I have also been left -- their cars are not qualified to be on the road some of them. My sister was left waiting for her ride with Logistic Care for four hours.

Transportation

My sister was also told on an appointment the morning of they couldn't get anyone there because they just didn't have enough drivers. I think that Logistic Care needs to go back to RIDE to become effective again and it was very efficient. My sister needs counselling and she will no longer use Logistic Care. And is on SSI only, can't work, and doesn't have the money for our RIDE program, which is one of the highest in the New England area for \$4 each way. So I just think that Logistic Care needs to go back to RIDE. I think the contract needs to be broken, whatever that takes. Because the other point was I didn't -- when Logistic Care was contracted out, I, myself didn't know when it was or how that happened. And I think it was a surprise to a lot of my friends who are now stuck with using it if they don't have enough money to use RIDE to get to their appointments. If people think that Logistic Care is running smoothly, it's not. It's that the complaints were never heard or never dealt with so people just stopped complaining. Thank you.

BETH PINKHAM: Thank you, Heather. Next we have Kristin Clark. Here you go.

KRISTIN CLARK: Hi. Kristen Clark. I am actually here for a friend of mine. She and her son are both disabled. They are on SSI. They got -- they were found eligible for Section 8 and SNAP last year. And the SNAP office at least the Wakefield SNAP office has piles, piles and piles of folders. I mean you can physically see them in the office. And my friend has gone through a really traumatic experience dealing with SNAP because they don't have enough staff there. And I don't know if the people who are hired are hired to be difficult and belligerent or if not having enough staff makes them so stressed out that they become belligerent. But my friend is not one of these people who come in with an attitude. She's very respectful, very polite and she has experienced nothing but hostility from these people. I helped her with the initial eligibility process

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for SNAP. She got it and that was okay. There were some problems with the SNAP card not working sometimes when she would be at the market, which was a humiliating experience. And that was food that was going to be wasted because it had to go back to wherever. And then she received her recertification packet in February from the Providence SNAP office and the return address was Providence SNAP office. So she sent all her information back to there. Her appointment was a phone appointment. Her original appointment. She did miss that. That was her fault. She called and apologized and made a new appointment. The letter she received confirming the time and date of her new appointment stated that she could either do the call or she could go into a field office. But she would need to get there at least half an hour before her scheduled phone appointment. So she wanted to make sure there were no difficulties so she had all her paperwork with her. She copied everything. She copied bank statements so she could show everything to show that she is eligible. She got to the office. The Wakefield office. And the woman who came out and waited on her, I just couldn't believe it. It sounded like something out of The Twilight Zone. So hostile. Well, you sent it to the wrong office so I can't do anything. And finally she agreed to take her in. And she looked at her computer and said, oh, you are getting the call now. Since you are not there, your benefits are going to be cancelled. My friend started to have a panic attack. She didn't understand why this person was so hostile to her. And she said but I have all the information and I thought that it was going to be in the computer and would be put in the computer from the Providence office, so that any field office would have it. And Wakefield is her home field office. And the woman said, it takes weeks, months for the information to get through. That's why we prefer the phone appointments. That's not my friend's fault. So she -- she was left with no idea of whether she had -- she was going to receive any food stamps for July or not. Oh she was also told that she had not given information about how much she pays for her Section 8 as opposed to how much Rhode Island Housing does. She did. There was no room for it on the original form so she put a sticky note on it. The person who did the intake for the original eligibility determination saw it. But he made a mistake and he put in the total amount paid by Rhode Island Housing. The combination of Rhode Island Housing's amount and her amount. They based how much -- what amount of food stamps she would give her on that and they blamed her that they made the error and they told her she would have to pay it back. She's on SSI! Her son's on SSI. She doesn't have any disposable income. There's no way she can pay this back. So she's just a mess. And again, it may not be totally these people's fault because they are in a no-win situation. They clearly do not have the staff to handle the amount of paperwork that's coming into them. But at the same time they don't have to be nasty. While she was there for her appointment she saw some other people come in who needed a translator and they had a toddler with them. And the two people there, one person was going to call the translator and the one who dealt with my friend said oh well, I will get to it and she left them there for an hour, and with a toddler. It's hard to occupy a toddler for an hour and keep them out of trouble. So I just was stunned by this whole process and I was so glad -- my son is also disabled. Perspectives are his service agency. I received a letter -- well he received a letter in the mail to inform us of these forums. I was so happy that these forums were going to be taking place because it's hard to get the word out, which do you talk to, and who can pass on the information to the pertinent people. So that's why I am here. Thank you.

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BETH PINKHAM: Thank you, Kristin. For anyone who just came in, is there anyone who wanted to comment to the panelists at all? Did we get to everybody? Oh, okay. All right. Does anyone have any follow-up questions or comments or anything?

AMY STONE: It's Amy stone. I was just curious as to how come there's no one from BHDH on the panel. That's a big issue I thought they should be here.

ALYSSA: They are coming to the other ones. It's just --

AMY STONE: I did the wrong one. I understand.

BETH PINKHAM: If you check in they can tell you which ones.

AMY STONE: Thank you.

KATE BOWDEN: Can I make a comment? Please don't allow that to dissuade you from saying anything because this will be transcribed and they will be made aware of things that are said. So we hope to hear from you if you have concerns.

AMY STONE: Sure. I will stand back up {LAUGHTER}. Thank you. I would say I guess my concerns fall within the education services and the transition within to adult services and I'm curious as to your take on this within your schools as to how things are going through that because of the consent agreement with DOJ and things in place it's a scary time for are families that are transitioning their children into adult services because the service providers are in a really tough place and aren't really able to provide services for the newly transitioned group age of students coming through. And really its self-directed supports seem to be the only option for them. That's a scary thing. And with all the changes with the Employment First Initiative, things are just a tough time for those families right now, for the students that are 18, 19, 20, 21, 22. Some are still sitting at home and I was just curious as to -- I think BHDH has made some improvements that I've seen regarding having assist schedule earlier, getting materials earlier, but even though they have that, there's no place to go afterwards. Also with the adult providers having to change their sites to be integrated as opposed to the segregated options which is wonderful for some, absolutely, and very difficult I think for other students that really need that space and that time for part of their day. And I was just curious as to where we might be heading in the next nine years of our ten-year plan with DOJ. That's all. Thank you

Independent Living

BETH PINKHAM: Thank you. Any other questions, comments, follow-up from anybody? Quiet crowd today. Okay.

JIM HICKEY: Anything you say here they follow up on this is this what happens? My name is Jim Hickey. And a friend of mine is on -- well, I've seen a lot of people on Section 8 and I don't know if this involves that. I am just going to state it any way. And when we went down to the office for this person on disability, in a wheelchair with no legs, but when we talk about the Section 8, the guy says, I told him that the landlord that he's with now -- we tried to get him to a different kind of housing.

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He said well you give up the Section 8. It's a gold ticket. You don't want to do this. They keep trying to talk him out of it. The guy really can't deal with this because the landlord he's with has to get extra money. When you get Section 8, I thought they get a certain percentage, 25 -- I don't know what it is. I know it used to be 25 percent. And he's not the only one. This is prevalent throughout the Section 8. Landlords request extra money on the side for these Section 8's. When I talked to this guy -- oh I never heard such a thing. There's no such thing. Really, you are behind the times. You are not out with it. You are not out on the streets. This goes on -- and if I know about it, like three or four different cases I know it must go on, on and on. So I just thought I would bring that up that extra money is being put out for these people to get these homes that are on Section 8, and that really lowers their income even more. So not only are they paying 25 percent, they are giving out an extra couple hundred dollars. I know that for a fact and why people here -- why nobody else knows that, I don't know. I mean, all you have to do is ask a few people out there. They are afraid. This guy's afraid for his life and this place that he's at. He's afraid they are going to do anything. They take dogs and they mess in front of his door. What they do is unbelievable. So I've taken a personal interest in trying to help this guy get a decent apartment. They are trying to put him in a place where there's no handicapped accessibility. They keep trying to talk him into this. The guy is really -- I mean people in that disability -- I don't understand it myself because I am not disabled. But I can see it in his eyes that he's scared and afraid to do anything. Jim, don't say this. Don't say that. Don't do this. But there's just a point where somebody out there really has to step in and watch over these people because they are scared. Thank you.

BETH PINKHAM: Thank you. Any follow up with that or any further comments, questions? Again, for folks that just came in, I don't know if anybody has any comments or any issues they want to bring to the panelists today. If you can just state your name, please.

WILL BEAVAOIN: Sure. I am Will Beavaoin, I guess the concern that I have has to do with the whole Medicaid redesign and the lack of people who receive services that are involved in the process of Medicaid redesign. I know that the people who are doing the work, sure after all have the best intentions. But a key constituency is missing from the table and I find that very concerning. So, I'd like to bring that forward as an issue. It becomes very frustrating to try to advocate when you are not at the table. So, part of the problem has to do with the fact that from the beginning, the constituents haven't been at the table. So all this has willed forward. Lots of new things have happened and people who are involved in the everyday life of having disabilities are not allowed a voice in what happens except in a reactive way. So we are already behind. We can't catch up. Everything is always reactive. So I think it's an important issue. Thanks.

BETH PINKHAM: Thank you. Any questions, follow-up, anybody? Again we have a quiet group today. Anything any of the panelists want to add while this is going on? Well, as we said, all of these comments will be taken into consideration and the transcript of today will be posted on the governor's commission website in the fall. Probably around November. So you will be able to see, you know, that comments were brought forward and go from there. We will be here, you know, for a little bit yet. So if anybody wants to stay and ask any of us, you know, more individualized questions or whatever, you know, we will be here. Otherwise, thank you for coming today, everybody.

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KRISTIN CLARK: One question, the paperwork I got said this is from 2 to 4. I don't know if other people will be coming that couldn't come.

BETH PINKHAM: We will be here until 4. Anybody is welcome to say that wants to stay until then. But yeah, we will be here until 4 if somebody comes, we are scheduled to be here from 2 to 4 but I don't want people to feel held up if they said their piece or whatever. Yes, Barbara,

BARBARA HENRY: I have one more thing I would like --

BETH PINKHAM: Let me bring you the mic.

BARBARA HENRY: Hi, my name is Barbara. I have another concern I'd like to bring up regarding RIPTA and also the RIDE program. I have been going to meetings and RIPTA is proposing that all disabled people come this October pay a dollar. All disabled and elderly passengers pay \$1 every time you get on the bus. I don't know if anyone here is aware of that. And if the bus goes -- my concern is also -- I also take RIDE. That RIDE will go up. And I'm sorry, a young lady over here mentioned that it is true. We pay one the highest prices in New England for RIDE. And if RIDE goes up to \$5, that's a lot of money to go one way on a RIDE van. So I just really think that for most of us here who cannot drive cars and you really rely on, you know, RIPTA or RIDE to get around, I really hope that you will really just advocate your concerns because they are really pushing for this, come October that everyone who is disabled or elderly, and you do pay \$25 for that bus pass. It's not free. That we are going to pay \$1. So I do believe that RIDE will go up. Thank you.

Transportation

BETH PINKHAM: Thank you. Any -- anybody else? Comments? Follow-up? Questions? As I said, we will be here until 4. But thank you all for coming and -- we will see where everything goes.

BETH: I have one more person who wants to make comments. So I am going to let them go.

DOUGLAS WOODWORTH: I am Douglas Woodworth and I am Deaf. I was at Rhode Island Hospital last month. I had surgery. And the day I was being discharged, I asked for VRI, which is video relay interpreting. It's a TV screen where there's an interpreter there remotely. And it wasn't available. They had to wait for an interpreter to actually come and interpret for me for my discharge which took a couple hours. I also had a friend waiting to give me a ride. I felt like Rhode Island Hospital should have the VRI service as back up to a live interpreter because as its needed, there's quick access. For example, another hospital like Kent County does have a VRI services. So I think that Rhode Island Hospital should have one as well. Thank you.

Accessibility

BETH PINKHAM: Thank you very much. Okay. We have one more person, Trent who has a comment to make. Let me just give you the mic. State your name and we will be all set

TRENT FERRARI: I am Trent Ferrari. And my concern is that people with all kinds of disabilities that have a placard that park in handicapped spots. It is such an issue for me because every single where I go and there isn't a day that goes by that I do not go to a parking lot in Rhode Island. I have to say that people in Rhode Island are incredibly

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uneducated and rude about people with disabilities. They don't care. They are disrespectful to them. And they put their shopping carts in the handicapped spots all the time. They have two good legs they can't walk from here to there. I put it back where it belongs. I have MS. I used to be a runner all my life since I was 19 and now I have MS. Okay I had to work through it and get through issues. But I am not a miserable person and I don't go blaming anyone else for it. I do what I've got to do and most of us do that. But people that are so entitled that they think that they can put their shopping cart last week at Dave's same thing. She gets out of her car over here she puts her bundles in and she gets out and she puts it right in the one next to me. I was sitting there because I had just gotten right back in. Of course I got out of my car and I said you are not going to leave that cart there. And she looked at me and I said you have two good legs, use them. You know, I am sick and tired of having to police what the police should be doing in this state. And in wintertime I go to Trader Joe's and they plow all the snow in the two little handicapped spots that they have. I go in there and I say to them, look out your window. Look where you have them plow the snow. Oh that was a big mistake. I am sorry. But it sat there for three months because God knows the snow didn't melt that easily this year. And you know, every single day it's a whole other issue. Today I was reading on Facebook about -- I don't know exactly where it was because I was in a hurry reading it trying to get into an appointment -- but Starbucks, okay, they banned a gentleman from going into their store because why? He had issues of people that are parking in the handicapped spots and Starbucks said you are banned from coming in here because you are harassing our customers. Now this has got to stop. I mean, when is it going to stop when people are aware? I read when Channel 10 did their thing about a year ago about it; that the people that wrote back on-line were so nasty saying you are nothing but a bunch of fat entitled people who are too lazy. No. This is not the case. We are disabled people and I would love to park at the end of the parking lot and walk in. And sometimes I will say to someone as they are going in, would you mind taking this cart or do you need a cart? They are like no. No thanks. I am all set. Whatever. They never think that the reason I am asking is so I don't have to return it and you know, God forbid anybody help anybody. This is my pet peeve is the placard is never enforced. I went to Wrentham and I parked in a handicapped spot in Wrentham. I got a \$350 ticket because my Rhode Island sticker had expired. I mean, and I am -- it's funny. It's weird because I am always the one yelling and screaming about all this stuff and I am the one who gets \$350 ticket. So I quickly renewed it and sent it and they let it go, of course. But it's just to the point where it's just unfair that they don't enforce the law and so many times I went to the compassion center one day. Get it, the compassion center. Okay. Some guy was parked in handy capped spot and I said to him, excuse me, do you have a placard. He said to me, go F yourself you F and Fn J. And I am like really, well I guess that's a no. So get the hell out. You know? I am just sick -- this is how I get. I get crazed and every single day, twice a day, Stop & Shop where to do they put the handicapped spots? The middle of the building where there is nothing but a big long wall and where the doors are, of course, there are two. And I think it's because the parking lot people that run the parking lots make so much money on the parking lots because I complained to Dave's and Dave's said we don't own the parking lot. You have to take that up with the parking lot people. Of course they pass the buck because nobody wants it deal with the issue. However, I asked them why is it that they are so far away when there's so many spots right next to the door and the handicap is over there. Like what good does that do handicapped people in the snow? In the rain? Or in hot weather or in any other time? So these are my pet peeves and thank you. I will give the floor back to someone else. But we have to do

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something about this because I'm tired of fighting with people over this and I seem to do this all the time with people. It seems like I constantly have to chide someone about being in the wrong place. So

BETH PINKHAM: Thank you very much

TRENT FERRARI: Yeah, well, thank you

BETH PINKHAM: Any follow-up, questions, concerns? Okay. Well, it's on record now. So thank you.

TRENT FERRARI: I am glad it's on record. Does that mean something will be done about it? Will there be more enforcement? Will there be a push towards having policemen all the time. People have threatened to beat me up because there was a guy sitting in a car one day waiting for someone and they didn't have -- it was Stop & Shop they didn't even have a card. I said do you have a card and he started calling me filthy names and acted like he was going to get out. Yeah -- and I'm like, so I got my phone out and took a picture of the license plate and said I will call the police on you. He says you do and you will be in big trouble. Well, you know what? This is absolutely ridiculous. My life shouldn't be threatened because I'm asking them to do something that's right. And it's totally unenforced and that's my beef. The cops are always ready to ticket you if you forget you're directional. But something like this that's really important to a lot of people in this state, they could care less about it.

DEB BELANGER: Can I ask a question? I just want to ask, is there -- because I don't know this. If there's a phone number where we can report those. Is there anywhere other than -- that you are aware of or anyone else is aware of?

TRENT FERRARI: I have no idea. But you know, these parking lots as I was going to say and I had kind of got by me -- they have to meet a specific quota for I guess -- these parking lots are a mammoth, Accessibility okay. And they have two little spots. And then the rest of them, they put over there so that they meet their quota. But putting them over there, just because they are meeting a quota does not help the people of Rhode Island who need them. Okay. All the ones in the front should be handicapped. I don't understand where they are coming from that they think that way. They are obviously not handicapped, okay.

BETH PINKHAM: Again any questions? Any follow up? Anybody have comments? See what the next hour brings.

TRENT FERRARI: Look I just want to say one more thing because I don't want this to be about me. When I do this, I am vigilant. Not so much for myself. I can actually still walk. It's difficult but I can. I watch other people that pull up that are in wheelchairs, that have real special needs and it angers me. You know, okay. So for me it's an inconvenience and that's fine. I mean, it's not fine. But nevertheless, there are so many people that have real special needs in this state that -- that makes it so difficult for them to just go out and go to the market. Every day easy thing that all of us do every day that we don't think second thought of. And these people it's an actual outing for them. For them

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they have to really work out and go in to get their groceries. They shouldn't have to work twice as hard once they get there. So it's about other people, like I'm saying. I don't feel special and entitled. I'm saying in general people need to be aware.

BETH PINKHAM: That's good. I think -- all right. I think we will -- again, we appreciate people's comments and we will be here if anybody wants to come and talk with any of us about their specific information or questions. We will be here until 4 just in case anybody else pops in. But again, thank you, everybody.

TRENT FERRARI: Thank you for having this. As you can tell I am bubbling over the top with this and I have had nowhere to put it. And when I saw it in the paper, I thought, oh my God. This is like my prayers have been answered. Somebody might listen, you know? So I thank you all for taking your time and this day to come here and actually listen because I think we need more of this to be able to get along and communicate and just to hear what issues that we all have. Maybe not everybody shares them but if people are more aware of it, they might be a little more kind. I think they don't really -- they are not doing it to be mean necessarily. They just don't think of it because they don't have that problem. You know? So I just think that it's great that you are all here too.

KATE BOWDEN: Thank you.

TRENT FERRARI: I know you do. You wouldn't be here if you didn't get it. All my friends are sick of hearing it, really. Here we go again. But no --

WILLA TRUELOVE: Hi, my name is Willa Truelove. Okay. Thank you. You can tell me to slow down or whatever. My comments today are about RIPTA and I feel like people in the state need more access to transportation and facilitating those processes. The Governor's Commission on Disabilities and The State Rehabilitation Council need to talk about what customers of RIPTA who have disabilities are needing to be able to go back and forth with the people at RIPTA because transportation is definitely inadequate at this time and we need to do better.

Transportation

BETH PINKHAM: Thank you. Okay. We do have within more person joining us for comments so I will turn the mic over to Carol.

CAROL DORROS: Carol Dorros. I just want to thank you for having this forum, first of all and I am sorry that I am coming late. I was interested in hearing what other people had to say but I didn't make it for that part. My son is 19 years old, about to turn 20. And biggest issues are significant cognitive and language delay and hearing loss, which deafness which contributed to that most likely, with some physical pieces that are less important. But so my understanding is this is a forum to talk about concerns

DEB BELANGER: Statewide

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CAROL DORROS: Statewide concerns. Okay. So we are entering into the adult world. And what I find concerning is that although there's been some wonderful work, particularly by RIPIN to help people understand what you need to do, it's very helpful. But I feel like it would be helpful to have a guide person, a person. There is a guidebook. I know there's a guidebook. But it's very -- you know there's a lot that goes into the next planning piece for your child with disabilities. And I really would love to have a personal guide, person. I'm not exactly sure how that would happen. You know, I'm sort of seeking out various people to find the people who seem to think like I might. But anyway, so that was my biggest concern. And my other biggest issue is employment, which I'm sure is a comment you have heard many times. I'd like to understand what the benefits are to employers who hire people with special needs. My understanding is that there are some tax benefits. But making those as well known and making those benefits significant so that -- because my question is why would they hire my son, even though he does have a lot of great characteristics when there are so many people who don't have jobs, you know, who may have more cognitive ability? Now he does bring other things. I understand that. But I think employment is going to be one of our major issues. Those are my two biggies.

Independent Living

KATE BOWDEN: May I ask a follow-up? You mentioned a cognitive delay. So I don't want to get too much into the detail of the disability itself. But is your son a person who you would hope would be headed for the adult services through DDD, the division of developmental disabilities? Is that something that has been discussed with you? Yes. So you would hope to have more hands-on guidance in the transition from school support to the adult services world, is that what you are saying. I see you nodding, yes. I think that's a very valid issue to raise and it will be in the transcript and this will be forwarded to legislators and decision making folks.

CAROL DORROS: I have one more thought. Thank you so much. I think it's really terrific that there was the expose a few years ago and things were changing in the state. So my bent is towards having folks be as integrated as possible in the world, in general. And I've been surprised at how calm the organizations I've been dealing with, which is a limited number, seem to be about the changes, which is great because they must have it under control. However, we went to meet with the organization we have been working with -- I guess I'm concerned about having an agency be willing to take us on because my understanding was, you are supposed to go and interview the agencies and you know, figure out the one that is right for you. We have been working with this agency for four years and then we went to meet with the adult people and they are like, well, we are -- we are really not sure we can take you. I'm like, really? Now, of course, that could be much more complicated than I am understanding, you know, that it's about his needs or something. I didn't get that impression. It's more about they're kind of full. So just a concern about quality agencies being able to meet the needs of folks that are out there. Particularly if you don't want to do like a full day program. Like if you just want to do something like we just want them to be work support. We are thinking about doing self-directed. So that's my other concern that there are quality agencies and that there's enough to go around.

Independent Living

DEB BELANGER: Can I ask a clarifying question? I have my own -- {LAUGHTER} I don't know if it's on though. Okay. So I just want to -- the last point I just want to state back to what I think I am

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hearing you say is we need to have agencies available for families, number one, that many -- some of them are full. But they also have the flexibility and the supports available to do kind of creative thinking around adults. So that we are not maybe just putting people in little boxes, maybe, or something -- really have that level of flexibility, is that what I heard you say

CAROL DORROS: Yeah. Because the idea I guess is to prevent isolation of folks, you know, with special needs and what I experienced at least partially is that some -- also looking at making sure people aren't just getting around doing -- around that by labeling it a different way. But yes, I think you got it.

DEB BELANGER: The other thing I would add about the first statement you made around needing a person, because I think it says that we can give some feedback as far as -- RIPIN does have staff that is now working over at BHDDH although they may not be able to sit down with you for hours and hours and kind of, you know, I shouldn't say case management. But they can answer a lot of the questions and give you some next steps so you can access that actually by calling RIPIN's resource center and they can make that connection with the staff that are assigned over there. That's just a little extra piece and we are working on that.

CAROL DORROS: Thank you. Good to know.

BETH PINKHAM: Thank you. Thank you very much.

KATE BOWDEN: Are we going to go on intermission now? Intermission until 4 or if someone else arrives.

BETH PINKHAM: Yeah.

CAROL DORROS: Okay. I forgot about housing. Major concern about where he's going to live other than with us. And the fact that in order to get him into a group home or a living situation, if that was our choice, we'd have to be, as I understand it, terminal or unable to take care of him. That's my understanding. So maybe somebody can speak to that. I mean I know there are some other possibilities for living situations. But that seems a little harsh to have to wait that long.

Independent Living

KATE BOWDEN: I can follow up.

CAROL DORROS: Great.

KATE BOWDEN: Just so everyone is aware. Through DDD it's my understanding if the person needs residential care, they can get residential care. You don't have to be dying or dead or terminating parental rights.

CAROL DORROS: What's the definition of "needs residential care"?

KATE BOWDEN: I don't have the definition off the top of my head. You do not have a legal duty to provide housing passed 18.

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CAROL DORROS: Right. But there don't seem to be choices. I think that definition -- I'm not trying to just, you know, pin you on something. But I think the definition of "needs residential care" actually would be important

KATE BOWDEN: Yes. And that would be through the process where they meet with you, do the assess and assist needs, that is how it's determined through the BDHH process where they look at needs and they assess funding and what the person in the family are looking for. That's a good question to ask the folks at DDD while you are going through that process.

CAROL DORROS: Right. Okay. Thank you. Anybody else want to speak to that actually. ROUGH ASCII 28

BARBARA HENRY: Can I say something?

BETH PINKHAM: I'm bringing the mic over. Here you go.

BARBARA HENRY: Hi. My name is Barbara. My son is 15 and he has autism and he has very limited speech and he has cognitive delays and everything you were saying I completely understand where you are coming from because I have no intentions of my son living with me the rest of my life. We are all going to die. We are not going to live forever. So I understand where you are coming from. I'm going to give you some very good advice. Get a good pair of sneakers. If I were you, I would really start getting out and on your own. Look -- start just going around and looking at everything on your own because you may call someone and they may give you some advice and that agency may have closed down a year ago. They may not even exist. And they may have had very good intentions on what they told you. But it just may not even be there anymore. And I started looking at things when my son was like little. And I think it's going to give you -- just keep a notebook or however you argue your things and really just -- because I think there's a lot of -- people are going to start giving you tons and tons of information and you are going to get a little overwhelmed. So if you can keep a notebook or however you stay organized and just keep that somewhere very private and it's going to help you just, you know, stay anchored. You know, I really think it will help you a lot. I hope that helps you in some way. Get involved with other parents that are in a similar situation. My son doesn't have hearing issues so I don't have that commonality with you. But I would definitely get involved with just other parents that are more on the same train of thinking that you are, that you are starting to think ahead and that you realize that your son is not going to be living with you and what are your next steps.

CAROL DORROS: Thank you.

BARBARA HENRY: You are welcome.

BETH PINKHAM: Thank you. Any other comments or thoughts.

KATHLEEN KUIPER: Can I follow up with that? Housing is an issue especially for folks with special needs. There are options out there and the options can be confusing and they can involve a really long wait but your son is young, and so are you. So this is the perfect time to get on those waiting lists and I would be happy to speak with you after and to give you some guidelines or some hints on