



State of Rhode Island and Providence Plantations
Public Forums
To identify the concerns of people
with
disabilities and their families

Wednesday July 25, 2007 3:30 – 5:30 pm

Barrington Public Library's Gallery Room

281 County Road, Barrington

Governor's Commission on Disabilities

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

Transcript

SHARON: I would like to welcome you all here. Can you hear me? Okay. I will try to use my old schoolteacher voice (LAUGHING). The Brain Injury Association of Rhode Island is the host of today's forum and my name is Sharon Brinkworth. I am the executive director of the Brain Injury Association of Rhode Island. And we welcome you all here today. And one of the reasons that -- the reason that we are here is that the state government and the sponsoring organizations -- you may have seen on the paper that you picked up out front about the forums. All of the sponsoring organizations and the government agencies want to hear from people with disabilities and their families. We want to hear about their concerns and their ideas, if they are having problems with different services and so what. So that's why we are here today because it's all about improving the lives of all Rhode Islanders.

Okay. We have a couple of rules we have to follow. And to ensure that everyone has a chance to speak, there will be a time limit of five minutes. And when the timekeeper announces your time as -- if you can finish that sentence and then sit down. And if there's time, when everyone has spoken who wants to speak, then people can come back up and speak a second time, if there's time. And Brian Adae here is going to be the timekeeper. So he will keep his eye on you.

And also when you do speak, I need for you to state your name and also if you are connected or affiliated with an organization, to say where that is. And we need to have that so that the CART reporter can get your name and your affiliation.

Now we have a table of fine panelists up here. And the panelists are here basically to listen to your concerns. But they may ask questions from time to time, if they don't quite understand what it is you are saying. So, that might happen. Otherwise they are here to listen to your concerns and to take them back.

Each -- I would like at this time for each of the panel members to introduce themselves and their affiliation. And remember too that when you ask a question of somebody out there to say your name again and your affiliation for the CART reporter, okay.

BRIAN: Good afternoon. I am Brian Adae from the Rhode Island Disability Law Center.

KAREN: I am Karen Lyons with the Governor's Commission on Disabilities.

KEN: Good afternoon. I am Ken Pariseau from the Neighborhood Health Plan of Rhode Island.

GWENDOLYN: I am Gwen Reeve, Shepard program director of the Multiple Sclerosis Society.

DIANNE: I am Dianne Kayala, the administrator of the Adult Health Program and Medicaid for the Rhode Island Department of Human Services.

PATRICIA: I am Pat Ryherd, Office Of Rehab Services in the Department of Human Services.

JANET: Hi. I am Janet Spinelli. I am with the Department of Mental Health, Retardation, and Hospitals. We work with people with developmental disabilities, mental health, and substance abuse issues.

LAURA: And I am Laura Jones from the Rhode Island Department of Health, Disability and Health.

SHARON: Thank you.

The first person who signed up and wants to speak, Camille --

AUDIENCE MEMBER: I didn't check to speak. I am here to observe.

SHARON: Okay. You did not check to speak.

Joy Dennis.

AUDIENCE MEMBER: Where would you like me to stand?

SHARON: You want to just stand and maybe come forward or just stand at your chair is fine.

AUDIENCE MEMBER: I will stand and come forward and hope I speak loudly enough.

Okay. What I am going to talk about is the talking book issue. Talking book of Rhode Island is obviously a state organization and I have no complaints about talking book of Rhode Island. My -- the difficulty is with the material -- equipment, so on. However, many patrons of talking book Rhode Island also use recording for the blind, which is in Russel, New Jersey. Also talking book library often checks with recording for the blind for material or its patrons. This prefacing remark is important because it isn't just that there are two entities and so on. The problem is with the new machines from both talking book and the blind. They are not compatible. And this is not the fault of talking book. However, it does complicate the use of reference materials from recording for the blind. Recording for the blind has made a proprietary claim, proprietary claim on its machine. In other words, you have to use their machines for their books. You can't use their books on talking book machines. Which means that only RFB at CD can -- CDs can be used on RFB players, CD players.

When I asked talking book plus librarians about this, I said that I would just wait until the talking book CD players were available. And that was when they told me that RFBs CDs were not compatible. So, more over I have discovered that from RFB, that one can pay -- excuse me -- one can play the CD only on their machine. Their CDs, their equipment, and so on. So that you cannot play any talking -- an RFB CD on the recording for the talking book.

I submit that this is a proprietary arrangement and discriminates those who cannot afford to buy an RFB player. I realize that the talking book plus provides the talking book player and that is a wonderful service. But there's a problem with doing the other.

RFB materials are often reference materials that users need for high school, college, university, and graduate school. I realize that talking book cannot of course recording for the blind to rescind its proprietary ownership. They can't because RFB is in New Jersey and it's not a state operated entity.

But could someone, someone urge them to do so. Perhaps someone could suggest the problem this poses for students especially. Thank you for your time and your patience.

SHARON: Thank you.

GWENDOLYN: I have -- Gwen Reeve, MS Society. I have a question. You purchase the machines and you only purchase one machine?

AUDIENCE MEMBER: Okay. I have not purchased -- the machines, I think the RFB machines may be available now. I'm not sure. They cost -- I suppose you can get them for the lowest for \$250. But they cost around \$300, depending on the type of CD player you use. And you can play the recording for the blind materials only on their equipment. You cannot play them on the talking book plus. And I realize that the talking book plus machine has not been issued yet. I understand that and that's not a complaint. But what -- when they are issued, we will not be able to use the recording for the blind. And they are -- the recording for the blind textbooks, for those who are unaware, are textbooks that are

paginated, so you can in Braille look, oh, page 32 and so on. You can go to different pages and so on. And they have reference charts. They read and so on. So it's quite useful for -- I would say any student from -- I would say even junior high on, in high school, college, and graduate school. So, this is a real problem.

Before this, if talking book plus did not have the material, they would check with recording for the blind. And they would send them -- RFB would send the material to talking book plus. They would send it to us. We could still play it on the talking book player. That will no longer be the case.

PATRICIA: For clarification, am I correct that the talking book recorder is free? There is no charge --

AUDIENCE MEMBER: That's correct. Thank you for asking that.

DIANNE: I have one question. Is there -- what would be your suggestion? I mean --

AUDIENCE MEMBER: Oh, the suggestion is somehow to make them compatible. If the machines -- I would think -- to make them compatible so that if someone wanted an RFB machine and wanted to purchase it, that's fine. But if they wanted to just use the talking book machine, the talking book CD player, the new one that will be issued, they should be able to play the recording for the blind. It's going to be a very awkward system. And yes, we will still be able to use the talking book plus machine. But we won't be able to use recording for the blind, unless you buy this machine that costs -- as you say you can get one as low as \$250 and they go up to \$320. And that is quite an expense for most disabled people.

DIANNE: Oh, sure. Thank you.

GWENDOLYN: This is Gwen Reeve again. I have a question. You said that the machine for the talking book is free. The recorder is free?

AUDIENCE MEMBER: Yes.

GWENDOLYN: How did it -- how is it that that's free and the talking recording for the blind machine is not free?

AUDIENCE MEMBER: It is not free because you join recording for the blind, become a quote member. And -- I don't have to pay this because I have been a member since before the flood. But there's a \$50 fee every year. And so you are a quote member. And other than those who have been grandfathered in, such as I, you have to pay this membership fee. So, it says that its members -- and they can -- but before, before these new RFB machines came out, they -- we could use the RFB, you know, cassettes and so on, on a talking book machine. You didn't have to buy a separate machine.

LAURA: I have a question. Laura Jones. My question is, is -- would -- what if the library was able to purchase several of these machines that people could check out? Is that something that would be a solution or would you -- do you read so much that you would really need it all the time?

AUDIENCE MEMBER: That would be a partial solution. However, it would be necessary really to have -- for an individual to be able to have the machine. I say if we can work out some the compatibility issue, then there wouldn't be a problem. No. I do think though that is a good suggestion to have libraries across the state have -- purchase some of these machines. And then that way people -- some people could listen at least at the library and so on because I don't think you want them taking them out of the library. They may not be returned. But that is a very good stopgap situation. But I do think you are correct. Especially college students would be reading so much and -- I think that would be -- and also high school students in a fast track program, on the academic high first fast track would have excessive amount of reading as well.

PATRICIA: Pat Ryherd. I have another follow-up question. Pat Ryherd from Office of Rehab Services. As far as college students, if an individual is a client of services for the blind and visually impaired, the state agency and the economic need is met, the agency would purchase the RFB recorder for that college student. It would -- isn't it true that a high schools would be responsible for providing that provider for a blind high school student?

LAURA: -- Laura Jones. That could be provided under individual education plan as a resource that they would need in order to function in school.

AUDIENCE MEMBER: Right. Then what about general readers, general -- I'm no longer in college or -- you can tell.

PATRICIA: I can't answer as far as general readers. But I could answer as far as students where Office of Rehab Services is helping the person become employed. So it would have to be part again of an individualized employment plan.

SHARON: Thank you, Joy. Thank you for your questions and comments.

I would like to introduce Bill Inlow who is also a panelist. We can squeeze you up here if you want to --

BILL: I would be glad to. Sorry I'm late, folks.

SHARON: Bill's from the Rhode Island Public Transit Authority.

KEN: I assume you didn't take one of the buses.

BILL: I didn't take one of the buses. They are always on time.

SHARON: Are there any other panelists who snuck into the room while we were talking? No, okay.

All right. The next person who has asked to speak is Grace Grout. If you want to stand --

AUDIENCE MEMBER: Or should I move forward?

SHARON: Just address us, the panel, because we are in a straight line up here in front of you.

AUDIENCE MEMBER: Okay. I am -- my name is Grace Grout. I am not affiliated with any agency per se. I am a consumer. I am an appreciative consumer of the RIDE program and have been since the early 1990s when I enjoyed full service living in Barrington center.

Upon moving to west Barrington in 1997, however, I found that I could no longer use RIDE weekday evenings or weekends. And -- I'm sorry -- I would like to know why my service has changed and what I can do to ensure that I may once again have full service. I have not officially been given an answer to my problem. And I am trusting that this will soon change.

I have few friends or family members that can help me out with transportation. I expect that one day soon I can take RIDE, for instance, to the Saturday meetings, monthly meetings of the national federation of the blind of Rhode Island and remain an active member.

It's a royal nuisance to say the very least to have to forego weekend and evening outings, as I'm a very active person. Everyone in the community will tell you I don't just sit around watching the grass grow.

I wish to have my situation addressed directly with patience and persistence. I will continue to seek a solution for my dilemma. Thank you very much.

SHARON: Thank you.

BILL: The --

SHARON: Just give your name.

BILL: The RIDE program has four parts, the department of elderly affairs, the department of mental health part, the Department of Human Services under the rite care part, and the part that I think this person is addressing is called the ADA or Americans with Disabilities --

AUDIENCE MEMBER: Can you speak up, please.

BILL: Part of the RIDE program, the ADA, Americans with Disabilities part of the program. That part of the program is called a paratransit program. Paratransit means comparable to trends geographically and time wise. What that means is the RIDE ADA program provides services where and when regular RIPTA buses operate.

For example, the 60 bus, regular RIPTA, large transit bus goes up and down County Road out in front of this building from about 7:00 in the morning until about midnight, 7 days a week. So a person in a RIDE ADA program living near this location would get service from about 7:00 a.m. in the morning until about midnight, seven days a week. This is all defined in the federal regulations, which is our attorney here today will tell you has the effect of federal law.

When you live in a different area, as you now do, Ma'am, evidently in west Barrington where there's only regular RIPTA bus service, perhaps during the weekdays and perhaps not on Saturdays or Sundays, as a consequence, the RIDE ADA program is restricted to those times near where those regular RIPTA buses are operating, again at the same time.

That's a procedure that RIPTA follows that's consistent with the letter of the federal regulation, which again has effect of federal law. And that's how we provide the program.

So, if you live near a bus line, if, when a regular bus is operating, you get good ADA service at that time. If you live in an area where there's not good RIPTA service or not as frequent, then the times that you get the service is defined by the times that those regular RIPTA buses operate.

Does that respond to your question? It's not the answer you want to hear but it is the fact.

AUDIENCE MEMBER: Okay.

SHARON: Thank you.

Thank you, Grace.

The next person to speak is maybe Paul Bohac. Did you want to speak?

AUDIENCE MEMBER: I want to speak. My name is Paul Bohac. I am a client of the Brain Injury Association and also -- what brings me the Brain Injury Association 21 years ago I was a student -- I graduated from Bryant College. I was working for Brothers construction and I drove my car erratically. The next time I woke up was three weeks later with two broken legs, mouth wired shut. I was in tough shape. Thank God that -- I had some really competent surgeons and I am here today. I suffered neurological damage. You can't see what happened to my brain. They call brain injury. It is -- I look pretty good. But if you looked at my brain, my brain is damaged. And because of that, I have made a lot of bad decisions because of my brain injury. But I can't say all it was probably but -- but long story short is I get services from lake view now prior to getting united cerebral palsy, PARI. They give me aides to help me with my daily living situation because I am high function. I don't have to -- like I don't need people to help me get dressed in the morning, things like that. But I do have needs as far as going to see -- my father's in a nursing home. An aide took me to see my father in a nursing home. The other day and I see my parents in Cumberland. These are essential services that I -- my agency provides me only through the help of getting funding through these organizations. So, basically I am here to ask you to keep on funding these agencies so that they can provide services for me and other people who have suffered brain injuries because it is a hidden injury. I do have needs. And there are people similar to me who have needs. I would like to have that continue. I guess that's -- I took the RIDE -- I am an active person like this woman is. I do get around. I take the buses and I ride my bike. I get around.

Unfortunately for me driving is too high functioning of a task. I can only handle too much. Driving is way too much for me. Even my bicycle I get in accidents. So thank God I don't have a car.

But anyway, all I want to say is keep on supporting our brain injury and giving funding for our organization.

DIANNE: Sharon, can I say something? What I wanted to say is because of the testimony of last year -- I am Dianne Kayala with the Department of Human Services. Because of the testimony of you and other folks last year, the program that you are talking about was increased. It was more than doubled over the past year. So, I want you to know that speaking up is a good thing.

AUDIENCE MEMBER: Thank you.

DIANNE: It was heard.

BRIAN: Brian Aday from the Disability Law Center. I wanted to respond to this fashion too, like my friend Dianne, as your part about speaking out and your voice being heard. I wanted to say without making any political commentary about the war in Iraq. But we are living in a time where we not only state but federal budget cuts and your voice being heard is very critical. Especially in context

with budgets, federal budget being drawn into spending a tremendous amount in the war in Iraq. But a wonderful opportunity if you want to continue to have your voice heard is to make sure you vote, as well as contact your federal legislators. In particular that we are seeing a tremendous number of people returning from Iraq with traumatic brain injuries. And that is something that politically I think at this point in Washington, I'm sure that Sharon can speak to -- is very important.

In fact, if any of you are not registered to vote, I would encourage you to do so. And we do have somebody here in the atrium, the entry way who is prepared to help register folks to vote if you have not already done so.

AUDIENCE MEMBER: When I watch TV and I saw the specials on the people from Iraq and basically those people from Iraq 20 years ago, I suffered what those people suffered. So -- I went to brain injury hospital they gave me OT, PT, speech. I couldn't speak. I had to learn -- I was like baby. I had to learn how to walk, talk, everything all over again. They call it traumatic brain injury for a reason because it is -- it's a hell I would not wish on anyone, what I went through. But I don't look it. I'm a tough guy. Thank you.

SHARON: Thank you, Paul.

I don't believe anyone else has signed up to -- oh, is there anybody in the audience who would like to speak?

Any of the panelists?

GWENDOLYN: --

AUDIENCE MEMBER: If I could make a quick statement. Just to notify all -- my name is Jeanne DiPippo and I represent Rhodes to independence and I am just doing a PSA actually. We will be having a job fair for those who are in need of jobs. It will be held October 30th in Warwick at the Sheraton post road, the airport -- the hotel there. And there will be no less than 30 representatives from employers who will be looking to hire people with disabilities as well as a resource center that will be helping with resumes and cover letters. In addition to that, there will be a resource center to help you with training and development if you need that type of service. There will be notices on TV, in your local newspapers, as well as in different agencies news letters.

Thank you.

SHARON: Thank you.

GWENDOLYN: All right. I am going to speak. My name is Gwen Reeve and I am with the multiple sclerosis society of Rhode Island. And I thought that I would take some time to talk about some issues that I hear about a lot from people in the community that do have MS. And for those of you who are not familiar with multiple sclerosis, it's a chronic progressive disease of the central nervous system which affects the brain and the spinal cord. And most people who are diagnosed with MS between the years of 20 and 50. Certainly there are people diagnosed earlier and people diagnosed later.

But one of the things that happens with people who are diagnosed in the prime of their life is that they've had the opportunity to work. And so many of them have significant work histories. Because they have significant work histories, when they need to go out on disability, and certainly not all of them need to go out on disability. But when they go out on disability and they can no longer work, and they have to apply for that permanent condition of disability.

They ultimately get Social Security disability income. And that's the amount of money that they would have made had they retired at the typical 65, 66 years old. So for many of them, that's, you know, \$1200, \$1500. Certainly not at the poverty level but certainly not high. And what happens, since they are no longer able to work, if they are not collecting or getting medical benefits through a spouse or through somebody else, they frequently rely on Medicare for their health benefits.

And what happens there is once they're determined to be disabled, they don't automatically get Medicare coverage. They have to wait two years for medical care to kick in. And that means these people are uninsured for two years. Okay. And the cost of multiple sclerosis is phenomenal. The medications that folks use

typically run at retail about \$2000 a month for one medication. So, we get a number of people in our office calling who can't afford their medication, can't afford to go see a doctor because they make too much to qualify for medical assistance and not enough to pay for their own medical care.

So, you know, what I would like to see at some point -- I don't know if it's going to be at the state or national level -- is some sort of stopgap or temporary medical coverage for people who are in that waiting period. They have been determined to be disabled. They can't work. They certainly can't pay Cobra payments which are pretty high because they are not making enough money. So they need some sort of medical coverage until the time that their Social Security disability with Medicare kicks in.

And again, I don't know if that's going to come from a national level since Medicare is national program. Or if it's going to come from the state, kind of stepping up to the plate which seems unlikely because of the cuts in budget. Anything that needs some sort of financial or fiscal note seems not get passed through the legislature.

I am kind of unhappy about that and I wish there was a solution because I can't tell you how many phone calls I get from people, again, who are in that I would say almost a limbo. They make too much to qualify for medical assistance which has pretty good benefits compared to Medicare and they don't make enough to purchase private health insurance. So that's a big issue for us.

Last year we were able to get the MS Society and the Governor's Commission on Disabilities were able to get MS injectable drugs put on to RIPAE's formulary, RI pharmaceutical assistance to the elderly. That seems to be the state pharmaceutical assistance program. But for folks disabled, one, you have to be 55 in order to qualify for that program. So again, you have people who are 40. They can't qualify for it.

And the co pay for RIPAE is something like 85 percent. So RIPAE will only pay 15 percent for a person with disability who is not a senior.

And right there it makes it prohibitive because if you have to pay 85 percent of something that's \$2,000, you can see you are not going to get the drug that you need to slow the progression of the disease down. So there's all these Catch-22s. And even though we got the bill put through last year, not that many people are able to utilize it because the co pays are too high.

So those are two big issues for folks with MS. And then you have all the other issues that many people with any type of disability face. We have housing, affordable housing problems, problems with accessible housing. Problems with transportation, which I'm sure Bill hears, on and on and on. These are the things that people have to live with on a daily basis. And many of our people don't have relatives that can step in and help out. They are living by themselves. They want the independence. So what happens, we get people who prematurely end up in nursing facilities because they want the help -- they want to live on their own. They probably could with assistance. But there's not that many options for them. That's just what I wanted to say. Thank you.

SHARON: Thank you.

PATRICIA: I have a question. Pat Ryherd. Have you found useful at all that some pharmaceutical companies will provide medications to individuals?

GWENDOLYN: At one -- Gwen Reeve. At one point they did. And it's not that they don't any more. But with the advent of Medicare part D, they've curved that back incredibly. So, people -- so they're not as generous as they used to be. They are quite stingy nowadays with their supplying the drug. They've also funneled people towards a couple other agencies, one of them is NORD, national organization for rare diseases, and Pen, which is patient -- it's the Montel Williams thing. And at one point we would refer people to those organizations. But they have since been inundated with requests. So they are no longer taking applications.

So, unless somebody can be really creative and point me in the right direction, there's not that many resources anymore.

If you are not on Medicare but your salary is low, you are in the low income bracket, they may assist you. But they are very reticent to help anybody on Medicare part D. And with Medicare part D, most of the co pays are 20 percent. And so, with a 20 percent co pay, if you are on a drug called "Ticabry" or whatever, that's \$600 a month that you will need to pay. And again, that's prohibitive for most people on limited incomes.

SHARON: Gwen, Sharon Brinkworth. I just was curious to know, do you have any statistics -- is MS, multiple sclerosis, on the increase? Is there more cases?

GWENDOLYN: That's a very good question, Sharon. I think the reporting is better and the diagnosis is better. So, because of the use of MRI, people are being diagnosed quicker. And sometimes people go in for an MRI for migraine or other issues and they in fact have MS. Not only is it possibly on the rise, I can't say that definitively. But we know that more and more children are getting it. And so, we figure about 10 percent of the population that has MS are children under 18 years old, which is something we did not really know about ten years ago. So, it is increasing.

SHARON: I guess, it's now time for me to say for those of you -- this is your first forum that you attended, it is -- the forum is held from 3:30 to 5:30. And so, we, as panelists, will stay here until 5:30 because we would not want somebody who just got off at 5:00 and rushed to get here and then have us all gone. So, that's why we are here to stay until 5:30. So, it's 4:15 now. You are welcome to stay, if you would like to stay. Or if somebody who didn't speak maybe wants to say something, that's fine too.

LAURA: Don't be shy.

SHARON: If anyone has a question or anything like that they want to ask. But we will stay. So, feel free to get up and walk around and come back and sit down, I guess.