

TYING NASHVILLE TOGETHER
HEALTH ACTION TEAM

CITIZENS' HEARING AND PANEL DISCUSSION
ON HOME AND COMMUNITY-BASED CARE

PANEL 4:
PUBLIC FUNDING AND POLICY ASSOCIATED WITH
HOME AND COMMUNITY BASED CARE AND NURSING
HOME CARE

MARCH 29, 2007
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PANEL MEMBERS:

JOHN ARRIOLA, Davidson County Clerk

BRIAN MCGUIRE, American Association of
Retired Persons

CAROL WESTLAKE, Tennessee Disability
Coalition

PATTI KILLINGSWORTH, Bureau of TennCare,
Long-Term Care Operations

TNT PARTICIPANTS:

TERRIE SPETALNICK, TNT representative,
Temple Ohabai Sholom

GERALD TAYLOR, Industrial Areas Foundation

RUTH DENNIS, Visions Baptist Church

1 MS. SPETALNICK: Good
2 afternoon. Welcome to Panel 4. Panel 4 is
3 Public Funding and Policy Associated with
4 Long-Term Care. I am Terrie Spetalnick, and
5 I'm a TNT representative from the Temple.
6 TNT representatives, please introduce
7 yourself and the member institution that you
8 represent.

9 MR. TAYLOR: I'm Gerald
10 Taylor, and I'm with the Industrial Areas
11 Foundation and work closely with Tying
12 Nashville Together.

13 MS. DENNIS: And I'm Ruth
14 Dennis with Visions Baptist Church.

15 MS. SPETALNICK: And the
16 panelists here to testify are John Arriola,
17 Brian McGuire, Brenda Gilmore -- okay. I'll
18 just read here. John Arriola is Davidson
19 County Clerk. Brian McGuire is an AARP
20 lobbyist. And I will say I got my letter
21 yesterday, the first one. Carol Westlake is
22 executive director of the Tennessee
23 Disability Coalition, and Patti
24 Killingsworth, Assistant Commissioner, Chief
25 of Long-Term Care Operations, Bureau of

1 TennCare. Welcome, everyone.

2 MS. DENNIS: Now, we will
3 begin with formal introductions from the
4 panelists, which will include opening
5 statements. Each panelist should limit
6 their opening statements to five minutes.
7 The TNT representative will proceed to ask
8 questions from the panelists. Each panelist
9 is allowed two minutes to answer each
10 question that applies to them. So,
11 Panelists, please be aware of our
12 timekeeper, who will alert you when you have
13 one minute remaining.

14 MR. TAYLOR: Mr. Arriola,
15 if you will, please --

16 MR. ARRIOLA: Thank you,
17 Mr. Taylor. Good afternoon. It's a
18 pleasure to be with you all and be a part of
19 a program that I have always felt was very
20 important to Tennessee, as far as public
21 policy on long-term care.

22 My name is John Arriola,
23 and I'm the duly-elected Davidson County
24 Clerk for Nashville. I'm a member of the
25 Tennessee Commission on Aging and

1 Disability. I was appointed by Governor
2 Bredesen as a delegate to the White House
3 Conference on Aging in Washington, D.C. I
4 have served for twelve years in the
5 Tennessee House of Representatives where I
6 was the assistant majority leader.

7 Really, I began my focus on
8 this issue primarily because my background
9 is in health care. I'm a former hospital
10 administrator, and my wife is a registered
11 nurse. I felt very strongly about this
12 issue and really, in 1998, working with the
13 members here on this panel and members of my
14 delegation, began to develop legislation,
15 hopefully, trying to set the foundation for
16 moving the State toward a more open policy
17 and laws that would enable people to -- give
18 them the ability to make choices between
19 staying at home or going into an
20 institution.

21 I think the biggest
22 challenge that we really have in our state
23 is funding and where to find that funding.
24 So thank you very much. I look forward to
25 hearing from the other representatives.

1 MR. TAYLOR: Thank you.

2 Mr. McGuire?

3 MR. MCGUIRE: Thank you
4 very much for having me. I told people -- I
5 just came from the dentist almost directly
6 here, and my upper mouth is numb. If I
7 start slurring or drooling, it's not for any
8 other reason.

9 Thank you very much for
10 having me. I've been with AARP for about
11 seven and a half years. I am a legislative
12 director. I organize volunteers. We have
13 about 700 or 800 volunteers that we work
14 with throughout the state.

15 We're a large organization,
16 as you all know. I represent people 50 and
17 older and their families. We have
18 38 million members across the country and
19 685,000 members in Tennessee. And we're
20 constantly working to try to organize those
21 folks. We have got about 70,000 people that
22 are active as far as here in Tennessee.
23 We'll write or call legislators and such.
24 So we're working very hard to try to improve
25 things.

1 Most of what we do in
2 Tennessee is health and long-term care, and
3 now, we're working more and more on consumer
4 protection issues, also. Long-term care and
5 creating a (inaudible) for Tennessee has
6 really been our focus pretty much for the
7 last seven or eight years, actually, before
8 I even started with the AARP.

9 Let me just start by
10 recognizing the fact that John Arriola here
11 has really been the leader for us, and we
12 would not have anything to work from right
13 now -- the things we're going to talk about
14 that we're going to build on, we wouldn't
15 have that base here, we wouldn't have that
16 foundation if it wasn't for John and, also,
17 for the other two folks here on the panel.

18 A lot of folks have put a
19 lot of work into this. And we're just
20 really getting started in a lot of ways, but
21 a whole lot of people have spent a lot of
22 time, for fifteen years or more, doing this.
23 And we're just really starting to make some
24 changes for the State. And we really need
25 to, of course. To back up just a little

1 bit, if you put it in perspective, the State
2 could be doing a lot better than we are now.

3 I think we're starting to
4 see a swing upward in how we do long-term
5 care, but for years and years, in Tennessee,
6 really, when you said long-term care, what
7 people heard and what was being referred to
8 was nursing home care.

9 Most of you know long-term
10 care is very, very expensive, whether that
11 care is provided in the home or in nursing
12 homes, but the fact is that the nursing home
13 care is really expensive. Typically, we're
14 talking about 50, 60, \$70,000 a year.

15 So for almost anyone,
16 unless you've got a lot of money, you're
17 going to -- over a few months or a year or
18 so, you're going to run out of money, and
19 you're not going to be able to afford to
20 continue to have long-term care, especially
21 care in a nursing home. So what happens is
22 that, really, for most of us, we're going to
23 need a safety net there to help us pay for
24 long-term care. Medicare only pays,
25 typically, for a couple, three weeks.

1 In a fairly standard case
2 in Tennessee these days, when you do enter a
3 nursing home, you typically will be on
4 Medicare. If you've been on Medicare for
5 two or three weeks, then you go on to
6 private pay and you'll typically spend all
7 your money. Depending on how much that is,
8 it may take a week or it may take a year or
9 so, but at some point, you're going to go on
10 Medicaid.

11 That's the case across the
12 country. 75 percent of nursing home
13 residents in Tennessee are on Medicaid. So
14 it's just a matter of time. If you think
15 you'll never go on Medicaid, chances are,
16 unless you're pretty rich, if you're in
17 long-term care for very long, you're going
18 to end up doing that.

19 So it's a very, very
20 expensive proposition, and we believe there
21 is a role for the State in helping pay for
22 it. Medicaid is a primary care for
23 long-term care around the country, including
24 here in Tennessee. Here in Tennessee, we
25 spend a bit over a billion dollars on

1 nursing home care for older folks and folks
2 with disabilities. That covers what they
3 pay for. I believe it is about 27,000
4 people. The comparison we like to make, I
5 think, demonstrates the issue in Tennessee.
6 You'll often hear this is the case. If you
7 look at the ratio of Medicaid spending --
8 okay. They want me to stop. I'll have
9 plenty of time to -- let's wrap up.

10 We really are, by really
11 any measure, not doing as well as the rest
12 of the states across the country, and we
13 need to start to balance our system. The
14 fact is that if we have a balanced system,
15 we can serve more people for less money.
16 That's been proved in other states, and
17 that's the direction we want to go. I
18 think, as we continue to talk -- I'll make
19 Carol finish my point there. We'll flesh
20 out some of these things.

21 MS. WESTLAKE: Thank you.
22 I'm Carol Westlake. I'll be happy to yield
23 my time to Brian. He does that so well. I
24 really appreciate that. I do work with a
25 organization called the Tennessee Disability

1 Coalition, and interestingly enough, the
2 coalition started in 1984 as an informal
3 group of people who got together and formed
4 a coalition for community services.

5 The entire point of a
6 number of disability groups getting together
7 and beginning to talk with one another was
8 the realization that no matter how you got
9 it, that is, your disability, whether you
10 were born with it, whether you acquired it,
11 whether you aged into it, no matter what
12 people called it, people would rather get
13 service in their homes and in their
14 communities than have to go someplace else
15 to get it.

16 That was really what
17 brought a group of folks who represented
18 people who were blind, people who were deaf,
19 people who had physical disabilities, people
20 who had cognitive disabilities, people who
21 had mental health problems together, to say,
22 you know what, we can do better in this
23 state. You shouldn't have to leave your
24 family. You shouldn't have to leave your
25 home in order to get the minimum amount of

1 services you need.

2 So it's really an
3 organization that has spent the last
4 twenty-something years trying to really talk
5 about these issues and really make some
6 progress -- and we have worked for years
7 with our friends at AARP, with John Arriola,
8 other folks, the Medicaid Bureau, now the
9 TennCare Bureau, all over the state --
10 really talking about how we do need,
11 absolutely, a balanced system.

12 It's good public policy,
13 clearly, for the State, in terms of its
14 economics, in terms of cost. It just makes
15 sense in terms of families, as well. For so
16 many working-age adults or families with
17 children who have disabilities, being
18 confined to a nursing home, having to go
19 into a institutional program is simply a
20 wasted life.

21 In order to get and keep
22 Medicaid to get the health care you need, to
23 get the services you need, you're forced
24 into poverty. You can't possibly work no
25 matter how able you are to work -- and most

1 people with disabilities are. Do you know
2 that unemployment among adults with
3 disabilities aged 16 to 64 is 75 percent?
4 Of that 75 percent of people who are
5 unemployed, 80 percent of them say they
6 would like to be working.

7 You can't work if you don't
8 have home-based care, community-based care.
9 You can't work if you're in a nursing home.
10 You can't work if you have to stay poor in
11 order to make sure that you keep Medicaid in
12 order to get services.

13 So what the State really
14 does need to do is take a look at how we
15 encourage productivity, how we encourage
16 inclusion in community, how we make sure
17 that we don't waste people's lives. If we
18 don't keep moms and dads in the workforce
19 because they have to stay home and take care
20 of disabled sons and daughters -- all of
21 those things are not good for our community,
22 and they are certainly not good for the
23 families that are in our community.

24 So our real goal is to try
25 to figure out how we get a balanced system.

1 The State does has an obligation, clearly.
2 Federal dollars absolutely have to come into
3 it. We can't just rely on Medicaid. We
4 have to go on a whole series, a broad
5 continuum. It's something we'll probably
6 talk about as we continue on in this panel,
7 the Options Program, Families Forward, a
8 variety of things.

9 It really will help make
10 sure that we're supporting individuals and
11 families in our community, that we are not
12 wasting lives and that people are getting
13 the services they need. Thank you.

14 MS. KILLINGSWORTH: Hi. I
15 certainly appreciate the opportunity to join
16 you. I'm Patti Killingsworth. I'm
17 assistant commissioner and, since February
18 1st, chief of Long-Term Care Operations for
19 the Bureau of TennCare.

20 Long-term care and, in
21 particular, home- and community-based
22 services is very much a personal passion for
23 me, as well a chosen vocation. My son was
24 born with significant health care problems
25 and disabilities many years ago, and we

1 cared for him at home for nineteen and a
2 half years until he passed away a couple of
3 years ago.

4 In addition, I've cared for
5 an ailing father and an aged grandfather at
6 home with a firm commitment that they would
7 remain in their home and not in a nursing
8 home. So this is something that I very much
9 believe in and care about personally as well
10 as professionally.

11 Maybe the best news of all
12 is that I think the four of us sitting at
13 this table all believe in the same things
14 and all want the same things and want to see
15 the State move in the same direction. So we
16 are united in that regard. The question is
17 how do we get there and how do we make it
18 work.

19 We spend a sum of almost
20 two billion dollars a year on long-term care
21 in Tennessee if you put together
22 institutional services and community-based
23 services. And when we talk about Medicaid,
24 home- and community-based services, we're
25 actually talking about a number of things.

1 We typically think of the Waiver services,
2 which are what we are all familiar with. We
3 do have two long-term care waivers that we
4 operate in the State of Tennessee.

5 We also provide some
6 services through our Medicaid program that
7 truly are community-based services. They
8 are services that are alternatives to
9 institutional care, primarily home health
10 and private-duty nursing.

11 We spend \$15 million
12 dollars a year in home health services and
13 another \$153 million a year in private-duty
14 nursing. And those services are provided in
15 people's homes and allow them to remain in
16 their homes so that they don't go into
17 institutions.

18 So if you put all of that
19 together, you come up with a total spending
20 of almost \$800 million a year that we spend
21 on home- and community-based services as an
22 alternative to institutional care. But we
23 still spend 1.2 billion on institutional
24 services, and particularly, when you pull
25 out the dollars that we spent for people

1 with mental retardation and you look
2 exclusively at persons who are elderly or
3 who have physical disabilities, the
4 percentage drops to less than 20 percent of
5 the dollars that we spend on home- and
6 community-based services.

7 So there's a lot of work to
8 be done in terms of rebalancing and really
9 effectively offering people choices. The
10 primarily Waiver Program that we have for
11 people who are elderly or who have physical
12 disabilities, we recently expanded, with
13 significant growth in terms of the number of
14 people who have participated in the services
15 that we provide through that program.

16 So now, we have approval to
17 serve and dollars to serve up to 3,700
18 people in that program. And we're currently
19 serving less than 1,200. That means I'm
20 sitting with 2,500 open slots; if you will,
21 2,500 people who, today, if they qualified,
22 could walk in and begin receiving these
23 home- and community-based services once they
24 go through the eligibility process.

25 The key is how do we let

1 people know and insure that they are coming
2 in and applying and accessing those
3 services. I think a lot of what we're going
4 to talk about today is more dollars. And,
5 clearly, we're going to need more dollars.

6 In order to have a
7 compelling argument for more dollars, we
8 have got to use the dollars that we have, so
9 we can then show that there's a need for
10 more and be able to truly then begin to
11 build the funding for home- and
12 community-based services. I guess I'll stop
13 at that, and we'll go from there.

14 MR. TAYLOR: Okay. Let me
15 start with a question. I guess I'm really
16 curious about this. Y'all have been
17 fighting this fight for a good number of
18 years. What do you believe have been the
19 most significant impediments as to why this
20 is not happening to the degree that it
21 should have happened in the state, since
22 it's still ranked the lowest state in terms
23 of dollars that are going towards this? Any
24 of you can respond to that. What has been
25 going on all these years? What have been

1 the major impediments of moving this along
2 faster?

3 MR. ARRIOLA: Well, I think
4 that the major impediment has really been
5 the idea of change, change in the
6 legislature and change really in the
7 institutional behavior and the whole
8 mind-set that the nursing home was the only
9 option. And I know that takes time, and it
10 takes -- it really takes the community, what
11 you all are doing here today and what has
12 been going on over the last several years,
13 getting the community involved and talking
14 with their legislators.

15 That makes a difference.
16 Let's face it, the legislators, the state
17 representatives and the state senators,
18 depend on people who vote and people that
19 are active in their community and talk to
20 their legislators about their needs, and
21 they do listen. And that makes a
22 difference, and we have seen that strength
23 from the community, really, from the ground
24 up. That is beginning to move, I think, a
25 lot of that change.

1 MR. MCGUIRE: I would agree
2 with that. I think when we look back over
3 the last few years, some of the initial
4 resistance was frankly from the nursing home
5 industry. I think we have seen that change
6 over the last few years.

7 They realize what we have
8 been telling them for a long time, that they
9 are in the perfect position to offer these
10 alternative services. They have the
11 kitchens to make the special meals. They
12 have the CNTs that can be cross-trained to
13 go into somebody's home. They have got
14 space for adult day care in most of their
15 facilities.

16 They are in the marketing
17 position to be able to offer people the
18 whole range of services that they might
19 need, whether they need someone to come in
20 just once a week or if they need more
21 frequent care, adult day care, and
22 ultimately, if they really, really needed a
23 nursing home. So they are in a place to
24 tell the family we can take care of you,
25 whatever you need.

1 signed up. We've got to do the outreach to
2 individuals. We've got to make people
3 aware.

4 We're really not that far
5 along now on that, in terms of adult day
6 care and the respite care, the assisted
7 living. Some of the new services that were
8 recently added, they are added on paper, but
9 they are really not available yet for
10 people. It does take some time, but I
11 think, as we get into the discussion here,
12 what we don't have quite yet is really a
13 system.

14 If you have a system where
15 you have a coherent eligibility process,
16 where we have what we call a single entry
17 point system, where you know where to go,
18 you can navigate through it real easily.

19 If you have a global
20 budgeting system -- and we'll talk about
21 this. This is the deal. If you've got
22 someone who needs long-term care and they're
23 eligible for Medicaid and they go through
24 the eligibility process, what we want is for
25 the State to look at that person and say,

1 "Well, we can help this person at home for
2 \$15,000 or we can help them in a nursing
3 home for \$45,000. Hmm, what should we do?"
4 We want to make that financial incentive
5 real clear and obvious so that they make the
6 obvious financial decision; that is, to help
7 the person at home.

8 So until we have a
9 financing system that really matches that
10 and puts those internal financial incentives
11 into long-term care and Medicaid in
12 Tennessee, you know, I don't think we're
13 going to see the results that we want. So,
14 ultimately, as we move forward and when we
15 start to have the systems on the ground,
16 that has got to be a part of this, the
17 budgetary system.

18 MS. WESTLAKE: I agree
19 that's really true. And my perspective also
20 as to why have we had to struggle so long
21 and haven't been able to get there has been
22 an overly frustrating one, and I think part
23 of it is just a flat-out resistance to
24 change. I think the other thing is, because
25 we have not addressed some of those really

1 serious policy issues about how do we
2 develop a system, we haven't gotten there.

3 I think what we have done
4 in this state, as we have supported home-
5 and community-based long-term care, as
6 people demanded it, as people have struggled
7 to take care of their family members at
8 home, we have begun, around the edges, to
9 develop a parallel system to the long-term
10 care system that is the nursing home system.

11 There was this sense for a
12 long, long time that you had to find new
13 money, that it had to be something
14 different, that it was a system, separate
15 and apart from the nursing home system, and
16 so you had to grow something from scratch
17 from the ground up. And there just aren't
18 the resources in this state to do that.
19 It's not going to happen.

20 If you're going to have a
21 system that actually puts people in the
22 right place, which is a place they want to
23 be, and deliver the services to them there,
24 you have to have an integrated system. And
25 it's clear things like global budgeting are

1 a piece of that.

2 In our world, we often talk
3 about money follows the person; that is, if
4 I'm in a nursing home and I want to get out,
5 the State ought to be willing to at least
6 spend some portion of the money they are
7 spending on me in the nursing home to
8 provide those services to me in the
9 community. It's absolutely critical.

10 We don't have any capacity
11 in our current structure, in our funding
12 formulas, in the ways we develop the system,
13 to do that. So I think that, really, trying
14 to grow a home- and community-based care
15 system, as a separate entity from the
16 institutional or long-term care system, has
17 really crippled our state and kept us from
18 being able to grow in the manner we can.

19 I think there are other
20 kinds of policy barriers that also, in terms
21 of how you get access to the system -- you
22 know, who can provide services to the
23 community, how you pay for that, those kinds
24 of things -- we have just not put that
25 infrastructure in place in ways that really

1 allow the system to grow.

2 MR. TAYLOR: Thank you.

3 MS. KILLINGSWORTH: I'll
4 take this from the state agency's
5 perspective, because at the same time that
6 we were creating a separate system, I think
7 we were creating a mirror system of an
8 institutional system and trying to do it in
9 the community. That's really not what home-
10 and community-based care is. So we've
11 created a system that is very medically
12 focused.

13 There are a lot of hurdles
14 and obstacles, if you will, to qualifying
15 for the program. In the beginning, you had
16 to have a 24-hour caregiver with you all the
17 time. Well, if you had a 24-hour caregiver
18 with you all the time, you probably didn't
19 need the services quite so much.

20 So now, we have moved away
21 from that a little bit, still not a long way
22 from that. And the question is how do we
23 really change how we think about home- and
24 community-based services and understand what
25 they are really intended to be and create an

1 intake process and enrollment process that
2 actually -- it just makes more sense to
3 people that it gives them the choice not
4 just of an agency provider to deliver their
5 care, but gives them some flexible in terms
6 of being able to hire family or friends or
7 neighbors who they have a relationship with
8 and feel more comfortable with.

9 How do we really begin to
10 fundamentally change that system so that it
11 works for people and they want to be a part
12 of it and it meets their needs and, quite
13 frankly, that they can qualify for? So we
14 have got a lot of work to do now, stepping
15 back and looking at not the way it's been,
16 but the way that it needs to be and how we
17 really restructure it to work for people,
18 going forward.

19 MR. ARRIOLA: I would like
20 to briefly follow up on two points. Of
21 course, I never envisioned there would ever
22 be a medical model. There was always
23 supposed to be a social model. And all
24 across the country, what was working then
25 and is still working today is the idea that

1 you don't have to jump through so many hoops
2 on the medical side, because they have got a
3 little medical, but it's mostly on the
4 social end that they need this assistance.

5 The other point, too,
6 really deals with trying to fill these
7 slots, but the key there is trying to make
8 sure that you have the reimbursement level
9 up to a rate that the community will buy
10 into, either to start a new business to take
11 advantage of that or bring an existing
12 business in from another county and know
13 that they can do those services for some
14 reasonable return on their investment.
15 That's part of the challenge that we have,
16 too.

17 MR. TAYLOR: You talked a
18 little bit about the problems facing the
19 major cities of the state. What about the
20 rural areas? What's been the experience
21 you've had in the discussion in the rural
22 parts of the state? What have local people
23 on the ground in the rural areas been saying
24 to legislators? I assume the service issues
25 in the rural areas would be as acute, if not

1 more so, than it would be in a city like
2 Nashville or Chattanooga or Memphis. So
3 does anyone have any experience with the
4 rural communities, and what people are up
5 against?

6 MR. ARRIOLA: Well, I can
7 just say what my colleagues then -- and what
8 I still hear them talk about today is they
9 just don't have the services in those rural
10 counties. I mean, they have to depend on
11 larger counties that -- you know, where the
12 population is -- that can help pay for that,
13 where they can send them 50, 60 miles to
14 someone's home to try to make it work. I
15 mean, that's the challenge, and of course,
16 that's going to raise your costs.

17 So the idea that it might
18 be more expensive when you are looking at
19 those rural areas trying to get the
20 services -- and, of course, that's what
21 Brian talked about, trying to get the
22 nursing homes to look at -- because they are
23 out there in the community also, and they
24 would have a perfect platform to take off
25 from, as long as they move toward the social

1 side more than the medical.

2 MR. MCGUIRE: I understand
3 that. There are some substantial challenges
4 in the rural areas. I mean, one is just
5 person power, having the providers to do it
6 and the home care workers to go out, to go
7 find and hire the people. This is what
8 Patti referred to, where you go to a place
9 where people actually have self-directed
10 care or have the opportunity to hire family
11 members or neighbors.

12 You've got to take
13 advantage of what's in the community. And
14 if you've got to go through an agency or
15 something -- there isn't an agency in some
16 of these counties, so we have got to be more
17 flexible in that sort of thing. A big part
18 of this is trying to find some alternatives,
19 because some people don't want to be home
20 alone or they can't really be home alone,
21 but they sure don't need to be in a nursing
22 home. This is why we're trying to add
23 assisted-living. It's in the Waiver now.

24 An assisted-living facility
25 is much more home-like. People have an

1 apartment, really. They have some
2 independence and flexibility. They are
3 alternatives to assisted-living.

4 In other states, there are
5 adult family homes that are typically three
6 people and one live-in person that is
7 helping take care of them. Then you have
8 other folks, home aides that come in to help
9 during the day as needed, you know, that
10 kind of flexibility.

11 John mentioned adult day
12 care. Nursing homes, a lot of places, the
13 senior centers, other places, can do adult
14 day care. Economically, it will never make
15 sense to have a free-standing adult day care
16 center in a whole lot of our rural counties,
17 but it doesn't need to be that. It can be a
18 lot of places that have got the space to be
19 able to do that. So we've got to be a lot
20 more flexible.

21 MS. WESTLAKE: I think
22 that's very, very true. And what we hear
23 from folks with disabilities in rural
24 counties are that the two biggest
25 impediments are having personal providers

1 available and transportation issues, in
2 terms of being able to get to a service or
3 get a service to them. And I think those
4 things are very, very critical.

5 Absolutely, we've said
6 again we have set up policy barriers that
7 really keep us from being able to use family
8 members and friends, for example, for who
9 could be a provider and who can't. You have
10 to use an agency. And there isn't an
11 agency, or the agency can't send someone 30
12 miles. It's just not going to happen. So
13 really, taking a look at those unique areas
14 and figuring out ways in order to do
15 things --

16 Another big problem for us
17 is the availability of nursing services.
18 Frankly, we have a nurse practice act, in
19 this case, that requires many activities
20 that people with disabilities need to be
21 done by nurses. If you need to be
22 catheterized, if you need -- you know, if
23 you're a quadriplegic, for example, and you
24 have diabetes and you have to take shots,
25 well, you can't self-inject because your

1 hands don't work, but nobody but a nurse is
2 allowed to self-inject you.

3 That's a very expensive way
4 to give a shot three times a day, especially
5 if you live 40 miles away from the nearest
6 health care facility. So we really need to
7 take a look at how we set up those kinds of
8 barriers and figure out solutions to those
9 to really make this work.

10 MS. SPETALNICK: I'm just
11 wondering, from a legislative standpoint,
12 practically, what do you recommend to
13 increase the sort of resources that are
14 needed for home-based care?

15 MS. KILLINGSWORTH: I'm
16 going to start back with where I started in
17 the beginning, which is, first of all, I
18 think we have to use the dollars we have on
19 the table to have a compelling argument for
20 why we need more. So we have got to expand
21 enrollment of the program and demand that
22 goes beyond the current dollars that we have
23 available.

24 Second, I think, the most
25 compelling argument for legislators is

1 frequently cost-effectiveness, and that's an
2 easy argument to make for home- and
3 community-based services, that it is more
4 cost-effective to provide services for
5 someone in their home than it is in an
6 institution. And we have to continue to
7 hammer that idea home. And you combine
8 with, one, it's the right thing to do, that
9 it's what people want, and it's more cost
10 effective, and that helps build the support.

11 The third thing, I think,
12 is as we talk about an integrated system or
13 a balanced budget, we have to realize that
14 our current long-term care system is
15 structured in such a way that if we are ever
16 going to really rebalance the system, we
17 have to look at how we fund nursing homes
18 and how we pay nursing homes in the state.

19 That will be a huge
20 challenge for us, but that is key, because
21 they are cost-reimbursed. You can't,
22 literally, allow money to follow a person
23 into the community, because when the person
24 leaves, those costs -- they get
25 redistributed across everybody else who is

1 already there. So you haven't really saved
2 the money; you just increased everybody
3 else's cost. And until we change that, it
4 will be very difficult for us to effectively
5 shift --

6 MR. TAYLOR: How could that
7 be done?

8 MS. KILLINGSWORTH: Most
9 states have moved to different types of
10 structures of reimbursement. They don't do
11 cost-based reimbursement. They do
12 reimbursement based on clinical acuity, if
13 you will, the level of need that people
14 have. So they have case rates. So you do
15 pay nursing homes, frequently, for the
16 people with higher levels of needs to remain
17 there.

18 So they may draw a higher
19 rate per person, but it then allows you
20 to -- and it's not always the people who
21 have lower levels of need who want to move
22 to the community, so it's not limited to
23 that, but it does allow you to pay based on
24 the level of need that someone has and not
25 simply to reimburse the cost, so money truly

1 can follow people to their setting of
2 choice.

3 MR. MCGUIRE: There's
4 enough money in the system, overall. It's a
5 matter of allocating the money properly.
6 The legislature has done what it can do,
7 frankly, starting off with legislation that
8 John passed a few years ago.

9 The legislature has
10 specifically supported all the things that
11 we're talking about, a single entry point
12 system, a full range of services, a rational
13 eligibility system, and a global budget.
14 We, the AARP, initiated and got support from
15 the disability community two years ago on
16 legislation that we passed that reiterated
17 that and urged the Governor to move forward
18 and make that happen.

19 These decisions can be made
20 by the Governor. He has started down the
21 road in a number of ways on this in terms of
22 the services. He put almost all the
23 services we asked for into the Waiver. The
24 eligibility process is slowly but surely, I
25 think, being ironed out. We're moving

1 slowly but surely toward a single entry
2 point system.

3 We have got a little more
4 work on all that to do, but the bigger steps
5 now are really creating the financial
6 incentives. What Patti said is really
7 pretty much right. We think that the
8 current system makes no sense. Basically,
9 we pay nursing homes for the costs that they
10 report to us up to a certain point.

11 It has absolutely nothing
12 to do with the kinds of services, the amount
13 of services that they are providing, the
14 acuity of the residents they are dealing
15 with, nothing at all. It doesn't relate to
16 the quality at all. They have a lot of
17 violations that the health department cites
18 them on. The payment system has nothing to
19 do with that. It doesn't respond to that in
20 any way.

21 States have taken several
22 steps the last couple of decades. So states
23 are generations ahead of us already in how
24 they pay nursing homes. Some states
25 actually contract, have separate contracts

1 with individual nursing homes that deal with
2 their particular acuity level. There are
3 cases in the system -- like Patti talked
4 about, there are lots of better ways. We do
5 it like no other state. It's a 30-year-old
6 system that makes no sense at all.

7 We understand there are
8 political issues with regard to moving here,
9 but I can tell you it is up to the Governor.
10 We have urged him over and over to do that.
11 We know it's political. We understand that,
12 but this is the new world. And, again, the
13 industry is responding and changing now.
14 Let's go ahead and do it. Let's go ahead
15 and get what we're paying for and not get
16 what we are not paying for.

17 When we start to do that,
18 then we'll stop paying for empty beds,
19 because right now, we're all paying if there
20 is a facility that has a bunch of empty
21 beds. We're essentially paying for that
22 extra overhead. And it doesn't have to be
23 like that when we can use the savings as we
24 defer people, as we develop the home- and
25 community-based service alternatives, and we

1 start to have fewer and fewer people.

2 States that have done this
3 have seen their nursing home population go
4 down and down and down. Those expenses go
5 down. You use that money to serve a lot
6 more people where they want to be, in their
7 homes.

8 We do have to change the
9 nursing home payments. Whether we are doing
10 this or not, we can save the kind of money
11 that we need, that the system needs, because
12 we don't have the money in the state,
13 unfortunately, to do this. Frankly, we
14 don't really need it.

15 MS. WESTLAKE: And I agree
16 with all that, but since Brian mentioned
17 sort of diverting from nursing homes, I want
18 to put in a quick plug that is a little off
19 topic. I think the other piece of what we
20 need to do as we begin to shift those
21 resources -- because I do believe all the
22 resources are there -- is that we also need
23 to give people who are in nursing homes the
24 opportunity to leave.

25 That is just not something

1 we have a mechanism for in this state right
2 now. The truth is, once you're in, they are
3 going to keep you, and there is really no
4 way -- every year CMS collects data about
5 people who say they want an opportunity to
6 leave the nursing home and get services at
7 home. There were over 6,000 people in
8 Tennessee who report every year they want
9 out.

10 There is no virtually no
11 mechanism for getting those folks out. So
12 we continue to spend more money than we need
13 to in many cases, perhaps, not all, on those
14 folks when they would actually rather be
15 someplace else. As we rebound, I think that
16 is part of what we need to think about, as
17 well.

18 MR. TAYLOR: Thank you.
19 That's very, very helpful. For a
20 middle-class household that's wrestling with
21 the same questions that we're talking about,
22 what's in our state to support middle-class
23 families? They obviously have more
24 resources to start with, but what's in place
25 for middle-class families that are wrestling

1 with these questions?

2 MR. MCGUIRE: Let me go
3 first. Let me, first of all, say that we
4 talked a lot about Medicaid. I'm not sure
5 about the other programs. Medicaid is
6 important, not just for people on Medicaid.
7 We don't have adult day care in 85 of 95
8 counties in this state. And a big reason
9 for anybody -- whether you're on Medicaid or
10 if you have got money, we don't have day
11 care for you in 85 counties.

12 The reason for that, one of
13 the main reasons, is that Medicaid doesn't
14 pay for it. Medicaid needs to be a primary
15 payer. Medicaid pays for long-term care.
16 We wouldn't have many nursing homes in the
17 state, frankly, if Medicaid didn't pay for
18 it.

19 So until Medicaid starts
20 participating in these alternative services,
21 we're not going to have these services for
22 anybody in this state. So it's real
23 important to understand that, that you can't
24 get adult day care, no matter how much money
25 you have, in those counties of the state.

1 And there are other examples of other
2 services like that that we can cite.

3 In answer to your question,
4 what we do have in this state is a very,
5 very small home- and community-based
6 state-wide program called Options For
7 Community Living. It serves less than 2,000
8 people. There are now between 4 and 5,000
9 people on waiting lists, total, across the
10 state.

11 The types of services that
12 they offer are very minimal. It's the basic
13 things that the Waiver used to offer,
14 essentially, in terms of homemaker services,
15 home-delivered meals, and not a whole lot of
16 stuff that people need.

17 What we're finding out
18 now -- it's sort of like the Waiver Program;
19 we didn't know eight years ago that offering
20 a good Medicaid Waiver Program would save us
21 money. Now, it's really obvious. Now,
22 we're starting to see states that are
23 starting to look at folks who are at risk to
24 go to a nursing home that aren't on
25 Medicare, close to being on Medicaid.

1 Let's start paying
2 attention to them. Whether they are going
3 to be on Medicaid or not, if we start to
4 make sure that they're being focused on,
5 that their issues are being identified and
6 dealt with and that services for them are
7 provided, whether they can pay for
8 themselves or they need a little assistance
9 with programs like the Options Program, the
10 more we start to intervene sooner, the more
11 we are keeping those folks off Medicaid and
12 those really high costs that start to come.

13 So we can delay some of
14 their needs and actually delay some
15 substantial payments for Medicaid too.
16 Places like Vermont are starting to have
17 more than just a real good universal
18 Medicaid system; it's a universal system,
19 across the board.

20 MR. TAYLOR: Any others?

21 MS. WESTLAKE: There's
22 another small program I'll tell you about.
23 It's a 7-and-a-half million program called
24 the Family Support Program. The Options
25 Program serves working-age adults with

1 disabilities and seniors. The Family
2 Support Program can actually help families
3 with children and even single seniors up
4 until their death.

5 It really is a
6 cross-disability cross-age program. It's
7 actually in the Division of Mental
8 Retardation Services, just by historic
9 location. It can provide very flexible
10 services, actually provide funding for
11 services, and families can really use the
12 money in any way they see fit.

13 It is like the Options
14 Program; it has a waiting list. It's
15 thousands and thousands of people long. It
16 serves a couple of thousand people. The
17 average expense per family, I will tell you,
18 runs about \$1,300 a year. The maximum
19 benefit could be \$4,000 a year.

20 It is not a substitute for
21 long-term care, but it really does help take
22 the edge off for families who need some
23 respite care, for families who may need just
24 a little extra help to make something
25 happen. It's been a very, very successful

1 program. It's been around since 1992, I
2 believe, and its evaluations clearly show it
3 every year as being one of the most popular
4 programs in the state. It's just not
5 enough.

6 It doesn't serve enough
7 people. The waiting list is too long, but
8 it can be a help to those who have managed
9 to get on that program. Again, it shows
10 that for families, for individuals, it
11 doesn't necessarily have to be a whole
12 package. If you can keep the people a
13 little safer, if you can keep the family a
14 little stronger, they are better able to
15 take care of family members at home.

16 MS. KILLINGSWORTH: I have
17 just a couple of things. One would be just
18 to be sure that everybody is aware that the
19 income standards for HCS programs, if you're
20 applying for a home- and community-based
21 care program, are much higher than they are
22 for regular Medicaid.

23 So if you have applied for
24 Medicaid before and have been turned down
25 and if you're applying for a home- and

1 community-based Waiver Program and you meet
2 the level of care criteria in order to be in
3 that Waiver Program, the income standards
4 are 300 percent of SSI as opposed to 100
5 percent of SSI. So it's three times as high
6 in terms of the income standards.

7 So a lot of folks can
8 qualify for institutional home- and
9 community-based care that might not qualify
10 for regular Medicaid as long as they have
11 the level of need that is required. That's
12 an important point.

13 The second is something we
14 haven't done yet but that we're looking at,
15 which other states have done and which we
16 have had greater flexibility to do; that is,
17 to participate in long-term care funding
18 partnerships where folks who have many money
19 and more resources can choose to purchase
20 long-term care insurance, and then later on,
21 if they actually need long-term care, when
22 it comes time for them to apply for
23 Medicaid, dollar for dollar, the value of
24 that policy -- that much of their assets is
25 not counted against them for purposes of

1 determining Medicaid eligibility.

2 So if you buy \$100,000 of
3 long-term care insurance, when it comes time
4 to qualify for Medicaid sometime down the
5 road, if you need long-term care, \$100,000
6 of what you own is not counted against you
7 in terms of qualifying.

8 It lets folk with a little
9 bit more resources qualify, but it does so
10 by encouraging them to purchase their own
11 long-term care insurance. It is something
12 that a lot of other states have done and
13 that we are looking at doing and are doing
14 analysis on to figure out if that's the
15 direction we want to go in the future.

16 MR. TAYLOR: Sure. As you
17 probably have noticed, this is a little
18 different kind of hearing, because we're the
19 citizens, and we're asking the professionals
20 and politicians to come speak to us. So
21 there is one question I would ask you as we
22 get ready to move out of this this
23 afternoon. We, TNT, are obviously, as an
24 organization, preparing ourselves to
25 initiate a major effort in this area with

1 those of you who have kind of led the way
2 over the years.

3 So what would you recommend
4 as a way of thinking about an organizing
5 campaign to move this process along faster
6 with more integrity in the next six months
7 to a year? What do you think needs to be
8 done? How would you see it, from your
9 vantage point, if you had the resources,
10 organizing resources, to move this campaign
11 along, to move it faster and harder? What
12 would you recommend and how would you see
13 that happening?

14 MR. MCGUIRE: Let me start.
15 I've been working with these other folks
16 here about this. Because TNT is a
17 Nashville-area organization, its ability to
18 do something statewide or that will happen
19 statewide will be the difficult part. What
20 I would suggest looking at is what's going
21 on here in Davidson County.

22 Where are we with getting
23 providers for the Waiver Program? What we
24 need to have in this county -- I think John
25 touched on it a bit -- is we need to have

1 ownership of this issue. We need to say
2 this is our responsibility to take care of
3 our elders and our folks with disabilities.
4 We need to make this happen.

5 We've heard from Patti that
6 we've got 2,500 slots, statewide. There's
7 plenty, here in Davidson County, for people
8 on the Waiver, but we've got to have the
9 infrastructure there and then get the word
10 out to them that it's there.

11 We need to find out from
12 our local officials and we need to find out
13 from our local providers what
14 assisted-living facilities and what
15 faith-based assisted-living facilities, for
16 instance, are going to step up and have some
17 assisted-living beds for people on Medicaid.

18 Who is going to start some
19 more adult day care centers around here?
20 I've been to a couple of them here around
21 town, three or four. They are all at
22 capacity. I don't know if they have any
23 slots they could open up for people on
24 Medicaid. Who is going to step up in this
25 town to offer some of these services?

1 Where is the area agency
2 here, in terms of recruiting those
3 providers? We all need to take ownership of
4 this meeting, make it happen. It's not just
5 the legislature's business or the business
6 of the Agency on Aging. It's your Metro
7 Councilperson's business. It's your
8 business. It's the mayor's business.

9 So we all need to take
10 ownership of the opportunities we're
11 developing now, in this Waiver Program,
12 particularly. I think there's notice on all
13 of us who live here in Davidson County to
14 make that happen, to create that.

15 That's what needs to happen
16 around the state, frankly, and I think TNT
17 could serve as a model for how other cities
18 and places around the state could do this
19 and make it happen. Local people make it
20 happen through local officials, both private
21 and public.

22 MR. ARRIOLA: And just to
23 follow up on that, I think it would be great
24 if TNT could work with the groups that are
25 here and just do an inventory as to what's

1 out there, what services.

2 Find out where we are now
3 in Davidson County and set up a group, a
4 team to just try to figure out where we are,
5 what is available, what programs and
6 services are available, and set some goals
7 as to where we would like to be, based on
8 our population, or whatever information that
9 you have.

10 I can see you all really
11 starting something that could easily spread
12 statewide from community to community.

13 MS. WESTLAKE: That's a
14 very good point. I think we have talked
15 about some of the state programs that are
16 out there, the Medicaid-run programs, but
17 the truth is that Metro Social Services
18 provides a fair amount of homemaker services
19 and other kinds of assistance to folks that
20 we haven't talk about yet today.

21 Of course, there's not
22 enough. There's probably a waiting list --
23 I know there's a waiting list for that as
24 well. But, really, as a community, how do
25 we begin to integrate those services with

1 other kinds of services?

2 One of the things that is
3 oftentimes a real challenge, I think, is
4 that every program considers itself a payor
5 of last resort. I once said I was going to
6 dedicate my professional career to finding
7 the payor of first resort, because I don't
8 think there is one.

9 Oftentimes, if you get a
10 little piece of something else, then people
11 tell you you don't need the other thing
12 because, after all, somebody gave you a
13 dribble. So now, you're off the list for
14 signing up for something else. And I think
15 as a community, we need to take a look at
16 that.

17 I think the other thing
18 that we can do, particularly in this
19 community, that TNT can help with, is the
20 whole piece about marketing these services
21 and really helping to create a demand,
22 really helping to fill those slots.

23 I mean, how do we figure
24 out who the folks are who are on the waiting
25 list for Metro Social Services programs and

1 get to them and see whether or not they can
2 make use of the Medicaid Waiver Program?
3 How do we go to the folks who are on the
4 Options Program and see if there's any way
5 we can get them on the Metro Social Services
6 Program or vice versa? I mean, we really
7 need a coordinated effort.

8 MR. TAYLOR: We've been
9 hearing people talk about the threshold
10 eligibility question. You've got us in a
11 catch-22. The threshold eligibility
12 question seems to be so high, the standard
13 for that is so high that that may be a real
14 reason why people are not qualifying for the
15 program. So what is your assessment of
16 that? We've heard earlier testimony from
17 people that that eligibility level is one of
18 the prevailing problems of getting the spots
19 filled.

20 MR. MCGUIRE: Well, let me
21 start. I'm sure Patti will want to say
22 something. The way it is right now is that
23 eligibility of -- really financial and
24 physical eligibility is essentially the same
25 for nursing homes as for the Waiver Program.

1 The Deficit Reduction Act passed by Congress
2 a couple of years ago requires that every
3 state, by next year, offer -- maybe it's
4 this year. I'm sorry -- to offer an easier
5 way for the physical eligibility to work in
6 your state. So it can be just a hair's
7 difference or a lot of difference.

8 We wouldn't want to see the
9 nursing home eligibility get any harder.
10 And you could do that, too; you could just
11 make that harder, make home- and
12 community-based services the same.

13 We would like to see them
14 look at some ways to really look at risk
15 factors for people that are at risk for
16 institutionalization, find those and help
17 those -- use those to develop a different
18 physical eligibility criteria for people
19 that are trying to receive care at home.

20 MR. TAYLOR: Ms. Killingswo
21 rth, could you speak to that, please? I
22 mean, we've heard a great deal about this,
23 and it sounds to us like we're in a catch-22
24 on this eligibility. The slots are there
25 and if we have more information and we

1 contacted more people -- but that's not what
2 we're hearing. We're hearing that the level
3 that you're requiring for the waiver is so
4 high that people are just getting pushed, in
5 effect, towards nursing homes.

6 MS. KILLINGSWORTH: You
7 know, it's interesting, because when we look
8 at the numbers of eligibility, of PAE
9 determination, level-of-care evaluations
10 that we deny, that number is not as high as
11 this discussion would lead you to believe.

12 The reality is that when
13 things come to us and they come to us with
14 completed information, most of these folks
15 do, in fact, turn out to qualify for
16 long-term care services. And I can't give
17 you the exact percentages. I can go back
18 and look at that.

19 We have been working on
20 developing a new tool, if you will, to do
21 level-of-care evaluations consistent with
22 what some other states are using for home-
23 and community-based programs which look at a
24 variety of things that we don't look at
25 today. Today, we look primarily at

1 functional deficits, and that's all. This
2 looks at a variety of other kinds of things
3 that really are more in line with
4 community-based care. That's one of the
5 things that we've been looking at doing.

6 I think we're interested in
7 re-looking, across the board, at the intake
8 enrollment process, at what barriers exist,
9 at what it is that is keeping people from
10 qualifying for the program.

11 Some of this, I think, may
12 be a lot about procedure as much as it is
13 about the actual requirements, because my
14 sense of things, in terms of what I see, is
15 that when the application gets to us in
16 those cases, it turns out to be approved.

17 So we've got to figure out
18 and be able to put together what we're
19 hearing with what we're seeing and figure
20 out where the gap is occurring and work to
21 change that.

22 MR. MCGUIRE: I would say
23 that Tennessee's overall physical
24 eligibility requirements are sort of in the
25 middle of where states are. We could be in

1 a lot worse shape, frankly.

2 MR. TAYLOR: Do we have a
3 couple of questions?

4 AUDIENCE MEMBER: I agree
5 with what she's saying that a lot of the --

6 MR. TAYLOR: Someone pass
7 her a mike.

8 AUDIENCE MEMBER: I
9 actually complete -- you know, send over the
10 pre-admission evaluations over to TennCare.

11 MR. TAYLOR: Would you
12 state your name?

13 AUDIENCE MEMBER: Stephanie
14 Nitti with the Area Agency on Aging and
15 Disability. I would agree that a lot of the
16 PAEs that we're sending over to TennCare do
17 get approved. We don't have a high number
18 of denials, but we do have a lot of people
19 that we turn away for the Waiver because
20 they are too functional.

21 So we're sending over very
22 appropriate referrals to them, based on what
23 the criteria is, but that still doesn't mean
24 that we're not having to turn down folks.
25 If they would not make it so difficult, as

1 far as what the actual physical requirements
2 are --

3 AUDIENCE MEMBER: Are those
4 people already in the nursing home?

5 AUDIENCE MEMBER: No. And
6 the other thing that I wanted to mention
7 that bothers me and troubles me is that a
8 lot of the clients I see have major medical
9 problems and, with the Waiver Program,
10 getting personal care and homemaking several
11 times a week -- that's not going to cut it
12 for that person.

13 And, yes, they can get home
14 health services in conjunction with Waiver,
15 but home health is designed to be a
16 short-term service. It's not designed to be
17 long-term, and I think that more folks that
18 qualify need to be able to get private-duty
19 nursing.

20 MR. TAYLOR: Any more
21 questions?

22 AUDIENCE MEMBER: I'm
23 (inaudible) with the Council on Aging. When
24 you asked something about who can help us
25 move this forward, I think one group or

1 really two groups that we haven't said a lot
2 about are the adult children of aging
3 parents and their employers. That their
4 parents are not getting the care they need
5 is keeping those people from working or they
6 are having to miss days of work. That
7 affects employers.

8 It affects the employee's
9 children too, who don't have the money to go
10 to college because their parents are paying
11 for their parents to be in some sort of
12 long-term care.

13 So I think, in terms of us
14 moving forward and who we can enlist,
15 getting employers to see how this will
16 benefit them and doing that through getting
17 the employees to mention this to their HR
18 departments is something we often miss.

19 MR. TAYLOR: Okay. Thank
20 you. I appreciate that.

21 AUDIENCE MEMBER: I want to
22 thank the panel for being here today and all
23 the people who accepted the invitation from
24 TNT to be here, because we have just learned
25 so much. I'm sorry we didn't have enough

1 time to really advertise this thing -- it
2 would take months -- to get the people here
3 that I know really need to hear this. It's
4 been wonderful for us.

5 I, in trying to get help
6 for my brother, experienced this whole
7 system, so I come with a passion to save him
8 and to give him the dignity to be on his
9 own. And he barely made it. Stephanie got
10 him through it because she understood what
11 it was going to take to keep him
12 independent.

13 I was shocked when I was
14 looking into home- and community-based
15 services in other states, because I found
16 out we're 50th and we're nine times worse --
17 when we wanted the lottery, shoot, we got
18 that in a year, didn't we? When we wanted
19 it, we went out and paid to get the person
20 in here, and we got it. Well, why? Because
21 money is coming in. Right now, money is
22 going to be going out if we give these
23 people the help.

24 I was very surprised when I
25 went into Oregon, and I typed in, in Google,

1 "Medicaid Waiver," and "Homestead" came up.
2 That was the first I heard that there was a
3 Supreme Court decision made about this.
4 And, Carol, I learned the details of it from
5 your Tennessee Disability Coalition's
6 newsletter. So could I ask you to address
7 this, just shortly?

8 MS. WESTLAKE: Okay, I can
9 do that. I do think it's very important.
10 One of the things that I think we all need
11 to be aware of is that people oftentimes
12 need long-term care services because --
13 well, you don't need them if you're not
14 disabled. That's the bottom line.

15 The Americans With
16 Disabilities Act makes it very clear that
17 it's a civil rights legislation that it's
18 anti-discrimination and essentially makes it
19 clear that when the Government provides
20 services, those programs and services need
21 to be offered to people with disabilities on
22 an equal basis.

23 Those services need to be
24 provided in the most integrated setting
25 appropriate for that person; that is, you

1 don't set up separate programs in separate
2 places. You try to make services
3 accessible, across the board.

4 There were two middle-aged
5 women in Georgia a number of years ago who
6 were in a long-term care facility who wanted
7 out. The professionals in their lives said
8 they were entitled to be out if they could
9 be served with home- and community-based
10 services, and the State simply didn't allow
11 them to leave the institution because they
12 said they didn't have a place for them,
13 didn't have services for them. Those two
14 women sued.

15 It went all the way to the
16 Supreme Court, and the Court upheld the most
17 integrated setting requirement in the
18 Americans With Disabilities Act, which says
19 that you can't lock people up if it is
20 possible for them to receive their services
21 in the home, in their homes or their
22 communities.

23 The Supreme Court decision
24 suggested that states would have a safe
25 harbor if they evaluated all their

1 programs -- and it's not just long-term
2 care. It has to do with every program in
3 state government -- to make sure they are
4 offering those services in the most
5 integrated setting, and if they are not,
6 that they have an active, working program
7 that is moving them in that direction.

8 The State has never had an
9 active Homestead plan. They decided that a
10 safe harbor for them, an administration ago,
11 was to ignore Homestead entirely, and if you
12 didn't talk about it, you would risk less of
13 a lawsuit than if you did.

14 I have sat in and I know
15 John has sat in many meetings and so did
16 Brian where there were big discussions among
17 policy-makers about whether they were more
18 likely to be sued over waiving those support
19 services or whether they were more likely to
20 be sued over Homestead. So which way should
21 they go? It's kind of a bad way to make
22 public policy, I must say.

23 The truth is we have an
24 absolute civil rights obligation to make
25 sure that people who are in the community

1 get to stay in the community and are able to
2 make that choice when they need long-term
3 care, and we have an absolute obligation to
4 make sure that people who have been
5 institutionalized have an opportunity to
6 leave if they are able to leave and are able
7 to receive services in the community. And
8 it's really a legal obligation that we're
9 not meeting.

10 MR. TAYLOR: Any other
11 comments on that before we wrap this up?

12 MR. MCGUIRE: Let me just
13 say one thing. I think y'all are
14 interested, and you can see this is really
15 generally, right now, a legislative issue,
16 per se, with one exception. There is a
17 bill. It's not AARP's bill at all, but it
18 has come forward to create a department of
19 aging and disability.

20 Right now, we have an
21 independent commission that administers the
22 waiver of the Options Program. We think
23 that this is a real opportunity to change
24 the system, as I talked about in the
25 beginning, to create a global budget,

1 because, hopefully, with one department with
2 all these services that serve older and
3 disabled folks, it would be an opportunity
4 to create a rational eligibility system.

5 Instead of having three
6 different governmental agencies do
7 eligibility, let's have one. The single
8 entry point system, obviously, would move us
9 in that direction. We think, if done right,
10 that that legislation could move us forward
11 substantially. It's Senate Bill No. 308,
12 House Bill No. 2063.

13 We understand that the
14 sponsor met with the Governor a couple of
15 days ago. He is supportive of it. The
16 Administration is working on an amendment to
17 that that will flesh out the proposal, and
18 again, it's really critical that it's done
19 right.

20 If we just raise the
21 commission to a department, then we haven't
22 done much. If we bring all the services
23 from the different departments and agencies
24 together and create a rational system, then
25 it does a lot to move us down the road.

1 MR. TAYLOR: We have time
2 for one more question. Then we're going to
3 have -- question?

4 AUDIENCE MEMBER: No,
5 comment.

6 MR. TAYLOR: Okay. A
7 one-minute comment?

8 AUDIENCE MEMBER: Yes.
9 Real quickly, thank you. First off, I just
10 want to say I've heard a lot of great
11 information, and I agree with a lot of this,
12 but first off, Area Agency does not have
13 several thousand people on the Options wait
14 list. There's 1,910 people, effective
15 today, on the wait list. And, again, that's
16 because of funding.

17 Certainly, another major
18 obstacle to us enrolling people in Medicaid
19 Waiver is we have to explain to them up
20 front about the Estate Recovery Act. And
21 when most people find out about this, they
22 opt not to participate.

23 The State Recovery Act
24 requires that at your death and the death of
25 your spouse, if you don't have a child with

1 a disability living in the house, then the
2 Government has the right to come back and
3 recoup the cost they spent on you. So some
4 of this information, we have to tell people,
5 and they, in turn, opt not to participate.
6 So we think --

7 MS. DENNIS: Can you state
8 your name?

9 AUDIENCE MEMBER: Clara
10 Kelly, Area Agency on Aging and Disability.

11 MR. TAYLOR: We have not
12 discussed that, but that sounds like a
13 significant problem.

14 MS. KILLINGSWORTH: Just as
15 an item that came up, those are federal
16 requirements. That's part of the federal
17 Medicaid regulations, which require that
18 states do have an estate recovery provision.
19 In fact, they strengthened that provision in
20 the recent Deficit Reduction Act to require
21 that we go back even further in terms of
22 asset transfers. So it's not something that
23 we can just simply opt to not do. It's a
24 federal requirement, as far as the Medicaid
25 program.

1 MR. TAYLOR: Okay. One
2 question.

3 AUDIENCE MEMBER: Is that
4 the same set of regulations that constitutes
5 the difference in you-all's financial
6 eligibility between home-based care and the
7 Medicaid Waiver where one is three times the
8 other? Why is there a difference in terms
9 of financial eligibility?

10 MS. KILLINGSWORTH: Basicall
11 ly, what the Federal Government has done is
12 provide for people who have higher incomes
13 to qualify for institutional or home- and
14 community-based care. Originally, it was
15 institutional only. Then they added a
16 provision which also allowed folks to
17 qualify for home- and community-based waiver
18 services at those same enhanced income
19 rates. It's all part of the Medicaid
20 regulations.

21 AUDIENCE MEMBER: Why is
22 the HCPS higher?

23 MS. KILLINGSWORTH: They
24 are the same. They are 300 percent of SSI
25 for either institutional or home- and

1 community-based services. It's a special
2 income standard that applies only for those
3 two types of categories of eligibility.

4 AUDIENCE MEMBER: Why is
5 that higher than just regular Medicaid?

6 MS. KILLINGSWORTH: Because
7 there was an understanding of how incredibly
8 expensive long-term care is and a need
9 for --

10 AUDIENCE MEMBER: Is that a
11 federal regulation or a state-level policy
12 decision? That's my question.

13 MS. KILLINGSWORTH: States
14 can, I believe, choose to apply
15 institutional income standards or not. We
16 have chosen to apply them and to allow
17 people to qualify.

18 AUDIENCE MEMBER: Thank
19 you.

20 MR. TAYLOR: Okay. I want
21 to thank you very much for coming. I want
22 to thank all of our people who have been
23 here through most of the day. I want to
24 thank all the members of the TNT team --

25 (Applause from the

1 audience.)

2 MS. THOMSEN: I want to
3 thank TNT for giving this issue such a great
4 focus, and I'm very hopeful that we, as a
5 health care group, are going to be able to
6 make a difference, and I would be very
7 disappointed if we didn't, so I will have
8 some information available.

9 MR. TAYLOR: I want to
10 thank our professional stenographer for
11 taking all of these minutes. We are going
12 to have a report, so this record will be
13 completed and done so that people will be
14 able to purchase some of her copy cost. If
15 you would like, you can get a copy of the
16 transcript.

17 We'll be contacting you to
18 begin what role we can play in the statewide
19 effort. We have a sister organization in
20 Memphis, so we do have some other
21 capabilities other than just in this county
22 to participate in the larger statewide work.

23 We want to thank you for
24 coming, from the state side, and being very
25 honest and frank with us about where we are.

1 I hope that, together, we can do something
2 very significant in the next year to move
3 this along. So, again, thank you for
4 coming, get home safe, and we'll see you
5 soon.

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