

2017 Public Forums on the Concerns of People with Disabilities and their Families

Concerns and Recommendations	1
Civil Rights	1
Education	1
Employment	2
Healthcare	2
Housing.....	2
Human Services.....	3
Independent Living.....	3
Transportation	3
Public Forum Transcripts.....	5
Bristol Public Forum July 24, 2017	5
Warwick Public Forum July 25, 2017	9
Cumberland Forum July 26, 2017	24
Peacedale Public Forum July 26, 2017	39
Middletown Public Forum July 27, 2017	54
Providence Public Forum July 28, 2017	55
Index.....	82

Concerns and Recommendations

Civil Rights

Concern: Parents with disabilities losing their child due to the termination of custody, pages [4](#) and [7](#)

Recommendation:

Concern: Lack of restrooms that allow caregiver and person with a disability of the opposite sex to use, pages [12](#) and [78](#)

Recommendation:

Concern: The lack of automatic doors in healthcare facilities, pages [29](#) and [52](#)

Recommendation:

Concern: Finding a directory of accessible restaurants, etc. page [76](#)

Recommendation:

Concern: Interactions with Police, who don't realize the person has a disability, pages [66](#), [66](#), and [68](#)

Recommendation:

Concern: Lack of awareness of the need for universal design, page [31](#)

Recommendation:

Education

Concern: Lack of training on the use of adaptive communication devices, pages [4](#), [7](#), and [54](#)

Recommendation:

Concern: Inclusion of students with disabilities without creating sensitivity on the part of students without disabilities, page [31](#)

Recommendation:

2017 Public Forums on the Concerns of People with Disabilities and their Families

Concern: Lack of accessible text books and on-line course material to students with vision impairments, page [7](#)

Recommendation:

Employment

Concern: The consent decree's requirement for competitive employment is a "one size doesn't fit all" solution, page [54](#)

Recommendation:

Concern: Will competitive employment increase socialization, page [54](#)

Recommendation:

Concern: The lack of job placement resources, pages [7](#), [19](#), [26](#), [32](#), and [79](#)

Recommendation:

Concern: The fear of losing Social Security Disability if attempting to work, pages [37](#), [71](#), and [73](#)

Recommendation:

Concern: The need to provide financial support to businesses that hire people with disabilities, page [80](#)

Recommendation:

Concern: Behavioral healthcare providers are not assisting clients return to work, page [74](#)

Recommendation:

Concern: People are being placed into "temporary" and "internships" that never become permanent jobs, page [54](#)

Recommendation:

Healthcare

Concern: There are not enough behavioral healthcare support groups, page [74](#)

Recommendation:

Concern: The state is not implementing the home and community based waiver, pages [13](#), [50](#), and [69](#)

Recommendation:

Concern: The difficulty getting respiratory supplies from the durable medical equipment providers, page [11](#)

Recommendation:

Concern: Funding cuts to Medicaid, page [34](#)

Recommendation:

Concern: The lack of knowledge of Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections PANDIS, pages [65](#) and [66](#)

Recommendation:

Concern: The lack of traumatic brain injury transitional housing, page [32](#), [39](#), [40](#), [45](#), and [68](#)

Recommendation:

Concern: The lack of protection against sports related brain injuries, [61](#) and [62](#)

Recommendation:

Concern: The lack of proper training for Certified Nursing Assistants regarding people with rare diseases, page [52](#)

Recommendation:

Housing

Concern: There are very few accessible apartments, pages [12](#) and [71](#)

Recommendation:

2017 Public Forums on the Concerns of People with Disabilities and their Families

Concern: There isn't enough affordable housing, pages [10](#), [16](#), [68](#), and [71](#)

Recommendation:

Concern: Housing modifications can be expensive, page [17](#)

Recommendation:

Concern: Apartment managers don't enforce environmental irritant free policies, pages [54](#) and [71](#)

Recommendation:

Concern: Public housing for persons with a substance use disorder, page [73](#)

Recommendation:

Concern: Shared Living Arrangements (SLA) do not work for everyone, page [55](#)

Recommendation:

Human Services

Concern: The process for applying for benefits can be overwhelming, pages [38](#) and [64](#)

Recommendation:

Concern: Periodic evaluations are incredibly daunting, pages [22](#), [23](#), and [33](#)

Recommendation:

Concern: Family income restrictions for child care assistance do not take into account the additional expenses of raising a family with children with disabilities., page [12](#)

Recommendation:

Concern: It is difficult to find out what resources/services are available, pages [17](#) and [47](#)

Recommendation:

Concern: Low wages for providers' employees and in self-directed services lead to high turnover and inconsistent quality of services, page

Recommendation:

Independent Living

Concern: There isn't enough assistance for family financial planning, page [23](#)

Recommendation:

Concern: Peer support groups should receive financial support from the state, pages [57](#) and [59](#)

Recommendation:

Concern: Are there peer support groups for victims of violent crime, page [48](#)

Recommendation:

Concern: Is government funding of personal care assistance being cut, page [20](#)

Recommendation:

Concern: Changes of the level of support services are not communicated to families in a timely manner, page [22](#)

Recommendation:

Concern: Transitional assistance is hard to find and needed at every change of ability and need, pages [11](#), [27](#), [32](#), [40](#), [42](#), [55](#), and [63](#)

Recommendation:

Transportation

Concern: Local automobile excise tax, does not exempt the adaptive equipment, page [29](#)

Recommendation:

Concern: LogistiCare service lacks "trustworthiness", pages [24](#) and [55](#)

Recommendation:

2017 Public Forums on the Concerns of People with Disabilities and their Families

Concern: Many drivers park in the van access aisle, page [27](#) and [28](#)

Recommendation:

Concern: There aren't always directional signage to disability parking [59](#)

Recommendation:

Concern: Drivers do not look out or stop for pedestrians crossing the street, page [10](#),

Recommendation:

Concern: Many crosswalks do not have curb cuts at both sides of the road, page [12](#)

Recommendation:

Concern: Curb cuts are not built to the access code, pages [13](#) and [14](#)

Recommendation:

Concern: There aren't sidewalks on roads in many communities, page [30](#)

Recommendation:

Concern: RIde vans are often up to a half hour later than the scheduled pick up, pages [7](#) and [58](#)

Recommendation:

Concern: RIde para-transit service areas do not include most of RI, pages [8](#), [9](#), [26](#), and [59](#)

Recommendation:

Concern: Travelers using RIde should be able to pay the fare by swipe card, page [60](#)

Recommendation:

Concern: There are not RIPTA bus shelters at most stops, page [8](#)

Recommendation:

Concern: There should be RIPTA bus stops at every elderly/disabled housing, page [31](#)

Recommendation:

Concern: Uber and Lyft do not have accessible vehicles, [29](#)

Recommendation:

Concern: Travel Training should be taught to students with disabilities, [27](#)

Recommendation:

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 Public Forum Transcripts

2 Bristol Public Forum July 24, 2017

3 Panel Members:

- 4 1. Rick Costa - The National Federation of the Blind of RI
- 5 2. Faye Zuckerman - Brain Injury Association of RI
- 6 3. Kristen Livesey - Office of Rehabilitation Services
- 7 4. Judi Drew - RI Governor's Commission on Disabilities
- 8 5. Liz Wiedenhofer - Living In Fulfilling Environments
- 9 6. Colleen Polselli - RI Department of Health
- 10 7. Anne Mulready - RI Disability Law Center

11 Public:

- 12 1. Barbara Henry
- 13 2. Michelle Callaghan
- 14 3. Bob Marshall
- 15 4. Frederica Athehas
- 16 5. Bill Henrich
- 17 6. Grace Pires
- 18 7. John & Beth Coccio
- 19 8. Angelina Stabile
- 20 9. Amy Romero
- 21 10. Ryan Laird

22

23 SPEAKER: -- basis for removing children from people -- from the custody of their parents, who have a
24 disability. It does happen, and I don't know whether it has happened in
Civil Rights: Parental Rights 24 Rhode Island. It probably has. We're just not aware of it, but I know in
25 other states, sometimes in divorce cases or other instances, children are
26 removed from their families, because their parent has a disability, and last year there was a bill that was
27 introduced, but it didn't even come out of committee, which stated that, you know, disability cannot be
28 only basis for removing a child from the parent's custody. So that's my concern and would like to see that
29 legislation passed. This point, I know there has been legislation passed in eight states. Just the two that
30 recall off the top of my head is Illinois and Maryland. They do have that kind of legislation, so that's my
31 concern. Thank you.

32
33 SPEAKER: Thank you. Frederica?

34 SPEAKER: Hi, everybody. My name Frederica Athenis. I'm a member of the National Federation of the
35 Blind of Rhode Island, and I am under the care of state services for
Education: Communication Access 35 the blind, and I'm not really happy. I mean, there's nothing that we
36 can do about the budget being busted, but my services have kind
37 of been discombobulated. I'm 15 years under the care of state services for the blind. I'm about to move
38 from Zoom Text to Jaws and because the budget is frozen, I need talking typing and tutor or that's only
39 available in a 30 day program that doesn't keep any of it, so all I get through is ASDF¹, and it's very
40 frustrating. I'm doing a lot of work for the National Federation of the Blind of Rhode Island. I'm the
41 secretary of the Providence Chapter, and I'm working on the minutes and I need to sharpen up and hone
42 down my computer skills and print envelopes. I am in charge of the minutes and I'm trying to get the
43 training for the Jaws program and not use a mouse, and it just seems as though, right now, maybe,
44 because it's summer; it's very difficult to get anything organized. I've recently come up with the -- I do a
45 lot of legislative work for the Federation. I went to the -- I went to Washington, to the Washington seminar
46 in Washington, DC and spoke with our senators and representatives about legislation that will affect the
47 blind. I have a lot to work to do. I have a lot of -- I have a fire in my belly, so they say. I'm doing a lot of
48 work in recovery for six years and I'm doing a lot of work with alcoholics anonymous, with the committee,
49

¹ "Asdf" are the four letter keys in the left hand-side home row of a standard QWERTY keyboard.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 with professional -- with a professional community and public information to work with senior centers to
2 get programs in, because I was an isolating alcoholic and it's prevalent. It's an absolute epidemic in the
3 United States with senior citizens, and I'm trying to get the program brought to all the senior citizens, so
4 once again, I have to hone in on my e-mail skills, on my communications skills, on my computer skills. I
5 am trying to learn how to print envelopes, and I just feel as though it's been a frustration of mine for my
6 15-year journey from sight into blindness, that I keep getting let down by state services for the blind. They
7 don't really know what to do with me. And I am just trying to -- I mean, there's nothing that did happen
8 right now, because of the budget. Everybody at the State House has got an attitude, and I would like to
9 be part of the Commission on Disabilities, and just for an example, I called Governor Raimondo's office
10 today and Kevin, the intern, who took my information, did not know anything about the Commission on
11 Disabilities, so I felt as though I fell on my face. The Governor's Commission has two telephones with
12 answering machines, and one sounds like it needs to be re-recorded. It's very unprofessional. I left a
13 message there. I left a message on the other answering machine, and I found out from Chris tonight that
14 Bob Cooper is in on vacation. So again, I fall on my face. It's a rainy, drizzly Monday. I can't seem to get
15 anything accomplished and I could use some help, so I don't think it's a legislative issue. I would just
16 thank you for letting me be heard, and I hope I can resolve these situations and have a very busy future.
17 Thank you.

18 SPEAKER: Thank you. Bill Hendric.

19 SPEAKER: Yes. Good afternoon. My name is Bill Hendric. I am here to make a couple of comments for

20
21 Transportation: RIde my daughter, Amy, who utilizes the service of the RIde bus. She -- my
22 daughter is quite high functional. We were able to get her an apartment
23 through Section 8 housing about three years ago. She lives about a mile from

23 our house. We live on Annawamscutt. She lives on Massasoit, which is about a mile and a quarter from
24 our house. I understand the fact that they can't pick her up to take her to work, because she goes to work
25 at 2:30 in the afternoon and only works until 5:30, on East Main Road. However, the three days that she
26 does work, two of the days they'll provide a taxi to take her home, usually, and on the third day, which is
27 Thursday, it's usually the RIde bus. However, like, for example, last Thursday, instead of picking her up
28 at 5:30, they came about five to 6:00. The daycare that she works at has a policy where they won't leave
29 until everyone goes home, so typically she'll call; dad, I don't have a ride. I say, honey, by the time I get
30 there, they will be there to pick you up, anyhow, and last week I called and the lady said to me, she said,
31 yes, I -- she said, he had problems with a prior client and so that is why he is running late, but he told my
32 daughter that he called them and told them to send a cab, so that she could get home early. And the
33 other point is, the taxi drivers have generally been agreeable to it, but the RIde bus instead of dropping
34 her off at her apartment, they have to drop her off a mile and a half further at Mount Hope High School,
35 and they won't even take her to our house, because it has to do with where the local bus stop is. Well, it
36 doesn't make any sense in the middle of winter to drop a girl off at the high school and then we have to
37 go and pick her up when, in fact, it's just a lousy location. They go right by her apartment. They go right
38 on Metacom, but they have got a silly law that the bus has to be within -- can't drop her off there, because
39 of the stops, and it does not make a bit of sense, and my daughter had a prior job in Warren, but she was
40 let go, because of discrimination. She found this job, and the people at the Mount Hope Center or Maher
41 Center were nice enough to interview her, and the people love her at this job, and she doesn't want to
42 leave it, but it's sad that since she has to ride -- the state has the RIde bus, they just aren't taking care of
43 it properly. So if you can do anything about it, it would be appreciated.

44 SPEAKER: Thank you. Bob Marshal.

45 SPEAKER: I'm not testifying.

46 SPEAKER: All set?

47 SPEAKER: Yup.

48 SPEAKER: If there's a check mark next to their name -

49 SPEAKER: Oh, I'm sorry, I thought that was a check mark. Barbara Henry.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 SPEAKER: Yes. Well, hello, everyone. My name is Barbara Henry. I'm a resident of Riverside, Rhode
 2 Island, and I'm blind and I'm a very proud mom of a young man named Justin, who has autism. I have a
 3 lot of things to talk about today, so please -- but I think they are important. I found out that my
 Transportation: RIPTA representative in my area is Mr. Amore. I'm sorry, if I am not saying his name
 6 correctly. And I -- at the last accessible ATAC meeting, I wanted to get a bus
 stop shelter for where I live. And I did go and get signatures for where I live.
 7 We have a lot of elderly and disabled people where I live on Crescent View Avenue. The bus stop,
 8 there's no shelter. There is not anything, and I think it's just really important, so I went and I advocated
 9 and I got the signatures. So hopefully at the next ATAC meeting, I will bring the signatures in. Another
 10 thing I wanted to bring up is I believe the ADA was passed 27 years ago, and correct me if I'm wrong, and
 11 27 years ago I was not in college yet, but 17 years ago, I gave birth to my son and I got my master's
 12 degree in the same year, and two things that are prevalent today
 Education: Inaccessible Text Books that I have noticed then is that college was not accessible. I had a
 14 reader all throughout my college and -

(END FILE 1)

15
 16 SPEAKER: -- a hundred percent more, you know, because the world is looking at you and feeling you
 17 and judging you and especially if you have children, and I'm not -- please, I'm not looking at any of you.
 18 I'm just expressing myself, and I really feel that especially, look at what happened to this man on the
 19 news. This disabled man that recently drowned in Florida and these teenagers, I know it's a totally
 20 different topic, but I'm going off topic and I am very sorry for that, but I have such a compassion and I'm
 21 just so -- I am here because I really care about disabled people and I just -- I really want to see things
 22 change within DCYF, and I'm really glad that our governor is a woman and
 Civil Rights: Parental Rights she is a mother, because I just -- I'm really fed up with people thinking
 24 that, especially the blind, that we cannot have children. That I don't know
 25 that we're -- I'm sorry. I'm going to be quiet now. Thank you.

26 SPEAKER: Is there anyone who has come in later that would like to testify?

27 SPEAKER: I would. My name is Angelina Stabile. I am on the GCD, the Legislative Committee, and I do
 28 belong to the National Federation of the Blind of Rhode Island, a proud member. I am the Legislative
 29 Director for the National Federation of the Blind of Rhode Island and the vice-president of the Greater
 30 Providence Chapter of the National Federation of the Blind and it is an honor to be a part of that group. I
 31 want to echo what our President Grace Pires had stated and Barbara Henry has stated about kids. That's
 32 why my husband and I didn't have kids, because even though he's sighted, they would -- DCYF would
 33 assume that he would do all the work, and that my child would be taken away from me. It's happened as
 34 close as Connecticut, and I don't care what anybody has said and I know DCYF (inaudible) about
 35 blindness and doesn't take your kids, because (inaudible). It is not true. It does happen. People have
 36 said, oh, my family lives downstairs; don't worry; don't worry; I have help; I have help. Now, how many --
 37 do sight mothers have to say that to their doctors in the hospitals after giving birth or social workers or
 38 anything like that? I think not. We have legislation there. It failed. It failed. It's a crying shame that it failed,
 39 crying shame, and also the man that talked about the Rhode bus. RIPTA has
 Transportation: Rhode leeway to extend a three-quarter mile, and they don't. It's a shame, shame,
 41 shame, shame. It's all about money. RIPTA cares nothing about people. They
 42 care about their bottom line, money, budget, money, and that is all I have say. Thank you.

43 SPEAKER: Thank you.

44 SPEAKER: Angelina, could you spell your last name for me.

45 SPEAKER: Yes, I'm sorry, S-t-a-b-i-l-e.

46 SPEAKER: i-l-e?

47 SPEAKER: Correct.

48 SPEAKER: Okay. Perfect. Thank you.

49 SPEAKER: Thank you.

50 SPEAKER: Is there anybody else that would like to speak?

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 SPEAKER: Yes, I would like to speak on behalf of my son, Matthew. He's --

2 SPEAKER: Please you state your name, please.

3 SPEAKER: Sure. I'm sorry. My name is John Cossio. I'm on the list. I just decided to speak. It's been
4 about two years since he graduated from high school, and it seems as
5 though the programs for him to get a job -- there isn't enough help out
6 there. We have had him apply for jobs in the community, but nobody will

Employment: Job Placement

7 hire an autistic kid unless they have some sort of support. They just don't even return phone calls as far
8 as the application. He does have issues now, because he had gotten into the routine where he just stays
9 home and he is getting to the point where he just wants to stay home, and we want to get him out there
10 and get him as a productive member of society, you know, because there have been times when he has
11 had jobs for a few weeks, but at one point, they cut the one position out. It does seem like, too, as far as

12

Transportation: RIdc

13 getting the rides to and from work, it has been left to the -- in this case, the
14 Maher Center, the actual social workers at the Maher Center had to pick him up
15 and drop him off, so -- and we did think that the RIdc was pretty much door to
16 door, but it sounds like that's not the case. You know, at this point it's been close to a year since he's had
17 a job and nobody within the Maher Center has actually said, all right, we have got another job lined up for
18 him. There's just nothing and phone calls end up not getting returned.

18 SPEAKER: Um-hum.

19 SPEAKER: We've checked with another agency looking Upwards and they've got a waiting list, because
20 they don't have enough people to take care of --

21 SPEAKER: I can certainly -- can I talk to you after the meeting?

22 SPEAKER: Okay.

23 SPEAKER: (Inaudible)

24 SPEAKER: Thank you.

25 SPEAKER: Yup.

26 SPEAKER: Can you speak up?

27 SPEAKER: I just let them know that I would be able to talk with them after the meeting to try to help them
28 access services.

29 SPEAKER: Anyone else?

30 SPEAKER: This is Barbara. I'm sorry I got emotional. I did have one more thing I wanted to bring up. Can
31 I bring it up, please?

32 SPEAKER: Sure.

33 SPEAKER: I -- I got this. Can everyone hear me?

34 SPEAKER: Yes.

35 SPEAKER: I got this -- I have Medicaid and my son has Medicaid. We have United Health, and I got a
36 phone at the DHS office on Elmwood Avenue, and I thought it would be a really good idea to, I guess, like
37 I said, my son is 17. He has autism. I'm trying to teach him, now, to
38 work on the phone. This phone is not accessible. I can't use this
39 phone. So I wanted to bring this up, because I really feel that this is

Education: Communication Access

40 really, once again, it's just -- it's not only, you know, if you are blind, if you just print disabled. I mean,
41 what if I didn't have a phone at home? What if I really needed this phone? I mean, I'm on a fixed income,
42 and you know, what if I was -- this, I really was depend -- and when I went to get the phone, it was -- I
43 have the box. I have everything, you know. I think the company is Safety Light. The person who, you
44 know -- I had my cane with me. He goes, oh, you are blind. You know, just really ignorant, but I really -- I
45 just wanted to really point this out. That there is -- I can't, I can't use this phone, at all. And I know that I'm
46 not the only person who has picked up this phone and is in this situation. So I think there is really, really
47 important to, you know, to address, because it's just another form of inaccessibility, so thank you.

48 SPEAKER: Yes.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 SPEAKER: Hi, I'm Frederica Athenis, again, and I would like to agree with Barbara. I have one of those
2 phones at home and can't use it, at all. I have in-coming phone calls. There is nice music. It's really
3 comical when it goes off. I don't even know how to answer it. And again, it was from the Department of
4 Human Services. This is considered my life line, because I'm a food stamp recipient and living on a fixed
5 income. It's totally inaccessible and I too am blind. I agree with Barbara a hundred percent. I don't know if
6 the Department of Human -- is there somebody here from DHS?

7 SPEAKER: No. No.

8 SPEAKER: Okay. I would like some help, as well. Thank you.

9 SPEAKER: We are going to take a short break now.

10 #####

11 [Warwick Public Forum July 25, 2017](#)

12 Panel Members:

13 8. Beth Pinkham - OSCIL

14 9. Richard Muto - Brain Injury Association of RI

15 10. Sharon Thistlewaite-Morra - Office of Rehabilitation Services

16 11. Gary Wittman - RIGCD

17 12. Judi Drew - RI Governor's Commission on Disabilities

18 13. Deb Golding - RI Department of Health

19 14. Tammy Russo - RI Parent Information Network

20 15. Elisabeth Hubbard - RI Disability Law Center

21 Public:

22 1. Debra Byrnes

23 2. Bob Marshall

24 3. Debra Sharpe

25 4. Tara Townsend

26 5. John Susa

27 6. Susanne & Barry Glucksman

28 7. Garabed Roosherian

29 8. Mellaine Ponthrian

30 9. Michelle Dickson

31 10. Maria Edwards

32 11. Christina Barttister

33 12. Heather Scey

34 13. Chris Marin

35 14. Siera Leone

36 15. Michelle Machado

37 16. Linda Bradley

38

39 BETH PINKHAM: Good afternoon, everybody. And welcome to the Governor's Commission on Disability
40 Forum. Just a couple of housekeeping things: If you go out the doors to the right, restrooms are down the
41 hall if you need them. Water fountain, and things like that, if you need them at any point, you know, help
42 yourself. We will be here from 4-6, and people can feel comfortable to stay, leave, whatever their
43 schedule allows. I'm Beth Pinkham with OSCIL, and we are the hosts of today's forum. We're glad to see
44 everybody here. What we're going to do now is let the panel introduce themselves, with a reminder, our
45 job here today is to listen and gather what your concerns and questions and so forth are in the disability
46 community. And then they go back to the Governor's Commission and that helps them formulate their
47 legislative agendas for the coming year. That being said:

48 RICHARD MUTO: Hello, I'm the Education and Resource Manager at the Brain Injury Association of
49 Rhode Island.

50 JUDI DREW: I'm a Commissioner for the Governor's Commission with Disabilities, but I'm also a full-time
51 faculty assistant Professor at Salve Regina University.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 SHARON THISTLEWAITE-MORRA: I'm a vocational counselor at the Office of Rehabilitation Services,
2 ORS.

3 TAMMY RUSSO: I'm the Family Voices Manager at Rhode Island Parent Information Network.

4 BETH PINKHAM: What we're going to do is we're going to start. People came in and checked off if they
5 wanted to be heard or not, and the first person we had is Debra Burns. If you could please use your name
6 for CART.

7 DEBRA BURNS: I'm here at the meeting, my name is Debra, and I'm here because I'm trying to get
8 something to do with the light where I live, Greenwich Village Apartments across from the mall. I got hit
by an 85-year-old woman who ran a red light. I have PTSD and anxiety
from getting hit. I also have a service dog, she got hit five days after I got
her, she lost her leg. People go, like, 90 miles through the light when it's

Transportation: Pedestrians

11

12 green. I called David Bennett, he promised me and my husband, "We'll get something done, don't worry
13 about it." This is three years later, August 21 will be three years. I was told by a lawyer they had these
14 meetings I didn't know about. There's a lot of disabled people, hearing impaired, or people in school that
15 can't walk, and they're afraid. Every time you cross the street they go through a red light. The police said
16 they can't do anything about a camera, but I don't know what my options are as far as getting something
17 done to do something. So, that's why I'm here.

18 BETH PINKHAM: Thank you, Debra. Any follow-up questions or comments?

19 RICHARD MUTO: Could you tell me where it is again; that light?

20 DEBRA BURNS: Greenwich Village. Right after the hotel, right on Route 5.

21 JUDI DREW: Where the Warwick Mall is.

22 DEBRA BURNS: Yes.

23 RICHARD MUTO: Oh, okay.

24 JUDI DREW: That whole light system there is strange.

25 DEBRA BURNS: I was told years ago, I lived there 12 years, I was told there was never a light before.
26 Before I got hit, some severely disabled guy got hit on a bike going to get cigarettes. That was like 10:00
27 at night. I got hit in the day. Now there's a light, and because it's called Lambert Lind Highway, people
28 speed. Kids live in the building. There's a school bus stop and also a RIPTA bus stop. It's scary.

29 JUDI DREW: I want to share one thing with you, we're really -- those of us here on the panel are not
30 really here to suggest to you options that you can follow in detail, but if you want to talk to any one of us
31 after the meeting and get ideas, that would be great. But as a commissioner, I can tell you that what
32 happens with the transcript from the forum is that the staff at the Commission read it, and then the
33 commissioners read it, and we identify areas of concern that either need advocacy or legislative
34 intervention. So, I can tell you that this certainly would be something that we would look at and try to
35 figure out, what can we do to help you and help other people that live in that area so that you're not afraid
36 for your life as you cross the street? Because I've seen people have to run.

37 DEBRA BURNS: I have four grandkids, and I'm worried that one of my grandkids will get hurt if I'm
38 crossing the street with them.

39 JUDI DREW: Just so you know, for any of you who testify, know we're not going to give you a solution
40 here, but we'll certainly read your testimony and try to help figure out what we can do to help.

41 DEBRA BURNS: Thank you.

42 BETH PINKHAM: Any other comments? Next we have individual signed in as, "Disabled Artist from
43 Coventry."

44 >>: Can everyone see this?

45 AUDIENCE MEMBERS: Yes.

46 PANEL MEMBERS: The panel can't.

47 >>: I would like to thank the Warwick Library for hosting this event, and also like to thank Ocean State
48 Center of Independent Living for hosting this event. I came today with 11 ideas to help the disabled

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 children and adults, the disabled artists, like myself, and if you would like, you could pass that along for
2 everyone to see. This is my emoji-con: "Artist in a Wheelchair." So, I have 11
3 Housing: Affordable 4 ideas, but I'm only going to focus on three. And I have something really, really
5 cool in my pocket that I will show you. Okay. These are my future ideas to help
6 the system. We need to have a truly portable housing data card for the disabled artist, single mother,
7 single father, elderly in distress, and the ex-convicts. Now, I could go into great detail, but for the sake of
8 others, and for the time that I'm allotted, I'm going to leave that idea with that right now. But, this would be
9 an example of the housing data card that you could take, truly, around the country, present it to the
10 landlord with the security deposit, he scans it, your subsidy comes here, it's there, and you can go from
11 as far away as Block Island, to all the way to Monterey, California. And you're housing information, your
12 housing benefit, your eligibility data, history, so forth, all on here. This would be given to you when you
13 meet the requirements. If you're a Veteran, you get a separate one. This comes to you when you get off
14 the aircraft carrier or you get off the military transport plane they give it to you. You can go anywhere you
15 want, information is here. Of course, with all the cyber breaches and stuff like that, it will have layer upon
16 layer of security so information won't be in danger of being corrupted. That's just a small idea. My second
17 idea is we need to create a new approach to the waiting lists in public housing projects. I see that two
18 things that I've come across in my dealings with this issue. The need to have a doctor's note to get on to
19 Independent Living: Transition 20 of the first floor apartment, which used to be given immediately. And
21 there won't be a waiting period for that. That idea that you need a
22 doctor's note to get on the first floor of an apartment is not needed.
23 That's idea number two. And idea number three, out of my 11 ideas, we are living in an age where we
24 need assistance in all of the stages of our lives. From kindergarten all the way on. Along the way, we
25 need transitional assistance, whether its food stamps, housing, the, that, and everything else, so forth.
26 What I want to suggest is that when you get to the stage where you are a disabled client and you need
27 assistance in picking a house. Now, the house can be anything from an SRO, a first, one-bedroom
28 apartment, a condo, a mobile home, manufactured home, mansion, or some people do prefer to live in an
29 out yurt-like structure. My idea for the future is social workers will also partner with real estate agents to
30 have a sympathy in helping to pick the right housing for the right disabled client. We say okay, in the
31 system we have now, waiting list. You're on a waiting list. This, that, and you're also going to go through
32 all kinds of other protocol. This is not going to be needed. You will be allowed to have a housing
33 advocate to your particular housing need, not one entity, agency that they call the administrator that
34 deals with that housing complex and that housing complex, no. If an individual who is in a disabled
35 situation needs assistance in finding a new type of housing than what they're currently in, this person, this
36 helper, will partner with the social worker, and then the social worker and the real estate person, possibly
37 someone who -- it would have to be something in between a property manager and a real estate agent.
38 Kind of person who knows, who has the experience, this is what you do when you get into this kind of
39 housing, this is what you do when you get into that kind of housing. And all that can benefit the individual
40 that's trying to get into a housing situation. So, anyway, I want to conclude with that third idea to wrap up.
41 I would like to also say that compassion on all levels of disability, mental and physical, will definitely need
42 to be an attribute for the future. Is there anybody that has any questions? Okay. Thank you very much.
43 BETH PINKHAM: Thank you. And I do work on housing issues with folks as part of my job at OSCIL, and
44 I can understand a lot of what you're saying, so thank you. We did have one more panelist join us, so if
45 you could briefly introduce yourself.
46 DEB GOLDING: I'm Deb Golding with the Rhode Island Department of Health.
47 ELISABETH HUBBARD: I'm Elisabeth Hubbard, Disability Law Center.
48 SUSAN HAYWARD: I'm Susan Hayward.
49 SETH MORGAN: I represent RIPTA, today.
50 JUDI DREW: I'm sure there will be a lot of comments.
51 SETH MORGAN: In my defense, I wasn't expecting to be here until about an hour ago. We had a
bereavement in the office.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 JUDI DREW: Go easy on you?

2 SETH MORGAN: Yes. I'll give my best answers.

3 BETH PINKHAM: Right now we've gone through everyone who requested to speak. We can open the
4 floor to anybody who wants to introduce themselves, who has comments, topics that they want to speak
5 about.

6 TARA TOWNSEND: I think there's another sign-in sheet; I signed in.

7 BETH PINKHAM: Let me grab it, you go ahead.

8 TARA TOWNSEND: My name is Tara Townsend. I'm Warwick resident and the mom of three children,
9 who's oldest has significant special needs, medically fragile,
10 Healthcare: Durable Medical Equipment G-tube. We have a lot of day-to-day issues we deal with. In
11 my role as a parent, I notice DME, durable medical

12 equipment, not many vendors in the state that provide it, and those that do, getting respiratory supplies
13 has been more difficult. You can't go between vendors, and it's one, "Get all your stuff from us or not."
14 We have Lincare. Our order is already three weeks late. We have options to change companies through
15 our health insurance, my son has Medicaid, but currently they're the only ones provided the heated
16 tubing he's been using since he got home from the NICU. He's been thriving and doing well. It's difficult

17 for us to navigate the systems and remain healthy and
18 Human Services: Child Care Assistance successful when he's continuing having barriers in getting
19 equipment he needs. Child care access, I have two other
20 children, and my check every week goes to child care. My husband and I both work, but we don't qualify
21 for assistance. Even if we did, right now we're at a home day care, and it's not a day care that works with
22 the state and we're not able to use assistance for the child care, and that's definitely a big barrier. I have
23 a two-year-old and luckily, my other son is going to be five, but we still have to pay for after school care
24 because I work. Those are two issues I did want to address tonight. Thank you.

25 BETH PINKHAM: Thank you. I know some other folks just came in, and I don't have the sign-in sheet
26 from out there. Did anybody come in and have anything they wanted to specifically say? You have the
27 floor.

28 JUDI DREW: Since there are newcomers, I want to reiterate what we said earlier that this panel is here to
29 hear what you have to say. If we have ideas that might be beneficial to you we'd be happy to talk with you
30 after the session is over or during our break. But as a commissioner from the Governor's Commission,
31 our role is to listen to testimony, review the testimony in the form of the transcript later on, and the
32 commission staff and the commissioners review it to see if there's anything we can do in terms of helping
33 individuals, either through advocacy or legislative activities, as in generating bills. So, some of what
34 you've just shared with us -- you were here last year.

35 TARA TOWNSEND: Oh, yeah.

36 JUDI DREW: I remember you, I remember these issues, and we said this is not okay. So, we were
37 listening, just so you know.

38 TARA TOWNSEND: I'm happy to collaborate on any legislation there.

39 BETH PINKHAM: Barry and Sue -

40 BARRY: I'm Barry not sue.

41 BETH PINKHAM: You're on.

42 BARRY: My wife and myself, our family, I've got three grown boys, two of them I very seldom see, and
43 the third one is in Washington, D.C. I'd like to congratulate your group because there are things that I can
44 see are improving, and that you guys are listening. We do some --

45 SUE: Do you want me to take over, Barry?

46 BARRY: No. Yeah, go ahead.

47 SUE: I don't really know what my husband's talking about. I left my list at home. One of the things that
really irks us is curb cuts and sidewalks; there are not enough of them.
Transportation: Pedestrians We have been out somewhere where there's no parking. The other end of

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 the sidewalk is where the cut was. Handicapped parking. We have a van, it let's Barry off on the right-
2 hand side. It opens up sideways. There may be spots where I can do that, but
3 Housing: Accessible 4 not enough for him to come with his chair to go up or down on the ramp. The
5 apartment complex where we were thinking of moving told us they had four handicap accessibility
6 apartments. There has to be at least 500 of them. This is down at -- I can't remember it. Right down
7 Route 2, opposite Tarbox, opposite Cardi's. There was a waiting list, three people before us. By the time
8 something is available, we could have passed away. So, there doesn't seem to be enough apartments.
9 When I'm talking about handicapped, I mean a roll-in shower, a roll-under sink where you can put
10 toothpaste and a hair brush. Rooms that are wide, hallways that are wide so that they are accessible. I
11 think that's all I can think of. Those are really very bothersome. People don't realize it unless they are
12 handicapped. The curb cut, we took a ride to, I think Scarborough one day last summer and I went to get
13 the car so I could pull it up to the curb cut. By the time I got there he was on the edge of the curb because
14 he couldn't see where it was. I don't understand why they can't put a bright paint on the curb cuts. He is
15 vision impaired, it has to happen to other people.

16 RICHARD MUTO: Could I say I did assist somebody in a situation very similar to Barry who also had
17 vision impairment and was in an electric wheelchair. I know what you're
18 Transportation: Pedestrians 19 talking about. They're not only not in the right places, but not maintained.
20 A lot of times there are deep holes in the sidewalk right before them, so it
21 became difficult to maneuver around them. In the wintertime they were not maintained. He couldn't leave
22 the sidewalk in front of his building because there was no shoveling on the curb cuts. So I do agree with
23 you. And I think it's really important that this is addressed. People do need the curb cuts maintained, they
24 need to be free and clear and also visible.

25 SUE: I just remembered two other things. Another thing is have family bathrooms. If we are -- wherever
26 we go, there's either a men's or women's room. If Barry has to use the
27 Civil Rights: Family Restrooms 28 bathroom, I have to go home. Target is great, they have a family
29 bathroom. The other issue is there's a restaurant that opened up in
30 Warwick right in Oakland Beach, and the ramp is made out of wood. Before I brought Barry in, I wanted
31 to check it out. It wasn't sturdy, I'd never take him there. That's another thing.

32 JUDI DREW: What I would like to suggest to you is after the meeting is offer or during a break, if you
33 could provide us names or the locations that you're referencing, that would be very helpful.

34 SUE: Sure.

35 JUDI DREW: Thank you.

36 SUE: Thank you.

37 BETH PINKHAM: Any other questions? Comments?

38 JOHN SUSA: I wasn't actually planning on saying anything, but a couple of things happened that
39 prompted me. My name is John Susa. I'm, right now the president of an organization called Personal
40 Lifetime Advocacy Network. I've been involved in developmental disabilities advocacy for quite a while. A
41 Transportation: Pedestrians 42 couple of things. I'd like to jump in on the curb cuts. I have a son who
43 uses a wheelchair, and specifically, I can tell you that from Atlantic
44 Avenue in Warwick, Atlantic and Warwick Avenue, all the way down to

45 Hoxie Four Corners, all of the curb cuts are inadequate and do not meet any kind of ADA codes. There
46 are curb cuts in virtually every intersection; however, they're too narrow, too steep, and anybody in a
47 wheelchair who would use them is likely to fall off either as they're going by them or as they're trying to
48 get up and make a turn either to the right or left. They're all incorrectly made. Every single one. That's the
49 problem of bad follow-through by inspectors who inspect the work that these contractors do to build these
50 things. This is a state highway, and I bet you that if you pick almost any other state road, you would find
51 similar things, especially when the roads were redone a couple of years ago. So, I frankly think that there
needs to be, that the Department of Transportation look at how they are following through on approving
these curb cuts after the sidewalks are fixed because we're just wasting money. Those of you who use
wheelchairs probably know that there are plenty of sidewalks that have telephone poles right in the

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 middle of them. Again, somebody is not following through and doing their job. We can complain and say
2 we need to do more, but when we do it and then we do a really bad job, we ought to be pretty upset, and I
3 am. That's one thing. I'd like the commission to actually do something through either the General
4 Assembly or through the Department of Transportation to look at better enforcement going forward,

Healthcare: Home and Community Based Care

5 rather than thinking about going backward. And when
6 we identify areas, especially long areas like that stretch
7 on Warwick Avenue, the state ought to do something

8 about repairing those sidewalks, not waiting until they're going to redo the road in ten years or whatever.
9 So the second thing that I'm here for is actually to encourage the Governor's Commission, to encourage
10 the Governor, and our federal legislators to insist that the state follow through on complying with the
11 home and community-based waivers that the Medicaid folks have changed, 2014. The rules changed
12 and they required a lot more integration and inclusion for people with development disabilities. A lot more
13 neutral case management. Required a lot more things that were really going to improve the quality of life
14 of people, and the states were supposed to be compliant by 2019. This year, under pressure from the
15 Governor's Association, and probably all federal representatives and senators, CMS has put this off
16 another five years. I think that's a mistake. I think it's making the life of people with developmental
17 disabilities more restricted than it ought to be made. And that's something that our elected officials have
18 kind of, and I'll use that famous word now that everybody knows, "colluded." I think they've been colluding
19 and putting this off. It does make for new kinds of work -- I'm out there all the time saying let's get moving.
20 In fact, I was here for what I thought was a meeting for people about that because one of the things that
21 the new home and community-based service waivers is going to require is something called person
22 centered planning and conflict-free case management. In other words, what the federal government is
23 saying is that they don't want the providers of services to be in charge of helping people decide what
24 services they want. They want people to say, "This is what I want," or "This is what I need in my life," and
25 then offer it, instead of having the provider world kind of control what is being offered. That's a really big
26 deal in terms of self-advocacy and self-determination. And we just keep putting it off, and thankfully there
27 is a new director for the Division of Developmental Disabilities, and she seems to be very interested in
28 trying to come into compliance. But, in general, the disability service system is not very anxious to follow
29 her lead, and I think we need to put a lot of pressure on a variety of people. But it has to start with the
30 federal government kind of putting their foot down and saying we're not going to let you put it off again
31 and again and again. So, if the Governor's Commission can reinforce that, I would be very happy. Thank
32 you.

33 JUDI DREW: Thank you for your testimony. I just want to reassure you that we are looking at curb cut
34 situations, Mr. Susa. We have staff whose primary role is to assess. This testimony will be looked at and
35 that person and/or people who are responsible for that will certainly see what we can do.

36 JOHN SUSA: If you want, I'd be happy to talk with them. My son, Mark, who is the person who uses the
37 wheelchair, has done a real life test of that strip of road because he uses
38 that strip of road quite a bit. I should say would like to use. He can't
39 because most of it is too dangerous. In fact, it's not safe for him to cross

Transportation: Pedestrians

40 Warwick Avenue at all from those two end points because none of the curb cuts where the lights are, are
41 safe. And I'll bet you, Lorna, wherever you are, she probably knows on the other part of Warwick Avenue
42 is probably just as bad. And that's ridiculous because they went through the trouble of putting them in, but
43 they made them wrong and nobody said anything about it.

44 CHRISTOPHER DeGRAVE: If everyone doesn't mind me speaking, I have no problem with speaking. I'm
45 the Assistant ADA Coordinator. I can tell you right now I've done this for about seven years, and I never
46 speak at these events, but many of the items are directly related to the job I perform in the State of Rhode
47 Island. I would like to at least make comment, and people can ask questions. Talk about curb cuts and
48 sidewalk maintenance. Many of those roads, whether they're state or municipal, it's all about the funding.
49 And right now, it's a split between the road way that is potholes, the bridges that are falling down, and the
50 sidewalks people use, people with disabilities and without disabilities. My job is to go out and look at all of
51 those items, balance them, and assist the Department of Transportation in making decisions to ensure
52 that they're compliant with federal law. Unfortunately, several years ago, my motion with that was

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 completely cut out from under me, to be frank. I was on a DOT, ADA committee which they have since
2 closed because of change in director, and they, I'm not sure if they didn't think the work was positive or
3 forward moving, but that was a big disgrace to me. I voiced my concern about it, and I hope others do, as
4 well. It was a way I could work with other departments, agencies as a part of the Department of
5 Transportation, and discuss these concerns. Discuss the fact that contractors are leaving jobs, and the
6 DOT isn't inspecting the job for ADA compliance. I am the only guy in the state that looks at the
7 accessibility of physical structures in the State of Rhode Island. That is another problem. And why am I
8 the only guy, and why aren't people piping up about that? Our office has limited staff, and I can only do so
9 much as one individual. Should it be our responsibility as the Governor's Commission on Disabilities to
10 be an inspector for ADA of projects of other agencies when the law needs to be met by them, just as
11 much as enforced by us? And really, for them to turn around, or agencies to turn around and say to us,
12 "Well, you're the authority. You need to be going out there and looking at it," is absolutely ridiculous to
13 me. Much of my job, sadly, is going out and looking at projects that were literally just completed, millions
14 of dollars of projects, time and money wasted that the state has to get a contract and go out again to fix,
15 paying more money for something they signed off on and already paid for that was non-compliant. The
16 Governor looks for things to save money, there's things right there. I'm way down at the bottom of the fish
17 barrel here, so don't shoot me. I'm just providing some real world truth from somebody who does this job
18 day in and day out who sees the struggles. I'm only one guy. I can go out there and tell the large state
19 agencies and fire off e-mails all day long saying, "You're violating state law," contact the Department of
20 Justice, take all the photos I want. I'm down here, and I'm one guy. I need your support just as much as
21 anybody else to get that word out to give us more supporting staff, give us more people to get the word
22 out to message, educate. A lot of my job can't be educating designers, building officials, architects when
23 I'm in the field chasing other people's mistakes that shouldn't happen in the first place. Obviously, budget
24 and money is a huge issue. They go out there and look at these roads and say it's an emergency repair.
25 A big hole in the road, pave this section, this section. Emergency repair. In the Federal Government it
26 says if it's an emergency maintenance repair, we don't have to touch the sidewalk. As soon as they found
27 out, local communities, towns, and the state, as long as they titled it "emergency repair," they don't have
28 to meet ADA. Everything is an emergency resurfacing repair, and it's ridiculous. That's aside from stuff
29 that's done incorrectly. That's a separate item. I've had conversations with cities and towns that want to
30 do 50 miles of road way and they say, well, you know, I can't do 50 miles of road way if you have to do
31 100 miles of sidewalk on either side. What is your solution to that? Well, find more money, bark at your
32 local legislative office, get federal support, and/or you should have done the maintenance over time and
33 not waited until all 100 miles of your roadway in your community need repair to the point they have to be
34 reconstructed. Most of these cities and towns, most of our state doesn't even know what's broken, so
35 how can we put something down when they don't know what needs to be fixed. Hopefully in time, in
36 pushing from my office, we've made a little -- and I thank you for saying that we've made some progress,
37 because that's something we never really hear. And that's much appreciated because somebody in my
38 office, like myself, that gets this day in and day out, that somebody that actually cares as the "typical
39 state employee" doesn't, I care a lot about my job and a lot about helping people with disabilities, and to
40 hear that means a lot to me, so thank you. And it's a tough fight day in and day out to speak to big agency
41 directors and people who go in saying, "I'm looking after my client," and not the federal law. I think the
42 state should have a full-time ADA Educational Coordinator that does training for building officials,
43 government officials, architects, and designers so we can spread the word and move awareness forward.
44 You can fine people all day long. The number one reason I hear all day is, "I didn't know." Or they didn't
45 want to know because wanting to know costs more money. But at the end of the day, if you've given me
46 options to motivate them and move the progress forward, that's the only way. To see the committees
47 folding up and people getting rid of job titles, not saying specifics, but within the state that are
48 strategically for the advocacy of people with disabilities and say a variety of things is just somebody out
49 there saying it's not important.

50 CHRISTINA BATISTA: Can I ask a question? My name is Christina Batista, and you bring up some really
51 great points. How can we help you? You say you go in and talk on behalf of clients. For people that have
52 disabilities, could that possibly be something we could do, people looking for jobs? People with
53 disabilities are always looking for jobs. Could we start something with that?

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 CHRISTOPHER DeGRAVE: Right now it's a budget issue. Our office right now has four full-time
2 employees. Four. We used to have ten. Every year they ask us for ten or more percent budget cut in our
3 office which comes down to submitting a budget with every other Friday off for the entire year, and a cut
4 of my salary by one -- 52 -- or 26 Fridays of salary per person to send back to the state because they
5 can't give us our small budget where some of these agencies have millions and millions of dollars of
6 budget. They want to cut our agency with more people down to less. Unfortunately, the payment piece of
7 it has to be volunteer right now. I have many people who offer to help and have come out with me in the
8 past to get involved in the community, and I welcome that assistance, absolutely. We have phenomenal
9 interns. Ben is one of them, from local colleges and universities. But unfortunately, Ben, the solution is
10 not an intern for three months. The state says, "Well, you got an intern." That's wonderful, but that doesn't
11 fix the problem of commitment. What can you do? Contact your local representatives and call the
12 Governor and say why do you have an assistant ADA Coordinator to nobody. I don't have a boss besides
13 Bob Cooper who is the Executive Secretary in the commission. Lovely work, but the ADA Coordinator of
14 the State of Rhode Island retired in 2012, the position was never filled. So, ask that question.

15 JUDI DREW: Not for not trying.

16 CHRISTOPHER DeGRAVE: 100 percent unrelated to the Commission. The work that the Commission
17 does, I full-heartedly, they are volunteers in that job, and I respect that. I work with a board of volunteers
18 who really have your best interest in mind, 100 percent. But, there's a layer of government above that,
19 and unfortunately a lot of what we do is held back from that. And I ask that you help and we get the word
20 out that there needs to be change. And I'm not Superman, and nobody in my office is. And the
21 Governor's Commission on Disabilities isn't Superman, unless we have your support and the support of
22 the community to do our jobs. Unfortunately, I have to pick and choose the things I can do and provide
23 the resources to the people that need it the most because I'm one person. So, that's all I have to say. I
24 hope I answered some questions.

25 JOHN SUSA: Wonderful. Thank you so much. I understand the dilemma. As I listened to you, I thought of
26 a friend of mine. His name is Joel Tremmel, he lives here in Warwick. He has history. One of the most
27 important things he ever did was about 35 years ago. He and a few other people who are wheelchair
28 users went to Kennedy Plaza and pulled up in front of RIPTA busses and said, "We are not leaving until
29 we can get on the bus.

30 CHRISTOPHER DeGRAVE: I can't condone any of those activities.

31 JOHN SUSA: That's known as civil disobedience. Non-violent, civil disobedience. Do you know what
32 happened? Every RIPTA bus in Rhode Island now has a wheelchair lift. It's the result of that four or five
33 people taking that public path. I can see in my head a dozen or so people in wheelchairs trapped in the
34 middle of a street here in Warwick because they can't get out of it because the curb cuts aren't safe. And
35 I can see TV cameras rolling and people paying attention to that.

36 CHRISTOPHER DeGRAVE: Sadly, the first person they would "can," is me, so I'm just telling you that
37 they would go back and say the ADA Coordinator -- it is what it is. I appreciate the comments. I welcome
38 any of you to call me to go above and beyond, and I will go above and beyond for you and look at specific
39 issues. Still have a lot of contacts with the DOT and other agencies. We're a resource provider.

40 >>: Thank you very much. I was curious, going back to something you said previously about the state
41 spending a lot more money on the curb cuts than they need to. Why are the contracts that are not
42 compliant allowed to go forward?

43 CHRISTOPHER DeGRAVE: That's a question for the DOT. Honestly, there are specific contracts. Things
44 that happen. One of my jobs is, obviously, to take complaints. I don't look at the contract, itself.
45 Somebody calls me says this section of road was just completed, like you did today, can you go out and
46 look at this particular roadway section? Whether it's new, old, what have you? I go out, determine
47 whether it's ADA compliant, and I go back to the organization and say who worked on this contract, what
48 was that about? I don't get into the innards of who they were and what they did. I obviously don't look at
49 the history of it. I say what's here now is not compliant, it needs to be fixed. That's the part I get involved
50 in. What the DOT does, is up to them.

51 >>: Is an ADA Coordinator presiding over the contracts before they go out?

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 CHRISTOPHER DeGRAVE: Again, I don't know. I don't work for the DOT. Thank you very much.

2 BETH PINKHAM: Thank you, Chris.

3 JUDI DREW: We should applaud him because he does very difficult work and works really hard.

4 CHRISTOPHER DeGRAVE: Thank you.

5 JUDI DREW: You're welcome. No, thank you, Chris.

6 BETH PINKHAM: Is there anybody else who signed in and asked to speak before we open the floor
7 again? Otherwise, we'll open the floor for any additional comments, concerns.

8 MALE SPEAKER (ARTIST): I just had a suggestion to perhaps bring to the attention of the panel. The

Human Services: Resources

state does provide pocket manuals the Rhode Island Guide to Services
for Senior Adults with Disabilities. So, again, what I have here is a
physical representation of where the state meets the federal combining

12 with the two. This one here is the from Governor Lincoln D. Chafee in 2012. This is 2015 to 2016, with
13 the honorable Governor Gina M. Raimondo.

14 RICHARD MUTO: I suggest we put the manuals not only on a CD like this and having one for every
15 library in the state -- that would be an interesting idea -- but also to update these with not just on-line
16 versions, but exact numbers and exact information as to which programs will be continuing from year to
17 year, governor to governor. This one happens to be a little thinner and this is a little thicker. Obviously
18 different color. Maybe I was thinking is there more services, or is it just the way that they designed it? But
19 we need to look at maybe redesigning these, and also making sure that we have an updated list of
20 services for all disabled to partake in. Thank you.

21 BETH PINKHAM: Any other comments?

22 RICHARD MUTO: I would suggest rather than a disk, go with a thumb drive because new computers
23 don't take disks anymore.

24 MALE SPEAKER (ARTIST): Maybe for every library in the state that would be something so that they
25 could put it in their reference section.

26 RICHARD MUTO: Uh-huh.

27 ELISABETH HUBBARD: I think Accessible Rhode Island did an App.

28 JUDI DREW: There's on-line resources. Frankly, I think we're really lucky we have the booklets, even
29 though they're out of date.

30 MALE SPEAKER (ARTIST): This is an example of where it stops at 2016, what about this year, 2017?
31 We should have one each, yearly, I think that's important.

32 DEBRA BURNS: They do have another one, senior expos they have those all the time. It's a white one.

33 MALE SPEAKER (ARTIST): Did it just come out?

34 DEBRA BURNS: They come out every year.

35 MALE SPEAKER (ARTIST): I stand corrected. There's a white one, I haven't had one yet. I'll see if this
36 library has a copy. Thank you.

37 BETH PINKHAM: Comments? Questions, or we can take a break and come back.

38 ELISABETH HUBBARD: I'm from the Rhode Island Disability Law Center, and every year we bring
39 information about voting rights and applications to register to vote. Its part of our work to make sure
40 people have the ability to vote, and that places are accessible. And also, doesn't give people with
41 disabilities any problems when they're trying to vote. So, I do have some flyers about voting rights and
42 the applications if anybody's interested, and if somebody needs assistance in filling out an application, I
43 can provide that, too.

44 BETH PINKHAM: We can take a break and let everybody take a rest for a few minutes. People are
45 welcome to stay. If you heard what you needed to hear, you can move on. We'll take a ten-minute break
46 and move on.

47 (BREAK)

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 BETH PINKHAM: As people are ready, we're going to open up the floor again. I want to add a couple of
2 comments during the break. This library was checked with and there is not a
3 Housing: Affordable 4 copy of the DEA manual. Also a comment made to me regarding something
5 being changed if a family member owns, like a two-family home and needs to
6 rent part of that to an individual with a disability, getting some type of voucher system in place to be able
7 to do that. I want to be able to put those in there, and if anybody wants to follow-up with comments on
8 those, fine. Otherwise, we can move on with comments, concerns people have.

9 JUDI DREW: I want to respond to that because the Commission is working now on issues related to
10 people getting tax credits for making changes to their property to accommodate disability.

11 CHRISTOPHER DeGRAVE: I don't know the number, but the break is pretty big.

12 FEMALE SPEAKER: Can I add, I was the person I was a little shy about bringing it up, but my son has
13 been having a very difficult time with changes, so he needs the support. He would love to stay in the
14 home, when I called the town housing they said, "No. We do Section 8 for others, but you cannot do it for
15 your own children." That was my concern. Almost like he's ready to be independent, but he's just, his
16 anxiety level is not doing well with change. At age 22, turning 23, to start getting him on his own, but yet...

17 CHRISTOPHER DeGRAVE: I see you're looking to modify your own home to be able to provide --

18 FEMALE SPEAKER: Doesn't need modifications, I just need to move myself from the home. That would
19 be his own apartment instead of going to an independent living, low income. This way I would move
20 myself from the home, and he could support himself.

21 CHRISTOPHER DeGRAVE: Provisions that would allow Section 8 funding.

22 JUDI DREW: She doesn't qualify for Section 8. >>

23 FEMALE SPEAKER: Not me. I'm sorry. It's basically me to move myself from the home so he can be an
24 independent individual with, obviously, supports coming in to help him and check him.

25 JUDI DREW: If you're someone thinking about doing a home modification, please contact the
26 commission. We can tell you about the program, we just got it passed.

27 MICHELLE: Michelle from the MS Society. It's actually pending in the state budget. We originally filed it
28 Housing: Modifications 29 and we partnered this year with AARP. It was supposed to be a tax credit and
30 last minute they decided it was an earmark, \$250,000. Obviously if they're
31 working on last year's budget because it's a new program, it doesn't exist, but

32 I think we're hopeful it's in both budgets. Obviously it can be taken out, but I don't see any indication.
33 We're waiting for the budget to advance. If you have more of an update? We're just really anxious and
34 haven't spread the word, but I mean this is a great opportunity just to raise it so if people are aware the
35 budget advances and we don't know the criteria. I don't know if you've heard any progress. I assume the
36 state can't start even working to create it until a budget is advanced, but maybe you know more.

37 JUDI DREW: I know a little more. I can't share a lot. What I can tell you is that the Commission worked on
38 what the criteria would be and how it would be implemented, and as soon as the budget is passed, we'll
39 make sure that people are notified, public notice.

40 MICHELLE: What you're saying sort of off the record is there is sort of work and discussions behind the
41 scenes, even though it's not formal.

42 JUDI DREW: There's some tweaking, but we're very excited about the amount of money and hope to put
43 it to good use.

44 FEMALE SPEAKER: The criteria, application. All of that. Is your sense that once the budget's passed it
45 may be up and running pretty quickly, or you think it's sort of months? What is your best guess?

46 JUDI DREW: I'm not going to guess. But you heard Chris talk about the lack of staff that we have, and so
47 one of the ways, one of the things we're examining is how can we implement it and staff it properly?

48 FEMALE SPEAKER: Is that only for adult modifying your home? Anybody who modifies your home?

49 JUDI DREW: For independent living, yeah.

50 FEMALE SPEAKER: For my son, say, obviously we already did it, put a ramp on the deck years ago, if
51 we were to do one in the front my mother could apply for that.

2017 Public Forums on the Concerns of People with Disabilities and their Families

- 1 JUDI DREW: There's also resources for modifications: Ocean State Center for Independent Living.
- 2 FEMALE SPEAKER: Even for children.
- 3 JUDI DREW: Doesn't matter. There's resources out there. My concern is a lot of people probably don't
- 4 know.
- 5 FEMALE SPEAKER: I know about most of them, and we're not eligible.
- 6 JUDI DREW: A lot of them are income-based. Their program is a needs-based.
- 7 BETH PINKHAM: We have some eligibility criteria financially, but at the very least we can do an
- 8 assessment and say these are the kinds of things we recommend be done or would help improve access.
- 9 From there whether -- we have some small funders of last resort that we can sometimes do some actual
- 10 access improvement with, but it is last resort. So we would have to based on income, based on there are
- 11 no other avenues that somebody could pursue for those modifications, things like that. So, it's always
- 12 worth a call to us to ask questions and see. Rental property is different. We can't do modifications on
- 13 rental properties, but we will still work with people who are in a rental situation who need modifications
- 14 because a lot of times they live in a building and need to request a reasonable accommodation or
- 15 landlords or other people may need access to information to make improvements. Some cities and towns
- 16 have community block grant funds where they do low interest loans or outright grants to folks who live in
- 17 that city or town to make some of the improvements. Programs through the Veteran's Administrations
- 18 and some specific disability groups like the Multiple Sclerosis Society. That's what we try to do. The
- 19 minimum we can do is an assessment to say here are the things that would seem to make sense. The
- 20 options that you would have. And from there we would make a plan with the individual to say now we
- 21 know what needs to be done, how do we get to it?
- 22 MICHELLE MACHADO: Could I speak? My name's Michelle Machado, and I work at OSCIL with Beth.
- 23 And similar to what Dr. Drew said, we do have a home access department that's very important to
- 24 maintaining a person's independence within the community. So I'd like to thank legislators for keeping
- 25 that in the budget, but I'd also like to urge them to increase our funding towards that department in order
- 26 to keep individuals within their homes. Within the last year, we have been able to do 171 home
- 27 modifications within a 15-month period for people, which encompasses ramps, bathroom modifications,
- 28 accessible showers and tubs. We did have a slight budget cut, though, with that program. It was originally
- 29 \$20 thousand for a person, now it is ten. We're hopefully hoping to get it back up. If we can urge
- 30 legislators to do so, that would be really helpful. Another issue that I see as a disabled person is, of
- 31 course, the housing situation. As a lot of people have mentioned. Because as a young adult, myself, I
- 32 would like to either own a home or go into disability housing; however, there's not enough housing for us
- 33 out there and we're on waiting lists for several years. So encouraging legislators to maybe look at
- 34 buildings and look at the construct of them and build more complexes, or let individuals own homes and
- 35 then modify them with the help of organizations like OSCIL.
- 36 JUDI DREW: Wouldn't it be great if apartment buildings that were built were universally designed so you
- 37 wouldn't have to worry about having a rolling shower. It happens in Europe.
- 38 DEBRA BURNS: I have something to say, there's a lot of disabled and elderly, and a guy on my floor,
- 39 he's paralyzed from up here down, so his mom takes care of him, she lives with him, and he has one of
- 40 the showers that the lady and the guy over here, Barry, were talking about -
- 41 >>: A rolling?
- 42 DEBRA BURNS: I think, so yeah, because they do have disabled apartments, and there's a lot of people
- 43 in wheelchairs who can't walk at all and they do put them in. If you were to move there, you would
- 44 specifically tell them you need one because this guy cannot a move at all, his mom has to do everything
- 45 for him.
- 46 CHRISTOPHER DeGRAVE: They can't penalize you, fine you, anything like that for modifying your own
- 47 apartment. I don't think that's the problem, usually. Obviously some of these are low-income, they don't
- 48 have the money, it's expensive to be able to modify. If that's the case and you want to modify and they're
- 49 not letting you, that's an issue you want to contact us about.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 DEBRA BURNS: I know where I live, they do have -- I don't know how many disabled apartments there
2 are, accessible, but there's 500 in my building, 500 apartments, so I figured I'd let you know.

3 CHRISTOPHER DeGRAVE: Depending on when the buildings were built, there has to be accessible
4 what's called A Units, B Units. Fully accessible, they market as full rolling showers, large hallways. And
5 there's other units that have to be easily modifiable. Sometimes they're not going to necessarily market
6 those because there's work involved in having to modify them. Or it means the person who is renting that
7 is going to be modifying it and that could bring up issues for them. You have to dig into that a little more. I
8 hate using the term "accessible housing," because accessible to you, isn't accessible to me, isn't
9 accessible to the next person. The way we always look at it, is it an apartment or house or what have you
10 with accessible features. These are the features this particular apartment has, you know what type of
11 accommodations you and your disability needs to utilize and you can pick the apartment or house by the
12 features. I can market my house as fully accessible and somebody can come in with a large power
13 wheelchair and say, "It's not accessible to me," so now it's not accessible to that person. I do this all day
14 long. Sorry.

15 JUDI DREW: Can't shut it off, right, Chris?

16 CHRISTOPHER DeGRAVE: Pretty much.

17 BETH PINKHAM: Comments?

18 MICHELLE MACHADO: I had a third issue, as well, with regard to the PCA Program, which is a
19 wonderful program that allows people with disabilities to
20 have personal care attendants to help them within their
21 home. With proposed Medicaid cuts, that's a concern with

Independent Living: Personal Care Assistance

22 regard to whether it's still going to be in existence, how many budget cuts we're going to face. In addition
23 to that, as a person who works and has a disability, I'm lucky enough to have my PCAs come to work with
24 me; however, the state puts guidelines with regard to how much we are able to work and earn and be on
25 that program. And I'm very thankful to be on that program, I don't want it to sound like I'm not; however,
26 as a person with a disability, we should be able to access these services because they're very important
27 to us. Our limitations, and I'm not speaking for everybody, but myself, my limitations are not going to
28 change. I believe the PCA program should not go based on rate of pay or hours worked, but maybe a co-
29 sharing program where you can actually pay into your services with regard to how much you pay,
30 similarly, as a father or a mother who doesn't have custody of their children on a full-term basis has to
31 pay child support. I think it should be based on rate of pay in dealing with that so that a person with a
32 disability, like myself, could still work full time and still earn a living.

33 JUDI DREW: Thank you. We'll take a look at your comments.

34 BETH PINKHAM: In the back?

35 FEMALE SPEAKER: Speaking of working. I have a son that, he's 32 now, and last year we began a self-
36 directed program because of behaviors. We had to do something. So,

Employment: Job Placement

37 agencies have access to a lot of contacts to find either employment or
38 volunteer positions. We want to keep him busy. I'm not even concerned
39 about employment and earning money, I'm not ready to deal with calling in the money to Social Security
40 and extra reviews and what have you, but with the state pushing for so many individuals with disabilities
41 to work some amount of hours, do they have resources that we can find, like, people who are looking to
42 employ someone or looking for volunteers that have disabilities that they're not concerned that it might
43 take this person three hours instead of one hour or have to have staff support going with them. It's really
44 hard to go anywhere and get any type of anything for them, and I don't know as a self-directed person
45 supporting my son, where to go, what to do. Does the state have resources that we can look into?

46 SUE HAYWARD: Yes. BHDDH has a person-centered program which was set up as a means to use
47 additional funds that were provided to our department to help people become employed. So I can meet
48 with you after. If you have to leave early, I can meet with you before and talk about it and connect you
49 with a social worker and talk about access.

50 FEMALE SPEAKER: Is this a service where they have to go and take classes where they have to be
51 employable? I've seen things about this, and I'm not quite sure how that works.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 SUE HAYWARD: Yeah, there are agencies that you can utilize who have staff to help who are certified
2 as job developers or job coaches. It's additional funding you can use to be able to hire someone to help
3 your son be able to meet him where he is in terms of his ability to be employed and what he might be
4 able to learn and use those services to help him find the job.

5 >>: We have the support. I have the support. I have staff. It's where do you go to get a job? Where do you
6 go to get volunteer work? They've been to the Walmarts, McDonalds, animal shelters. Is there ever a
7 posting, "I'm looking for someone --" just like an intern?

8 FEMALE SPEAKER: I know the state is very short, it's very frustrating. My son is with an agency, he's
9 apparently a very good worker, but he can't get enough hours. Right now he's working four hours a week.
10 I do not wish to disclose where he's working. Started at eight hours, they got slow, and cut him back to
11 four. Every day, "Mom, am I going to get my hours back?" He's advocated for himself, approached the
12 manager, "I want my other day back." The agency, to find employment, as a mother, I said what can I do
13 to find a job for my son? Because it seems like everywhere I go so many places need help. Please apply,
14 whatnot. So frustrating. As a mom, I would have no problem, but then they're going to -- they don't want
15 mom to go in and fill out an application and say, "He is very marketable. Show him what to do two or
16 three times, he's got it down pat. He'll even want to do it more." I see your frustration. I didn't want to do
17 direct, I just depended on an agency to do it because this is so new to me. Apparently, yes, it is
18 frustrating.

19 >>: He was never able to get anything with the agency. They simply tried to do volunteer work. It's where
20 to go to do this. He has the supports that are willing to help him.

21 JUDI DREW: I'll be happy to talk both of you afterwards and address your concerns.

22 >>: We're just sharing ideas, but like I said, the state, yes, everyone is short with work and employment,
23 but there are people who want to be, even as volunteer, not even the money part, but to be productive,
24 be part of the community.

25 JUDI DREW: Let me introduce you to a representative from ORS.

26 SHARON THISTLEWAITE-MORRA: There are offices that can get involved.

27 >>: Frustrating because it's only four hours. Apparently, it's supposed to be nine, the minimum, from what
28 I understand is supposed to be nine, he only has four and they're still holding onto him.

29 ELISABETH HUBBARD: He hasn't reached --

30 >>: They have it hanging over his head, this is just slow now, but they've been saying this since I, think
31 May, now we're going into August. So, again last night he said the manager was in and he was training
32 someone else, and you know, we're going into August. "It's August, and I haven't had my extra day."

33 JUDI DREW: Let's talk after the meeting.

34 FEMALE SPEAKER: And I'm very familiar with ORS, too, I have a daughter with disability and she is
35 receiving services. She's much higher functioning than my son, so I know all the services. I want to know
36 how to get a job or a volunteer position. He would go wash fire trucks or buses, anything. He's a liability.

37 JUDI DREW: Let's talk afterwards.

38 FEMALE SPEAKER: Okay.

39 JUDI DREW: That's one of the things the students in my program are trained to do: assess individuals
40 with disabilities to find employment that matches their disabilities. I know about that stuff.

41 >>: Okay.

42 MALE SPEAKER (ARTIST): I would like to add some ideas to this situation. Perhaps, in the future, there
43 could be some kind of drop-in center creation that could provide maybe a voluntary position of disabled
44 people. Not unlike the Oasis which is in Pawtucket, but I think that model needs to be improved for the
45 future. And also, I think in regards to the comment about being a liability that's obviously a legal issue
46 between the employer and the employee, but maybe they'll be a distinction so that the volunteer could
47 not be considered a liability, and maybe that would be something for the legal part of the panel, the
48 Disability Law Center, to work on. Some kind of clause or special contract to meet these people with
49 disabilities of all kinds. Yes. We have the agency over here that has the vocational rehabilitation services,

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 and they do the assessment for the disabled; however, sometimes, the assessment needs to be
2 changed. Also, sometimes it should be more centered around the actual disabled person, and not the
3 policy around what determines that assessment. You both have disabled siblings that are capable and
4 energetic to continue what they want to do, the state and the system should be bending over backwards
5 to provide anything and everything for that particular situation. That's it. Thanks.

6 >>: I have a daughter who has -

7 JUDI DREW: Could I stop you for a second? Could you identify yourself?

8 ALBERT HEROUX: Albert Heroux. I have a daughter who has Autism. She was diagnosed when she
9 was three, and she's 30. I read about this, and I left work early to come
10 here and present my problem to see if it was unique or whatever. I work
11 for the state, so I understand how the state works to a certain point, but

Independent Living: Supports

12 the problem has been getting worse with her each year. Her purchase order for her care that the state
13 provides for her through Options ends May first. That's her anniversary date. I do payroll every two weeks
14 for the caregivers, and when I sent that paperwork in, Options was notified by the state that the benefits
15 were cut back from 75 hours to 25 hours. Told them, didn't tell us, so the two caregivers worked for one
16 week and didn't get paid. We were told the following week, two weeks after the anniversary. We did a SIS
17 right away, made the appointment, like they suggested. Went through them. A SIS is not what I have a

Human Services: Evaluation

18 problem with. I understand you do reevaluation. We were supposed to do
19 this every three years, we somehow fell through the cracks and it became
20 almost ten. It became a power struggle and filed a complaint and found
21 out a whole bunch of people filed a complaint with the same individual. So that was fine. Got taken care
22 of, done it over, got it straightened out. This year comes up, same thing happens, two weeks after May,
23 I've got people working now, actually one couldn't work because there wasn't enough hours, the other 20
24 or 25 hours, five hours a day. No way a person can live on five hours a day. She continued working her
25 regular hours, even filled in a little bit what the other one couldn't do. At least the five days a week my
26 wife could go to work. We did the 109 and 110. Had hearing on the 18th of May, and we weren't notified
27 of anything on that until the first week of July. In the meantime, I called different people in the state trying
28 to find out where that stood, started with social worker and worked my way up. Because it got to the point
29 where the woman that was working for five hours a day and putting 40 hours a week in said, "I no longer
30 can do this because the state is taking too long, so I'm going to need to quit." By her having to quit would
31 force my wife to quit because cannot leave Nicole alone. She needs somebody to look after her 24/7. If
32 she was in this building and the fire alarms went off, it would not mean a thing to her. If she talked to you
33 and you had a conversation with her, she would go home with you, not even question it. My wife would
34 have to quit. She was turning in her notice to quit when we got noticed from Options, and not the state,
35 saying okay, they had the reevaluation, went through the system, and they're going to reinstate the
36 hours. We don't find out until after, again, state delay. My thing is the state should do this process three to
37 four weeks or more ahead of time so that if they say we're going to cut the hours back, which I
38 understand, I have no problem with reevaluating, if somebody has half of what's required under the plan
39 we set up, you change or adjust; that's okay. Don't wait until after it expires then tell you. Do it four to six
40 weeks ahead, we're going to do this so we can start doing the paperwork, having the hearings and get an
41 answer by the anniversary date for the individual. I don't think that's too much to ask for, but it seems to
42 get worse, out of hand. I know there's short staffing, I well understand, I understand that, but the time
43 frame should not be a problem. That should be adjusted even with short staff so we can still get an
44 answer ahead of time. That's all I ask. Thank you for listening.

45 JUDI DREW: Kathy, do you want to respond to that?

46 SUE HAYWARD: Sue. Actually, I would like to talk to you outside, if you don't mind. It sounds like you
47 have been through a lot of channels and appeals process. I would like to connect with you outside. Thank
48 you.

49 BETH PINKHAM: Thank you. In the back.

50 >>: I would like to just add that I can relate to this man's issues. My son has more hours than he does per
51 week, and for the third year in a row, we're getting our letter telling us that he is back to a Tier C. I just

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 submitted my ISP, his plan renews September first, we just submitted it last week. Also use Options, he's
2 self-directed, day program and community...whatever... I want to know
3 when will this end. He's not a C, Never was, never will be. He gets two-to-
4 one supports. So I sent an e-mail immediately to the individual I received
5 the letter from to please confirm to me because last year, I believe, yes, it was dated 2016, we received
6 an e-mail when we did the initial self-directed plan that began September first, it was approved at the
7 funding level with extra monies, whatever it's called, and that it was in effect, the S110, until August 31,
8 2018. So I sent an e-mail asking to please confirm that this Tier C is not a problem because I have this
9 S110 that just went in with the ISP, and I just, I don't know, it's frustrating. And then I think he's due for
10 assist next year. What do I have to do to get him back-up to where he always was at that higher tier? You
11 have to make him sound like the monster of the world and what he needs is the supports he's getting
12 right now. The best thing we ever did for him, for me, for our whole family is the self-directed. And to be
13 able to continue this, we need to maintain the level of supports we're receiving, and to me, this is like a
14 constant, constant worry that next year it's not going to be here. The agency that he was at wouldn't
15 service him without two-to-one. It's frustrating. They don't change. They don't get better. He's been this
16 way since he was this big. He's six foot tall, 260 pounds and maybe three or four years old in his mind.
17 When he gets upset, you have a powerful human being there. How do you get past this constant need for
18 evals and tiers, et cetera?

19 SUE HAYWARD: It was implemented a number of years ago and recognized that it wasn't fully capturing,
20 and in November it was revised, the SIS A. The questions were triggered by certain other questions and
21 go deeper into some of the other issues being raised. They're evaluating how well that is working and if
22 it's actually capturing all the things it needs to. You're very correct. There were a lot of people submitting
23 requests through that 109 process --

24 FEMALE SPEAKER: Correct. Right.

25 SUE HAYWARD: That was part of the recognition if we're getting this many requests for additional
26 funding, perhaps the tool needs to be revised. Reevaluate that tool and see if it's actually capturing. They
27 have changed the time frame that it's done now to every five years, instead of three years.

28 FEMALE SPEAKER: He shouldn't need to have it done next year?

29 SUE HAYWARD: I don't know --

30 FEMALE SPEAKER: It would be three years; it was done in '15.

31 SUE HAYWARD: Correct me if I'm wrong, it sounds like he didn't have the experience of going through
32 the SIS A.

33 FEMALE SPEAKER: No he has not.

34 SUE HAYWARD: It sounds like what's been happening, since that SIS A has been put in place. When
35 people are requesting additional funds for that 109, and it looks like the amount of funds requested would
36 actually be a jump in tier, then the decision has been to have that person have the SIS A, is this tool
37 working, and is it an accurate reflection? I don't want to keep everybody. I can give you my phone
38 number, and I would be happy to talk with you about this further. I'm the supervisor, I work in Cranston,
39 Warwick, down to Westerly area. It's quite possible I might know your sons or daughters, and I'll do
40 whatever I can to help answer the questions that you have.

41 FEMALE SPEAKER: Thank you.

42 JUDI DREW: Thanks, Sue.

43 MICHELLE MACHADO: So, one thing I wanted to discuss is one of the challenges that I have is financial
44 planning. I know about the ABLE account² and I've opened up one,
45 and I put money into it, but I just want to speak with someone on a
46 one-on-one level to fully understand the program, and the

47 scenarios and all of that to help me with that.

48 TAMMY RUSSO: Benefits planning.

² ABLE Accounts, which are tax-advantaged savings accounts for individuals with disabilities and their families

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 MICHELLE MACHADO: I was on ORS, but my case is closed.

2 TAMMY RUSSO: You can re-open it at any time.

3 SHARON THISTLEWAITE-MORRA: There's an application on-line, or you can call.

4 TAMMY RUSSO: They can do that one-to-one counseling with you for the financial planning.

5 MICHELLE MACHADO: And they would be familiar with that kind of stuff?

6 SHARON THISTLEWAITE-MORRA: At 40 Fountain Street, which is the office of ORS, once a month you
7 can come to an orientation if you need help filling out the application or just have questions answered.

8 You can go to the orientation, as well.

9 MICHELLE MACHADO: All right. Sure.

Transportation: LogistiCare

HEATHER SCHEY: My issue is with LogistiCare. Someone has to bring it up.

12 BETH PINKHAM: It's only ten of six.

13 JUDI DREW: I'm shocked it took this long.

14 HEATHER SCHEY: You guys were hoping. My biggest thing is, I'm a visually impaired individual. I am
15 fortunate enough to have moved within four blocks of my employment. I am fortunate enough to either
16 get a ride or walk back and forth to work. Sidewalks is another issue, which was already discussed. So,
17 as far as the medical appointments, my sister is also visually impaired and no longer goes to a counselor
18 or medical appointments as she should because of the lack of trustworthiness with LogistiCare. When the
19 free medical trips were provided by RIPTA, she never had an issue. There was never an issue. Late
20 occasionally, sure, maybe an occasional driver would forget her, but it was not a consistent basis. She
21 had tried LogistiCare many, many times. They were four hours late picking her up. Trying to drop her off
22 at a wrong building. She didn't always know. She got out of the car once, turned to the driver and said, "I
23 don't think this is where I should be." Sure enough he said its 300 such and such a street. "That's not the
24 street. You have the right number, but you don't have the right street." If she didn't have some residual
25 vision, she would have been dropped in an odd place where she wouldn't have known what to do. So, I
26 believe, and I know this is where I feel that LogistiCare should be stripped of their contract, and I believe
27 that if, in fact, it is possible, I don't know that it is, but if it could go back to Paratransit and have it
28 organized the way it was working before and have RIPTA's funded for it, continue getting that funding so
29 they can do the medical as they were doing when it wasn't an issue. There's so many issues wrong with
30 it. Most of the cars shouldn't even be on the road. I tried twice when I was first -- when the program was
31 forced on us. We just got a letter in the mail, nobody knew what was coming, and I got in a car, the car
32 smelled like pot smoke. And so, I mean, it's just, there are so many issues and so many levels of checks
33 and balances that aren't being done, and it's a really broken system and it needs to be fixed. Thank you.

34 JUDI DREW: Thank you for your testimony. Appreciate it.

35 BETH PINKHAM: We do have six or seven minutes left. We have time for a few more questions or
36 comments, or if people want to start to catch individual people at this point. Did we get to everybody? I
37 guess what we can do. I know some people want to meet individually. We can let that happen. We'll be
38 here for another seven minutes or so, so if somebody has anything they want to get on the record, please
39 do. Thank you for coming today, everybody. Lots of good comments and information.

(BREAK)

41 BETH PINKHAM: Just so everybody knows, the event is officially over. It's five past now, and CART will
42 be leaving. We can wrap things up and move conversations along. Thank you, and thank you for coming.

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44 [Cumberland Forum July 26, 2017](#)

45 Panel Members:

- 46 1. Cliff Cabral - Seven Hills Foundation
- 47 2. Debra Sharpe - Brain Injury Association of Rhode Island
- 48 3. Mike Lombardi - Office of Rehabilitation Services
- 49 4. Judi Drew - RI Governor's Commission on Disabilities

2017 Public Forums on the Concerns of People with Disabilities and their Families

- 1 5. Dawn Wardyga - RI Governor's Commission on Disabilities
- 2 6. Rui Cabral - National Federation of the Blind of RI
- 3 7. Deb Garneau - RI Department of Health
- 4 8. Kate Sherlock - RI Disability Law Center
- 5 Public:
- 6 1. Pam Whalen
- 7 2. Faye Zuckerman
- 8 3. Beth Pinkham
- 9 4. Brian Nichols
- 10 5. Linda Bruneth
- 11 6. Lori Barden
- 12 7. Jennifer Charboneau
- 13 8. Lindsey Morin
- 14 9. Leng Parenteau
- 15 10. Georgette Brouseau

16

17 JUDI DREW: .The first thing I want to share with you is that we'll be introducing ourselves across the
18 panel here. And what I'll do at this point is determine the order of speakers, I will call each speaker
19 when it's your turn. And we'll allow you to ask questions, we'll have a wrap up, we'll definitely be here
20 until 6:00 p.m. even if no one is here. Just in case someone is getting out of work late. So, we want to
21 thank you all for coming, for taking the time out of your day today to come and speak to us as a panel
22 and I personally as a member of the Commission am appreciate of your time. What we do is after the
23 public forums are completed in August, the sponsoring agencies including the Governor's Commission
24 on Disability will review testimony and prepare recommendations which will be posted on the web site
25 by the end of November. The recommendations and the transcripts will be printed and sent to the
26 state and congressional officials and members of the General Assembly so be assured your testimony
27 will be seen not just by us but by others. Recommendations will be used to develop policy and
28 legislative initiatives for the next year or until accomplished. Some aspects of prior testimony from
29 prior years that we are still working on in terms of a legislative agenda. The Rhode Island Disability
30 Law Center's panelist here to my right, my left actually, your left, will be available to register anyone
31 who is a citizen and not currently registered to vote, where they live and to vote at the end of the
32 testimony -- I don't understand that but that's okay, people can also file a change of address if they
33 moved and we have information here and I am sure she would be happy to talk with you. Next thing
34 we'll do is ask the panel members to introduce themselves, let me start at the end and go across.

35 KATE SHERLOCK: Good afternoon, I am here from the Rhode Island Disability Law Center and as
36 she kindly shared we are available to help anyone who needs to register or reregister to vote and also
37 have a voting rights flier available on the table. So, the disability law center is Rhode Island's
38 protection and advocacy system. We do three main advocacy around three main things, abuse and
39 neglect, access to services and civil rights. Because we were funded by the federal government, we
40 have to do priority setting every year. And as part of our priority setting, we sit on this panel and
41 information that we learn on the panels around the state help us with our priority setting for the next
42 fiscal year which for us starts October 1st, 2017. So thank you for coming.

43 CRISTY RAPOSO: from RIPTA.

44 DEBORAH GARNEAU: From the Rhode Island Department of Health.

45 MIKE: From the Office of Rehabilitation Services.

46 RUI CABRAL: From the National Federation of the Blind of Rhode Island.

47 JUDI DREW: The process so you know, I forgot one thing, do you all have cell phones? Would you
48 please take them out and put them either on vibrate or shut them off. As a courtesy to the speakers. I
49 can tell you that this panel is not here to yell over noise this panel is not here to solve problems for
50 you. We are here as a listening entity, to hear what your concerns are. In order to do this and in order
51 for us to properly register your comments. When I call on you if you have asked to speak already, if

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 you could please introduce yourself, say who you are very briefly so that the CART person will be
2 availability write that into the record for us. And then, after we're done with all of the speakers if
3 anyone here did not sign up to speak but would like to speak publicly, we welcome you to do that and
4 we can also have questions and answers and back and forth during the course of the process. Any
5 questions about this?

6 SPEAKER: Do you mind if we don't stay until 6:00?

7 JUDI DREW: Feel free to go. If you want to speak and you're done, feel free to go. We're here
8 because this was a public announcement, we said we'd be here until 6:00 we honor that in case
9 people can't get here earlier. Okay. Panelists have to stay but you can leave.

10 JUDI DREW: May be some good conversation, just saying. Again, we are here to listen. If we think we
11 have ideas for you or services you may not be aware of that you may benefit from having access to,
12 we would be happy to talk to you, we'll have a break for 15 minutes around 5:00 and maybe members
13 of the panel may come to you and ask for more information. So we'll try to deal with your issues in a
14 side bar kind of situation. Rather than the big forum. Okay? Has everyone that came in that wants to
15 speak signed up? Okay. So I am going to go first with Pam Whelan.

16 PAM WHELAN: That's me.

17 JUDI DREW: I guess we can say your name is Pam.

18 PAM: Yes, and I'm here to represent my husband Michael Whelan, he is in a wheelchair and goes to
19 dialysis and the social worker has been trying to get him rides so he doesn't have to count on some of
20 his family members who may not always be able to do it. He just started dialysis in January of this

21 year and had an under the knee leg amputation last month. I have the letter
22 Transportation: Rlde that he just received from RIPTA dated July 13th, 2017, that says that they
23 are pleased to welcome him to our paratransit service. But then, at the end of

24 the letter, it says, be aware that your trips are also subject to ADA eligibility and must start and end
25 within a quarter of a mile of a RIPTA bus route, which I know you can help me with that. Your home
26 address is outside of the ADA corridor so trips to and from your home will not be eligible. So even
27 though he was accepted, he can't get a ride from where we live in Cumber land because we are not
28 near a bus route. So we can move or go to a family member's house near a bus route which makes no
29 sense, the dialysis center is ten-minute from where we live and anyone near a bus route would be like
30 20 minutes away so it's like going all out of the way in order to get there. He is depending on his father
31 who is 80 years old who sometimes is like out of breath trying to push him in the wheel chair. I am able
32 to take him on Saturdays because that's my day off. So, right now, we have been able to do it with the
33 different family members, but, as far as his father and friend goes, that's 80 years old, you don't know
34 how long they'll be around so I figured I would get on this right away. The social work has done a lot,
35 though, trying to call different programs for us. And one program said that they would give him a ride
36 but it would be \$48 round trip and we were only ten minutes away. And being disabled, he can't afford
37 that. And the other, another program that we contacted, they said that because he does not have
38 Medicaid and he is under 60 he doesn't qualify. And that's all I have to share. For now. Thank you.

39 JUDI DREW: Okay. Did you want to respond?

40 CRISTY RAPOSO: I'd like to follow up with you later about a survey we're doing as part of a
41 transportation coordination plan for the state but unfortunately that is the ADA law is we're only
42 required to provide Rlde service to any home within 3/4 of a mile of a bus stop.

43 PAM WHELAN: Do you think maybe you could, do you know of any other program that is we could try,
44 or --

45 CRISTY RAPOSO: I don't personally know.

46 JUDI DREW: Let's talk during break, if you can stay until 5:00ish, is that all right?

47 PAM WHELAN: Yes.

48 JUDI DREW: Okay, thank you, Pam. So the next person on the list is Fay Zuckerman.

49 FAY ZUCKERMAN: I don't need to talk, here representing the Brain Injury Association of Rhode
50 Island, I was here on Monday. I didn't checkoff I wanted to talk. Just look at the check marks.

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1 JUDI DREW: All right. Where is Beth?

2 CHRIS: Might have hit the rest room.

3 JUDI DREW: Only other person that checked off she would like to speak is Lori Barden.

4 LORI BARDEN: I'm from Rhode Island Parent Information Network herewith a few things. Last week I
5 was lucky enough to attend the Pawtucket RIPTA public forum and something brought up there that

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Transportation: Travel Training

hit home when I came back to the office was around transportation training for our transition youth. And how we are an employment first state but many of the children who never receive drivers

licenses are held back from finding better employment because they are ill equip to actually take a bus and follow routes and make either eye contact or change in the respect that it's, that social barrier they need to overcome. So transportation training is something really big we would like to see and we would like to see partnerships with the transition academies and CAP agencies to provide that and that transportation training could be looked at from all aspects. I think of the later in life disability where

Employment: Job Placement

people who have relied on their own transportation their entire life, driving themselves to and from and now all of a sudden find themselves unable to drive due to any number of reasons. So

transportation training is one area. Going back to employment first, an employment first state, we would like to see more partnerships with our businesses and looking at opportunities to really look at the federal credits and how to entice businesses to work more with the disabled population. We are lacking that enterprise spirit, especially around so many event that is happen in our state for new business owners, entrepreneurs, female business owners and diverse, underserved populations. So employment first is a really important thing that we need to see as a focus. And then the last part, later

Independent Living: Transition

in life disability, both professional and personal I guess for me at this point. I look at the work that's being done in order to service all realms of life. But when you go from being a typical functioning

adult to all of a sudden having some form of catastrophe whether a physical disability or because of a physical disability caused other disabilities, there is no real set transition. Because it's not a transition, it's a jump and dive. And when you are either the loved one or the caretaker of that person, there is less support for you, you don't necessarily know where to go. And when you couple that with language barriers, we as a state don't do the best job to really become very aware of both cultural and language discrepancies in our programs and our facilitated support groups. I look at the fact that we have few Spanish support groups. In Pawtucket we have few Cape Verdean, Woonsocket, few Cambodian support groups so the dynamics of the communities are not necessarily being served. Great to have a bunch of English documents and we can rely on Google translate for some things but the cultural aspect is missing so that's part of the support group atmosphere. But then people who may not have support at home don't necessarily know where to go. And they don't know how to navigate that giant change or transition in their life that's happened. And we find that shut-ins increase, that social behaviors decrease and it's something we need to focus on because our populations are rising. Our baby boomers are living longer than anticipated, our Gen-Xers are that sandwich generation that now have to worry about their child with maybe a disability and a parent with a disability. And we need to be able to support that group. That's really it.

JUDI DREW: That's it for the list of people that signed up to speak. So, wait a minute, no, that's it. Any additions?

JENNIFER: That would be me.

JUDI DREW: Did you sign up to speak? Didn't you check it off?

JENNIFER: That's okay. I just, I didn't realize it was going to be kind of the way it is. I thought it was somewhere where I could talk about some of the things that being disabled are helpful in certain places. I think mainly its parking is huge. Huge. Problem for disabled people. And I have come to realize that it's not only

Transportation: Parking

normal people, or I'm normal, too, but disabled people, also problems as well. Most people do not know that those lines are for people like me who own a van and can drive myself around but can't walk

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1 so I have to take the scooter. Those lines are so I can get in and out of my van. And even disabled
2 people have a tendency to park in those lines. I don't know if there's a way that they can put up, I
3 mean they put up the handicapped signs for the spot but if they can put something in front of those
4 lines saying, not a parking spot, this is for van access or whatever. The place I bought got my van
5 from, Ride Away, they gave me a sticker, please park 8 feet away. Nobody looks at that. And a lot of
6 the, a lot of stores like Stop and Shop in Woonsocket, they don't have any lines. I actual will I have to
7 park in their fire, the around the actual store itself there is an area wide enough for me to park and pull
8 out there. There is nowhere else for me to park if did, I couldn't get out of my van because there would
9 be someone on either side of me at all times. I actually asked the fire people because they are there
10 constantly getting dinner or whatever, and I asked them, is it okay if I park here? And he looks around
11 and, like, well, you can't really park anywhere else, can you? No I can't. He's like, then you go right
12 ahead. It's just, you know, why do some Stop and Shop places like in Lincoln, they, I mean I realize

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Transportation: Uber & Lyft

that they just have opened up within the last ten or something years,
and they put in the correct parking areas for van access. Some places
don't. Or most places where their handicapped parking is is like all the
way down the other side from where the actual door is. So that was just something I wanted to put out
there as something that, you know, ADA or whatever should maybe say, you need to change some of
these things. The other thing, I wasn't going to talk about this but her talking about the traveling, I have
no idea who I could talk to about this, but, I mean, Uber and now Lyft are the things out there, and
having a handicapped van, I would love to go and take handicapped people around to doctor's
appointments, dialysis. Problem is, I can't tie them down. But, like, is there somewhere out there that
maybe could help get something, kind of a group together that, they have the vans and, or they know
people that have the vans that are willing to do it and maybe they could go with them that would be
willing to help tie the people down in the vans so that, you know, it was never a -- you wouldn't have to
rely on things like RIPTA and not being near a bus line because, if I didn't have my van, I live in
Burrillville, there is no bus line. Anywhere near there. And have I a doctor's appointment tomorrow if I
didn't have my van, I wouldn't be able to go. So, I don't know if, you know, you guys know of anything
or can talk to someone about, mention that, you know, someone brought this up to discussion,
something like that.

JUDI DREW: That's a really creative idea. Uber has it, why not, everybody walking around can get a
lift somewhere, why can't handicapped people in handicapped vans.

JUDI DREW: There are lots of reasons that I could go into from a liabilities standpoint.

JENNIFER: I know some of them, yes.

JUDI DREW: It's a wonderful idea that we can brain storm on. In one hearing many years ago, the
Governor's Commission was able to get funding for accessible taxis and that came out of testimony
from people talking about lack of access to transportation ***. Know we take these seriously and do
our best to figure out ways to help.

CHRIS: With regard to the parking situation at Stop and Shop or wherever, parking is something the
Governor's Commission deals with all the time, tomorrow I am going out to address two complaints to
look at the scenarios so feel free to contact us and we will go out and do an investigation.

JUDI DREW: Just so you know, you are not alone, the hearing we had yesterday, this issue came up
then, too.

JENNIFER: Oh, really?

JUDI DREW: Yeah so it's a common problem, I think it could be easily re-involved, maybe pass
legislation saying the lines marked area should say accessible wheel chair van only right in the line
itself.

JENNIFER: Like I was saying, it's not just people driving other cars and whatever, it was actually at
the Stop and Shop in Lincoln that has the lines. So I park there and I had just gotten back in, I finished
shopping, just gotten back into my van and a lady parks in the lines. And I
rolled down my window and I said I'm going to be leaving if up want to
move over and she said, oh no, I do this all the time. She was

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1 handicapped, sure, but she's like, I do this all the time, it's no problem, I was like, yeah, but if I had to
2 get out, I wouldn't have been able to. I would have to wait for due whatever you did and come back out
3 and move.

4 JUDI DREW: I can think of a couple solutions that I won't go into here but we can certainly talk about it
5 on the Commission. It is a big problem. Is there anyone that just came in that would like to talk to the
6 panel? We're friendly. No? Okay. Well we're here. You want to take a break? We can't cease the
7 hearing.

8 KATE SHERLOCK: no but let the reporter take a break while nobody is here.

9 JUDI DREW: I'm okay with that if you want to take a five or ten-minute break.

10 (BREAK)

11 JUDI DREW: We have a nice lady that would like to testify again, related to a different topic. Would
12 you introduce yourself?

13 JENNIFER: Jennifer, C-H-A-R-B-O-N-N-E-A-U. We were talking about excise tax, I am being charged
14 based on not just the value my van but the value my van plus all of the handicapped accessible item

15 that is have been put in it. So it costs me about \$67,000 for my van.
16 Transportation: Auto Excise Tax And that's what I am getting taxed on instead of the \$35,000 that
17 anybody else could have paid just to get that van. And I do know

18 that there are towns in Rhode Island, Newport, James town, that do not charge excise tax for
19 handicapped people and towns like north Providence that charge half price and towns like Burrillville
20 where I live that they charge it on \$70,000. I just feel that, you know, the federal government doesn't
21 charge you tax on handicapped vehicles, the state doesn't charge you tax on handicapped vehicles,
22 why does the town need to? There aren't all that many handicapped vans like that out there. Do they
23 really need to get the large lump sum of money from people that are on disability to begin with and
24 can't afford it? It's almost a, almost a month, costs about a month of my pay for the excise tax. I only
25 get paid once a month. So it's not really you know. I don't have a lot of money. My husband and I can't
26 afford to buy a house. I always say I'm van poor, not house poor.

27 JUDI DREW: Yeah. That's why I wanted you to testify, because this is a really important issue that a
28 lot of us didn't know about. At all of the hearings I have been to over I don't know how many years, I
29 don't think I have heard that topic brought up, have you, Christine? I've never heard that brought up
30 before.

31 JUDI DREW: So I think this is important, something to talk about with community providers to see if
32 there is general consensus.

33 JENNIFER: I know the gentleman is trying to do away with the excise tax. What city do you live in?

34 JENNIFER: Burrillville. And, yeah, that would be great. There are a lot more handicapped people out
35 there than I know of. But, compared to the number of people in the state to begin with, you know, it's,
36 they can give the handicapped people a little break now and then. Because we don't get them all that
37 often.

38 RUI CABRAL: In most towns, most towns have significant discounts on folk who is own property so it's
39 actually, some disabled discounts. So it's stunning that there is essentially a surcharge in your case.

40 JENNIFER: If I bought a house I would get a discount on the house tax because I am disabled but not
41 because of the car I have sit can in the driveway.

42 JUDI DREW: Thank you for putting that on the record, it's definitely something we'll take a look at.

43 JENNIFER: Okay. So you if you don't want to stay, you don't have to stay.

44 LORI: Mom spelled it short for a reason. So we were just talking about the location of these public
45 opportunities to speak. And Jennifer, I saw you coming out of your van as I was walking. And, it would
46 be really wonderful if better description was available because had this said Hayden Center,
47 Cumberland Library there is an entrance there with handicapped accessible parking that's a lot less
48 difficult to navigate than through the hallway. Just a comment because, for folk that is may look at it,
49 all right, it's at the library, to get here we walked by two seminar rooms.

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1 JENNIFER: Not only that, I drove by this place, my GPS -- I did two loops. Like, you just passed it. Oh,
2 you passed it again. I don't see anything. I see the station, I see this. So I asked someone, yeah, just
3 down the street after the church. I'm like no it's not. It's this little thing on that sign out there. The
4 Monastery. It doesn't say Cumberland Library anywhere, it's like a complex.

5 JENNIFER: Unless you live here you have no idea.

6 JUDI DREW: Duly noted.

7 LORI: We continued our conversation. So, in Pawtucket, this is a RIPTA thing, came to my mind after
last week's discussion, but, in Pawtucket there is the downtown bus station
and it's at the old Peerless center because we are all Rhode Islanders so
we get that connotation, it's the Main Street, but it's, Main Street and

Transportation: RIPTA

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11 Roosevelt. At the new visitor center but to get there from the population that need it is leaving this and
12 coming down Roosevelt, past the police station, past city hall and the fire department and across the
13 giant street with so much traffic in the morning because there is a high school at the top of the road
14 and come to Kennedy Manor, large, 13 floor handicapped and disabled living center. And, you
15 continue going and there is a child care center, there is an office for DCYF, there is a church and so
16 on, so on. But there is no bus stop at that happen end. This population has to literally cross a large
17 street and continue walking, or, driving or however they get there, to a bus stop. And I understand
18 because of populous, that stop makes sense, however, for the population that's going to use it, it
19 makes no sense. So if you're a single parent who relies on transportation to get your child to day care
20 so you can then take that transportation to get to your job, you are transport that go child in a carriage
21 or however you are, literally, probably a good tenths to two tenths of a mile, almost a quarter of a mile
22 and that same population of seniors and disabled that live in Kennedy Manor are trying to get from
23 there to the bus because they may not qualify for something else to pick them up. So that's a big
24 issue. And the accessibility for the RIde van or LogistiCare in that area is horrific because of the
25 congestion of traffic. So if we're looking at accessibility for disabled and older population and I will
26 lump it together because at a certain point age counts as a disability. We're doing a disservice, just the
27 other part we were talking about.

28 JUDI DREW: Thank you for bringing up an issue that we have heard before. But I'm glad to hear that
29 there are other people raising their voices in terms of getting something changed. We are aware of
30 there are a lot of spots around the state having problems regarding access for pedestrians and lack of
31 bus stops.

32 LORI: Sidewalks are a big issue in Pawtucket, Central Falls, Warwick, where people truly use public --
Burrillville doesn't have sidewalks. I can tell you Burrillville has no
sidewalks. But, I look at Pawtucket and having the opportunity this
past fall to literally walk a lot of Pawtucket and get through Pawtucket

Transportation: Pedestrians

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36 there is not a truly safe patch you can say, oh, this is a good mile I can walk where I won't trip, fall, my
37 wheelchair won't get stuck, the ramp is there. So, sidewalks.

38 JUDI DREW: Appropriate curb cut, yeah. So sidewalks, curb cuts, huge issues. Access to public
39 buildings, city hall is horrific in Pawtucket. Cumberland to get to the city hall, right down the road, have
40 you to pray you can get into the parking lot right there, otherwise you are crossing a very busy broad
41 street and that doesn't always work. So, it's just the accessibility that we are limiting who can be part
42 of the public experience.

43 JUDI DREW: Thank you.

44 JENNIFER: I don't know who, again, the Department of Health, it kind of has to do with a lot of doctor
45 offices and buildings specifically and I know Lincoln is huge complex of all these brick buildings with
different doctors and stuff. I go into so many doctors' offices that do
not have a button, have I to physically open that door myself and I'm
like trying to get this to go in and forward and back. I'm like why do

Civil Rights: Automatic Doors

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49 doctors' offices not have handicapped buttons to get in. Is that something, I mean?

50 JUDI DREW: Well --

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1 DEB: The Department of Health has regulations around accessibility and accessibility of, there are
2 specific ADA regulations for medical facilities. So, when an agency or a provider is applying to the
3 department for a certification of occupancy and a condition of need, then we will look at the
4 accessibility requirements. And ensure that they are meeting them. But that only happens like once,
5 you know, when they first open, or when they're trying to do a different service, or to do some sort of
6 expansion. Other than that, there are no proactive, you know, ways in which we are ensuring
7 accessibility. We do have a complaint system and, you know, as well as the Governor's Commission
8 on Disabilities also investigates based on complaints. So there is that capacity that's available. So it
9 doesn't have to be a big thing, but it's to say, you know, you can't get in. And then, folk also work with
10 landlords or with, you know, the owners of the property.

11 JENNIFER: These are brand new buildings, last five or something years and I would have thought out
12 of any building, that, MRIs, mammograms, everything is done in this building and I can't get in if I can't
13 get the door open or there ant is he someone coming in and out.

14 JUDI DREW: Where is it located? Blackstone Valley place? Yeah.

15 DEB: Might be the weight of the door.

16 JENNIFER: Yeah, they're not.

17 KATE SHERLOCK: Disability Law Center has prioritized access to health care for a number of years.
18 So we don't promise to take every request, but we do when we can.

19 JENNIFER: I found out when, I was working for Putnam Investments and my manager came up to me
20 one day because I didn't know who to complain to and I mentioned it to HR, I can't get into the

Civil Rights: Physical Access

21 bathroom that's closest to where I am, can't get in the building because
22 they didn't have the buttons or whatever and my manager came over
23 one day like, why don't you give me a list of what needs to be

24 handicapped accessibility here and I said, have I a better idea. You sit in my wheelchair, I'll sit in your
25 seat, you go around and you tell me. And he did. He was like, oh my God. Yeah, that's what I go
26 through every day. And sometimes, I feel like, like this, if you're not in the situation, you don't know.
27 Okay, yeah, she's in a wheelchair, who cares, she can get in. How? It's like it's not easy to wheel one
28 side of a wheel and pull a door at the same time. I hate to complain about things like that, it's just, you
29 know, being disabled myself, some of those things annoy me, after a while. It's funny, I say, I
30 understand why a lot of people say old he were handicapped people are so angry. And I'm only 47
31 years old and I can see myself when I'm 60 or 70 being an angry disabled person. I understand. I
32 mean they have been disabled a lot longer than I have. And it's gotten a lot better for me, since I have
33 become disabled so I can understand why, I mean, they, they couldn't get anywhere years ago, into
34 anything. They couldn't go to a restaurant because they didn't have a ramp.

35 RUI CABRAL: That didn't happen on its own, it happened with a lot of people complaining persistently.

36 JENNIFER: I just don't know where to complain.

37 RUI CABRAL: I realize that. But it is through that action. I understand it may come off to some people,
38 no one in this room will take it as angry but to the casual observer who is not familiar, comes off as
39 cranky or angry or you know, be grateful you have X, Y and Z. But to anyone who has been involved
40 in any fashion in disability rights movement, it doesn't come out that way at all, we are just trying to
41 stay on equal footing.

42 JENNIFER: Yeah.

43 JUDI DREW: Let me just share some information with you about that issue. Americans with
44 Disabilities Act has a tech access board. That board is responsible for am putting forth regulations and
45 guidelines for how things are built, how buildings are built, parking lots, and a certain number of
46 parking space that is must be handicapped accessible, et cetera. One of the challenges is always,
47 when you have new properties where architects will design them and design them with accessible
48 options. And builders will build them without those options. And because there is not enough
49 inspectors to inspect, sometimes buildings get built even with state money that are not built with
50 handicapped access. So it's a statewide, nationwide issue. And when you're dealing with older
51 doctor's offices or older buildings, medical buildings that you want to get into. Unless they are doing

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 some type of remodeling, they are under no obligation to make changes. Unless people raise
2 complaints with the Department of Health and disability law center, there is enough of a concern, a
3 landlord can be worked with often but those doctors' offices are in buildings where they rent space so
4 it's not their responsibility, it's their landlords.

5 JENNIFER: Those I completely understand. It's the new buildings. ADA was a long time ago.
6 Everything since then is supposed to be done.

7 JUDI DREW: There is a doctor's office here in Rhode Island, the access is through a loading dock,
8 where the doctors' offices are. I won't say who and where it is.

9 KATE SHERLOCK: Well, yeah, it's not just doctors' offices. It's not that long ago it was a town hall.

10 JENNIFER: There is a pizza place near us. They can't let me in because the only ramp they have is
11 into their kitchen. Unfortunately you don't get my money. If I can't get in.

12 JUDI DREW: Consumer voice.

13 JENNIFER: Believe me I do tell friends when things like that happen, like, I can't go there. Of course
14 then they don't want to go there.

15 JUDI DREW: Lori, did you have another comment.

16 LORI: I got a text message from my middle schooler. We do a great job in the state on occasion. And
17 it's like special occasions for students with disabilities where there is a sense of inclusion and that it's

Education: Inclusion

18 celebrated so I think Dare to Dream³ Middle School, I think of the Special
19 Olympics and unity teams and so forth but not a fantastic job around
20 (inaudible) awareness and around disability sensitivity, and we don't do a

21 fantastic job incorporating the social experiment process. We have an opportunity to make a stance,
22 we are a small enough state where we able to get the inclusion of our 39 school districts and extra 12
23 charter school districts to work in conjunction together and have a unity day a day in October that
24 other states recognize as National Bowling Awareness Day and not just the seldom half dozen or two
25 dozen people wearing orange that day where you know what they're doing. I feel professionally we
26 have this entire group of parents who will be calling who will say, my kid is being bullied, my kid is
27 being made fun of. Or, the cyber bullying is an issue, kids with disabilities want to be accepted and
28 they won't stop trying to be accepted. But we don't have the structure around it to really support
29 awareness. And our quote unquote nondisabled students don't necessarily under[stand] the impact of
30 a comment that may seem washed over from their peers but with somebody who requires, I don't want
31 to use the word requires, but for somebody who is less socially available, or is less socially
32 comfortable, or has that awkward outer appearance or inner ability to communicate in a social setting,
33 it could be detrimental so I think as a state we have an option to build up a generation that can make a
34 positive change because it's being implemented into their daily school routine. Or on a statewide level
35 acknowledging that we want to do something different. I mean, we have bullying policies for every
36 school district. But do parents really know where to find it? I can tell you they don't because they come
37 to our bullying and harassment workshops and don't know their schools have policies or that the state
38 has a policy. So, there is an opportunity to get that information out there.

39 JUDI DREW: Thank you. Anyone else?

40 GEORGETTE BROUSSEAU: I do, my name is Georgette Brousseau. And I am here mostly to

Independent Living: Transition

41 educate myself but my reason for doing that is, sorry, this is hard, I
42 have a son with a significant disability who is now 22, so entering
43 adult services, I teach, and so I felt much more able to handle that

44 world. Adult services are entirely different. As I said I am here to educate myself. But, in addition to
45 that, my husband who was an attorney in the state had a massive stroke about four years ago and so I
46 am now, I find myself in an unenviable position to be both of their advocates. As I look at your
47 information and listen to what we're discussing today, I would mention something in regard to him

³ Dare to Dream Student Leadership Conference Unique to Students with Disabilities

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 that's been a concern for me and our family since he got sick. He has been in a nursing home, he has
2 significant cognitive and physical impacts as a result of his
3 Healthcare: Traumatic Brain Injury stroke and related complications. About a year after the stroke,
4 the nursing facility he was in, first of all, in the beginning, I began
5 to wonder, how could I be the person to take care of both of them? And continue to work. Sorry. My
6 husband's needs are significant enough that he hasn't been able to come home. About a year after the
7 stroke, the nursing facility recommended that we go to a brain injury program called neuro (inaudible)
8 in Massachusetts, for intensive rehab after he was no longer even qualifying for rehab in the nursing
9 facility. We attempted to do so, we did. He was expected to be there for a 3 to 4 month stay. After two
10 months, they said that, they suggested we find a nursing facility. Because with the cognitive impact he
11 suffered, that he was a good candidate for continued progress. My concern is that Massachusetts has
12 supported living environments for people with brain injury. Rhode Island has very limited resources in
13 that regard. We live in Gloucester. NeuroRestorative told me they were identifying spaces but that
14 seems to have gone by the wayside. He continues to reside in a nursing facility, he is 61 years old.
15 They told us to find a nursing facility with both restorative care and a good activities program. Which is
16 not doable. So we did, he is at a nursing facility called Bay Berry Commons in Burrillville, that does
17 have an in-house day program. But, it is a memory care program but that program is really not suitable
18 for a 61 year-old, it's suitable for an elderly Alzheimer's patient. So that's my big concern in the State
19 of Rhode Island, what are the opportunities for people, especially young people that have brain injury.
20 My son has a significant disability and in some ways, it mirrors my husband's and I look at, there are
21 no longer group homes in Rhode Island, not to suggest that that's what I would be looking for, but
22 something for both of them to have, my son continues to reside with me but I look at long-term and I
23 have no life any more. I am caring for these two people -- sorry.

24 JUDI DREW: Its okay, take your time.

25 GEORGETTE BROUSSEAU: And on a good day, beginning to work. The paperwork, the processes
26 are incredibly difficult, incredibly daunting to advocate. The time spent just for my son alone, it's a full-
27 time job. Today I had a meeting with ORS, tomorrow I have another
28 Human Services: Evaluation SIS eval⁴. every day there is something, every day. They each have
29 their own to do list. That's just a different concern. But, it is incredibly
30 daunting. It's a tremendous amount on a family that already is having to take a lot more time than the
31 typical family just to care for their disabled member. So I guess those would be my two big concerns is
32 what are the opportunities for people with brain injuries in Rhode Island and how do we streamline the
33 process for families to make it easier. Especially when the disability is not a question, it's not a minor
34 disability. If it's a significant disability that's well documented, do we really need to be inundated with a
35 tremendous amount of paperwork and phone calls and meetings? For instance, I just mentioned

36 meeting with ORS today, that's the thirds jobs initiative I have done
37 Employment: Job Placement through supported employment initiative, career plan in his plan with
38 Seven Hills, the ORS, that's just one aspect of his care a lot of
39 redundancy, it's tremendously difficult to get through all of these processes and to constantly
40 advocate. So, streamlining of the processes, I feel is sorely needed, to be able to say help support
41 family that is are trying to support individuals with disabilities.

42 JUDI DREW: I noticed in your testimony that you didn't include having access to respite care.

43 GEORGETTE: Can you tell I might need it? He does have a -- my son does have a significant amount
44 of supports. But when he was evaluated a year and a half ago, the process has been changed since,
45 so it is slightly different now, from what I understand but I don't think it will make a difference for us in
46 terms of what I understand the new SIS looks like. My son has a regressive form of autism and today
47 looks like he has Alzheimer's at 22 years old. So he was typically developing until 3 and a half so it's
48 just continuing -- he has continued to lose skills over the years. A year and a half ago when he was
49 evaluated, I guess the levels range A to E, he was identified as having a C. It was not enough and I,

⁴ The Supports Intensity Scale (SIS) is an assessment tool that evaluates practical support requirements of a person with a developmental disability.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 my husband had just gotten sick. I pushed to, I did an appeal, aside from having to advocate for him to
2 just get services on time because his birthday is in February and I was in the middle of the school year
3 and couldn't afford to not have services immediately so he could continue, that took a lot of energy on
4 my part, I did work with people that were helpful and it did happen but it was very time consuming and
5 once we went through the appeal process he was given additional hours. And his plan -- up
6 September 1st, I go back to work two days before that, been meeting since June to update it. I
7 received a letter saying, we submitted another appeal to maintain the level of service, then I received
8 a call to say they wanted to reevaluate, do another SIS (sounds like) which is tomorrow morning and I
9 received the letter saying he get a level C of service so now the plan writer who is Claire Rosenbaum

Human Services: Caregiver Supports

10 from the Sherlock Center said are they going to your appeal in
11 the meantime so he doesn't have a lesser amount of services
12 especially while they continue with the process of the SIS. And
13 that's another thing to do on my-to-do-list. In addition to that phone call where they said, I said you just
14 submitted the appeal he said, yes, this is the new eval. in light of the appeal. My concern I, I don't think
15 my son's level was appropriate, I do think he has a greater level of need than they identified initially
16 and he has continue today regress. But like I said, it's more than just my son, if the state doesn't want
17 to have the appeal process which I have heard a number of people say, no longer wants to engage in
18 these appeals, the whole other side of my picture which is my husband's disability and me being a
19 sole support for both of them and continuing to try and work is not reflected in a SIS even if it's
20 accurate. So right now his level of hours allows me to go to work and to spend time with my husband
21 every day, my son goes but not, it's not appropriate for him to be in the nursing home every day in fact
22 I almost had to call the police the other day because he wandered off on me while we were there and I
23 had a maintenance person, a nurse and two CNAs helping me to look for him, he wandered over to a
24 warehouse nearby. I am now buying him a GPS to try and keep track of him. I doesn't -- even one of
25 the worker who is helped to find him he wouldn't speak to, autistic, he retreats and doesn't engage. So
26 even when she found him she said he wouldn't come to me. So, I just find myself in this very
27 unenviable position and really feel like my husband is sitting in the nursing home forever is not
28 appropriate. And the level of work load on me is ... not sustainable. Long-term. Just because I think it
29 could be done a lot smarter a lot more streamlined and a lot more family friendly. It already takes a
30 significant amount of time to care for your disabled family member. So, to have to constantly have
31 your to do list of what does he need to do for me next is, for him, next, it's daunting. It's tremendously
32 daunting. And I look at myself doing it but I know at least I can, I think it's very unfair to other peep who
33 will maybe cannot. I do teach, I know a lot of family that is the families are not necessarily able to
34 advocate to the level that I do for my son and I don't think that's fair for individuals with disabilities to
35 have to work so hard. I am not sure what the answer is but as I go through these processes, like I said
36 looking at all the redundancy and how there are so many pockets of what you need to do. If I am
37 working with you on this, you don't know how many other things I have on my plate because you are
38 not engaged in them but I as a family member are handling them all and it's something I think we
39 could do a better job of. We are talking a lot about person centered planning now and I just hope it
40 doesn't become another avenue with another set of processes and paperwork. We do self-directed
41 services, I think it's very much person centered. In fact we were with an agency at first because I didn't
42 want to hold this whole ball of wax and it wasn't optimal, I couldn't even continue to work because
43 there were just lots of times where they were unavailable. And sometimes would come in, okay v to
44 leave early today because I have this training tomorrow and there were just a lot of time and I could
45 not continue to maintain a job with that and I had to switch to self-directed services, those are much
46 better and I think much more person centered. In our case and I feel like his services are appropriate
47 right now. But to just maintain those is a tremendous amount of work. And so I hope in whatever
48 efforts we are make to go revamp the system in terms of person centered planning, that we can
49 streamline things to some extent and really make that meaningful as opposed to just another set of
50 processes and paperwork. Because it's just not doable. My son could never do it on his own behalf.

51 JUDI DREW: I am going to thank you for sharing your story. You did a great job. In sharing a very
52 difficult experience. Is there anything you can tell me that I don't know about opportunities for brain
53 injury programs?

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 JUDI DREW: Can you respond.

2 DEB: Have you connected with the Brain Injury Association? We don't have a spectrum of services in
3 Rhode Island. There is certainly efforts through our Medicaid agency to see what they are and even
4 the appropriateness of other kinds of living arrangements that are not elderly focused nursing homes
5 and what does that look like for even adults with disability that is need that level of care. So there are
6 some, but that's a huge issue in our state, is, the range of appropriate care. I don't know if, at times,
7 the Brain Injury Association has been more strategic and I think, Kate, you worked with them, as well,
8 around this, but looking at how they can collectively bring forward some of the issues and kind of like
9 the case studies of family that is are trying to navigate the system and what kinds of services could be
10 available and really work with the state on, how can we develop these kinds of resources. I haven't
11 heard so much of that most recently but I know there has been efforts in the past.

12 KATE SHERLOCK: I will tell you briefly that the Governor's Permanent Advisory Commission on
13 Traumatic -- on Brain Injury has been in existence since 1996, I am not sure when it became part of
14 their role to submit a report annually to the General Assembly and the Governor, but either in '86 or
15 some time since then, and in June of this year, I believe for the first time a report was actually
16 submitted. I won't say it's an all-volunteer, because there are state agencies represented, and then
17 there are people like me who work, so I'm paid to be at the table even though it's a, sort of a volunteer
18 commission. The one thing that I know is available, sort of newly available is Seven Hills which was
19 our sponsor today. And unfortunately there is not a representative here, but they have been approved
20 to provide non-24 (sounds like). I know you had the experience with neuro restorative in Mass, the
21 three group homes for people with traumatic brain injuries in Rhode Island which also include acquired
22 brain injuries are operated by them so I don't know if they explored whether your husband was
23 appropriate for any of them at the time that he was in Massachusetts. There were two at the time,
24 (inaudible) and Charlestown.

25 KATE SHERLOCK: Two in Charlestown and one in Westerly. Anyway, Seven Hills has been
26 approved to approve non 24/7 but it can be up to 23 hours a day. They have only served one client
27 that I'm aware of. They served that person pursuant to the personal choice waiver. But that is
28 something that they do. I have no idea whether that's appropriate for your husband or not but I am
29 happy to try and brain storm with you if I can be of any help. We'll touch base.

30 JUDI DREW: Cliff Cabral who was supposed to be here today is the Vice President of those, he
31 oversees all of those services, including those programs. So he might be a person you would want to
32 reach out to, it's too bad he wasn't here today so you could talk to him but since you're already in the
33 system and receiving service from one side t may be worth your while to contact them. When my
34 husband was at NeuroRestorative in Mass (inaudible) we live in Glocester but also 23 hour, I have a
35 son who needs 24/7 support, I don't know if I could have my husband do the same and try to maintain
36 a job and so forth even if there were staff coming in. I just don't know. I know how overwhelmed I am
37 right now and I just, I would love to say that he could but I am concerned about that. I just would like to
38 know that there was something. Even for the disabled, developmentally disabled, I am told we have
39 limited our residential options. I just know transitioning through high school, we were asked how would
40 you like to live on your own, with independently, et cetera, and it was always with family and that was
41 completely what we wanted. My son graduated from high school, my husband's stroke was a month
42 later. So he lost his, the level of his support like overnight. So that's the concern for me, is not just, it's
43 a big concern for my husband but also for my son that there are no (inaudible) which is like an adult
44 foster care kind of an option and there doesn't seem to be anything else. Some meetings we have
45 attended there has been discussion about Rhode Island developing an array of residential options but
46 they don't exist right now and I know it's a concern not only for me but several other family members
47 that have voiced that concern and I believe have started to discuss that.

48 RUI CABRAL: The elephant in the room here is the proposed Medicaid cuts that are going to make
49 some of this even more potentially challenging. So that's something, in all of
50 Healthcare: Medicaid your spare time, to keep an eye on. Absolutely. And the other side of that is
51 my husband doesn't even get Medicaid. We're forced to spend all of what
52 we saved for retirement so I can no longer even contribute to retirement, my son, because that's what

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 you have to do. So, financially and otherwise it's a significant burden, to have those situations that you
2 never anticipated.

3 RUI CABRAL: Right but as it stands, the difference being obviously once you do spend that down, that
4 safety net as it stands is at least there to continue his care. That's right, unless it gets cut, you're
5 absolutely right.

6 RUI CABRAL: So, I have a father-in-law who, my wife and I are power of attorney for who is in a semi
7 similar situation, he is in his late 50's, he has pretty significant Parkinson's and he is in a nursing
8 home. And so, a lot of what you said seems very familiar. I filled out 30 page Medicaid applications
9 and I work in the industry in the health insurance field. So I was familiar with them. Most people aren't.
10 And I have been to many Medicare/Medicaid planning meetings quarterly meetings on his care, and it
11 does stack up with just one person, never mind two. Right. And in light of that, having to pay down
12 medical bills over a \$100,000 a year for one individual, I can itemize it with federal taxes but get hit
13 with Rhode Island because you can't itemize Rhode Island taxes so have I to spend that down but
14 have to be careful not to spend that down at the same time because of the tax implications. So it's just
15 a difficult situation. It's different than when you're elderly, I think.

16 JUDI DREW: Thank you for sharing.

17 JENNIFER: What is the difference between Medicare and Medicaid?

18 RUI CABRAL: Medicare is for folk who is are over 65 or are disabled and under 65; Medicaid is
19 specifically income based program, two versions of it, more traditional is for moms, kids, children with
20 disabilities, adults with disabilities. The more recent flavor of it that is all over the news is the Medicare
21 -- Medicaid, even I do it, expansion program where able bodied low income adults were added on for
22 the first time, below a certain threshold which is about \$16,000 a year. But they do have two very
23 different functions. Now some people are dual eligible, Medicare and Medicaid. So adults with
24 disabilities who are low income are dual eligible.

25 JENNIFER: What do they consider low income, if I am making on my Social Security Disability for my
26 Medicare -- if I am making like over what, \$1,100?

27 RUI CABRAL: You would probably be, there is a little more that goes into that particular program
28 because they look at assets and just as she was just describing, that's why they are spending down all
29 of their assets before they are even Medicaid eligible.

30 JENNIFER: So because of my \$70,000 van I probably wouldn't be.

31 RUI CABRAL: There are exceptions for personal vehicles and all sort of -- there is a reason the 30
32 page application is a 30 page application but the short and sweet answer is your income in and of
33 itself is pretty close to the borderline, too me it's worth applying.

34 KATE SHERLOCK: It's very complex but there is also the Medicaid Buy-In plan for people who are
35 working and need services to keep working.

36 JENNIFER: Unfortunately nobody wants to hire me because I can't walk or write, I don't have the
37 dexterity anymore, so, computers, cash registers. Having to take a nap during the day.

38 RUI CABRAL: That's a situation where your income may be such that you may want to consider
39 applying, you then would become Medicare/Medicaid eligible and pick up essentially the other 20%
40 that Medicare doesn't cover. And certainly there are benefits to not having co-pays, deductibles, et
41 cetera.

42 JENNIFER: I pay \$200 a month so I don't have to pay that extra 20%. Have I personal Blue
43 Cross/Blue Shield as well as my Medicare. So I don't have that 20%. But that's expensive, too.

44 RUI CABRAL: Certain if you told me you made \$1,500 or something like that, I would have said, no,
45 probably not worth it. Or, have you less of a shot.

46 JENNIFER: For me it would be not worth it then.

47 RUI CABRAL: It would be worth it though.

48 JENNIFER: No, I make more than that, luckily I had a good job for the ten years before I became
49 disabled because if I didn't, but, luckily working at Putnam, I had a good job.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 JUDI DREW: Can I ask you a question, have you talked to the Office of Rehab Services? You are a
2 young woman, worked at a highly skilled job. It would be worth it for you to speak with the Office of
3 Rehab Services to see if they can do something to assist you with technology.

4 JENNIFER: Who are they through?

5 JUDI DREW: Mike Lombardi right here. It would be worth it for you to explore that.

6 JENNIFER: Only job I could get now is being a greeter at Wal-Mart.

7 JUDI DREW: Probably not, actually. That's the point. The vocational rehabilitation program is
8 designed to assist people with disabilities to return to work if you want to do it and you're highly skilled.

9 JENNIFER. Do they, the lawyer that got me my Social Security he said if you plan on going back to
10 work, talk to me first because, because if you work too much then they cut down on

11 MIKE: We would have benefit counseling, get a representative to talk to you and do a detailed report
12 to tell you how much money you can make before your medical or
13 Social Security benefits would be effected. So there won't be a blind
14 door hitting you. At one point if telephone wasn't feasible for you
15 financially, we would say, okay, stop. It's all your choice. You drive the program. We develop a plan
16 together.

17 JENNIFER: I think the hardest thing is, I mean, yeah, I would love to work. I hate the fact that I am on
18 disability. My husband is like you worked all those years for it so now you're using it, I'm like, yeah, but
19 I'm not working, I am a 47 year-old woman who has to take a nap during the day to get through the
20 second half. And can't type on a computer for longer than a half hour/45 minutes and have I to take a
21 break. And it just, it's hard, you know how a loft husbands, they don't like the wife bringing in more
22 money than them; I don't like the fact that I, the only money I can bring in one way or the other is just
23 that disability once a month. Most people would be like, you're on, you don't have to work, you're fine.
24 Don't complain. You wake up whenever you want, go to bed, take a nap whenever you want.

25 RUI CABRAL: For most people that are disabled and I was born blind, most people who are disabled,
26 it goes beyond, yes, is there a certain percentage who get used to that, if you will. But there is a
27 certain percentage of people, its well beyond the check. There is a certain value in work and
28 contributing to society through work. Many people who are on disability contribute to society in
29 thousands of other ways. But, it's that gratification of doing work, getting paid for it, et cetera. So I
30 understand where you're coming from. I was on SSI for a period of time, and like I said, I have been
31 working in the health insurance space for the last 15 years. Own a home, have two kids, where is the
32 white picket fence, it's somewhere. But have I a friend considering disability because of ailments who I
33 didn't really think, he could work, let's put it that way. He is the opposite of you. And basically, I said to
34 him, you want to have a child and if you want anything like what I have got, that doesn't come through
35 a monthly check. He's been working for the last year. Minimum wage but he's been working. So there
36 are people who can and there are people who for good medical reason can't and that's what the
37 program is there for.

38 JUDI DREW: So please talk to Mike when we're done. That would be wonderful.

39 JENNIFER: I think the hardest part about being disabled is, people that, no offense so anybody here
40 but people that aren't, and they look at me like, and I know, my husband said, it's because you don't
41 look 47 years old, they look at you like you're a kid. Like why the hell are you in that scooter. It's kind
42 of like, in the mall people actually, walk by me and say, I wish I had one of those. There are times
43 when I have gotten pissed off because I am sick of hearing that. I look at them like, I'd like those legs.
44 Like you want to switch? You give me your legs, you can have this, not a problem. It's amazing how
45 some people, and I think some people it's because they don't know what to say so they'll just make a
46 joke like that. But kind of like, she was saying about being bullied. It's not a joke. If you don't know
47 what to say then don't say anything. I come across a lot of times, kids. Kids are great, they come up to
48 me like, oh, what happened. Is there anything I can do? And their parents are standing there saying,
49 don't bother her. I'd rather they ask me and learn at this age because at your age, that's why you're
50 acting the way you are. Because you weren't, when you were younger, you didn't have the guts, or the
51 giels or whatever to go up to someone and say, hey, what's wrong, is there something I can do, or,

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 hey, that's kind of cool, why are you on that or whatever. These days, I grew up and you respected the
2 elderly and the disabled. That doesn't exist anymore. Either one. You go to the mall and five people
3 come running up from behind you and go in the mall first. Do they stop and hold the door for you? No.
4 They just go on.

5 KATE SHERLOCK: Charge by.

6 JENNIFER: It's amazing. I'm like, hello. How are people bringing up kids these days? And I grew up
7 where, yeah, my father had a leather belt on top of the fridge. Now they'd be like, yeah g ahead, I'll call
8 the police kind of thing. This community this country has, I don't know, it's just totally turned around
9 unfortunately.

10 JUDI DREW: Well thanks for your questions about benefits counseling and those resources because I
11 am sure, and I do want to encourage you to talk to Mike and access ORS. And be open minded by
12 option that is are available to you through technology. Okay? So, thank you.

13 GEORGETTE: When I spoke about the amount of paperwork that is on the person advocating for the
14 person with a disability, my perspective has been, I feel that it is that,
Human Services: Applications 15 the amount of paperwork is that to some extent in trying to tease out
16 who are the people that have a justifiable disability versus those who

17 could do something else. I feel like there is so much documentation out there to show when someone
18 has a significant disability that, to me, seems it would be easier to say, okay, these are the people,
19 don't have to be repeated phone calls and assessments and paperwork and, to me it would seem that
20 you can validate the justified and question the others more as opposed to, one of the reasons I met
21 with ORS today was, I got a letter from SSI for my son saying if you don't do, his ORS application with
22 school had run out if you don't redo it or go to another employment network we will subject you to
23 more medical review. Now, I already had to deal with that when he started to get SSI at 18. They had
24 contacted me, we set up a phone interview, I set it up at a time I was available, during my work hours,
25 when I was able to have a conversation, they refused to speak to me because I didn't have my son
26 there to say, they could speak to me. He doesn't have the cognitive ability to know who I am speaking
27 to and why. So, it was silly to then have to end the call, take another day out of work, take a day out of
28 work, rather than take the time that I had set aside when I was available during work to just take that
29 phone call. And I set it up on a day my husband needed to go to an appointment anyway so I was able
30 to do both and the woman said I am going to call you again, want to have another call and I said to her
31 somewhat frustratedly, how often do we need to do this? Because I am out of work today for this
32 purpose and she ended up saying, she said we do it more frequently with people in the beginning and
33 they haven't actually called back. I think the fact I said I actually had to take the day out of work to do
34 this made her realize that somebody was working. So she hadn't called back but getting this SSI letter
35 recently saying if you don't meet with ORS or get another employment network, get involved with
36 another employment network, then, we're going to subject you to more medical reviews. I said, okay,
37 let me meet with ORS again. Bottom line after we met, she said what you're doing is appropriate given
38 his level of needs right now and we don't think going further employment wise is the most appropriate
39 thing for him. So I am back in the boat of, okay, now he'll come up for more medical reviews. So it's a
40 bit unwieldy as a process. I just don't feel like it supports the family as much as it could. I think if it's a
41 well-documented, clearly you have, my son has, there should be a way to tease that out and put less
42 energy there in terms of the bureaucracy and more energy where you are a little less sure.

43 JENNIFER: I have met life, have I to fill out the paper every month to let them know I am still disabled.
44 I'm like, this isn't getting any better.

45 GEORGETTE: Going to change. Some of it I feel is just that way of just determining whether or not it
46 is a justifiable disability.

47 JENNIFER: Exactly, do they really need this. I said do you ever do this if you don't need to because
48 it's such an incredible amount of work, unbelievable. They're killing so many trees out there because
49 of it. Only now am I starting to get one set of paperwork as his representative payee as opposed to
50 two. I kept get it would go of everything, one to me and one to my son. That was silly. Now all of a
51 sudden somebody seemed to have realized and are sending it to me for him.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 RUI CABRAL: See, efficiency. Every federal document I have has a disclaimer at the bottom in terms
2 of the paperwork reduction act. I laugh, what was it before now because this is unbelievable.

3 JENNIFER: When I started working at Putnam they said this is a paperless company. When I left 14
4 years later, all the paperwork I had and I threw it out, how many trees did they have to kill for all of this.

5 JUDI DREW: Okay, thank you for sharing your testimony. Both of you are raising really important
6 points. At this point we're really not taking testimony, this is just general conversation so just be aware
7 there is not being any record taken. If you wanted to talk with her, this is a good time to do it since
8 we're not taking testimony.

9

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10 [Peacedale Public Forum July 26, 2017](#)

11 Panel Members:

- 12 1. Meredith Sheehan - National MS Society
- 13 2. Lisa Onorato - Brain Injury Association of RI
- 14 3. Grace Pires - Office of Rehabilitation Services
- 15 4. Tammy Russo - RI Parent Information Network
- 16 5. Kathleen Kuiper- RI Department of Health
- 17 6. Jack Ringland—RI Governor's Commission on Disabilities
- 18 7. Kate Bowden - RI Disability Law Center

19 Public:

- 20 1. Bonnie Winsor
- 21 2. Jane Williams
- 22 3. Kimberly McMaegles
- 23 4. Kharissa Wilson
- 24 5. Cynthia Swift
- 25 6. Mary LoPresti

26

27 MEREDITH SHEEHAN: We are very glad that you showed up today. My name is Meredith Sheehan and
28 I am the health care provider engagement manager for the National Multiple Sclerosis Society. So I
29 primarily work with people with MS throughout Rhode Island. And I'm moderating the public forum today.
30 We have a lovely group of panelists here to listen to whatever concerns you came out to express today. I
31 just want to read something from the Governor's Commission on Disabilities that talks just a little bit more
32 about the public forums; what the purpose is; what to expect after the forums are over in terms of follow-
33 up and action items, after we're done. So the purpose of these public forums is to identify the concerns of
34 people with disabilities and their families, in order to assist the state to develop programs to improve the
35 quality of lives of people with disabilities. To be sure everyone has a chance to speak, please keep your
36 comments to the point. Although, there are so few of you; it's okay if you talk a little more. If you have a
37 critical problem that needs to be addressed, then panel members will be available at the end of the
38 hearing to direct you to the proper agency for help. After the public forums are completed, which should
39 be in early -- which will be in early August, the sponsored agencies will review the testimony, prepare
40 recommendations, which will be posted on the Governor's Commission website by the end of November.
41 The recommendations on the transcripts will be printed and sent to state and congressional officials and
42 to members of the General Assembly. The recommendations will be used to develop policy and
43 legislative initiatives for the next year or until they are accomplished, which can take several years, but
44 these forums have produced a lot of success stories, so anything you want to share that can help guide
45 some policy going forward is wonderful and very well appreciated. The Rhode Island Disability Law
46 Center is here. Kate is here from there. And she can register anyone to vote or assist with any questions
47 about the voting process or file a change of address, if you have moved since the last election. So I am
48 going to let the panelists introduce themselves. This isn't meant to be, you know, combative, back and
49 forth or anything like that. The panelists are here to listen to your concerns, and a lot of them will sit on
50 work groups at the end of the public forums to review testimony, and again, sort of come up with some

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 possibilities for legislation for going forward or policy changes that may or may not go to be legislative, so
2 I'm going to let them go down the line and introduce themselves and then we can hear from you guys.

3 KATE BOWDEN: Hi, my name is Kate Bowden. I'm a staff attorney at the Rhode Island Disability Law
4 Center and I handle our voting grants and also other case work.

5 TAMMY RUSSO: Hello, everyone. I'm Tammy Russo. I'm manager of the Family Voices Program at the
6 Rhode Island Parent Information Network.

7 LISA ONORATO: Hi, I'm Lisa Onorato. I work with the Brain Injury Association of Rhode Island, and I'm
8 currently facilitating 24 support groups for -

9 KATHY KUIPER: Hi. My name is Kathy Kuiper. I'm based over at the Rhode Island Department of Health,
10 Health Equity Institute.

11 GRACE PIRES: Hi, my name is Grace Pires and I'm a vocational and rehabilitation counselor at the
12 Office of Rehabilitative Services.

13 MEREDITH SHEEHAN: And I just wanted to introduce Barbara Polechetti. She is not an official panelist
14 today, but she is a representative from RIPTA. Often transportation issues come up as concerns, so
15 Barbara is here and can address those concerns as well. So good. Does anybody want to kick us off with
16 any concerns or questions or personal stories that you may be having issues with?

17 BONNIE WINSOR: I wouldn't mind kicking us off and talk a little bit.

18 MEREDITH SHEEHAN: Perfect.

19 BONNIE WINSOR: I am Bonnie Winsor and I work -- I'm a behavior analyst and a certified brain injury
20 specialist at NeuroRestorative of Rhode Island. We have three
21 Healthcare: Traumatic Brain Injury community homes. I facilitating support groups for - don't like to call
22 them group homes. I like to call them community homes, because

23 sometimes from the hospital setting to back home there needs to be a place in the middle for folks to
24 work on some challenges. So a lot of the folks at NeuroRestorative are (inaudible). The days, they work
25 on their rehab and then there are no services to help them to get into their own apartments, and while
26 they're at the facility, they're limited with job skilled training and also job placement. They're a part of the
27 waiver, so they can't keep their money, so there is no incentive to work. So we see a lot of challenges
28 with folks that have been with us and they're ready to move to the next step, and there are no services for
29 them to move forward, if they have TBI. As far as that little bit of help that you need when you're out in the
30 community, while you're still transitioning into your own -- back into your own life, so to speak. We see
31 that an awful lot at Neuro Restorative and another thing is, psychiatric services for people with TBI is
32 extremely lacking. It comes under the umbrella of mental health and sometimes it's the TBI, not a bipolar
33 disorder or anxiety disorder. It is the TBI that is (inaudible) their behavior or the anxiety, so we see that
34 we're not getting the proper services for the folks that we serve, so --

35 MEREDITH SHEEHAN: Anyone want to respond or maybe some additional questions? Anyone?

36 SPEAKER: So are you saying that once they are going to be leaving NeuroRestorative that they -- there
37 is no transitioning?

38 BONNIE WINSOR: No real transition services. A gentleman in our facility was offered an apartment a
39 couple of months ago and because there was no one to help him with
40 Independent Living: Transition those few (inaudible) a week, out in the community, he had to turn
41 down a chance to be on his own and living in his own subsidized

42 apartment. So we're going to continue to work on that, but that actually happened a couple of months ago
43 to one of our participants, and he is still with us, and he's okay with it, but it would have been great if we
44 would have been able to advocate for him and get him the services that he needed to continue
45 progressing, once he got out in the community in his own apartment.

46 SPEAKER: Thank you. Do they have proper insurance or --

47 BONNIE WINSOR: Yes.

48 SPEAKER: They do have insurance.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 BONNIE WINSOR: Most everybody is covered by Medicare, Medicaid or maybe they have Neighborhood
2 Health or maybe some other kind of the insurance that they have.

3 SPEAKER: And the discharge planning process, does that include any, like, any help in getting some,
4 maybe, personal care attendants or --

5 BONNIE WINSOR: Yes, our program director did look into certain places. I believe, cerebral palsy
6 (inaudible) was brought and a few other folks, but they just, you know, couldn't take him on, and it was
7 really tough to have to say to him, I'm sorry, there's nothing out there right now to help you, and so that
8 was tough for him. You know, he took it well, but it does happen, and the couple of people before that,
that we found, you know, the apartments for and the after services, it
worked out, but for him, it just didn't work out, and he's very high
functioning and he's been working really hard on his challenges.

Healthcare: Traumatic Brain Injury

11

12 SPEAKER: Now, are you saying, when you tried to get ahold of (inaudible) or other agencies. Was it
13 because of -- that they just had no more space in their agency for that or was it because of some issues
14 that he might have been dealing with, that he could not?

15 BONNIE WINSOR: He doesn't have any issues that they identified. It was actually finding the services
16 and moving forward. UCP couldn't take him, and there was a few other places that the out-program
17 director, Rose Marie Coffee, tried to get services for him, and they just did not -- it never panned out and
18 then when we -- because sometimes you get the notice for the apartment. It comes and it's, like, okay,
19 next week we'll see you. It's, like, okay, this happens very quickly, sometimes, and she tried, and it just --
20 we couldn't get him in, and he ended up losing the apartment, so it was very sad for him.

21 SPEAKER: There's a lot of Medicaid benefits, Medicaid, Medicare benefits that are home based through
22 our Medicaid waivers, so that might be something that you might want to pass on to the director --

23 BONNIE WINSOR: Yes.

24 SPEAKER: -- To take a look into.

25 BONNIE WINSOR: I think it would have been time, too, because they're, like, oh, here's an apartment
26 and then you have to be there and in by a certain time, and when you try to apply for the services, it might
27 take more time --

28 SPEAKER: Oh.

29 BONNIE WINSOR: -- To get the service

30 SPEAKER: Time --

31 BONNIE WINSOR: Yes, the apartment is ready. Come and see it now. And then when you are trying to
32 set up the services, because you can't set the person up for services, if they're still in your program.

33 SPEAKER: Right.

34 BONNIE WINSOR: You know, and so he didn't -- you can get them set up, but you have to have a date,
35 you know, okay, so on this date, you're going to need services; that's when you're moving out. We've had
36 success in the past, but it just didn't work out for him this time. I think it was timing. Apartment is ready.
37 Services aren't. Services are ready. Apartment is not. It just seems like that happens once in a while.

38 SPEAKER: That (inaudible) something. I'm glad that you reported out on it.

39 BONNIE WINSOR: It would be great if there was, you know, some more independent living situations for
40 them or services that -- where they could live in their own apartments and I'm talking -- when I say, folks
41 with brain injury or folks that need support, that is less than 24-7, so that they can get used to being back
42 on their own, because the folks with brain injury, it's not a developmental disability, but sometimes it's
43 covered under the same umbrella and it's not the same, because folks are trying to get back to their life
44 that they had before the brain injury or at least get back to some -- you know, their family, friends, the
45 things that they're missing while they were hospitalized or while they were in rehabilitation. Kharissa, do
46 you want to add anything? This is Kharissa Wilson and she has been working with people with brain
47 injuries for ten years.

48 KHARISSA WILSON: Yes. And what, ultimately, I would love to see happen, would be like Bonnie said, if
49 there was, like, we're the only one in Rhode Island right now. We're the only facility that services adults

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 with TBI and I would love to see more of those, of course. There is a big, big need for them, and as
2 Bonnie said, it's the after step. After they have stayed in the
3 Independent Living: Transition 4 rehabilitation and got to the step where they're ready to move forward,
5 I really feel like there needs to be a next step. Some people aren't
6 able to entirely go out and be in an apartment by their own, you know, by themselves, but a little more
7 freedom than what they have, kind of, a little more independence. Like, there is -- I think there is another
8 step missing before the, okay, you can go home. And that's the step, I think, we're missing altogether.
9 Like, I would love to see more. I had -- it would just open up a whole --

10 MEREDITH SHEEHAN: Yes, yes, how many can your facility accommodate?

11 BONNIE WILSON: We have 21.

12 KHARISSA WILSON: Yes.

13 MEREDITH SHEEHAN: 21?

14 BONNIE WILSON: 21 beds. Right now, we have 20 residents. So speaking of residents, we have a
15 couple of residents here. This is Jane and this is Kim. Jane, would you like to say something about what
16 you would like to see move forward for yourself?

17 JANE WILLIAMS: Well, I'm still learning more about my personal disability. And I'm sure that's probably
18 something that's going to be an ongoing process for me. I am dealing with it and handling my disability as
19 time goes on, the more information and knowledge I have. So right now, my biggest issue is my memory
20 disorder. I find that it's a source of frustration for me, not to be able to recall and remember things, you
21 know, I should know. And I have learned techniques such as keeping a calendar and keeping a notebook
22 and all the things that aid me, but it's still kind of frustrating. I get to the calendar and I (inaudible.) I open
23 a notebook and forgot what I wrote down. So it's -- with me, it's still -- the brain injury is still new to me,
24 but I'm learning more and more each day, how to manage it, and getting better and better at it, so it kind
25 of cuts down on my frustration. I have a lot of frustration, which I don't know if that goes hand-in-hand
26 with having the disease itself or it's just separate and apart, that I just get so frustrated, personally, and
27 not realizing that it's the disease that's causing the frustration, so with me, I'm still in the learning stages
28 and coping stages at the same time. Coping with the disease, but learning more about it to cope, so it
29 goes hand-in-hand, and it's a process that I'm learning will take time. I've had excellent help; people to
30 talk to, that are suffering from the same disease, wonderful doctors. Bonnie has been just a wonderful
31 person, a go-to person, as well as other staff members. Kharissa as well as all the staff members when
32 you need to talk, because you don't understand at that moment what is going on; what's happening, so
33 these two are available to me and they offer comfort. They offer information, and it just makes the whole
34 process a little bit easier until the next day and then we start all over.

35 SPEAKER: Then we start all over.

36 JANE WILLIAMS: We start all over again.

37 BONNIE WILSON: What would you like to see for your future, Jane; what kind of services?

38 JANE WILLIAMS: I -- basically, my whole thing is in wanting to gain my independence back. I realize that
39 it's not going to be the same as it once was, so I have to learn to enable myself to work with what I have.
40 And I'm not sure. I'm still familiarizing myself with services that are out there to me. I don't know
41 everything that's available to me, once I get out there, and I am hoping that once I get out and I become
42 more familiar with the services being offered, I'm hoping it will be adequate enough for me and then if it's
43 not, what do I do, so that's where I am right now.

44 SPEAKER: And when you -- Bonnie or Kharissa, is there a case management piece that is offered if they
45 do transition out into homes?

46 BONNIE WILSON: Yes.

47 SPEAKER: There is?

48 BONNIE WILSON: South -- what is it, South County -- they changed it. It was Tri Town. Now, it's Tri
49 County Community Action.

50 SPEAKER: Okay.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 BONNIE WILSON: I had to remember the name. I also have a brain injury. The South County -- yes, Tri
2 County Community Action. We have a case manager, her name is Elizabeth and she helps with the
3 transitions, and in the facility each participant has a case manager, who is also a staff, who works with
4 each participant based on their own need, so --

5 SPEAKER: They're also known as Tri Cap.

6 BONNIE WILSON: They have many names. That is why I had to look for the name.

7 SPEAKER: And they --

8 SPEAKER: In South County?

9 BONNIE WILSON: Yes, South County. That's why I kept thinking South County --

10 SPEAKER: They do wonderful, wonderful work in the community, Tri Cap does, and they are very
11 wonderful people to go to when you're looking, searching, because they kind of have the answers for
12 you.

13 BONNIE WILSON: What about you, Kim? What are you looking for, for the future for yourself?

14 KIMBERLY MCMAEGLES: For the future. I know my eyes will never be the same, but -- because of my
15 brain injury, but I am learning to deal with it and new ways to cope, and I just want a normal life, again,
16 somewhat normal, you know. I mean, I haven't been at the house long.

17 SPEAKER: A couple of months, right?

18 BONNIE WILSON: A couple of months.

19 KIMBERLY MCMAEGLES: A couple of months; it's been that long?

20 BONNIE WILSON: Yes. A couple of months.

21 KIMBERLY MCMAEGLES: (Inaudible) in the elevator.

22 BONNIE WILSON: I told you not to tell anybody we got lost in the elevator.

23 KIMBERLY MCMAEGLES: No, I don't mean that one.

24 BONNIE WILSON: Oh, you don't mean that one. Oh, I just told on us. And Jane's been with us for five
25 months, so --

26 SPEAKER: In a different elevator.

27 BONNIE WILSON: Jane and Kim are our newest residents, two of our newest residents.

28 SPEAKER: What is your typical duration of stay?

29 BONNIE WILSON: It varies. So one gentleman, he stayed with us for a year and a half and moved
30 forward, and there are some folks that have been with us for ten years or more. So it does depend on the
31 level of care needed. You know, behavior management, it's a concern. Health concerns are also -- you
32 know, so medications. For example, if someone has a lot of medications to take, outside of their living on
33 their own, they might need someone to come in a couple of times a day and help them with their
34 medicines.

35 SPEAKER: Set up the nursing and do things like CNA type work. BONNIE WILSON: Yes.

36 SPEAKER: And those services are available through Medicaid, so I would encourage the discharge
37 manager to make contact with DEA the Department of Elderly Services, and they also support those with
38 disabilities.

39 BONNIE WILSON: Oh, they do, so for example, if a person -- yes, that's absolutely true. If someone has
40 a disability, but they are not elderly, they can use those services?

41 SPEAKER: As long as they have a disability that would make -- and they have certain income eligibility,
42 but if you can (inaudible) kind of the Medicaid and your residents that are Medicaid eligible --

43 BONNIE WILSON: Yes.

44 SPEAKER: -- that is a very big array of services that might be able to help them in home-based
45 community services. So I would definitely encourage a closer relationship with them, and they can
46 absolutely call me, if they wanted to. I can try to give them some numbers. They also have a little pocket
47 guide available that we could give your residents when they do transition out, so that they have, like, a

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 little guide of services of where they can access these kind of things. And it's all through the Department
2 of Elderly Affairs. And they also do that kind of services for those with disabilities, adults with disabilities.
3 It's not for children. It's for adults, specifically, for the adults with disabilities.

4 BONNIE WILSON: We serve adults only. We don't have any children --

5 SPEAKER: Okay.

6 BONNIE WILSON: -- in our program.

7 SPEAKER: So DEA would be a really nice connection. I do know that they have an advisory council
8 meeting that happens, and I can look up that information, if you want to give me your e-mails or
9 telephone numbers --

10 BONNIE WILSON: That would be great. I did leave my e-mail over there. I can give you my phone
11 number.

12 SPEAKER: Yes, I can definitely take those down, and I can look into those forums, and I would
13 encourage you, in person, to attend, because the Department of Elderly Affairs, all of their -- all of their,
14 like, partners, especially like the legislative partners -- I am thinking, like, the actual -- it's Craig -- the
15 Lieutenant Governor is actually -- his staff is there.

16 BONNIE WILSON: Oh, wow.

17 SPEAKER: And they talk mostly about this kind of stuff, like, long-term care like this and DEA would be a
18 really great array of services, and if you go by Medicaid eligibility, that opens a big -- a big array of
19 services that your residents may qualify for, but of course, there is criteria they have to meet, so they
20 have to --

21 BONNIE WILSON: There is kind of a shortage on housing, too, so I had a couple of folks this week ask
22 me, if I can leave, (inaudible) make some phone calls, and, you know, get some applications for housing,
23 so a couple of the places we called, they are not accepting anybody on their list, so you feel kind of bad
24 that you have to say, all right, right now, they are not accepting anyone. We will try in a couple of more
25 months or we will try, and it's, like, your constantly playing tag to get some folks on the list, because we
26 do have a couple of people that would be successful on their own, and you know, we want them to be as
27 -- you know, have their freedom, be out in their apartment, and like, using the RIPTA buses and out going
28 to the store. Right now, it's where -- it's 24-7, so they go with staff. You know, we try to be very relaxed.
29 You know, we're not out there telling everybody what to do. Don't do this. Don't buy that. That's not what
30 we do. It's about choices. About people making their own choices when, you know, they're out in the
31 community, but a lot of our participants say, I want to be on my own; I want to be on my own.

32 SPEAKER: Yes, and I -- that's -- and that's, you know, a lot to do (inaudible) of letting them know that
33 there's some hope to be on their own.

34 BONNIE WILSON: Yes, choices.

35 SPEAKER: I very much commend you guys on that, but definitely long-term services and supports
36 through DEA might be very -

37 SPEAKER: That's awesome to know.

38 SPEAKER: That's good to know.

39 SPEAKER: The last gentleman that, you know, he had to give up the apartment, that was a big piece that
40 we will run into. Like, he didn't need any personal care. He didn't need help with personal care, because
41 they're, like, oh, we kind of can't send the CNA in, if he doesn't need personal care. Well, he just needed
42 the medication part of it, really, that was kind of all he needed and --

43 SPEAKER: And there are, you know, there's a lot of different -- there is Meals on Wheels that's available
44 through long-term services and supports. So that they can receive meals, delivered by your (inaudible)
45 seasonal. Some sort of connection or your senior center has a connection with that. So those long-term
46 services and supports would be a really great (inaudible) for your --

47 SPEAKER: Is there a listing of those types of services that --

48 SPEAKER: In that pocket guide at the Department of Elderly Affairs --

49 SPEAKER: Okay.

2017 Public Forums on the Concerns of People with Disabilities and their Families

- 1 SPEAKER: -- you will be able to find a lot of the long-term services and supports.
- 2 SPEAKER: Okay.
- 3 SPEAKER: It's a tiny -- I think this year's cover is white. Last year -- I may have last years. It's purple, but
4 I can certainly try and find, you know, some of those.
- 5 SPEAKER: You can probably apply on-line or ask them for one on-line.
- 6 SPEAKER: Yes, they have a website. Long-term Services Division does have a website and there is a
7 listing of the types of services that may be available, but again, the criteria is pretty strict.
- 8 SPEAKER: Yes.
- 9 SPEAKER: So it might not be something for everybody -
- 10 SPEAKER: Right.
- 11 SPEAKER: -- just try and keep that in mind and not everybody qualifies for it. Yes, and they just need to
12 meet certain criteria, income eligibility, disability, you know, and things like that, but they're definitely --
13 that is a great place to start. And they do have an advisory committee that is open to the -- and it's a
14 public meeting, just like this is, so you could go, and you know, listen in on what the plans are, and they
15 meet, I think, it's in Providence, though, but they're people that -- they take on regionally placed, like,
16 case workers, so we can definitely -- I think that would be a really nice --
- 17 SPEAKER: I am not sure if NeuroRestorative has our resource guide.
- 18 BONNIE WILSON: Yes.
- 19 SPEAKER: They do, okay. Because I (inaudible) that you could have with the resource guide, and that
20 has a lot of various agencies that would be really helpful.
- 21 SPEAKER: And I think the manual might even -- sometimes it goes --
- 22 BONNIE WILSON: Um-hum.
- 23 SPEAKER: -- the manual, the pocket manual, (inaudible) if you can call, and they could mail this out to
24 you.
- 25 BONNIE WILSON: That's wonderful. You want to add anything, anybody? Lisa? Are you glad you came?
26 Good.
- 27 SPEAKER: Where is your facility?
- 28 BONNIE WILSON: Charlestown, we have two homes in Charlestown and one in Bradford, Rhode Island,
the Westerly area. Bradford is eight rooms, eight bedrooms. The
Healthcare: Traumatic Brain Injury one in Charlestown is eight, also, and the other one in Charlestown
is five.
- 31
- 32 SPEAKER: They do good work. I'm glad that they're there.
- 33 SPEAKER: Very good work.
- 34 BONNIE WILSON: You guys are easy to help. You all want to help yourself. It makes it easy.
- 35 SPEAKER: I never knew that there were these services available.
- 36 SPEAKER: You have hope. There's a lot of services available.
- 37 SPEAKER: That makes me feel a lot better.
- 38 BONNIE WILSON: When you talk about someone being in a long-term nursing home care, long term, I'm
39 talking five years or more, and you know, nobody wants to live at Zambarano. So at least, in the
40 community setting that we have, there is some, you know, going out shopping, a place for -- a
41 comfortable place for family and friends to come visit.
- 42 SPEAKER: And like you said, that next preparation step for really going --
- 43 SPEAKER: (Inaudible) Rooms available now or are you -- is there a waiting list?
- 44 BONNIE WILSON: So we do have one bed that's going to be open, but I believe that they have a list of
45 people waiting, yes.
- 46 SPEAKER: I'm sure, because your services are really needed. BONNIE WILSON: Yes.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 SPEAKER: And I'm sure those spots fill up fast.

2 BONNIE WILSON: They do. They do.

3 SPEAKER: I'm really glad to hear -

4 BONNIE WILSON: Right now we're doing a little renovating. We're making a few of our bathrooms more
5 handicapped accessible, and because we have folks that have all different challenges, from physical to
6 emotional, just all the way across the board, so we're doing a little bit of work on all three of the houses,
7 just to, you know, make them a little bit more accessible to everyone.

8 (END OF FILE 1)

9 SPEAKER: I think the point that she was raising about people having other challenges as well, I mean, I
10 have the brain injury, but I also suffer from -- my memory is effected, and I'm working on that, and I've
11 noticed that it has gotten better over the past year. I've seen improvement. My doctor has seen
12 improvement, but the memory disorder is there, and it's a source of frustration for me, as it would be
13 anyone who's losing your memory. The other thing, too, is my anxiety. I have high anxiety, and I don't
14 know, so it's all these things that are coupled with having the brain injury that you have to -- you're
15 working on your brain injury, but you are also dealing with other issues, and you need help with those, as
16 well. I'm trying to work really hard on my frustration that I get and my anxiety and trying to improve -- keep
17 on improving my memory disorder, which like I said, has gotten better, but it's still not a hundred percent.
18 My doctor is not sure it ever will be. I am at an age where senility could be setting in, so right, I have that
19 to look forward to, so my point is that even though you're focused on your brain injury, you still have --
20 you know, I'm getting older. I'm going to be considered aged very shortly, probably while we're still here,
21 and you're dealing with that, as well, and combining that with what's going on with your brain disorder, so
22 it's a whole lot that you're struggling with, and like I said, my age thing really bugs me. I don't want to get
23 older. I think about that all the time, so it's -- it's all these things outside that -- it's not just dealing with
24 your brain injury. It's all the other things that go along with that and that you have to focus on and deal
25 with and try to get better at, and I will be constantly looking for services that are going
26 to be able to help me with these other issues that I have.

27 SPEAKER: And you know, if you have health insurance, too, that helps.

28 SPEAKER: Yes.

29 SPEAKER: You can set yourself up for a lot of different types of out-patient therapies to help with that.

30 SPEAKER: Counseling.

31 SPEAKER: Counseling, yes.

32 SPEAKER: Sometimes it is going to be valuable --

33 SPEAKER: Physical therapy.

34 SPEAKER: -- just being able to talk -- physical therapy, absolutely.

35 SPEAKER: All things like that. I mean, there is a lot available through your health insurance.

36 SPEAKER: Yes.

37 SPEAKER: So those are some things that maybe when it comes time for your discharge, you might want
38 to open up that conversation with the discharge planner at your own facility --

39 SPEAKER: Yes.

40 SPEAKER: -- to let them know that you would like some help in lining --

41 SPEAKER: Yes.

42 SPEAKER: -- those services up before you leave.

43 SPEAKER: That's very good information. That's good to know.

44 SPEAKER: Now, do they have those services within Neuro Restorative, like, cognitive therapy?

45 BONNIE WILSON: Yes, right now we are doing a Brain in Play. I don't know if you guys have ever heard
46 of it. It's wonderful, Brain in Play International. We do the breathing and cognitive therapy along with

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1 some exercise to regrow brain cells, so we're kind of involved in that program right now. It's been
2 successful, so far.

3 SPEAKER: What is the program called, please?

4 BONNIE WILSON: Brain in Play. They are located in Warwick. Wonderful people. They accept
5 insurance, so it's wonderful.

6 SPEAKER: Yes. And you guys will have that when we (inaudible). It's good to know.

7 BONNIE WILSON: Jane and Kim are both participating in it, currently.

8 SPEAKER: It's been very helpful, and the information they give you, you can take back with you and
9 apply and put in -- put into play, what they taught you, and what's helped me is the breathing exercises
10 that I use at night, if I have a -- sometimes problem sleeping and just learning to deal with my anxiety, so
11 a lot of -- it's really been useful for me and then to go back to the home, the house and apply what was
12 learned and I have seen personally, in a short period of time, improvement in myself.

13 SPEAKER: It's a wonderful program.

14 SPEAKER: That's good.

15 SPEAKER: (Inaudible) worked very well.

16 SPEAKER: And with, you know, the counseling services available, all of that might be things, too, to look
17 into to help with some of that.

18 SPEAKER: It's just good to know that once I get out there, which they're planning now for me; I want to
19 know that when I get -- I don't want to get into a crisis situation with myself out there being -- oh, I want to
20 be independent and then you get out there, what the hell do I do now. So I want to know what services
21 are going to be available, where can I turn, who can I go to, depending on what my need is at that time,
22 and also to avoid a crisis situation, and (inaudible) right back where I started from.

23 SPEAKER: You're (inaudible) already, just being cognizant of that, so it is out there. And there are many
24 things that can help you to be more independent. Our state is moving

Human Services: Resources

 more toward, you know, people residing in the community longer and in
26 a long-term care facility, like, setting, the Zambarano or a nursing home

27 or something like that, so there has been a lot of different rules made on both the federal level and the
28 local level, so that we can enable people to stay in their homes longer, so things like this -- like, the Meals
29 On Wheels, we mentioned. There are out-patient therapies like counseling, physical therapy,
30 occupational therapy, speech therapy. All of these therapies are available through your insurance.

31 SPEAKER: That's the whole (inaudible). That is the whole (inaudible), right there.

32 BONNIE WILSON: (Inaudible) all those services.

33 SPEAKER: Yes.

34 SPEAKER: So those are all available and then with your connection, when you guys do -- when and if
35 you guys do apply for long-term services and supports, that will also open up other things, like, home
36 health aides, and CNA even going right up to skilled nursing. So you know, there are different things that
37 are available, if you are eligible for Medicaid and other Medicare services.

38 SPEAKER: And my guess is that Neuro would not allow you to leave unless all these services are --

39 BONNIE WILSON: Right, we absolutely don't. That's why we (inaudible) to have that glitch with that one
40 participant. Everything was not lining up the way it was supposed to, so the folks at the apartment were,
41 like, now or never, and then, you know, he had to have the whole thing set up. A year before that, we
42 successfully transitioned a couple of people very successfully, so it does depend on what services are
43 available at the time; we are finding that.

44 SPEAKER: You guys are doing really good work. Thank you.

45 BONNIE WILSON: And thank you. It feels wonderful to (inaudible). Thank you for everything that you
46 guys do for (inaudible) folks. You guys want to go or you want to stay for a little while? You want to
47 listen? Okay, good. You want to stay. All right. Let's stay.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 MEREDITH SHEEHAN: Yes, stay, if you would, join us. Thanks so much for coming out today. My name
2 is Meredith Sheehan. I am the healthcare provider engagement specialist at the National MS Society, so
3 I deal with people with MS in the State of Rhode Island, and we have some multiple panelists with us
4 today to kind of take in all the testimony, personal stories, any issues that you came out here today to
5 discuss. We just had a wonderful conversation on traumatic brain injury and everything associated with
6 that. So I'm just going to quickly have the panelists introduce themselves, so you know, which
7 organizations they are from and then since we're kind of an intimate group, we'll just, you know, it will be
8 very informal. If you have something you would like to share with the panelists, it really does help us
9 shape policy, going forward. We have had a lot of success stories that come out of the public forums.
10 Everything that you say today will be transcribed into a testimony booklet, and it will be reviewed by --
11 well, we send it to Congressional and General Assembly members, and we also transcribe them for work
12 groups, who, after the fact, will get issues on healthcare, transportation, care supports, whatever it may
13 be, and we, you know, the Governor's Commission on Disabilities uses all that testimony and works
14 (inaudible) priorities for, you know, next year and the year after, so it's great. It's definitely so helpful to
15 hear as much as you're willing to share. It certainly does help us a lot. So I'll just start with Kate --
16 KATE BOWDEN: Hi, my name is Kate Bowden. I'm a lawyer from the Rhode Island Disability Law
17 Center. We have a number of different grants and help with disability -
18 TAMMY RUSSO: Hi, I'm Tammy Russo. I am the manager for the Family Voices Program located at
19 Rhode Island Parent Information --
20 LISA ONORATO: Hi, Lisa Onorato from the Brain Injury Association of Rhode Island and currently
21 facilitate support groups throughout the state.
22 KATHY KUIPER: My name is Kathy Kuiper. I'm based over at the Rhode Island Department of Health,
23 Health Equity Institute.
24 GRACE PIRES: Hi, I'm Grace Pires. I'm a vocational rehab counselor at the Office of Rehabilitation
25 Services.
26 MEREDITH SHEEHAN: Great. Whatever, if you'd like to go first; do you have - obviously, you came for a
27 reason, so --
28 SPEAKER: Yes. I went to the one in Warwick yesterday. My name is Cynthia. I work at Ocean State
29 Center for Independent Living, so I just saw a few faces yesterday.
30 SPEAKER: Oh, okay.
31 SPEAKER: That's my neck of the woods, so I (inaudible) here, but yes, yesterday was the first one I had
32 ever been to. It was really interesting, so --
33 SPEAKER: And just for -- you folks are NeuroRestorative. Ocean State Community Center for
34 Independent Living is another -- another service that, one, upon your discharge, you may want to check
35 in with, because they can help to modify homes --
36 BONNIE WILSON: Yup.
37 SPEAKER: -- to make them more handicapped accessible and to meet your needs, so that's another
38 great connection that you might want to collect cards on.
39 SPEAKER: Yup.
40 SPEAKER: Feel free to call.
41 BONNIE WILSON: I'm familiar with your organization.
42 SPEAKER: Good.
43 BONNIE WILSON: My brother, he has cerebral palsy, so --
44 SPEAKER: Okay.
45 BONNIE WILSON: Yes, I'm very familiar with them.

Independent Living: Peer Support

SPEAKER: I was wondering, this might be a little off, but does anybody know what the support groups will be for a victim of crime -- violent crimes?

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- 1 SPEAKER: Is it -- can you (inaudible), please.
- 2 SPEAKER: Any support groups for victims of violent crimes.
- 3 SPEAKER: Oh, yes, I'm not --
- 4 SPEAKER: Unless, I'm just not finding it.
- 5 SPEAKER: To --
- 6 BONNIE WILSON: Traumatic injury from a violent crime.
- 7 SPEAKER: Yes.
- 8 BONNIE WILSON: Yes -- yes.
- 9 SPEAKER: I have to look into that.
- 10 SPEAKER: Yes, we'll look into that. And get Kharissa and Bonnie's e-mails, because I do think that they
- 11 are -- I can't think of it off the top of my head (inaudible). It might be the Center for Justice.
- 12 SPEAKER: Yes.
- 13 SPEAKER: The Center for Justice might have something.
- 14 SPEAKER: Or even the Attorney General's office.
- 15 SPEAKER: I would contact the Attorney General's office.
- 16 SPEAKER: I think they do, do advocacy victims -- like, a general --
- 17 SPEAKER: They have a compensation fund. There's a --
- 18 SPEAKER: Yes.
- 19 SPEAKER: -- compensation fund through the state, which is administered, I think, through the Treasury
- 20 Department.
- 21 SPEAKER: Yes.
- 22 SPEAKER: But that would be different from the support group.
- 23 SPEAKER: Right.
- 24 SPEAKER: Victims --
- 25 SPEAKER: Yes, there is a -- yes, there was actually -- at the Center of Justice actually (inaudible) they
- 26 actually had a lot of information on that fund, because of -- I think it was \$200,000 something like that.
- 27 SPEAKER: I wouldn't speak on the details, yes, but it's available.
- 28 SPEAKER: Yeah, there is a victims fund that is available, so --
- 29 SPEAKER: Will that be for when I'm discharged or --
- 30 SPEAKER: I'm not sure on the details.
- 31 SPEAKER: Right.
- 32 SPEAKER: But it is something to be aware of.
- 33 SPEAKER: I know. I saw that --
- 34 SPEAKER: Attorney General's, yes. Give them a call.
- 35 SPEAKER: Okay.
- 36 SPEAKER: I have (inaudible) out-patients before.
- 37 BONNIE WILSON: Okay.
- 38 SPEAKER: But they asked what my expenses are.
- 39 SPEAKER: So --
- 40 SPEAKER: So I'm going to have different expenses when I leave, because of my handicap.
- 41 BONNIE WILSON: Yes.
- 42 SPEAKER: You know.

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- 1 BONNIE WILSON: While you are in with the services, your expenses are covered by the waiver and by
2 your Social Security. So when you move forward, I would think that you would definitely have, you know,
3 different expenses, because you'll have electric and --
- 4 SPEAKER: Yes, but -- and the other thing I know about this victim's fund is you only have so much time
5 to file it.
- 6 SPEAKER: That's correct, so if you think you're eligible, you should contact them right away, because
7 there are deadlines.
- 8 SPEAKER: Do you know how long it is?
- 9 SPEAKER: No, I don't.
- 10 SPEAKER: No. All right. I may be too late, but thank you.
- 11 SPEAKER: Yes, I would look on their website for a support group. I'm sure there's some.
- 12 MEREDITH SHEEHAN: Wonderful. What is your goal --
- 13 SPEAKER: I'm pretty new there. I head up a new partnership with the YMCA and OSCIL, which sounds
14 like its health and fitness, but it's really for social and recreational opportunities, because we know a lot of
15 folks really don't have that.
- 16 MEREDITH SHEEHAN: Right.
- 17 SPEAKER: And it's great if everything else is in place, but if you never leave your home, it's not so great,
18 so I guess after a couple of years of focus grouping, you know, we really heard the need, so --
- 19 MEREDITH SHEEHAN: Well, good luck with that.
- 20 SPEAKER: Thank you. Thank you.
- 21 SPEAKER: Where is that?
- 22 SPEAKER: My agency is on Warwick Avenue, kind of close by the airport. Actually, 50 to 51 percent of
23 our board are folks with disabilities and the staff is -- half of our staff are folks with disabilities, too, so it's
24 very cool from that perspective, but we are not just, like, you know, oh, our mission statement, but we're
25 not like that. You know what I mean?
- 26 BONNIE WILSON: Right. We're kind of the same. We have people with traumatic brain injury, family
27 member with cerebral palsy. Everyone has their own challenges, you know.
- 28 SPEAKER: Right, right.
- 29 BONNIE WILSON: When we speak, we know what we're saying, because we've felt it in our hearts
30 before, so definitely.
- 31 MEREDITH SHEEHAN: That is it. Thank you so much.
- 32 SPEAKER: Thank you.
- 33 MEREDITH SHEEHAN: Hi.
- 34 SPEAKER: Do you want me to like say why I'm here or just introduce myself?
- 35 MEREDITH SHEEHAN: Sure, both.
- 36 MARY LOPRESTI: All right. So I'm Mary LoPresti. I live in North Kingstown. I'm the mother of a ten-year
37 old boy, who has Mitochondrial Disease⁵. He's profoundly disabled. In fact, I was late, because he had
38 two appointments up in Providence, and I didn't know about this today, except that I could call the New
39 England ADA Center and they couldn't answer my question, so they said, that question, you need to
40 contact the Governor's Commission on Disabilities, and when I went to the website, I saw it. And I
41 attended a listening session four years ago up in East Providence.
- 42 MEREDITH SHEEHAN: Okay.
- 43 MARY LOPRESTI: And everything was just hunky dory; life was great and I thanked everybody, and the
44 only problem we had was access to the (Inaudible) Aquatic Center at URI --

⁵ Mitochondrial diseases are a group of disorders caused by dysfunctional mitochondria, the organelles that generate energy for the cell.

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1 MEREDITH SHEEHAN: Yes.

2 MARY LOPRESTI: -- During the construction period.

3 MEREDITH SHEEHAN: I remember that, actually.

4 MARY LOPRESTI: You've got a good memory.

5 MEREDITH SHEEHAN: Well, if you --

6 MARY LOPRESTI: I don't know -- we really have no -- yeah, we haven't really gone back there, but
7 anyway, my main concern these days is that my son's
Healthcare: Home and Community Based Care 7
9 CNA agency closed in April. And after nine years of
10 having consistent care, which we felt, as his parents, as
11 taxpayers, was the most cost effective way to take care of him, just went down the tubes, and I -- I left it
12 in the car. I have my notebooks with all the agencies I contacted and it was just, no, no, no. It was we
13 don't have enough CNAs; North Kingstown is too far away; your hours are not compatible with our
14 availability. We got connected with an agency, very sporadic care. The quality, I don't know if it's just --
15 we were very fortunate with the agency that we had, so we are right now (inaudible) a new model of care,
16 which I think is going to cost the state more, but it's getting somebody in the door, so I approached our
17 social worker and said, can we get more nursing hours. My son has a G tube. He is going to be having a
18 surgery coming up, maybe we can get a nurse easier than the CNAs, so we now have nurses three days,
19 but then we have three days with nobody, so we're trying to piece together an HBTS worker this shift, and
20 can we get somebody here and there, and so we -- right now, my husband and I can't plan too far into
21 future. It's just -- so I have to say, when I contacted folks at the state house, I started with my rep
22 (inaudible), Senator Sheehan and the Governor's office. I think at first it was a lot of hand holding; we're
23 with you, and I sent an e-mail April 25th and nobody replied, to which I am greatly disappointed. You
24 know, I tend to (inaudible) support of the administration and government in Rhode Island, but this just
25 kind of soured me, so having no way to get a voice, I thought this might be an opportunity. On April 11th,
26 there was a forum for Rhode Island Home and Hospice Care. It was in the rotunda, and at the request of
27 Nicholas Oliver, who was head of that, I came and I spoke -- spoke to a few agencies that had reps there,
28 but there was just that one agency, that they've only been able to provide very sporadic care. I think from
29 what I can tell, it seems like a lot of the aids are maybe located in the Providence area. And for what
30 they're paid, it's not worth their time to make the drive to North Kingstown for a three hour shift.

31 SPEAKER: I agree with you.

32 SPEAKER: I --

33 SPEAKER: There is not that much --

34 MARY LOPRESTI: No, and I would implore those who are making policy to really look at this. As I said, I
35 know these folks. They come into my home. They are not paid a whole lot. I know that. They're driving
36 junk cars. You know, they tell me what goes on. Nobody is living any kind of luxurious lifestyle,
37 whatsoever, but they deserve a just wage. I don't think anything was voted on regarding that, so --

38 SPEAKER: Yes.

39 MARY LOPRESTI: If there's anything that I can do to move that forward, I would be happy to.

40 SPEAKER: Actually, I think that legislation they did -- they did put -- appropriate money for it, but
41 unfortunately, because we are at a budget impasse right now, we are operating on last year's budget, so
42 that's why the money hasn't been appropriated for the wage increases, BUT I do know --

43 SPEAKER: Are you talking about the (Inaudible) wage increase?

44 SPEAKER: Yes.

45 SPEAKER: Because I don't know -- are these --

46 SPEAKER: These are CNAs.

47 MARY LOPRESTI: Certified nursing assistants.

48 SPEAKER: Right, so CNAs wouldn't necessarily come under the (Inaudible) agency. I would just --

49 SPEAKER: Okay. All right.

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1 MARY LOPRESTI: I know that there are two. There were probably two bills. One had to do with nursing
2 and allowing parents to have choice of who the nurse would be, to go to school with their child, and I was
3 told from a rep at our nursing agency, that I think there was no action taken on that before the Assembly
4 closed out. As far as the CNA thing, I (inaudible) anything, so I mean, from a taxpayer's standpoint, it's
5 probably going to cost more to have a nurse, but my son can't be sitting in a chair all day. He needs to go
6 in a standard. He needs to be bathed. You know, I have four other children. I care for an elderly father-in-
7 law in our home, so I just can't be doing that, so anyway, so if there is any way that I can get involved, I'm
8 definitely an advocate. I am on the leadership team of our town (inaudible), so I'm one of those people
9 that feels like if I can be here to represent others, I will do that, so --

10 MEREDITH SHEEHAN: No, it's a rare disease, right? It's under the umbrella.

11 MARY LOPRESTI: Oh, yes, yeah, it's complex, yes.

12 MEREDITH SHEEHAN: Yes, so because I work closely with the woman who kind of founded the Rare
13 Diseases United Foundation, which I believe their headquarters is on the East Bay and she's all over.

14 MARY LOPRESTI: Okay.

15 MEREDITH SHEEHAN: Patricia (Inaudible) is her name. I would go to their website just to reach out to
16 her, because she seems to have a, like, gigantic information book in her head. She knows everything.
17 And she may be able to help, because two of her children live with rare diseases as well.

18 MARY LOPRESTI: Um-hum.

19 MEREDITH SHEEHAN: So she is wholly familiar with the cost, you know, intensity of the treatment in
20 caring for somebody with a rare disease, so I would just Google them and look them up and reach out to
21 Patricia, because she's been in D.C. She has been here. She's kind of all over, in the advocacy world.
22 She may be very helpful.

23 MARY LOPRESTI: Okay, yes. I think it's something, like, though the Assembly needs to look at this, like,
24 Healthcare: Training we need to be identified in properly training CNAs, so they (inaudible). We had a
25 girl come in to a meet and greet three weeks ago, and when she left, my
26 daughter was like -- mom, she looks overwhelmed. And it's really not that
27 complicated, and she said to them, I can't take on this case, and we used to always have CNAs coming
28 in, and once they were trained, you know, they knew what to do, and I don't know if it's the quality that
29 changed or it has something to do with their training.

30 SPEAKER: So develop some standards.

31 MARY LOPRESTI: Yes, and do they have, like, state oversight? I mean, I know they're licensed, but the
32 quality seems to be significantly less than the other agency that we had.

33 SPEAKER: Right.

34 SPEAKER: Are you willing to share with us the name of the agency that closed?

35 MARY LOPRESTI: Oh, yeah, it's Health Touch. It was part of CNA -- Care New England, which was, like,
36 I was infuriated that Care New England, you know, because they were losing money, would be doing
37 this, and we couldn't take any of our CNAs, because one -- like, somebody went to an agency that
38 doesn't take Medicaid, so they couldn't do it. Another girl was going to be -- it was like a URI nursing
39 student, who was going to be graduating, going off. Somebody went to work for the VNA, like, this -- one
40 of those CNAs that does, like, the quick kind of -- quick home visits, not like for an extended period, and
41 somebody (inaudible) get a job, so we went through the four people who cared for him.

42 SPEAKER: So the agency quit and the four people who had been giving the care through that agency --

43 MARY LOPRESTI: Um-hum.

44 SPEAKER: -- Went other places, and you couldn't capture them.

45 MARY LOPRESTI: Correct.

46 SPEAKER: I have seen this before.

47 MARY LOPRESTI: Yes.

48 SPEAKER: What program is paying for the in-home services? Is it Katie Beckett?

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1 MARY LOPRESTI: Yes, yup, um-hum.
2 SPEAKER: Does it look like you would be able to get an RN to do the services?
3 MARY LOPRESTI: So we always have just one person -- one day a week, we have a nurse. That agency
4 was able to get us somebody to pick up two more days.
5 SPEAKER: So three days.
6 MARY LOPRESTI: Now, he is going back to school. When he goes back to school in September, nobody
7 -- a nurse isn't going to want to work 3:30 to 6:30. They want to come out and work a longer shift, but
8 now, in the summer, we have that option, because his ESY program⁶ gets him home at 11:00, so you
9 know, looking at more of, like, a meatier eight-hour shift, and we have one nurse that said she could pick
10 up more hours to pay for her Uber, if we could, you know, if they wind up right, and so -- but that's it, so
11 we have -- the other three days don't have anybody.
12 MEREDITH SHEEHAN: If we could just pause for a couple of minutes. They need to change the tape in
13 their recorder --
14 MARY LOPRESTI: Oh, okay.
15 MEREDITH SHEEHAN: -- so you can keep giving your testimony. We will a take a quick (inaudible) and
16 a bathroom break. Something like that. (QUICK BREAK) (END OF FILE 2) (FILE 3 IS EMPTY) (TALKING
17 IN THE BACKGROUND)
18 MEREDITH SHEEHAN: Perfect. Okay, so we got the tape changed, so we're up and recording. Could
19 you tell me -- I am sorry, I had to cut you off in mid thought, but did you have any other --
20 MARY LOPRESTI: No, I don't want to dominate the conversation.
21 MEREDITH SHEEHAN: No, no.
22 MARY LOPRESTI: I think my biggest thing -- actually I had good luck with the Governor's Commission on
23 Disabilities. So I'm so, like, the advocate, at large. I went to out-patient
24 Civil Rights: Automatic Doors rehab for (inaudible) therapy and (inaudible) automatic doors, so they
25 may have just relocated from one location to another; so time for
26 planning. They said, yes, we thought about that. What I did find out, the person at the Governor's
27 Commission on Disabilities confirmed what somebody at the ADA in Washington said is that the
28 automatic doors are not required, so got that answered and then the girl I spoke to today, she was going
29 to be at the Cumberland Listening Session. I said, here's my homework. I am going to go check these
30 places out. They claim that they're not supposed to have handicapped signs, and so it was great. She --
31 Christina (Inaudible), so yes, I don't see -- the majority, I think, of what we've experienced in terms of care
32 in Rhode Island services for my son has been very good. This thing, it's a huge setback. I mean, it's for
33 an emotional level and support at home. It's very, very difficult. You know, because I also have children in
34 the home that are kind of like, who's this. They see different people coming in and training and then
35 people not necessarily giving my son great care. They're people saying, like, I have to do that. And they
36 weren't used to that. They were used to people who came in, who would automatically, the first thing they
37 would say is, how's Michael today and would chat with the kids, and so it's something that's, I think,
38 changed, and I think maybe we were a little bit sheltered for a while, so -- but that is it.
39 SPEAKER: That's enough.
40 SPEAKER: It's a lot (inaudible)
41 MARY LOPRESTI: Thank you. Thank you.
42 MEREDITH SHEEHAN: Thanks' everybody for sharing your stories. We really appreciate it, and like I
43 said, we do actually take the information and do something with it. So we definitely appreciate any info
44 we can get, so thanks so much. So we're here until 5:30, so you're not kicked out. If there is anything --
45 you have (inaudible), we would be happy to talk, you know, one-on-one as well, so -
46 #####

⁶ Extended School Year (ESY) is a program which may provide a disabled child with services during the summer months.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 Middletown Public Forum July 27, 2017

2 Panel Members:

- 3 1. Linda Ward - Opportunities Unlimited
- 4 2. Teresa O'Brien - Office of Rehabilitation Services
- 5 3. Colleen Polselli - RI Department of Health
- 6 4. Casey Gartland - Perspectives Corporation
- 7 5. Rory Carmody - RI Governor's Commission on Disabilities
- 8 6. Matthew Blair - RI Disability Law Center

9 Public:

- 10 1. Eugene B. O'Brien
- 11 2. Diana Kriner
- 12 3. Jack & Sue Casey
- 13 4. Kelly Reeves
- 14 5. Keathy Nelson
- 15 6. Shire Collins
- 16 7. Michael Collins
- 17 8. Taoi Arclante

18

19 [There wasn't a transcript from the Middletown Public Forum, below are notes from the panel members]

20 One individual in the audience and his mother discussed a school in MA that he had attended as a

21
22 Education: Communication Access

21 teenager and young adult; it was a boarding school aimed at helping individuals with communication and sensory disorders; they were taught how to better communicate through the use of

23
24 music; many of the members of the audience and the panel expressed interest in learning more about the program.

25
26 Multiple parents with children receiving services from the Maher Center expressed concern that the Day

27
28 Employment: Consent Decree

27 Program Services were going to be ending because they are considered sheltered workshops; there was significant anger that the Consent Decree is in place, that parents and individuals receiving

29
30 services were not consulted, and that the State did not attempt to push back on the decree, as other states have (presumably) done. The parents, as well as the individuals with developmental disabilities within the audience, expressed resentment that the jobs they had in the workshops, where they were able to be with their friends, were decided on as 'not good enough' by individuals other than themselves, and that they were not consulted. Competitive employment isn't working for the "old timers" with intellectual and developmental disabilities

31
32 Some parents also expressed concern that the jobs their children were being pushed into were not as supportive, did not allow for as much community interaction as they were promised, and did not allow for any more opportunity for growth than the sheltered workshop positions. For example, one parent talked

33
34 Employment: Temporary Jobs

30
31 about his son, who was consistently kept on as a temp at a university, despite performing well and enjoying his job. He was consistently told that for budgetary reasons he could not be brought

32
33 on as a permanent employee, yet he watched other, non-disabled individuals be hired as permanent employees. Diana Kriner (parent of a daughter with disabilities) spoke about businesses being willing to have young adults volunteer for internships but after are not willing to hire the young adult (despite high praises regarding their work during the internship.

34
35 Employment: Competitive

36
37 One parent testified that the young adults with disabilities are out in the community doing meaningful work that allows them to most definitely socially interact with the community and people without disabilities.

38
39 An individual with a disability expressed disappointment over what she feels is a lack of accessible

40
41 Housing: Multiple Chemical Sensitivity

39
40 housing for her disability within the State; she has a respiratory disorder which makes it difficult to be in

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 apartments as the scents from other residents can drift in, despite the common precautions taken by
2 building management (purifiers, ventilation system, non-smoking interiors, etc.); she also had a complaint
3 about the process of getting HUD housing and the voucher program; she has been at past Middletown
4 forums with these complaints, however, she declined to leave contact information for potential resources
5 to be in touch.

Housing: Shared Living Arrangements

6 A couple people expressed concerns of the lack of housing
7 options. Shared living arrangements will not work for
8 everyone.

Human Services: Wages

9 Several people talked about the low wages at agencies and self-directed
10 services creating high turnover.

11
12

13 Concern over transition services from the child to adult programs, particularly for children with
14 developmental disabilities; Diana Kriner from RIPIN explained that
15 school systems should start the transition process, and help to walk
16 parents through the steps, at the beginning of high school. She also

Independent Living: Transition

17 mentioned that these services should include a discussion of post-secondary education possibilities and
18 gainful employment, rather than only the transition into a group home environment, which many people
seemed surprised to hear.

Transportation: LogistiCare

19 Two or three of the parents in the audience expressed their
20 satisfaction with RIde services in the past; however, they said they
21 were unhappy with LogistiCare and what they felt was a lack of

22 oversight and accountability for the company.

23

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24 [Providence Public Forum July 28, 2017](#)

25 Panel Members:

- 26 1. Debra Sharpe - Brain Injury Association of Rhode Island
- 27 2. Kathy McCabe - Office of Rehabilitation Services
- 28 3. Judi Drew - RI Governor's Commission on Disabilities
- 29 4. Casey Gartland - Perspectives Corporation
- 30 5. Francisco Sousa - National Federation of the Blind of RI
- 31 6. Beth-Ann Langlois - RI Department of Health
- 32 7. Elisabeth Hubbard - RI Disability Law Center

33 Public:

- 34 1. Paul & Joanne Benoit
- 35 2. Cary Fidenbaum
- 36 3. Elianna Breslan
- 37 4. Sarah Ingles
- 38 5. Will Beaurous
- 39 6. Brenda Clement
- 40 7. Beverly Portras
- 41 8. John Butler
- 42 9. Richard Muto
- 43 10. Kelly Ribeiro
- 44 11. Charles Feldman
- 45 12. Heide Snowsterd
- 46 13. Ken Howell
- 47 14. Lori Barden
- 48 15. Rebecca Bannet

49

50 JUDI DREW: I'm the program director for the rehabilitation counseling program, and I am also a
51 Commissioner for the Governor's Commission on Disabilities, and I have the happy pleasure of calling

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 the list of those of you who said you wanted to speak and also to give the guidelines for how we are
2 going to operate this meeting. So first of all, I want you to know that the Commission is delighted that
3 those of you that are here, who want to speak, will have an opportunity to be heard, publicly. I want to
4 advise you that your testimony is being recorded, and what we will do with this recording is examine it.
5 We will share it with our partner organizations, like, the Brain Injury Association and the Rhode Island
6 Disability Law Center. And what we're looking for are issues that you've raised, in terms of your
7 experiences as individuals with disabilities and in the community, in terms of lack of access or needs that
8 you might have, where there are not services that are being provided that might help you as a family
9 member or as even as an individual. So be assured that we pay attention to what you have to say. We
10 review it. Lots of times this testimony ends up creating legislation on behalf of individuals with disabilities.
11 Other times it creates an opportunity for advocacy on the part of the commission and our partners, so that
12 we can go to our legislators and ask them to change regulations or assist us in creating legislation that
13 would help you with your issues, so the first thing I'd like you to do, so everyone take out your cell
14 phones, please, and please make sure they're on vibrate or turned off, whichever is your preference, but
15 just as people testify, sometimes it's a difficult thing for some people to speak publicly about their
16 experiences, and we want to honor that by making sure that there are no distractions. Okay, is that okay
17 with everybody? Everybody get that? Okay, so I'm going to read you some of this. Some of this is already
18 covered, but I just want to read some of it to you. The other -- after I introduce myself, I'm going to go
19 across -

20 SPEAKER: Casey -

21 JUDI DREW: -- I'm going to go across the table and have people introduce themselves. Then let's see, I
22 have already told you the purpose of the public forums. I've told you what's going to happen afterwards.
23 The Rhode Island Disability Law Center's panelist, who is -

24 SPEAKER: Not here at the moment.

25 JUDI DREW: Okay. Well, is there supposed to be somebody here? Elizabeth?

26 SPEAKER: Elizabeth, yeah.

27 JUDI DREW: Well, if Elizabeth is able to get here, her role, in addition to listening to the testimony, will be
28 to register anyone who is a citizen and not currently registered to vote where you live or to vote at the end
29 of the -- or to vote, at the end of the testimony, and people can also file a change of address, if they have
30 moved since that last election, so hopefully, she will be here and she can assist you with that. Next thing I
31 am going to do is ask the panel members to introduce themselves, and I'm going to start here with Kathy.

32 KATHY MCCABE: Okay. Hi, I'm Kathy McCabe. I'm from the Office of Rehabilitation Services. I'm a
33 senior rehabilitation counselor. I cover all parts of the East Bay, Barrington School Department, adults
34 from Bristol, Barrington and Warren, and sometimes I fill in, in East Providence and Providence.

35 FRANCISCO SOUSA: Hi, my name is Francisco Sousa. I am representing the Federation for the Blind,
36 Chapter -- Bristol Chapter. I have no title, really. I just go to the meetings or the NFB meetings in Bristol
37 and I'm here to answer any questions you have.

38 JUDI DREW: Thank you.

39 DEBRA SHARPE: Hi, I'm Debra Sharpe. I'm the executive director of the Brain Injury Association of
40 Rhode Island. We're a 501c3 nonprofit organization, providing public education and services and
41 programs to survivors of brain injury.

42 JUDI DREW: And the Brain Injury Association is a co-sponsor of this public forum, too.

43 BETH-ANN LANGLOIS: I'm Beth-Ann Langlois. I work at the Rhode Island Department of Health in
44 conjunction with the Rhode Island Parent Information Network and I specialize in the Office of Special
45 Needs at the Department of Health.

46 CASEY GARTLAND: I'm Casey Gartland. In addition to being a Commissioner, as well; I'm a CA Director
47 at Perspectives Corporation. We are one of many agencies in Rhode Island that provide supports to
48 adults and children with developmental disability and intellectual disabilities.

49 JUDI DREW: Okay. The next process is to ask if anyone has come in, who has not signed in, number
50 one, and then number two, if you did sign in, you may have changed your mind and you decided you

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 wanted to speak, and initially you didn't say that you wanted to. Is anyone here -- no, okay. All right, so
2 here's what's going -- what we are going to do. There are listening devices, if any of you need listening
3 devices. There are listening devices available. Correct, Ben?

4 SPEAKER: Yes.

5 JUDI DREW: Okay. And as you speak, what we would like you to do, if you would, please, for the record,
6 is to say what your full name is, your first name, your last name and what community you're from,
7 because that also helps us identify representatives that may need to be made aware of your needs, and
8 people we can actually identify to work with. So there's only -- there is no interpreter. Ben, at this point
9 there is no interpreter?

10 SPEAKER: No.

11 JUDI DREW: Do we have -- no CART service.

12 SPEAKER: No CART services. That's why, sorry, we're recording it, guys. I meant to tell you that, so if
13 you -- this is all for the record, so if you could just -- when you testify, just make sure to speak loud and
14 clear, so that we have it on video.

15 JUDI DREW: Okay, thanks.

16 SPEAKER: Yup.

17 JUDI DREW: So after everyone who has asked to speak has spoken, we can go back and ask them to --
18 the panel can ask questions. We will take a break around 4:00, 4:15 and we will go through a second
19 round.

Independent Living: Peer Support

CHARLES FELDMAN: In case some of you run organizations like
Oasis. It has been proven, and there is evidence, that if someone

22 with a mental illness encounters a peer who is in recovery that they feel more comfortable talking with
23 them and sometimes peers can, you know, engage people in recovery, whereas clinical staff alone
24 cannot do that. We're not competing with clinical staff. We're here to increase the productivity and the
25 efficiency of clinical staff by providing an adjunct service, and many times people need support during the
26 day before they can return to school, before they can return to work. And we offer support groups at
27 Oasis that allow people to talk about things that sometimes they tell us, they have never been able to
28 bring up anywhere else before, and you know, the Administration of Behavioral Health of the Department
29 is encouraging everyone to go back to school, go back to work. We've had cases where people have
30 been there for a couple of weeks and then they are ready to go back. We've had cases where people are
31 working full-time and they need time off, so they come in to get support and then they can go back to
32 work. We've had cases of some people who may not return to work because they still have issues they're
33 dealing with, and that support is, I mean, there's one case I'd like to point out of an Oasis member, who
34 was -- started off going to a day program at a community mental health center, then got involved in
35 Oasis. This is many years ago and when she was homeless, she (inaudible) workshop and it led to her
36 owning her own business, and now she's married, owns her own home, but without that initial support,
37 that wouldn't have happened, and so what I am encouraging is for the state to support the idea of peers
38 supporting each other, because without that support the recovery won't happen and then people will
39 relapse. People end up in hospitals, emergency rooms and in hospitals and emergency rooms and even
40 jail and prison and even suicide. But when people do have access to their peers as well as clinical
41 treatment, because the system as a whole needs more funding; peer support needs more funding, but
42 the system as a whole needs more funding, then people can recover, go back to school, go back to work
43 and lead meaningful lives and that's my (inaudible). Well, one other thing even though we speak about
44 serious and persistent mental illness. A couple of years ago I came to one of these forums and they had
45 the CART service and so I said I have one thing to say, supercalifragilisticexpialidocious, and the woman
46 looked at me and she began to type and she got it pretty close. We have a sense of humor, too.

47 JUDI DREW: Thank you for your testimony. (APPLAUSE)

48 JUDI DREW: Applause is okay. We can't clap, but -

49 SPEAKER: No, you can't -

50 JUDI DREW: I'm sorry.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 SPEAKER: I said, you can't play favorites, come on.

2 JUDI DREW: No, we have to be neutral. Is there anyone on the panel who would like to ask a follow-up
3 question? SP

4 JUDI DREW: Okay.

5 SPEAKER: I'm not really familiar with Oasis. I think you're on North Main Street.

6 CHARLES FELDMAN: Right.

7 SPEAKER: Right. And it's kind of a day -

8 CHARLES FELDMAN: It's a wellness and recovery center.

9 SPEAKER: Right, right. Now, where do you get your funding?

10 CHARLES FELDMAN: Well, it's interesting you should ask that, because a couple of years ago we lost
11 our funding, and right now we're volunteering to keep it going, but if the state ever passes a budget, we're
12 back in there this year. So it comes from a block grant that's passed from the federal government through
13 the state, and we, finally, after a lot of advocacy, got some funding restored in the budget this year and
14 then you all know what happened with the budget. It hasn't been passed yet, so we're still hoping that --
15 Health?

16 CHARLES FELDMAN: Yes, yes.

17 JUDI DREW: Well, thank you for your testimony.

18 CHARLES FELDMAN: You're welcome.

19 JUDI DREW: It's an important topic.

20 CHARLES FELDMAN: Right.

21 JUDI DREW: Okay. Next person on the list who asked to speak is Heidi.

22 HEIDE SNOWSTERD: That's me. I'm here in two capacities today.

23 JUDI DREW: Well, Heide, before you continue, if you want to say your last name, Heide.

24 HEIDE SNOWSTERD: My name is Heide Snowsterd.

25 JUDI DREW: And you are from?

26 HEIDE SNOWSTERD: I live in Providence, but I volunteer all over the state.

27 JUDI DREW: Okay.

28 HEIDE SNOWSTERD: And that being said, I am here in two capacities, so I'll speak as fast as I can.

29 JUDI DREW: You can take your time.

30 HEIDE SNOWSTERD: Because I know -

31 JUDI DREW: We are here for two hours.

32 HEIDE SNOWSTERD: I know we're on a time constraints and I want you all to like me and listen to me.
33 All right. The first reason that I'm here is I am involved with the Developmental Disabilities Council. And I
34 want to make you guys aware of some of the priority areas that we have, some of the things that we are
35 working on. I think it's important that we all share what is going on in our councils, so that people can
36 benefit and know what's coming up out there. So the Developmental Disabilities Council, they focus on
37 accessibility, transportation, housing, public education and employment. We have a Speakers Bureau
38 and we have a Developmental Disabilities Coalition that meets once a month and talks about issues
39 important to people with disabilities. It's open to the public and it's also for folks with disabilities. We also
40 have the Speakers Bureau that a lot of the people on Coalition are on, and we do public education, when
41 requested, to the groups that want to hear it. We have a variety of topics. If you go on www.riddc.org, you
42 can see the topics that we have and you can request us to come out and do presentations, especially the
43 people, please, that are working in the high schools, because as Charlie said, mentoring is very, very
44 important, and we want to help with public education, that people with disabilities are just people and we
45 want to show young people and people of all ages what they are capable of. Also, the Developmental
46 Disabilities Council is sponsoring Small Business Saturday on the Saturday after Thanksgiving at the
47 Crown Plaza. We're having a Business Expo and it's for people with and without disabilities. We're

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 looking for really high-end businesses, not everybody that applied will be accepted. It has to go through
2 committee, but I encourage all to attend, and if you know of somebody with or without a disability that has
3 a high-end small business, we are looking for people that might want to be there, and that website is
4 sbsshopri.com. And that is about all I want to say on behalf of DDC. I'll answer any questions that you
5 have. I also have quite a few concerns as a person with a disability. And unfortunately, for you folks, I
6 was unable to make it to the RIPTA forums, so I'm going to give you some RIPTA suggestions here.

Transportation: Parking

7 Won't that be fun? First of all, the parking in this library for the RIde buses
8 and for people with disabilities is really, I feel, unsafe, and it needs to be
9 accounted for. The parking for the challenged, because I don't like the word
10 handicapped, is basically on the street. And you have to cross over. There is no real safe driveway. You
11 know, the buses are big, the wheel chairs are big, and it makes you feel unwelcomed and unsafe.

Independent Living: Peer Support

12 Especially, I think, it's a paradox when you are a person with a
13 disability and you're trying to voice your concerns, and you are
14 looking at the situation saying; well, how the heck do I even get in
15 and be the voice for others who can't be the voice for themselves. I don't think it's fair, but the other things
16 I want to say about RIPTA is I volunteer at the Impossible Dream playground in Warwick. Love it. I've
17 been there for three years volunteering every Thursday, and help them on the scene, do a lot of their
18 phone answering, organizations, things of that nature, and I play with the children. RIPTA, a couple of
19 years ago, I used to be able to go there at night. If they had events from 6:00 to 8:00, I could go be with

Transportation: RIde

20 the kids, help them out. You know, it's kind of like an extended family feel, which
21 is important. A couple of years ago, RIPTA changed the route, so that bus 71
22 doesn't let me go to the Dream past 6:30, because I have to use a RIde program
23 for my safety. And I don't think that's right. I think once something -- a location is deemed RIde eligible, it
24 should be RIde eligible for as long as RIde is open. I don't think it should be RIde eligible at certain times,
25 and I don't think they should be allowed to change the bus routes as often as they do, because it impacts
26 people trying to get back to the community, trying to live as independently as possible in their lives. Also,
27 I suggest that RIde enforces the rules that they have. A lot of times they say if people are no shows for
28 three times in a row, they get taken off the program, but they never enforce it. And if you don't enforce the
29 no show rules, those of us that use the RIde program properly, and are ready, on time and pay the
30 money; we pay the price and we're late to your appointments, because we have to wait for these constant
31 no shows. I don't think that's fair. Also, I think that Massachusetts on the RIde program, they have a
32 swipe card, and the swipe -- as long as you prepay, you can swipe the card to pay your RIde fare. RIde
33 still has it, so you have pay the cash, and I think that's very inconvenient for those of us that have to get
34 the ones together, get the quarters together. I think a swipe card would be much, much easier. Also, I
35 want to, just as a human being, I want to piggy back on what Charlie said, and the most effective tool for
36 folks with disability is peer mentoring, and we need a lot more peer mentoring and leading by example in
37 this state, at all ages, so that instead of hearing what's not possible, you see through example what is
38 possible, and one of the other things that -- speaking on behalf of the DDC, again, not just me, but one of
39 the other things we're very committed to, is person centered thinking and planning, because who knows
40 better than the person, what they want out of their lives and it needs to be more from the people than
41 from the people in the lives that think they know what's best for them, that haven't really taken the
42 person's feelings into account, and that is about all I can think of that I want to say right now. If that
43 changes, I'll let you know. I know it was a mouthful, so if you have any questions for me, I'm here.

44 SPEAKER: I have a question.

45 SPEAKER: Okay.

46 SPEAKER: Heide, at one time, if I'm not mistaken, the RIde program used to take the RIPTIKs; are they
47 not taking it anymore?

48 HEIDE SNOWSTERD: They are, but let's talk about those. I'm so glad you asked me that.

49 SPEAKER: Well, I wanted to talk about payment options, so thank you, yes.

50 HEIDE SNOWSTERD: The RIPTIKs are doable.

51 SPEAKER: Um-hum.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 HEIDE SNOWSTERD: The only problem is, is that they're very hard to get.

2 SPEAKER: Okay.

3 HEIDE SNOWSTERD: They are always out of stock at Stop & Shop. It's very difficult to go, like, to the
4 Kennedy Plaza area and they are also very clumsy. You used to have the books
5 that ripped off the tickets. Now, you have the big booklets with the bigger tickets
6 that fall all over the place, so I just think that a swipe card would be much, much

7 easier. Also, a lot of the drivers -- I don't like the seniority based system. I think it should be a merit based
8 system and the drivers that do the best, listen to the clientele, get accolades from passengers; those are
9 the drivers that should be making more money. It shouldn't just be based on seniority, because the
10 problem with seniority is that some of the drivers are wonderful. Some of the drivers have very bad
11 attitudes. And they take the position of, oh, you can't say anything to me; you can't do anything to me; I
12 have seniority. And this is a customer service based organization. And the drivers that care and that are
13 doing the job right are the drivers that deserve to be making more money, so I would like to see RIde,
14 some day, go on a merit based system. That's just my thoughts.

15 JUDI DREW: Did that answer your question?

16 SPEAKER: It answered my question, yes, thank you.

17 JUDI DREW: Kathy, did you have a question? Okay.

18 SPEAKER: If I could just repeat. I work for RIPTA. Okay, so I just wanted to introduce myself and let you
19 know that I'm here in the room and I am listening to everything you said, and I've taken some notes and
20 I'm happy to chat with you at the break or after the meeting, as well.

21 SPEAKER: Thank you.

22 SPEAKER: I'm sorry, we weren't able to -

23 HEIDE SNOWSTERD: I -- you know, I'm very thankful that I have my own voice and I have a lot of
24 options in my life, which means I have a very full life, so they just -- thank God. I appreciate that every
25 single day and I wouldn't be able to do that without a lot of people in this room, but they just didn't gel with
26 my schedule, and I'm glad you're here.

27 SPEAKER: And that is why I came here today, because I know everyone can't be -

28 JUDI DREW: Thank you. Could you introduce yourself?

29 SARAH INGLES: Sure. My name is Sarah Ingles. I'm a planner with RIPTA. I'm actually the project
30 manager for the coordinated (inaudible) process that we have underway right now, so I'm happy to chat
31 with anyone about that. It's ongoing. We have a survey on-line that people can complete to talk about
32 their experiences, not only with RIPTA's fixed route and para-transit, but also about any human services
33 transportation, whether its municipal van or you know, the senior center or a health center (inaudible)
34 care. And that will be going on through most of the month of August. It will be on the agenda for August's
35 ATAC meeting, the Accessibility Transportation Advisory Committee, so if folks attend those or would like
36 to -- and what else? Again, I'm here and happy to talk. If anyone is interested in taking the survey and
37 can't do it or would prefer not to do it on-line through our website, I can take any e-mail address or a
38 mailing address and get it to folks that way as well.

39 HEIDE SNOWSTERD: Are you -- just a question, are you also willing, for those of us who have difficulty
40 with writing and things of that nature, are you willing to meet with people and have them fill it out?

41 SPEAKER: Yes. We do have limited resources for you know going out and meeting, but yes.

42 HEIDE SNOWSTERD: Okay, thank you.

43 JUDI DREW: Sarah, is that the extent of what you want to say for now?

44 SARAH INGLES: Yes, thank you.

45 HEIDE SNOWSTERD: Thank you for listening to me. I know I took a very long time.

46 JUDI DREW: That was not a long time, at all. The next person on the list is Kelly Ribeiro. Hi.

47 KELLY RIBEIRO: Hello.

48 JUDI DREW: Kelly, don't forget to introduce yourself and tell us where you're from, okay.

2017 Public Forums on the Concerns of People with Disabilities and their Families

- 1 KELLY RIBEIRO: My name is Kelly Ribeiro. I'm from Lincoln, Rhode Island (inaudible). I'm a 21-year
2 brain injury survivor, and I have come this far, in part, with thanks
3 Healthcare: Concussion related Injury to the Brain Injury Association (inaudible.) I would like to share
4 the stories of two children. The first is 14. He was playing a team
5 sport at the middle school level and while playing, recently, he took a soccer ball to the left side -- right
6 side of his head. He was knocked out, and this is his second experience this school year. The difference
7 is now he is got a brain -- has brain injury symptoms. The parents, uneducated on the subject, allowed
8 their son to play after one week out, as directed by the sports medicine doctor he was referred to. Next, is
9 a 17-year old senior, a ball player as well, who, while playing, fell back and hit his head, the back of his
10 head. He then sat out with ice. He continued his school day and went home and noticed his vision was
11 impaired, as it is still today. He finally went to Dr. Exil this week, 12 weeks after his fall. These incidents
12 show the need for concussion related injury support, education, along with the parents being educated as
13 well. Thank you.
- 14 JUDI DREW: Thank you. Thanks, Kelly.
- 15 KELLY RIBEIRO: Is that all?
- 16 JUDI DREW: No, I have some questions for you. Brain injury -- traumatic brain injuries are one of my
17 areas of expertise.
- 18 KELLY RIBEIRO: Um-hum.
- 19 JUDI DREW: And one of the areas I've been particularly concerned about is sports related injuries -
- 20 KELLY RIBEIRO: Um-hum.
- 21 JUDI DREW: -- in kids, teenagers, and you know, late teens.
- 22 KELLY RIBEIRO: Um-hum.
- 23 JUDI DREW: I'm concerned, because -
- 24 KELLY RIBEIRO: Why late teens?
- 25 JUDI DREW: Why late teens, because that's the neuro developmental time that's really important.
- 26 KELLY RIBEIRO: Oh, okay.
- 27 JUDI DREW: Yes, so if that gets disrupted, even more so than a younger child, it can be very difficult to
28 pass into adulthood.
- 29 KELLY RIBEIRO: Okay. Sorry.
- 30 JUDI DREW: And achieve some goals that you have. It's disruptive, not to mention, it can be very
31 disabling, so my concern is this. My understanding is that every coach in the State of Rhode Island,
32 regardless of their sport, has to be trained in head injury. So what I'd like to know is were both of these
33 situations in the same community?
- 34 KELLY RIBEIRO: I believe so.
- 35 JUDI DREW: Okay. Can you speak to me during the break?
- 36 KELLY RIBEIRO: Oh, sure.
- 37 JUDI DREW: So we can identify what community that it is, because I would like to go to that -- reach out
38 to that community and insure that that training is taking place.
- 39 KELLY RIBEIRO: Um-hum.
- 40 JUDI DREW: Because if the coaches had been properly educated on concussion protocol, based on the
41 latest neuroscience that's out there, neither child should have been allowed to play.
- 42 KELLY RIBEIRO: I agree.
- 43 JUDI DREW: Okay.
- 44 KELLY RIBEIRO: And the parents are uneducated. They have -
- 45 JUDI DREW: Well, it's not the responsibility of the parents, actually. It is, but it's not.
- 46 KELLY RIBEIRO: (Inaudible)

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 JUDI DREW: No, it's the coaches and the school's systems responsibility to make sure the coaches are
2 properly educated in that protocol and I would like to reach out to that school system.

3 KELLY RIBEIRO: East Providence.

4 JUDI DREW: Individually, as a human, and talk to them.

5 KELLY RIBEIRO: It's East Providence.

6 JUDI DREW: East Providence.

7 KELLY RIBEIRO: I went to high school with both of their moms.

8 JUDI DREW: Okay. All right. You can be sure I'm going to reach out to East Providence High School,
9 school system.

10 KELLY RIBEIRO: And I do know, for a fact, a year or two ago, the East Providence school system
11 replaced the turf with the cheaper of the two.

12 JUDI DREW: Are you talking about artificial turf?

13 KELLY RIBEIRO: Yes, but they went with the more affordable, rather than the one that -

14 SPEAKER: Is more cushiony.

15 KELLY RIBEIRO: Yes, the one that's suggested.

16 JUDI DREW: One is more, like, concrete when you fall on it and the other one has kind of a rubber -

17 KELLY RIBEIRO: Yes.

18 JUDI DREW: -- kind of response -

19 KELLY RIBEIRO: So they went with the cheaper of the two as a school system.

20 JUDI DREW: Okay.

21 KELLY RIBEIRO: And the workers, because I have a friend who works for the town -

22 (END OF FILE 1)

23 KELLY RIBEIRO: -- the city, rather, was told when he asked questions; he didn't have the right.

24 JUDI DREW: Okay.

25 KELLY RIBEIRO: And his name is -

26 JUDI DREW: I am not going to say anything publicly about that, but what I will say, too, is that as part of
27 your testimony, when we go back and review testimony -

28 KELLY RIBEIRO: Um-hum.

29 JUDI DREW: -- this -- I will personally -

30 KELLY RIBEIRO: Oh, I shouldn't have said his name.

31 JUDI DREW: I will make sure that this is flagged.

32 KELLY RIBEIRO: Oh, okay.

33 JUDI DREW: So that we can make sure that across the state those regulations\legislation is in place to
34 insure that.

35 SPEAKER: Can I ask a question about what you had said earlier about it's the coaches and the school's
36 responsibility.

37 JUDI drew: Sure. Could you identify yourself, please?

38 LORI BARDEN: I'm Lori Barden and I'm from Rhode Island Partners Information Network, and actually,
39 I'm asking this question as a parent. So what about non-school based organizations? So I see -- I'm
40 pretty fortunate. My kids, their extent of sports is chess, so concussions are a low threshold for them. But

41
42 Healthcare: Concussion related Injury

43 I mean, I see -- I mean, I have girlfriends, and their kids are
44 playing umpteen different soccer programs, and they're on paid
45 teams, and it's not a school (inaudible), so what is the regulation

44 or what is the requirement there, when it's an outside of a school domain? Because then I feel like it does
45 rely on the parents.

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1 JUDI DREW: Right.

2 LORI BARDEN: The parents need to be educated to an extent, because you are not falling on the school
3 system.

4 JUDI DREW: Right, so one of the things that Rhode Island Parent Information Network might want to do
5 is provide public education programs around concussions for children.

6 SPEAKER: We do that.

7 SPEAKER: (Inaudible)

8 JUDI DREW: You are already doing it, good.

9 SPEAKER: Yes.

10 SPEAKER: We do a lot of it.

11 JUDI DREW: Let's talk -

12 SPEAKER: Maybe we could do a community information session together.

13 JUDI DREW: Yeah, that we would (inaudible) see what happens -

14 KELLY RIBEIRO: I suggested and I am hoping that the Brain Injury Foundation listened, too, to do their
15 part about having a concussion. Oh, boy, someone who can detect concussions at every ball field.

16 JUDI DREW: Oh, boy, athletic trainer.

17 SPEAKER: Yeah, athletic trainer.

18 JUDI DREW: That's what I mean, a lot of trainers, in most states, are required to be there and have had
19 this training.

20 SPEAKER: But they are not required.

21 KELLY RIBEIRO: And where are they?

22 JUDI DREW: They're not required in Rhode Island.

23 SPEAKER: No.

24 KELLY RIBEIRO: So we have -- so that could happen. And we had kids leaving like RIC and URI who
25 need some experience under their belt. I am not saying every baseball diamond. I mean, for every field.
26 Maybe it's three baseball games and then another three, if they would volunteer their time to help kids
27 like my friend's son, who was given ice. And my other friend's son who was knocked right out and was
28 suggested to go to a sports medicine doctor. I mean, what the heck is that? I had a sports medicine
29 doctor. He took screws out of my leg, you know. He is not educated in the brain. And the kid is young. His
30 whole life is ahead of him.

31 JUDI DREW: Right.

32 KELLY RIBEIRO: And the other one, occipital lobe. He hit his head hard. His vision is affected. I just think
33 that we need someone -- I don't know where they came from. Concussions didn't exist 25 years ago.

34 JUDI DREW: Yes, they did.

35 KELLY RIBEIRO: Yes, but -

36 JUDI DREW: They were there.

37 KELLY RIBEIRO: What the heck?

38 JUDI DREW: We just didn't know it as well as we know it now. The technology to identify is different, but
39 thank you for your testimony and your advocacy.

40 KELLY RIBEIRO: Thanks.

41 JUDI DREW: Wonderful. Thank you. Okay. Yes, Heide.

42 HEIDE SNOWSTERD: I would also like to say, I'm not speaking on behalf of anybody, in particular. I'd
43 just like to share some things about -- some stories that I have been
44 Independent Living: Transition hearing, and I think that it's very important that -- you know, we all
45 have different abilities. We all have different disabilities, but we all
46 have something we can give to this community. And I think that it's very important that ORS and

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1 rehabilitation counselors and things of that nature really try to do more for folks that are labeled, non-
2 communicative, nonverbal, in the transition stages, and instead of looking toward employment, they look
3 toward quality of life arenas for these people, because everybody has a right to the best life possible, but
4 everybody also has a right to state what that best type of life can be. And so I really urge you to think
5 about looking outside of the box and maybe, you know, having other options, having more person
6 centered planning in your transition, in your rehabilitation, more funding for, like, people who maybe they
7 cannot work on the books, because of benefit constraints, but they would be wonderful in a stipendiary
8 position or something like that or maybe people want to go into their own small businesses, but more real
9 specific, person-to-person centered planning, when it comes to quality of life and encouragement to
10 never stop setting goals as long as you are alive. If you can do something at 19, it's something you have
11 always wanted to do and you are able to do it; you should do it, but it has to start with young kids and go
12 throughout life.

13 JUDI DREW: Okay, thank you. So the next person on the list is Beverly Portras. Beverly.

14 SPEAKER: She might have just stepped out for a minute.

15 JUDI DREW: Oh, okay.

16 SPEAKER: I think she might be coming back.

17 JUDI DREW: Then Lori, you're the next one on the list.

18 LORI BARDEN: Lori Barden. After hearing a lot of things on Wednesday (inaudible), I went back and
19 spoke to some of the staff at RIPIN and asked what were things that were concerns of theirs. Earlier this
20 year the biggest issue was the UHIP catastrophe, and obviously, hitting
21 some of our harder hit populations in the State of Rhode Island, so we
22 would like to see either services not stopped, in that case, ever again or

23 better plotting and planning, and someone's voice on disability being at the table when someone decides
24 to, you know, spend \$300,000 plus on changing a system, so that was definitely something, because our
25 call center became inundated, and when they are sitting on the phone and -- they are sitting on the
26 phone, they're not really helping people when they're sitting on hold for two and a half hours. So that was
27 the big issue at the (inaudible). Another thing is the time of year of these particular open forums. We
28 appreciate that the American Disability Act is being celebrated and its anniversary is being recognized,
29 but a Friday in July, I'm really impressed with the number of people that are in this room. It's not
30 necessarily the best time of year, and when I was looking at who was here, I am happy that RIPTA is
31 here, because it was one of my first notes. Was like, this is Providence. This is going to be a big
32 commuter area. We really should have RIPTA at the table, probably more so than we needed in
33 Cumberland, because Cumberland, that particular location, has no RIPTA stop. So that brought up some
34 other dialogue, but that was just my opinion on that one, and I'll keep it at that. For the time of year, it
35 would be great if this was available throughout the year, whether it be done in segments and throughout
36 the state, so -

37 SPEAKER: Quarterly or something.

38 LORI BARDEN: Something of the nature -- lots of people, you know, an opportunity to come out, who
39 aren't in town. There are people in Rhode Island, who have disabilities, who actually vacation and they
40 aren't around, so I think we miss that, and it's not communicated, so broadly that everyone knew that they
41 could write testimony and submit it by a particular date. So better communication on that part, whether it
42 be in conjunction with their doctor's offices, in conjunction with the hospitals, anything like that. And then
43 looking at Veteran's support. We understand that there's a VA. We understand that that's part of the
44 process, but they are not just a veteran. They are a Rhode Island citizen. They are a Rhode Islander.
45 They live in Rhode Island, so they're not just -- it's not just the VA. Just like my kid is not just that kid with
46 this particular diagnosis. He's a little boy who plays chess, but we need to look at things in a more holistic
47 approach, and having different faces at the table, but being able to turn around and say, you know what, I
48 don't need to go to the VA for this, but I might be better off if I go to Oasis. That might work for me,
49 because that peer support, but options because I think people are tied into one particular title and not
50 necessarily given the options of others that are throughout the state. And that is really it, so thank you.

51 JUDI DREW: Thanks. You have brought up some important points. Can I just respond to that?

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 LORI Barden: Um-hum.

2 JUDI DREW: And then I'll come back to you Kelly. And Beverly, and thank you for coming back in the
3 room, because we will talk with you in a minute, okay. I just want you to know why we have the forums at
4 this time of year. It's because we need the lead time from this time through the early fall to identify what
5 legislative agendas we want to move forward, and to identify what the advocacy needs to be, and then
6 the General Assembly goes into session in January, and they work from January to June, so to have a
7 public forum take place while they're in session is not useful to any of us, so over the years we've used
8 this period of time, and perhaps we could do it earlier in the summer. Rather than July, maybe we can do
9 it in June, but the Legislative Assembly is still in process, so this is the one period of time that gives us
10 enough time to collect data from the public, to then review all of the testimony and all the things that take
11 place to figure out which areas are advocacy, which areas need to be dealt with legislatively or
12 regulatorily, if that's a word. I'm not sure it is.

13 SPEAKER: (Inaudible)

14 JUDI DREW: It is, okay. If it's not, I made it up. We all can do that, can't we?

15 SPEAKER: Yeah.

16 JUDI DREW: Anyway, so that is why we have it at this time. I understand your concern, because I have
17 always felt, like, gee, I wish we could hear from people more frequently, but this is the only way we can
18 get this done in time for working on legislative agendas cooperatively, because we tend to start working
19 with the General Assembly before the session starts, actually, so -

20 SPEAKER: May I just add something?

21 JUDI DREW: Sure.

22 SPEAKER: Would it be possible to do something where it's an on-line opportunity for people to submit
23 concerns, because let me tell you, people are pretty heated June 26th, the night after the General
24 Assembly checks off boxes or walks out.

25 JUDI DREW: Right.

26 SPEAKER: And they have time to cool off and others are more upset about things that are happening in
27 the community in the winter, because accessibility is limited.

28 JUDI DREW: Sure.

29 SPEAKER: So I just think that the opportunity for people to know where they can go and have that either
30 an open forum or be able to comment or what is your concerns, something that maybe available on a
31 website.

32 JUDI DREW: Um-hum.

33 SPEAKER: And then that website is shared throughout all agencies, so they can share it, so RIPIN would
34 have that link on our website.

35 JUDI DREW: That's a great idea, but as you heard, on Wednesday, the Governor's Commission budget
36 has been cut over the years. At one point we had ten staff people. We now have four, and the rest of us
37 are all volunteers. So I love your idea and Casey and I will certainly bring it up, because I think it's a great
38 idea, but who's going be there to read all of this; who's going to be there to channel it, and who would be
39 there to disseminate it to the parties? We'd have to probably get another volunteer or fellowship or
40 something to deal with that. But we'll look at it, because I think that's a wonderful idea. So thanks. Thanks
41 for your idea. Beverly, you wanted to talk.

42 BEVERLY PORTRAS: Yes.

43 JUDI DREW: Can you please tell us what your first name is, your last name, and community you are
44 from.

45 BEVERLY PORTRAS: Okay. My name is Beverly Portras. I'm here to speak and advocate on behalf of a
46 son, who has tick born encephalitis and to be
47 able to say to you, that there's a sense of
48 urgency among your first responders, our
49 medical responders, to know that there is a difference between encephalitis and mental illness, and there

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 needs to be a workup, so that we can identify that this is different than psychiatry, so when you get lost in
2 psychiatry and I have to tell you all, we're very antiquated. It's a disgrace. I can say to you it's been a
3 blessing for me, but it's also a cross, because my son has a brain injury. So -- and I'll be clear, this is
4 what happened. In our state, okay, I live in Little Compton, Tiverton, Rhode Island. Beautiful. I didn't care
5 if I had the smallest house in Little Compton; I felt so privileged. Oh, my God. My son's favorite animal
6 was a deer, and it has nothing to do with deer. We don't know. We are not ready. We are not ready for
7 this acute onset. When somebody becomes arthritic, their knee swells up. You see it. You can't deny it,
8 okay. When somebody has -- now, they know it causes heart block. That's not a guess. It causes heart
9 block. For my son, you know, he was a young man that played soccer. He went to private schools. I
10 couldn't afford it, but I felt privileged having grown up in Fall River. All I wanted was a good foundation, so
11 long story short, of what I am trying to tell you, there were some developmental delays. There were some
12 things that were concerning me. By the time he got to junior year, I was, like, okay, what's going on here.
13 We had a very talented young man, kind of slipping socially. What is with this anxiety? What's going on
14 here? And there is such thing called PANDIS⁷. If you don't know it, we need to know it.

15 SPEAKER: Um-hum.

16 BEVERLY PORTRAS: We need to be telling our teacher.

17 SPEAKER: Yup.

18 BEVERLY PORTRAS: Let's look for this. Okay please, let's look for this, because when it becomes an
19 autoimmune condition, it's gone too far. Okay. We're chasing it,
20 Civil Rights: Interactions with Police so what I am trying to tell you is this. I've a young man. We live in
21 a beautiful area. He can walk his dog and come back with 50

22 ticks, and I'm not lying. I am not lying. Each one of those ticks is capable of laying 3,000 eggs. How the
23 heck are we going to catch up? We are not, so if we're not able to catch up, for God sakes our
24 psychiatrists and our first responders in the ER need to know what organic brain disease is. When you
25 have a CT Scan that says lesions, frontal lobe, and I don't know what it is. My son is acting odd. He is
26 confused, paranoid, sensitive to light. What is this? So the first thing they do is they look at behavior. I'm
27 telling you; we are in need. We are in crisis in Little Compton and Tiverton, because when the police see
28 this odd behavior in a young men, I can tell you all, odd behavior, diagnosed with schizophrenia, and I
29 am saying what is -- what is this? What would cause lesions in the frontal lobe? Lyme Syphilis, within 30

30 seconds a psychiatrist will tell you this, right? I'm here to tell you
31 Healthcare: PANDIS Neuroborreliosis⁸, when it's in your central nervous system is going to mimic
32 every single mental illness, every one. And it's going to change depending on
33 what pathogens and where it's moving in your body, but the insult is the same. So my plea to you is this,
34 we need to work, at the expense of my son, I'm ready; you can call me. I don't have time. Sold my house,
35 sold my fancy car. It means nothing. I have a brain injury. I'm Age 61. When it gets late stage, you're
36 looking at early onset dementia. I can tell you, because it's a spirochetal infection. Neurology, where are
37 you going with this, because we've been taught 28 days of doxycycline, you are good. No, no, you are
38 wrong. That's if you caught it, so if you didn't catch it, and it relapses, then you say, okay. You talk to the
39 people. Now, my son has already been diagnosed with schizophrenia. He's on Medicare. Who is going to
40 treat? No one is going to touch that kid, because he is schizophrenic. That's his diagnosis. Wrong.
41 Psychosis can present with many mental conditions, and we have to teach psychiatry that there's an
42 obligation here to wellness, not death wishes. Wellness. Okay. How does a brain become well, by not
43 being inflamed. How do you do that? Better diet, increased blood flow, so when you have a brain injury
44 doctor, believe me, I have been to Columbia University. I am, like, what is going on here; my son is acting
45 like he has got dementia, autism. What is this? So this is what I am saying. When you see this, it's very
46 acute. And so they say, this is classic schizophrenia. It is. It may present this way, but it could be late
47 stage Lyme. Okay, so now, with that being said, you get your treatment and you're moving along, and so
48 my son, he had his (inaudible) six weeks. Treated with his anti-psychotics. We are decreasing the anti-
49 psychotics, back to work, back driving. He goes and gets a tetanus shot. He starts looking like T Rex,

⁷ Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDIS)

⁸ Neuroborreliosis, also known as Lyme neuroborreliosis (LNB), is a disorder of the central nervous system.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 drooling. I'm, like, what is this? I'm not a psychiatrist. I don't know what this is. It's an odd movement,
2 disorder. I am trying to figure it out, and he was kind of like reprimanded for not taking his medications,
3 tampering improperly, whatever, back in the psychiatric ward, back
4 on meds and I'm saying please test for (inaudible) infections. My
5 son has Babesia⁹. So what is Babesia? It's blood infection.

6 Babesia is loaded. We're loaded in Westport. There's a hundred strains of Babesia. I didn't know what my
7 son had until we went to Connecticut, because they say, if you are relapsing, you need to test for other
8 strains. What are they? We don't even know here. So if I called Dr. Gore, and I said, please, Dr. Gore my
9 son honestly -- I'm so humiliated. We have got an indecent exposure charge here. He became catatonic.
10 They put him in. They doubled his anti-psychotics, please. Oh, Beverly, you know, we're not taking new
11 patients. Well, the minute you put mental illness on anything, you can just forget it. So I can say that I'm
12 here to advocate for those people; how many thousands of people or hundreds of people are
13 misdiagnosed. This is my son. He will listen to things and touch things and do things hundreds and
14 hundreds of repetitive times, because he has multiple infections that were not caught early. So then when
15 you go to psychiatry. He had IVIG¹⁰. You change your (inaudible). Things drop. You don't get your
16 treatment. You relapse, again. I'm going to tell you. We need help here. We need help there, and we
17 need help in our judicial system, legal system. When they see somebody with a brain injury, they think its
18 mental illness. You have such a deficit, okay. We want to call everybody. It's a brain injury; I'm sorry. So
19 when you are talking to somebody that is agreeing with you and you know they have a communication
20 deficit, a brain injury is invisible. It deserves the same attention that a heart attack would have. The same
21 urgency that a stroke would have. The same sense of value that everybody has a need to protect
22 (inaudible)? Are you kidding me? Why am I being burdened when I beg and plead for a stipend to stay
23 home with my son, and they say, oh, he is aggressive, kick him off this program, because you know, and
24 I am thinking to myself, we're missing it here. Brain injury is not a pretty picture, encephalitis is not pretty,
25 okay. We need to give these people oxygen, and it needs to be understood that oxygen will heal, just like
26 a diabetic will heal from oxygen. We need to heal from the inside, so when I asked for neurology, and I
27 ask for -- you know, I went to Columbia University. I am going to wrap this up real quick. I went to
28 Columbia University, I said, I have got a son who's being, you know, tormented here by the police, and
29 it's not that they don't care. It's just that they need to care. If he was in a community like Newport, they'd
30 care. I am in an affluent community. I am not an affluent person, but I'm a bother. He's a nuisance, so
31 let's just arrest him, so we can force treatment. Wrong. It's wrong to do this to people. So here he is being
32 publicly humiliated, communication deficit, isolated from the community. Are you kidding me? With a
33 relapsing condition, how am I going to cure Babesia, Bartonella¹¹, Mycoplasma, reoccurring Spirochetal
34 Borrelia¹² infection? Now, they can tell you that if you save the tick and you send it to UMASS, they will
35 document it. They will tell you what your pathogen panel is. You can save it. Refer to it. You can test for
36 all the spirochete infections now. There is not just one. You can test, if you want. If I had a lot of money,
37 believe me, I'd be, not like desperate housewives. I'm desperate, yes, but not so pleased and pleased
38 as (inaudible) in an oxygen tank, as she's on bedding for oxygen, too, but this is what I am saying. We
39 are missing it here, and it's critical. We are missing something that's a real threat to our community, so I
40 thank you for the opportunity, and if anybody wants to know anything about it, when my son, his
41 medications were being delivered, they were treating people with blindness. They were treating people
42 with deliveries for heart block. They were treating people that could not walk, all because we're not ready
43 to identify tick born infections. So if your pathogen load is heavy and you're immune system is
44 compromised, it becomes an autoimmune encephalitis. That's different. Anybody can go on autoimmune
45 encephalitis (inaudible,) huge in Europe. I am begging and writing and pleading with doctors, they said,
46 plasmapheresis, clean the blood, clean the infections. You tell me where I can get that here. It's not going
47 to happen. I go to Butler, and I say, listen, can you please help me. I know that you detox people that
48 have drug problems. I need plasmapheresis. Beverly, we don't do that here. I said my son needs to detox

⁹ Babesia is a malaria-like parasite

¹⁰ Intravenous immunoglobulin

¹¹ Bartonella are bacteria that live primarily inside the lining of the blood vessels.

¹² The **spirochete Borrelia burgdorferi** is a tick-borne obligate parasite.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 all these things, please. I can go to -- I went to all hospitals. Well, then if I can't get that, help me with
2 cognitive therapy for brain injury. I'm sorry, we don't have that here. Where is it? I can go to our Lady of
3 Fatima. Where is it? I have been to them all, Newport, Rhode Island. There's nothing here, so tell me
4 where I can go; another state where I can take my son, where they can look at brain injury and its
5 complexities of an autoimmune condition and not be burdening me, because in my community, they look
6 at it, like, you know, what is this; this odd person here. He needs to move to Mass. where there are better
7 resources for mental illness. This is brain injury, okay, and encephalitis, if it was the Zika virus, all hands
8 on deck. And I say, thank you, God. We've got the Zika virus. This is going to wake everybody up. No, it
9 didn't. Ebola, all hands on deck. Oh, they saw it in the eye of a doctor, whatever. I recently went to a
10 hematologist, very recent, I said, because autoimmune encephalitis they're using cancer treatment and
11 it's working. They're attacking the B cells. Its working, so I said to him, listen, this is the direction. I need
12 your help. He took one look at my son's history; he apologized. He said, we are missing this, totally. So
13 our first responders are not ruling out Lyme and all of the co-infections. When I called the Health
14 Department, I don't have time to put everything in writing, when I have got a son that's so anxious and I
15 am calling them, saying, why isn't tick born encephalitis on your website? Beverly, we never heard of
16 such a thing. I said, are you kidding me? You're in the Health Department. I am telling you it exists, so put
17 it out there, and there's a sense of urgency to alert people. We need to be talking about this. We need to
18 be telling our children in the schools that if they have delayed growth or ADHD and they have difficulty
19 with symptoms that are, you know, attention or cognitive declines, we need to be thinking about
20 encephalitis and what kind of immune insults are going on here, so that's my story. And I am going to
21 thank you, because I know everybody here has a value -- collectively, we need people at the Newport
22 County Mental Health and psychiatry to stop dumping people into, you know, okay, you are coming in, in
23 two days. Here's your X amount of milligrams. You are off. Check in with your Newport County Mental
24 Health. This is a medical condition. It's not right that I get a booklet of 170, 200 pages and then I've got to
25 figure it out myself. I figured it out myself, and I am asking for your help. I said, start putting medical in
26 these communities. They're overloaded as it is, but you look for a cause; it doesn't take long, so if you
27 need cognitive therapy, where am I supposed to go? They're still searching for a bill in Massachusetts.
28 You need it right away. You need it right away, when speech -- and then I can go to Butler and they say,
29 Beverly, we're going to sign up your son for the cognitive therapy, blah, blah, blah. You go there and they
30 are all up in arms. Your son came here. This is -- he is using one word answers. He can't be fluent. Well,
31 where am I supposed to go? Connecticut. Tell me where to go?

32 (END OF FILE 2)

33 BEVERLY PORTRAS: And it's a disgrace that our legal system doesn't have an advocate for mental
34 health or brain injury survivors. Okay. That is not acceptable. It's
35 Healthcare: Traumatic Brain Injury not acceptable. I don't care what anybody says here, if you have a
36 brain injury, then you need somebody as soon as you walk into that
37 courtroom and you need to be able to say, my son has a brain injury; we need an advocate today, now.

38 SPEAKER: Have you tried Spalding in Boston?

39 BEVERLY PORTRAS: Yes (Inaudible). I got a referral from Columbia University, and I went to Spalding.
40 Within a half hour, she said, your son has a brain injury, within a half hour. No history. No nothing. Okay, I
41 am pleading and begging all over here in Rhode Island and Mass. She said, how long has your son been
42 talking like this? I said, for years. Because psychiatry can say, oh, it's disorganized. It's this. It's that.
43 Within a half hour, she did a PET scan. There was hypo-metabolism throughout the brain. What is that?
44 Alzheimer's. Okay, so when your body is threatened by chronic inflammation, it's fighting to survive. It
45 produces its own anti-bodies to fight infection, so I'm telling you, if this can happen to a young kid, how
46 many people are being missed?

47 SPEAKER: Thousands.

48 BEVERLY PORTRAS: That's what I am saying, so I'm not here to point fingers. I am here to say, there is
49 a sense of urgency for brain injury. It is no different, and you know, if you know that Alzheimer's is

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 coming, just like your chronic Encephalopathy¹³ for your football players, okay, then we need to be talking
2 about this, not just for athleticism, but immunology needs to be on board. I recently found, and I said to
3 (inaudible), you know, (inaudible), she happens to be a brain injury doctor. I thank God, so she restarted
4 the spirochete treatment. My son's brain woke up. We became part of the psychoses study at Columbia
5 University. Sent it to Germany. She called me. She said, Beverly, have you read the book, "Brain on
6 Fire." I said, I have. I said, I'm telling you; I tell the doctors; I said, my son, you give him those anti-
7 psychotic meds, he is on fire. He is screaming. He's being absurd. He's acting bizarre. He is literally, put
8 a match to him; he is on fire. She said, well, this is a book called "Brain on Fire" and it has to do with a
9 virile infection that attacks the brain. So there is what I am telling you all. It could be anything. So we have
10 to be much more attentive to our children. You could be outed anyway. Your immune system is probably
11 fine. Your immune system may not be. It doesn't matter whatever pathogen it is. It depends really on the
12 trauma, what you're carrying already, and it may be dormant for a very long time. You have a divorce.
13 Wake up, because it's coming. If you had Lyme disease, I have met hundreds of people; they say, I had
14 Lyme disease. I caught it quick. And I say, no, it's sleeping. It's all good, but we're all united in this, and
15 it's no joke. Because we didn't do our homework in the 80s, we have a serious problem right now.

16 JUDI DREW: Beverly, this testimony is so important. And you have identified a (inaudible) issue, just like
17 you said.

18 BEVERLY PORTRAS: Right.

19 JUDI DREW: So thank you very much for sharing your story.

20 BEVERLY PORTRAS: You are welcome.

21 JUDI DREW: We really appreciate it. And it will give us a lot to talk about in Commission, as we review
22 things that we can maybe move long, suggest, encourage, talk to the state department.

23 BEVERLY PORTRAS: But it should not take a year and a half, for somebody that wants to stay home to
24 care for a brain injury survivor, a year and half to get a small stipend and then to have it taken away.

25 JUDI DREW: So -

26 BEVERLY PORTRAS: Why, because we don't have resources in our community, in your state? Why
27 because I'm not meeting your expectations?

28 JUDI DREW: Can you talk very briefly, because we want to take a break. Okay. Can you talk about the
29 stipend situation? Where did it come from and who took it away?

30 BEVERLY PORTRAS: The Rhode Island Stay [at] Home Program. My son is an athlete, okay, he was
always an athlete. He moves. He does -- he is
completely normal if he has a basketball, and you know,
it's the communication deficit and the executive

Healthcare: Home and Community Based Care

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34 functioning, so you know, I knew that we had a cognitive deficit. I already know all of that, and I was
35 trying to get my son to get treatment, so I went into the Brain Injury Association, you all know, and I said
36 to them, look, I mean, I have a very acute situation here, and I said, I need to be with my son. I said, he is
37 going to end up being incarcerated. I said, it's not understood.

38 JUDI DREW: Okay.

39 BEVERLY PORTRAS: It's a Rhode Island Stay At Home Program.

40 JUDI DREW: Okay.

41 BEVERLY PORTRAS: So when I first went, you know, my son was there. I did all the speaking. I
42 presented. Brain injury is completely invisible.

43 JUDI DREW: Okay, so who took it away?

44 BEVERLY PORTRAS: They did, because when they came -

45 JUDI DREW: That program gave it to you and then had to take it away?

¹³ Encephalopathy does not refer to a single disease, but rather to a syndrome of overall brain dysfunction; this syndrome can have many different organic and inorganic causes.

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1 BEVERLY PORTRAS: Took it away, yes, because when you are in late stage Lyme, you are not calm,
2 sitting like this. There is agitation. There's flare-ups. There is all kinds of different manifestations, and my
3 son has a lot of courage, but any stressor -- any stressor will kick up agitation.

4 JUDI DREW: Okay, so is there concern that -

5 BEVERLY PORTRAS: Yes.

6 JUDI DREW: -- you would have difficulty caring for him at home? Was that the rationale?

7 BEVERLY PORTRAS: Yes, and I explained to them that I have to work with the police, and he has a dog

Civil Rights: Interaction with Police

9 that he doesn't -- you know he doesn't, like, to have it on a leash,
10 so this one day -- and I said, listen, this is an ongoing problem. It's
a cognitive deficit. He really does need a mentor; that's another

11 thing, a mentor to be socially appropriate. And they all agreed and they said, Beverly, this doesn't exist.
12 What you need to do is find a place, bring him to the ER and leave him there. I said, I will not. I said, just
13 because you want him to fit in some kind -- not everybody's injury is going to be, you know, the same. So
14 I said, but I am willing to hold him accountable. I am willing to advocate. I am going to be there, so they
15 said that they felt like, you know, I couldn't control him. He was letting the dog loose. My communication
16 and all of our deficits were not something that fell within their program. I said, well, I am so glad that your
17 brain injury survivors are so high functioning that they are calm and they are contained. And they never
18 have agitation and they don't yell and shout and swear and scream and become frustrated. I'm so happy
19 for you, that you have a job that allows you to care for people, because they're so well, but those of us
20 that fall under the cracks, if I end up under a bridge, so be it. I'll be there until the very end, to the last
21 breath.

22 JUDI DREW: Thank you very much.

23 BEVERLY PORTRAS: You're welcome. (APPLAUSE)

24 JUDI DREW: So how about if we take a ten minute break.

(END OF FILE 3)

26 SPEAKER: (Inaudible)

27 JUDI DREW: But there's nothing we can do about it except, next year, not use this site.

28 HEIDE SNOWSTERD: The site is not very accessible.

29 (TALKING ALL AT ONCE)

(BACK FROM BREAK)

31 JUDI DREW: So we're back in order now. We're on the record. There is a videotape.

32 SPEAKER: There was a representative from RIPTA here.

33 SPEAKER: There is?

34 SPEAKER: Yes.

35 JUDI DREW: Yes. You could have a seat and talk to us.

36 (TALKING ALL AT ONCE)

37 JUDI DREW: Okay. Feel free to stand.

38 SPEAKER: (Inaudible) damage and I (inaudible).

39 JUDI drew: Okay.

40 SPEAKER: I just happened to see this as I came by and I hope (inaudible). I need to move (inaudible)

Housing: Multiple Chemical Sensitivity

41 and I have a lot of special needs. They don't show, but I have
42 (inaudible) arthritis, Fibromyalgia¹⁴, chronic fatigue and
43 physical damage from a car accident, and it's terrifying to try

44 and find a place to live, because I can't have smokers in my building, so I need a no smoking lease, that's

¹⁴ Fibromyalgia is a disorder characterized by widespread musculoskeletal pain accompanied by fatigue, sleep, memory and mood issues.

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1 going to be enforced. We had a problem in my building where I am now, I have lived there 21 years with
2 a no smoking lease and smokers still cause trouble. It's not (inaudible) about that. I am on a special diets
3 with three freezers. They have to go somewhere. My husband is self-employed. I do odd jobs on
4 (inaudible), and so we need business things, so we need at least a two bedroom apartment. We need no
5 mold. I mean, like, there is a whole list of requirements that don't fit, like, a wheelchair. I was in a
6 wheelchair for two years. I don't belittle that. That's a big project, too, but -- and by the way, the entire two
7 years (inaudible) I could stand up, because I never got through the waiting list for wheelchair accessible
8 housing. The whole two years I was in the chair from the accident, never, I crawled up the stairs. I had
9 the chair in the house and a chair in the car. That's how it was. That wasn't here. That was in The
10 Massachusetts, but the (inaudible) is when your disability doesn't fit the box. And also limits your income.

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Employment: Social Security Disability

That's the other problem is that, you know, I'm on Social Security and Disability and I'm allowed to work a certain amount. I'm not allowed to make more than a \$1,000 a month,

even if I'm brilliant and make \$200 an hour, you know, so I am only doing five hours of work. It doesn't matter. You can't -- that's really a problem with the housing and every other need that comes with disability is your income is so limited, and they sit on it that way. It's, like, okay, so you can't have COLA, ha-ha, so let us do more, if we can do it, around our disability, you know, and being in an on-call position is great, but they -- I mean, anybody knows what this (inaudible). Most of them have (inaudible), so then you can take advantage of your good days if you get called, anyway. I don't want to take up all the time, but that is it, but like, right now, it is very emotional for me. I don't know where we're going to move. Luckily the landlord is fixing up the building. He hasn't, like, said you've got to move out tomorrow, but

Housing: Affordable

we've been looking for a month. We have enough money to buy a little house, \$200,000. I mean, (inaudible) talk about money. In this neighborhood, its nuts. A cottage is \$350,000. I don't understand it. It's, like, okay, people with money could have nice houses. I have nothing against that, but the rest of us need somewhere to live. And when you have extra issues, it's terrifying. My poor husband is stuck in this with me. He could live almost anywhere, if it's the first floor, because he has a lot of equipment for his work, but you know, I have all these limitations. I mean, it has been an incredible blessing, we had the right landlord for the first 21 years, who we just tripped over by accident, so -

JUDI DREW: So if I understand your testimony correctly, then your concern is that it's difficult to find housing, where it -- you can have your needs met.

SPEAKER: Right.

JUDI DREW: In terms of how the housing is organized.

SPEAKER: Right.

JUDI DREW: And being mold free and -

SPEAKER: And smoke free and -

JUDI DREW: And accessible.

SPEAKER: Like, having your needs, like, listened to and not laughed at or people saying, oh, you are picky. You don't like carpets, you know, well, no, because they make me sick, and the part that's really terrifying is that I will just -- people look at me, they don't think I am disabled. I say, I run on vitamins and prayers, but I also realize I run on

Housing: Accessible

having the right environment at home, and if I lose that, I (inaudible), because before I figured out what the right environment was, I spent most of my time in bed with blinding headaches, and you know, couldn't do anything for myself and had to (inaudible) charity besides Social Security and lie about it, because you're not allowed to, and that's crazy. Oh, I shouldn't have said that on the videotape, but it's, like, I don't want to be like that. I want to be, you know, out there, and I don't want to take charity. I am not a person who should need to take charity.

JUDI DREW: Um-hum.

Housing: Affordable

SPEAKER: You know, anyway, and Section 8 can't hold up the world. We need frugal housing. We need housing built while training people to work. While -- I don't know what, you know, invent something, use tractor trailer boxes,

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- 1 whatever. We need safe, clean housing that's built right to begin with. That's built to not cost a fortune.
2 We don't need a mansion. I mean, I need some extra space, because of my food issues, but most people
3 don't even need that, and if we were desperate enough, I don't know, somehow we'll make that work, you
4 know, hang a refrigerator from the ceiling; I don't know.
- 5 SPEAKER: I just want to respond to that. I agree, I mean, I think at another forum I was at, we were
6 talking about, you know, new construction. We should consider universal design instead of just having
7 some accessible units, you know.
- 8 SPEAKER: Right.
- 9 SPEAKER: Universal design, which is -
- 10 SPEAKER: I'm very happy to work with people on this. I have a lot of ideas about this. I actually used to
11 do carpentry before I got so sick. And I have some ideas on how things are built and what would work
12 and that you can really plan it; drawers under the bed. You just, I mean, I (inaudible) well, actually
13 somebody in a wheelchair maybe could, if it was built right, use drawers under the bed, so just, you
14 know, that there are ways to build a house that's comfortable to live in if somebody's not going out so
15 much, you know, computer little corner or whatever.
- 16 SPEAKER: I do have two suggestions, though. One is, you know, there are ways that you can use any of
17 your extra income, and there's special accounts that you can use to pay for working to help you in your
18 career or for helping to -
- 19 SPEAKER: Like a (inaudible)
- 20 SPEAKER: Yes.
- 21 SPEAKER: I had. That's how I got my first vehicle.
- 22 SPEAKER: Yes, and if you could think of other things that you might need, the other things that you might
23 want to do is to talk to the Ocean State Center for Independent Living.
- 24 SPEAKER: Okay.
- 25 SPEAKER: So what they do is they are an agency that helps to -- people to turn their housing and
26 making it more accessible.
- 27 SPEAKER: Um-hum.
- 28 SPEAKER: So if you were to find something that you could afford, that you could figure out how to, you
29 know, find some ways to make it easier for you, and they might - I think, you have -- sounds like you
30 (inaudible) design.
- 31 SPEAKER: Right.
- 32 SPEAKER: You know, somebody -
- 33 SPEAKER: (Inaudible)
- 34 SPEAKER: -- Accessibility, could figure, between the two of you; how they could -
- 35 SPEAKER: Would they do something like talk to a landlord, who doesn't understand how important no
36 smoking is?
- 37 SPEAKER: No.
- 38 JUDI DREW: Yes, no, that's -
- 39 SPEAKER: That's one of the reasons we have to go from where we are, and it probably won't work
40 anyway (inaudible) for the building and he needs to make his money, but -
- 41 SPEAKER: Those cases are hard to -
- 42 SPEAKER: He says he doesn't want to do no smoking leases. Nobody smokes anymore, and I can't take
43 that chance.
- 44 JUDI DREW: Yes, I don't know anyone that (inaudible).
- 45 SPEAKER: There's a lot of people like -
- 46 JUDI DREW: I know.

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1 SPEAKER: I mean, we've had cases like that, and it's just hard for them to prove that the other person is
2 smoking.
3 SPEAKER: Yes.
4 SPEAKER: Yes, and that's really what it hinges on.
5 SPEAKER: We had to threaten to move out after 15 years living there, and my landlord finds that
6 (inaudible). I don't know what you are doing, but she has never complained in 15 years, but she is willing
7 to move all that stuff, you know, I (inaudible), and luckily the guy went, because he would have dragged it
8 out for another six months.
9 SPEAKER: (Inaudible) but also talking to the benefits planners, who are people who can consult with you
10 on your Social Security benefits and figuring out how to balance
11 your earnings and working and help you also (inaudible)
12 coverage. They can help you figure out some things that you
13 can do. They know the math.
14 SPEAKER: But I sort of talked to some people, but every time I have ever gone to the Social Security
15 office, I got -
16 SPEAKER: These are not Social Security people.
17 SPEAKER: Well, ORS. I worked for the Office of Rehab Services and one of the services that we can
18 provide is benefits counseling and (inaudible).
19 SPEAKER: You know.
20 SPEAKER: I can give you a card.
21 SPEAKER: That's great, because I don't remember things, and I'm (inaudible) all the time. Thank you
22 very much.
23 SPEAKER: You have to be willing to work with -- your kind of work is on a part-time basis, anyway.
24 SPEAKER: Yes, I know (inaudible) internet.
25 SPEAKER: Okay. All right. It probably wouldn't be me.
26 SPEAKER: That's okay.
27 SPEAKER: But you can call me and then I can get (inaudible) to the right person. Okay.
28 SPEAKER: (Inaudible)
29 JUDI DREW: No worries. Thank you.
30 SPEAKER: No, it's -- I can't be the only one.
31 JUDI DREW: You are not.
32 SPEAKER: I am giving money to the guys on the corners, you know, it's crazy. All right, thank you.
33 JUDI DREW: Thank you and good luck to you.
34 SPEAKER: Thanks.
35 JUDI DREW: Okay. Cary -- hi, Cary.
36 CARY FIDENBAUM: Hi.
37 JUDI DREW: Can you give us your full name and what town you're from.
38 CARY FIDENBAUM: Cary Fidenbaum, Providence, Rhode Island.
39 JUDI DREW: Thanks.
40 CARY FIDENBAUM: I didn't know this was going on -
41 SPEAKER: Where is the testimony? It's just, like, work on this -
42 CARY FIDENBAUM: I look at Providence and (inaudible) a building. There is, like, we're covering drugs
43 and alcoholics. I just (inaudible) because in Europe and other countries, once
44 you (inaudible) do drugs or you're an alcoholic, you get blocked out.
45 (Inaudible) group homes for the rest of your life. Once -- if you're willingly
46 doing that to yourself, you're really hurting your body and doing that versus you don't get a job. You don't

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1 get (inaudible) building and housing, and I believe that. If you're willingly doing that to yourself, in this
2 country, we pay way too much attention to recovering drugs and alcoholics and stuff like that, and I think
3 it's a waste. I think it's a waste of taxpayer money. If you would see -- most of my life I've gone through
4 my life; I actually tried to -- minding my own business, but (inaudible) many things (inaudible) rational
5 views, anti-Semitism. Where I live, now, people call me a dirty Jew all the time. People call me -- they get
6 on my case for this. They get on my case for that, and you know, and I have been to psych hospitals and
7 I have been threatened, once they find out I'm Jewish, you know, and I think what the state really needs
8 to make groups, like, either a Butler Hospital or make groups for people who are -- who have been

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10 Healthcare: Behavioral
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victims, you know and not spend another cent on recovering drug and alcoholics, because you know, like I said, they did that to themselves. They don't need any sympathy. You know, so I would encourage the state to really

12 make groups of people, who have not been (inaudible) good people help. I have always helped people.
13 I'm always a person who is able to help and helps people, goes all out of his way to (inaudible), you
14 know. Anybody has a problem, I'll listen to them. I'll be their friend. I'll be -- they all say, I should have
15 been a psychiatrist. You know, I know how to listen better -- my mother's boyfriend said that. He doesn't
16 listen to anybody. So you know, I know how that feels, but you know, I think the money is miss-spent in
17 this state and in this country. I think people, there should be more groups. I go to groups, but people
18 there, are, you know, and even the people there, because there's a lot of people in the groups that have a
19 lot of problems, and you know, a lot of them they talk (inaudible) the whole time, so the time isn't spent
20 well. People don't get to speak about their problems, because there's one person monopolizing the
21 conversation, so I think there should be more groups, and you know, Providence Center should make
22 groups at night or something or Butler Hospital should have groups at night. People have been victims.
23 People who are, you know, really have been victims and make it special for racial views or anti-Semitism
24 or things like that, and really, you know, things that people could get help on. I think I have whatever --
25 my mother is 80, 90 years old. I have no family in town, and I don't know where to get the help that I
26 need, because there is really no group for me. I always mind my own business, but I've always seen
27 people -- maybe I'm a big guy. You know, the bigger they are, the harder they fall. I have heard that
28 expression many times, and people want to make trouble for me, and I don't know why, because I always
29 try to mind my own business, but you should really look into groups for people that need the help and that
30 have been victims and just try to help them to get by, because I think with proper help, they can get jobs,
31 and also, the thing is, the Providence Center doesn't really -- and places like the Providence Center, like,

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23 Employment: Job Training
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Butler Hospital, they really push medication. They're not pushing jobs. They are not pushing going back to school. They're not pushing -- they don't push that, and I'm not saying you need -- but people need motivation.

35 People say, you know, we want you to -- eventually (inaudible) been two years (inaudible) young enough,
36 you can go to college. You can get a job. You can get off pills. You're going to get off of all of these things.
37 Get off of the roller coaster. They don't do that. I have been to Providence Center for years. And I did go
38 back to college when I was 28 and I got my masters and a bachelors. I worked for six years as a
39 professor in Cleveland, but I never heard anybody say that their job -- their case manager or their
40 psychiatrist or psychologist is pushing them to go back to school or get a job or something like that. It's
41 too bad. We push medication, but we don't push going back to school.

42 SPEAKER: Are you interested in getting a job?

43 CARY FIDENBAUM: Yes, I am.

44 SPEAKER: Okay. I'm from the Office of Rehab Services and I did bring some applications with me. They
45 are on that table over there.

46 CARY FIDENBAUM: I went to the ORS.

47 SPEAKER: Oh, yes, okay.

48 CARY FIDENBAUM: And I had a problem. The lady said -- I don't want to mention names, but she was
49 taking personal calls the whole time, and I asked -- I called to speak to the supervisor. The supervisor
50 never called me back, so that's just -

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- 1 JUDI DREW: I can tell you from personal experience, that I have students in my program that work at the
2 Providence Center that do, do vocational counseling -
- 3 CARY FIDENBAUM: Yes.
- 4 JUDI DREW: -- to help people get jobs, so I know that the Providence Center does have a vocational
5 program. It's very active. There's a lot of people in it.
- 6 CARY FIDENBAUM: Right.
- 7 JUDI DREW: So I guess what I'd like to do is encourage you to go back and talk to whoever you were
8 working with, and say, I know that you have a vocational program, would you link me up with it.
- 9 SPEAKER: I have a name of somebody there who works in the vocational program.
- 10 JUDI DREW: Me, too.
- 11 SPEAKER: (Inaudible)
- 12 JUDI DREW: Yes, I do, so -
- 13 SPEAKER: I can write the name down.
- 14 JUDI DREW: Do you want to come talk to him on a sidebar and give him the information.
- 15 SPEAKER: Now, or -
- 16 JUDI DREW: No, now, because it's almost quarter of 5:00.
- 17 SPEAKER: Okay.
- 18 JUDI DREW: So I don't want -
- 19 CARY FIDENBAUM: I mean, like I said, I think we have -- there should be more groups, also. Try to
20 encourage Rhode Island Center, Butler Hospital, Bradley. There are certain groups, there's groups for
21 OCD and ADHD, but there needs to be groups for more things.
- 22 JUDI DREW: Um-hum.
- 23 CARY FIDENBAUM: Groups, like, every night that a mental health (inaudible) go to every night.
- 24 JUDI DREW: Were you here when the gentleman from Oasis was talking?
- 25 CARY FIDENBAUM: No.
- 26 JUDI DREW: Do you know about Oasis on North Main Street?
- 27 CARY FIDENBAUM: I have gone there before, but people just kind of -- they just -- they don't (inaudible)
28 to the rules. They start talking and they just (inaudible) they are going off on tangents and they -
- 29 JUDI DREW: Okay.
- 30 CARY FIDENBAUM: -- nobody tells them to be quiet. It's frustrating, because I have gone and I have
31 never got -- they talk so much, I've never got my turn.
- 32 JUDI DREW: Okay. Okay. Well, I think you're raising some really important issues.
- 33 CARY FIDENBAUM: Yes.
- 34 JUDI DREW: And again, we are going to review the testimony
- 35 CARY FIDENBAUM: Okay.
- 36 JUDI DREW: And this is certainly feedback we can give to the providers. Okay.
- 37 SPEAKER: You can ask (inaudible) Providence Center.
- 38 CARY FIDENBAUM: Thank you.
- 39 JUDI DREW: Okay. You're welcome.
- 40 CARY FIDENBAUM: Thank you.
- 41 JUDI DREW: Thank you for being here.
- 42 SPEAKER: I will say that the mental health clinics are not providing a number of vocational services that
43 they have in the past.
- 44 JUDI DREW: That's true.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 CARY FIDENBAUM: Yes, they should.

2 SPEAKER: That could be one of the issues.

3 CARY FIDENBAUM: And if you want -

4 JUDI DREW: It's a funding issue.

5 SPEAKER DREW: It's a funding issue.

6 CARY FIDENBAUM: And if you want, I'm willing to lead groups. I am always willing to lead a group. I am
7 a trained (inaudible) to lead a peer -- I'm in training to be a peer counselor.

8 JUDI DREW: Are you?

9 CARY FIDENBAUM: Yes, and also, I'm training to lead groups that you have at various locations through
10 the city.

11 JUDI DREW: So then the suggestion that I would have for you, then Cary, is for you to talk to the
12 Providence Center and say, look, I'm trained as a peer specialist.

13 CARY FIDENBAUM: No, no, I'm not yet. I am just starting the classes.

14 JUDI DREW: Okay, once you're done, that could be a role that you could definitely have both at the
15 Providence Center and also at Oasis.

16 CARY FIDENBAUM: Right, I guess what I'm trying to say, there's people that need help in this city that
17 aren't getting it and I would like to advocate for them to get that.

18 JUDI DREW: Yup, thank you.

19 CARY FIDENBAUM: Thank you.

20 JUDI DREW: All right. Have a good evening.

21 CARY FIDENBAUM: You, too.

22 JUDI DREW: Okay. Paul and Joanne. Hi, I assume it was the two of you.

23 PAUL BENOIT: It's the two of us.

24 JUDI DREW: Because you came in together.

25 PAUL BENOIT: Yes.

26 JUDI DREW: Yes.

27 PAUL BENOIT: I'm sorry we came in late and missed some of it, but that's as soon as we could get here.

28 JUDI DREW: Okay. Could you please introduce yourselves and full name -- first names, last name and
29 where you're from?

30 PAUL BENOIT: Paul and Joanne Benoit. We're from Harrisville, Rhode Island. Okay. Joanne's voice is a
31 little weak, so she wanted me to do the talking, but she can do the color commentary, if I miss anything.

32 JUDI DREW: Okay.

33 PAUL BENOIT: But so Joanne had a stroke five years and three months ago, and she had many strokes
34 that are quite devastating, so it's a significant change to all of our lives. And she has many aftereffects
35 from that, certainly, (inaudible) is the one that's most obvious, but she has significant recurring pain,

36

Civil Rights: Accessible Directory

38

which of course, is not so obvious, but it effects lots of things that she
does. What we wanted to talk about, a little bit, was access. And I
guess there's a few things we'd like to revisit, though. First of all,
39 there are many places around that are quite accessible to wheelchair users, but you can't tell, because
40 they don't tell you unless you call or unless you have been there. So part of access, I think is letting
41 people know. I mean, can you imagine that you are accessible and nobody knew where the wheelchair
42 ramp was. Well, if you want to know to go to a restaurant, you actually have to call every restaurant and
43 ask them if there is accessibility, then you have to define it, because the person on the phone doesn't
44 really understand what accessibility means in your particular case, so you know, it's not - the places are
45 not accessible, because the information is not accessible, so access is information as well. And I would
46 propose some kind of crazy things, like, is anybody here from the Providence Journal? Okay. No. Why
47 not? Why aren't they interested in this subject? The Providence Journal runs some nice articles about --

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1 this is just an example, but they run a nice article about, here's this great restaurant, and here's the good
2 things that we ate and so on, and it cost this much, and this is how much the tip was. Why can't they say
3 at the end of that, this restaurant is fully accessible? It has a wheelchair ramp in the back. It has
4 accessible parking, but be careful, because there's no van accessible parking, and oh, by the way, they
5 don't have a family restroom, and if there was a standard description, and I'm not saying I'm qualified to
6 tell you what it should be, but if there was a standard description that always described the accessibility
7 of a place, like, a restaurant, and the Providence Journal said, we're going to put that in; after every one
8 of our reviews, we're going put that in there, because people should know, and the people are reading
9 this, who are not disabled, they will become more conscious of disability just by having that information.
10 Why not, every ad, in the Providence Journal? I'll pick on them, but why not, every ad, in the Providence
11 Journal have a little block that says, what the accessibility is of that particular facility. Make it standard, so
12 that it gets out. Kind of like curb cuts. You know, you can't do a road without a curb cut. Well, how about
13 you can't do an ad without a little piece on accessibility? Because access is information, not just
14 (inaudible).

15 SPEAKER: I work for the Rhode Island Department of Health, in an office of attorneys. I was originally
16 hired under the facility grant (inaudible) work that the (inaudible) center did give to the Rhode Island
17 Department of Health to create a facilities guide. Your feedback to accessible Rhode Island will be heard
18 loud and clear to add -- it's something to add to their accessibility guides, because not only do we have
19 an actual guide book, that you just keep in your glove compartment in your car to see, like, all right, what
20 is accessible; who has a bus line. You know, all the points of accessibility for each institution in Rhode
21 Island that you know, anything. Really everything and anything that you know, but they also have an on-
22 line source, too, to say, like, you guys are planning a night out and you want to walk; you can look right
23 on-line and you can say, you know, go on accessibilityri.com (inaudible) and find out which locations are
24 fully accessible and I think to your point, adding -- if they could add that piece of kind of a disability, like
25 for those looking for -- the accessibility location is, you know, on the east side of the building, facing the
26 parking lot, like, descriptions of where the (inaudible) are. Where the accessible handicap doors are.
27 Where the parking is. That would be a really nice thing for them to add, if they (inaudible) but we -

28 SPEAKER: They have some commentary, but it's not to that extent, but I think it could be beefed up a
29 little bit.

30 SPEAKER: I think it's -

31 SPEAKER: I do -

32 SPEAKER: (Inaudible)

33 SPEAKER: Yeah, yeah.

34 SPEAKER: Yes.

35 PAUL BENOIT: So since this is all valuable.

36 SPEAKER: Yes.

37 PAUL BENOIT: And (inaudible) our suggestion is, let's get it out there, a standard.

38 SPEAKER: Yes.

39 PAUL BENOIT: So it's not like those disabled people can go look up something. No, if they want to
40 (inaudible) information about our facility. We want to tell people about how accessible we are and there's
41 a standard way to do it, and people in Rhode Island will get used to the fact that these are important
42 pieces of information. This should be able to be done voluntarily by some organizations right in
43 Providence. They could do it voluntarily. And then there are some specific things about wheelchair and
44 restroom access that are also important. People don't understand restroom access. Oh, yes, we've got
45 restroom access. Check the box. Well, you know, there is restroom access and there's restroom access.
46 I need (inaudible), so we need a family restroom. The fact that they've got a stall in the ladies room
47 doesn't help us. You know other than the facility having to block off that restroom, because it's not fair to
48 the women going in and out, that there's a guy in there, so they have to block it off. (Inaudible) they have
49 to block off the restroom. That's not fair to anybody else, but knowing that there is a family restroom

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1 would be helpful and who should have a family restroom. How many of you have been to the Rhode
2 Island Convention Center for an event? Okay, is that handicapped accessible?

3 SPEAKER: No.

4 PAUL BENOIT: You know, they don't have a family restroom. They do not have a family restroom. More
5 than that, not only do they not have a family restroom, but the staff has
6 no idea that they don't have a family restroom. So we were there for an
7 event and we tried every restroom and eventually asked some people

Civil Rights: Family Restrooms

8 and eventually asked someone, and you know what, we finally found out; somebody directed us to the
9 nurse's station, where they have a nurse's room, kind in the Convention Center and they have a restroom
10 that's accessible that you could use, but nobody knows. So access, the theme here is that access is
11 information, not just a ramp.

12 SPEAKER: Um-hum.

13 PAUL BENOIT: What did I forget?

14 JOANNE BENOIT: (Inaudible)

15 PAUL BENOIT: Okay, good.

16 JOANNE BENOIT: Well done.

17 JUDI DREW: Thank you. That's really important testimony. You've offered some really wonderful ideas,
18 so thank you. We look forward to reviewing that.

19 PAUL BENOIT: Thank you. I appreciate you running these events and collecting this information. It's so
20 important, because so people with disabilities understand their disability, but most of us don't understand
21 everybody else's disability. And we need to take care of everybody's disabilities, and so your listening is
22 an important step in making that happen.

23 JUDI DREW: You weren't here for my introduction, so just so you know what the Commission does with
24 this information is we have a legislative committee that reviews -- they organize all the information and
25 then they review the testimony and then the Commission itself reviews the testimony and the Legislative
26 Committee makes recommendations to the full Commission about what pieces from the testimony should
27 go forward and we should work on for legislative agenda -

28 PAUL BENOIT: Um-hum.

29 JUDI DREW: -- for the coming year and then other information that may not be legislatively oriented, we
30 share with providers, like, the Brain Injury Association or ORS or the Federation for the Blind and the
31 Disability Law Center, so that if there's things that need to be taken care of, they can be.

32 PAUL BENOIT: Good.

33 JUDI DREW: So -

34 PAUL BENOIT: Good.

35 JUDI DREW: It's not going on deaf ears, is what I am saying.

36 PAUL BENOIT: (Inaudible) you got the Providence Journal and the Valley Breeze and all those other
37 folks added to the list, because there's things they could do voluntarily -

38 JUDI DREW: Um-hum.

39 PAUL BENOIT: -- that they might be happy to do. They don't know, either. There is a whole disability
40 thing. People don't know what they -

41 JUDI DREW: Yes. And that could be relatively easy for us to accomplish in the next year, so -

42 PAUL BENOIT: And you -

43 SPEAKER: I actually live -- I actually work with somebody whose husband works for the Journal now, so I
44 could mention it to her.

45 JUDI DREW: Okay.

46 SPEAKER: That could be an easy fix, I think, maybe.

47 JUDI DREW: It would be lovely.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 PAUL BENOIT: It would be fantastic and great PR. If there's something, like, it's in the food section of the
2 Journal every week, fantastic.

3 JUDI DREW: Yes.

4 PAUL BENOIT: How many people read that?

5 JUDI DREW: Yes, you are right.

6 SPEAKER: I really appreciated his comment about the family bathroom, though.

7 JUDI DREW: Um-hum. I'm sure you did.

8 SPEAKER: Because it is something, mean, I could think of numerous restaurants where it's not there,
9 and they do have a stall, but for anybody who needs to be in there -

10 (END OF FILE 4)

11 SPEAKER: -- that may not be of the same gender; it's an issue. It is. And you know, I have had to block
12 the bathroom, because you know, so, yes, I would love to see that pushed forward.

13 JUDI DREW: Me, too. Okay, we've heard testimony from everyone who has said that they would like to
14 testify. Is there anyone here left that would like to add? I know, Kelly, you want to say something, so is
15 there anyone else here who has not spoken yet, who would like to share -- no, okay, so Kelly, what would
16 you like to share?

17 KELLY RIBEIRO: Just quick. Someone was talking -- I don't remember who it was, but was talking about
18 going to ORS for job -- oh, it was that guy. So there is no help in the State
19 of Rhode Island for cognitive rehabilitation. I was referred to ORS and I
20 was -- previously, I was well educated, great job, then I got hurt, and
21 now, this is me. I was referred to a factory job, counting pieces. There is nowhere for someone that wants
22 to go back to their professional career. And I can't -- personally, I've been out of work, because of what
23 happened. I have nowhere to go to get help to get back to who I was or to fix the new me. I have nowhere
24 to go in the State of Rhode Island.

25 SPEAKER: How long ago was it that you worked with ORS?

26 KELLY RIBEIRO: About a year.

27 SPEAKER: Oh, just a year ago. I will say that I remember some years back when there were more
28 opportunities for persons with head injuries, and those kind of programs don't seem to be as available,
29 but I think that what we could do; I don't know, I don't want to ask you who you worked with or anything
30 like that.

31 KELLY RIBEIRO: No.

32 SPEAKER: But we do use job developers, who help our clients get placements, and even though you
33 have a very specific disability, you could be referred to a job placement person. You know, I think the
34 right placement person could assist you. You were probably evaluated, maybe; is that what you're talking
35 about first?

36 KELLY RIBEIRO: Well, I -

37 SPEAKER: They had you do some kind of evaluation first, right?

38 KELLY RIBEIRO: Yes.

39 SPEAKER: But after that, then there should be job development and placement services.

40 JUDI DREW: Kathy, why don't you and I speak with Kelly after we are done?

41 SPEAKER: Okay.

42 JUDI DREW: Okay. Because her situation may be different, and you might want to ask more questions.

43 SPEAKER: Yup.

44 JUDI DREW: And we shouldn't do it in an open hearing.

45 SPEAKER: Okay.

46 JUDI DREW: Yup. All right, so you can -- are you able to stay afterward?

47 KELLY RIBEIRO: Yes.

2017 Public Forums on the Concerns of People with Disabilities and their Families

1 JUDI DREW: And we can talk to you.

2 KELLY RIBEIRO: Um-hum.

3 JUDI DREW: Great.

4 SPEAKER: I have a quick question.

5 JUDI DREW: Yes.

6 SPEAKER: Is there any division that supports businesses filling out federal grants to establish additional
7 funds for job access for the disabled? I mean, there are federal
8 grants available, but researching them, they're, you know, 28
9 pages long, umpteen, umpteen -- you have to -- like, is there any
10 division within the state that actually says, hey, we would love to help you fill out this grant, so could you
11 employ people who are not employable right now?

Employment: Support for Business

12 JUDI DREW: You don't need a grant. You can -- you can -- Labor and Training, both the Labor and
13 Training -- Department of Labor and Training, any one of the netWORKri offices or ORS, you can work
14 with counselors there, who will certify an individual who has a disability to go to work and be trained, and
15 the employer is able to apply for a targeted job tax credit.

16 SPEAKER: But I'm even talking about those who are entrepreneurs who are starting businesses who
17 may say, hey, I have this great idea, but I have no money to start this. The tax credit is not going to help
18 without the funding to start the program.

19 JUDI DREW: Are you talking about non-disabled employers or employers with disabilities?

20 SPEAKER: Non-disabled.

21 JUDI DREW: Okay. Small Business Development Center. That is the only one I know of. If you were
22 talking about a minority owned business or a woman owned business or a business for a person who has
23 a disability, who wants to start a business, there are all kinds of ways that they can be assisted in getting
24 state and federal contracts and getting priority. And that's a route that a lot of folks will take.

25 PAUL BENOIT: I know your time is up. I just want to mention something about this, because I don't know
26 if you know about Walgreens Distribution Center in Connecticut, just north of Hartford. They built that
27 from the ground up to employ people with developmental disabilities.

28 JUDI DREW: Right.

29 PAUL BENOIT: And unlike workshops that you pay them three bucks an hour, these people make full
30 pay. The same pay as their non-developmental disability person next to them, and they did it by
31 developing the jobs and the job sites and developing the computer screens and touch screens, so that it
32 will work for them and it is fantastic. If you get a chance to go on a tour, you go there. It's fantastic and I'll
33 leave you with this one thing. A guy asked the plant manager, is there a lot of friction, because you know,
34 you've got people who have no disabilities who are working and other people who are disabled, who may
35 need more help? Do you ever have any difficulties? He said, absolutely not. He said this warehouse has
36 less friction than any other, because people love to help the other people. And it's just like a whole
37 different environment, so Walgreens Distribution Center is just north of Hartford, fantastic.

38 JUDI DREW: Great. The Walgreens organization is a member of the US Business Leadership Network
39 and that was one of the commitments they made as a partner -

40 PAUL BENOIT: Yes.

41 JUDI DREW: -- in the USBLN.

42 PAUL BENOIT: And the vice-president of distributions, his son was developmentally disabled.

43 JUDI DREW: Um-hum.

44 PAUL BENOIT: And he said we can do better.

45 JUDI DREW: Right.

46 PAUL BENOIT: And they built this thing from the ground up. And it's with no government help.

47 JUDI DREW: We need more people like that.

48 PAUL BENOIT: No government help.

2017 Public Forums on the Concerns of People with Disabilities and their Families

- 1 JUDI DREW: I'm sure they get government support from targeted jobs tax credits, though.
- 2 PAUL BENOIT: I don't know, because -
- 3 JUDI DREW: I doubt that they don't.
- 4 PAUL BENOIT: They pay them full freight and they have to do the full work, and they did force them to
5 put a bus line in there.
- 6 JUDI DREW: Yes, okay. Too bad we couldn't do more of that.
- 7 PAUL BENOIT: Why not?
- 8 JUDI DREW: All right. At this point, it's after 5:00. We thank you all for being here and thank you for your
9 testimony, and thank you for participating. Sarah, please don't leave.

2017 Public Forums on the Concerns of People with Disabilities and their Families

Index

Civil Rights

- Accessible Directory, 76
- Automatic Doors, 30, 53
- Family Restrooms, 13, 78
- Interaction with Police, 66, 67, 70
- Parental Rights, 5, 7
- Restrooms, 31

Education

- Communication Access, 5, 8, 54
- Inaccessible Text Books, 7
- Inclusion, 32

Employment

- Competitive, 54
- Consent Decree, 54
- Job Placement, 8, 20, 27, 33, 79
- Job Training, 74
- Loss of Benefits, 37
- Social Security Disability, 71, 73
- Support for Business, 80
- Temporary Jobs, 54

Healthcare

- Behavioral, 74
- Durable Medical Equipment, 12
- Home and Community Based Care, 14, 51, 69
- Medicaid, 35
- PANDIS, 65, 66
- Training, 52
- Traumatic Brain Injury, 33, 40, 41, 45, 61, 62, 68

Housing

- Accessible, 13, 71
- Affordable, 11, 18, 71
- Modifications, 18
- Multiple Chemical Sensitivity, 54, 70
- Shared Living Arrangements, 55
- Substance Use, 73

Human Services

- Applications, 38, 64
- Caregiver Supports, 34
- Child Care Assistance.
- Evaluation, 22, 23, 33
- Low Wages, 55
- Resources, 17, 47

Independent Living

- ABLE Account, 23
- Peer Support, 48, 57, 59
- Personal Care Assistance, 20
- Supports, 22
- Transition, 11, 27, 32, 40, 42, 55, 63

Transportation

- Auto Excise Tax, 29
- LogistiCare, 24, 55
- Parking, 27, 28, 59
- Pedestrians, 10, 12, 13, 14, 30
- Ride, 6, 7, 8, 26, 59, 60
- RIPTA, 7, 30
- Travel Training, 27
- Uber & Lyft, 28