

1 POPULATIONS IN NEED OF LTSS AND SERVICE DELIVERY ISSUES

2 - - -

3 WEDNESDAY, JULY 17, 2013

4 United States Senate,

5 Commission on Long-Term Care

6 Washington, D.C.

7 The Commission met, pursuant to notice, at 1:40 p.m.,

8 in Room SDG-50, Dirksen Senate Office Building, Bruce

9 Chernof, Chairman of the Commission, presiding.

10 Present: Chairman Bruce Chernof, Vice Chairman Mark

11 Warshawsky and Commissioners Javaid Anwar, Judith Brachman,

12 Henry Claypool, Judith Feder, Stephen Guillard, Chris

13 Jacobs, Neil Pruitt, Carol Raphael and Grace-Marie Turner.

14 Also present: Staff Director Larry Atkins

15 OPENING STATEMENT OF CHAIRMAN CHERNOF

16 Chairman Chernof. All right, if we could get started,

17 that would be wonderful.

18 My name is Dr. Bruce Chernof. I am the Chair of the

19 Long-Term Care Commission, and on behalf of all of the

20 commissioners I want to thank you for being here today. It

21 is great to see so many folks in the audience.

22 This is a very important issue, and the Commission as a

23 whole really believes that raising awareness and listening

24 carefully is an important piece of our work, and so today is

25 another step in that direction.

1 I want to take a moment and recognize our Staff
2 Director, Larry Atkins, who has done a great job helping the
3 organization move forward. The most visible evidence of
4 that for all of you is the fact that our web site is finally
5 up.

6 We are officially a creature of the Senate. So, if it
7 looks a lot like a Senate web site, it does for good reason.

8 The web site is www.LTCCommission--all
9 together-LTCCommission.Senate.gov. On that web site, you
10 will be able to find information such as press releases, the
11 materials from our public briefings, as well as an ability
12 to address the Commission directly.

13 Every commissioner here believes it is important that
14 we are open and listening to the general public, to folks
15 who care about this issue. There is a specific framework we
16 ask you to use, but we would encourage you to go to the web
17 site, use that framework. You will then send it to us
18 through an email attachment, and Larry and his team will be
19 reviewing that. And all the commissioners will see all
20 those materials.

21 With that, I want to turn it over to Mark Warshawsky,
22 my Vice Chair, for his comments, and then we will begin.

23 OPENING STATEMENT OF VICE CHAIRMAN WARSHAWSKY

24 Vice Chairman Warshawsky. Thank you very much and
25 thanks to the panel, both this current panel and the next

1 panel. It has been a little bit of a whirlwind to organize
2 these public hearings, and so we are very grateful to you to
3 sort of do it on short notice.

4 And, in terms of today's hearing, I personally will say
5 that I am very eager to hear what the panelists have to say.
6 I think I speak for the whole Commission, that we are here
7 to learn a lot.

8 So, thank you again.

9 Chairman Chernof. Great. With that, we will begin
10 with our first panel. We are going to as each panelist to
11 present in turn, and then we will open it up to the entire
12 Commission for questions.

13 We have a couple of commissioners who could not be with
14 us today for personal reasons, but they have provided
15 questions. So Mark and I will try to ask those questions on
16 behalf of those commissioners.

17 With that, if we could start with David Braddock--this
18 first panel, I should say, is a focus on the subpopulations
19 who use long-term services and supports, and their needs.

20 And so, with that, we will turn to David Braddock.

1 STATEMENT OF DAVID BRADDOCK, PH.D., COLEMAN
2 INSTITUTE FOR COGNITIVE DISABILITIES, UNIVERSITY
3 OF COLORADO

4 Mr. Braddock. [Off microphone.] Thank you very much,
5 Mr. Chairman.

6 Court Reporter. Turn your mic on.

7 Mr. Braddock. Thank you, Mr. Chairman. I am delighted
8 to be here.

9 I am going to provide an overview of intellectual and
10 developmental disabilities for the panel today, and we are
11 going to go through a number of slides. I presume that you
12 either have some printed out, and you do not need to turn
13 around. So my statement, of course, has been delivered for
14 the record.

15 Let's go ahead and move to the first slide.

16 I am going to talk about current trends in the field of
17 intellectual and developmental disabilities, and some
18 factors that are influencing demand today and are likely to
19 influence demand in the future.

20 Next slide, please.

21 The demand for residential services is growing quite
22 rapidly. Between 1980 and the present, the number of
23 individuals with intellectual and developmental disabilities
24 in long-term care services has increased from about 260,000
25 individuals to almost 600,000 individuals, and we see

1 projections of in excess of 700,000 individuals by 2020.

2 Next slide, please.

3 For the first time in the 30-plus years that we have
4 been collecting information from all of the states and
5 localities in the United States and the Federal Government
6 on public spending for people with intellectual and
7 developmental disabilities, we identified a decline,
8 adjusted for inflation in fiscal year 2011--no doubt, one of
9 the many consequences of the Great Recession.

10 Next slide, please.

11 We now have--and this is perhaps the most important
12 slide that I will introduce today in terms of giving you a
13 sense of what is going on in our field. We now have 14
14 states, counting the District of Columbia, erroneously, as a
15 state, without state-operated institutions for people with
16 developmental disabilities.

17 So, over the course of the last 25 years, this has
18 unfolded with great angst and politics, as you can imagine,
19 in the American states. But we are on this trajectory to be
20 an institution-free field within, in my opinion, the next 15
21 or so years.

22 I may be wrong. There may be a few states that will
23 hold out, but I doubt that they will have the Federal
24 Government to be assisting them in doing so at that time.

25 Next slide, please.

1 The number of closures of state-operated institutions
2 for people with intellectual and developmental disabilities
3 is up to 168 institutions now.

4 And we were unable to find a single closure--the states
5 only opened them--prior to 1969. We found the first closure
6 in 1969, and now the total is 168. And you can see the
7 scale of the increase here is quite dramatic.

8 Next slide, please.

9 Here is a list--you can take a look at it later and see
10 if your state is on the list, if anything has closed in your
11 state--of the most recent institutional closures just in the
12 last four years. The incentives that the states now have to
13 use the Home and Community-Based Services Waiver Program
14 under Medicaid to provide supports in the community and to
15 support families has, so far, outstripped the single model
16 of institutionalization, and the states have begun closing
17 many, many institutions and saving money in the process to
18 be able to support more people.

19 Next slide, please.

20 I have projected the trajectory of the institutional
21 census nationally, with sensitivity, and we are looking at
22 about 2022 to 2030 when, according to current trends in
23 closures, the last institution would close.

24 That is not to say that there will not be some states
25 that will wish to maintain institutions, but the Federal

1 Government may move to a position someday where they will
2 say to states: We will permit you to do that, but we are
3 not going to fund you for it. You can fund it with your own
4 resources.

5 Next slide, please.

6 Six hundred and thirteen thousand people with
7 developmental disabilities--intellectual and developmental
8 disabilities--live in formal out-of-home placements where
9 Federal, state and, to some extent--modest extent--local
10 governments are involved in their care and support.

11 The vast majority of these--77 percent, to be specific--
12 live in settings for 6 or fewer people, most of them in
13 settings for 3 or fewer people.

14 This is a revolution that has occurred over the last 25
15 years--moving from the institutions to the smaller,
16 supported living settings, and then more support for
17 families, not enough, but more.

18 Next slide, please.

19 Supported living on the far right of this chart is the
20 least expensive option to support people with intellectual
21 and developmental disabilities. You give them what they
22 need.

23 In an institution, you automatically give them
24 everything, whether they need it or not, because it is
25 provided 24 hours a day.

1 Many people with intellectual disabilities do not have
2 total needs. They have, rather, not so much episodic needs
3 as you see in mental health, but rather, they have modest
4 needs perhaps for personal support. Many of them have jobs.

5 So the most expensive option, on the far left here, is
6 state-operated institutions--average cost for 1 person, 1
7 year, \$220,000 versus the \$26,000, supported living.

8 Next slide, please.

9 The Home and Community-Based Services Waiver, which was
10 authorized by Congress in 1981, made a tremendous difference
11 in our field.

12 Next slide, please.

13 Here you can see, in the red, roughly half of all the
14 resources emanate from the Medicaid home and community-based
15 services waiver now in the developmental disabilities field,
16 with a total of \$56.5 billion in resources in the field.

17 Seventy-seven percent of those fifty-six billion
18 dollars are associated with Medicaid funds from Washington,
19 plus the match that the states and some local entities
20 provide for that.

21 So Medicaid is where it is at in this field.

22 Next slide, please.

23 You can see how the home and community-based services
24 waiver has grown from nothing in 1982 to \$18 billion, and
25 for the first time we see a decline in this past year in

1 resources. And the support for intermediate care facilities
2 for people with intellectual disabilities, which essentially
3 means state-operated and private-operated institutions for
4 lots of people, is down to \$8 billion a year.

5 Next slide.

6 Six hundred and twenty-seven thousand people now in the
7 field, being supported by the Home and Community-Based
8 Services Waiver, as you can see from the early days in 1982-
9 1983 right up to 2011--627,000.

10 Next slide.

11 Now current trends are supports waivers. I am not
12 going to go into detail on this. You can look at your
13 leisure later.

14 But they are much more individualized, and they are
15 economically efficient, and they are a new way of doing
16 business in the states, where you give a person what they
17 need, not more than they need, but just what they need.

18 Next slide, please.

19 Innovations in several states are authorized here.
20 Washington State has four waivers tailored to individual
21 needs. States are developing what we call supports waivers
22 now, emphasizing employment, support brokers, financial
23 management services and person-directed goods and services
24 for those who need it. There is much more sophistication in
25 the delivery system these days--more finely tuned, more cost

1 effective.

2 Next slide, please.

3 Now, quickly, community supports and family support and
4 supported living.

5 Supported living, first.

6 Next slide.

7 It emphasizes choice. It emphasizes ownership by
8 someone other than a service provider.

9 Think about it for a moment. Why should there be a
10 service provider in your life? Why shouldn't you have the
11 opportunity to make choices yourself?

12 People with intellectual disabilities--the vast, vast
13 majority of them--have the capacity to make choices for
14 themselves if properly educated in choice-making skills.

15 So ownership by somebody other than the service
16 provider and then this individualized support is where we
17 are today and where we are headed in the future.

18 Next slide.

19 Family support is defined in a lot of different ways.
20 You give a family what it needs. You do not necessarily
21 have to give it respite services if it does not require
22 respite services. If it does not require financial support,
23 you do not have to give it financial support. Maybe you
24 just give it assistive and medical technology, or you give
25 it some family training and family counseling.

1 But there are a variety of supports that a family can
2 get, and they are listed here in my presentation that you
3 can review at a later time.

4 Cash subsidies have not become as popular as we thought
5 they would. The states seem to be pulling a bit away from
6 cash subsidies directly to families in payments and
7 vouchers, but they are doing a bit of it in a number of
8 states.

9 Next slide.

10 Now I want to stress on this graphic the red part at
11 the bottom is the number of families supported by state I/DD
12 agencies in one way or another, and you can see for 2011 it
13 is 13 percent. The vast majority of caregiving families are
14 not supported at all by state agencies. They provide the
15 support themselves, and they receive perhaps some cash
16 payments from the Federal Government for income maintenance
17 and support and so forth in the Adult Disabled Child
18 Program.

19 So parents--families--are at the nexus of this
20 particular challenge in American domestic policy.

21 Next slide, please. Okay.

22 Supported employment has plateaued. We had very high
23 hopes for techniques that were developed in the 1970s and
24 1980s to provide training for people with intellectual
25 disabilities.

1 Most people with intellectual disabilities do not have
2 nearly the degree of intellectual disability you may think
3 that they do. It is limited. And, therefore, they can
4 work. They can engage in many things that contribute to the
5 economy.

6 However, we have not done well in the last 10 years.
7 Our economy has been so up and down, and supported
8 employment has been one of the entities that have suffered
9 as a result. So we are plateauing at about 116,000 people
10 nationally.

11 More investment--if the Commission could recommend more
12 investment in supported employment for people with
13 intellectual disabilities, this could help us economically.

14 Next slide, please.

15 We like to measure the commitment that the states give
16 to I/DD services by looking at the amount of resources they
17 commit to developmental disabilities. And, if we divide it
18 into their aggregate statewide personal income, we can tell
19 the difference between the states.

20 And guess what? There is a 600 percent difference in
21 the states. Now I believe in diversity, but this degree of
22 diversity is taking things a little bit too far.

23 So, next slide, please.

24 You will see what I mean. New York, top left--\$9.51
25 per \$1,000 of personal income for every person that lives in

1 the State of New York. Okay, that is what they commit in
2 fiscal effort.

3 Let's look back at the other side, down at Nos. 50 and
4 51--Mississippi and Nevada, \$1.45 and \$1.07.

5 So, by luck of the draw, where you live, which state,
6 makes a tremendous difference in terms of the resources that
7 get allocated for people with developmental disabilities.
8 And we have some states that do a great job, and we have
9 some states that do not do a great job.

10 Next slide, please.

11 Aging caregivers--big issue. Increased longevity of
12 people with intellectual disabilities--a good thing but also
13 more costly because they are living lives now that are
14 approaching normal life spans.

15 That is to say merely because you have an intellectual
16 disability, unless you have what we call "comorbid
17 conditions"--say heart problems and so forth--you have an
18 average life span, provided you are provided with decent
19 care and support.

20 So fiscal conditions in the states are factors that, of
21 course, influence demand for these services. States are in
22 a crunch today, and so we have seen some reductions that are
23 very significant.

24 Next slide, please.

25 Most people with intellectual and developmental

1 disabilities live with family caregivers. There are about 5
2 million people with intellectual and developmental
3 disabilities in the United States. Three and a half million
4 of those live with family caregivers and are touched little,
5 if at all, by the service delivery system. Perhaps they
6 receive some income maintenance payments, and that is it.

7 It is pretty much, you know, the Wild West in this
8 field. If you have a relative with developmental
9 disabilities, then you are going to have to pay out of
10 pocket for a lot of services. Now you are lucky if those
11 services are even provided.

12 Seventy-two percent live with family caregivers.

13 Only 13 percent, that 613,000 figure I showed you at
14 the very beginning of this presentation, live in supervised
15 residential settings like group homes, individualized
16 placements and the remaining state-operated institutions.

17 Some live alone or with a roommate--another 700,000--
18 but are not in supervised settings.

19 Next slide, please.

20 Family caregivers by age--take a look at this green
21 slice on this pie chart. Caregivers, aged 60-plus--852,000
22 people caring for people with developmental disabilities in
23 their own home are 60 years or older, and they are getting
24 older. This is a big challenge in the field, and this is
25 out of a total of 3.5 million people with intellectual

1 disabilities.

2 Next slide, please.

3 Longevity--this is a good problem--is increasingly
4 significantly for people with intellectual and developmental
5 disabilities, and we believe that in the future, except for
6 those with the most severe intellectual impairments, they
7 can be expected to have a life span equal to that of the
8 general population. Because you have an intellectual
9 disability does not necessarily mean that you have other
10 compromised conditions that could shorten your life span,
11 provided you are provided with decent support.

12 Next slide, please.

13 Direct support staff wages are a big problem in the
14 field. The average wage is \$10 an hour. So, basically, we
15 are at or near or below the poverty level, and we get
16 unnecessarily high turnover. We do not get people who will
17 stay long enough in the jobs to do this critical,
18 individualized support that is necessary for the individuals
19 in the out-of-home placements--the 600,000 I mentioned
20 earlier.

21 Next slide, please.

22 About half of the states reduced spending for
23 development disabilities services in the last year we
24 collected data--2011. This is the first time this has
25 happened.

1 So I want you to understand that people with
2 intellectual disabilities, and particularly their families,
3 are certainly feeling the brunt of the Great Recession and
4 what I like to call its aftermath because the Great
5 Recession may be over, but the aftermath is not.

6 Next slide, please.

7 If you want to go to your state and you want to look up
8 with our particular interactive features on our web site,
9 you can go to your individual state, and you can look and
10 see how much resources are being allocated for people with
11 developmental disabilities in a lot of detail.

12 So I am going to stop here on the next slide and show
13 you the 15 different kinds of charts we can do individually
14 for each state in the country.

15 So those of you who wish to go more deeply into this
16 and look and see what kind of resources and where people are
17 living, and so forth, you can do that individually on your
18 state.

19 I think that is the last slide although I am not sure.

20 Let's see. It is.

21 Thank you very much for permitting me to testify today.

22 [The prepared statement of Mr. Braddock follows:]

- 1 Chairman Chernof. Thank you very much.
- 2 I would now like to turn to Stephen Kaye, please.

1 STATEMENT OF H. STEPHEN KAYE, PH.D., UNIVERSITY OF
2 CALIFORNIA AT SAN FRANCISCO

3 Mr. Kaye. Thank you, Dr. Chernof.

4 I am Steve Kaye from the University of California-San
5 Francisco, where I direct the Center for Personal Assistance
6 Services. Our center is funded by the National Institute on
7 Disability and Rehabilitation Research.

8 On the next slide, you will see the 12 million
9 Americans who need long-term supports and services, and the
10 first thing to notice is that nearly half of them are non-
11 elderly. If you start at the top with the purple bars,
12 those are people who live in institutions, they are mostly
13 living in nursing homes, and they are mostly elderly people.

14 But the other three colored bars are community
15 residents, and the numbers are about equal between the two
16 groups--almost 11 million of those people. The green are
17 people with a high level of need--multiple self-care
18 activities. The red are a medium level of need. And the
19 blue is low level of need, which is they need help with
20 daily activities, but they do not have any self-care needs.

21 And in this presentation--if you could click once on
22 the slide, please.

23 In this presentation, I will deal with the green and
24 the red groups--people with medium and high level of need,
25 who live in the community. So I am not going to talk about

1 institutional residents even though they are important as
2 well.

3 And I am going to be providing an overview of the
4 characteristics of working-age adults--children and working-
5 age adults who need long-term care.

6 On the next slide you can see what the children look
7 like in terms of their disabilities. There are about an
8 equal number of kids with physical and intellectual or
9 developmental disabilities. There is also a fair component
10 of children with mental health disabilities. But the big
11 thing to notice in this Venn diagram on the left is the
12 amount of overlap there is among those three groups,
13 especially overlap between physical and I/DD and other
14 cognitive disabilities.

15 Another thing to notice is that three-quarters of
16 children have had their disability since birth or infancy.
17 So they have grown up with a disability.

18 And on the next slide, in contrast, is young, working-
19 age adults, 18 to 44 years old. Here, physical disability
20 becomes a bigger component because now we are starting to
21 see the effects of injuries, like back problems, paralysis,
22 other sort of nervous system things.

23 And, in this case, a majority of the people have had
24 acquired disabilities. Many of them went through their
25 entire childhood without a disability. So they are a

1 somewhat different group.

2 And even more different is, on the next slide, adults
3 45 to 64 years of age. Physical disability really dominates
4 in this group. There are also quite a few people with a
5 mental health disability, most of whom also have a physical
6 disability, and there are a few people with cognitive
7 disabilities. And there is also overlap.

8 Most of the people in this group, 82 percent, have
9 adult onset disabilities. Only 11 percent have had a
10 disability their entire life.

11 And the causes of disability here--essentially, the
12 main causes--are injuries and chronic health conditions.

13 So these people are more like the elderly population.

14 And, in the next slide, you will see that most children
15 and working-age adults needing LTSS live in or near poverty.
16 About one-third of them live in poverty, and another
17 approximately one-third live at less than twice the Federal
18 poverty level.

19 Okay. So where do they get their services from?

20 David Braddock mentioned this, on the next slide.

21 Only 5 percent of non-elderly LTSS users who live with
22 family members get paid help. So 95 percent of the time
23 they are just getting family caregiving. And even among
24 people who live alone or with roommates, only a quarter of
25 those get paid help. So paid help is really not that big a

1 deal compared to family caregiving, and yet, for the people
2 who use it, it is critical.

3 On the next slide, we address the question of who pays
4 for the minority of people who get paid help. Among
5 children, it is mostly Medicaid--about three-quarters.
6 Among working-age adults, it is, again, mostly Medicaid, but
7 Medicare starts to have a role among working-age adults for
8 people who are eligible for it. Among the elderly, Medicare
9 is actually predominant, at 56 percent, and Medicaid is 22
10 percent.

11 Now people will tell you that Medicare does not pay for
12 LTSS. I say, yes, Medicare does pay for it because I define
13 LTSS in terms of help with daily activities, and Medicare
14 home health does actually provide that.

15 On the next slide, since Medicaid is the main source of
16 funding for home and community-based services for non-
17 elderly people, I thought I would talk a little bit about
18 what that involves.

19 And there are the waivers that David Braddock
20 mentioned. There are 288 programs--waiver programs--in all
21 states. They offer intensive services for specific high-
22 need populations. So, on the chart, there are waivers for
23 different types of disabilities and different age groups,
24 and the services may not be the same.

25 The services vary, and different states have different

1 waivers. So, depending on in what state you live, you are
2 going to get a different array of services, possibly nothing
3 at all.

4 Also, other than waivers, there are persona care
5 services programs that are available in 32 states. It is an
6 optional Medicaid benefit at the discretion of the states.
7 PCS programs provide help with daily activities to a much
8 broader population. So it is sort of everybody who needs
9 it, who is eligible for Medicaid.

10 All states have the home health benefit. It is a
11 mandatory part of the Medicaid plan. And these are meant to
12 be health care services, but in fact, a lot of people get
13 health care services along with help with their daily
14 activities.

15 Another thing that is going on with Medicaid is many
16 states are involved--they already have transitioned or they
17 are proposing or in the process of transitioning to a
18 managed long-term services and supports system, which is, on
19 the one hand, a way of streamlining the system--a way of
20 integrating acute care and long-term supports and services.
21 It is happening in 30 states. Advocates worry that it is
22 happening too fast, and the outcomes may not be good.

23 And, finally, there are some new home and community-
24 based services options under the Affordable Care Act. A few
25 states are starting to take those up.

1 On the next slide, problems with Medicaid HCBS--there
2 is a huge amount of fragmentation, as you saw, and this
3 causes confusion and inefficiency and, perhaps more
4 importantly, gaps in services, and inequity across
5 disabilities and ages. Maybe you are eligible for a
6 children's waiver, and then you age out of it, and you have
7 no services.

8 And the fact that most of these programs are optional
9 to the states means, as David Braddock was saying, there is
10 a huge variation across the states in what services are
11 available and to whom.

12 Programs tend to ration services, and that rationing
13 results in unmet needs for services. There are currently
14 about a half-million people on waiting lists for waivers
15 throughout the states. That is a lot. It is a high
16 fraction of people who are getting services.

17 And the PCS programs and the waivers, both, tend to
18 place caps on the number of hours or the amount of
19 expenditures per person. So, for example, you might get
20 assessed that you need 200 hours, but the program only
21 provides 100; too bad, you are only getting 100 hours.

22 These programs may not provide all the services that
23 people need. Working-age adults and children with LTSS
24 needs rely heavily on technology, and that technology can be
25 expensive. And it may not be provided under the program, or

1 they may not provide the right kind of technology that
2 really allows the person to be independent.

3 And, finally, only some of these programs offer
4 consumer control, consumer direction of services, which is
5 something that non-elderly people with disabilities--I would
6 say all people with disabilities, but especially non-elderly
7 people with disabilities--seem to prefer. So it limits
8 their independence.

9 On the next slide, I wanted to make the point that the
10 goal of LTSS provision is not just surviving and being able
11 to remain in your home, but it should also be integration
12 and participation.

13 And, if you look at participation data among working-
14 age adults who need LTSS, it is pretty shocking. Only 9
15 percent have jobs. Only 39 percent participate in leisure
16 or social activities compared to 89 percent of people
17 without disabilities. Only 56 percent get out of their
18 house with friends or family. I think that means the
19 remaining 44 percent stay home all the time. And only 26
20 percent participate in community activities. So these are
21 very low levels of societal participation.

22 And, finally, on the next slide, I would like to talk
23 about the policy needs of non-elderly LTSS consumers. I
24 strongly believe that policy must foster participation, not
25 hinder it.

1 Hindering, for example, is getting a job should not
2 jeopardize your long-term supports and services. Most
3 states have rather draconian asset limits. Some of them
4 have strict income limits. This is a problem.

5 And this business of short-changing people--if you are
6 not meeting people's needs, if you are short-changing them,
7 the thing that goes first is participation. So maybe you
8 cannot get a job because you do not have somebody to come at
9 the right time and dress you every morning and get you out
10 and get you ready.

11 Laggard states--there are states that have not done
12 much to rebalance their system in favor of home and
13 community-based services. That institutional bias must be
14 overcome.

15 My research shows that rebalancing of a system toward
16 HCBS does not increase expenditures. They should know that.

17 And the fragmented programs in the Medicaid system
18 should be streamlined. But as I mentioned, too rapid
19 streamlining--for example, a shift to managed LTSS--can be a
20 bit dangerous, and advocates are worried about that.

21 Finally, policy must support people who do not qualify
22 for Medicaid. They may not know where to turn for help with
23 their situation. They may not know where to find quality
24 workers.

25 Families, who are the bulk of providers, need supports.

1 And there are a lot of people, as I showed you--a lot
2 of them--a lot of people who are relatively poor, at or near
3 poverty, and they cannot afford private-pay help, which is,
4 I think, where this Committee comes in.

5 Thank you.

6 [The prepared statement of Mr. Kaye follows:]

1 Chairman Chernof. Thank you very much.

2 If we could turn next to Kevin Martone, and then,
3 Robyn, we are not quite in order. We will come to you as
4 our last speaker on this panel.

5 So, Kevin, please.

1 STATEMENT OF KEVIN MARTONE, TECHNICAL ASSISTANCE
2 COLLABORATIVE

3 Mr. Martone. Good afternoon, everybody. Thank you for
4 the opportunity to testify.

5 Next slide, please.

6 I will be talking about mental health today.

7 Just way of a quick background, I am the Executive
8 Director of the Technical Assistance Collaborative in
9 Boston. We are a national nonprofit consulting firm on
10 human services issues. And, previously, I was the State
11 Mental Health Commissioner for New Jersey and President for
12 the National Association of State Mental Health Program
13 Directors.

14 Next slide.

15 Just basic definitions for mental illness:

16 Mental illnesses refer to brain disorders generally
17 characterized by dysregulation of mood, thought and/or
18 behavior.

19 They are disorders of brain circuitry that really,
20 ultimately, often play out in chemical imbalances in the
21 brain and, depending on the parts of the circuitry affected,
22 often result in the development of various symptoms. And we
23 then categorize those symptoms into various diagnoses.

24 I do want to drive home the point that violence is not
25 the norm when we talk about mental illness, and that is a

1 very important point to make.

2 But it is also important to note that the symptoms of
3 mental illnesses, as they play out, can be extremely
4 debilitating and disruptive to a person's overall
5 functioning.

6 Next slide.

7 When we talk about prevalence, I think it is important
8 to also consider long-term care settings, that mental
9 illness can be a primary driver for a person's need for
10 long-term support services, and it can also be a secondary
11 issue where another condition is the primary disorder.

12 But when you look at the prevalence of mental illness
13 throughout the country, more than one in four individuals
14 have a diagnosable mental disorder. That is over 61 million
15 Americans over 18 years old.

16 When you boil that down to individuals who have a
17 serious mental illness--some of the more visible mental
18 illnesses that we think of, like schizophrenia and schizo-
19 affective disorder and bipolar disorder--about 6 percent of
20 the population has those, roughly 14 million people. That
21 is the population that we think of more, who may tap into
22 the long-term care system.

23 Mental disorders are the leading cause of disability in
24 the United States and Canada, and depression affects more
25 than 7.4 million of the 40 million Americans aged 65 years

1 or older.

2 Next slide.

3 Among long-term care recipients in the community,
4 reported rates of psychiatric morbidity exceed 40 percent,
5 and most adults in nursing homes have some clinically
6 significant psychiatric or behavioral problem, with
7 estimates of prevalence ranging from 65 percent to 91
8 percent.

9 I think the bottom line that I wanted to drive home in
10 these prevalence figures is that more people than we
11 typically think have some form of a diagnosable mental
12 disorder, and that plays into long-term services really,
13 again, as a primary issue or secondary issue.

14 Next slide.

15 When it comes to medical comorbidity, roughly 68
16 percent of adults with a mental health disorder also have at
17 least one comorbid medical disorder, and 29 percent of
18 people with medical disorders have a comorbid mental health
19 condition.

20 Next slide, please.

21 A staggering statistic, I think, that is very important
22 to know is that people with mental illness, on average, die
23 25 years sooner than the general population. One of the
24 reasons why we do not see large numbers of people in the
25 institutional side, like in facilities like nursing

1 facilities, over the age of 65 is because they just simply
2 do not live that long.

3 Next slide.

4 Two points to point out in this graph here--if you look
5 over at the right-hand part of it, for individuals without
6 mental illness who are admitted into nursing homes,
7 obviously, most of those individuals are over 65 years of
8 age.

9 When you look over at the far left, for individuals who
10 are admitted into nursing homes with more of the severe or
11 serious mental illness, you can see the age of the
12 population changes fairly significantly. And the 31 percent
13 figure even there is sort of striking, that 31 percent of
14 those types of admissions are between the ages of 18 and 54.

15 One of the things that I will touch on here without
16 going into detail is, generally, people who are presenting
17 with a mental health condition are screened through the
18 PASRR process. And the second level of the PASRR process
19 addresses the level of mental illness and whether they meet
20 that nursing level of care. If you look at the data across
21 the states, across the country, there is really is wide
22 variability in admissions into nursing facilities, which
23 points to variability in how the PASRR process is
24 administered.

25 I think for the Commission, from your standpoint, that

1 may be something to take a look at in terms of the overall
2 PASRR process and the role it plays for people with mental
3 illness admitted into nursing facilities.

4 Next slide, please.

5 Next slide.

6 When it comes to mental health, generally, the overall
7 policy direction at this point focuses on at least what I am
8 calling the 4 Is. The first thing is really Olmstead and
9 ADA and community integration, whether it is forced through
10 litigation and settlement agreements or voluntary efforts on
11 behalf of states; integration with primary healthcare;
12 integration with substance abuse; and, at a very basic
13 level, integrated health records and electronic health
14 information.

15 Obviously, Medicaid is a large focus in the mental
16 health service delivery system. It is a predominant payer
17 on the public side.

18 Managed care plays a significant role in delivering the
19 services for mental health.

20 A lot of the mental health focus is more on prevention
21 and early intervention, which is a good thing. The field
22 really needs to go there at a basic level, in terms of,
23 obviously, can we prevent the onset of these illnesses, but
24 also preventative in terms of can we serve people earlier on
25 in their illness to prevent those long-term support service

1 needs.

2 I think when you boil this down, really, I think the
3 overall principles here are that the mental health system's
4 focus or priorities are really trying to focus on recovery,
5 reducing the need for facility and nonfacility-based long-
6 term support services and reducing the cost for those who
7 will need long-term support services.

8 Next slide.

9 Next slide.

10 Generally speaking, the service needs for people with
11 mental illness are similar to the other disability groups.
12 I am really just going to highlight the points in red there.
13 But they generally need an array of services that really
14 address ADLs and IADLs, ranging even for people with mental
15 illness, as far as assistance in terms of eating and
16 dressing, up towards managing home-based environments and
17 medication management--things like that.

18 Next slide.

19 These are basically some examples of the type of
20 services that are out there in a community, known as
21 evidence-based practices working. You know, whether people
22 can access those is a different point. But the point is
23 that we know of evidence-based practices that can work out
24 in a community, and all of these are cheaper Medicaid
25 alternatives to institutional settings.

1 Next slide.

2 Next slide.

3 And, next slide.

4 So where are people? I think this is an important
5 slide.

6 So, generally speaking, when you talk about mental
7 illness, whether it is primary or secondary, there are about
8 500,000 people across the country with some form of mental
9 illness in nursing homes. About 125,000 of those have a
10 serious mental illness and are under the age of 65.

11 Comparatively, if you look at the homeless population,
12 you are talking about 285,000 individuals; jails and
13 prisons--231,000; state hospitals--35,000.

14 And a very interesting statistic is the number of
15 emergency department visits for people with primarily a
16 mental health or substance abuse presenting condition.

17 Other folks, obviously, then are served in group homes.

18 There is a large contingent of individuals who are
19 served in a board-and-care industry down to permanent
20 supportive housing and private residences.

21 I think if you tend to think about what does mental
22 illness look like, what is the visible face of mental
23 illness, we think about the homeless population. We can
24 walk down the street in D.C. today and see that.

25 But, if you look at the numbers out there, there is a

1 nonvisible population of folks with mental illness who are
2 in nursing homes and jails and prisons and state hospitals,
3 and those are issues that really have to make us think about
4 where we want to make our interventions and address those.

5 The Department of Justice is focusing a lot of its
6 efforts under the Civil Rights Division and the Americans
7 with Disabilities Act in terms of trying to move people into
8 the most integrated settings, out of nursing homes, state
9 hospitals and the board-and-care industry. And there are
10 settlement agreements and active litigation in several
11 states on these specific issues.

12 Despite these numbers here, which are high, the vast
13 majority of people with mental illness and serious mental
14 illness do not live in settings like this, and they are out
15 there in more independent settings.

16 Next slide.

17 So why do we have so many people in those settings,
18 though?

19 And I think in addition to the inability to access
20 services because of resource availability out there, you
21 also have these other problems--poverty, affordable housing
22 crisis and things like that.

23 I just want to highlight the affordable housing crisis.
24 Nowhere in the country, not in one jurisdiction, in one
25 rental housing market in the country, can a person with

1 disabilities, on SSI, afford a place to live.

2 And if you are going to think about what is a direct
3 contributor to institutionally-based long-term support
4 services--and I think this is going to stand up across
5 disabilities--the affordable housing crisis out there for
6 people with disabilities is it.

7 And that is an area that we really need to think about
8 how we can do better. Part of that is if we continue to
9 spend significant state resources in institutionally-based
10 systems, we lose the opportunity to use those funds to
11 leverage housing resources out there.

12 Next slide, please.

13 Next slide.

14 Next slide and next slide.

15 And, one more slide.

16 Medicaid is the largest payer for mental health in the
17 United States. Individuals with mental health disorders
18 represent about 11 percent of the individuals enrolled in
19 Medicaid but about 30 percent of all Medicaid expenditures.

20 We talk a lot about home and community-based waivers,
21 but a lot of the mental health services in the country are
22 also delivered and financed through Medicaid state plan and
23 optional services--things like the rehabilitation option,
24 health homes, 1915(I) state options, things like that.

25 Next slide.

1 A quick breakout in terms of distribution of Medicaid
2 on long-term care spending--you will notice in mental health
3 facilities the number is very low, comparatively. It is
4 largely because Medicaid does not pay for individuals
5 residing in institutions for mental diseases. So that cost
6 is borne largely at the state level.

7 The problem with that is the states are not able to
8 maximize or leverage FFP, and at the same time, states are
9 not able to use those potential resources to fund non-
10 Medicaid, but important, services for individuals.

11 Next slide.

12 Cost comparisons: State hospitals--onwards of \$250,000
13 and up per year per bed. Nursing homes--80,000 or so. Down
14 to supportive housing figures, which we heard earlier--
15 somewhere in the \$20,000 mark--and that includes rental
16 assistance for housing.

17 Next slide.

18 Next slide.

19 Just a quick important point--as a result of the
20 recession between fiscal years 2009 and 2012, over \$4
21 billion was cut out the public mental health system. Again,
22 that creates a situation where we lose Federal matching
23 funds, and we also lose access to services and money that
24 can also be leveraged to support the other needs.

25 Next slide.

1 You can go to the Opportunities slide if you can, and I
2 will finish up.

3 So I think I wanted to really close on evidence-based
4 practices exist. Community-based, evidence-based practices
5 exist, and they are much more cost effective and produce
6 better outcomes than institutionally-based services, by and
7 large. That does not mean that people do not necessarily
8 need institutional-based services at some point.

9 Opportunities exist within health care reform and the
10 Affordable Care Act. Initiatives like Money Follows the
11 Person and balancing incentives and health homes are good
12 opportunities for folks.

13 One important point on the Money Follows the Person
14 Program is that because Medicaid dollars cannot be spent in
15 IMDs a person with mental illness coming out of IMD is not
16 eligible for MFP. MFP could be a very good program for
17 people with mental illness, but because of the IMD exclusion
18 it often is not a resource for people.

19 Olmstead and community integration are great
20 opportunities for folks. The mental health parity revisions
21 that are going into effect are good opportunities. And the
22 integration of behavioral health care and primary health
23 care are good opportunities.

24 So I will end it at that and take your questions when
25 you are ready.

1 Thank you.

2 [The prepared statement of Mr. Martone follows:]

1 Chairman Chernof. Thank you very much.

2 And now we will hear from Robyn Stone.

1 STATEMENT OF ROBYN STONE, PH.D., LEADINGAGE CENTER
2 FOR APPLIED RESEARCH

3 Ms. Stone. Hi. Thank you so much for having me.

4 I feel like this is, in some ways, déjà vu. I was just
5 calculating the first commission that I was on in 1989. I
6 was in my 30s, and now I am speaking to you, and I am in my
7 60s. So one of these days I am hoping we will get this
8 right.

9 I am here today to talk about the elderly long-term
10 care population. I am the Executive Director of the Center
11 for Applied Research and Senior VP for Research at
12 LeadingAge.

13 Next slide, please.

14 I wanted to actually preface this by saying a couple of
15 things.

16 One is I stole from every piece of data that I could.
17 These are not my own calculations.

18 One of the problems that we have for actually looking
19 at the long-term care population in the elderly is that we
20 do not have the most recent data on the nursing home
21 population. So it is very hard to put these data together,
22 and I think there is a need for better data going down the
23 line in terms of how we look at this population.

24 I also want to make the preface that embedded in a lot
25 of these data are post-acute populations, and I believe very

1 strongly that we need to be thinking about the post-acute
2 and the long-term care populations separately, particularly
3 for the elderly. It is very difficult to talk about long-
4 term care these days in the elderly because it has blurred
5 so much.

6 A person who is in rehab and a skilled nursing facility
7 for 20 days, in my definition, is not long-term care. And
8 most of these data embed both skilled nursing and home
9 health that is post-acute and that is short-term.

10 These days, when you look at that population, they are
11 either rehab or they are really sick, and they are a very
12 different population with a lot more medical needs.

13 So I throw that out to you because we have done the
14 best we can with the data we have.

15 But one of the things we need to do--and I think this
16 needs to be a recommendation--is we need to start pulling
17 out the post-acute care population, getting estimates of
18 them and getting costs and data around service utilization
19 because they are very different from the long-term care
20 population.

21 So, having said that, we estimate--and these are data
22 from 2004-2005, and you can see the difference in the
23 percentage--while about a half of the population in long-
24 term services and supports is under 65, there is a much
25 larger percentage of the elderly population than the under

1 65 who need long-term services and supports.

2 That, I think, is a really important point in terms of
3 not only the population today but the risk in the future.
4 So it is a much higher risk among the elderly population
5 than it is among the under 65 population.

6 Next slide.

7 This is, again, using Mr. Kaye's data. Looking at the
8 elderly population needing long-term care services in the
9 U.S. by all residential settings, using 2004 and 2005 data,
10 you can see that there were about 5.4 million community
11 residents and another 1.3 million institutional residents.
12 If you narrow that the ADL--the Activities of Daily Living
13 population--you have a much smaller population.

14 I think this is also important because we need to
15 figure out what is our definition of long-term care.

16 Those who need activities of daily living is a much
17 smaller subset of the larger, broad definition that includes
18 all kinds of functional needs, including people who may need
19 financial assistance or medication assistance--what we call
20 the Instrumental Activities of Daily Living.

21 This is not just a semantic question. It actually has
22 very strong policy and cost implications. So thinking about
23 these definitions and how we actually want to parse out the
24 long-term care population among the elderly is going to be
25 very important.

1 Next slide.

2 Also looking at the percentage of Medicare enrollees
3 unable to perform one or more physical functions--this is
4 another way of slicing it, but it gives you the sense of
5 what happens over time.

6 Clearly, among the 85 and over population, we are
7 looking at a very, very large percentage of that population
8 who need some type of long-term services and supports--40
9 percent among men and at 56 percent for women. So 85 and
10 over is a really important threshold, and that is only going
11 to get more exacerbated in the future in terms of where we
12 think about these cutoffs and looking at the population.

13 If you look at the 65 to 74 population, it is only 1 in
14 5 women and 13 percent of men. It escalates substantially
15 among the 85 and over population.

16 Next slide, please.

17 If you look at race--do not look at the bottom. This
18 was done with me bleary-eyed on Saturday night.

19 I will tell you what these three categories are. White
20 is the first, the second category is Black, and the third is
21 Hispanic.

22 And I think the point that I want to make here is that
23 race does matter, and Blacks in particular are much more
24 likely to need long-term services and supports--a quarter of
25 Black men and 34 percent of Black women in 2007. So there

1 is a racial difference.

2 This is very important because by 2030 we are going to
3 see substantially increased minorities among the elderly
4 population in this country. One-third of the population is
5 going to be non-White.

6 That is very different right now. We have a primarily
7 White elderly population. By 2030, it is going to change
8 dramatically.

9 We need to be thinking about those minority, non-White
10 populations, particularly because they are more likely to be
11 lower income and because there are substantial cultural
12 competence issues that really have to be addressed around
13 how we think about not only the financing but the delivery
14 systems for these populations.

15 You can move to the next slide.

16 Also, looking at the distribution of the age 65 and
17 over with functional limitations by residential setting,
18 this is a way of sort of cutting again the pie. Traditional
19 community basically means people who are living in their own
20 homes. Community housing with services is a way of thinking
21 about a long-term care population that is living in some
22 type of residential setting. And a long-term care facility
23 is the nursing home.

24 The most important piece here is that you can see the
25 dramatic differences in that we have very, very high acuity

1 in the nursing home among the long-term care population--67
2 percent of them, 3 or more ADL limitations. Whereas, if you
3 look at people living in the traditional community, it is
4 only 7 percent and 14 percent in that very high group in
5 community housing with services.

6 Now, however you cut this in the pie, the bars may look
7 different, but it is absolutely true that we have a very
8 high--much more highly functionally disabled population in
9 the nursing home--a lot of that, by the way, having to do
10 with the dementia.

11 And my feeling is if we pulled out the post-acute care
12 population out of the skilled nursing, we would be able to
13 look at this population in much more detail. Right now, the
14 post-acute is in those data.

15 So it makes it much more difficult for us to
16 understand, but nevertheless, I will argue that we a much
17 more highly disabled population living in the nursing home.

18 If you move to the next slide--also, just to give you a
19 sense of what has happened on people living in nursing homes
20 over the years--this just shows you exactly what we all know
21 from 1973 to 2004 and that trend is continuing. We see that
22 there is a substantial change in the people who are using.
23 Both by age and across the board, we see a change except
24 for--and the highest decrease has been from 21 percent to
25 13.9 percent of that 85 and over population, primarily

1 because many have moved to assisted living and also more
2 people are staying at home.

3 And I am going to conclude with a couple of comments
4 around that.

5 Next slide, quickly.

6 This is also selected characteristics of residential
7 care residents in the United States. Residential care is
8 any residential facility that is not a nursing home and that
9 has four or more beds and 24-hour oversight. This comes
10 from the new data that has just been released over the past
11 year.

12 I think the most important things here are that the
13 vast majority of people living in those residential settings
14 are White, 70 percent are female, and 54 percent of them are
15 85 and over.

16 This is, I think, the new sort of space for us to think
17 about in terms of the future of long-term care--what are
18 residential options going to look like?

19 This is the population that is not living in their own
20 homes. They are not living in nursing homes.

21 So, if you move to the next slide, this is elderly
22 residential care residents with Medicaid by age--the 65 to
23 74-year-olds, 39 percent; the 75 to 84-year-olds, 16
24 percent; and the 85 and over, 10 percent.

25 So your very elderly are almost all private pay in

1 residential environments. These are your people who are
2 paying for assisted living in the private sector.

3 But, if you look at the 65 to 74, you see an increase
4 in the Medicaid population. This is really the movement of
5 folks into adult foster care and those types of
6 environments.

7 I think we have got potential to think about shifting
8 more in the direction of residential options in the next 30
9 years for people who are not in nursing homes. We have got
10 to figure out a way to make it affordable.

11 Next slide, please.

12 This is the percent of residential care residents
13 receiving assistance with activities of daily living. This
14 is all residents living in non-institutional residential
15 care. Thirty-eight percent of them are three to five ADLS--
16 pretty high acuity level. And we believe those acuity
17 levels are going up all the time, if you look at assisted
18 living and other residential environments.

19 Next slide--household wealth of the non-
20 institutionalized older population by disability status. I
21 just wanted to throw in one piece of data. This came out of
22 2002, a long time ago now.

23 But, if you look at the people with no disabilities and
24 you look at the people with three or more disabilities, I
25 think the story is pretty clear. There is a pretty strong

1 correlation between having a disability and having low
2 income.

3 And, of course, we can argue about the chicken and the
4 egg there, but I think it really underscores the fact that
5 the major point is we need to be thinking about
6 affordability and how we look at financing and service
7 delivery options for the future.

8 If we move to the next slide--projected lifetime long-
9 term care needs for persons turning 65 in 2005--you know,
10 this is all, by the way, predicated on the notion that
11 nursing home--our system stays the same. So, right now, we
12 are really looking at a pretty substantial chance of using
13 some type of long-term care in the future.

14 One thing I would say about these data is that they
15 include the post-acute in there. Again, if we do not pull
16 the post-acute population out, it is really hard for us to
17 predict long-term care use because we are predicting short-
18 term post-acute use as well. So I always have to put this
19 caveat in there because I think we have to redo this wit
20 data that makes sense.

21 If we move to the next slide, I also wanted to show the
22 distribution of the population aged 85 and over in 2012 and
23 2032. This point has been made before, but I think it is
24 important for us to understand.

25 The populations look very different in different

1 states. For example, in 2012, Florida had the highest rank
2 of people aged 85 and over, 3 percent of their population.
3 Hawaii had the highest rate as well. Utah had the lowest
4 rate compared with about 2 percent of the population in the
5 U.S. being 85 and over, which is the population that is
6 going to be most in need of long-term services and supports.

7 If you look at 2032, Hawaii is No. 1, Florida is No. 2,
8 Vermont is No. 3, and Utah is 51st with the U.S. at 2.9
9 percent.

10 We could cut this a million and one ways. The point is
11 that we are going to have tremendous variation in the United
12 States, and we really need to think about that, not only in
13 terms of financing but how we look at the supply side
14 because it does not mean the same in every single state.
15 That does not mean people should not have access.

16 If you move to the next slide--the percent of 65-plus
17 population with some kind of self-care difficult in 2010--
18 this is another way of cutting it. Mississippi is No. 1 at
19 11.7 percent, Alabama is No. 2 at 11.3 percent, and Wyoming
20 is No. 50 at 4.9 percent. You probably know something about
21 Mississippi and Alabama versus Wyoming, but these are really
22 important data in terms of looking at sort of the way we cut
23 things across states.

24 And, finally, the next one is the percent of 65-plus
25 population with cognitive difficulty in 2012--again,

1 Mississippi, Alabama; North Dakota is 50th.

2 So how do we deal with these things across states? I
3 think this is a really important and very, very thorny
4 question.

5 Next slide.

6 That is it. Let me conclude with a couple of things.

7 I think we need to be thinking about affordability. In
8 the future, we are going to see more haves and have-nots but
9 a lot more have-nots.

10 I just came from a Federal Reserve Board meeting this
11 morning. They just released a new report on the insights of
12 financial experiences of older adults. The Federal Reserve
13 Board is finally getting into long-term care and the needs
14 of the elderly.

15 And the picture is grim, so the questions around
16 affordability of options.

17 I can foresee in 20 years that nursing homes will be
18 primarily post-acute. That means we need significant
19 residential options for people who either do not have homes
20 to live in or can no longer remain in their own homes.

21 And, how do we think about financing and supporting all
22 of those things in the middle?

23 So that is one piece.

24 The second is really thinking about this change in the
25 distribution of White and non-White. I do not even think we

1 have begun to sort of tip the iceberg around what that is
2 going to look like in the future.

3 The third is, I think, the unknown about dementia.
4 Every day, you read a new article. One day, it says we are
5 going to have less. The next day, you read that if you have
6 depression you have a three-fold chance of getting--risk of
7 getting--dementia.

8 I think we are really in this sort of very unknown
9 world around the future of cognitive impairment, but it is
10 definitely--unless it goes away, it is going to be a major
11 driver, just by sheer volume of elderly and the 80 and over
12 population that is going to be increasing. So we need to
13 really think about options for people with cognitive
14 impairment.

15 My sense is that most of those folks do not need to be
16 in nursing homes, but the question of what kind of options
17 are available for them and how do we think about the
18 financing in that respect.

19 And I think I will stop there.

20 [The prepared statement of Ms. Stone follows:]

1 Chairman Chernof. I want to thank the panel for an
2 excellent set of presentations and move quickly to our
3 commissioner on my right, Stephen Guillard, please.

4 Commissioner Guillard. Thank you very much, my
5 appreciation to the panel as well.

6 I just have one observation and one quick question, if
7 I may.

8 On the observation, I could not agree with you more,
9 Robyn--and we have had this discussion--that the assessment
10 of the nursing homes is biased inherently by the longer-stay
11 patients versus the short-term, post-acute patients.

12 One of the statistics is that 65 percent of the patient
13 days in nursing homes across the country are funded by
14 Medicaid. And so people view that as a disproportionate
15 shift of funding--and some could legitimately argue that--
16 when, in fact, 65 percent of the funding only covers 25
17 percent of the individuals that are--65 percent of the
18 patient days, not the funding.

19 The patient days cover only 25 percent of the patients
20 that are cared for in nursing homes because the vast people
21 moving into and out of nursing homes, within 30 days of
22 care, are funded by Medicare, and very, very, very little is
23 funded by private, long-term care insurance.

24 So your comment is right on target and helps explain
25 sometimes why public policy gets clouded by statistics.

1 My question, moving on, is for Dr. Braddock in an area
2 that I am not that familiar with, but I found your comments
3 and presentation very interesting.

4 I had one question, and we were talking about this as a
5 panel earlier, and it dealt with training. Within that
6 segment of care, how is training handled for the employee
7 population, generally, and who is responsible for that?

8 Mr. Braddock. I gather you are primarily referring to
9 people who are working in community settings.

10 Commissioner Guillard. Yes.

11 Mr. Braddock. The best thing I can say about that is
12 that we do have an entity that is providing computer-
13 assisted training, in which you can through a programmatic
14 experience where you are taught the ABCs about the content
15 that can be transmitted that way.

16 The only way it can really be done well, of course, is
17 to be well supervised by an experienced person who is
18 engaged with great sophistication with people with
19 intellectual disabilities and knows what they are doing and
20 work as a mentor.

21 But we do have training programs that now are provided
22 through computers, in group homes and so forth, to be able
23 to train those staff. We have had this for about 10 years
24 now, and it is getting better and better.

25 In other words, you can be hired into a job without any

1 background, but you have got to have that training in order
2 to stay in that position.

3 And there is a lot more sort of extending of this
4 particular approach that needs to be done nationally, but I
5 believe we are a little bit ahead in this regard with
6 respect to developmental disabilities perhaps over some of
7 the other disability groups.

8 But you have certainly hit on an extremely important
9 point.

10 The best teacher is an experienced person who has been
11 working with individuals with intellectual disabilities for
12 quite some time and to share that knowledge with another
13 individual because people with intellectual disabilities,
14 like all people with disabilities, are individuals and they
15 have preferences and needs. You have got to see them that
16 way, and you have got to respect them, and you have got to
17 understand their rights and their dignity.

18 We need more Federal support to diffuse this training
19 across the country because right now it is completely
20 optional. It is not required.

21 Commissioner Brachman. First of all, I want to thank
22 all the panelists for very interesting presentations.

23 And this is a question for all of you, if you would
24 address it, and I am focusing on regulatory barriers.

25 So, for persons who are currently eligible for public

1 funding in the programs that you deal with, for the
2 disabilities that you deal with, what regulatory barriers
3 exist that limit or impede service delivery or prevent
4 improved quality of care or innovative and creative kinds of
5 service care?

6 David, if you want to start.

7 Mr. Braddock. Why does it take a waiver to get into
8 the community or get family support?

9 Why shouldn't it take a waiver to get into an
10 institution?

11 Think about it.

12 Of course, institutions were the backbone of out-of-
13 home residential placement for decades. Centuries, in fact.
14 That has really changed, but our approach to this particular
15 area has not.

16 And I would suggest that we take a very close look at
17 making the community and family, choice one, and if that
18 cannot be provided--and in nearly every instance it will be
19 able to be provided--then we get a waiver.

20 And, if some states want to put a few people in
21 institutions for the next, shall we say, limited period of
22 time until they can do better, then we do it that way.

23 Mr. Kaye. Yes, I mentioned the institutional bias, and
24 that is the concept. Institutional services are required as
25 a component of every state's Medicaid system, and home and

1 community-based services are optional.

2 Vermont tried something interesting, which was to do
3 away with the entitlement to one type of service or the
4 other and simply say that if you had a high level of need
5 you could choose between home and community-based services
6 and institutional services.

7 That sounded like a good model to me. I am not sure
8 that in practice it worked very well, but I would head in
9 that direction.

10 Chairman Chernof. And I am just going to hop in and
11 remind commissioners that we have a second panel. So I will
12 ask all of us to keep our questions to a single question and
13 to a single person, if that is okay.

14 It is a fabulous question, but you have asked an open
15 question. So, if there is any other panelist who would like
16 to respond, that is great. Otherwise, I will move us
17 forward.

18 Ms. Stone. The only thing that I would say is that the
19 elderly question around what we have to deal with is much
20 broader than that. Remember that the vast majority of
21 elderly are not on Medicaid. There is really a big
22 difference between the under 65 and the over 65 populations.

23 So many of our elderly people do not qualify for
24 Medicaid. They are above Medicaid. The regulatory barriers
25 for them do not exist. They can pay in the private market

1 if they could pay in the private market. The problem is it
2 is not affordable for most people.

3 So it is somewhat of a different question, I think,
4 when you are dealing with the elderly than with the non-
5 elderly population.

6 Commissioner Anwar. Hi. Good job, all, in your
7 presentations. Thank you so much for being here at the
8 short notice, I am told, that the panel was put together.

9 My question goes back to the ability of providers. We
10 are seeing that a lot of care for the disabled is provided
11 by family or very close family and friends.

12 And I am just wondering, and a question to all maybe--
13 and David is better suited to answer that, but anybody can
14 pick up on this--is that, what tools are provided or are
15 available in different states?

16 Is there a state or some states doing better than
17 others as far as family care is concerned--because as a
18 physician, we see all the time that a slight change in the
19 condition of the patient--the patient who was being managed
20 very well by their family, although a very caring and close
21 family, is now brought into the emergency room and needs a
22 slightly higher level of services.

23 And I was wondering if there are tools available to
24 teach the family how to manage and handle the basic,
25 everyday living things.

1 Mr. Braddock. Excellent question. I would say that,
2 in general, family support is in the ascendancy in the field
3 of developmental disabilities.

4 I do not think of a single state, however, that I could
5 say, oh, yeah, they really got it right, because the
6 statistics we have show vast numbers of families that do not
7 receive even any contact from the state agencies whatsoever.
8 They are pretty much on their own.

9 And the crisis is with families who are led by aging
10 folks, who have relatives with intellectual disabilities and
11 developmental disabilities living at home.

12 Siblings do a lot. We have, in the last few years, had
13 a national organization organize itself in developmental
14 disabilities, exclusively for siblings to be in it and to
15 advocate for more resources and support to siblings because
16 what ends up happening is that the parents are no longer
17 able to care for the individuals and their brothers and
18 sisters do it.

19 So that is about all I can say in the interest of time
20 at this point.

21 Mr. Kaye. If I may add, let me point you to what I
22 think is a promising practice. Do not faint, but it is the
23 Veterans Administration. They provide family members--
24 primary family caregivers--of post-9/11 veterans with
25 stipends, training, respite care, expense payments and

1 something else.

2 Health insurance, yes. Somebody said that behind me.

3 Amazing. And this is, I think, a model.

4 Mr. Martone. If I could just very quickly--on the
5 mental health side, family psycho-education and intensive
6 family support services is recognized as an evidence-based
7 practice. It tends to be funded more by state funds and not
8 a Medicaid service, but it is one of those areas where when
9 you look at the magnitude of the cuts to states, you know,
10 it is one of those services that gets cut out first.

11 And it is one of those things that if you can make your
12 investments there, you may have a better likelihood of
13 having people succeed in their home-based environments than
14 tap into other long-termed support services.

15 Commissioner Jacobs. Thank you, Mr. Chairman.

16 Dr. Kaye, I was curious. We talked this morning a
17 little bit about work incentives and your statistic that 9
18 percent of those needing long-term services and support work
19 outside the home.

20 I am kind of curious if there are any data on those
21 that are able to work--I am guessing it is more than 9
22 percent, less than 100 percent--want to work, and then
23 perhaps some can work inside the home as opposed to outside
24 the home.

25 And then what are policies that can be used?

1 And we have seen some in terms of asset cliffs or
2 income cliffs, and all that sort of thing, to encourage
3 that.

4 Mr. Kaye. In fact, I usually have the numbers for the
5 statistics for how many want to work and how many feel they
6 are able to work. I do not have it for this population--the
7 LTSS population.

8 Yes, it is much more than 9 percent.

9 There are problems, though, because we have kind of
10 separated the concepts of disability on the one hand and
11 health on the other. But, in fact, I mean, you saw how many
12 people have disabilities due to chronic health conditions.
13 Those people are not in such great health.

14 So some people may not feel they are able to work, and
15 perhaps legitimately so, because they are tired, they are in
16 pain, they do not feel well, or their health is up and down,
17 and they cannot work.

18 So it is not anywhere near 100 percent who feel they
19 are able to work or who want to work.

20 Yeah, I mentioned the issue with asset limits. I think
21 that is the biggest thing.

22 Many states have Medicaid buy-in programs that allow
23 people who go to work to continue their LTSS if they start
24 paying a premium. I think that is a very good practice and
25 should be more widely used.

1 I mean, I think a barrier to working is the assessment
2 and the caps on services. People are not assessed for
3 participatory activities. So you may need help dressing,
4 bathing, et cetera.

5 But what if you need help when you are at work to go to
6 the bathroom or something like that? States allow you to
7 use your hours for that, but they do not give you extra
8 hours because, okay, now you have a job; so you really need
9 this.

10 Or, you want to go to the movies; so you need this.

11 And so I think that is a major barrier.

12 Chairman Chernof. And for sake of time, I am going to
13 defer to Vice Chair.

14 Vice Chairman Warshawsky. Thank you. Thank you,
15 Bruce.

16 I just had two questions, and they are both for Robyn.

17 And, actually, I think they are the same question. So
18 I am asking one question, and it is really understanding
19 these charts.

20 So the one chart says Elderly Residential Care
21 Residents with Medicaid, by Age, United States, 2010, and
22 you show the younger population is a much higher number. I
23 think this may relate to what your conversation with Stephen
24 was, but I just simply do not--it is not intuitive.

25 One would have thought-

1 Ms. Stone. Not intuitive for me either, you know, and
2 my speculation is that we are looking at a different cohort
3 issue around use of the non-institutional residential
4 options.

5 So it is not intuitive to me, but it is definitely a
6 difference in use of what is really assisted living and
7 other kinds of residential options, which in these data are
8 probably adult foster care, board-and-care homes, anything
9 that is four or more people living together in the same
10 group homes, but--yeah.

11 Vice Chairman Warshawsky. Oh, I see. So this is not
12 necessarily long-term care services.

13 Ms. Stone. No, these are not long-term care. This is
14 residential non-nursing home.

15 Commissioner Feder. But if they are receiving--but
16 these were getting support from Medicaid for health
17 services, or are they purchasing personal care services in
18 the home?

19 Ms. Stone. It is not. There is no definition around
20 that. It is purely whether they are on Medicaid or they are
21 not. So they could be receiving services for--

22 Commissioner Feder. For health care.

23 Ms. Stone. Yeah, but I mean if you think about it, the
24 truth of the matter is these are all 65 and over, Judy. So
25 Medicare would be covering their health.

1 Commissioner Feder. Well, except the Medicaid
2 supplementation. So Medicaid-

3 Ms. Stone. Yeah.

4 Commissioner Feder. You are right. You are absolutely
5 right.

6 I mean, my guess is there is cost-sharing.

7 Ms. Stone. This is mostly some cost-sharing and
8 personal care--is what I am-

9 Commissioner Feder. You do think it is personal care?

10 Ms. Stone. I do, yeah, because that definitely--I
11 mean, it is a Medicare population. It is not the under 65.

12 Vice Chairman Warshawsky. Okay. Well, that was--well,
13 okay.

14 Ms. Stone. Yes. This is not--are you familiar with
15 this database?

16 This is the new database that just came out of NCHS,
17 which is a residential care study that is done, non-
18 institutional. So this is not nursing home.

19 This is their best way of trying to capture assisted
20 living, board-and-care, adult foster care, all of the
21 variation in residential settings. And it is a nationally
22 representative sampling. I think RTI fielded it.

23 Vice Chairman Warshawsky. Okay. My other question--I
24 am not sure. Again, maybe we could talk about that later.

25 The other chart was Percent of Elderly Population in a

1 Residence of Nursing Facilities, and this is looking at it
2 over time, from 1973 to 1974 to 2004.

3 Ms. Stone. Right.

4 Vice Chairman Warshawsky. So, for the 65-plus, there
5 is a very small decline, from 3.8 to 3.6.

6 Ms. Stone. Right.

7 Vice Chairman Warshawsky. But looking at the component
8 ages, there is a much more significant decline.

9 How do you do the algebra there?

10 Ms. Stone. These are the data. I mean, this is the
11 population--the percent of the entire group.

12 Vice Chairman Warshawsky. Oh, the percent of--

13 Mr. Kaye. Because of the age distribution of the
14 population.

15 Ms. Stone. Yeah. It is an age distribution.

16 Vice Chairman Warshawsky. Oh, the age. Oh, I see.

17 Okay. All right.

18 Ms. Stone. It is just an algebra question.

19 Vice Chairman Warshawsky. Okay, got it. All right.

20 Thank you.

21 Ms. Stone. I mean, the point that was made in the
22 chart is that you are looking at substantial decreases in
23 the 85 and over population, which, to me, is the most
24 significant.

25 Commissioner Raphael. Let me just echo the thanks to

1 the panel.

2 I have a question for Dr. Stephen Kaye.

3 I was struck, listening to the panelists as you looked
4 at your population segment, that you all spoke about a shift
5 from institutions to home and community-based options and
6 supported living, and you all spoke to some degree about the
7 state variation. But, as you showed the numbers, the
8 supported living and home and community-based options are
9 considerably less costly on a unit basis.

10 But one of the concerns is always, will the number of
11 units increase and will people be more apt to use this
12 public good than an institutional public good?

13 And I know, Dr. Kaye, you have done work really looking
14 at what the budgetary and fiscal implications are of these
15 kinds of shifts, and I am wondering if you could just
16 amplify your studies for us.

17 Mr. Kaye. Well, it is true that more people do present
18 themselves for services when they are offered home and
19 community-based services.

20 I mean, I sometimes call institutional services
21 rationing by lack of desirability because nobody wants to go
22 into a nursing home; so people do not apply.

23 So more people are served when a state expands its home
24 and community-based services; more people are served. That
25 is a good thing, isn't it? Public programs are supposed to

1 serve people who need them.

2 And, when you look at the experiences of states, you
3 find that home and community-based services do not actually
4 break the budget. They are not the reason that costs for
5 long-term supports and services have been going up over
6 time.

7 In fact, the states that have well established programs
8 and home and community-based programs actually do a little
9 better than other states at containing their costs.

10 A recent statistic model that I did showed that if you
11 kind of gradually and carefully rebalance your state's long-
12 term supports and services system you actually do save
13 money, not a huge amount of money, but you save money over
14 either doing nothing or kind of willy-nilly going and
15 rebalancing very rapidly.

16 The same study also showed that if you cut your home
17 and community-based services you end up spending more.

18 Commissioner Pruitt. Yes, my question is for Robyn.

19 I appreciate your input--a lot of interesting
20 information here. I, especially, enjoyed your comments
21 about the post-acute population, and I believe you mentioned
22 that the numbers would look very different if we factored
23 out the dementia population.

24 I know we do not have the data, but your chart that
25 refers to the Medicare enrollees and where they are in the

1 setting of services, and the ADLs and IADLs-if you factored
2 out those populations, what would you guess that these
3 numbers would change?

4 What would the population look like for folks served in
5 the community versus long-term care facility?

6 Ms. Stone. There are other data that would suggest
7 that we have, even on the long-stay in nursing homes, a
8 higher acuity level--a substantially higher acuity level--
9 than we have in the community.

10 And, you know, I think this is why when we think about
11 something like Money Follows the Person, on the long-stay
12 side, I believe we are going to see a lot more shifting of
13 non-elderly folks in those nursing homes into the community-
14 -because they can move into the community.

15 I think the level of acuity among the long-stay nursing
16 home population right now is pretty high.

17 And the question is, is that primarily very end-stage
18 dementia, and is it possible that we could actually serve
19 them in the community?

20 The point is that I do believe that right now we have a
21 higher--Brenda Spillman's work over a 20-year period has
22 shown that the acuity levels in nursing homes has gone up.

23 The question is, is there a way to actually help think
24 about a way of supporting some of those folks--many of those
25 folks--in the community over time--because I think most of

1 the nursing homes are moving in the direction of post-acute.

2 And you are going to have to struggle with that around
3 where does Medicare fit in here, but to my mind, Medicare is
4 really not a major player in the long-term care world.

5 That does not mean that long-term services and supports
6 people do not have acute and primary care needs. It is just
7 how you want to struggle with the animal of long-term care,
8 which is a different animal than the acute and primary care
9 world.

10 And I know somebody is going to talk about integration
11 and coordination. That is very different than thinking
12 about the long-term care as its own piece.

13 Commissioner Pruitt. Thank you.

14 Commissioner Feder. Okay. So I am going to ask one
15 question, respectful of the time, and I would really
16 appreciate if you would each give us a brief answer to this
17 question.

18 You have all talked about variation across states, and
19 many of you have talked about reliance on--I think all of
20 you have talked about reliance on family care. A lot of--or
21 the bulk of--the population of your particular group not
22 taking advantage or not using services, not having them
23 available.

24 I would like you to talk about the flip side--the
25 consequences, how you perceive what is happening to people

1 who are in states with very limited services, looking into
2 the future, what it implies, and how you would define the
3 unmet need or underservice, if you think that is a problem
4 or is everybody getting along okay.

5 Mr. Braddock. Well, you know, the answer. They are
6 not.

7 But I would like to say maybe this is a point to inject
8 a comment about technology.

9 Commissioner Feder. Excuse me. I do, but there is
10 some disagreement on it. So I would appreciate hearing it
11 from you.

12 Mr. Braddock. I think that maybe this is a point to
13 inject a comment on the future of technology and its
14 possible role with respect to addressing cross populations
15 that we have discussed today.

16 We have been in fields that have been very heavy on
17 touch. We have not necessarily done a great job with touch
18 and all that that means and entails. We pay people to do
19 these jobs, and we do not train them very well.

20 But I would say that we have a technology revolution
21 occurring in this country that is unbelievable. It is
22 really worldwide. And I can envision a future in which the
23 role of technology can empower individuals in long-term care
24 to have perhaps fewer individuals to support them in those
25 homes but have a much greater world connection in meaningful

1 ways, not where it becomes exclusively technology-based, but
2 in part technology-based, in part people-based, and we get
3 the best of both those worlds.

4 I do not really see any way we could provide services
5 to so many families that have people with needs, with
6 respect to disabilities generally or with intellectual
7 disabilities in particular, without relying on new
8 technologies.

9 And we have--you might call it--personal support
10 technologies. Examples would promote independence, guide
11 one in work tasks that one carries on, on a daily basis, be
12 able to notify a medical center if there were a problem in
13 the home, be able to connect and communicate with friends,
14 et cetera.

15 And we are beginning to see some of these technologies
16 by largely small companies in the technology revolution that
17 is much larger--you know, beyond the arena today. We are
18 supporting these kinds of initiatives through the Coleman
19 Institute, and lots of other groups around the country are
20 doing so as well. We have training programs in
21 developmental disabilities that are computer-based now
22 around the country.

23 So I think it is very important for the Commission to
24 look to the role of technology in the future in enhancing
25 the quality of care, not replacing care, but in enhancing

1 it.

2 Mr. Kaye. I think you touched on what I think is a
3 central issue, which is whether people's needs are met or
4 not.

5 I often say that I do not think there is any such thing
6 as unmet need for paid help and unmet need for government
7 program; there is just unmet need for long-term services and
8 supports. So are your needs met or not is the big issue.

9 And, if your needs are not met--there is a fair amount
10 of literature. There is lots of bad consequences that
11 results from not having your needs met. The most obvious
12 are institutionalization and hospitalization and mortality.

13 We have a paper from our center about all sorts of
14 adverse consequences of not getting the help you need--
15 unintentional weight loss, falls, not being able to get the
16 food you want, loss of dignity through not getting your
17 clothes changed, having to stay in bed all day. There are
18 all sorts of bad things that happen.

19 Of course, I always emphasize participation. Well, you
20 do not get the help you need; you stay home, and you do not
21 participate in your community.

22 So I think that is the key issue.

23 Ms. Stone. You know, the vast majority of long-term
24 care for the elderly is done by families. The first time I
25 analyzed data was in 1982. So we are talking about 30 years

1 of analysis of family caregiving, and it has not changed one
2 iota. It is still about 80 to 95 percent of all the care
3 that is provided.

4 What I am mostly concerned about is the affordability
5 piece, and that is not necessarily the Medicaid program
6 although I think we have to think about the Medicaid
7 program. It has done a pretty good job actually of meeting
8 the needs of poor people and people who spend down.

9 We have a lot of people who are modest and middle-
10 income who cannot afford options, and this is what we have
11 to deal with in the future of financing long-term care for
12 the elderly. We are not just talking about a poor
13 population here. We are talking about a middle and modest-
14 income population.

15 And, how do we think about supporting a family that
16 will continue to do this, but as needs increase, we do not
17 have an infrastructure?

18 There are no affordable residential options for people,
19 for example, who can no longer stay in their homes. And
20 that, to me, is a serious question that goes beyond
21 Medicaid.

22 We do have to think about saving Medicaid and looking
23 at the inequities across the states, but I actually think we
24 also have to think about this middle and modest-income
25 population, which is only going to grow post-recession, in

1 the next 30 years. And, how do we think about dealing with
2 that?

3 Mr. Martone. Basically, I mean on the mental health
4 side, institutional settings--nursing homes, psychiatric
5 hospitals, board-and-care facilities, boarding homes,
6 residential care facilities, things like that that tend to
7 be more costly to the system.

8 You know, we also will see more lost earnings. There
9 is a figure out there that serious mental illness costs the
10 United States an estimated \$193.2 billion in lost earnings
11 per year. So we are also losing out on the potential for
12 people who can, and who want, to work but have really
13 limited opportunities in that area.

14 And I think one interesting thing that will play out
15 over the course of the next several years, when it comes to
16 the ADA and Olmstead enforcement, is that we tend to think
17 about that as moving people from facility-based settings
18 into community-based settings.

19 But there are some recent cases, the last one most
20 recently out of North Carolina, where cuts to services, cuts
21 to personal care services that are leaving people at risk of
22 institutionalization, are being perceived or upheld by the
23 courts as a violation of Olmstead because they threaten
24 people's community tenure and may lead them into
25 institutionalization. And, as that takes traction in states

1 across the country, if we continue to see cuts to the state
2 side, it will be really interested to see how that plays
3 out.

4 Chairman Chernof. So I will ask our last two
5 commissioners to really have one question for one person,
6 please.

7 Commissioner Turner. Dr. Braddock, I was particularly
8 interested in your comment earlier about the use of
9 technology in the future. And I think, to follow up on
10 Judy's question, as the Long-Term Care Commission, we need
11 to think long-term as well.

12 Because needs are so specific, of these various
13 populations that you all have so well described, allowing
14 technology to support their needs allows that kind of
15 individualization.

16 You mentioned, however, the use of vouchers and other
17 cash subsidies, which really promote this ability for
18 individuals to get the kind of care that is most appropriate
19 for them, is on the way. And I would be interested in
20 knowing more about that, why, and also what policy changes
21 might be able to reverse that direction.

22 Mr. Braddock. I can speak to family support in respect
23 to developmental disabilities, exclusively, and in regard to
24 that issue, the first family support cash payment was made
25 in the 1800s. The State of Kentucky provided a family

1 support cash subsidy to families that individuals with
2 intellectual disabilities in their homes.

3 States tried this within the last 25 years, but they so
4 feared it becoming such a large, expensive program that they
5 only went a very small step toward supporting it. So there
6 is no state that does this great, and there are many states
7 that do not do it at all, and there are many states that do
8 it just a little bit.

9 So states are frightened. They are worried about the
10 woodworking effect.

11 To my way of thinking, there must be a way to do this
12 properly and economically, efficiently, because that is
13 where people with disabilities are living. With regard to
14 developmental disabilities, they are living with their
15 families.

16 The families--it is a Russian Roulette. If you have a
17 family member with intellectual or developmental
18 disabilities, you get hit with the burden of costs. If you
19 are lucky to live in a state that has family support, they
20 probably restrict that family support dramatically so that
21 it is just a little bit of help and then you get some
22 support in the home as well.

23 We simply talk family here in the United States with
24 respect to supporting families in so many respects, but when
25 it comes to right down where the rubber meets the road, we

1 do not support families.

2 It is sort of gotcha! Now you will have to work this
3 out. You will have to become quite a bit more successful in
4 your line of business so you can support an individual that
5 has a disability in your home.

6 And we do not have a safety net; we really do not.

7 So I think it is something that the Commission has to
8 look very carefully at. Are we really a country that
9 supports families or not when it comes to disabilities, or
10 are we country that empowers families?

11 Commissioner Claypool. Thank you all.

12 I am chafing at the fact that I only get one question,
13 but again, thank you all for your testimony. It was very
14 helpful.

15 To Kevin Martone, I would ask you to describe for the
16 Commission what PASRR is and then please provide us with--you
17 mentioned recommendations. Could you be more specific about
18 what we should be doing in regard to PASRR?

19 Mr. Martone. Yeah. I am not an expert in PASRR, but I
20 mean, it is really a Federal requirement out there to screen
21 individuals for their appropriateness into a nursing
22 facility level of care.

23 There is a stage--there is a phase 1 part of that
24 process that really assesses whether a person may have a
25 mental illness. And then the phase 2 part of that is really

1 assessing the degree of that mental illness and to the
2 extent that that person actually, really, does need or can
3 benefit from the nursing facility level of care. That is
4 administered locally in the states.

5 The challenge and what we see in terms of trying to put
6 that together is the variability in admission rates into
7 nursing facilities across the states.

8 And I do not have the data on which states are high and
9 local, but there is definitely variability in the admission
10 rates, which, to me, suggests variability in how the PASRR
11 process is applied at the state level.

12 I mean, I think my general recommendation would really
13 be to take a look at that and see if there are ways to
14 tighten that up.

15 When we look at it from an Olmstead and community
16 integration perspective, we know that a lot of people--many
17 people--with mental illnesses want to live in the most
18 integrated settings. But largely because of the shortage of
19 access into appropriate services or service interventions,
20 almost by default, nursing facility level of care is the
21 appropriate intervention. And I think that, from a concern,
22 really needs to be tightened up.

23 From a higher level policy perspective, it maybe drifts
24 a little bit from PASRR, but when you start to look at the
25 housing options, I mean, states struggle not only with the

1 services but the housing side, as I pointed out.

2 And there are models out there that work really well.
3 The newest model out there--I mean, it is all based on a
4 supportive housing context, but from a funding context--is
5 the HUD Section 811 program, which provides basically rental
6 assistance to individuals with disabilities.

7 The nice thing about this model is it really--and it
8 comes from a collaboration between HUD and HHS,
9 predominantly CMS. It forces interagency agreements at the
10 state level between housing agencies and, predominantly, the
11 Medicaid agency. And, going forward, that is producing a
12 tremendous amount of new housing opportunities for people
13 with disabilities.

14 That can also be mirrored, I think, going forward, in
15 the 202 program for older adults, to create additional
16 housing options for older adults who may have various
17 disabilities.

18 Commissioner Claypool. Thank you.

19 Chairman Chernof. On behalf of all the commissioners,
20 I really want to thank all of you for an excellent panel
21 and a great set of questions. Thank you for your time and
22 your written testimony.

23 If we could have the next panel come up promptly
24 because we would like to move forward as quickly as
25 possible.

1 For my commissioners to my left, revenge is sweet. We
2 will start with you guys first when it comes to questions.

3 Great. As you guys are getting settled, I would remind
4 each of you that we have got a timer in front of you, with
5 your mic, and we really would like you to keep your comments
6 to 10 minutes so that we give commissioners a chance to ask
7 you questions.

8 With that, if we could start with Randy Brown.

9 I guess I should start by saying this session will
10 really focus on coordination of care and workforce issues,
11 and we have five really wonderful speakers to help us think
12 about that.

13 So, Randy Brown, if you would take us off, that would
14 be great.

1 STATEMENT OF RANDALL S. BROWN, PH.D., MATHEMATICA

2 Mr. Brown. Sure. Thanks.

3 I have been working on care coordination for people
4 with chronic illness for about 20 years now. So I have been
5 asked to talk today about what I think is the current state
6 of knowledge about what works and what does not work based
7 upon findings from Federal demonstrations and published
8 papers.

9 And by what works, I mean care coordination
10 interventions for people with chronic illnesses that reduce
11 the number of preventable hospitalizations by enough to at
12 least cover the care coordination costs and, if not,
13 generate savings.

14 I am going to focus mostly on interventions in Fee-for-
15 Service Medicare which still covers three-quarters of all
16 beneficiaries because that is where the most credible and
17 available evidence is.

18 I am not going to spend time talking about the fact
19 that X percent of beneficiaries account for Y percent of the
20 cost because everybody knows those statistics. And it is
21 pretty clear if you want to save money for Medicare and
22 Medicaid in the short run, especially, you have to focus on
23 people who use a lot of expensive services.

24 Next slide, please.

25 So what I want to talk about today is three things--

1 each, very briefly:

2 What do we know about effective care coordination?

3 What can we do to enhance the likelihood of success?

4 Even the options that have some potential for success also
5 have a high likelihood of failure unless we learn from the
6 last 15 years or more of research.

7 And, finally, I will say a little bit about what I see
8 as the major barriers to success.

9 Next, please.

10 There are a lot of studies claiming very large effects
11 of care coordination--that a lot of these are weak and
12 unreliable. But there is a solid body of rigorous studies,
13 and here is what I think these studies tell us about
14 interventions do and do not produce real reductions in the
15 need for expensive health care services.

16 I will start with a CBO study from January 2012 and
17 summarize the findings from Medicare demonstrations on care
18 coordination in Fee-for-Service, which concluded that there
19 was very little evidence that Fee-for-Service-based disease
20 management works based upon 10 different studies involving
21 over 30 programs, and most of these were telephonic disease
22 management programs.

23 That study says that most of these telephonic programs
24 had no effects, and even the ones that do, were not very
25 large. So the savings were likely to be minimal if they

1 existed at all.

2 But the CBO studies were maybe a little too negative
3 about care coordination in general. The programs listed on
4 this slide were in rigorous studies that find significant
5 favorable effects on hospitalizations, but the effects are
6 entirely concentrated among the high-risk subset of
7 patients.

8 The first group is transitional care models. There are
9 three models there that are well known--Mary Naylor's model,
10 Eric Coleman's and the RED model--and there are variations
11 on these out there.

12 These programs reduce the 30-day readmission rate of
13 Medicare beneficiaries who are discharged from hospital by
14 about a third, which is pretty impressive. But they are
15 short-term, and what we would like to do is be able to have
16 a shot at reducing all the hospitalizations, not just those
17 that have already happened after a train wreck. So we need
18 a more comprehensive and ongoing intervention.

19 I also want to highlight Steve Counsell's GRACE model,
20 which served low-income seniors with multiple chronic
21 illnesses and functional impairments, using a team comprised
22 of advanced practice nurses, a geriatrician, a social worker
23 and a primary care physician, and they had electronic health
24 records. That program reduced hospitalizations and
25 emergency room use but, again, only for a high-risk subset

1 of the people that they targeted and only after the first
2 two years.

3 But today, I want to focus mostly on the Medicare
4 coordinated care demonstration. We published a paper in
5 JAMA in February 2009 that had pretty discouraging overall
6 results. Only 1 of the 15 programs saved money.

7 But a follow-up study that we did in Health Affairs
8 last June shows that 4 of the 11 programs, with enough
9 enrollees to study subgroups, reduced the number of
10 hospitalizations by about 15 per 100 beneficiaries per year
11 but, again, only for this high-risk subset of chronically
12 ill beneficiaries.

13 Next slide, please.

14 This slide shows estimates from the follow-up study of
15 the coordinated care demonstration, which provides what I
16 think is the best source of evidence for care coordination
17 in the Fee-for-Service anyway and what seems to
18 differentiate the effective from the ineffective programs.

19 We had 11 programs that operated for 6 years with
20 random assignment in each program. This slide shows the
21 four programs that had significant effects on
22 hospitalizations for the high-risk subgroup, which is
23 defined by people with CHF, coronary artery disease chronic
24 obstructive pulmonary disease, and a hospitalization in the
25 year before they enrolled in the program to note severity.

1 As you can see from the third column of this table,
2 these are very high-risk patients, averaging about 1.4
3 hospitalizations per beneficiary per year over the 6-year
4 follow-up period.

5 The effects are very similar in size across the 4
6 programs--about 15 hospitalizations per 100. They are a
7 little higher for the HQP site, but that is a small sample
8 there. So there is a big confidence interval around them.

9 The results are significant for each of the programs
10 and highly significant when they are pooled--at least about
11 11 percent reduction each year for 6 years. So it is not a
12 short-term effect. It is an ongoing thing.

13 And these hospitalizations generate savings, so about
14 \$1,500 per person per year in 2005 dollars.

15 It was especially meaningful because the four
16 successful programs are four different types of
17 organizations. One was an academic medical center in Center
18 City, St. Louis. One was an integrated delivery system in
19 rural Iowa. One was a nonprofit quality improvement
20 provider. And one was a hospice home health agency in the
21 Southwest. So it does not take a particular type of
22 organization to do this.

23 This is not the only way to identify high-risk cases,
24 of course, that can be impacted, but this is an easy way--an
25 easy group to identify--and it accounts for about 18 percent

1 of all Medicare beneficiaries and about 38 percent of all
2 Medicare costs in a given year. So it is doable and
3 meaningful.

4 Next slide, please.

5 But remember that 7 of the 11 programs in the
6 coordinated care demonstration and a lot of other care
7 coordination programs fail to reduce expensive services. So
8 we need to focus on what distinguishes the successful
9 interventions from the unsuccessful ones.

10 Here are six common features that most of the four
11 successful programs in the coordinated care demonstration
12 had, but very few of the unsuccessful--the seven
13 unsuccessful--ones did.

14 In the successful programs, the care coordinators had
15 frequent face-to-face contact with patients, about one per
16 month for the first year at least, to establish a trusting
17 relationship.

18 Second, the care coordinators had strong rapport with
19 the patients' primary care physician, either through a
20 preexisting relationship, being located on the same medical
21 campus or attending office visits with the patients.

22 Third, the care coordinators used motivational
23 interviewing and other proven methods for actively engaging
24 patients, educating them and helping them overcome their
25 personal barriers to adherence to medication and self-care

1 recommendations.

2 Fourth, they found a way to consistently learn about
3 hospitalizations while the patient was still there and had a
4 timely and comprehensive intervention to help them return
5 home with a good understanding of what they and their
6 caregivers needed to do to avoid a readmission.

7 Fifth, they played an active in communication, making
8 sure that patients communicated important information to
9 physicians and that the patients understood what they heard
10 from their providers and that primary care physicians
11 received test results, referral findings and other key
12 medical information from the patients' other providers.

13 And, sixth, the effective programs had strong
14 medication management. The care coordinators had reliable
15 information about patients' medications and access to a
16 pharmacist or medical director who could make sure the
17 patients were on the medications they should be, that their
18 mix of medications was compatible and that the patient was
19 not overmedicated. And they also had information on changes
20 in medications that took place after a hospitalization.

21 Next slide, please.

22 But we need to expand the look at the evidence to make
23 the point that the evidence suggests that what is effective
24 differs across some key subgroups of high-need beneficiaries
25 and beneficiaries in different living arrangements. And

1 those that need more than just medical care, obviously, have
2 different needs, and if they do not have an intervention
3 designed explicitly to meet those types of needs, it is not
4 likely to be effective in reducing the need for
5 hospitalizations and holding down cost.

6 The second key point is that Medicare needs to look for
7 both managed care and Fee-for-Service models that are
8 successful for high-need beneficiaries. The two sectors are
9 both going to continue to exist. They have different
10 strengths and weaknesses that need to be overcome or
11 capitalized on. So the models differ in the two sectors.

12 And the table in this slide here shows some of the care
13 management models, with the strongest evidence that they can
14 meet the needs of different subgroups of high-need
15 beneficiaries. I do not have time to go through this slide,
16 but basically, the other groups are people who are in a
17 nursing home, people who are in the community that need
18 long-term support services, people that have multiple
19 chronic illnesses that are pretty severe but do not need
20 long-term support services, and then those with less severe
21 chronic illnesses.

22 Next slide, please.

23 So what can we do to increase the likelihood of success?

24 We need to require that programs have the features that
25 nearly all the successful past programs have found to be

1 important. The new demonstrations that are going on by CMMI
2 are pretty prescriptive. So some of these things are
3 happening.

4 We need to focus on high-risk patients. Medical homes
5 demonstrations, for example, are expected to provide a home
6 for all beneficiaries, but the savings are going to depend
7 almost entirely on what they do to coordinate care for the
8 sickest 20 percent.

9 You need to pay enough for those cases and not so much
10 for the others to focus the programs' attention where it
11 needs to be and to adequately compensate the programs that
12 serve a high-need mix, and that does not appear to be what
13 is going on at the moment. There is a higher premium for
14 the high-risk cases, but the differential is too small.

15 We need to feed back timely information to programs and
16 physician practices. They need to know how they are doing
17 on both quality and cost efficiency so they can adapt. The
18 new CMMI initiatives, like CPC--the comprehensive primary
19 care--and the multi-payer initiatives, have this feedback
20 built in.

21 And, fourth, the intervention should build in studies
22 of operational issues. There are a lot of unanswered
23 questions about which assessment tools work best--which fall
24 prevention program, which depression management screen,
25 which motivational interviewing technique. And there are a

1 number of demonstrations that have built-in learning
2 collaboratives so participating programs or states can share
3 what they are learning and their techniques for teasing this
4 out.

5 So, next slide, please. This is the last slide.

6 These are just some potential barriers to success. And
7 to avoid running over any longer, I will just say that
8 basically excessive attention to rapid cycle learning can
9 lead to the wrong answers. We all want the right answers
10 quickly, but quick answers are often wrong answers.

11 And then I will just leave it at that.

12 We also need information centers for providers.

13 So, thanks.

14 [The prepared statement of Mr. Brown follows:]

- 1 Chairman Chernof. Thank you very much.
- 2 If we could turn to Josefina Carbonell, please.

1 STATEMENT OF JOSEFINA CARBONELL, INDEPENDENT
2 LIVING SYSTEMS

3 Ms. Carbonell. Good afternoon. Thank you for the
4 opportunity to testify before you and with the rest of the
5 colleagues that have been in the first panel and the second
6 panel--those before us.

7 My name is Josefina Carbonell, and I currently am in
8 what my son calls the 3.0 version of my life. I am in the
9 private sector, sometimes labeled as the dark side.

10 I work with Independent Living Systems, and Independent
11 Living Systems is a long-term care management company that
12 works with health plans mostly, counties and states, to
13 manage the long-term care capitated programs.

14 We are also administering--on the second side, right.

15 We also assist health plans and contracted entities to
16 administer patient-centric Medicare and Medicaid special
17 needs populations.

18 We also have been part of the care transition CMS pilot
19 in 14 states, which now is funded through the community care
20 transition programs across the country and also in private
21 pay. So we are in the care transitions model, using the
22 Coleman model, self-empowerment model, to assist people
23 through their acute transitions back into the community.

24 And then we also specialize in special diets,
25 particularly using the special diets and nutrition programs

1 as interventions for chronic care management, both acute
2 out-of-the-hospital but also at home for the long-term care
3 programs.

4 I will focus my comments in the role that I am playing
5 right now, the role that I played in the past in policy at
6 the national level, as a provider in South Florida for over
7 30 years, and now in the private sector, helping manage the
8 long-term care plans with the medical and acute side of the
9 equation.

10 If we look at the successes that we have had--and we
11 have got some data that I can submit for the record--we need
12 to continue to move away from the fragmentation to
13 integration. I think Dr. Kaye spoke about that earlier, and
14 all of them spoke about that.

15 We need to make sure that we have good financial
16 alignments and incentives that play a critical role, and
17 that we have the ability to do global budgeting across not
18 only the long-term services and supports but also into the
19 acute piece.

20 We need to facilitate partnerships. I cannot stress
21 partnerships, partnerships, partnerships--many times--among
22 traditional home and community-based and long-term services
23 and supports providers, both in the aging and disability
24 worlds, but also, more importantly, the partnerships that
25 need to be bridged between the health plans and the health

1 care delivery systems and our social supports.

2 We need to incorporate a very important, strong social
3 component. It cannot be siloed. I cannot begin to tell you
4 the kinds of conversations that we struggle in, day in and
5 day out, trying to discuss the importance of the social
6 component in long-term services and supports, to make sure
7 that it is not taken over by the medical and clinical--that
8 medical and clinical is the core, but that the long-term
9 services and supports have the very important use of
10 integration of the social component to be a key driver.

11 Consumer engagement. The consumer engagement happens
12 to be the most important empowerment role that we can use
13 for the long-term services and supports if we are to create
14 the kind of long-term care system that we all wish to grow
15 old with.

16 We really to include the consumer, the participant, the
17 beneficiary, the patient--however we want to label that
18 client--as true partners in the engagement of their care.

19 I think some of the former persons also talked about
20 that.

21 And we need to look at different affordable housing and
22 housing models and supportive models. For instance, we are
23 looking at--we have had some successes in talking and
24 discussing with nursing homes, large and small, throughout
25 the country, about the opportunities and need to involve

1 additional interventions, including skilled nursing
2 facilities, ALF hybrids, adult daycare and respite. You
3 know, the need to--the opportunities that exist with the
4 institutional-based care to reduce hospitalizations.

5 But it needs new payment models, new flexibility on
6 bundled payments, et cetera. And, again, a good opportunity
7 is the current opportunity that we have in front of us to
8 really work and have the institutional SNPs--ISNPs--play a
9 critical role in how we model the future and what that will
10 look like.

11 And then, of course, last but not least and very
12 important, we need to appropriately identify the quality of
13 care measures for the combined models of care--again,
14 partnerships and quality.

15 If we look at partnerships--the next slide--I have
16 divided what health plans have as strong points and what the
17 traditional long-term services and supports, home and
18 community-based care providers and agencies have as their
19 strengths.

20 And you can see that there are tremendous opportunities
21 on the health plan side--of course, the managed care
22 experience, the integrated experience, mostly focused,
23 again, on the acute side and on the health side, with little
24 knowledge on the long-term services and supports.

25 It certainly has the capital to build the programs and

1 fund research, but it also has the analytic and information
2 technology capabilities that will be needed to be able to
3 support those kinds of systems and the ability to,
4 obviously, create new payment mechanism and align financial
5 incentives.

6 The important part about this piece on the cost really
7 relates to the program design and to having the availability
8 and flexibility to do a broader mix of home and community-
9 based services that is currently not available under the
10 Medicaid waiver programs or the other kinds of programs that
11 are in place by states before the managed care development.

12 Certainly, there is experience in acute care, but
13 again, they are not necessarily well understood by consumers
14 outside of the health realm. And, with that, it is
15 important to make sure that we work with them to do that.

16 On the traditional provider side, it is very important
17 to understand that in states the reform efforts in Medicaid
18 are turning to risk-based managed care models in
19 particularly 34 states. I think we recently, last night,
20 saw the release of the AARP study talking about this and
21 just a snapshot of what is happening in states.

22 So, again, this is a very important opportunity. We
23 have had very good success in reaching out and bridging
24 those two relationships between the traditional home and
25 community-based care providers at all levels in the

1 community and making sure that we do not replace them with
2 more medically-oriented case managers and other forms of
3 care when we have a whole cadre of trained individuals
4 throughout the country to make sure that we take advantage
5 of not only their community presence but their trust in the
6 community and their access to communities of color and of
7 experience in the long-term care.

8 The next is social factors. I think it is important
9 that we focus on functional capabilities and the social
10 factors.

11 Lessons learned--it works best when it goes beyond the
12 medical care.

13 Nutrition is a very important in out-of-hospital
14 discharge and how it will be used, or overlooked,
15 particularly if we do not pay attention to the nutrition
16 intervention with medication management and with long-term
17 services and supports in chronic care.

18 I think on the home and community and long-term
19 services side, it is also important that we do not overlook
20 the community living program that has been started and the
21 base that is available under the Older Americans Act and to
22 be able to maximize the partnerships and the social factors
23 and the trained personnel and the quality of community-based
24 interventions--that we do not create a new system but that
25 we build upon what the success that have been achieved.

1 The other piece that I want to point out in this is
2 also two issues.

3 Transportation is a critical component that needs to
4 not be left out of any conversation in long-term care
5 services and supports and certainly in any of the duals or
6 intervention.

7 We saw it very vividly in the pilot with the care
8 transition, how 35 percent of the population actually went
9 back and was rehospitalized because they lacked access to
10 transportation to come back to their primary care physician
11 and do that follow-up care out of the hospital.

12 So, again, transportation is something we talk about,
13 but we really need to make sure that we include it as part
14 of the piece.

15 The other aspect is very important--the ethnic and
16 cultural influences of care, in the model of care. Language
17 and culture play a critical role in the social factors that
18 impact important care to many of our populations,
19 particularly because of the diversity of our aging
20 demographics.

21 The importance of personal care management--more of a
22 concierge service. It is no longer--it is important that a
23 person has one contact and that that person is in charge of
24 coordinating care for that individual and that that
25 individual has access to that care coordinator at all times.

1 The consumer and family engagement I cannot stress
2 enough. I think most of the other speakers have spoken
3 about that. It is critically understanding the role that
4 the family and caregivers play in long-term services and
5 supports. So it is important that we pay attention to this
6 throughout the entire continuum.

7 Certainly, having been engaged in New York--and I can
8 talk about that later--the importance of personal care and
9 family caregivers is so important in the piece.

10 And last, but not least, and the last slide, the
11 quality outcomes, if we can go to the next one. This is a
12 busy slide, but the most important message out of this is
13 these are the measures that we have developed as it relates
14 to both our work in the last 11 years in long-term care
15 services and supports and the last 4 years that we have been
16 building the systems behind it, to make sure that we improve
17 both the accountability of the programs and, most
18 importantly, the accountability to the consumers and the
19 clients that ultimately drive this whole system.

20 So we have developed a spoad of quality outcomes that
21 address this again, not only the consumer buy-in and
22 empowerment, but it manages the long-term services and
23 supports and patient people throughout the entire continuum
24 of care, from the patient's and the provider's lens.

25 So that means that through the patient's lens the

1 entire system falls into place. Supporting that is a whole
2 technology platform that integrates all of the participants
3 along the continuum of care, and that is a critical
4 component.

5 In summary, the last slide, three areas I want to talk
6 about.

7 I think in policy we need to continue to break down the
8 silos and work on that. I think the financial incentives.
9 Again, the implementation of evidence-based quality of care
10 measure are going to be critically important as we move
11 forward.

12 Then the delivery system--ensuring that there is a
13 partnership between the traditional providers and the health
14 plans, that we also promote new models of nursing homes and
15 housing and affordable housing to meet the needs, and that
16 there is a technology platform in the delivery system to
17 make sure that there is communication along the continuum.

18 And then, of course, ultimately, most importantly,
19 consumers and continue to enhance the engagement and
20 empowerment of consumers and the integration of self-care
21 concepts and support for caregivers.

22 Thank you.

23 [The prepared statement of Ms. Carbonell follows:]

1 Chairman Chernof. Thank you very much.

2 If we could now hear from Lynn Feinberg, please.

1 STATEMENT OF LYNN FEINBERG, AARP

2 Ms. Feinberg. Good afternoon and thank you very much
3 for the opportunity to testify today on the realities facing
4 family caregivers and those for whom they care.

5 As some of you know, I have now worked in the field of
6 aging, focusing on family care issues, for nearly 30 years.
7 And I am very rewarded to hear so many of my fellow panel
8 members and the first panel also speak about the importance
9 of better recognition and support for families.

10 Caring for an aging relative or friend is the new
11 normal of family life in the United States for millions of
12 people, and it is a growing public issue. It is also an
13 intensely personal issue affecting real people in our
14 country, every day, in all walks of life.

15 In 2009, about 42.1 million family caregivers in the
16 United States provided unpaid care to an adult with
17 limitations in daily living. The estimated economic value
18 of their unpaid contributions was \$450 billion 2009, more
19 than total Medicaid spending for all populations that year.

20 The average U.S. caregiver, to give you a picture, is a
21 49-year-old woman who works outside the home and spends
22 nearly 20 hours a week, the equivalent of about another
23 part-time job, providing unpaid care to her mother for about
24 5 years. More than 8 in 10 are caring for someone age 50
25 and older.

1 Most people who need long-term services and supports
2 rely on their families for help, such as with eating,
3 bathing, dressing, paying bills, providing transportation
4 and social support.

5 In addition to helping with these daily activities,
6 family caregivers are increasingly serving as the de facto
7 care coordinators, trying to help their loved ones get the
8 care that they need while risking their own health and
9 financial security.

10 The challenge ahead, as we have already heard and I
11 will emphasize again, is to better recognize and ease the
12 burden on the largely invisible, isolated and unpaid
13 workforce of family caregivers in our country.

14 There is a lack of understanding of the complexity of
15 caregiving today and the human toll it takes on those
16 providing and receiving it, unless it happens to you
17 personally. And I would imagine among the Commission
18 members there are a number of you who have already
19 experienced the intense intimacy, the meaning and also the
20 strain of providing care to someone that you love.

21 A recent study conducted by the AARP Public Policy
22 Institute and the United Hospital Fund shows that the role
23 of family caregivers has dramatically expanded in recent
24 years to include performing medical nursing tasks of the
25 kind and complexity that was once provided in the hospital

1 or nursing homes or by home care professionals.

2 In this national study, almost half--about 46 percent--
3 of family caregivers reported performing medical nursing
4 tasks for their loved ones with very little training or
5 preparation in addition to assisting with long-term services
6 and support needs. These tasks include managing multiple
7 medications, like administering IV fluids and giving
8 injections, which are very scary if you are not a physician
9 or a nurse who is trained in these procedures, providing
10 wound care, preparing food for special diets and operating
11 specialized medical equipment. As Susan Reinhard has said,
12 these are tasks that would make nursing students tremble.

13 Family caregivers are an essential part of the
14 workforce in health care and in long-term services and
15 supports. Settings change. Providers change. We certainly
16 know systems change. But the person and the family remain
17 constant.

18 Family members are now part of the delivery of health
19 care in addition to long-term services and supports,
20 influencing health care decisions and serving as the eyes
21 and ears for communication and coordination with a range of
22 providers.

23 Family members are also assuming an increasingly larger
24 health management role in the home, with little preparation,
25 suggesting that the medical home is, in reality, the home of

1 the person with chronic care needs.

2 The success of most care plans often rests on the
3 shoulders of the family caregiver. If a family member
4 becomes sick or can no longer cope with caregiving tasks, it
5 can lead to nursing home placement, not what most people
6 want, and possibly higher public expenditures. Therefore,
7 effective outcomes in care settings, in the home and
8 hospitals and in community-based care, depend on knowing the
9 needs and risks of both the individual as well as the family
10 caregiver.

11 Research shows that caregiving usually exacts a heavy
12 emotional, physical and financial toll, and family
13 caregivers are themselves at risk. Our written testimony
14 goes into much greater detail about this, but let me share
15 just a few main points.

16 First, the health effects of caregiving are
17 particularly sobering. In fact, some experts now view
18 family caregivers as a vulnerable group themselves and
19 family caregiving as a public health concern.

20 Caregivers commonly experience emotional strain and
21 mental health problems, especially depression. Various
22 studies have linked family caregiving with serious health
23 consequences including heart disease, hypertension, stroke,
24 slower wound healing, sleep problems, increased use of
25 psychotropic drugs and even death among highly stressed

1 spouse caregivers.

2 Family caregivers have also reported financial
3 hardships as a result of caregiving. The financial impact
4 is particularly severe on family members when it affects
5 their ability to work and their future retirement security.
6 One study suggests that family caregiver, age 50 and older,
7 who leave the workforce, who quit their jobs to care for
8 their parent, lose on average nearly \$304,000 in wages and
9 benefits over their lifetime.

10 The aging of the population, as we have heard this
11 afternoon, and changing patterns of family life will affect
12 nearly every American family in the future. The statistics
13 are startling, they are personal, and they are no longer
14 abstract. In 2026, only 13 years from now, the U.S. can
15 anticipate a surge in its oldest old population, those most
16 in need of long-term services and supports, as the first of
17 the Baby Boomer celebrate their 80th birthdays.

18 And I will not be that far behind.

19 Forthcoming research from the AARP Public Policy
20 Institute looks at the potential supply of family caregivers
21 between 1990 and 2050. What we did was to construct a
22 caregiver support ratio by comparing the number of potential
23 caregivers, those age 45 to 64, the most common age for
24 family and friends to provide care, to the number of people
25 in the high-risk years of 80 and over. And my written

1 testimony goes into greater detail on the methodology.

2 But, bottom line, our research suggests that as the
3 Baby Boomers age into their 80s, beginning in 2026, the
4 caregiver support ratio will shrink dramatically, from 7.2
5 potential caregivers per potential frail elder in 2010 to
6 4.1 in 2030. It will continue declining to 2.6 by 2050.
7 These national trends will be reflected in the widening care
8 gap in every state in our country.

9 Sharp declines in the availability of family caregivers
10 will add to the burdens of already stressed families. The
11 future looks very unlike the past.

12 Our written statement includes a number of
13 recommendations that we hope the Commission will look at
14 closely, to recommend greater recognition of, and support
15 for, family caregivers.

16 And one of these recommendations is to develop and
17 implement a national strategy to recognize and bolster
18 families in their caregiving role. The strategy should
19 identify the specific actions that government, communities,
20 employers, providers and others can take because it will
21 take a village.

22 Family caregivers are the cement holding America's
23 long-term services and supports infrastructure together.
24 Providing meaningful support for family caregivers is one of
25 the least appreciated but important issues we must grapple

1 with in the coming years as our population ages.

2 As a country, we need to raise the visibility of and
3 support for caregiving families so that they do not burn
4 out. That is really the bottom line for us as we deliberate
5 the crisis in long-term services and supports.

6 But we must also guard against building a long-term
7 services and supports system that relies too heavily on
8 family caregivers. Family members and friends who
9 voluntarily take on the caregiving role should be offered
10 support, not expected to assume greater responsibilities
11 without help.

12 We urge you to focus on the individuals and their
13 families behind the policy discussion--the faces of families
14 struggling to help a parent with Alzheimer's disease or a
15 loved one at any age with a disability or a husband caring
16 for his wife with multiple chronic conditions and functional
17 impairments.

18 We thank the Commission for acknowledging and
19 recognizing family caregivers, and we look forward to
20 working with you to address these issues that will face us
21 all.

22 Thank you.

23 [The prepared statement of Ms. Feinberg follows:]

1 Chairman Chernof. Thank you very much.

2 If we could turn to Joanne Lynn, please.

1 STATEMENT OF JOANNE LYNN, M.D., ALTARUM INSTITUTE

2 Dr. Lynn. Good afternoon, members of the Commission.

3 I am Dr. Joanne Lynn. On behalf of the Center for Elder
4 Care and Advanced Illness at Altarum Institute, I am pleased
5 to be invited to contribute to your search for the ways we
6 can achieve reliable care at a sustainable cost.

7 As a geriatrician, I serve thousands of people in
8 various settings, mostly in their homes.

9 As a researcher, educator, public health official and
10 Medicare program officer, I have come to understand various
11 perspectives on the health care issues that face frail,
12 older adults in our society.

13 And, like all of us in the room, I am an old person in
14 training, and I fear for our future.

15 Most of us will live to become frail when we are old.
16 Some will succumb to cancer or heart disease when young. I
17 am a geriatrician, so young is under 80 or so.

18 But most of us will live in to our 80s, 90s and beyond.
19 We will become increasingly disabled and frail, enjoying all
20 we can of life despite various illnesses, worsening muscle
21 weakness and declining overall reserves, and half of us will
22 also struggle with cognitive impairment.

23 The person can click the slide a couple times, and all
24 of it will come up. There you go.

25 And, one more.

1 Keep going. There you go.

2 One more.

3 [Laughter.]

4 Dr. Lynn. Yes, we had to have a visual behind you
5 guys.

6 So we can expect to have years of depending on others
7 for help with our daily needs. As matters stand now, care
8 provided to frail, elderly persons is poorly planned and
9 regularly inflicts inappropriate services, unnecessary and
10 unwanted treatments, and overwhelming personal, financial
11 and emotional costs.

12 So how can we change our own futures?

13 Not by relying on Federal resources alone or state
14 resources alone, and certainly not by expecting that each
15 individual can figure it out for him or herself. Too many
16 people are already too old or too poor to save enough, and
17 the system is too complicated and nonsensical. Any one of
18 these approaches by itself ensures failure, and failure
19 would mean crippling costs to the society and abandonment of
20 dependent elderly people.

21 Simply put, services for frail, elderly persons,
22 individually and as a group, need to be planned far better
23 than they are currently. Most things that go wrong are
24 predictable, and many are preventable, and nearly all can be
25 improved with forethought.

1 We have models of care that meet the needs and reflect
2 the priorities of frail, elderly people. But tradition,
3 habits, rules and incentives all keep us mired in
4 dysfunction. Those who are involved in serving frail,
5 elderly people should be expected to, and should be freed
6 to, implement best practices.

7 A major opportunity lies in developing some community-
8 level management of the delivery system for frail, older
9 people. Consider that someone who needs to be spoon-fed,
10 for example, cannot travel somewhere else to get that. They
11 must be served where they live. Community-level monitoring
12 and management would allow us to become efficient as well as
13 reliable.

14 People in the latter phase of life have priorities that
15 are quite different than people in the phase of life of the
16 rest of us in this room.

17 As we approach the end of life, we will usually value
18 relationships and shun isolation. We will value keeping
19 control of what we can manage, and we will disdain being
20 regimented or warehoused. We will also seek comfort and
21 reliability, and we will want to avoid disruptive or painful
22 interventions. We will not be generally eager to leave this
23 life, but most of us will have come to terms with the fact
24 of mortality.

25 Contrast these priorities with the care system we have

1 today, which is structured around the hopes and fears of
2 middle-aged men and women.

3 Anyone on Medicare anywhere in the country can get
4 emergency services and dramatically invasive medical
5 interventions, but you cannot get a home health aide to fill
6 in while your family caregiver heals a broken arm. You
7 cannot get eyeglasses or hearing aids or preventive dental
8 care.

9 What we now need is to build a care system that takes
10 into account the hopes of an 88-year-old woman living in
11 Social Security income. Let's address her fears and needs.

12 A care plan to meet the needs of most people in this
13 room would be pretty simple, but the plan that is needed
14 when you are frail and disabled is usually complicated and
15 must take many disparate factors into account. And that is
16 exactly why a frail, elderly person needs a care plan--one
17 that reflects an honest assessment of his situation, his
18 likely future and his preferences as to how to live that
19 future.

20 We do not even have a way to put a comprehensive care
21 plan into our evolving electronic health record system.
22 Meaningful use requirements for hospitals and physicians to
23 earn financial support for electronic health records do not
24 require documentation of functioning, likely future course
25 or care plans.

1 We do not have any way to measure the quality of care
2 plans against outcomes even though for frail, elderly people
3 this is nearly all that matters. Are we serving this
4 person's priorities effectively?

5 The most important outcome in frail, elderly persons,
6 from their perspective, is how you can live in the life
7 remaining. Yet, we neither serve that aim nor measure how
8 well we are doing.

9 Today, a physician like me can order up any treatment
10 or test for a frail, elderly patient, no matter how
11 expensive and no matter how thin the evidence that it will
12 do any good, with virtually no regard to cost. Yet, we
13 cannot get a home health aide to keep the person clean,
14 provide a good nutritious meal or a place to live unless we
15 put the person in a nursing home. This has to be the most
16 expensive scheme for supporting housing, food, hygiene and
17 personal care that one could imagine, and it has been the
18 source of all manner of dysfunction.

19 Virtually all other countries provide housing and food
20 for disabled, elderly persons, but we do not.

21 Virtually every other country provides support for
22 family caregiving, but we provide so little that you can
23 barely see it.

24 We begrudge providing social support services, leaving
25 them as a set of poverty programs that come and go, causing

1 service gaps and frustration. In contrast, we treat medical
2 services as an open-ended entitlement. This mismatch is
3 already extremely expensive and will become more so as the
4 number of frail, elderly persons in this country will rise
5 sharply starting in about a dozen years.

6 For those who continue to hope that the family can step
7 in to save the day, the facts are against you. We will have
8 too few family members, and they will often have to work or
9 will be disabled themselves.

10 The budget-focused proposals that are now circulating
11 in Washington focus on getting the financial incentives just
12 right in Medicare and Medicaid. The prevailing wisdom seems
13 to be that if you could just get the financial incentives
14 right the clinical service array would somehow follow. This
15 is implausible in terms of logistics and in terms of cost.

16 We must directly fix the service delivery arrangements,
17 the scope of concern and the financing together, aiming for
18 highly reliable services, reflecting both the general and
19 the diverse priorities and needs of frail, elderly people,
20 and also deliberately aiming for lower per capita costs.

21 This Commission must be committed to reshaping the
22 service delivery system.

23 We should talk, for example, about how we can enable
24 local entities to take a leading role in measuring and
25 managing the supply and quality of services for all frail,

1 elderly residents across a geographic community. Community-
2 based planning could readily be implemented on a broad
3 scale.

4 Once we have good care plans for every frail, elderly
5 person, a local coalition or agency could monitor
6 performance by aggregating and geomapping the service needs
7 identified on those care plans. This would make it easy to
8 see where the community has undersupply, oversupply or
9 quality problems, and it would pave the way for efficient
10 action to optimize services.

11 For your consideration, we have developed some
12 achievable policy recommendations. I will only briefly
13 mention them here. There are more details in the written
14 testimony.

15 Go ahead to the next slide.

16 So recommendations around quality and coordination of
17 care would include metrics for physicians that would
18 incentivize and then eventually require comprehensive care
19 planning for frail elders.

20 Next slide.

21 Direct care workers should be given a fair deal on
22 income, access to their own health care services, solid
23 baseline training and ongoing opportunities for further
24 education and expansion of skills.

25 Next slide.

1 Family caregivers should be provided with both general
2 guidance and hands-on training about how they can, if they
3 agree to do so, provide supportive services to their loved
4 one, and they must be given access to their own respite
5 services.

6 And, finally, the communities should be allowed and
7 enabled to take on some monitoring and management of the
8 elder care system. To do so requires standardization and
9 availability of data and reexamination of the role of
10 geographic concentration and provider competition.

11 We wish you the greatest success possible in the short
12 time you have. We hope that you will count on us to serve
13 as full and enthusiastic partners in our mutual quest to
14 improve long-term care.

15 But remember no one wants you to tell us how to finance
16 the system we have. You need to lead us into a better, more
17 reliable, more appropriate and much more efficient system.

18 Thank you.

19 [The prepared statement of Dr. Lynn follows:]

1 Chairman Chernof. Thank you very much.

2 And, finally, we would like to hear from Carol Regan,

3 please.

1 STATEMENT OF CAROL REGAN, PARAPROFESSIONAL
2 HEALTHCARE INSTITUTE (PHI)

3 Ms. Regan. Thank you.

4 I hope you are all still willing to listen to one more
5 person today.

6 Wow! Thank you.

7 [Laughter.]

8 Ms. Regan. Now I get to talk about the direct care
9 workforce.

10 Thank you, Commissioners.

11 My name is Carol Regan. I am the Government Affairs
12 Director at PHI, the Paraprofessional Healthcare Institute.
13 We are a national nonprofit organization that works to
14 improve the lives of people you have heard a lot about
15 today, who need long-term services and supports, by
16 improving the quality of the jobs of the people who provide
17 those services.

18 And, given that 70 to 80 percent of care in long-term
19 services and supports--and care is given by the front-line
20 paraprofessionals--our belief is that you cannot ensure that
21 there is quality of care for people unless you make sure
22 that there is quality of the jobs and the caregivers.

23 So, today, nearly everyone is connected to a family
24 member or friend living with functional limitations, who
25 requires hands-on, direct care services or who personally

1 requires these services and supports.

2 And often, from these very personal connections, flow
3 stories of care services that are daunting, difficult or
4 even possible to find, care that is unreliable, hurried,
5 inconsistent and care that lacks important competencies and
6 cultural sensitivities.

7 These lived experiences stand in sharp contrast to what
8 we all want and expect from any of our health care
9 providers--care that is easily found, that is qualified and
10 competent, and that its trustworthy and reliable.

11 Accompanying these stories are also the testimonies of
12 direct care workers, many of whom take deep satisfaction and
13 meaning from their caregiving roles, yet receive near
14 poverty wages.

15 As a result, almost half of direct care workers in this
16 country live in households that rely on public assistance,
17 and many go without health insurance even though they work
18 in what are indisputably among the most dangerous jobs in
19 this country. They have the highest rate of injuries, with
20 back injuries from lifting, et cetera. The strains that we
21 heard Lynn talk about earlier on family caregivers are
22 experienced by many paid caregivers as well.

23 In 2008, the Institute of Medicine delivered a fresh
24 analysis and set of recommendations concerning the direct
25 care workforce and its role in the health care workforce for

1 an aging America. Five years later, very little has
2 changed. There remains a glaring absence of coordinated
3 Federal policy leadership directed at improving the Nation's
4 direct care workforce, despite the ever escalating demand
5 for long-term services and supports.

6 Direct care workers now account for 31 percent of all
7 U.S. health care workers, far outnumbering the health care
8 practitioners such as nurses, physicians and therapists.
9 They also outnumber, nearly three to one, all allied health
10 occupations such as medical and dental assistants, and
11 physical therapist assistants and aides.

12 Our long-term care system currently invests \$88 billion
13 annually--42 percent of all long-term services and supports
14 spending--on the direct care workforce. Such a massive
15 investment suggests that issue of the direct care workforce
16 should be considered not in isolation, like Joanne
17 mentioned, but rather, directly linked to the issues of
18 financing and payment.

19 PHI applauds the Commission for your commitment to
20 address workforce issues concurrently with the need for a
21 better financing system and a better way for paying for
22 long-term services and supports.

23 In our recommendations, PHI urges the Commission to
24 take one step further by embedding minimum workforce
25 standards as an essential design element in all of the

1 Commission's financing and payment recommendations.

2 We urge you to consider four workforce domains. I am
3 going to summarize these because you will have them in your
4 written testimony.

5 The first is payment and procurement policies which
6 implicitly determine the parameters of worker compensation.
7 These policies are a key driver of the direct care workforce
8 jobs.

9 Across the country, we have ad hoc approaches to rate-
10 setting for Medicare home and community-based services.
11 These are the norm, not the exception. Without systematic
12 methods for setting, rebasing or updating payment rates,
13 these rates tend to be tied to the ups and downs of a
14 state's fiscal condition, with occasional improvements
15 attributable to effective advocacy by consumer groups,
16 provider trade associations and unions.

17 In contrast, Medicaid nursing facility reimbursement
18 rates are derived largely from systematic and regular
19 rebasing methodologies, and they are usually updated
20 annually based on some kind of inflation factor.

21 The impact of these different rate-setting approaches
22 on direct care jobs is readily apparent in our data.
23 Nationally, direct care workers employed in nursing
24 facilities earn, on average, \$2 more per hour and are 30
25 percent more likely to have health insurance than their

1 counterparts in home care.

2 The Federal Government does not require state
3 reimbursement rates to convey the minimum standards, support
4 quality outcomes or even encourage cost effectiveness, nor
5 does it provide any guidance to states concerning the
6 development of effective rate-setting policies and adequate
7 payments.

8 The second domain is training. I was delighted that a
9 number of people talked about this on the first panel as
10 well as this panel.

11 Our country's approach to direct care worker training
12 is in urgent need of modernization. Federal training
13 requirements for home health aides, hospice aides and
14 certified nurse assistants were first established 25 years
15 ago and have not been updated to reflect the increasingly
16 complex needs of today's long-term care consumers.

17 In addition, current Federal training requirements
18 require too much on clinical tasks and too little on
19 teaching the kind of communication and relational skills
20 that help deliver person-centered care.

21 And, believe it or not, there are no Federal training
22 requirements for upwards of a million personal care aides
23 who provide personal assistance and make up what is now the
24 fastest growing occupation in the country--more than any
25 other health care or other occupation.

1 Finally, current Federal direct care worker training
2 requirements are often setting or program-specific with
3 insufficient attention paid to rationalizing these job
4 titles across the competencies required. These outdated
5 systems limit the ability of workers to move between
6 settings and advance in their occupations.

7 So we need to modernize the training in a whole number
8 of ways, which I outline, around consistent standards and
9 skills, et cetera.

10 The third workforce domain relates to the promise of
11 new models of coordinated care that look more holistically
12 at health and long-term care needs and lowering costs. If
13 these models are to be successful, we really need to
14 explicitly allow for the expanded role for direct care
15 workers.

16 Because these paid caregivers are uniquely embedded in
17 the lives of these clients, they are well suited for
18 observing and reporting changes in client conditions. With
19 enhanced training in health education, disease prevention
20 and system navigation, direct care workers could assist with
21 care transitions, recognize early warning signs and prevent
22 hospital readmissions and participate in chronic disease
23 management, work with family caregivers, as Lynn mentioned--
24 and many are paid family caregivers--and support other kinds
25 of behaviors.

1 And, fourth, we are beginning to understand that a
2 strong caregiving infrastructure is as essential to a well
3 functioning economy as roads and bridges, but we have very
4 little of it. In this age of online communities, dating
5 platforms and automated human resource management systems,
6 there is no reason that we cannot develop scalable business
7 models for connecting independent providers and self-
8 directing consumers that are high volume, low price, high
9 efficiency and low cost.

10 These types of solutions are desperately needed in
11 order to support models of service delivery where consumers
12 can self-manage their care and hire their own direct care
13 workers with or without public funding. For example,
14 multifaceted matching services registries could support
15 consumers and workers to find each other. They could be
16 linked to other intermediaries to provide training, respite
17 and emergency backup services.

18 Now I am going to summarize very briefly our
19 recommendations, and we have some very specific ones.

20 You will see some similar themes from what you have
21 heard earlier. So I was very pleased to hear about that--
22 mostly around data, affordability and quality and turnover.

23 In the area of payment and procurement, we recommend
24 that Medicare and Medicaid conditions of participation be
25 revised to require that providers adopt minimum compensation

1 standards for direct care workers.

2 We know from the data that the one way to improve
3 turnover, which costs this country, on average--and this is
4 an old statistic--about \$2,500 per worker, and that is paid
5 by employers and taxpayers.

6 To reduce turnover, two things need to happen. One,
7 you need to improve the wages, and you stabilize the
8 workforce, and two, providing health insurance.

9 And, increasingly, we are getting data about providing
10 training that will improve retention.

11 Secondly, we urge the Commission to request a MACPAC
12 analysis of state home and community-based reimbursement
13 policies in order for CMS to develop guidance regarding
14 effective payment and procurement methods that generate
15 rates that are adequate to elicit a sufficient supply of
16 competent workers.

17 Regarding training, we recommend two actions--
18 implementation of the Institute of Medicine's recommendation
19 for increasing minimum training standards for home health
20 aides and certified nurse assistants, and implementation of
21 minimum Federal training standards for personal care aides
22 based on the results of the demonstrations that are working
23 in six states right now, called the Personal Home Care Aides
24 State Training Demonstrations, which will conclude this
25 September.

1 Regarding workforce infrastructure to support
2 community-based living, we urge you to direct the
3 Administration for Community Living to create demonstration
4 projects in collaboration with CMS, to develop the
5 infrastructure to support self-directed services, including
6 matching service registries that allow both consumers and
7 independent providers to access the resources they need to
8 manage a choice of care and manage their own care.

9 Fourth, with regard to data and workforce monitoring,
10 we have several recommendations, including having CMS
11 include data collection as part of all their waiver
12 applications and personal care option services in data that
13 Medicaid submits now; the Department of Labor should review
14 the occupational industry codes used by state and Federal
15 Governments and employer surveys; and, third, that we have
16 development of national job quality workforce indicators for
17 direct care occupations, collecting things such as job
18 vacancies, turnover rates, staffing levels, wages and
19 benefits, so we can better understand and create incentives
20 for adequate and safe staffing and greater workforce
21 stability.

22 Finally, we urge you to support the creation of a Home
23 Care Workforce Advisory Panel to provide guidance on issues
24 regarding increasing the supply of personal care aides,
25 improving wages and benefits, and ensuring access to

1 personal care services for consumers.

2 The CLASS Act faced a number of structural challenges,
3 which is the reason we are here today, but one thing it got
4 right was the need to address workforce issues in a focused
5 and comprehensive manner.

6 In closing, the direct care workforce offers tremendous
7 value as an underutilized asset in our health care
8 infrastructure, one that can be leveraged toward improving
9 the goals of access, quality, efficiency and cost. It is a
10 historic workforce, both in terms of size and growth, and it
11 has only begun to receive policy and practice attention that
12 will allow it to realize its valuable potential. Direct
13 care workforce investments have become more urgent with each
14 day as our social fabric strains to support the hands-on
15 caregiving requirements so many of us need.

16 Thank you very much for this opportunity to testify.

17 [The prepared statement of Ms. Regan follows:]

1 Chairman Chernof. Thank you very much.

2 Commissioners, I will ask you to keep your questions
3 sharp and to an individual.

4 I am going to actually take the Chair's role here for
5 one second and ask a question on behalf of Laphonza Butler,
6 a commissioner who could not be here today. It is going to
7 be for Lynn Feinberg, please.

8 So, based on everything we have heard today, maybe you
9 could speak a little bit about why the workforce issue is
10 often overlooked in long-term services and supports policy
11 discussions.

12 Ms. Feinberg. Well, the workforce issue in long-term
13 services and supports is primarily the family and close
14 friends, and I think that again, as I said in my testimony,
15 families are invisible. There is virtually little
16 recognition.

17 What is unique about long-term services and supports is
18 that the provision of care, along with direct care workers,
19 who are partners with families and friends, is largely on
20 the shoulders of families.

21 In the health care system, our delivery system is based
22 on health care professionals, social service professionals,
23 but not the case in long-term services and supports.

24 What we have not done, I believe, a good job enough in
25 is better recognition for this unpaid, large workforce of

1 family and friends because family caregiving is a role; it
2 is a relationship. But for many families that are
3 undertaking this and because of the complexity of the task
4 that they are doing, they consider this to be also a job.

5 Chairman Chernof. Henry, would you like to start us
6 off with questions?

7 Commissioner Claypool. Sure. I was also going to go
8 to a workforce question and would direct it to Carol Regan
9 from PHI.

10 Could you be a little more explicit about the types of
11 training that you believe primarily the direct care
12 workforce that is responsible for primary care--which you
13 have noted there are no training requirements. You
14 mentioned that there may be some general needs around the
15 needs of the individual, but please tell us more.

16 Ms. Regan. Thank you, Henry. It is a good question.

17 I think there is a balance of skills that are about
18 being able to identify some basic clinical issues around the
19 care and needs of an individual, but more importantly, I
20 think there is an issue around relational skills,
21 communication skills, those kinds of things that are really
22 needed in order to--whether you are in a nursing facility or
23 in a person's home.

24 I think we would also argue that the kinds of training
25 that are most effective are adult learner-based, centered

1 kind of training. You need on-the-job training. You need
2 actually hands-on training.

3 And with consumers, who we have worked really closely
4 with at PHI, one of the things we do in addition to our
5 policy research is develop curricula. We have worked very
6 closely to develop curricula for consumers who direct their
7 own care, and that means two things.

8 It means both understanding and being able to
9 communicate with the individual and their family about what
10 they need--how they like to be bathed, how they like to be
11 touched, what kind of lifting is best for them and okay for
12 the worker to not injure themselves. You know, what are
13 their other kinds of preferences that they need?

14 So some of it is around working with a care plan that
15 is good and that the direct care worker is part of. So they
16 are not isolated from the care plan that is being developed
17 --Joanne mentioned this--by the physician and nurse and
18 social worker, but they are part of that.

19 And it also includes other things sort of around meal
20 planning and preference.

21 So it is a whole range of skills and needs that are
22 partly based--they have to be individualized because people
23 have different particular physical or health conditions but
24 also some general training around how to identify problems
25 and how to communicate those problems and how to do certain

1 things like range of motion, give baths, help lift and help
2 transfer people.

3 That answers your question?

4 Commissioner Turner. Thank you all for this wonderful
5 picture that you have given us of the challenges and
6 opportunities in the caregiver profession.

7 I was struck by Ms. Feinberg's and Ms. Regan's
8 testimony in particular about the need for Federal training
9 standards, a Federal coordinated plan and a Federal
10 strategy. And, at the same time, I hear over and over about
11 the need for really individualized care; every patient is
12 different.

13 And I would really like to ask Dr. Brown, based upon
14 your research and looking across programs, how do we
15 reconcile this, and what can we learn from the experience we
16 have seen so far of programs about how we reconcile this
17 individualized need for care with developing Federal
18 strategies when there are really so many community-based and
19 local needs and local resources involved?

20 Mr. Brown. It is a good question.

21 What the programs tended to do is they would have
22 guidelines and protocols that the care coordinators would
23 follow in general, but they also did not want to take the
24 medical expertise and the knowledge of the patient that the
25 individual had.

1 So it is all about the hiring of the people because you
2 have to end up depending a lot on the judgment of this care
3 coordinator. They know the family. They know the
4 situation. They know the goals.

5 There needs to be a big focus on the goals of what the
6 patient and the family are. You need to know where you want
7 to go before you decide to run off and do something, like
8 Joanne was talking about.

9 So it is this fine balance between wanting to give
10 people enough structure that they know how to do a care plan
11 and things like that--how one wants to be touched--but they
12 also can use their clinical judgment, their medical judgment
13 and their just common sense and people skills to do what
14 needs to be done for the individual.

15 Commissioner Turner. So you would say that the ability
16 to have flexibility is really crucially important.

17 Mr. Brown. Absolutely, yeah.

18 Commissioner Feder. Randy, I have got another question
19 for you.

20 As you examined the programs that work and the programs
21 that do not, and looked at care coordination, most of it we
22 know is primarily--and the current innovations--directed--is
23 focused on acute care; very little, if any, on long-term
24 care although some of the sites that you note do that as
25 well.

1 And I know that you know of the evidence on population,
2 not just with chronic needs but the Medicare population with
3 chronic care needs and long-term care needs, who end up on
4 the highest cost list.

5 And you have emphasized that the care coordination
6 efforts have to be targeted in order to be efficient.

7 So I wondered if you would talk a little bit about what
8 you think about including functional assessments as a
9 targeting mechanism and including long-term services and
10 supports and available family care as part of coordination
11 even if the individual is paying for those themselves.

12 Mr. Brown. It is absolutely essential.

13 One of the programs that we studied, where they did
14 focus on the medical side of things--but all the successful
15 programs said that about 15 percent of their patients needed
16 long-term supports and services, too, where there was a
17 heavy family--so they were frail as well.

18 A lot of the people were not frail. They just were
19 sick. And, for those people, the social worker was
20 essential. They said they could not imagine how they did
21 the program without them.

22 And, typically, a nurse was caring for them because
23 they had multiple chronic illnesses and they needed medical
24 knowledge. But they did not know what kind of resources
25 were available locally, and so they needed that social

1 worker.

2 I think sometimes they would trade off, too. If it
3 turns out that for a particular patient their problems or
4 their medical stuff was pretty much under control but their
5 social network was a mess, then the social worker would take
6 over for a while and knew when to get back. So it was this
7 team arrangement--is what seemed to be most effective.

8 Steve Counsell's GRACE program is a particular one to
9 focus on because they use a geriatrician. So they were
10 attuned to the particular problems of frail, older people,
11 and that is the population they were serving, unlike a lot
12 of the care coordination demos.

13 Commissioner Pruitt. Thank you all for your testimony.
14 It was very insightful.

15 Dr. Lynn, my questions is for you.

16 You mentioned about the care planning process and the
17 inability to put a comprehensive care plan on an electronic
18 medical record.

19 I also know there has been efforts over the years to
20 create a common assessment tool, you know, that is common
21 among sites of service.

22 What is your opinion of why we have not really been
23 able to achieve a comprehensive assessment, and what steps
24 could this Commission take to aid that effort?

25 Dr. Lynn. The biggest single reason not to create a

1 common assessment tool is that everybody is making money on
2 the chaos of the current system, and so there are very
3 strong groups that are wanting one or another assessment
4 tool.

5 There are additional reasons--that one assessment tool
6 may be a little better in one range of patients and clients
7 than another.

8 But this pursuit for optimizing for very small segments
9 means we do not ever have a way of communicating across
10 settings.

11 So, when I was at CMS, we developed the CARE tool,
12 which was meant to be a uniform assessment instrument for
13 the elderly. It does not work so well for mentally ill, but
14 it could. It would be a fairly easy modification.

15 It was disrupted at the last moment and not made as
16 much a part of the new MDS and OASIS instruments as it
17 should have been because there was such allegiance to past
18 ways of calculating the payment rates and not enough time to
19 fix that.

20 But that is the kind of thing that is just outrageous.

21 At the present time, it is like we are working in
22 different countries. A person who is using the ERFPI tool
23 in an inpatient rehab facility has no direct of
24 communicating in the language of the home care agency or of
25 the nursing home, and those are just the three dominant

1 elements. Then you get the hospital and the physician
2 involved, and you are just talking chaos.

3 So, yes, of course, we should have a common instrument.
4 It should be common across all settings. And if you want to
5 use another instrument, please feel free, but at least use
6 this one because the most important thing in living with
7 chronic conditions is that chronic piece.

8 You have to be able to see how a person has done across
9 time. And if we are all using different scales and they are
10 not readily commensurable, it is just gibberish.

11 So, yes, we desperately need there to be a common
12 instrument. It needs to go across all settings. We need to
13 begin to get hospitals and, for that matter, doctors
14 involved in doing such assessments so that we can see how
15 people are coming out and sort of what their life is like.

16 One of the ways we keep from knowing the things we need
17 to know--Robyn was speaking to some of this earlier--is that
18 we simply do not establish databases that make sense. So
19 let's do.

20 Commissioner Pruitt. Thank you.

21 Commissioner Raphael. So I have quite a few questions
22 on how we get from here to there, but I am just going to
23 address one question to Lynn.

24 In terms of the next 5 to 10 years, what do you think
25 is the most important thing that we could recommend that

1 would make a difference in the lives of caregivers across
2 the United States?

3 Ms. Feinberg. Thank you for asking that question.

4 I think that the most important thing that the
5 Commission could recommend--and I will build on what David
6 said earlier--is to answer the question, are we a country
7 that supports families or not?

8 So one strategy to deal with that would be to recommend
9 that we develop a national strategy to look at how we better
10 recognize, assess and support and address the needs of
11 family caregivers who--if they go away, we are in really big
12 trouble.

13 Australia did pass legislation in 2011 to establish a
14 National Carer Strategy in Australia. In the U.K., they use
15 the term, carer rather than caregiver. Caregiver is also
16 not the best word either, but we are not talking about the
17 language here.

18 But that is also part of it--workforce language. All
19 these things need to be grappled with.

20 But I think if there could be a national strategy to
21 actually look at, from the employer perspective, a lot of
22 the issues affecting families because more women are in the
23 workforce now and juggling these work and caregiving issues,
24 as well as men.

25 So, from the government, from the private sector, from

1 employers, from faith communities, what is our national
2 strategy to develop specific actions to tackle this problem?

3 Vice Chairman Warshawsky. I want to also thank the
4 panel for their very interesting presentations, and in
5 particular, I want to thank some of the members of the panel
6 for their very specific recommendations. I think we are in
7 that mode in the Commission to do so.

8 But, at the same time that I say that, I will note that
9 a challenge that I have with some of the specific
10 recommendations is it sort of opens up a Pandora's Box. Why
11 not give people Social Security credit for child care as
12 much as you give it for family care, or why this particular
13 workforce should get minimum compensation as opposed to
14 other workforces?

15 But, anyway, that is sort of with regard to the
16 specifics.

17 But my question is to Dr. Lynn.

18 We very much appreciated your testimony.

19 And I am very sorry that George Vradenburg was not here
20 because he wanted us to also have people who "think outside
21 of the box"--something really quite radical. I will say
22 that it is radical--what you are proposing--but still, I
23 think, grapples in a very original way with the issues.

24 The concern I have--and this is my question--is the
25 local entities that you envision dealing with--I think it is

1 fair to characterize your view as the over-medicalization in
2 this population of the frail, elderly, and that is where so
3 much cost is.

4 How can we be confident that that really would provide
5 the resources to provide resources in the other areas which
6 you recommend?

7 Dr. Lynn. I think there is very good evidence that we
8 can build the care system that comes in at a lower per
9 capita cost by a substantial redistribution from the medical
10 care side to the social supports. But, in the final
11 analysis, we do not actually know that until we try it out,
12 and we need some places and people who are willing to try it
13 out. And let's see. You know.

14 I see over and over again in the work I am doing in
15 various parts of the country, people sent home from the
16 hospital after \$50,000-\$60,000 hospitalizations to living
17 situations that are just untenable. They are going to be
18 back in the hospital because that is what someone like me
19 can do for them--is to put them back in the hospital.

20 I cannot give them a place to live. I cannot give them
21 a bed. I cannot give them a non-abusive family caregiver.
22 But I can put them back in the hospital when they start
23 going sour again.

24 So we run up these enormous bills for no good end.

25 And I think that at least at this time there is enough

1 money in the system for the people that we need to serve,
2 but we need to dish it up in very much more prudent ways.

3 Now will that work?

4 Can we stand to change that much?

5 Can we develop the stories, the pathways, the ways we
6 put this on television that make this make sense?

7 I do not know, but I know that if we do not, we will
8 learn to walk out on people, that there are going to be an
9 awful lot of us who do not have adequate savings or
10 insurance, who do not have six daughters or daughters-in-law
11 and are the mercy of what our communities can provide.

12 If we do not figure it out, we will figure out how to
13 walk away. And that would be, I think, devastating to an
14 awful lot of people.

15 So I hope we can do it.

16 Chairman Chernof. So I want to channel another
17 commissioner who was not able to be here today because I
18 think Mark's question really builds on where George would
19 want to go.

20 And so I guess he would ask, so how do we take the next
21 step? Is this really a bundling issue?

22 Be more specific about what it means to redistribute
23 funds in a policy context.

24 Dr. Lynn. I think that you need to free the people who
25 are most shoulder-to-the-wheel and closest to the issue and

1 let them figure out how to build a care system that works.
2 Steve Counsell's GRACE program has already been mentioned.
3 There are 20 programs like that around the country, maybe
4 100.

5 The VA system is already at 60 percent reduction in
6 hospitalizations in their home-based primary care mainly by
7 liberating people from all these rules.

8 I think we need to increase the scope of what we pay
9 attention to. It is not Medicare and Medicaid and the
10 privately paid co-insurance. It is also how you live. Once
11 you are very disabled in old age, it is the housing. It is
12 the transportation. It is the food, as well as those other
13 things.

14 I am not saying my field is irrelevant. It just is not
15 dominant.

16 So I think we have to figure out how to do those
17 transfers, how to live within our means and not pursue every
18 last little thing that conceivably might make a difference
19 in the medical care arena while completing ignoring all
20 those others.

21 And, as to the local management, I do not know how
22 thick that local management needs to be, but I know that
23 right now I cannot tell you whether Washington, D.C. is
24 doing better or worse than it was five years ago because we
25 do not organize data that way.

1 I cannot tell you whether our pressure ulcer rate is
2 better or worse or whether our bankruptcy rate or our spend-
3 down rate is better or worse.

4 We organize by the hospital, the doctor, the nursing
5 home, the home care agency, and yet, the patients--the
6 clients--move around among all of them. It would be like
7 evaluating school systems by not even just how you are doing
8 in math and science and English but how you are doing in
9 teaching a particular chunk of math and punctuation in
10 English.

11 We need to bring it together to see the whole.

12 And then the layer in local management may be
13 relatively small. It may be largely job-owning. I am not
14 sure. Maybe we have to control 2-3 percent of the assets.
15 But it has to be there or we miss our on what matters to
16 people.

17 Commissioner Brachman. This question is asked to
18 Josefina Carbonell.

19 I am impressed with the breadth of your background and
20 the areas in which you have worked, and this really
21 addresses some of your earlier work perhaps.

22 In terms of direct care delivery and, in particular,
23 choice of care delivery and thinking about low-income and
24 minority neighborhoods, do you find a difficulty in--or did
25 you find and do you see a difficulty in delivery of care in

1 those particular neighborhoods, or access to particular
2 kinds of care--residential care versus home and community-
3 based care?

4 And I wonder if you might address that issue, please.

5 Ms. Carbonell. I think I want to answer this way. In
6 general, I think that we do not have the adequate long-term
7 services and supports, home and community-based care support
8 infrastructure in place.

9 I think that we have an existing core set of providers
10 that are doing miracles in communities and particularly in
11 at-risk or language-limited communities and cultural
12 communities and that are trained and trusted, that could be
13 lifted up, lifting the level of care and training, and the
14 level of participation and infrastructure that could be
15 built.

16 I think the other thing I wanted to say--I think also
17 answering your question and some of the comments from the
18 rest of the commissioners--is that we have a unique
19 opportunity in front of us right now, looking at us. Not
20 years from now. Now.

21 We have innovation initiatives happening in the duals.

22 We have innovation initiatives due to budgetary and
23 recession and economic downturn in states with Medicaid
24 reforms that are going into the long-term care services and
25 supports and that are looking at managed care and the

1 integrated models.

2 So we have the ability--this Commission has the
3 ability--the government, HHS, CMS, ACL have the ability to
4 be able to sit down together and work from the community-up
5 and from the Federal level-down to make sure that we do not
6 miss the opportunities that we have to build, to use the
7 economic downturn as an opportunity to build the kind of
8 infrastructure and the quality of the infrastructure for the
9 long-term services and supports that we have.

10 I think there is money out there with Medicare and
11 Medicaid. We need to be looking at the financial alignments
12 of those incentives to make sure that we give the
13 flexibility and the choices for people to have that care and
14 that we have the right services, in the right language, in
15 the right neighborhoods to be able to be given.

16 And I think we have everything starting at us, right in
17 front of our faces, and we are missing the opportunity.

18 I stress to you because that is at the threshold that I
19 am in. I am at the threshold of trying to implement these
20 programs in several states across this country. And I am
21 talking Florida, which is Medicaid. I am talking Illinois,
22 which is duals, Michigan, Ohio, New York, California.

23 We are currently in that landscape, on the ground, with
24 community providers of all in the long-term care services
25 and supports, with health plans that have won the contracts

1 to be able to implementing this, with states that are
2 strapped both with lack of data and lack of resources and
3 that they must move to greater efficiencies in the work.

4 And we have a willing HHS government and payer in CMS
5 that is looking at ways to improve that capacity.

6 It is right in front of us. Let's not have this
7 Commission or our country miss the opportunity to be able to
8 begin to build the faces, to make sure that we include the
9 caregivers, make sure that we have comprehensive assessments
10 across the country and that we have an adequate, trained
11 workforce, both formal workforce and direct care workforce,
12 as well as family caregivers and informal caregivers.

13 Chairman Chernof. With that, I want to conclude our
14 second public meeting of the Long-Term Care Commission.

15 On behalf of all of the commissioners and my Vice
16 Chair, Mark, I want to thank each of the panelists today,
17 from both panels, for a really fabulous job, both in terms
18 of your written presentations and your public presentations.

19 For everybody who is here in the room, I want you to
20 accept the challenge that our last speaker gave us. Since
21 we are on a threshold, we are looking for good ideas.

22 The Commission has a web site available--
23 www.LTCCommission.Senate.gov. Given our very short time
24 frame, we are inviting ideas through the web site. Please
25 use the web site opportunity to forward ideas that you may

1 have that did not get discussed today.

2 And, with that, I thank you all very much.

3 [Whereupon, at 4:42 p.m., the Commission was
4 adjourned.]