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STATE OF CONNECTICUT
DEPARTMENT OF DEVELOPMENTAL SERVICES

Re: Public Comment on Draft DDS Five-Year Plan
(2017-2022)

Public Hearing Held at the
Legislative Office Building, Rooms 1A and 1D,
300 Capitol Ave, Hartford, Connecticut,
on December 6, 2016, beginning at 10:00 a.m.

Held Before:

MORNA A. MURRAY, COMMISSIONER
Hearing Officer

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Simsbury, Connecticut 06070
860.651.0258
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APPEARANCES:

For Connecticut Department of Developmental
Services:

- Elisa Velardo
- Peter Tolisano
- Joshua D. Scalora
- Sarah Cook
- Kathryn Rock-Burns
- Christine Pollio Cooney
- Peter Mason
- Cres Secchiaroli
- Jordan A. Scheff
- Eugene Harvey
- Siobhan Morgan
- Robin K. Wood
- Daniel A. Micari

1 (Hearing commenced: 10:00 a.m.)

2

3 MS. MURRAY: Good morning, everyone. Is
4 everyone ready to get started?

5 I am Morna Murray, Commissioner at DDS.
6 I want to welcome you here, and thank you for
7 being here this morning.

8 Before we begin, I would like to ask our
9 staff here at DDS to introduce themselves
10 starting with Eugene -- I'm sorry, starting
11 with Rod.

12 MR. O'CONNOR: Rod O'Connor, Legislative
13 Liaison.

14 MR. HARVEY: Eugene Harvey, Director of
15 Southbury Training School.

16 MR. SCHEFF: Jordan Scheff, Deputy
17 Commissioner.

18 MR. SECCHIAROLI: Cres Secchiaroli,
19 Fiscal Administrator.

20 MR. MASON: Peter Mason, Director of the
21 Operations Center.

22 MS. COONEY: Christine Pollio Cooney,
23 Legislative Affairs.

24 MS. ROCK-BURNS: Katie Rock-Burns, Chief
25 of Staff.

1 MS. COOK: Sarah Cook, Acting HR
2 Administrator.

3 MR. SCALORA: Joshua Scalora,
4 Organization Development Manager.

5 MR. TOLISANO: Good morning. Peter
6 Tolisano, Director of Psychology.

7 MS. VELARDO: Elisa Velardo, Regional
8 Director.

9 MS. MURRAY: Thank you.

10 I am going to just make some very, very
11 brief comments, because I know you're here to
12 give us important information from you. The
13 first thing, if anyone who wants to sign up
14 and hasn't, please see Rod. He has the
15 sign-up list.

16 A couple of details. This is a public
17 hearing, not a legislative hearing. We will
18 not be able to respond to anything that
19 you've said. First of all, it would take too
20 much time. And secondly, we're here to
21 listen to you and we're here to hopefully
22 just get comments about the five-year plan.
23 Because of the time constraints that we have
24 we would really appreciate you sticking to
25 that as a topic for this morning.

1 And please know that I will not be
2 responding, none of the staff will be
3 responding, not because we're not interested
4 in your comments, but because that is not the
5 purpose of this hearing. We want to hear
6 what you have to say. It will be
7 transcribed. We will be reading it and we
8 will have it on our website for other people
9 to look at.

10 On that note, please know that it will
11 be a public record, so make sure that if
12 there's anything you don't want on a public
13 record, you don't say it. There's another
14 hearing this afternoon. In case anyone
15 doesn't know, that begins at four o'clock.
16 It goes from four o'clock until
17 seven o'clock.

18 And then the only other thing I'll say
19 is that the five-year plan is still a work in
20 progress. That's why we're here. One of
21 the -- I will just note a few of our goals
22 with the five-year plan.

23 We're moving away from our traditional
24 legacy system with that and we are looking to
25 support self advocacy increasingly, and also

1 to maintain and enhance transparency of DDS
2 in all respects. But most importantly of
3 all, we are really looking to sustain
4 services over the years. I know that there's
5 a lot of competing interests when it comes to
6 this in terms of the budget that we have
7 right now, but just so that you understand
8 where we're coming from I wanted to mention
9 that.

10 So we're going to have three minutes per
11 person. We do have a buzzer, I apologize for
12 that. And that's the only way we can stay on
13 track and get everybody up who wants to
14 speak. So we're going to start, and number
15 one is Shelagh McClure.

16 SHELAGH McCLURE: Good morning. I'm
17 Shelagh McClure and I'm Chair of the Council
18 on Developmental Disabilities. And I just
19 wanted to comment on three issues which align
20 with the council's priorities, and those are
21 residential services, employment and
22 transportation.

23 We believe that Connecticut is still way
24 too reliant on its legacy institutional
25 system. And although you have stated in the

1 plan the intention to move away from that
2 reliance, there's really nothing in the plan
3 that indicates that intention in a way that's
4 meaningful in our view.

5 Recently the two regional centers were
6 closed, but the overwhelming majority of
7 those residents moved to other regional
8 centers. In our view, this was a wasted
9 opportunity and it was particularly
10 troubling, given that the stated intention
11 was to expand services.

12 Southbury Training School and the three
13 regional centers remain open, and the draft
14 plan provides no roadmap for closing. Even
15 though the census of Southbury is soon to
16 reach 200 residents, in which many people
17 consider sort of a tipping point for
18 institutional closing based on costs, our
19 council has called on the Governor and the
20 Legislature to close all state institutions
21 by 2020 and have presented that case over and
22 over again.

23 We believe for the cost of the
24 institutions, that we could serve all of
25 those residents and many people on our

1 residential waiting list for the same cost.
2 So we're looking for the department to lead
3 by putting a roadmap for closure in this
4 plan, and that we believe based on the best
5 practices as well as fiscal responsibility
6 would be something that ought to be in this
7 next plan.

8 We also support the privatization of
9 group homes, but we believe given this cost
10 savings that would be associated with those
11 privatizations, that there is an opportunity
12 for expansion of services for people on the
13 waiting list there, and we don't see that in
14 the plan either.

15 So one of the things that we really are
16 quite concerned about is we see nothing in
17 this five-year plan to deal with the
18 residential waiting list, and we believe that
19 that's a huge hole in this plan. We
20 understand the fiscal constraints that the
21 department faces, but there are opportunities
22 with the efficiencies with respect to
23 privatization and if there were institutional
24 closings.

25 Thank you.

1 There's other -- I'm going to submit
2 written testimony with other issues that
3 we're addressing.

4 Thank you very much.

5 MS. MURRAY: Thank you, Shelagh.

6 Next up, we have Tom Fiorentino.

7 TOM FIORENTINO: Thank you. I am Tom
8 Fiorentino, president of the ARC Connecticut
9 Board of Directors. As important, I'm the
10 father of a 26 year old with intellectual
11 disabilities with who lives with us at home.

12 I reviewed the plan in both capacities,
13 parent and board chair, board president. I
14 saw nothing in there that gives me any hope
15 for my son in the future in this five-year
16 plan, because as Shelagh mentioned -- and she
17 is my wife, so I don't have to say this, but,
18 hey, it doesn't hurt -- the residential
19 waiting list is not addressed.

20 I thought of coming in here and just
21 blasting this plan, but I know that there are
22 people here who know this plan has
23 deficiencies and who want to serve these
24 people. So with that in mind, I think the
25 first thing that has to happen is you need to

1 have in your plan something that says, when
2 you come up with more efficient ways to
3 deliver services you retain those savings to
4 expand services. That those savings can not
5 go back to the general fund when there are so
6 many people in need.

7 I realize this will make some people
8 unhappy, but part of leadership is sometimes
9 making people unhappy. And without your
10 ability to use already appropriated funds --
11 and we all go to those hearings and we beg
12 the Legislature to put them in, and then five
13 minutes later they're getting cut and they're
14 going to other purposes.

15 Any plan has to allow you when you are
16 efficient and you are creating more
17 integrated into-the-community placements to
18 retain those savings to serve more people --
19 part of that, by the way, can be used not
20 just to create more services, but in your
21 private, in your community providers where so
22 many people work and where over 90 percent of
23 your services are delivered. Their wages
24 need to be raised to a living wage where both
25 they can afford to provide the vital services

1 they provide and their employers are not in
2 this constant state of instability with
3 people leaving because they're unable to pay
4 people what they're worth.

5 So I also would say that I agree with
6 what Shelagh said. There's nothing in your
7 plan that talks about institutions. I think
8 the handwriting is on the wall about that,
9 but you would think that the plan would
10 mention, what is the plan for closing the
11 remaining institutions?

12 Hopefully the money saved will be
13 retained and used in the system, including if
14 there's any sale of the property or other
15 assets that that money is retained to serve
16 more people in the system and to make your
17 entire system viable by elevating the people
18 that work in it, while at the same time
19 expanding services.

20 I just want to say one of the things I
21 found missing in this that's so vital is,
22 there's nothing that gives our community
23 hope. There's no way forward. It's more a
24 document that explains why there is
25 retrenchment. It explains that we're going

1 to try and do things better, but really
2 doesn't hold out anything to people that
3 says, there's a better way forward. That's
4 part of your job, too, and I'd like to see
5 that in the plan.

6 Thank you.

7 MS. MURRAY: Thank you, Tom.

8 Next we have Sandra Peloquin. Is that
9 correct?

10 SANDRA PELOQUIN: Hi. My name is Sandra
11 Peloquin. I have three siblings who live at
12 home, with my husband and myself, who are all
13 developmentally disabled. They are 69, 71
14 and 74 years old. I have chosen to keep them
15 at home with myself and my husband, and their
16 ages bring additional needs and medical
17 attention.

18 This is not something that everyone is
19 capable of doing. The DDS plan, the
20 five-year plan pushes the expectations that
21 everyone will be able to care for their loved
22 ones at home without providing additional
23 funding for supports that makes this
24 manageable.

25 Because the homecare model saves the

1 State money in the long run they should be
2 investing in more funds for services and
3 supports for families that have chosen this
4 path, rather than neglecting it.

5 DDS must understand the full effects of
6 the cuts to service budgets, such as the cuts
7 to the consumers' activity fees for outings.
8 Not all -- not everyone can afford to pay for
9 activities to keep their adult loved ones
10 occupied at home. Everyone deserves to have
11 a fulfilling life, not matter weather they're
12 cared for in a group home setting, or a home
13 with their family.

14 The people who care for my siblings work
15 physically demanding jobs that put their
16 safety at risk. They deserve to be protected
17 by workers' comp insurance, which is paid for
18 through the consumers' budget. About \$5,000
19 of the annual budget goes to workers' comp
20 insurance. However, if there was a group
21 insurance plan it would only cost hundreds a
22 year, which would free up funds for more
23 hours of service or activities for the
24 consumer.

25 Because I don't have workers at night I

1 have to wake up to toilet my siblings, or
2 tend to other needs. As I get older this is
3 becoming more difficult for myself. If I had
4 more funds available I wouldn't have to put
5 myself at risk to do this. Please do not
6 forget individuals and their families in
7 homecare settings when drafting the final
8 five-year plan.

9 Thank you.

10 MS. MURRAY: Thank you, Sandra.

11 Next up is David Pickus.

12 DAVE PICKUS: Good morning,
13 Commissioner. My name is Dave Pickus and I'm
14 the President of District 1199, New England
15 SEIU. We represent 26,000 healthcare workers
16 in Connecticut.

17 10,000 of our members provide care to
18 the Department of Developmental Services as
19 public employees, private agency workers and
20 homecare workers. 1199 is a major
21 stakeholder at DDS in how these services are
22 delivered. At 1199 we are uniquely
23 positioned to speak about issues facing DDS
24 because we represent workers in both the
25 public and the private sector. Many of the

1 people from the industry you will be hearing
2 from today are exclusively from one or the
3 other.

4 And for the last 15 years DDS has failed
5 to develop a coherent plan of action for the
6 clients and its charge. There's been an
7 haphazard approach to deinstitutionalization
8 and privatization of group homes. The
9 private sector has been grossly underfunded,
10 and the refusal to address the State's
11 growing waiting list is unconscionable.

12 DDS must stop using the waiting list
13 crisis as a political football. Promising
14 desperate parents that all their hopes lie in
15 closing certain homes or laying off certain
16 workers is not a plan. Expanding programs
17 and funding services for those on the waiting
18 list should be a top priority of this
19 department.

20 In a study partnered by the University
21 of California Berkeley and University of
22 Connecticut found that low-wage workers in
23 our state access \$486 million in public
24 assistance annually. That amount is almost a
25 third of our total projected budget deficit.

1 And as I mentioned, we represent workers in
2 the private and public sector, and we know
3 that these workers are among the low-wage
4 workers seeking public assistance, those in
5 the private sector in home care, because
6 their 11 or 12-dollar an hour job is not
7 enough to make ends meet.

8 Our State's solution to the budget
9 deficit should not be turning middle-class
10 payers into working poor. If we are serious
11 about providing quality care to people with
12 disabilities, then you have to be serious
13 about providing the proper funding to pay a
14 living wage to these workers, otherwise we
15 increase the number of working poor, the cost
16 of public assistance increases and high
17 turnover causes lower quality care for
18 clients.

19 DDS employs 2500 employees and there's a
20 unique opportunity to build toward the future
21 needs of people with disabilities. Last year
22 1199 proposed a thoughtful policy approach to
23 the current budget challenges and needs of
24 DDS. We maintained that public/private
25 system must be continued and improved upon.

1 Similar to DMHS, the plan found ways to
2 utilize the trained workforce DDS is already
3 invested in, while helping to get services to
4 those desperately in need of it. I strongly
5 urge you to revisit and adopt the policies we
6 recommended last year.

7 Thank you.

8 MS. MURRAY: Thank you, David.

9 Next is Dorothy Fish.

10 DOROTHY FISH: Good morning, everyone.
11 My name is Dorothy Fish.

12 The five-year plan does not include any
13 language about maintaining services for the
14 very medically involved individuals who
15 reside in state regional centers and group
16 homes.

17 Our son is a client and resident at the
18 Hartford regional center. He is 48 years old
19 and needs a home with 24-hour nursing staff.
20 He is a brittle diabetic that requires four
21 insulin injections a day, and testing of his
22 blood sugar six times a day. This is only
23 one of his many medical issues. He is also
24 legally blind.

25 The staff is his family, giving him the

1 same excellent care that my husband and I
2 gave him for 32 years and can no longer do.
3 The staff is so aware of warning signs that
4 indicate that he is becoming hypoglycemic.
5 Some of these signs take years to recognize,
6 which they have developed. Besides our son
7 needing all this medical knowledge and care
8 given to him by the staff, they treat him as
9 if he was their son, a brother, or a family
10 member.

11 The private residential providers
12 licensed by DDS are not funded enough to
13 insure their workers are paid living wages
14 and benefits, resulting in a high turnover
15 rate that can ultimately drive the quality of
16 care down.

17 My son is happy, has endearing names for
18 each of the staff members. The staff members
19 at the Hartford regional center have been
20 with him for many years. Changing his home
21 and staff would be devastating to him.
22 Please consider my son and many others who
23 need a high level of care when drafting the
24 final five-year plan, and advocate for more
25 funding for DDS.

1 Thank you.

2 MS. MURRAY: Thank you.

3 Next we have Lindsay Matthews.

4 LINDSAY MATTHEWS: Good morning. Can
5 you hear me? I'm here to urge DDS to listen
6 to my story, to suspend cuts and to provide
7 quality care to all individuals with
8 disabilities in our state.

9 First, I want to thank the DDS workers
10 who have cared for my son for so many years
11 of his life. We can truly be proud of them.
12 I owe them a debt of gratitude I'll never be
13 able to pay. Thank you, guys.

14 I'm George Griffin's mother. My name is
15 Lindsay Matthews and I'm the mother who filed
16 the lawsuit against the Department of
17 Developmental Services, and defendants Morna
18 A. Murray and Thomas A. Dailey. In the
19 lawsuit I'm seeking an order barring DDS from
20 taking away George's professional state
21 caregivers' care and replacing them with
22 highly exploited, non-skilled substitutes who
23 are paid less than half the cost of living in
24 Connecticut.

25 These workers get infrequent raises, are

1 forced to live as paupers, while at the same
2 time living in the richest country in the
3 world in one of the richest states in the
4 country.

5 As the basis of my lawsuit I refused to
6 submit the HIPAA because I believe the
7 practice of using private medical information
8 for business purposes is unlawful. In fact,
9 in the course of the nonprofit shopping for
10 contracts with the State the only covered
11 entity that actually provides medical care is
12 the one that's finally chosen.

13 How did we get here? How did we get to
14 the point where there are very few resources
15 and importance given to funding the health
16 and well-being of those who cannot care for
17 themselves, those who cannot even speak? We
18 got here because our developmentally disabled
19 family members can't defend themselves.
20 They're easy to attack, to steal from, to
21 ignore. To some they're budget cuts, line
22 items, black numbers printed on a page.

23 It wasn't until I initiated a lawsuit
24 that a flood of confidential horror stories
25 about nonprofit care began to flood my way.

1 They came from parents, guardians and
2 siblings with families in nonprofit care.
3 The more media work I did, the more e-mails
4 and phonecalls I got.

5 Thank you for letting me talk today.

6 MS. MURRAY: Thank you.

7 Please understand, not to pick on
8 anyone, but every time we clap we loose some
9 time. So just keep that in mind. I don't
10 want to interrupt everyone.

11 Christine?

12 MS. COONEY: Before we move on to the
13 next speaker, we've secured an overflow room
14 because we can't have people standing in
15 front of the doors.

16 So we have Room 2B, as in boy, behind
17 the elevators is open. The sound is
18 streaming through. You can hear everything
19 that's going on. So we request that if you
20 don't have a seat, that you please move
21 upstairs into Room 2B and you should be able
22 to hear everything. We'll give it one minute
23 for everyone to get upstairs so you don't
24 miss anything.

25 Thank you so much. Again, that's 2B, as

1 in boy.

2 MS. MURRAY: All right. Thank you,
3 Christine.

4 I'll just call the next person so you'll
5 be ready, but we'll still wait a minute.
6 It's JoAnne Forman.

7 And if people could be conscious -- when
8 the doors open it is very loud in here and
9 distracting to the person who's speaking, so
10 if we could try to keep the doors shut, that
11 would be great.

12 Thank you.

13 JoANNE FORMAN: Thank you. Good
14 morning. My name is JoAnne Forman and I
15 reside at 110 Griswold Drive, West Hartford,
16 with my husband Jeffrey and 32-year-old
17 daughter Emily.

18 Emily a sweet and sensitive young lady.
19 She's a big UConn basketball fan and a master
20 of music trivia. She currently works at HARC
21 in their supported employment program for
22 which we're very grateful. If things
23 continue as they are with DDS, Emily will
24 live with us until we die, and then all that
25 she knows and is familiar with will turn

1 upside down overnight, something no one
2 should have to endure.

3 Despite being born with an intellectual
4 disability, Emily's life has been filled with
5 many advantages. The Town of West Hartford
6 has served her well both educationally and
7 socially. That level of support has changed
8 drastically since she turned 21. Emily has
9 had at least five different DDS caseworkers
10 in ten years. I never felt that there was
11 someone who was truly advocating for her.

12 Not that they weren't wonderful people
13 who had the best of intentions, and very
14 kind, but they were clearly overworked,
15 stressed out and really had very little to
16 offer, which I think was upsetting to them as
17 well, particularly in most recent years.

18 Emily has been on the waitlist to
19 nowhere for the past 14 years. If DDS had
20 been honest with the stakeholders ten years
21 ago we would have made different planning
22 decisions avoiding the mess we're in now.
23 But then again, that was then and here we are
24 now.

25 This five-year plan I think has good

1 points and some not so good points, but we
2 can't drag our feet any longer and change
3 needs to happen. That being said, here's
4 some of my concerns and questions.

5 First, the plan talks about increasing
6 employment opportunities for all supported
7 individuals. This is an excellent goal and I
8 think something we'd all agree with you, but
9 I have firsthand experience looking at what
10 HARC has had to deal with in terms of looking
11 for placements and job sites. That those are
12 not expanding, but to the contrary, are
13 diminishing. It's getting harder and harder,
14 I think, to find worksites for some of our
15 children. So I think we need to address
16 that.

17 Second, the plan does not address, as
18 others have said, concrete steps on how to
19 reduce the waitlist and provide residential
20 supports for individuals seeking such
21 assistance. As the plan states, we need to
22 develop efficiencies to serve more people.
23 Again, this needs to be a priority.

24 We've talked about Southbury Training
25 School where so much money is being spent for

1 very few people. There are hundreds of
2 people getting/receiving supports and
3 thousands receiving hardly anything.
4 Something needs to be addressed with that.

5 One way to achieve greater efficiency
6 and fairness is to look creatively at ways to
7 share or pool resources to meet the needs of
8 individuals. We've talked about that. There
9 might be ways of looking at residential sites
10 where someone with more needs can share staff
11 with someone with less needs, and that sort
12 of thing.

13 I talk with parents all the time, and
14 they're very willing to stay involved and
15 collaborate as long as DDS does their share.
16 We're not looking for a free handout. These
17 are our children. They're our obligation.
18 We need to take ownership for them, but this
19 is something you can't do alone. This is a
20 lifelong commitment.

21 If budgets are lean then I think the
22 department needs to be considerably more
23 efficient in doing business, which the plan
24 suggests, and if it's not lean enough we need
25 to advocate for more funds.

1 Thank you very much.

2 MS. MURRAY: Thank you. I really
3 appreciate everyone sticking to their time
4 periods. I know it's difficult.

5 Next, we have Jamie Whitman. Jamie?

6 JAMIE WHITMAN: This is a statement on
7 behalf of Mr. Robert Petitti, resident of
8 Leverage House, East Hartford, Connecticut.
9 My name is Jamie Whitman and I would like to
10 testify on what the DDS five-year plan is
11 lacking.

12 Bobby Petitti is my cousin. He has been
13 a resident of Leverage House, East Hartford,
14 for approximately three years. He is 27
15 years old, but has the intellectual capacity
16 approximately of a seven year old. For the
17 past three years he has been receiving
18 one-on-one care that has given stability to
19 his daily living, which has substantially
20 improved his quality of life.

21 However, in November Bobby received
22 notice that continuation of his services is
23 soon to be terminated. Not only is Bobby
24 going to lose his one-on-one care, his
25 funding is also going to be cut in half. In

1 addition, he is now expected to obtain a job
2 for a minimum of 30 hours per week.

3 Bobby has a history when feeling
4 overwhelmed of becoming violent, throwing
5 punches, kicking, leading to the need for
6 restraints and/or running away. It is self
7 defeating for the State to cut his services.
8 Ultimately it will cost the State more money
9 if they cut his services, because Bobby will
10 become, what we call in nursing, a frequent
11 flyer in the emergency room. I know this
12 because of his past history.

13 If Bobby has a meltdown 20 times each
14 month at a minimum cost of \$5,000 per ER
15 visit, the State will be billed 100,000
16 dollars each month or 1,200,000 in just one
17 year. Without his one-on-one care Bobby will
18 revert to the scared, out-of-control, angry,
19 frustrated and violent person he was prior to
20 receiving one-on-one care. The State has the
21 obligation to keep Bobby safe. Instead he
22 will become a danger to himself and others.

23 Additionally, while Bobby is at the ER
24 his group home will be left short staffed
25 because staff will need to be with him at the

1 ER. How can it be that the people,
2 especially DDS and DSS, the experts, who
3 exist to help and advocate for Bobby are the
4 very ones sending him to his doom?

5 Surely you know in your heart of hearts
6 that if you cut Bobby's services you are
7 abandoning him and failing him miserably.
8 The message you are sending is that the
9 people who are developmentally challenged are
10 expendable.

11 Janet Storz, Bobby's mom, has been told
12 that the reason Bobby is losing his services
13 is because he's doing so well. The State is
14 not being honest here. These cuts in
15 services have nothing to do with Bobby doing
16 so well, when instead has everything to do
17 with state budget cuts and their
18 privatization.

19 The State wants to deceive us into
20 thinking that these cuts and privatization
21 are changes that will actually benefit our
22 loved ones. Do not take us for fools.
23 Clearly, if anyone should continue to receive
24 state funding it is the developmentally
25 challenged. It is your job to fight for

1 those who cannot fight for themselves, not
2 turn your back on them.

3 It is a shame that the very organization
4 that families count on and trust to advocate
5 for their loved ones is the same organization
6 now pushing for these cuts. You forget that
7 your first obligation is to those who cannot
8 fight for themselves. Losing these services
9 will be devastating for Bobby.

10 Know that we as Bobby's family are in
11 this for the long haul. We will continue to
12 fight to maintain his services. Please do
13 not continue down this path of doing less
14 with more and accepting Governor Malloy's new
15 economic reality where the quality and amount
16 of DDS services are going to be reduced for
17 all of Connecticut's developmentally
18 disabled. Please include advocating for more
19 funding in the five-year plan.

20 Thank you.

21 MS. MURRAY: Okay. Next up, we have --
22 I apologize if I'm not reading this
23 correctly -- Leibert Lewis.

24 LEIBERT LEWIN: Lewin. Good morning one
25 and all, family members. My name is Leibert

1 Lewin and I have been working at ARC for the
2 last 14 years. I am a direct care worker
3 with participants who have developmental
4 disabilities.

5 I love my job, but I cannot work just
6 one job to take care of the needs of me and
7 my family. After 14 years I only make 12.25
8 an hour. In reality our agents, most of the
9 coworkers make only 11.55. They also do not
10 usually make it to 14 years.

11 As much as we love our work, we do make
12 ends meet on such low wages. That means we
13 experience high turnover rates, usually work
14 short, short shifts. Not only do we as staff
15 suffer because more of our burdens falls on
16 us, it also means our participants suffer
17 because we do not have the resource to take
18 care of their need to the level we would like
19 to, and that they deserve.

20 Our field has just flat funding for
21 years, and that experience cuts in various
22 areas. One place I have personally
23 experienced the cuts in our agency is the
24 respite and recreation department. Both of
25 those departments provide service for

1 participants who have residential placement.
2 That means those folks live at home with
3 their family or guardian, and comes to us so
4 their family and guardians take care of other
5 needs -- are participants in activities that
6 may not get to be involved in otherwise.
7 Cutting this budget means that those
8 participants lose out on being able to
9 socialize with their peers. Their families
10 have no time to be able to take care of them
11 on their own.

12 This isn't fair for anyone. If DDS
13 continues to close down public sectors
14 programs and increase our workload, but do
15 not increase private sector funding, that
16 things will only get worse. We are already
17 short staffed and unable to meet the needs of
18 people who we serve. We cannot take an
19 additional participant -- but not have the
20 proper funding to do so.

21 Flat funding or decreased funding is not
22 the answer. Increase the funding, is the
23 solution. The State cannot continue to
24 balance a budget on the backs of the workers,
25 our most valuable resident in the state.

1 Behind me here I can see a lot of
2 families, that I've worked with their loved
3 ones for here. They may not know me, but I'm
4 telling you guys, I'm in there for the long
5 haul and I'll keep doing what I'm doing until
6 we make an agreement.

7 Thank you.

8 MS. MURRAY: Thank you.

9 Just a reminder, if people can try to
10 pay attention to the buzzer. I hate to
11 interrupt people. I know you have many
12 important things to say, but if you could
13 just try as much as you can to respect the
14 needs of other people to speak this morning?

15 And I notice that there are different
16 members of our General Assembly who have come
17 in and out of this hearing. So I want to
18 thank them for being here this morning and
19 for your interest and concern for all of the
20 issues before us.

21 So next we have Carol Lasch. And after
22 that will be James Schmidtt, if you could
23 just be on deck?

24 CAROL LASCH: Good morning, all. My
25 name is Carol Lasch and I'm a group home

1 worker from Whole Life. I also am a member
2 of 1199.

3 I've worked for Whole Life over nine
4 years. I love the work I do and feel proud
5 of the care that myself and my coworkers
6 provide for our residents, however due to the
7 lack of funding we are consistently
8 understaffed. The understaffing at our group
9 homes create an unsafe environment for our
10 residents and ourselves. It undercuts our
11 ability to give them the support that they
12 need.

13 We often end up working without the
14 necessary number of workers on shift. This
15 creates an unsafe situation for both
16 residents and staff. We are unable to take
17 our residents out on outings that they
18 deserve. We have behavioral residents and
19 sometimes they need more than one person on
20 shift to be able to care for them, but due to
21 understaffing we work alone a lot.

22 Sometimes when we are short staffed we
23 end up having to put our residents in their
24 rooms to keep them safe from each other.
25 This is unfair for our residents and unsafe

1 for them and us. We often have spoken to
2 management about the dangerous conditions
3 that understaffing causes, but they are
4 unable to change it because of funding.

5 I'm a healthcare worker who can't afford
6 healthcare. I haven't gotten a
7 cost-of-living raise for the whole nine years
8 that I've worked at Whole Life. Like most of
9 my workers, I work a second job in the field
10 to be able to makes ends meet. I often end
11 up working 80 hours a week. Some of my
12 coworkers have to work three or four jobs
13 just to support their families. This isn't
14 fair for us or the people that we take care
15 of and serve.

16 Many of my coworkers have been at our
17 agency for as long as I have, or more. When
18 we retire who will take care of our clients?
19 The entry wages are so low that our agency
20 has a very high turnover rate. Our clients
21 deserve a stable workforce. If the budget
22 for DDS is cut more over the next five years
23 we the workers will suffer, but our residents
24 will suffer more.

25 I am here today to tell DDS that we need

1 full funding for all the services we provide,
2 whether in the public or private sector. All
3 of our residents deserve to live in homes
4 that are adequately funded and staffed, and
5 all of us who care for them deserve to be
6 paid a living wage.

7 Thank you very much for letting me
8 speak.

9 MS. MURRAY: Thank you.

10 James, and then you have Teresa
11 Rostkowski.

12 JAMES SCHMIDTT: Good morning. My name
13 is James Schmidtt. I'm the father of twin
14 nonverbal autistic boys named RJ and Gunner.
15 In the 17 years since they were diagnosed DDS
16 programs have been critical to the stability
17 of our family life.

18 Our first introduction to DDS programs
19 was the use of the John Dempsey Respite
20 Center in Putnam for both boys one weekend
21 per quarter. This provided our boys with a
22 safe environment with specially trained
23 staff.

24 Gunner was introduced into the VFP
25 program, now known as the BSP program, on

1 October 11, 2006, when we were unable to
2 maintain his safety due to his escalating
3 behaviors common with severely autistic
4 children. Even after securing our house with
5 locks and alarms, Gunner has been able to
6 escape from his home. He requires direct
7 line-of-sight supervision at all times. Due
8 to the VFP program Gunner received further
9 treatment at the Lakeview Neurorehabilitation
10 Center in New Hampshire for two months when
11 his behaviors were unmanageable for his home
12 environment.

13 RJ was added to the BSP program on
14 February 21, 2012. This program allowed the
15 hiring of personal support individuals that
16 provide a safe environment in RJ and Gunner's
17 home setting, as well as help them with the
18 activities of daily life and to participate
19 in their community.

20 My boys currently attend River Street
21 School in Windsor. And as they will age out
22 in a year and a half, my wife and I are
23 extremely concerned how we will care for them
24 as we continue to age. My boys will always
25 require 24-hour care.

1 DDS services have been and are essential
2 to my family maintaining our family unit.
3 Although it does not exist anymore, the John
4 Dempsey Center and its staff were a valuable
5 resource to our family from 2000 to 2013.
6 These centers and group homes need long-term
7 staff because special-needs persons require
8 skilled and consistent care. The workers
9 need to make a livable wage so they can focus
10 on one important job, taking care of our
11 residents.

12 The State looks to save money through
13 privatization, and vital services like music
14 and speech therapies are reduced, or
15 sometimes outright eliminated. There isn't
16 even any guarantee that the future cost
17 savings will be reinvested into the homes and
18 services to allow more people to benefit from
19 the program who are currently on the waiting
20 list, or those who will soon be added to it.
21 There shouldn't even be a waiting list.
22 These families now are in crisis. They can't
23 wait. I know.

24 In closing, I'm just concerned with the
25 rolling over of the budget and not increasing

1 it, because the demand for services are
2 growing and the current demand will not be
3 met by DDS.

4 Thank you.

5 MS. MURRAY: Thank you very much.

6 Teresa, and then Maria Baroncini.

7 TERESA ROSTKOWSKI: Good morning. My
8 name is Teresa Rostkowski. I have a
9 34-year-old daughter with down syndrome.

10 And actually, unlike a lot of these
11 testimonies that we've heard, she's rather
12 high functioning and she's very bubbly and a
13 nice individual. However, she can't take
14 care of herself on a daily basis and live
15 alone. And because she does seem to be on
16 the better spectrum there are no provisions
17 for somebody like her, and I'm afraid people
18 like her will fall through the cracks.

19 We'll take care of her as long as we
20 can, but then what? I mean, she's very
21 vulnerable. She's very trusting and wants
22 attention very badly, and that attention can
23 really have bad consequences.

24 So as you do your budgets, please don't
25 let these individuals fall through the

1 cracks. That's all I have to say.

2 MS. MURRAY: Thank you.

3 Maria, and then Dawn DiNoto.

4 MARIA BARONCINI: My name is Maria
5 Baroncini, and my sister Rebecca Lobby
6 currently lives in a state-run group home in
7 Cheshire. I'd like to talk about what I find
8 is missing from the five-year plan.

9 Becky has cerebral palsy and is
10 intellectually disabled. She's funny and
11 smart and beautiful and strong. She's
12 nonverbal, so I thank you for allowing me to
13 be her voice today.

14 A little over 20 years ago after a
15 marked increase in aggressive and dangerous
16 behaviors forced an emergency placement. My
17 sister went to live at what would become her
18 home, Pondview Group Home under the
19 professional caring client-centric and loving
20 supervision of the group home manager and
21 staff. I remember very clearly the day we
22 brought Becky to Pondview to begin a new
23 chapter in her life. We were scared to go.

24 Both my parents, Cliff and Ester Lobby,
25 who are here today, and I drove her out to

1 Cheshire from our hometown of Southbury. The
2 home was clean and organized, the staff
3 friendly, and from what all we could see, the
4 professionalism with which the staff carried
5 themselves gave us every reason to believe
6 she would be cared for properly and treated
7 with dignity and respect. Those
8 preconceptions would prove themselves true as
9 the years went by and Becky became a
10 permanent part of this new home, as she
11 became a friend, a family member and loved
12 one.

13 In my opinion, as the State protects the
14 best interests of a child before them in a
15 child custody case, so should the State
16 protect the best interests of the
17 developmentally disabled. To risk them
18 losing their current families, their
19 coresidents who have become siblings, their
20 staff who have become parent figures would
21 not be in their best interest.

22 To do so would set them back years in
23 adjustment and emotional and physical
24 stability. To do so would cause a disruption
25 in their lives so great it would take, in my

1 sister's case, years to repair. To do so
2 would knowingly and willing risk the breakup
3 both physically and emotionally of a family.

4 I'm not naive to the plight of the State
5 of Connecticut's economy. I read the
6 five-year plan and I understand the potential
7 cost savings in relation to privatization,
8 but no matter the outcome, whether I decided
9 to keep my sister in her home, or hand her
10 over to an unknown private agency, Becky's
11 safety and well-being must be protected.
12 Should it come to privatization we need to
13 know that the staff will be qualified, that
14 the agency coming will be equipped to care
15 for my sister's needs.

16 We need to know what hourly wage the
17 home will be put out to bid for. We need to
18 be assured that if the disastrous decision is
19 made to hand her over to their care, to an
20 entirely new entity, that these homes will be
21 put out to bid in a manner that will attract
22 trained, experienced staff who will want to
23 stay for the long haul, staff who can because
24 they can make a living by doing so. They'll
25 be dedicated to their jobs and the people

1 they care for.

2 The best interests of those we love must
3 be protected, those who cannot speak for
4 themselves, the best interests of those who
5 are often forgotten and looked over need to
6 be protected. It's very simple. It's their
7 right.

8 MS. MURRAY: Dawn DiNoto, and then next
9 we have Gaetano Taccone.

10 DAWN DiNOTO: I'm going to begin with a
11 quote from the DDS website. People with
12 disabilities want the same thing as anyone
13 else. Like most people, they hope to live a
14 long, healthy, productive and happy life.
15 When they look back they want to know that
16 they were respected and valued in their
17 community for their unique characteristics.
18 In contributions to their community, they
19 want varied activities and they want
20 organized involvement.

21 So these are the words that were
22 captured in the DDS vision five years ago.
23 The initial focus of this plan for the coming
24 five years begins this way, however we need
25 to talk about how to assist people with

1 disabilities to live the vision DDS set out
2 to begin with.

3 There are ways that we can still reach
4 out to families and individuals with
5 disabilities to support them, regardless of
6 the budget, in creative, innovative ways. We
7 need to find ways to support them.

8 They celebrate diversity in such a way
9 that it's important for us to honor them.
10 When DDS refers to the paradigm shift at the
11 end of this five-year plan packet, I say that
12 is where we need to start, not end.

13 In all cases an individual can have
14 emotional, physical, medical and cognitive
15 challenges not limited to a category for a
16 primary disability, such as intellectual
17 disability based on IQ. IQ is no longer a
18 research-based supported methodology and DDS
19 must come to terms with this as it creates a
20 significant discriminatory factor.

21 Consider those families with individuals
22 like my daughter, Anisa, who has multiple
23 challenges, and that coexist in often
24 unpredictable ways in her life, all of which
25 are valid and all of which must be considered

1 in her planning.

2 I hope that the self-directed model
3 would provide me with the options to do this
4 for Anisa. I am grateful for the budget I
5 ready and willing to put my all into being
6 creative and flexible, training a
7 self-directed staff and looking for community
8 resources.

9 It is my hope that this paradigm shift
10 will include the following, provide waiver
11 options for self-directed care providers that
12 include those listed under the autism waiver
13 for those individuals who have coexisting
14 autism and mental health challenges; provide
15 continuity rate of compensation for staff in
16 conjunction with the level of need of the
17 individual, so that if we are able to seek
18 additional support services through some DSS
19 programs, through Community First Choice,
20 that we can maintain our trained, consistent
21 and familiar staff.

22 I would like to close by asking that we
23 revisit the term stakeholders, and that we
24 become more specified in the five-year plan
25 to be able to say which of those areas that

1 you are asking the families to be supportive
2 of, and what is the responsibility of the
3 Department of Developmental, and Department
4 of Social Services.

5 I would appreciate consideration for the
6 written statement that I've submitted and I
7 would like to open better communication for
8 those families who are not able to access the
9 autism waiver that's on the website that's
10 not accessible to individuals based on IQ.

11 Thank you.

12 MS. MURRAY: Thank you.

13 Just a reminder that we do have an
14 overflow room in 2B where you can see and
15 hear everything that's going on here.

16 Gaetano is next, and after that we have
17 Fred Hyde.

18 GAETANO TACCONE: Good morning. My name
19 is Gaetano Taccone. I am the father of twin
20 daughters 35 years of age who have been
21 mentally challenged since birth. I realize
22 it took a lot of effort to draft a five-year
23 plan. Thanks to all involved for this great
24 undertaking.

25 However, the to-do-more-with-less policy

1 which created this increasing insurmountable
2 backlog of services and supports for our most
3 vulnerable residents is failing. Sharing
4 responsibility with departments with similar
5 difficulties without resolving the inherent
6 issues is just another way of passing the
7 buck.

8 The phrase, within available
9 appropriations, was repeatedly used
10 throughout the plan. Although I get it, past
11 experience shows that this is the doorway
12 that funding supports and services walk
13 through, and our disabled pay the price.

14 I feel that one phrase in the plan on
15 page 20, the second paragraph, describes the
16 reality I have through the DDS. I quote, DDS
17 needs the full engagement and participation
18 of all stakeholders to complete this work,
19 and we value all partners willing to develop
20 and change with us.

21 The keywords are -- as far as I'm
22 concerned -- is, partners willing to develop
23 and change with us. I can only assume that
24 DDS values partners willing to do things
25 their way. It seems that DDS has

1 transitioned from smoke and mirrors to a
2 shell game.

3 Thank you for the opportunity to express
4 my opinion. Thank you.

5 MS. MURRAY: Thank you. Fred Hyde and
6 then Abu Bakr, I believe. Again, I apologize
7 if I'm mispronouncing anything.

8 FRED HYDE: Good morning, Commissioner,
9 members of the staff, ladies and gentlemen.
10 My name is Fred Hyde. I'm a consultant in
11 the health field, and teach in this field and
12 policy at Columbia's business school. But
13 I'm an outsider in your area. I was asked by
14 SEIU 1199 Northeast to take a look at
15 privatization generally, and human services,
16 and also the expenditure of funds in
17 Connecticut in this area.

18 There are three things that I come away
19 with. One, and I know you probably have all
20 felt this at times, is the tremendous courage
21 and commitment of the people who work in this
22 field, public and private, institution and
23 community, staff and clients.

24 The second is that Connecticut doesn't
25 have a lot of skin in this game. It's very

1 interesting to have looked historically using
2 Professor Braddock's materials to compare
3 Connecticut to other states. We are
4 apparently about 90 percent dependent on the
5 Medicaid program compared to, for example,
6 55 percent Massachusetts.

7 We have, and I know we've all noticed
8 this, a new and unreliable business partner
9 in Washington. If I were in the business of
10 planning for five years I would not be
11 relying on the Medicaid program, because
12 we've got some other very, very expensive
13 providers.

14 As just to name one, we have a very
15 large healthcare system in this state who's
16 top ten executives all earn more than a
17 million dollars a year on average. So you've
18 got some expensive participants in the
19 Medicaid pool.

20 The amount of money the State puts in
21 net of the federal share has actually fallen
22 in half between 1986, 1996 and the present,
23 adjusting for the value of dollars. So
24 that's my first conclusion, is Connecticut
25 does not have a lot of money in this game and

1 the money that it does spend is now in peril.

2 My second conclusion, and I've created a
3 website so everybody can take a look at these
4 things at their leisure, the address is pause
5 button for five-year DDS plan dot org. Pause
6 button for five-year DDS plan dot org.

7 Privatization is a cruel hoax in complex
8 human services. It really has not
9 consistently saved anything and it has
10 produced a great amount of scandal and
11 compromise. The people are committed, but
12 the idea that somehow you're going to save
13 money through privatization is a ruse.

14 Let me give you one quick example.
15 Every state employee in the State of
16 Connecticut has assigned to him or her a
17 number for benefits and, for example, for
18 pension benefits that number is 80 percent
19 fiction. It's the ghost of Christmas past.
20 It's the unfunded pension liability. It
21 stays there even if you lay that employee
22 off.

23 So the idea that you're going to -- was
24 that the bell? I'm sorry. So pause button
25 for five-year DDS plan. Thank you for the

1 opportunity.

2 And Commissioner, thank you very much
3 for your service.

4 MS. MURRAY: Thank you. And just a
5 reminder, everyone's full remarks if you've
6 submitted them will be in the record for us
7 to review. I know three minutes is not a
8 long time.

9 Abu, and then Beverly LaPorte will be
10 after that.

11 ABU BAKR: Yes. Ladies and gentlemen,
12 staff, legislators, DDS workers and
13 consumers. Hi, my name is Abu Bakr. You
14 were close, Bakr.

15 While I've done a lot of different types
16 of work in my career, I've always worked in
17 fields that had direct engagement with other
18 people. This has helped me develop an
19 inclusive behavior that made caring for
20 individuals with disabilities a great fit.

21 About 12 years ago I decided to take a
22 certified program for community health
23 workers. That showed me how many consumers
24 with disabilities or chronic conditions had
25 no choice but to use emergency rooms for

1 basic health care. That inspired me to begin
2 working with consumers in home-based settings
3 where I felt I could improve the quality of
4 their lives. I'm here today to talk about
5 real-life challenges by consumers in IC, in
6 the DDS homecare services.

7 This DDS five-year plan should have more
8 specifics on how the agency will improve the
9 homecare program to lift up homecare workers
10 and services up to the same good quality
11 standards that other DD services have
12 attained.

13 For the past four years I have provided
14 home care for two of my consumers with
15 developmental disabilities. One consumer is
16 becoming more independent and has moved on to
17 his own residence. I help him pay bills, go
18 shopping, the doctor's appointments.

19 But the other consumer, he has more
20 physical challenges and I take him to
21 therapy, doctor's appointments. I've been
22 trying to work with him on basic hygiene and
23 skills to be more physically healthy. A lot
24 of the time in the gym.

25 There are no real boundaries to this

1 work. I'm here to foster and support them in
2 their independence in any way they need. For
3 example, during the consumer's recent move
4 his electrical and gas weren't turned on, on
5 his new place like they were supposed to be.
6 They were supposed to be an hour after we
7 received the keys.

8 I ended up calling the utility company
9 about five o'clock, oh, 4:45 in the
10 afternoon, about 15 minutes before they
11 closed to remedy this problem. And luckily I
12 had a customer service person who was very
13 flexible. That's not exactly part of my job
14 description, but I couldn't leave him without
15 lights and without gas in his apartment.

16 There are other challenges to this work.
17 My work through the State of Connecticut DDS
18 waiver program is paid by the State. With
19 both of my consumers I am just paid a modest
20 13 and 15 dollars, respectively.

21 In closing, I just want to say because
22 my time has lapsed that, you know, we need
23 state-funded group worker's policy and comp
24 to protect all workers and consumers.
25 Finally, caregivers like me need a living

1 wage to take care of our own homes and
2 families.

3 Thank you.

4 MS. MURRAY: Thank you. I'm going to
5 say here, we're going to be here until
6 twelve o'clock. If by chance we finish
7 early, if people want to sign up with Rod to
8 add additional comments that they couldn't
9 fit into a three-minute period, that's fine.
10 We'll stay here until noon. So if we do have
11 time for that I want to offer that to people.

12 Beverly LaPorte, and then Adrienne
13 Benjamin.

14 BEVERLY LaPORTE: Hi. Mine will be
15 short. My name is Bev LaPorte, and I would
16 like to talk about what is missing from the
17 five-year plan.

18 My son, who has a seizure disorder and
19 is developmentally disabled, has lived in the
20 same public-sector group home for 23 years.
21 They care for all his needs, 24 hours a day,
22 7 days a week. He visits with me every
23 Sunday, and while he is very happy to come
24 home, he is equally as happy going back to
25 his house with his other group home family.

1 Sadly, his brother died six years ago
2 which was very traumatic for him. His
3 behavior has regressed to the point where he
4 could not talk and his seizure activity
5 increased significantly. It took months for
6 him to regain what he lost and that was only
7 with the diligent and dedicated help of
8 having his group home family with him. I
9 cannot imagine what will happen to him with
10 privatization.

11 Suddenly, everyone who has been his
12 constant stability, and cared for him for 23
13 years will be taken away and replaced with
14 unfamiliar staff that is inexperienced and
15 not medically qualified. The familiar faces
16 will be gone. Strangers will now be caring
17 for him, and thus his stability and
18 consistency will be gone.

19 There is nothing in the five-year plan
20 that advocates for more funding for DDS, and
21 that's all I have to say.

22 MS. MURRAY: Thank you.

23 Adrienne, and after Adrienne we have
24 Rick Bush.

25 ADRIENNE BENJAMIN: Good morning. My

1 name is Adrienne Benjamin. Can you hear me?

2 Push the button. Hello. I'll start
3 again.

4 My name is Adrienne Benjamin. I live in
5 New Britain. I have a 20-year-old daughter
6 who goes to Gengras School. She has very
7 severe disabilities, intellectual disability.

8 She's a huge fan of the DDS residence
9 center and I feel like I always have to give
10 a shout out to the Newington respite team.
11 They're amazing, and she loves going there.
12 She's been going there for 13 years and it's
13 wonderful for her and for our family.

14 I know many of you from my involvement
15 on the governor's council, but I'm speaking
16 for myself today, not for the council. I
17 recognize this must have been a daunting task
18 coming up with a five-year plan, and I
19 appreciate the intensity of that job. But I
20 do want to think of this plan from the
21 perspective of, we're talking to the
22 Legislature. We're talking to the Public
23 Health Committee and the Appropriations
24 Committee to tell them what this -- what DDS
25 needs, what DDS works on, what DDS is.

1 And I feel like -- so it's an
2 opportunity to put both the strengths and
3 positives forward, but also the critical
4 issues facing DDS. And I think the report
5 has failed in terms of really explaining the
6 severity of the problems facing DDS. And I
7 must say, I do not think the problems facing
8 DDS are your fault. It's chronic
9 underfunding. The waiting list has been --
10 really?

11 MS. MURRAY: Given your service on the
12 council, take another minute.

13 MS. BENJAMIN: Thank you.

14 The waiting list has been egregious for
15 over 20 years. It states on page 5 that's
16 there's 657 people on the emergency and
17 priority one list. That's incredibly
18 alarming, and I think the report should
19 detail -- the five-year plan should detail
20 what is going to be needed to address the
21 needs of these 657 people.

22 I know there's a longer longer-term
23 waiting list. I'm not addressing that right
24 now. But some of these are emergencies. I
25 don't know if it's 30 people or 50 people,

1 but I feel like it has to be spelled out in
2 the report what kind of personnel will be
3 needed, what kind of costs are needed, what
4 kind of resources are needed to address these
5 priorities.

6 When we call it a priority, it should
7 mean that, and I think we should address that
8 head on. And I think we should also remind
9 the Legislature and thank them for the
10 \$4 million they managed to find a few years
11 ago which went to house another hundred
12 people where the parents were over 70 years
13 old.

14 I have a little gift for you all. It's
15 a graph, an unauthorized graph made with
16 authorized DDS numbers. So I'll bring it up
17 there if you guys don't feel offended.

18 MS. MURRAY: Adrienne, if you could wrap
19 up, and then anything that you submit will be
20 available publicly.

21 MS. BENJAMIN: This is a graph -- I
22 think should be included in the plan, about
23 the actual level of need of the total DDS
24 population.

25 Thank you.

1 MS. COONEY: Commissioner, sorry. I
2 just want to jump in a second. It's
3 Christine over here.

4 For the folks up in 2B, I was just up
5 there and -- I let them know, but I just
6 wanted everyone to know that I did ask.
7 Unfortunately we can't get the video
8 streaming up in 2B. They can hear everything
9 that's being said down here, they just can't
10 see you -- but speak clearly.

11 And we did call CT-N. We attempted to
12 get the video stream in there and it's a --
13 they have too many things going on right now,
14 so we can't do it.

15 But I apologize to those up in 2B who've
16 been asking. I just wanted to address the
17 request, that we did check into it and we
18 can't do it. So this will all be transcribed
19 and will be on the website verbatim.

20 And also we've had a request to check
21 our timers not being super scientific. So
22 I'm going to turn it over to the digital
23 cellphone timer and we'll have exactly three
24 minutes going forward.

25 Thanks.

1 MS. MURRAY: Thanks Christine.

2 Rick Bush and then Jane Patsas.

3 RICK BUSH: Hi. My name is Rick Bush.

4 I am the legal plenary guardian for my sister
5 in law. Her name is Maria. She's 57. She's
6 mentally disabled, and she's been on DDS
7 services for about ten years. And the amount
8 of energy, effort, time and organization that
9 it took to develop her staff and all of the
10 different people that surround her in her
11 life has probably consumed about five years
12 of that time, just because of the level of
13 complexity of her situation.

14 And when I hear about transitioning from
15 one organization to another to try to take
16 over her, you know, her health care and her
17 needs, the level of stress that it creates in
18 my mind -- because I'm really the one doing
19 it, I'm the one who's helping to organize
20 it -- is so overwhelming and so fast.

21 We work so hard to get all of these
22 different people into their positions and to
23 take that, that network and to transition.
24 It just took -- to me, seems such an
25 overwhelming and daunting situation.

1 And then on top of that, to do it, to
2 try to save money, to put it into the hands
3 of organizations who are for-profit
4 organizations, or to privatize that and to
5 take it out of the motivation for what I see
6 as care. Like, the people that work now in
7 DDS are motivated, in my opinion, by care.

8 If you take that motivation away and you
9 motivate people by money, you completely
10 break the entire point of the system. You
11 don't allow people to exist with a supportive
12 helpful staff. You have people who are on
13 time clocks that are being forced to stay
14 into budgets. And in my opinion, it would be
15 a very, very large mistake to try to
16 privatize the system.

17 I think the DDS system is flawed,
18 obviously. It's not a perfect system, but I
19 think it serves an unbelievably important
20 purpose, as obviously it does. And to try to
21 privatize it I think is a giant mistake.

22 That's it. Thanks.

23 MS. MURRAY: Thank you.

24 Jane, and then Joseph Gannon.

25 JANE PATSAS: My name is Jane Patsas.

1 Thank you for listening to all of us today.
2 I really appreciate this. Communication is a
3 wonderful thing to happen and I hope it will
4 eventually go both ways.

5 I'm here to talk about two of my
6 children who are in care right now. The
7 first one is Coreene. She is of course older
8 than this now. She was a near fatal drowning
9 accident when she was less than a year old in
10 her grandmother's pool, and mom was a very
11 young mother. She was put up, and put into a
12 nursery, which was an institution for babies
13 then.

14 I think she's very bright. I was
15 teaching her to read when she was four.
16 She's nonverbal. She's not able to move
17 around. She's not able to dress herself,
18 feed herself, do anything for herself. She's
19 lost more of her physical abilities lately.

20 She's had different communication
21 devices through the years, and now she has a
22 Tobii, but she has no speech therapist. She
23 has nobody to set this thing up with her.
24 She has no one to work with staff so that she
25 can communicate. She couldn't vote this

1 year. She had no way to communicate.

2 At least the staff where she's living
3 now -- it's a state-run group home. They
4 know her. They know nuances with her if
5 something is going wrong. She's very fragile
6 medically at this point. She needs the
7 speech therapy as well as other people in the
8 state system. They need it, too. This is
9 something that really should not be ignored.
10 In fact, it should be increased for the
11 amount of time and the services with the
12 speech therapy for the people that were
13 getting it before. But she really needs
14 this.

15 My other child that I'm going to talk
16 about today is David. We adopted him when he
17 was nine. He was in a state-run facility up
18 in Putnam. He, of course, has down syndrome.
19 He's deaf, and therefore has a communication
20 problem also.

21 He does do some signing. He has
22 behaviors and recently a year ago we had to
23 have him placed because of his behaviors. He
24 would be up and down all night long and doing
25 strange things in the house.

1 So he went into a private group home.
2 Which, okay, physically he can get around,
3 but the problem is he can get around. And
4 they needed to know that he had to be
5 supervised at all times if they took him into
6 the community.

7 And I stressed this with them, that he
8 had to be, not just in line of sight, he had
9 to have his site on whoever was with him,
10 because he only sees this way. If he doesn't
11 see you in front he will start to run looking
12 for you. He's not trying to get away.

13 MS. MURRAY: I apologize. The buzzer
14 now is very subtle, and it just went off. So
15 if you could just wrap up? Thanks.

16 MS. PATSAS: Okay. Anyway,
17 communication was a problem with the group
18 home, because they let him get away in a
19 Walmart. And I don't know what the
20 particulars are of it, and they refused to
21 give me information about it.

22 I know they're stonewalling. Eventually
23 I will get the information, but that's a
24 scary thing, especially that they knew that
25 he was vulnerable and out there in the

1 community, and they left him in a Walmart,
2 alone. And that's all I have to say.

3 Thank you all for your time, and keep
4 the communication going.

5 MS. MURRAY: Thank you.

6 I guess we're switching back to the old
7 buzzer, which will be loud, because I want
8 people not to know.

9 Okay. Joseph Gannon is up, and then
10 Steven Williamson.

11 JOSEPH GANNON: Good morning, and thank
12 you very much. My name is Joseph Gannon. I
13 work for DDS in a public respite. I've
14 worked for the department more than 30 years,
15 and in respite for more than 18 years.

16 In 18-plus years I have seen the demand
17 for respite services increase while the
18 opportunities for families to utilize respite
19 and other services are decreasing. Around 16
20 years ago at the Putnam respite we would
21 invite and service as many as 16 guests per
22 week. Several years ago that number was cut
23 to 12 per week, then to 6 guests per week.
24 And this was not due to decreased interest,
25 but rather to staffing over time constraints.

1 About five years ago the Putnam respite
2 was moved to a smaller location in Storrs.
3 The Storrs respite has six guests capacity
4 due to staffing cuts and building layout,
5 however there are some weeks we can only
6 accommodate three guests.

7 The length of the visits has also been
8 cut by a full day. Guests leave respite no
9 later than 10 a.m. Monday morning. It is
10 also important to note that families
11 requesting respite services used to be
12 offered three to four visits a year. That
13 number dropped to one or two with some
14 families losing respite services completely.

15 Many of the ladies and gentlemen who
16 wish to utilize respite services have already
17 experienced other service cuts and are now
18 losing desperately needed services. For many
19 families respite has been a life changer.
20 Respite, according to families I have talked
21 to, has allowed them to keep their loved ones
22 at home knowing they would be able to get
23 occasional breaks.

24 What I see and hear about is -- actually
25 I think -- let's see if I can read my own --

1 is actually privatization. What I hear a lot
2 of times is privatization. What I actually
3 see and hear about from families is service
4 elimination. Once services are eliminated
5 there is no guarantee they will ever come
6 back.

7 The ladies and gentlemen who are
8 eligible for DDS services and their families
9 need a real plan to save services. The cuts
10 need to stop now. Families are being asked
11 to wait and told things might get better.
12 Many families would love to have that luxury.

13 The truth is, however, that many
14 families at this very moment are wondering
15 how they're going to make it through the next
16 two months, two weeks, two days and some in
17 the next two hours. Families need services
18 right now.

19 Thank you.

20 MS. MURRAY: Thank you, Joseph.

21 Steven Williamson and then Phil
22 Bartlett.

23 STEVEN WILLIAMSON: You're getting a
24 twofer. I am speaking for Phil.

25 MS. MURRAY: Okay. Great. If you could

1 just say that on the record?

2 STEVEN WILLIAMSON: Yeah.

3 Hi. Thank you. I'm really nervous.

4 It's amazing the stories that we've
5 heard so far, especially from people who have
6 children in the department.

7 My name is Stephen Williamson. I've
8 been working in the department for 32 years.
9 The first home I worked at ran for 26 years,
10 and we had 6 residents from the Mansfield
11 Training School. It was amazing to me, as
12 someone who had never done that work before,
13 to see them grow into their own people. They
14 were no longer in an institutional setting.
15 We had one gentleman who we didn't know knew
16 how to write until it came up one day, and he
17 was able to write his name, just like you and
18 I would do.

19 So that was an amazing experience for me
20 for 26 years. There are several things
21 happening with the five-year plan that I can
22 see from the perspective as a worker. One of
23 the main things is what I perceive is a lack
24 of oversight in the homes that have been
25 privatized already. The Governor speaks

1 about nonprofits, but none of these agencies
2 that I'm aware of are nonprofit.

3 There's a profit to be made, and it
4 doesn't necessarily come for the workers who
5 are working directly with the residents. I'm
6 not sure where private agencies go for
7 physical therapy for their residents, or
8 vocational training. I'm not exactly
9 involved in that, so maybe it's there and I
10 don't know it. I don't understand why the
11 high standards that are expected of me and my
12 coworkers don't seem to be expected in the
13 private sector.

14 I've heard of homes that have non-med
15 certified staff passing medications that are
16 controlled substances. I believe that's a
17 federal -- against federal law. We've all
18 heard about the wages in the private sector
19 leading to very high turnover.

20 For the gentleman that I work with now
21 inconsistency in staff is a big deal.
22 Imagine if you're in your home and you have a
23 stranger coming in every month, somebody
24 different that does things differently from
25 day to day, and expects different things from

1 you. None of us would be happy with that and
2 that is what's happening.

3 Consistent staff fosters care and
4 relationship building. It fosters supports
5 that people grow to depend on. It helps them
6 thrive and become their own people. Staff
7 become like family. That's been my
8 experience in this department.

9 I'm not just a state worker with a big
10 pension. The public seems to view us that
11 way. I get it. I'm a taxpayer as well.
12 People who don't actually do this work often
13 can't see the true costs of lives disrupted,
14 bonds broken, reactions to stresses of
15 hearing that your home is going to be taken
16 away from you.

17 This is my second thing. Phil Bartlett
18 is here with us. He is one of our residents.
19 Sorry. I have a letter that he wrote. It
20 will just take me a minute.

21 I am Phil Bartlett. I live at Stafford
22 Road group home with three other housemates.
23 It has been over 25 years since I've called
24 this place my home. My home is where I feel
25 safe and comfortable, where there's services

1 being provided to me around the clock.

2 The staff here knows me well and they
3 are now my family. I don't want to move. I
4 don't want to lose my housemates. I don't
5 want to use my staff. Can you hear me? My
6 life matters. Please return my happy days,
7 days without crying, days without fear, days
8 about feeling worthless and bullied, days
9 that I can do my required programs with a
10 smile. I invite all of you to come witness
11 my lifestyle. It is simple, basic, yet
12 functional and fulfills all of my needs.

13 I beg all of you in plain English to
14 give me my life back before it's too late.

15 Signed, Phil Bartlett.

16 Thank you for your time.

17 MS. MURRAY: Thank you, Steven and Phil.

18 Next we have Kiev and then Timothy
19 Coleman.

20 KIEV FEDEROWICZ: Good morning, panel
21 members. My name is Kiev Federowicz. I'm a
22 home manager for the State, and I've been in
23 the DDS field for 33 years.

24 My journey with the department has
25 brought me in contact with dozens of

1 individuals with a variety of needs, hundreds
2 of staff, and just scores of family members
3 and guardians in a variety of worksites
4 throughout the state, and I'd like to speak
5 on their behalf.

6 I begin my journey in the institutional
7 setting in Mansfield Training School. In my
8 career I participated in the
9 deinstitutionalization process, development
10 of community-based group homes, the expansion
11 of department programs, and training of
12 hundreds of staffs in physical and
13 programmatic management.

14 As a third generation healthcare
15 provider in the State, I've been on the front
16 lines of some of the leading changes in
17 philosophies, expectations, cultural
18 adaptations and reformations my entire life.
19 In this time I have never experienced any
20 plan as devastating as the one that I see
21 being proposed now in front of me.

22 Firstly, there seems to be no mention on
23 how the department plans on developing
24 resilience against economic tides to protect
25 and grow funding for our individuals, whether

1 they be served by public or private.

2 As a state worker I've never been a
3 particularly vocal challenger against
4 privatization. Indeed, I believe that many
5 agencies in their own way do provide services
6 better in some areas. The issues that I see
7 now are the changes on how they're being
8 pursued -- is how quickly they're being
9 implemented.

10 The speed and process with which we're
11 being told we must dismantle our system is
12 just devastating. The agency who proclaims
13 to be the center of change in order to
14 support the individuals has placed protected
15 health information on a public portal. That
16 prior providers are allowed to shop for these
17 individuals and encouraged to bid on them to
18 provide services, services which have been
19 provided in many cases by the same staff in
20 the same homes for close to 20 years.

21 Now these individuals are being asked
22 within the space of several months to give up
23 their caregivers and the people that
24 connected them with their families and
25 communities, and replace them with a

1 reportedly lower-cost version that is
2 allegedly of the same quality. How often
3 does it occur that in any industry anywhere
4 that you can get the same quality of services
5 for a third of the cost?

6 Moreover, what of long-term effects that
7 these changes will have on these individuals?
8 We've heard from a lot of our family members
9 today about what it has taken in order to
10 develop some of these communities, some of
11 these families, some of these connections.

12 The agency's own mission seem -- excuse
13 me. The agency's own missions are these
14 people are to have a stake in the decision of
15 who is to care for their needs. Will they be
16 able to recover from the loss of the
17 long-term relationships they have forged with
18 the staff that have cared for them for the
19 better part of two decades?

20 In the home I currently manage we have
21 seven staff who, with combined knowledge and
22 expertise, adds up to over 175 years. The
23 individuals in our care have lived there
24 together in some cases in the same home for
25 close to 20 years. I ask again, can a group

1 of staff that have less combined experience
2 than one single current staff, and is being
3 paid for a third of the wage, be able to
4 provide the same quality services? It's a
5 rate that's comparable to working in a box
6 store chain.

7 It is a tragedy that our leadership has
8 not assured parody of compensation in this
9 field and stopped the auction of individuals
10 to the lowest bidder. Would you choose this
11 model for the care for your loved ones? I
12 will not argue that services cannot be
13 provided for at a better cost. What I will
14 state is that the mechanism that will
15 equitably evaluate the abilities between
16 different providers does not exist and needs
17 to be looked at.

18 Thank you for your time.

19 MS. MURRAY: Thank you.

20 Timothy, and then John Allen.

21 TIMOTHY COLEMAN: Good morning,
22 committee members. Thank you for this
23 opportunity to testify before your committee.
24 My name is Timothy Coleman. I am here to
25 testify against the five-year DDS plan.

1 I have worked for the Department of
2 Developmental Services for 33 years now. I
3 currently supervise two public homes in the
4 north region. One home has approximately 13
5 residents, residential staff; and 6
6 non-ambulatory, medically fragile, acutely
7 ill residents. These residents require
8 extensive 24-hour around-the-clock nursing
9 care. The second home has approximately 14
10 residential staff and 6 behaviorally
11 challenged men. These residents require
12 intensive around-the-clock supervision.

13 During my tenure I have seen governors
14 come and governors go. With each
15 administration we are faced with budgetary
16 cuts, impossible workloads, unrealistic
17 budgets, running homes with less staff, which
18 ultimately compromise the quality of care,
19 supervisors running multiple homes, et
20 cetera.

21 These budgetary cuts result in creating
22 more overtime as positions are left vacant.
23 Mandatory overtime has become routine.
24 Privatizing much of the DDS public sector is
25 an unrealistic attempt to save the taxpayers

1 money. More importantly, it will harm the
2 individuals we serve. I'm exhausted with
3 defending the concept this administration
4 portrays as the state employees are the
5 highest paid, privatization is always the
6 answer.

7 The home I supervise admitted an
8 individual who almost died at the negligence
9 of a private-run home. Sadly, the staff at
10 the private home were unable to recognize
11 signs of distress. This lack of training
12 resulted in the individual aspirating on
13 food, almost dying.

14 The private sector staff did not have
15 the experience or longevity with this
16 individual, which translated into the staff
17 not being equipped to handle this individual.
18 This one incident resulted in approximately a
19 six-month hospitalization stay, an
20 intubation, followed with a gastric tube
21 insertion, then a nursing home for
22 rehabilitation before coming to the home I
23 supervise, where she is receiving specialized
24 care.

25 The difference between public sector

1 staff whom cared for her for years before she
2 went to the private sector and private sector
3 staff whom did not know her well almost cost
4 this individual her life. This individual is
5 now thriving and becoming stronger each day.

6 Public employee staff are trained to
7 assist the most difficult and challenging
8 individuals. Most of these individuals are
9 too medically involved for them to safely
10 translate -- transition into private care
11 with a lack of funding makes these private
12 agencies ill equipped to handle these
13 individuals. Is privatization really cheaper
14 to the taxpayers of Connecticut?

15 My wife, since retired, also supervised
16 a public group home in the Brooklyn area.
17 The previous administration insisted in
18 closing this home. This closure occurred
19 despite much debate and pleas from parents,
20 advocates of guardians. Approximately five
21 years later the home still sits vacant,
22 vandalized, property devalued.

23 I am always concerned when politicians
24 use the most vulnerable clients with threats
25 of closure, of conversion. I shudder to

1 think the ramifications of ending public
2 homes and the overall burden this will ensue
3 on taxpayers on an already growing deficit.

4 I attended each of the Governor's first
5 debates years ago. I distinctly remember him
6 saying, privatization is not the answer. His
7 change in position will have devastating
8 results on the economy, taxpayers, consumers,
9 parents and unemployment, not to mention a
10 soaring deficit.

11 I implore you to reconsider the decision
12 with supporting the DDS five-year plan. Hold
13 this administration accountable for a
14 sensible resolution. As the Governor once
15 said, privatization is not the answer.

16 Thank you.

17 MS. MURRAY: Thank you.

18 John Allen, and then we have Frank
19 Ducharme.

20 JOHN ALLEN: Good morning, Commissioner,
21 administrators, ladies and gentlemen. My
22 name is John Allen. I am an IFS family
23 support worker in the north region. Please
24 consider the following concerns when crafting
25 your five-year plan.

1 I along with my fellow DDS family
2 support workers am in several homes where the
3 caregivers are elderly, often in their
4 seventies or eighties. They have difficulty
5 caring for their adult children with a
6 developmental disability. We may assist them
7 with direct care, such as bathing or
8 grooming, taking the individual to medical
9 appointments or into the community for
10 recreation. We have also done this for
11 parents who have to go into the hospital for
12 surgery and need help with their child while
13 they are recuperating.

14 Sometimes the parents have their own
15 issues which compromise their ability to
16 provide care. We have worked with parents
17 who have had mental health issues, physical
18 or medical issues, as well as financial
19 limitations. We have worked in many nice
20 homes. We have also worked in homes with
21 hoarding, and homes with infestations.

22 In my job I have brought people from
23 alleged abusive situations to safe houses. I
24 have worked and am working with DDS clients
25 whose parent has gone into long-term care

1 facilities, leaving them home alone. I along
2 with my coworkers provide support until a
3 long-term solution can be found.

4 The IFS respite centers provide much
5 needed relief to families who need a break.
6 It's my feeling that without the respite
7 centers and family support workers the demand
8 for placement could be much higher. My
9 coworkers and I have been asked to assist in
10 the homes where the home health aide has
11 quit. Some families have complained that
12 they cannot find aides to work the hours
13 needed, or that they cannot get an aide to
14 stay.

15 Although we are not home health aides,
16 family support workers along with many other
17 DDS staff have specialized training and many
18 years of experience working with individuals
19 with developmental disabilities that some
20 home health aides may not have. We have been
21 asked to assist until more help can be
22 secured. What I've described is just some of
23 what we do as family support workers, is we
24 have to adapt to the needs of each situation
25 presented to us.

1 There has been emphasis on helping the
2 elderly caregivers in recent years.
3 Currently there are ten family support
4 workers supporting the north region, which
5 extends north and east to the Massachusetts
6 and Rhode Island borders. Going into the
7 families' homes I see the overwhelming need
8 for support firsthand. Many families are
9 looking for help, not looking for help to be
10 taken away. I look forward to continue
11 helping them as a trained, experienced, DDS,
12 IFS worker.

13 Thank you.

14 MS. MURRAY: Thank you, John.

15 Frank, and then Tom McCann.

16 FRANK DuCHARME: Good morning. My name
17 is Frank DuCharme. My son resides at
18 Beelzebub in South Windsor, Connecticut.
19 I'll make it short and brief.

20 The level of care that my son has
21 received in the last 30 years cannot be met
22 by private agencies. A perfect example, the
23 fire at South Windsor/Manchester home on
24 Birch Street last week. These people are not
25 qualified or trained to handle situations

1 like these, which there will be many, many.
2 This is why DDS is qualified and trained with
3 these clients. They are families to our
4 loved ones.

5 Vinfen, V-i-n-f-e-n, was in charge of
6 the Birch Street home in South Windsor, which
7 was privatized roughly three weeks ago. The
8 proof is in the pudding. I have a report
9 here, and I'll hand it -- give them to you,
10 and you can look at it, from the police
11 department, what transpired at that fire.

12 MS. MURRAY: Thank you.

13 Just a reminder that anything you want
14 to submit will go into the record, so please
15 do that, if you can.

16 Tom, and then Hakim Foster.

17 TOM McCANN: I'm going to be brief.
18 I've been in the State of Connecticut for a
19 very long time. When I heard that the State
20 was going to be closed, I couldn't believe
21 it. So I decided to go into a private
22 agency, which would be Mark. Because I know
23 the staff there, and I know that I'll be
24 treated great.

25 But the staff that we have now, they

1 don't do this for money. They do this
2 because they care about us, and we care about
3 them. So I'm asking you, why can't you open
4 your eyes? We need the staff. We don't need
5 them to leave.

6 Thank you.

7 MS. MURRAY: Thank you.

8 Hakim, and after that is David LaBier.

9 HAKIM FOSTER: Hi. My name is Hakim
10 Foster. I'm in supportive living. I've been
11 in supportive living for 14 years. I agree
12 with him. Without the staff, it will be
13 nothing.

14 And when I first heard about it too, I
15 was devastated. I was heartbroken. You
16 know, I know family, you know, I was young.
17 When I was a kid -- I was at least about 14,
18 15, and my mother didn't know what to do with
19 me. She, you know, directly to DDS and ever
20 since then, I -- my life changed a lot.

21 And Governor Malloy, I feel like he's
22 taken, you know, people I care about in DDS,
23 people I call mom and dad, people I call
24 friends, people I call brothers, sisters, you
25 know, and other clients like myself.

1 And, you know, for the regular, you
2 know, I don't want to loose something that,
3 you know, if it wasn't for DDS I wouldn't be
4 here today. I'm going to be honest with you.
5 I'd probably be in trouble with the law, you
6 know, being a teenager, growing up with my
7 mom and dad, you know, my real parents it was
8 kind of rough.

9 But I made it through, and it was my mom
10 and that idea to put me in DDS, and ever
11 since then it was, you know, my life changed.
12 I mean, I did a good job. They keep me out
13 of trouble. My sports with special olympics.
14 I did it all.

15 And now that Governor Malloy wants to
16 change it, it hurts me to say goodbye, and I
17 don't want to say goodbye. And I just want
18 to continue doing things like it is, like you
19 know, smooth and everything. But it hurts
20 me.

21 When I first heard about it, my neighbor
22 Gene downstairs told me about it. When I get
23 home from work one day -- he was very upset.
24 I go, what's wrong.

25 He goes, well, I heard it on the news

1 Governor Malloy is changing things.

2 When I heard that I cried myself. I
3 tried to hold it in, but I went in my room
4 and I cried. And I said, something has got
5 to be done. And I want to be one of, you
6 know, the other guys in DDS to be the voice
7 of the voiceless.

8 And I'm here today to do that, to put
9 my, you know, how I feel about it in this.
10 And this is what I'm saying, I want to keep
11 DDS and my staff and friends. And because
12 without DDS I don't know what I would be. To
13 be honest with you, I don't know what I would
14 be. I don't know whether I would be dead or
15 in jail, and that's the truth.

16 And you know, if it wasn't for DDS my
17 world wouldn't be what it is today. I
18 wouldn't probably have a job. I probably
19 wouldn't have a place to live. I probably
20 wouldn't stay with my mother. I don't know
21 where I would be.

22 And you know, and with DDS they really
23 got me to the point that I'm a good athlete
24 and I love DDS, because that's my second home
25 and my second family. And it just kills me

1 to find out Governor Malloy wants to do
2 something for -- what is he thinking? You
3 know, what is his problem? What did we do to
4 him? You know what I'm saying? I'm speaking
5 for everybody who's in DDS. What did we do?
6 We're just innocent bystanders, sitting back,
7 can't do anything. We can't control it.

8 Well, I'm here to say we could. We are
9 the voice of the voiceless, and we can change
10 it. We can keep it like it is, and this is
11 what it is, and we're going to keep this, you
12 know.

13 I mean, personally me, I don't want to
14 go to a private sector. I have a cousin and
15 she works there, but if I could keep things
16 like this, yeah, I want to do that. And
17 that's my goal right now and that's my
18 mission right now, because with special needs
19 and everything and work, I like the things
20 the way it is. That's my personal opinion
21 and I'm going to stick to it. That's the
22 bottom line, you know.

23 Thank you.

24 MS. MURRAY: Thank you.

25 Then David. After David is Judith

1 Klemba.

2 DAVID LaBIER: I apologize if my words
3 don't flow as well. I wasn't planning on
4 speaking today originally.

5 I've been working with the disabled
6 population for 25 years. At first I was in
7 the private sector agencies. I worked for
8 two different sectors. And for the past 15
9 years I've been with DDS at a state-run group
10 home.

11 The first group I was assigned to I'm
12 still in -- for 15 years, which is a
13 consistency of care that does not exist in
14 the private sector where very frequently you
15 have college students passing through on the
16 way to their real careers.

17 I can only call a state group home as a
18 living tradition. The new people coming into
19 the house learn from staff that have already
20 been there for several years before you have,
21 and when it comes to client care that's very
22 important. It's not something that can be
23 passed on in two weeks, or even two months of
24 transitional training into a private group
25 home.

1 We have an individual in our group home,
2 a woman who is nonverbal, but over the years
3 you learn how to communicate with her and you
4 learn her signals. If our house is
5 privatized she'll never ever voice heard
6 again.

7 We just recently received a very
8 medically fragile man into our house. The
9 whole team assembled, physical therapy,
10 occupational therapy, the nurses. This is
11 something that does not exist in the private
12 sector, at least not that I'm aware of. They
13 have physical therapy only as long as
14 insurance will cover for it, and they only
15 work on rehabilitation. Whereas in the state
16 group homes they work on abilitation so
17 people don't become cramped and disfigured as
18 time goes on, which is something that is not
19 going to be continued in the private sector
20 unless costs are raised so much that there's
21 no cost benefit to privatizing.

22 In my experience in the private sector
23 one agency I worked with had taken two
24 individuals out of Southbury Training School
25 to give them what they thought was going to

1 be a better life. The female ended up dying,
2 she choked to death. And the male was sent
3 back to Southbury because they couldn't
4 handle his behaviors.

5 So the people on the outside, they may
6 think a place like Southbury, you know, is
7 awful. It's their home. It's what they
8 know. It's their friends. It's their
9 family. In every group home people live
10 consistently with the same people every day,
11 and see the same staff every day. Like I
12 said, I've been there for 15 years. There's
13 people who have been there a lot longer than
14 15 years working with the same individuals.

15 And to privatize would take the voice
16 away from at least one individual who I have
17 a good relationship with. This woman, that
18 you have to take time and really, over the
19 years, learn how to communicate with her.
20 Over a two-week transitional period, or two
21 months, she'll never be heard from again.

22 And I would just like to close by saying
23 a couple of things that we're not -- no one
24 is looking at selling -- buying and selling
25 houses. They're buying and selling people,

1 which is something that I thought was over in
2 this country.

3 I'd like to close by saying -- I'd like
4 to close briefly in saying that I am a state
5 employee and a state group home. I am also
6 an ultraconservative Republi-tarian, a
7 combination between a Republican and a
8 Libertarian. So if I'm saying that
9 privatizing state group homes is a bad idea,
10 you can take that to the bank.

11 MS. MURRAY: Judith, and then Paul
12 Tavernier.

13 JUDY KLEMBA: Judy Klemba?

14 MS. MURRAY: Yes, I have Judy. Sorry
15 Judy.

16 JUDY KLEMBA: Hi, my name is Judy
17 Klemba. I would like to talk about what is
18 missing from the five-year plan. If I were
19 to sum up all of the services that are
20 important it would take a day just to
21 remember all of the services provided in my
22 son's life.

23 Let's start with schooling. Day
24 treatment services took Mark for a such a
25 short time to adjust to, that where behavior

1 modification was the basis of getting a
2 handle on how to keep a fidgety kid quiet
3 long enough so he could learn to read, write
4 his name and learn to sit in a chair.

5 Mark finished day treatment service when
6 he was around 12, and did go into
7 Talcottville High School in West Hartford
8 until he was 21. When the Church Street
9 Group Home was built, Mark and five other
10 guys were put into a real home. Staff and
11 services were provided so that Mark could
12 have speech therapy right in his own house.
13 When we saw Mark blossom into the man he is
14 today -- he loves, actually, the sensory room
15 at the Hartford regional center and many
16 other activities that are provided around
17 town.

18 Mark was taught how to assemble chips
19 and screws -- clips and screws and put them
20 into packages. Mark has been working in a
21 job for over 20 years for CFW. I can't
22 imagine how Mark would function without the
23 staff that has made him sandwiches, packed
24 lunches for him, shave him every day and give
25 him the pills he needs to be pain free, and

1 teach him about cleaning his room, knowing
2 when Mark is sick and getting him to the
3 doctor when necessary.

4 The staff is always happy to be involved
5 with making sure his clothes are clean and
6 that he has a haircut, and his grooming is
7 always just so. The staff always knows what
8 should go in Mark's room to make him happy
9 and safe.

10 The State has been so perfect in every
11 way, making sure the best staff was hired and
12 watching over Mark like he was their own. I
13 would hate to see underpaid staff come in and
14 not get as personally involved, because they
15 most likely won't stay long enough to really
16 get to know the guys.

17 I'm worried without proper background
18 checks the wrong kind of people will be
19 taking over our kids. The most important
20 thing for the mentally disabled is that
21 someone understands when they are sick and
22 how to read what's going on with them. The
23 high turnover in the private provider
24 residential programs is not conducive to a
25 continuation of care that is necessary for a

1 high quality of life for this population.

2 That's it. I'm just saying continue
3 what you're doing and fund what needs to be
4 funded, and save our kids.

5 MS. MURRAY: Thank you.

6 Paul Tavernier and then after Paul -- is
7 Paul here?

8

9 (No response.)

10

11 MS. MURRAY: Okay. Tom Higgins.

12 TOM HIGGINS: Good morning, everyone.
13 My name is Tom Higgins and I've been employed
14 at DDS North Region for the past eight and a
15 half years, the last seven of which I've been
16 at 248 Ridgewood Road in East Hartford. I'm
17 a retiree from New York State at Hudson
18 Valley DDSO. I also worked a management role
19 in a private civil agency here in
20 Connecticut, as well as being in management
21 in Hudson Valley DDSO.

22 Personally I have 50 years of experience
23 with developmentally disabled individuals, as
24 my neighbor and Cub Scout den mother had a
25 child who was born with down syndrome. I

1 used to babysit him when he came home for
2 visits from Hudson Valley where he had lived
3 and his mother worked, and I was later to
4 work also. I also had her son as one of
5 those in my care in a group home, and I also
6 buried him when he died. Therefore, I would
7 like to offer a little perspective.

8 The training and experience I received
9 at both Hudson Valley DDSO and here in DDS,
10 in Connecticut was much more in depth and
11 intensive than that of the private civil
12 agency that I worked for. That is not to
13 disparage them. They did the best they could
14 with what they had, however due to the
15 particulars that nonpublic agencies operate
16 under they cannot offer the continuity and
17 quality that DDS affords the individuals we
18 serve.

19 That is because they -- by and large,
20 over pay scales that are not conducive to
21 hiring and attracting -- excuse me, hiring
22 and keeping a dedicated staff pool. It is a
23 sad fact, but true nonetheless. I witnessed
24 this personally. Too high degree of turnover
25 and low job satisfaction were part of the

1 mix.

2 We are all aware of Connecticut's
3 financial issues, but this is not the fault
4 of the individuals we serve, nor the
5 employees who provide the continuity and
6 quality care. Historically, government as
7 well as upper management has not wanted to
8 think outside of the box and listen to staff
9 input on how to manage costs, and still
10 provide what the mission is all about. 1199
11 Northeast and its members both want to work
12 with the government and management, but the
13 reverse appears not to be the case.

14 We hear much talk these days about
15 infrastructure. What about the human
16 infrastructure? The individuals that we
17 serve need DDS, and so do their families.
18 DDS employees need and want their jobs, and
19 they are willing to help the State with the
20 problems that we are currently undergoing.
21 Is the State willing to listen?

22 We live here, we pay taxes, raise
23 families, buy goods and services and support
24 the social fabric of this state. We should
25 work together and not continue with this

1 us-and-them impasse that plagues the State,
2 and the world at large.

3 It has been said that one can tell what
4 a society is truly like by how it treats it's
5 weak and infirm. How do we measure up here
6 in Connecticut? Privatization in and of
7 itself does not work. It may have part of
8 the solution, but not all of it. Just ask
9 Massachusetts and what they went through.

10 Thank you, and happy holidays.

11 MS. MURRAY: Thank you.

12 Lindsay Matthews, and then James Rutt.

13 LINDSAY MATTHEWS: Thank you.

14 I'm here to urge DDS to listen to my
15 story, to suspend cuts and to provide quality
16 care to all individuals with disabilities in
17 our state.

18 First, I want to thank all of the DDS
19 1199 SEIU workers who have supported and
20 taken care of my son all of these years, and
21 who continue to do the most magnificent,
22 incredible, thankless job I can imagine. So
23 thank you to all of you workers who do this
24 kind of work.

25 I am George Griffin's mother. My name

1 is Lindsay Matthews and I am the mother who
2 filed the lawsuit against the Department of
3 Developmental Services and defendants Morna
4 Murray and Thomas Dailey. In the lawsuit I
5 am seeking an order barring DDS from taking
6 away George's professional state caregivers,
7 and replacing them with highly exploited
8 non-skilled substitutes who are paid less
9 than half the cost of living in Connecticut.

10 These workers get infrequent raises and
11 are forced to live as paupers, while at the
12 same time living in the richest country in
13 the world, in one of the richest states in
14 the country. As the basis of my lawsuit I
15 refused to sign the HIPAA form, because I
16 believe the practice of using private medical
17 information for business purposes is
18 unlawful. In fact, in the course of the
19 nonprofits shopping for contracts with the
20 State, the only covered entity that actually
21 provides medical care is the one who wins the
22 contract.

23 How did we get here? How did we get to
24 the point where there are very few resources
25 and importance given to funding the health

1 and well being of those who cannot care for
2 themselves, those who cannot even speak? We
3 got here because our developmentally disabled
4 family members can't defend themselves.
5 They're easy to attack, to steal from and to
6 ignore. To some they are budget cuts, line
7 items, black numbers on a printed page.

8 It wasn't until I initiated a lawsuit
9 that a flood of confidential horror stories
10 about nonprofit care began to come my way
11 from parents, guardians and siblings with
12 family in nonprofit care. The media work I
13 did -- the more media work I did, the more
14 e-mails and phonecalls I got with more pleas
15 for help.

16 One day I was out bicycling and
17 approached a woman along with her son who was
18 in a wheelchair. He couldn't talk and she
19 was afraid that subtle clues from him would
20 be missed or ignored now that he is in
21 private nonprofit care. She pleaded for help
22 from me to get her son into state care, but
23 the only thing I could do was to take her
24 e-mail address and to try to connect with her
25 every now and then to support her.

1 A few months ago while at work a woman
2 learned I was the parent who filed a lawsuit
3 against DDS, and approached me. She told me
4 that ever though her daughter was in a group
5 home that is privately run, she's stable, but
6 the problem is she, the sister has to do
7 yeoman's work to keep her daughter's -- her
8 sister's health care stable. For families we
9 can't be there to guard and protect a family
10 member in a nonprofit. The stress levels on
11 marriages and family life can be devastating.

12 Private nonprofit versus public care,
13 let's stop arguing about that. We all know
14 that the same level of care provided by
15 well-trained professional union workers
16 cannot be delivered by workers who get paid
17 \$12 an hour, no benefits, no raises and have
18 to live as paupers.

19 And these lower income jobs actually
20 hurt the economy of our State because these
21 workers then need public assistance for food,
22 electricity and some health care. We demand
23 that the State of Connecticut give us what it
24 has always provided and maintained, a system
25 of health care for our developmentally

1 disabled citizens, a system staffed by
2 professionally trained, well-paid workers who
3 stay in these jobs year after year, who take
4 care of our children, and become family to
5 us.

6 Thank you for listening.

7 MS. MURRAY: Thank you.

8 James, and then we have Lenora Hogan
9 Harris.

10 JAMES RUTT: Hello. My name is James
11 Rutt, and I have a brother Louis Rutt that's
12 been residing at Beelzebub Road also. I have
13 a long history, you know, working with my
14 brother through the system.

15 My brother, when I was ten years had to
16 be taken out of the home. He was very
17 violent. He would have outbursts. I
18 remember when we got to my childhood days
19 when chairs would be flying I would get under
20 the table. He had 20 years that were spent
21 in a private home down in New Jersey that,
22 because of funds, really couldn't keep going.
23 It really deteriorated, and so did his
24 emotional well being. I actually brought him
25 into the state system on an ambulance at

1 midnight into Norwich, Norwich State
2 Hospital.

3 Since being with the State I've seen
4 conditions improve, and improve, and improve.
5 And I can go back to a time when I was in
6 school. I would study special education. I
7 worked as a federal worker, actually, at the
8 Walter E. Fernald School which was -- or
9 Institution, which was the first in the
10 country.

11 And back then in the seventies if you
12 could only see the way that the people were
13 warehoused then, it was basically a warehouse
14 situation most of the time. They weren't
15 wearing clothes. There was very, very little
16 help. I think back then they were paid \$2 an
17 hour. Of course, there's been a lot of
18 inflation since then, but it was still low
19 pay for then for the type of conditions they
20 had work in.

21 One day there was actually a strike and
22 I had to replace some of the state workers
23 that were working. I spent a night in a crib
24 ward with the conditions that were
25 horrendous, that none of us would ever want

1 to experience.

2 The reason I bring this up is because
3 how far things have come, and my brother does
4 not speak. He was born deaf. He's had a
5 history of self abuse, tearing at his arms
6 because of frustration, not being able to
7 communicate. He's been, through the years,
8 it's been 37 years in the state system.

9 I think he's close to 30 years at
10 Beelzebub. He was at Mansfield Training
11 School. All along he's improved. He's had
12 consistent help from Mansfield in the state
13 system and has done phenomenal. It's only
14 really in the past probably five to ten years
15 that he's stopped the self injurious
16 behavior.

17 He still has outbursts once in a great
18 while, but he's a happy guy, a real happy
19 guy, and I would hate to see that change. I
20 don't know how it would be explained to him
21 that people that he's been working with for
22 so many years will be pulled away from him.

23 I think the biggest testimony are the
24 people that came up here that live in the
25 group homes. It's heart wrenching to hear

1 them speak about how they feel about the
2 people that are working with them.

3 So I do hope that as legislators you can
4 get this taken care of and keep things as
5 they are, because I think we're down to the
6 last critical people that are being taken
7 care of by the State, and these other people
8 that need the most help, and we shouldn't
9 turn our backs on them now.

10 Thank you for your time.

11 MS. MURRAY: Thank you.

12 Lenora. Lenora, you have the honor of
13 being the last person to testify this
14 morning.

15 LENORA LOGAN HARRIS: Then I'm going to
16 try to get through this.

17 Hi. My name is Lenora Logan Harris. I
18 come to you with 30 years of experience
19 working in the field of human services, most
20 currently working with individuals
21 residentially entrusted to the care of the
22 Department of Developmental Services North
23 Region as a supervisor of developmental
24 service workers.

25 I am here truly in mourning through this

1 life-altering experience with colleagues and
2 individuals collectively affected with the
3 completions of privatizations, as my home --
4 I claim it as my home, because I share it
5 with the residents that live there -- closed
6 as of September 1st of this year.

7 And I come also with those who have
8 homes that are pending with future potential
9 similar outcomes, and those with uncertainty,
10 folks who accepted the joint responsibility
11 to uphold the DDS vision and mission
12 statements as, not so much of a rule, but as
13 a second nature guide for performance while
14 supporting folks in their homes and their
15 private lives, maintaining their personal
16 growth, worth and with dignity and respect
17 and compassion.

18 Folks like the individuals, in many
19 cases, bonded with us as surrogate family
20 through many hours of dedicated service,
21 interactions, challenges and achievements,
22 biological losses and gains -- and that, I
23 never thought I could do this -- or but with
24 your help, I did. And I can't wait to see
25 what else I could do with your commitment and

1 assistance.

2 But most importantly, I am here as a
3 family member, the baby sister to a man
4 striving with the help of DDS staff members
5 to be the best man he can be while living
6 with autism.

7 Folks like our parents who struggled
8 with the decision to place their loved one in
9 the care of persons some 32 years ago, folks
10 that they who hoped would provide him with
11 the same level of care that they did the
12 first 19 years of his life, allowing him to
13 gradually -- allowing us to gradually know
14 and feel reassured that he was in good hands
15 with people who loved him the way that we do
16 in a safe and nurturing environment where his
17 choices and basic human rights are respected
18 and encouraged through positive means.

19 Parents and families who now are aging
20 and weary with illness, heightened with the
21 uncertainty with their loved one's future and
22 inability to provide care for them
23 themselves, as his home is slated for
24 privatization this January.

25 It isn't too late to make good on the

1 promise agreed upon originally some 32-plus
2 years ago, more or less, for others who
3 continue to care as it exists. Please
4 consider and seriously review alternative
5 resources for concession. When doing so be
6 mindful of the overall health and safety of
7 those we've promised to protect and develop.

8 Take the time to seek counsel from those
9 of us who live and work with these persons on
10 a day-to-day basis beyond what is written in
11 the reports that you see come across your
12 desk, that you hear in the news and that you
13 see in the Special Olympics, or your
14 neighborhood grocery stores, because there is
15 much that is not written and much to be
16 experienced.

17 Please note that their lives matter, and
18 they're vital -- the programs as they exist
19 are vital to their existence. And the
20 quality of care should remain the same as it
21 is now.

22 Thank you for your time.

23 MS. MURRAY: Thank you, Lenora.

24 That ends the morning session. I wanted
25 to just let everyone know that we'll be back

1 here in this same room at four o'clock this
2 afternoon.

3 Thank you all very much.

4

5 (Recess: 12:00 p.m. to 4:00 p.m.)

6

7 MS. MURRAY: Before we get started, if
8 there's anybody here that wants to speak and
9 hasn't yet signed up, would you see Rod over
10 there -- oh, I'm sorry. Yeraida, over there.
11 Okay. I think we'll get started. We moved
12 to a larger room because of the crowd this
13 morning.

14 Welcome everyone, and thank you for
15 being here. My name is Morna Murray and I'm
16 the Commissioner at DDS.

17 There's some staff up here from DDS.
18 We're here to listen to you, and I'd just
19 like to ask our staff to please introduce
20 yourselves on the mic so we can pick it up on
21 the record.

22 If we could start with you, Sibbhan.

23 MS. MORGAN: Siobhan Morgan, the
24 Director of the Waiver Unit.

25 MS. WOOD: Robin Wood, Director of

1 Family Supports and Strategies.

2 MS. VELARDO: Elisa Velardo, Regional
3 Director, North Region.

4 MR. MASON: Peter Mason, Director of the
5 Operations Center.

6 MR. SCHEFF: Jordan Scheff, Deputy
7 Commissioner.

8 MS. COONEY: Christine Pollio Cooney,
9 Legislative Affairs.

10 MS. ROCK-BURNS: Katie Rock-Burns, Chief
11 of Staff.

12 MR. MICARI: Dan Micari, Director of
13 Quality Management Services.

14 MS. MURRAY: Okay. So we are here for
15 an informational hearing about our DDS's
16 five-year plan, which we are statutorily
17 required to file every five years.

18 So I want to just say a couple of
19 things. Number one is, we're really here to
20 listen, and that is it. We cannot respond to
21 questions in this, in this forum. And it
22 really is an opportunity for you to provide
23 your comments and suggestions, proposals,
24 what ever you would like about the five-year
25 plan as it's been filed. It's still in draft

1 form.

2 Also keep in mind that we have a
3 transcriber here. There will be an official
4 public transcript from this proceeding, so
5 everything that you say or submit will be
6 part of the record. If there's anything, any
7 private information or anything that you
8 don't want to share, please don't testify to
9 that, because anything that is shared will
10 become part of that record and made public.

11 So just a couple words on behalf of DDS
12 in terms of our five-year plan. I hope all
13 of you had a chance to look at it. It's
14 fairly detailed, but again it's an overview
15 of the next five years. We're not going into
16 everything that we're doing, obviously. It's
17 a strategic document.

18 In it -- some of the highlights from it
19 is that, you know, we are very committed to
20 moving away from our legacy system of past
21 years, and we're looking to support self
22 advocacy efforts as much as we possibly can
23 for the people that utilize our services, and
24 families as well. And our biggest goal at
25 this point really in terms of the overall

1 climate in our budget, and as well as our
2 desire to become more streamlined and
3 efficient at DDS, is to create sustainability
4 within the agency.

5 That is something that we have to look
6 at from all angles, and we realize that there
7 are many competing interests when it comes to
8 sustaining and maintaining services, both for
9 people who receive services currently and
10 those who are waiting for services.

11 And we do have a commitment at DDS and
12 it will continue to be a commitment, and it
13 will evolve in many different ways of being
14 transparent, both within the agency and also
15 to the public. So we look forward to
16 partnering with you in developing a final
17 five-year plan. And I think with that, I
18 have said everything I'm supposed to say.

19 Please make sure when you come up that
20 you push the microphone button to testify.
21 We have a buzzer that will go off, sadly, at
22 the end of three minutes. I don't want to
23 cut you off. I don't want to interrupt you,
24 so I'm going to ask you to please monitor
25 yourselves and try to stay within that

1 three-minute window.

2 We'll be here until seven o'clock, so if
3 you've got some friends that want to testify
4 and they're not here, text them or give them
5 a call. Right now we have eight people
6 signed up, and so we'll get started with that
7 right now.

8 And I will call the first person, who is
9 Debbie Marocchini. And please make sure you
10 state your name for the record.

11 DEBBIE MAROCCHINI: Debbie Marocchini.
12 My daughter Taren is developmentally disabled
13 and has been in the DDS system for ten years.
14 I would like to speak about what is missing
15 from the five-year plan, and that is there is
16 no plan on how to maintain consistent care
17 for my daughter and those like her.

18 Taren was in two private group homes.
19 The first one couldn't control her behaviors,
20 so they heavily medicated her to a point
21 where she was in the Institute of Living.
22 After that she was moved to another private
23 group home and her condition worsened. She
24 had to be moved to the Hartford regional
25 center on an emergency placement where there

1 were wonderful staff that took care of her.
2 They took the time to get to know her. She
3 had a quality of life. She was drastically
4 improved.

5 She then was moved to Farmington. The
6 Farmington home was then sold private. Then
7 she was moved to East Hartford -- and now the
8 East Hartford home. She has to move again
9 back to Newington. She's moved six times in
10 the last ten years, and I just need to know
11 what is the plan? The consistency of care
12 the population depends on -- I just don't
13 know what's going to happen.

14 Thank you.

15 MS. MURRAY: Thank you.

16 Next up is Lori Gaglione.

17 LORI GAGLIONE: Hi. Thank you. My name
18 is Lori Gaglione and I'm the legal guardian
19 and sister of my brother Joey Cepeda who
20 resides at 67 Mountain Road. Joey has been a
21 resident of the center for 42 years. He was
22 placed in the center when my mom was
23 diagnosed with cancer. We live in Newington,
24 so we were very fortunate to have a placement
25 close to home.

1 Joey has a need for 24-hour nursing
2 staff that this placement provides. The
3 five-year plan doesn't have any language
4 about maintaining services for medically
5 involved individuals. Joey is epileptic who
6 has grand mal seizures, high blood pressure,
7 and over the past year has had severe
8 intestinal issues that required
9 hospitalization. The five-year plan doesn't
10 provide any concrete information regarding
11 the care our family members deserve. We need
12 details.

13 The staff has been my rock over the past
14 42 years. They have become my lifeline to
15 Joey. I cannot provide the constant care
16 that Joey needs. The staff has been
17 consistent, well trained to deal with this
18 behavioral issues, as well as to provide fun
19 outings in the community.

20 Joey is nonverbal and communicates with
21 limited sign language and vocal cues. The
22 consistency of the staff enables them to
23 understand Joey's needs and react to when
24 there is an important issue. Joey does not
25 react well to change. My concern is that

1 with all the changes the staff will not be
2 consistent.

3 When there are too many changes Joey's
4 behavior changes and his seizure activity
5 increases. Joey has an individualized
6 learning/training program and has thrived
7 with the staff. The consistency that the
8 staff has, has enabled us to have comfort in
9 knowing that Joey is in a safe place with
10 staff that loves him as family.

11 My whole life has been dictated by what
12 was best for Joey, who I married, where I
13 lived, when -- what I have done. I'm asking
14 to put yourself in our position as well as
15 all these other families that have come
16 forward with their stories to ask you what
17 you would do if you were in our position.

18 The five-year plan does not take into
19 account the relationships that have been
20 developed over the years. There is also
21 nothing in the five-year plan about
22 advocating for monies -- funds -- I'm sorry.
23 I can't read it. There's also nothing in the
24 five-year plan about advocating for more
25 funds to the agencies about the public and

1 private sectors are properly funded. We are
2 desperately seeking your help. Privatization
3 is not the answer, and it comes at the
4 expense of the care, life, and the health of
5 our loved ones.

6 Thank you so much for listening.

7 MS. MURRAY: Thank you.

8 Next we have Henry Lognin. Is Henry
9 here?

10
11 (No Response.)

12
13 MS. MURRAY: Okay. We can come back to
14 him.

15 Let's see. Ron Langner.

16 RONALD LANGNER: Good afternoon -- or
17 good evening, actually. My name is Ronald
18 Langner. I live in Tolland, Connecticut.

19 I was really very disappointed to read
20 the proposed five-year plan of the Department
21 of Developmental Services, which is really
22 supposed to outline the goals of the agency
23 for the next five years.

24 The document lacks clearly defined
25 goals, and without clearly defined goals it

1 is impossible to determine if any significant
2 progress will be made over the next five
3 years. For the past four years my wife and I
4 have worked with other families with the ARC
5 of Connecticut to advocate for better
6 services for children with intellectual and
7 developmental disabilities.

8 We have done research. We have written
9 reports. We have offered testimony to
10 highlight the inefficiencies and wasteful
11 spending within DDS. We have urged DDS to
12 close outdated and outrageously expensive
13 institutions and to use the savings to do
14 something about the waiting list. I am
15 encouraged that DSS has continued to follow
16 the national trends toward community-based
17 residential supports, and away from public
18 operated, expensive institutional care.

19 Unfortunately, a continued commitment is
20 not clear in the five-year plan. It barely
21 mentions the waiting list. It also does not
22 acknowledge that there are now waiting lists
23 for day services and respite care. I read
24 the document trying to figure out exactly
25 what DDS has in mind for the next five years

1 and I found this summary paragraph on
2 page 20. Let me quote. I'll read it to you.

3 We will seek to prioritize agency
4 projects in a way which will allow DDS to
5 learn and absorb new ways of operating before
6 initiating new business practices.

7 Strategically we will focus on building a
8 strong foundation, improving care
9 competencies in the first phase.

10 The second phase will allow us to
11 achieve early progress in implementation of
12 new programs leading us to projects focused
13 on active evolution in the delivery of
14 sustainable and informative supports in phase
15 three.

16 In phase four DDS will be transformed
17 into a responsive, modernized organization.
18 Some people may by necessity fall outside of
19 the strategic framework, but by and large the
20 agency intends to follow this model to find
21 success.

22 Now these statements, while they may
23 sound very elegant, are also so general and
24 obtuse that they could apply to any business
25 I can think of. What does that paragraph

1 state about how DDS will meet the needs of
2 families?

3 In reality, DDS seems to be saying to
4 families relative to the waiting list and
5 other core services, hey, see us again in
6 five years when we have transformed the
7 agency into a trans-responsive modern
8 organization, and we may have an answer for
9 you by then. DDS really can do better, and
10 DDS must do better in the next five years.

11 Thank you.

12 MS. MURRAY: Thank you.

13 Next up is Ben Shaiken.

14 BEN SHAIKEN: Hello, and good afternoon.
15 My name is Ben Shaiken and I work at the
16 Alliance, the voice of community nonprofits.
17 Community nonprofits serve more than half a
18 million people in Connecticut, thousands of
19 whom are individuals with intellectual and
20 developmental disabilities.

21 Programs and services provided by
22 nonprofits are a vital part of all our cities
23 and towns, allowing individuals and families
24 to live productive lives in the community and
25 contributing to making Connecticut a great

1 place to live and to raise a family.

2 Community providers serve the majority
3 of individuals in the DDS system with
4 residential, day and employment services
5 offering services of the highest quality.
6 Tens of thousands of wonderful staff and
7 workers support these individuals every day.

8 I'd like to thank the department, first
9 of all, for giving the public the opportunity
10 and ability to offer comments on their plan.
11 I want to acknowledge the progress that the
12 department has made in the last five years.
13 As highlighted throughout the document, we'll
14 be submitting detailed written comments about
15 the plan, but I'd like to take the
16 opportunity to note several key points today.

17 The department should use this document
18 as a starting point for creating a more
19 specific and targeted plan to provide
20 services to more individuals. Currently
21 thousands of families are waiting for
22 services, and this plan could be an
23 opportunity to reduce the number of families
24 who are entitled to services, but are not
25 receiving them.

1 In the midst of the State's budget
2 crisis this is a daunting proposition, but
3 with adequate support from the State
4 nonprofits they provide high-quality
5 cost-effective services to more individuals
6 and families while saving the State
7 significant dollars.

8 By integrating individuals into our
9 communities we can make serious progress to
10 increase the number of individuals and
11 families who receive the care and the support
12 that they need, and I hope that the
13 department's five-year plan can integrate an
14 action plan to achieve those goals.

15 Thank you very much for this
16 opportunity, and have a wonderful evening.
17 Thank you.

18 MS. MURRAY: Thank you.

19 Next up is Roland Bishop.

20 ROLAND BISHOP: Good afternoon,
21 everyone. My name is Roland Bishop. I am
22 the secretary-treasurer of CSEA SEIU Local
23 2001. I'm an elected leader of a labor union
24 that represents thousands of workers across
25 the State, including over a hundred dedicated

1 instructors at the Department of
2 Developmental Disabilities.

3 I'm here today to discuss the proposed
4 plan to privatize 40 state-run group homes
5 and the range of services for intellectually
6 disabled, and the layoff of over 600 state
7 employees who currently work for DDS. And
8 again, it's the plan -- it's a poorly planned
9 rushed to save money at the expense of our
10 state's most vulnerable citizens, and some
11 are here.

12 This proposal may intend to save money,
13 but we public employees know too well the
14 pitfalls of privatization. Some of those
15 pitfalls are, does it produce the promised
16 savings, the numbers on a spreadsheet? And
17 it frequently brings with it other downfalls,
18 including corruption if we look at past
19 history. And you know, the quality of
20 services that are provided will diminish. So
21 cutting these vital services and laying off
22 public workers directly harms these
23 residents, some of whom are here today.

24 The DDS system of care must remain a
25 core governmental function, which is one of

1 the Governor's bullet points on his planning.
2 We strongly demand that you postpone any
3 decisions until you sit down with the
4 stakeholders, and as a previous speaker says,
5 a specific targeted plan.

6 The stakeholders include the workers and
7 the front-line workers who provide the care.
8 Only together can we move forward to address
9 some of these pitfalls that I've outlined
10 earlier, and it's in the best interests of
11 the individuals with the disabilities, their
12 families, the workers and their families.

13 Thank you for listening. Have a good
14 day, and have a great holiday.

15 MS. MURRAY: Thank you.

16 Next is Rich Rothstein.

17 RICHARD ROTHSTEIN: Good afternoon,
18 Commissioner Murray, Deputy Commissioner
19 Scheff, and the DDS management team. Thank
20 you for all you do for the families that face
21 the challenge of intellectual disabilities.
22 We're quite thankful for all that's done --
23 obviously there's more that needs to be
24 done -- and thank you for the opportunity to
25 offer comments on the draft five-year plan.

1 Today I'm speaking on behalf of
2 Connecticut DDS Families First, a nonprofit
3 organization formed entirely and operated
4 entirely by parents, grandparents and
5 siblings of those with intellectual
6 disabilities. Our goal is to educate and
7 advocate working closely in partnership with
8 families, other advocacy groups, obviously
9 DDS, providers, educational institutions,
10 legislators, anyone who will listen. But the
11 broader our partnership, the better off we're
12 going to be.

13 Besides the overall funding for DDS our
14 focus has been on waiting lists, and
15 principally the residential waiting list.
16 We're very supportive of DDS and its
17 management, and we recognize there needs to
18 be a continuing evolution of the agency and
19 its services.

20 I'm only going to talk about a couple of
21 things. Because of time limitations we're
22 likely going to be filing detailed comments
23 at a later time.

24 This is a very difficult time for all of
25 our agencies, and DDS has faced a number of

1 challenges this year that weren't
2 anticipated, and everything has continued.
3 Services have continued to all that receive
4 them. So it's been an extra stretch, and
5 preparing a five-year plan for any business,
6 organization or agency is a very difficult
7 task, having participated in it directly
8 before.

9 In our view, the DDS five-year plan is
10 very broad and very general, lacking many of
11 the details that we'd like to see in a plan.
12 And we feel that the document should be used
13 as a report to the Legislature to whom this
14 is delivered about what our needs are,
15 recognizing that there's only so much money.

16 But in order for the Legislature to
17 determine what the funding should be for our
18 core services, as compared to other core
19 services in other agencies, we think that the
20 report should include information about what
21 the needs are. The statute that requires
22 this report actually seems to require that,
23 Section 17-211a6, which requires that the
24 plan estimate the type and quantity of staff
25 and other -- and client services that will be

1 needed over the life of the plan.

2 So how many people are going to age out
3 of DCF programs? How many people are going
4 to graduate from there at age 21 and need day
5 programs? How many people need residential
6 programs? What is the estimated need for
7 respite, family support grants and other
8 things that DDS does, and does well?

9 Some of those things are fairly easy to
10 estimate, or guesstimate. Some of them are
11 more difficult, particularly residential
12 needs. And we really believe and we've been
13 working with the department to develop some
14 kind of census tool where we can survey all
15 of the individuals that have LON scores to
16 come up with what the needs might be.

17 We applaud the formation of the IP
18 partnership and we would suggest that the IP
19 partnership include a broad spectrum of
20 families, and from individuals in advocacy
21 groups, because it's only if we have a broad
22 representation will we really know what the
23 needs are and work towards common solutions.

24 We would also suggest that the regional
25 advisory and planning councils and the

1 council on developmental services also be
2 used more actively in the planning process.

3 We will submit the comments at a later
4 time. Thank you very much for your time, and
5 we look forward to working with you in
6 partnership into the next five years and
7 beyond.

8 Thank you.

9 MS. MURRAY: Thank you, Rich.

10 Lindsay Matthews.

11 LINDSAY MATTHEWS: Thank you. Good
12 afternoon, everyone. I'm here to urge DDS to
13 listen to my story, to suspend all cuts and
14 to provide quality care to all individuals
15 with disabilities in our state.

16 First of all, I'd like to also thank the
17 1199 DDS workers who have taken care of my
18 son and protected him and encouraged him and
19 loved him over the past 51 -- 50 years --
20 perhaps that long -- because they are family
21 to us, and I can never thank them enough for
22 all of the wonderful care that they've given
23 us and our family and the supports that
24 they've given us. So DDS should be proud of
25 these workers because they've done a

1 magnificent job.

2 I am George Griffin's mother. My name
3 is Lindsay Matthews, and I am the mother who
4 filed the lawsuit against the Department of
5 Developmental Services, and defendants Morna
6 Murray and Thomas Dailey. In the lawsuit I
7 am seeking an order barring DDS from taking
8 away George's professional state caregivers,
9 and replacing them with highly exploited,
10 non-skilled substitutes who are paid less
11 than half the cost of living in Connecticut.

12 These workers get infrequent raises and
13 are forced to live as paupers, while at the
14 same time living in the richest country in
15 the world, and in one of the richest states
16 in the country.

17 As the basis of my lawsuit I refused to
18 submit the HIPAA form, because I believe the
19 practice of using private medical information
20 for business purposes is unlawful. In fact,
21 in the course of the nonprofits shopping for
22 contracts with the State, the only covered
23 entity that actually provides medical care is
24 the one who wins the contract.

25 How did we get here? How did we get to

1 the point where there are very few resources
2 and importance given to funding the health
3 and well-being for those who cannot care for
4 themselves, those who cannot even speak? We
5 got here because our developmentally disabled
6 family members can't defend themselves.
7 They're easy to attack, to steal from and to
8 ignore. To some they are budget cuts, line
9 items, black numbers on a printed page.

10 It wasn't until I initiated a lawsuit
11 that a flood of confidential horror stories
12 about nonprofit care begin to flood my way
13 from parents, guardians and siblings with
14 family in nonprofit care. The more media
15 work I did, the more e-mails and phonecalls I
16 got with pleas for help.

17 One day I was out bicycling and
18 approached a woman along with her son who was
19 in a wheelchair. Her son was in private care
20 and our conversation revealed that she had to
21 go to her son's group home every day for fear
22 that he would not get his medications on
23 time. He couldn't talk and she was afraid
24 that subtle clues from him would be missed or
25 just ignored. She pleaded with me for help

1 to get her son into state care, but the best
2 I could do was get her e-mail address and
3 contact her and support her from time to
4 time.

5 A few months ago, while at work, a woman
6 who learned I had filed a lawsuit approached
7 me and asked if I would listen to her about
8 her sister, the care of her sister. Her
9 sister's life in a nonprofit group home was
10 somewhat stable at the moment, but the
11 problem was that she had to spend almost
12 every day following up, checking up, and it
13 took a lot of her time as well.

14 Her problem was that she had to work
15 almost full-time to keep her sister's health
16 stable, including that of working as a
17 citizen pharmacist, detective, investigator,
18 researcher, social worker and advocate.

19 For families who can't be there to guard
20 and protect a family member in a nonprofit
21 the stress levels on marriages and family
22 life can be devastating. Who's needs come
23 first? The children at home? The care of an
24 aging grandparent? Or the child who, because
25 of his or her handicap, is forced to live in

1 an unstable situation away from home?

2 This is the face of private care and
3 just some of the negative impacts it has on
4 families. If they can get it, private care
5 means they pay for it themselves. They pay
6 for it with round-the-clock vigilance, worry
7 and fear. They pay for it when the
8 nonprofit, struggling financially by the
9 State, skimps on staff and services. And
10 they pay for it when they have to live with
11 the fact that the safety net they have always
12 expected to have would be for them is now
13 gone.

14 Private nonprofit versus public care,
15 let's stop arguing about that. We all know
16 that the same level of care provided by
17 well-trained, professional union workers
18 cannot be delivered by workers getting paid
19 \$12 an hour. And these low-income jobs
20 actually hurt the economy of our State,
21 because these workers then get public
22 assistance for food, heat and electricity.

23 We demand that the State of Connecticut
24 give us what they have always provided to us
25 and maintained, a system of health care for

1 our developmentally disabled citizens, a
2 system staffed by professionally trained
3 well-paid workers who stay in these jobs year
4 after year, and become like family to our
5 children and to us.

6 Thank you.

7 MS. MURRAY: Thank you.

8 Before I move onto the next group of
9 people, I just want to double back and see if
10 Henry Lognin is here yet?

11
12 (No response.)

13
14 MS. MURRAY: Okay. If anybody sees
15 Henry, just tell him to flag us down if he
16 comes in.

17 Next up is John Allen.

18 JOHN D. ALLEN: That's a tough act to
19 follow.

20 Hi. My name is John D. Allen. I know
21 that there was another John Allen here
22 earlier today, and there's three in state
23 service.

24 I'm a member of 1199, and I'm a helpline
25 case manager for the south region in New

1 Haven where two case managers support 1200
2 people that are not on a waiver. I've been a
3 state employee for four years, but have
4 worked within the DDS system for 26 years.
5 Most of that has been with lead agencies
6 among the private provider nonprofit network.

7 I want to make four points today. In
8 2008 my doctoral research looked at how staff
9 within this network facilitate quality of
10 life issues for those served, and what my
11 study revealed and what I witnessed firsthand
12 over my career is that there is a marked
13 difference between state and private staff.
14 First is that one of the -- that every one of
15 the 30 staff that I interviewed in the
16 private sector held multiple jobs, and some
17 more than two full-time jobs.

18 In 2008 staff wages were 12 to 14
19 dollars an hour, and little has changed in
20 eight years. Multiple jobs and family and
21 personal responsibilities can manifest in a
22 fatigued and preoccupied direct care
23 workforce.

24 Second is the attrition noted among
25 private staff. There is less loyalty to

1 low-wage jobs, jobs that can be physically
2 demanding and often involve tremendous
3 personal and professional risk.

4 Third is an empirical observation about
5 the recent dismantling of DDS through layoffs
6 and vacancies. The work provided by DDS
7 staff is not easily duplicated in the private
8 sector. People with intellectual
9 disabilities often require those able to
10 recognize nuance that comes from years of
11 working with this population.

12 On the helpline I've made best efforts
13 to locate professionals able to duplicate
14 clinical team services including
15 psychiatrists, speech therapists,
16 behaviorists and even support workers. Many
17 community providers do not possess comparable
18 skills. The infrastructure is just not
19 there.

20 Last, our individuals are a specific
21 population with unique needs. Private sector
22 clinicians do not learn in their trainings
23 how to serve our folks. Rather, it is best
24 learned over time with direct experience. I
25 am concerned that we seem to be discarding

1 our experts, since the private sector does
2 not appear willing, interested, or able to
3 serve our people, and especially for those
4 individuals who are most challenging.

5 We need to keep viable both public and
6 private systems of support in order to react
7 quickly, and especially for emergencies that
8 often occur. Services will evolve, but I am
9 fearful that the recent changes are being
10 haphazardly implemented and certainly
11 occurring too quickly for the private sector
12 to absorb.

13 Thank you for your time.

14 MS. MURRAY: Thank you, John.

15 Next we have Mark, Mark Quesnel,
16 followed by Fred Hyde.

17 MARK QUESNEL: How are you? I assure
18 you my comments are going to be very brief
19 and not detailed. As everybody knows, this
20 comes from personal experience working in the
21 department.

22 I'm Mark Quesnel. I'm a supervisor in
23 the north region. I've been working for DDS
24 for 26 years. I always tell people it's
25 exactly half my life now, you know, to put it

1 in perspective. So I've seen a lot of good
2 stuff, a lot of good care that was given to
3 the DDS clients over the years. And lots of
4 times staff have gone above and beyond their
5 job duties and, you know, I commend them for
6 that.

7 This department had a division to
8 exemplify each individual's need, and
9 interests are of the utmost importance. And
10 I've always followed those, you know, the
11 vision statement. And I've tried to
12 supervise my staff in that manner over the
13 years.

14 Recently my group home was slotted for
15 conversion, and a lot of the people that I
16 serve have very intense medical conditions
17 that require specific training and nursing
18 delegation to direct care staff who work on
19 the floor. And I see, you know, group homes
20 being closed and, you know, we receive staff
21 from these group homes.

22 And there, you know, it takes a lot of
23 training to get them really up to the level
24 that our clients deserve. And I just feel
25 that, you know, private providers, if they

1 come in and we're not here, you know, how do
2 we -- what is the plan to properly train this
3 and how to take care of the, you know, the
4 intense medical needs of my clients in the
5 particular group home?

6 I just don't think that it was well
7 thought out and, you know, I believe that we
8 need to just step back and think about the
9 clients that we serve and, you know, I guess
10 that's it. Thank you.

11 MS. MURRAY: Thank you.

12 Fred Hyde is up, and after Fred will be
13 Linda Kautzner.

14 FRED HYDE: Commissioner, and members of
15 the staff, ladies and gentlemen, thank you
16 for letting me take a second bite at the
17 apple.

18 I think I got the privatized egg timer
19 this morning, a few seconds short of a
20 minute. I didn't do myself any favor either
21 by misstating the address of the website that
22 has been created with my report. And so, for
23 the record it's
24 PauseButtonForDdsFiveYearPlan.Org.

25 There are two reasons that you might

1 want to look at this website. First it's got
2 a bibliography of all the studies that I
3 could find. You know, this era of
4 privatization began with President Reagan and
5 the first studies that really seemed to track
6 the human services came in the late eighties,
7 early nineties. I put in there every study I
8 could find. You'll find two dozen studies.
9 And if you have some more, by all means, send
10 them along. I'm am happy to post them --
11 which have one consistent bottom line, few if
12 any savings, notwithstanding promises,
13 deterioration of services. The more complex
14 the service, the greater the deterioration,
15 the higher the likelihood for scandal.

16 Now a second thing that will occur to
17 you when you visit this site, and I really,
18 with all of you will be moved, and if we
19 weren't moved, we wouldn't be human -- by the
20 stories brought here, brought daily by the
21 dedicated men and women here, but also by the
22 stories on this website.

23 I solicited these stories. I anonymized
24 them so as to reduce any fear there might be
25 of, either invasion of privacy or

1 retaliation. And I posted there an affidavit
2 indicating that I vouch for their accuracy.
3 There are 50 stories on this website that
4 show in myriad ways why you're not going to
5 save a nickel in privatization, why the
6 unintended expenses -- that are nobody's
7 fault.

8 They're not things that you say, oh, my
9 God. We're going to have to have emergency
10 room, and nursing home, and a variety of
11 other expenses logged in so that we know what
12 the all-in cost is, but we do owe it to
13 ourselves to learn from the experience of
14 other states.

15 One final thing I'd like to repeat, and
16 especially for you, Commissioner, because you
17 obviously have been a valued and trusted
18 member of the Governor's cabinet. You could
19 do him, on the way out, a great favor, and an
20 honor to all of these people, to explain that
21 the coming changes in Medicaid will render
22 irrelevant whatever risks have been taken
23 here in Connecticut, and will destabilize
24 those states that are most dependent on
25 Medicaid.

1 Most recently I spent a lot of time in
2 New York. I'll give you a sense of, you
3 know, this morning I said we had a lot of
4 hands in the till for Medicaid in
5 Connecticut. You've got a lot of hands in
6 the till in the nation. Our state budget, a
7 little north of \$20 billion. New York's
8 Medicaid budget, \$60 billion. Okay.

9 So there are a lot of folks who are
10 going to be going for block grant money who
11 are bigger and badder than we are. We don't
12 want to be in competition with them with
13 waivers that leave discretion entirely in the
14 hands of Washington staff. You've got to get
15 some more state money into this system.

16 If you just did what Massachusetts did,
17 notwithstanding the problems they've have, in
18 terms of putting your own money in as the
19 State of Connecticut you would be so much
20 better off. Public and private would be much
21 better off. And if you could give your
22 Governor that message on the way out, you'll
23 do him a great service.

24 MS. MURRAY: Thank you.

25 Linda, and then after Linda will be

1 David Adams.

2 LINDA KAUTZNER: Hello, ladies and
3 gentlemen. My name is Linda Kautzner and I
4 would like to talk about how the five-year
5 plan will harm individuals by allowing for
6 and encouraging privatization of services.

7 I am the guardian of my brother, Ricky
8 who is 55 years old. I love him very much.
9 My brother lives in a state-run group home
10 with four other individuals. Ricky has lived
11 in this group home for over 30 years. He was
12 one of the first residents to move in when it
13 was built. Previous to that, he was living
14 at the Waterbury regional center. My parents
15 worked very hard to get him into Pondview,
16 which is more of a residential home setting.

17 My brother and many other residents in
18 these group homes are comfortable, happy, and
19 well cared for, and have been for a long
20 time. Unfortunately, some of these people do
21 not have family members involved in their
22 lives and they do not have advocates that
23 will speak up for them. I am here to speak
24 on my brother's behalf since he cannot speak,
25 and for all those who do not have someone to

1 speak for them.

2 I'm here to ask you -- excuse me, to
3 look into your hearts and see what
4 privatization will do to these individuals.
5 Their lives will be turned upside down.
6 Their health could become compromised. They
7 will not understand why the people who have
8 taken care of them for years, and who know
9 them so well, are no longer there. They will
10 not be able to voice their distress and
11 dismay, except in behavior outbursts which
12 could lead to them being injured or others
13 being injured.

14 I'm also asking you to do whatever is in
15 your power to stop this privatization from
16 happening. The individuals in these
17 facilities and group homes are human beings.
18 They're not cattle or a prized bull that gets
19 auctioned off to the highest bidder or the
20 lowest bidder -- or the only bidder. They
21 deserve our love, our respect and our care.
22 They do not deserve to have their lives
23 turned upside down by politics.

24 What is the price and/or cost of
25 privatization? How can anyone think this is

1 right or fair to do to these defenseless
2 individuals? Talk about going after the
3 weakest link.

4 The wonderful, well-trained and
5 dedicated brothers in my group home who take
6 care of him have also saved his life a number
7 of times. They know him so well that they
8 can tell when something is not right with
9 him.

10 Just recently, this year my brother did
11 not look right to them. His behavior was off
12 and his coloring was not right. He was taken
13 to the hospital where it was discovered that
14 he had a major blockage. I don't know if I
15 mentioned before that he couldn't speak. He
16 was in the hospital for a few weeks. It was
17 very scary. If not for the quick thinking of
18 the staff who knows him so well, he could
19 have died. I cannot express enough to them
20 how much they mean to me, and how grateful I
21 am for the care they give to him.

22 You cannot put a dollar figure on the
23 care of a family member, especially one who
24 is as vulnerable as my brother, and others.
25 The thought that they are well taken care of

1 by well-trained, dedicated people who love
2 them is priceless. I can sleep at night
3 knowing that he is well taken care of.

4 The thought of privatization and
5 untrained, low-paid people, personnel being
6 with him and not knowing what his needs are
7 or what his wants are is a very scary thing
8 for all the family members here and for
9 anyone that has a relative in the system.
10 The staff at this group home give my brother
11 continuity and consistency. That is what he
12 needs. The change in the turnover of people
13 would be detrimental.

14 In closing, I just want to say that the
15 budget is a major problem that needs to be
16 addressed, but the way the Governor is doing
17 this is putting a burden on these vulnerable
18 individuals and is not the way to go. Please
19 find another way. Please leave my brother
20 and his friends in the group home with the
21 same familiar staff and care that they have
22 come to rely on. They deserve that.

23 Thank you for your time.

24 MS. MURRAY: Thank you.

25 And next up is David Adams, and he will

1 be followed by Peggy Embardo.

2 DAVID ADAMS: Is this on? Thank you.
3 Thank you all for coming. I really
4 appreciate it. And thank you for the
5 wonderful words that you've given that come
6 out of your heart and out of your
7 experiences. I really appreciate it, because
8 I'm a stepfather of a son who has been cared
9 for in DDS homes, and I know what you're
10 talking about.

11 I also happen to be a retired professor
12 of psychology at Wesleyan, and I know as a
13 psychologist how important continuity of care
14 is, that with privatization to start changing
15 the caregivers is a tremendous blow to our
16 children. They depend on it, not only
17 because it's their family, but also because
18 those who have experience as their caregivers
19 know when there are signs of illness.
20 Whereas, a revolving door of people who are
21 not well trained and do not have experience
22 with our children, they don't see the signs.
23 They don't react. They don't save them.

24 As for saving money, it turns out that
25 privatization doesn't save money, as

1 Professor Hyde mentioned. Yeah, you cut the
2 wages of the workers, but you increase the
3 salaries of the managers, and you have an
4 enormous duplication of specialized services.
5 It doesn't save money.

6 Now finally, I want to say something to
7 the Governor and the Legislature. I know
8 that's not the purpose of this hearing, but
9 it needs to be said. Two facts. First of
10 all, as Professor Hyde has shown, the State
11 of Connecticut has cut in half in recent
12 years its contribution to DDS by increasing
13 the reliance on federal funds instead. Well,
14 that's a devastating direction. Connecticut
15 needs to come forth with this, with the money
16 for DDS.

17 And second of all, the second fact which
18 is obvious to everybody, it's the elephant in
19 the room. The rich are getting richer and
20 the poor are getting poorer. But the rich
21 are getting richer in Connecticut.
22 Connecticut is a rich state. There's money
23 in this state.

24 If the Legislature would go after the
25 rich in this state -- they could just start

1 with Yale University with its, I don't know,
2 4 or 5 billion dollars sitting there and not
3 paying taxes. The money is there. The need
4 is there. The business of the Legislature is
5 to put them together to get the money for the
6 needs of our children.

7 Thank you.

8 MS. MURRAY: Thank you.

9 Peggy Embardo, and Peggy will be
10 followed by Patti Spaulding.

11 PEGGY EMBARDO: Good afternoon. Can you
12 hear me? My name is Peggy Embardo and I'm
13 testifying today in response to the five-year
14 plan, which you've published. And this is
15 the line that struck me, which is why I wrote
16 this testimony and came to talk to you.

17 As there are more individuals requesting
18 residential supports than appropriations will
19 allow the department to support, DDS
20 maintains a waiting list for these services,
21 period. My family is one of those families
22 on the waiting list, and I would like to
23 describe what it's like for me.

24 My son, Robert, my only child is 27.

25 His diagnosis is autism and his disabilities

1 resulting from that are quite severe. He
2 uses single words to express concrete needs,
3 bread, pretzel, the important things; has no
4 sense of safety; doesn't realize that
5 sometimes he must stop eating; can't make
6 reasonable food choices. He lives largely in
7 the present, which means that it's really
8 difficult, if not impossible, to change
9 behaviors that need to be changed.

10 I've read that it takes a village to
11 raise a child. It's especially true with
12 mine. Providing 24-hour support and
13 supervision for an adult is not a job for one
14 person alone. No one has that much energy.
15 I could keep my son safe and I can keep him
16 happy, but not usually both at the same time.

17 All families who have children with
18 disabilities face challenges they never
19 expected to face. I am eternally grateful
20 that my son did not present his father and me
21 with challenges we couldn't handle that would
22 have forced us to seek help from the State to
23 keep us all safe.

24 But now it feels like we did too good a
25 job raising him. If we had been less able to

1 handle him when he was a teenager, he might
2 not still be living with me today. Now he's
3 grown up, his father has died, and I'm
4 getting older. I won't always be able to
5 manage him, but even more importantly, I want
6 to see him settled.

7 He's always going to need a high level
8 of supervision. When I'm dead he's going to
9 be living somewhere where they don't really
10 know him, and I just fear that his primal
11 needs won't be met because people just don't
12 know who he is. He's not enough of an
13 emergency to get assistance right now, even
14 though he's been on the waiting list since
15 before his father died 11 years ago.

16 I'm his only caregiver. I can't trust
17 him to cross the street or to handle any
18 household emergency. Caring for him requires
19 the same commitment that caring for a newborn
20 baby demands, but he's six feet tall and I'm
21 not the young mother I was once. It's my
22 nightmare to be the little old lady with
23 osteoporosis barely able to negotiate the
24 supermarket, but being there with my
25 strapping son at my side who's asking me for

1 more bagels.

2 And someday I'm going to die, too, and
3 there will be no one to care for him except
4 DDS, and they won't know how to do it because
5 despite my best efforts it just hasn't worked
6 so far. He deserves better and so does his
7 peer group, other adults whose disabilities
8 get in the way of them surviving on their
9 own.

10 Thank you.

11 MS. MURRAY: Thank you.

12 Patti Spaulding, and after Patti is
13 Lucia Nunez.

14 PATTI SPAULDING: Hello. My name is
15 Patti Spaulding. I've been blessed to work
16 for DDS for the last 29 and a half years. I
17 have thoroughly enjoyed my job. I've met
18 wonderful people. I still go back and visit
19 people that I no longer work with on a daily
20 basis. It's been a pleasure. I've seen the
21 changes.

22 I started my career at Mansfield
23 Training School where we then went to group
24 homes settings. And yes, we were able to
25 access the community more. I worked with

1 clients that were very handicapped and
2 physically needed assistance, and their PT
3 that they were getting on a Monday through
4 Friday basis went away. We then went on the
5 insurance, which did not provide that.

6 And so yes, there are many great things
7 that happen when you close the institutions,
8 but there are very -- there's so many things
9 that they miss. The PT, the OT, having
10 people of that stature on call when you're
11 needed. A wheelchair is not working right
12 anymore and you can just call someone and
13 they'll be there. You know, it's just --
14 it's invaluable.

15 I now work in the East Hartford office
16 at DDS and I help provide rent subsidy on a
17 monthly basis for the individuals that are in
18 homes on their own. And again we're cutting
19 from them as well. These are people that
20 we've put into individual homes or in their
21 own apartments, three people CRSs.

22 And again we're saying, yes, this is
23 what you should be doing, but we're taking
24 the funding away so they can do that so at
25 the end of the month they might be able to go

1 out and to be in their community.

2 The more we take away from them on both
3 the public and the private side they're the
4 ones that are losing out. They're not
5 getting to go out and do the wonderful things
6 people do, even to go have coffee, you know,
7 because we're not paying for this now, or
8 we're not paying for that. And it is an
9 overall thing, and I get that we need to cut
10 back, but we're just cutting back in the
11 wrong places.

12 I just feel it really needs to be
13 addressed better than the way we're going.
14 They deserve it. They've done nothing to,
15 you know, have these difficulties. They've
16 not, you know, they were born as wonderful as
17 they are, and we need to support them and we
18 need to help them get through it.

19 Being from, you know, the public side of
20 things all my career I do go out to private
21 providers. And if we're going to cut their
22 funding once we move them out into the
23 private sector, what is their quality of life
24 going to be? They are going to have
25 inadequate staffing, because the provider

1 can't pay when we're not giving them the
2 funding properly. It's terrible all around,
3 and the legislators need to come up with some
4 money to help provide for these people that
5 need all these services.

6 I really wasn't planning on speaking,
7 but I thank you all for listening to me. And
8 have a good night.

9 MS. MURRAY: Thank you.

10 Lucia Followed by Josephine Huerta.

11 LUCIA NUNEZ: Hi, my name is Lucia Nunez
12 and I have been a homecare worker for 25
13 years. My current work is paid for by the
14 State of Connecticut through the DDS homecare
15 waiver program.

16 I have been with my current client, who
17 has an intellectual disability, for six
18 years. He depends on others to do everything
19 for him, provide personal care, guide him to
20 the door, help him into the car and buckle up
21 the seatbelt for him. We usually go out into
22 the community. We go to the movies and to
23 the park, and in the summertime to the farm
24 because he loves the animals. I also had to
25 teach him to eat his food which he could not

1 do before.

2 But he -- because I worked in a day
3 program before caring for him, I knew the
4 kind of skill and care he would need in order
5 to -- for him to be more independent. Prior
6 to my care his mother couldn't work. Now she
7 can hold a job because she knows she can rely
8 on me for caring for her son.

9 I really like helping those who are less
10 fortunate, and he is like a son to me. But
11 there are challenges to providing his type of
12 care under the current DDS homecare program.
13 The DDS homecare waiver only provides funding
14 to pay me \$15.75 an hour, working 30 hours
15 per week with my client. And that is not
16 enough to make ends meet.

17 I have to hold two more jobs. And I
18 work, like, 90 hours a week which doesn't
19 leave me much time for spending with my son,
20 or sleeping, or resting, or taking care of
21 myself. If I was paid a living wage I would
22 not have to work 90 hours a week, which will
23 allow me to stay in this field a long time
24 doing the work I love.

25 The DDS homecare waiver program also

1 does not provide basic job benefits. I also
2 need benefits for just healthcare, which I
3 currently pay through another job, and it is
4 very expensive and with poor coverage. I
5 also receive no traditional paid time off.
6 The last time I took time off was when my
7 father passed about three months ago. I
8 haven't really taken a vacation in two years.

9 Our clients and their families depend on
10 us for their independence. We need a living
11 wage and other benefits to make this work
12 obtainable for us. We're calling on the DDS
13 in our five-year plan, and homemakers to
14 ensure enough funding to meet our client
15 needs, while also funding for a good job to
16 meet our needs.

17 Thank you.

18 MS. MURRAY: Thank you, Lucia.

19 Josephine.

20 JOSEPHINE HUERTA: Hello. Thank you for
21 letting me speak today. My name is Josephine
22 Huerta, also known as "Tutti" Huerta, and
23 Josefina Maria Huerta Martinez, is the long
24 version of my name.

25 I am an IFS case manager in the north

1 region for the Department of Developmental
2 Services going on ten years. I have been in
3 the human services field since 1992 starting
4 in the private sector. I have seen a lot in
5 almost 25 years working with a variety of
6 different people here in this great state of
7 Connecticut, a great state because we have so
8 much here besides, you know, the riches. We
9 also have oceans, rivers, mountains and so
10 much diversity, a diversity that just keeps
11 growing. Every time I turn around there's so
12 much, so many different types of people,
13 languages.

14 What also makes this state so great is
15 the way we care for our folks with
16 disabilities. We have the most devoted and
17 committed people working in the public
18 sector. I have witnessed this. They work to
19 provide the best care for some of our most
20 challenging and vulnerable people.

21 As a case manager my role is crucial as
22 an advocate for those who cannot speak, or
23 express themselves in most cases. Case
24 managers also act as liaisons between
25 families and agencies helping individuals to

1 maintain their entitlements and supporting
2 the families with coordinations of respite.

3 I have a lot of families, sometimes
4 single parents who they just can't do it.
5 They can't care for their individuals any
6 longer and case managers have to somehow
7 coordinate some respite time for them.

8 This is a great state and we have great
9 services. We must keep those great services,
10 and that means no privatization of our
11 current public services.

12 Thank you.

13 MS. MURRAY: Thank you.

14 Next up we have Lisa Aponte, and she
15 will be followed by Carrie Jacques.

16 LISA APONTE: Hello. My name is Lisa
17 Aponte and I'm a supervisor of case
18 management with the Department of
19 Developmental Services. I have worked at DDS
20 since 1998 serving as a bilingual case
21 manager for over 16 years, being promoted to
22 supervisor last summer. I am also the
23 sibling of an individual with an intellectual
24 disability who receives services from DDS.

25 My sister Jessica, pictured here, first

1 became eligible for DDS services in 1994. My
2 mother experienced some significant health
3 issues and was hospitalized twice that year
4 for several weeks. Our family was eligible,
5 not only for case management supports, but we
6 received emergency respite and in-home
7 supports.

8 My mother and I, who like so many of the
9 families DDS serves, were committed to
10 keeping our family member at home. It was
11 because of the skilled and resourceful
12 workforce who provides these direct supports
13 that we were able to do so for as long as we
14 did. It was only when both my mother and my
15 sister's health declined and each required
16 comprehensive care, that residential
17 placement in a group home for Jessica was the
18 only option. And in 2008 fortunately she was
19 able to be placed.

20 Jessica lived at home with my mother
21 until she was 30 years old. She'll be 39
22 next month. What's important here is that my
23 mother and I were able to keep Jessica home
24 for an additional 14 years. As a supervisor
25 of case management I know that group home

1 vacancies are few, and placements in them are
2 difficult to obtain. The majority of
3 families that I've worked with are not always
4 seeking to place their family member in a
5 group home. They just want help.

6 That help first comes in the form of
7 case management. The case manager assists in
8 referring the individuals and families to
9 resources to obtain respite behavioral
10 consults and individual and family supports,
11 as well as local and community-based services
12 to obtain home care, connect with advocacy
13 groups and network with other individuals and
14 families.

15 The case manager works with the family
16 to facilitate the transition from school to
17 adult services, which can be sometimes
18 anxiety provoking and a daunting process for
19 the family. Case managers at times serve as
20 a lifeline for the person or the family
21 member when there's no one else to talk to
22 who can understand how difficult it is to
23 balance the challenges of caring for a person
24 with an intellectual disability, with the
25 stressors of family, work and life in

1 general.

2 The years of expertise and experience
3 that the case management staff at DDS has are
4 invaluable. I have witnessed on both a
5 professional and personal level how case
6 managers work tirelessly to support
7 individuals and families. As a supervisor I
8 have the honor of working alongside highly
9 trained and experienced case managers and
10 other DDS professionals to deliver quality
11 supports on a daily basis. This includes
12 working collaboratively with community
13 providers to triage in emergency situations,
14 to support individuals to remain with their
15 families and not put further strain on an
16 already overburdened healthcare system.

17 As a sibling of a person with an
18 intellectual disability, my family, more
19 importantly my sister, has been blessed to
20 have knowledgeable, hard-working and
21 dedicated case managers to support all of us
22 through the last 22 years.

23 I wish to end by saying the following.

24

25 (Speaking Spanish.)

1 Our families need our services. I know,
2 because I too am one of those families.

3 Thank you.

4 MS. MURRAY: Thank you, Lisa.

5 Carrie?

6 CARRIE JACQUES: I brought support,
7 another therapist who also works for DDS in
8 the private sector. This is Paul Scrivano.

9 We don't have to share the chair.

10 MS. MURRAY: Just if you can make sure
11 your name is on there for the record. Thank
12 you.

13 CARRIE JACQUES: My name is Carrie
14 Jacques. I'm the PT supervisor for the North
15 Region of DDS. I've been with the State 37
16 years, so a little more than half my life.
17 Although not all full-time, because the State
18 was kind enough to let me go part-time when
19 my kids were young, and I appreciate that.

20 And I would just like to say that, thank
21 you for the opportunity to work with
22 everybody that I see around here over the
23 years. I don't have any -- I was asked to
24 speak, so I put a few thoughts together here.

25 Therapy within DDS, OTs, PTs, speech,

1 there's an expertise that you gain over the
2 years working with this population and it's
3 not always easy in the private sector to find
4 a therapist familiar with this population.

5 I've had I think -- sometimes when you
6 think of a therapist it might be, oh,
7 somebody broke a leg. So maybe they're
8 casted. Then they come out of the cast. You
9 exercise them. Whereas, with our population
10 if it's somebody with cerebral palsy you're
11 really looking at a lifetime of care with
12 developmental disabilities, and there's a lot
13 of training that goes into direct care staff,
14 the caregivers working with the individuals
15 in addition to what the therapist does.

16 For example, someone with cerebral palsy
17 might be training the caregiver on how to
18 check all the bony prominences as part of
19 their routine care for areas of pressure. If
20 they have developmental reflexes, for
21 instance, if I lay them on their back and
22 they go into a lot of extensor tone, or I lay
23 them on their stomach and they go into a lot
24 of flexor tone. I might be training the
25 staff on how to position into sideline, or

1 other functional positions for function.

2 I might be assessing for mobility skills
3 and that's a big area -- because I'll tell
4 you just get a custom wheelchair, you're
5 talking a 13-page document. You've go to
6 justify -- you might need a face to face with
7 a physiatrist. So it's very time consuming,
8 and I think that's part of the difference
9 between public and private, is what's
10 billable and what's not billable. And this
11 is why we'll get calls from the case managers
12 to sometimes go out and try to assist with
13 the private sector.

14 For instance, I've done environmental
15 assessments when the private provider
16 couldn't get someone to come out and do that
17 for safety. And maybe I'll say, okay. You
18 can use grab bars in the bathroom. You can
19 use that handheld shower. Maybe they need
20 some kind of support underneath, you know, a
21 couch with less depth and some padding under
22 it to get up. So those type of services, a
23 lot of the training isn't always covered.

24 I will say, be it private group homes or
25 public group homes, my general impression is

1 that anybody working in this field has a big
2 heart and they want the best for the
3 individuals living in that environment, and
4 they just can't always get it in the private
5 sector, because it's not billable.

6 So you know, you think about as we
7 privatize, it's one thing. Okay. We're all
8 going to retire at some point, myself soon.
9 And as you leave state service those
10 individuals are going to miss you, but it's
11 not like the whole home is leaving. So you
12 have caregivers with a lot of expertise. I
13 just wish we could kind of slow things down,
14 because they really are a resource and I'd be
15 happy to help figure out a way to keep a core
16 team of therapists to go out and help with,
17 you know, the communities with those evals,
18 be it OT sensory evals or PT evals.

19 And if there was some way you could
20 slowly, not just move a whole house out and
21 keep some of your resources as you
22 economically have to move towards
23 privatizing -- it just seems like everything
24 is happening much too quickly.

25 Do you want to add anything? I'm sorry

1 I used all the time.

2 PAUL SCRIVANO: My name is Paul
3 Scrivano. I've been a physical therapist for
4 over 30 years. Most of my years have been
5 working with people with developmental
6 disabilities and intellectual disabilities.
7 I've worked in the private sector. I've
8 worked in public. I also have been a case
9 manager for DDS for the ICF facility in
10 Newington.

11 As a case manager I got a bit
12 disillusioned because the people we work with
13 were no longer people. They were a LON
14 score. And I've noticed that as we are
15 privatizing they're not considered a person
16 anymore. They're considered a number, and
17 that number is a value of this much money.

18 It's frustrating to be in a meeting with
19 my managers and directors saying, oh, that
20 house isn't medically fragile. The LON
21 scores don't show it.

22 And then I have to say, well, wait a
23 minute. Six months ago somebody was in the
24 hospital and almost passed away. They got
25 sepsis, which is a blood infection which

1 basically can be deadly. We've had two
2 people go into the hospital, come back. They
3 can't walk anymore and need extra services.

4 As a public therapist we have the staff
5 to go to those houses daily, if not a
6 therapist, a trained RTA or another
7 therapist, and get those people up and
8 walking. We provide -- in the south we have
9 an aquatic therapy program that we do that
10 one of the people I worked with, it was
11 instrumental in him, getting him to walk
12 again after he was sick and hospitalized for
13 a bowel blockage.

14 He was scared to walk. He had a lot of
15 fear. I spoke to the guardian and we
16 suggested, well, let's try and go back to the
17 pool. We got in the pool that one day. The
18 next day he was starting to walk with his
19 crutches again. Then we got him in the pool
20 twice a week. And again, Carrie can attest
21 to it, because she's starting the therapy
22 pool in the north region, how much time
23 consuming it is for the therapists and the
24 staff.

25 This is a service that DDS provides.

1 We've had -- I've been part of some RFPs
2 where houses have been privatized and they
3 come out on the block and say, well, we can't
4 afford to send a therapist to do the pool.
5 We thought we just dropped them off at the
6 pool and the hospital does the service, but
7 it's not billable time.

8 I also work -- I'm starting to do some
9 evals for the private CCH program. And what
10 I'm getting is they have a therapist come to
11 the house to do therapy, but the issue is the
12 day programs. The therapist can't come to
13 the day program and use billable service. So
14 now they want me to go to the day program and
15 do the training, which I have no problem
16 doing, but that's a big need that is being
17 lost in the shuffle.

18 I think we're going way too fast. I
19 have been very disgusted with things that
20 have happened. I'll be point blank. I have
21 come home from work very upset many days --
22 I'm getting a little emotional now just
23 thinking about it. I don't like that they're
24 numbers. I don't like that we talk about
25 houses saying, well, the numbers are too low.

1 We'll have to move people out and move a
2 higher number, because that will be more
3 money and it will be more marketable.

4 We're selling people. This isn't what
5 you're supposed to give. We're health
6 services. We should not be selling people.
7 This is so wrong on so many levels. We can't
8 be shuffling people to make it more
9 marketable. How horrible is that?

10 Another point I want to get out there
11 is, there are families at home that need
12 help. There was a woman that spoke earlier.
13 Privatizing the State of Connecticut is going
14 to take up all of the private providers.
15 Where is the money going for the private
16 agencies to take the people on the waiting
17 list? It's not going to work. Why is no one
18 getting that? Why is no one saying that?
19 Are people afraid to say the truth?

20 The truth is, if we privatize 30 homes
21 where are the people on the waiting list
22 going to go? Is the savings going back to
23 DDS? No, it's going to the general fund. No
24 one is saying these things. I think it's
25 about time that we got heard -- if I still

1 have a job tomorrow.

2 Thank you so much.

3 CARRIE JACQUES: He's fired.

4 PAUL SCRIVANO: And by the way, I'm not
5 related to Jon Lovitz at all.

6 MS. MURRAY: Thank you both.

7 Next we have Mary Ann Duval.

8 MARY ANN DUVAL: Hi. I'm here actually
9 representing Mallory Buckingham who was
10 unable to be here. She's a guardian for a
11 person who has recently moved into the north
12 region.

13 I would like to start though with, as a
14 speech pathologist for most of my adult
15 life -- and I've been working for the
16 department since 1981 -- to ask everybody to
17 please sit on your hands. Lock your lips.
18 You can't get up and walk.

19 And let somebody beside you on either
20 side, even though you can't turn your head,
21 let them know you're very thirsty, very
22 hungry, in pain or you need to use the men's
23 or ladies' room.

24 So this is from Mallory.

25 To whom it may concern, as you discuss

1 the five-year plan for DDS I'd like to remind
2 you of the many lives negatively affected by
3 the layoff of DDS clinical staff this year,
4 especially the 14 speech language
5 pathologists on May 3, 2016, a decision made
6 without forethought or planning.

7 Both ICF and public group homes now
8 operate without communication support. The
9 science is clear that with our special
10 nonverbal, or limited verbal population,
11 behavior is communication. For those with
12 and without severe behavior challenges
13 communication is a human right. DDS
14 psychologists and behavioral specialist staff
15 are worried that individuals are being given
16 medications to control behavior, which
17 appropriate communication supports would
18 help.

19 You might remember Jenny, the brave and
20 beautiful woman who appeared in a moving
21 commercial by 1199 SEIU in July using her
22 Tobii voice output device, AAC, alternative
23 and augmentative communication, which is
24 controlled by her eye movements. She asked
25 the Governor to bring back the speech

1 therapists who were laid off May 3rd.

2 Jenny Veronovitch lived at the ICF
3 Meriden regional center for almost 30 years.
4 She's nonverbal because of the poor motor
5 control her condition creates, but she's very
6 smart, she's funny and she loves to tease.
7 She has used various voice output devices to
8 communicate for 20 plus years, and is limited
9 now to using her yes/no eye gestures to
10 answer questions when she is without her
11 communication device. She was forced to move
12 to the Hartford regional center when Meriden
13 was closed earlier this year because none of
14 the group homes in the community could
15 support her physical needs.

16 She had been receiving a range of one to
17 four hours of speech pathology AAC support
18 per week from me when I was her speech
19 pathologist from the spring of 2012 to May 3,
20 2016, in Meriden. Communications support
21 included updating the operating system on a
22 monthly basis and weekly updates of the
23 messages she uses to talk with her mother in
24 Las Vegas via video chat, and her friends and
25 staff, with Jenny directing the question and

1 news that she wanted to ask or share with her
2 many communication partners throughout the
3 day.

4 Now at the ICF Hartford regional center
5 her \$20,000 device is collecting dust. She
6 is only approved to have a speech pathologist
7 train her new staff on how to set up the
8 device for her, to be able to use it with her
9 eyes and her nonverbal communication
10 guidelines. There's no active treatment plan
11 to maintain her communication with family,
12 friends and staff, the most important area
13 for her quality of life.

14 Her mother lives far away in Nevada, so
15 she asked me and Lee Lowery to be Jenny's
16 legal co-guardians as a backup if her mother
17 cannot be reached for any reason, while the
18 people who are receiving AAC communication
19 support at the ICFs are now going without
20 speech pathology services. So are the DDS
21 public group homes, where there are more men
22 and women like Jenny who are also left
23 without their basic human right of
24 communication.

25 This serious issue of dysphasia, or

1 swelling disorders is also severely
2 negatively affected by the layoff of the
3 speech pathologists. Adequate swallowing
4 monitoring and management was a procedure,
5 and now the swallowing problems are addressed
6 in response to emergencies, a dangerous and
7 unacceptable situation for the thousands of
8 individuals with developmental disabilities
9 throughout the state.

10 Any five-year DDS plan must include
11 rehiring and refilling the vacant speech
12 pathology positions to end the human rights
13 abuse of denying communication potential and
14 the unnecessary choking and pneumonia rasp
15 being imposed on those vulnerable people who
16 are put in DDS trust, whether DDS private or
17 public group homes, or ICF regional centers.

18 Mallory would be happy to answer any
19 questions you may have, and she put her
20 contact information at the bottom.

21 MS. MURRAY: Thank you.

22 Jill Hall is next, and she is followed
23 by Jeffrey Wong.

24 JILL HALL: I would like to thank the
25 leadership in the room for being here and the

1 opportunity to speak today. Pleading the
2 importance of what needs to be said is hard
3 to do in three minutes, so I'm going to get
4 right to it -- especially hard for Parents,
5 which I am.

6 My name is Jill Hall. I read the plan.
7 I read the draft and I found the amount on
8 which the department spoke to transforming
9 the agency without providing details
10 concerning. I would hope DDS could be
11 forthcoming about these projects and the
12 future of DDS services. And most of all, I'm
13 here to ask the leadership of DDS to better
14 engage the guardian groups that have been
15 under engaged to date.

16 In my opinion I feel that there are
17 three types or groups of guardians. The
18 first group are guardians of clients who are
19 appropriately placed, and they're being
20 served well by the private sector. The next
21 are families like Peggy and Robert's. These
22 are parents who have adult children and they
23 need help, and they don't have services.

24 And then the last group of guardians are
25 individuals like me. I have an adult child

1 residing in a state operated facility. This
2 latter group is by far the minority of DDS
3 guardians, and our voice has not been
4 represented in this plan, or the previous
5 plan.

6 This is evidenced by the plan having
7 said, we are moving completely away from
8 legacy systems in favor of ever-increasing
9 community integration, even though that is
10 not in the best interests of all families, or
11 all clients, or even our state.

12 So I'm here today to also urge the DDS
13 leadership to ensure you have the truest
14 understanding of the Supreme Court Olmstead
15 decision which calls for a full range of
16 services to support individuals with ID.
17 This includes state-run facilities and
18 state-run programs and facility-based
19 settings. In short, programs, public
20 programs need to remain a choice.

21 Now a state-run program or a placement
22 wasn't my family's first choice, but it
23 became a necessity, really a safe haven. You
24 see, my son lives in a DDS run group home
25 solely -- solely because the private sector

1 failed him. Multiple private sector
2 providers refused to care for him, and when
3 the State sent him out of state, that private
4 provider failed to keep him safe.

5 So the facts of these important matters
6 really are held -- may I continue?

7 MS. MURRAY: Yes.

8 JILL HALL: They're really held by your
9 smallest group of guardians, and I plead you
10 to engage us as you develop this plan,
11 because we know the problems in the current
12 system. We can detail how the private sector
13 is ill equipped to serve all individuals with
14 ID. And as I've said, we know this
15 experience tragically because of abuse and
16 neglect our family members have experienced.

17 We also know -- we're very reasonable --
18 we know that there are individuals living in
19 regional centers who might fare well in the
20 private sector. And we can tell you that
21 there are individuals living in the community
22 who have significant unmet quality of life
23 and safety issues who would be better served
24 in regional facilities.

25 So these mismatches exist, even though

1 they're not acknowledged. And there is a
2 strong need for really open and honest
3 discussion about -- and we need to examine
4 the State's utilization and underutilization
5 of the current resource available.

6 And most importantly, and in closing,
7 you must include the guardians, this smaller
8 group of guardians, not just the majority of
9 guardians, or the family organizations that
10 have lobbyists.

11 Thank you for your time.

12 MS. MURRAY: Thank you.

13 Jeffrey Wong? Oh, there you are --
14 followed by Brandon Walker.

15 JEFFREY WONG: My name is Jeffrey Wong.
16 My brother Michael Wong is in a state-run
17 group home. He's been a client for about 35
18 years and he's in an excellent situation
19 today.

20 About 25 years ago my mother was at one
21 of these hearings detailing the horror of the
22 experience that the family had when my
23 brother was placed into private care and he
24 was -- so my brother originally went under
25 the care of the State in his early twenties

1 when he became violent in the home. He has
2 extreme obsessive-compulsive disorder. He
3 has some limited speech. He has explosive
4 behavior issues, and he is about six feet
5 tall. And he became violent in the home and
6 he had to be placed into a state-run group
7 home.

8 But about ten years later -- about 25
9 years ago he was placed in private care. He
10 was put into an apartment in Danielson where
11 he -- the agency did not provide
12 round-the-clock supervision. He was
13 wandering the streets. They would stock his
14 refrigerator with a bunch of food, despite
15 what we told them.

16 My brother can't handle having -- he has
17 odd behaviors related to food. He cannot
18 handle having a bunch of food in the
19 refrigerator, and then taking a little bit
20 out at a time to eat. He would either eat it
21 all at once and get himself sick, or he'd
22 throw it out and have nothing to eat. And so
23 eventually this agency, I guess, gave up on
24 my brother and he was placed back into care
25 with the State. And you know, we've had an

1 excellent result since then.

2 So he's in a group home on Stafford Road
3 in Mansfield. He's with three other fellows
4 who all have -- are capable of aggressive
5 physical behavior. And it's only because
6 they're under the care of career
7 professionals who have made it their career,
8 this business their career and who get to
9 know these people as individuals and know how
10 to deal with them on a day-to-day basis.

11 As was previously said, behavior is
12 communication and the only way that that
13 communication occurs is when you know the
14 individual well. And we all know that when
15 these people -- when people are farmed out to
16 be placed under the care of a for-profit
17 agency with a high turnover, there's just no
18 way those people get to know the clients and
19 understand their behaviors and are able to
20 provide the care, you know, that they need.

21 So you know, I'm trying to think, well,
22 if you don't have a family member in this
23 situation, you know, I was trying to think.
24 You know, once we adopted a little dog from a
25 shelter. Right? And so, you know, many of

1 you I'm sure have pets. So if you can
2 imagine your pet, you know, suddenly was
3 shifted to a new residence with strangers
4 every few months, or even if that pet got to
5 stay in your house, but every few months a
6 different group of people came in to take
7 care, you know, you would feel sad for your
8 pet.

9 So placing, you know, I think you have
10 to decide. Are the disabled people, you
11 know, are they real human beings? What kind
12 of care do they deserve? Do their parents
13 love them any less because they're disabled?
14 Do their siblings love them any less? Or are
15 they just real human beings that have very
16 complicated and detailed care that just
17 benefits from long-term stable relationships?

18 So I just would ask you to please
19 advocate on behalf of us to the State to
20 treat the population humanely and to do the
21 right thing.

22 Thank you very much.

23 MS. MURRAY: Thank you, Jeffrey.

24 Brandon Walker.

25 BRANDON WALKER: I have to put on my

1 reading glasses. I can't see with my other
2 ones.

3 My name is Brandon Walker and I'm a
4 supervisor in the north region for DDS.
5 There's many problems with privatizing the
6 public sector group homes, many reasons why
7 the State of Connecticut should not privatize
8 all of their group homes. One of the biggest
9 reasons is that the State doesn't pay the
10 private sector enough money to maintain
11 committed workers.

12 There are some agencies that pay their
13 employees \$11 an hour, which is less than a
14 \$1.50 over minimum wage. No one can live on
15 that. So it makes the employees less
16 committed and they're always seeking new
17 employment, which in turn creates a high
18 turnover rate for the private agencies and
19 that directly affects the people that we work
20 for.

21 Some of the state workers have worked
22 with some of the people that we serve for
23 over 20 years. They have become family and
24 that's just wrong and inhumane to make such a
25 drastic change to someone who doesn't have a

1 voice. It is evident that many of the people
2 that have gone to the private sector have
3 returned to the State because many agencies
4 cannot and will not deal with challenging
5 individuals and their behaviors. One of the
6 reasons for that is the lack of dedication
7 because they don't have the longevity that
8 state workers do.

9 A few months ago one of the state-run
10 group homes, Pleasant Row was converted to
11 the private sector. Some of the state
12 workers staff still keep in touch with some
13 of the people who we work for. One of the
14 people that still lived there told the staff
15 that the new staff don't take care of them
16 like they did, and that they miss them
17 working with them, and it makes them sad that
18 they don't see them anymore.

19 We have to remember that all life
20 matters, even those without a voice. Don't
21 privatize any more of our group homes.

22 Thank you.

23 MS. MURRAY: Thank you very much.

24 We've come to the end of our list, so
25 I'd like to ask if there is anyone here who

1 has not yet testified who would like to
2 speak?

3 You're not Henry by any chance, are you?

4 TOM DOWNEY: No, but I'll be Henry if
5 you want me to be.

6 MS. MURRAY: You don't have to.

7 TOM DOWNEY: I've had many aliases.

8 MS. MURRAY: If you could state your
9 name?

10 TOM DOWNEY: My name is Tom Downey. I'm
11 a DDS case manager from the west region in
12 Waterbury, and I want to tell a story about a
13 gentleman named Malcolm. He's one of my
14 people. And I hope that you hear what I have
15 to say and you make adjustments that things
16 don't happen to other people, that happened
17 to Malcolm.

18 I met Malcolm about 30, 35 years ago
19 when I worked at Southbury Training School.
20 I didn't have him under my care, but I knew
21 him and I saw him. He was a very
22 independent, free man who walked around and
23 wanted to get out and wanted more freedom,
24 and he did. He advocated for that. He had
25 an agency advocate for him.

1 And he eventually ended up in the
2 private sector and had a good life. He lived
3 in his own apartment, rode his bike around
4 town, walked around town and then his health
5 started to deteriorate. As his health
6 deteriorated he was placed in a group home
7 with the same agency, and a couple of years
8 ago his health started to decline even more.
9 And last year he was put in a nursing home,
10 and the agency cut and ran and abandoned him.

11 Now Malcolm is still in the nursing
12 home. He's 65 years old. I went and saw him
13 today. He asked me to tell you to get him
14 out of the institution he's in -- and that we
15 have a commitment to Malcolm. We gave him a
16 commitment. He was actually technically
17 committed to us by probate court, and here we
18 are bailing on him and he's asking, help, get
19 him out of the nursing home.

20 It's ironic. If he had stayed at
21 Southbury he would have good care. He'd have
22 committed state workers taking care of him
23 and he wouldn't be in a nursing home. So
24 privatization isn't really helping Malcolm.

25 Thank you.

1 MS. MURRAY: Thank you. Is there anyone
2 else who would like to speak who has not yet
3 spoken?

4 Thank you. Again, if you could just
5 state your name and spell it for the record.
6 Thank you.

7 LAUREN INCOGNITO: My name is Lauren
8 Incognito, I-n-c-o-g-n-i-t-o, just like the
9 word. And I have to apologize because this
10 is very extemporaneous and I'm ongoing off
11 the cuff. So I'm certainly not going to be
12 as eloquent as many of the folks we heard
13 here today.

14 But I feel like I need to actually thank
15 the department, and I get the sense with
16 everything that's going on you may not feel
17 like you're the most popular right now. But
18 as an employee I have to say the department
19 has had an incredible effect on my life.

20 When I first took the job I remember
21 saying to myself, oh, I'll stay a year. That
22 was almost 19 years ago. While working for
23 the agency I was able to have my children, a
24 set of twins and an eight-year-old. And due
25 to medical complications and interventions

1 what could have caused me hundreds and
2 hundreds and thousands of dollars possibly,
3 cost me maybe a thousand, and that's because
4 I worked for this department, and as we all
5 know, great insurance. We're very fortunate.

6 Through the department I was able to go
7 back to school. I was able to get my
8 master's in social work. There's nothing
9 special about me, and that's not the
10 direction that I meant to take. There are
11 people in this room, that they're fantastic,
12 who I've worked with over the years. And
13 honestly, it's been an honor and privilege to
14 work with them, because they're great people.
15 And like everybody else, I'm just trying to
16 get it right. And half the time I feel like
17 I'm not, but you try every day.

18 So I feel like as an employee I need to
19 say, thank you. And again, it's almost 18
20 years ago. I'm in a position now where I do
21 have another full-time job, but I stay with
22 DDS. I work third shift two nights a week.
23 I get up in the middle of the night, I leave
24 my family, I go to work. There's a holiday,
25 I'm at work.

1 Why do I do that? I don't necessarily
2 have to do it anymore because my situation
3 and circumstance have changed. And again,
4 there's nothing special about me, but I
5 stayed because, honestly, it's been an honor
6 and a privilege to take care of some of these
7 folks and to have the things in my life that
8 I have now because I've worked in this
9 department. So to a very large extent I want
10 to thank you for that.

11 And I don't know that there's a lot of
12 private sector folks who feel the same way.
13 Many of my friends who are in the private
14 sector who I've met over the years, they're
15 not there anymore and it just sort of
16 reiterates the turnover. So again, nothing
17 special about me, but we have some amazing
18 people in this department with a lot of
19 years.

20 And I would guess that most of the
21 reason why many of them have stayed is
22 because they know, despite some of the not
23 great things in the department, that we're
24 really fortunate. And that has an effect on
25 the people who we care for and it has an

1 effect on their families. And it just
2 reinforces, rather, the continuity of care
3 that we all want for our folks.

4 Thank you.

5 MS. MURRAY: Thank you, Lauren.

6 Yes, sir. Yes, absolutely.

7 JIM PICCIONE: My name is Jim Piccione.
8 That's P-i-c-c-i-o-n-e. I'm DDS South
9 Region. I've been with the State for 29
10 years. I started when I was five -- but I
11 was kind of the same way. I started with the
12 State, thought I wouldn't stay very long. I
13 just had gotten out of the service and I
14 thought I would stay for five years until I
15 got my record contract. And here I am today.
16 I love what I do, and it also prepared me for
17 having a son who has developmental
18 disabilities.

19 But what I have to say in the larger
20 picture about things is, as stated before by
21 other individuals, I think privatization is
22 just a bad deal all around, having been with
23 the State as long as I have and seeing both
24 ends of things. I also own a homecare
25 agency, too, a private duty homecare agency.

1 And one of the things that riddles my
2 business is the fact that what I charge my
3 customers determines what I can pay my
4 employees.

5 So my employees get a wage similar to
6 what private employees in a group home
7 setting would get. And what that leads to is
8 a large attrition rate, a large turnover rate
9 and a lot of my employees will limit their
10 hours because they're really relying on state
11 services also. So if they do too many hours
12 with me they lose those services. So they're
13 encouraged not to work also, but it's a bad
14 deal all around with no savings.

15 And then if the effort is made to
16 privatize, then it's going to be a net loss
17 because there's going to be a lot of
18 resources and money expended trying to turn
19 over to that system. But the bigger picture
20 is it's going to break up a network of really
21 complex care that's taken decades and decades
22 to really refine, and refine, and even refine
23 even further to get to the level of care that
24 these people get nowadays.

25 It's forgetting about the big picture

1 and that is that these are people. They're
2 not pizzas or boxes or widgets. They're
3 people, and we'd be abandoning them if we
4 turn them over to private care, which would
5 just severely reduce the quality of their
6 care.

7 MS. MURRAY: Thank you.

8 Is there anyone else who would like to
9 speak? Yes.

10 HENRY LOGNIN: Thank you. My name is
11 Henry Lognin, L-o-g-n-i-n. And I'd like to
12 say something about DMR. I want to keep the
13 program going, because they take care of me
14 and I love what they do. And I appreciate it
15 and I don't want the Governor to take my
16 program away.

17 That's all I have to say, and thank you
18 very much.

19 MS. MURRAY: Thank you, Henry. We've
20 been waiting for you all night.

21 Is there anyone else here who would like
22 to speak tonight?

23

24 (No response.)

25

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MS. MURRAY: We're here until seven. We will be here until seven. We can take a five-minute break, if people would like to do that and come back.

(Recess: 5:45 p.m. to 7:00 p.m.)

(Hearing concluded: 7:00 p.m.)

CERTIFICATE

1
2
3
4 I hereby certify that the foregoing 190
5 pages are a complete and accurate computer-aided
6 transcription of my original stenotype notes taken of
7 the Public Hearing in re: Public Comment on Draft DDS
8 Five-Year Plan (2017-2022), which was held at the
9 Legislative Office Building, Rooms 1A and 1D, 300
10 Capitol Avenue, Hartford, Connecticut, on December 6,
11 2016.

12
13
14
15 _____
16 Robert G. Dixon
17 Certified Verbatim Reporter
18 CVR-M 857
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