

ELDER JUSTICE COORDINATING
COUNCIL

Panel Four: Advancing Research

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3 Speakers Panel: Advancing Research

4 MS. GREENLEE: So welcome to the last panel.

5 It's very good to have you here. Thank all of you for
6 sticking around.

7 One of the hard things in putting together
8 the day is that all of these issues are equally
9 important, and so I appreciate you staying around as we
10 talk about "Advancing Research." As you can tell, the
11 more we know, the better, and we need to hear more from
12 the medical and research side.

13 So let me introduce our last four speakers
14 and thank them for being with us.

15 Robert Wallace, M.D., is the Director of the
16 Center on Aging, the Department of Epidemiology,
17 University of Iowa.

18 Next to him is Mark Lachs, Doctor, M.D.,
19 Director of the Center for Aging Research and Clinical
20 Care, Weill Cornell Medical College, which I think is
21 in New York, not Ithaca.

22 DR. LACHS: Correct.

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1 MS. GREENLEE: Yes. I passed my Cornell
2 quiz.

3 (Laughter.)

4 MS. GREENLEE: Ying-Ying Yuan, Ph.D., is at
5 Walter R. McDonald Associates, Inc.

6 Xinqi Dong, who is MPH, M.D., is the Director
7 of the Rush Institute for Health Aging, Rush University
8 Medical Center, which is in Chicago.

9 So, esteemed panel, let me turn it over to
10 Dr. Wallace and have you kick us off and we'll learn
11 some more and have some Q&A with the group.

12 DR. WALLACE: Thank you very much. I'm
13 delighted to be here. And thank you all for hearing us
14 out.

15 I'm a medical epidemiologist, and so this
16 will be a little different than what you've heard, but
17 not too different.

18 MS. GREENLEE: That's okay because if you
19 said the same thing, we really wouldn't want you up
20 here. We want you to say something new.

21 (Laughter.)

22 DR. WALLACE: So my assignment was to make

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1 suggestions for scientific directions for the federal
2 government. That's really daunting, and I understand
3 that, and I'll be gentle.

4 I want to start by enunciating a few
5 principles. First, what we know about existing
6 research on elder mistreatment and policy intervention
7 should be catalogued; we should write it down, we
8 should know what we know and know what we don't know.
9 And until we do that, we can't really progress. That's
10 the grunt work of science, and it is not glamorous, but
11 it really needs to be done.

12 The second general principle is that targeted
13 research themes are needed here. I spend most of my
14 time doing research funded by the National Institutes
15 of Health, where they're looking for the great ideas
16 and they don't give too much direction. But I think
17 we really know what the problems are. You've heard them
18 today, and we need targeted research on specific areas.

19 I think, as others have said, there are a
20 number of things that the federal government can do
21 beside spending money on research. Everyone has pled for
22 better data, and I share that goal. Commissioner

1 Astrue said that starting off, and I think that's
2 very, very important. These data could include
3 justice, social and environmental programs, housing,
4 urban design, informative clinical information, and so
5 on. There is just a lot of information in the
6 possession of the federal government that under the
7 right circumstances needs to be shared.

8 Secondly, I think that the government can
9 promote the interaction between the public sector and
10 the financial industry, and that's been pled several
11 times today, and I'm in complete agreement with that.

12 Finally, I think federal agencies
13 should evaluate their own elder mistreatment-related
14 policies, that they should retain some of their funds
15 and perform a thorough evaluation of what they're
16 doing and whether it works. In medicine,
17 we call that evidence-based practice,
18 and I think that should be true of policies
19 as well. And so I wouldn't send out 60 million inserts
20 in Social Security checks to have people remember that
21 it's a problem until you know what the side effects are
22 of those, just as if you were developing a new drug.

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1 For the rest of the time, I wanted to quickly
2 mention some of the targeted areas that are
3 important. A lot of smart people have come before me
4 here today, and you've heard their recommendations

5

6 One fundamental need is to have more
7 qualitative social and psychological studies of the
8 dynamics of older people in families and households
9 that might lead to mistreatment. This is very
10 difficult, and I understand that, because it involves
11 the intimacies and struggles of private lives and how
12 they are revealed to social institutions such as the
13 church, networks of friends and relatives, the police,
14 the health care system, the justice system, and various
15 other helping organizations that are very important to
16 all of us. But this dynamic is central to accurate
17 surveillance of mistreatment, and if we're going to do
18 the counts and we need the counts mostly for program
19 evaluation, they have to be done and they have to be
20 done right.

21 The federal agencies must not only share
22 their data, again under the right circumstances,

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1 they must do it with a common taxonomy and
2 nomenclature of elder mistreatment. We do this
3 for the 20,000 rubrics of the diseases that we talk
4 about in medicine, and so why not for elder
5 mistreatment? I would suggest enlisting the help
6 of the National Library of Medicine, which has thought
7 about all of this and has programs and activities to
8 advance this nomenclature. The best example
9 for me is to use words like "neglect" and "self-
10 neglect" when really we might be talking about poverty,
11 disability, and cognitive impairment and all the
12 other misfortunes that can happen to older
13 people if things don't go right.

14 Another targeted research area is to explore and scrutinize
15 various state laws on elder mistreatment. The nation is a
16 laboratory for this because the states do it all differently, and
17 so it offers an opportunity, in fact, to see which programs, which
18 policies, which laws actually work well. Laura Mosqueda said it
19 with respect to California a few moments ago, that there is
20 great variation even within different parts of the state, and my
21 argument would be that we should use ourselves as a
22 laboratory for what works and what doesn't work.

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1 I wanted to put a pitch in for a discipline
2 that traverses the law and health, and that's forensic
3 medicine. It's a starving orphan discipline that
4 really does need help. In addition to all the social
5 and legal interventions, we need to be able to diagnose,
6 to use the medical term, elder mistreatment in a better
7 way than we do now. So if an older person comes to the
8 emergency room with a fracture or a soft tissue injury,
9 we would like to have a blood test to see whether
10 that person fell, in which the interventions are
11 different, or was pushed. And we don't have that. We
12 detect elder mistreatment in the clinic.

13

14

15 As was said earlier this afternoon, another
16 targeted research area is to have government target
17 helpful technology. I'm very much a fan of it.
18 While there is no technology that is going to easily
19 identify elder mistreatment, there are technologies,
20 for example, electronic sensors, that now are
21 beginning to measure the quality of social
22 interaction, not your personal

1 behaviors, but their overall quality, and if you can
2 do that, then maybe you can take it a step further and
3 explore whether there is imminent abuse or
4 imminent mistreatment of one sort or another. This is
5 just simply not so far away, and so technology needs to
6 help us.

7

8 The last initiative that I want to talk about
9 is really my own home discipline in medicine, which is
10 preventive medicine. I think we know very little about
11 how to prevent abuse and mistreatment. What you've
12 heard today are the dilemmas, the problems, and the
13 very difficult social issues, but what I
14 would like to argue is that there is a role for
15 prevention, and my basic approach to this would be to
16 try to make elder mistreatment a first order public
17 health issue as well as a clinical and social injustice
18 issue.

19

20 Think about, as Ms. Tumba said,
21 the last time you saw a public service announcement on
22 elder mistreatment. It just simply doesn't happen. I

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1 don't even know that they work, but if they do, we
2 should be seeing them, and I think it's really very
3 important to take all forms of domestic violence and
4 institutional violence and make it part of public
5 health and face up to it.

6 These are just a sampling of ideas. We're all
7 writing white papers, and we'll suggest more to all of
8 you. And I very much appreciate your time. Let me
9 just say that these are old problems, they've been
10 around for a long time, and I think it takes courageous
11 and really leadership to move this whole field.

12

13 Thank you very much.

14 MS. GREENLEE: Thank you very much, Dr.
15 Wallace.

16 (Applause.)

17 MS. GREENLEE: This is the doctors panel.

18 Dr. Lachs? I'm calling you all "Doctor" and
19 just having fun with it.

20 (Laughter.)

21 DR. LACHS: Thank you, Kathy. I'm going to
22 start with an unprepared statement, as I listened

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1 today. I think that we need to acknowledge that
2 cognitive impairment and incapacity is the 800-pound
3 gorilla in the room.

4 (Laughter.)

5 DR. LACHS: It's what separates this form of
6 family violence from every other. It complicates
7 everything we do, whether you're a service provider, a
8 researcher, you're dealing with policy, the paradoxes
9 of protection versus safety, dignity versus ageism, and
10 we need to sort of be really upfront about that, and
11 it's an important theme I think that's come through
12 here.

13 Relatedly, I've been asked to talk a little
14 bit about two laws or procedures or policies, well
15 intended as they may be, that really harm elder abuse
16 victims potentially and really interfere with research,
17 and I'm talking about HIPAA and Human Subject
18 Protection, and I believe that the pendulum has swung
19 too far in the other direction, and I say this as an
20 NIH-funded researcher who has worked in this area for
21 25 years and as someone who is a clinical geriatrician
22 who runs the New York City Elder Abuse Center.

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1 The theme here has also been that, as MT
2 said, this is a team sport. Laura Mosqueda's vignette
3 about multidisciplinary collaboration to help victims
4 was extremely compelling. And elder abuse cannot be
5 fixed in a silo, and yet HIPAA is a silo fortifier in
6 many cases in the area of elder abuse and neglect. You
7 know, at the New York City Elder Abuse Center, each
8 week we get presented the most vexing and difficult
9 cases in the city, every month I hear about a physician
10 who wants the help of the team but believes he or she
11 needs the sort of blessing of an abuser who might be
12 for an incapacitated patient the person effectively
13 making decisions.

14 Each month I hear about a social worker who
15 may be the most important person in a victim's life for
16 a decade, that person gets taken to the emergency
17 department, and that social worker is excluded from
18 interacting, yet the abuser is given full access, full
19 access, even though there are parts of HIPAA that are
20 misunderstood that deal with domestic violence by
21 hospitals, physicians, et cetera.

22 HIPAA also assumes beneficence of families.

1 So an older person gets admitted to the hospital who is
2 a victim, that individual wields enormous power over
3 who can visit, over who gets information conveyed,
4 excluding other loving family members, in the most
5 extreme cases, whether or not end-of-life heroic
6 measures are deployed or withheld, often in violation
7 of an advanced directive or at the mercy of an abuser
8 potentially.

9 We have all seen, as clinicians, situations
10 in which older adults are given less than optimal
11 environments or health care with the belief that those
12 resources will then come back as an inheritance to that
13 individual.

14 In the areas of research, there are IRB
15 provisions in human subject protections. Often those
16 individuals are often the people who might consent for
17 a victim to be in a study, paradoxically. And there
18 are again many ways in which we would like to follow
19 people in studies from silo to silo to silo and yet
20 human subject protections -- and many of these are low
21 risk observational studies, we just can't do them
22 because these very well-intended provisions, laws,

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1 guidelines, policies preclude us from doing that.

2 So let me make a few recommendations, which
3 again will be detailed in my white paper. I think we
4 need to convene a panel of ethicists, clinicians,
5 community clinicians, to explore the HIPAA and IRB
6 issues surrounding elder abuse and make specific
7 recommendations about how to address these. And I
8 think it's critical that these people not be from the
9 generic domestic violence field. We cannot subsume
10 this problem under that rubric. I think these are
11 people who need to understand cognitive impairment,
12 incapacity, and the issues that have been raised here.

13 Laura touched on my next recommendation,
14 which is you need to give direction to hospitals and
15 physicians about existing HIPAA rules and how they're
16 being applied and misused because there is a great deal
17 of misunderstanding, and that wouldn't cost a cent, I
18 mean, to effectively give guidance so that research can
19 be conducted and victims can be served.

20 I think there are several areas that need
21 research. I think how protective service workers
22 assess decision-making capacity and how the accuracy of

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1 such assessments could be improved; that was a subject
2 also of the last panel. All of the IRB and HIPAA
3 issues are predicated on that that I've described.

4 I think we need new methods for assessing
5 victims, and while protecting them in research,
6 allowing them to participate in research in a safe and
7 respectful way, I think that balance, that sweet spot,
8 could be achieved.

9 I think IRBs should be composed of members
10 with research and clinical expertise in domestic
11 violence generally and elder abuse specifically. Often
12 a young researcher will submit a complicated elder
13 abuse proposal to an IRB, and it's people who are used
14 to drugs and devices, you know, it's a completely
15 different skill set.

16 I think we need to provide guidance to the
17 growing number of multidisciplinary teams like Laura's
18 and mine about how we can continue to care for people
19 in a respectful way that allows the flow of information
20 safely and how those teams can refer people to research
21 projects because I think those are the best
22 opportunities we have to conduct research because of

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1 the numbers and the expertise involved.

2 And then, finally, I'll echo several other
3 panelists today, we need national leadership in the
4 field, a voice, a sustained voice, at a federal level.
5 The absence of such a sustained voice up until today
6 has been ironically ageist.

7 Thank you.

8 MS. GREENLEE: Would you talk briefly before
9 we move on, give us a lay definition for IRBs and sort
10 of just tell the audience so we all know.

11 DR. LACHS: I'm sorry. Yeah. IRB stands for
12 Institutional Review Board. Those are the entities
13 that effectively and very appropriately review research
14 to make sure that subjects are protected. They go by
15 other names in some institutions, Human Investigation
16 Committee, but they're very, very necessary. I mean,
17 some of the saddest chapters in American science
18 involve abuse of subjects, particularly vulnerable
19 subjects, from the Tuskegee airmen to a variety of
20 other sad stories. Those should never be repeated. But
21 I think the pendulum has swung a little too far in the
22 other direction as we try to do this research because

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1 otherwise it's just not going to get conducted.

2 MS. GREENLEE: Okay. Thank you.

3 Ying-Ying Yuan. Hi. Welcome.

4 DR. YUAN: Good afternoon. I'm very pleased
5 to be here, and although I'm not an attorney, I would
6 like to start with two disclaimers.

7 (Laughter.)

8 DR. YUAN: My first disclaimer is that I
9 really speak to you very humbly. I am not an expert in
10 elder abuse, as most of my colleagues are here, nor
11 have I really had the opportunity to research the
12 history of the issue of data collection in elder
13 justice, although I'm going to talk about data
14 collection.

15 My second disclaimer is I'm going to talk
16 from a sister field, of child abuse and neglect, and
17 the national effort to collect data on child
18 maltreatment sponsored by the federal government, but I
19 am not speaking on behalf of the federal government.

20 With those disclaimers, I would like to talk
21 a little bit about the lessons that we have learned in
22 designing and implementing the National Child Abuse and

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1 Neglect Data System. Secretary Sebelius mentioned this
2 earlier in her remarks, and it is a keystone within the
3 field of child abuse and neglect.

4 NCANDS, as it is known by us, is housed in
5 the Children's Bureau of the Administration on
6 Children, Youth and Families within ACF within the
7 Department of Health and Human Services. It today is
8 in its twenty- second year of national reporting and
9 every year we collect over 3-1/2 million case level
10 records on individuals who have been alleged to be
11 maltreated.

12 So from the beginning, some very critical
13 decisions were made by the federal government, some
14 intentionally, but some unexpectedly, which have
15 influenced the field for so many years. There are three
16 of them which we think are quite important.

17 The first was that it would be built on a
18 partnership between the federal government and state
19 governments. The concept of a federal-state
20 partnership has underlain the issue of the development
21 of the system for more than 20 years and that many
22 efforts would be made to sustain this partnership.

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1 A second point, which is a little bit more
2 controversial, and has even been studied by the GAO in
3 terms of other systems, is that this system would be
4 voluntary. It would not be a mandated system.
5 Participation would be voluntary by the states, and
6 therefore data collection would not be regulated
7 through rulemaking and regulation but would need to be
8 approved by the Office of Management and Budget. Those
9 of you who are involved with federal government know
10 that the OMB process is what researchers who work under
11 grants don't know, but all contractual collection is
12 conducted only with the approval of the Office of
13 Management and Budget. And NCANDS has been approved
14 from the very beginning; every 3 years it goes up for
15 that approval.

16 Thirdly, the decision was made that data
17 would be collected annually, and it would be collected
18 in a common record format. So many decisions based on
19 this fact alone have influenced the implementation.

20 I would like to just mention -- not get into
21 all the technical details of that system, but I would
22 like to mention the lessons that we have learned in

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1 regards to two things, with regards to implementation
2 and with regards to return on investment.

3 In terms of implementation, the principle of
4 starting from existing strengths but striving for
5 aspirational goals has influenced the design from the
6 very beginning in that the early design included
7 several data elements which were recognized could not
8 be fully reported on; but the field as a whole, meaning
9 all 50 states participating in that initial design
10 recognized that they should be included as something
11 one should strive for.

12 The other thing, in starting from existing
13 strengths, was to decide to base the system in agencies
14 that had the most data, not perfect data, and nor with
15 all data, but with those that had the most data
16 and in an automated form. If you consider over 20
17 years ago, we were far behind what is available now. We
18 were really in our infancy, but that decision was made,
19 that this system would be based on automated systems.
20 Part of that also was to develop the relationship
21 between agencies that the federal government had a
22 relationship with so that that relationship could be
fostered.

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1 A second point that we learned through
2 implementation was that peer leadership was critical.
3 Although the federal government supported it through
4 the Office of Child Abuse and Neglect, and later the
5 Children's Bureau, through annual technical assistance
6 meetings and providing technical assistance to the
7 states directly, peer leadership of the states
8 themselves among colleagues is a critical piece.
9 I think the evidence from today is that there are
10 leaders in the field of elder abuse who should also be
11 participating in that design of the future system, and
12 then lead their counterparts further along.

13 Today, there continues to be a National State
14 Advisory Group for NCANDS that meets annually in
15 addition to an all-state meeting, and it is through
16 these mechanisms that this peer relationship among the
17 states and the departments has been developed.

18 The third point from implementation is
19 something that I think is critical today and probably
20 even more critical than it was 20 years ago in that
21 information technologists must be involved from the
22 very beginning of the design of the system. One cannot

1 rely solely on practitioners and policymakers. Systems
2 are already out there, there is already automation, it
3 is these people who know what are the future directions
4 for technology, what are going to be the foundations
5 for the design of the systems.

6 The federal government, in the NCANDS
7 experience, recognized the need for building this
8 infrastructure, this technical infrastructure, for
9 collecting data at state and local levels and increased
10 the funding for state systems in multiple ways. One of
11 these was the SACWIS system, which is the Statewide
12 Automated Child Welfare Information System, that had
13 enhanced funding for any state that wished to
14 participate. CMS has a current initiative now with
15 also enhanced funding. And these are huge
16 opportunities for developing systems.

17 In the national meetings that we hold yearly,
18 more than half of the representatives come from the
19 information technology side, sent by their states to
20 participate. They are either the actual programmers,
21 designers, business analysts, or data quality assurance
22 people who work with their automated systems.

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1 The implementation has also been very much
2 influenced, and I think more subtly, before the social
3 services even knew what this term meant, of return on
4 investment. It was through the leadership of the
5 federal government that recognized there must be a very
6 fast return. This return was the emphasis on
7 getting something visible to people very quickly.

8 NCANDS started in 1988 with its initial design.
9 By 1991, in less than 3 years, there was already a
10 design which was sent to OMB for approval. By 1992,
11 national data were collected and published. So in less
12 than 4 years the result of this investment of the
13 federal government, which was not extreme, was already
14 out there. Over the years -- we're now in this twenty-
15 second year of reporting -- the data have become much
16 more comprehensive. The reports have increased hugely,
17 but that initial report I think helped to motivate
18 people and to see that there would be use for the data.

19 The second point was an ongoing use of the data,
20 not solely just to have a report that goes out there,
21 but the federal government and ACYF have used the
22 data in multiple ways including in terms of their own

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1 performance monitoring of the states and in reporting
2 to Congress in many ways. Today, probably over 30
3 government reports rely on these data as part of
4 national initiatives, including Healthy People 2020,
5 including the statistical abstracts, et cetera.

6 Furthermore, the data are published on the
7 internet and on the average hit is over 600,000
8 hits a month, average. The month that the report comes
9 out, the hits are over a million hits. The
10 recognition that people are using the data is very
11 important to the people who are reporting the
12 data. So it is a very nice cycle that people see there
13 is a reason to do this, and we have been able to
14 communicate right down to the social workers why it is
15 important that they contribute to this effort.

16 The third point in terms of return on
17 investment is probably not to put all your eggs in one
18 basket. While investing in a national data system,
19 other means of collecting data on elder abuse could and
20 should be conducted in parallel. This has proven true
21 in child abuse and neglect also. You cannot assume
22 that one system, two systems, three systems will answer

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1 all your questions. So, for example, from my
2 perspective, research needs to be supported on the
3 characteristics and risk factors associated with elder
4 abuse independent of a national data collection system,
5 although that might also inform the topic.

6 Prevention programs and early intervention
7 programs, as has been mentioned earlier, need to be
8 developed, evaluated and replicated.

9 Thirdly, the feasibility of integrating
10 existing datasets to gain a cross-agency perspective
11 should also be conducted. I don't think that the
12 existing feasibility of this has really been taken to
13 the level that needs to be taken. While not
14 simplistic, the maximization of existing data sources
15 is something that all of us are involved in these days.
16 We all know the term "big data," we all know the term
17 "data analytics." This is the future: to maximize
18 what is already being collected, to maximize
19 that investment.

20 We see that these kinds of approaches will
21 therefore influence policy, and programs, and will
22 influence the technologies that exist for the kinds of

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1 data that we want to collect as social service
2 programs, which is very different from what business
3 environments need to collect. So as a collective
4 voice, we can also influence the nature of information
5 systems that will support the fields that we work in.

6 In summary, based on the NCANDS perspective,
7 we believe that national data are not beyond the reach
8 of elder justice, and, furthermore, that this will not
9 be without challenges, but the reward is certainly
10 clear, it will be a foundation for the future for
11 understanding the needs of our elders.

12 Thank you.

13 MS. GREENLEE: Thank you very much.

14 (Applause.)

15 MS. GREENLEE: Xinqi.

16 DR. DONG: Thank you. It's a great pleasure
17 to be here and I'm very humbled to be able to provide
18 testimony on elder justice through the lens of culture
19 and community in our increasingly diverse population.
20 And today I testify as a geriatrician who care for
21 vulnerable older adults and their struggles through
22 their physical as well as psychosocial well-being, our

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1 complex health care system. Moreover, I sit before you
2 as an epidemiologist who has conducted research on
3 elder abuse using our diverse populations and critical
4 role in the community in the prevention of elder abuse.
5 But furthermore, as an immigrant who came to this
6 country at the age 17, and the grandson of a man who
7 dedicated his life towards advocating for social
8 justice, I witnessed firsthand my grandfather, as well
9 as my family, suffering from him being the victim of
10 repeated violence and sent to prison at age 75 during
11 the cultural revolution.

12 In 2010, approximately 20 percent of the
13 older adults over the age of 65 are minorities, with
14 8.4 percent African Americans, 6.9 percent Hispanics,
15 3.5 Asians, and 1 percent Native Americans. From the
16 2010 census, the minority population is growing
17 rapidly. In the last decade, the rate of growth for
18 the white population has been 5.7 percent, yet for the
19 Hispanic population, it's been 43 percent, with 43.3
20 percent in the Asian population, 18 percent in the
21 Native American population, and 12 percent in the
22 African American population.

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1 Recent studies have expanded our knowledge of
2 elder abuse in diverse populations. Evidence suggests
3 that the prevalence of financial exploitation, it's
4 almost three times higher, and psychological abuse is
5 almost two times higher in African American older
6 adults than white older adults. A recent study in the
7 low income Latino population indicated 40 percent of
8 the older adults have experienced abuse in the last
9 year, yet only 2 percent were reported to authorities.

10 In the Chinese population, despite the high
11 culture expectations of filial piety for older adults,
12 18 percent of U.S. Chinese older adults have self-
13 reported elder abuse. Despite this alarming data, the
14 severe lack of research has directly hampered our
15 ability to devise targeted prevention and intervention
16 strategies. Etiological research is needed to explore
17 cultural norms expectations in the perception,
18 determinance, and impact of elder abuse in our diverse
19 populations. However, significant challenges exist in
20 the preparation of conduct, age, and research in
21 diverse populations especially on culture-sensitive
22 issues.

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1 In Chinese population, many assumptions that
2 Chinese are a homogenous society, yet there are more
3 than 56 minorities, there are 20 million Muslims in
4 China. Linguistic and culture diversities are vast.
5 For example, in Chinese language the word "dementia"
6 literally translating to "zhe Dai" which means
7 crazy and catatonic. The word depression is synonymous
8 with the word "schizophrenia," and elder abuse elicit
9 unbearable family shame and a frank violation of the
10 most sacred culture norms. We've heard a lot about
11 decisional capacity today, and yet in Chinese culture,
12 it is accepted norm for the first born child to assume
13 decisional capacity for the older adults even though
14 that person has ability to make decisions. It is
15 common for a family member to withhold cancer
16 diagnosis to their parents if family deem that's
17 in the best interest. Other may argue otherwise, but
18 that is a common practice in our culture.

19 In order to devise intervention or prevention
20 strategies, linguistic culture complexity nuances are
21 critical to provide deeper understanding of elder abuse
22 in diverse communities. One approach could be the

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1 community-based participatory research approach, or
2 known as CBPR, could be a potential optimal model to
3 explore issues about abuse in diverse communities. CBPR
4 necessitates a partnership between academic
5 institutions and community organization and key
6 stakeholders to examine relative issues. The
7 partnership is required for reciprocal transfer of
8 expertise and need to build infrastructure in the
9 community toward sustainability. And recent elder
10 abuse research in Native American, Latino, and Chinese
11 communities have demonstrated success, enhancing
12 infrastructure network for community-engaged research
13 and the community academic partnerships.

14 With the funding of NIA and the National
15 Institute of Minority Health, private foundations and
16 community organizations, we have started the PINE
17 Study. In Chinese, it's known as "HuaRen Song Nian
18 Yian Jio."It is one example, perhaps, for collaboration
19 between academic and community, leveraging the
20 principles of CBPR to advance scientific knowledge on
21 elder abuse, filial piety and psychological distress in
22 Chinese population. We instituted a community advisory

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1 board of key stakeholders that guide our ongoing
2 collaboration and issued grassroots education
3 initiatives on health and psychosocial well-being
4 facing the Chinese population.

5 And we have also devised software technology
6 where the data could be collected simultaneously in
7 both simplified traditional characters as well as
8 English without the need for translation to capture
9 both quantitative as well as qualitative data to really
10 provide in-depth understanding of issues on elder
11 abuse.

12 The PINE Study is a population-based
13 epidemiological study. As of yesterday, there were
14 2,650 Chinese older adults in the greater Chicago area.
15 And with strong community support and bilingual and
16 bicultural research team, 89 percent of our samples
17 have agreed to participate in an in-depth interview of
18 very personal issues. In addition, through the
19 integration grassroots civic engagement of culturally
20 appropriate activities such as calligraphy, Tai Chi,
21 Chinese poetry, water painting, et cetera, Chinese
22 older adults have been more than willing to share their

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1 stories with us through this close family conflict, the
2 things that they have not told their physicians, their
3 neighbors, and their family members.

4 Over the last 2 years, I have had the
5 privilege to be, as Congressional Policy Fellow, Health
6 Aging Policy Fellow, I had the privilege to work with
7 policymakers on elder justice issues both national and
8 internationally, moreover, as a member of IOM Global
9 Violence Prevention Forum, together with Kathy
10 Greenlee, and we have continued to push for prevention
11 of elder abuse and violence towards our most vulnerable
12 populations.

13 In my community, violence towards older
14 adults is not just elder abuse but also self-directed
15 violence, such as suicide. And globally, suicide in
16 Chinese population accounts for 20 percent of suicides
17 in the world, and Chinese older adults have a rate of
18 five times higher than younger adults in the U.S.
19 Chinese older adults, particularly Chinese older women,
20 has the highest suicide rate than any other racial
21 ethnic groups. Among many etiology, family conflict is
22 a predominant factor in the suicidal ideation and

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1 attempts. Our current work in the PINE Study will hope
2 to more precisely understand those relationships
3 between elder abuse, cultural factors, and psychosocial
4 distress.

5 In conclusion, and in my humble opinion,
6 without understanding culture and community issues
7 related to elder abuse, it's a house without a
8 foundation, it's a tree without a root, it's a blind
9 man feeling an elephant without a true understanding. I
10 hope the Elder Justice Coordinating Council will
11 consider investing in community-based participatory
12 research to understand complex linguistic and cultural
13 issues surrounding elder abuse in our diverse
14 populations, integrate culture and the community issues
15 on elder abuse into the professional education and
16 training on aging issues, and recommend inclusion of
17 community members and key stakeholders in the
18 multidisciplinary team dealing with elder abuse at the
19 city, state, and national level, as well as in an elder
20 justice advisory board as well.

21 So today, it is a great honor to be here
22 today. I also want to give special thanks to Assistant

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1 Secretary Kathy Greenlee, whose personal dedication has
2 inspired us all to continue advocating for the
3 prevention of elder abuse in our diverse populations.

4 Thank you.

5 MS. GREENLEE: Thank you very much.

6 (Applause.)

7 MS. GREENLEE: David.

8 MR. SPIEGEL: Dr. Lachs, and really anybody
9 else on this panel, I have a global question, and I
10 apologize because this really would apply, I think, to
11 the testimony of really many of the people who have
12 testified today. Dr. Lachs, you mentioned the 800-
13 pound gorilla, which is, of course, cognitive issues,
14 and I would have asked this question of Dr. Mosqueda as
15 well --

16 MS. GREENLEE: She can answer, too, so you
17 can poll the whole audience if you would like at this
18 point.

19 (Laughter.)

20 MR. SPIEGEL: My background is in litigation,
21 and MT kindly speaks of the "veil of tears" that occurs
22 in litigation because that's after all the bloodshed

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1 has occurred. So I would like to take you to the other
2 end of the spectrum, to the prevention end of the
3 spectrum, before the "veil of tears" occurs.

4 For any federal agency on this panel, all of
5 them, all of us, FTC, all of us, have consumer
6 education programs, we have outreach programs that
7 occur. What role -- is there a role for consumer
8 education given the 800-pound gorilla? And if there is
9 a role, who would you target, who would you reach out
10 to in order to get an effective preventive message out
11 to the persons who are most likely to be susceptible to
12 elder abuse?

13 DR. LACHS: This is a great research question
14 as well. We're beginning to understand a little bit
15 about early vulnerability to financial exploitation. We
16 heard earlier today from a panelist about someone who
17 was financially exploited and yet in the face of
18 substantial education, and we saw a video of someone
19 who had supposedly sort of warned the older person
20 about that she had become a victim continued to engage
21 in the behavior. So I think for those individuals, the
22 education should not be directed at the victim, it

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1 should be directed at the social network of the victim,
2 the adult child. That man spoke poignantly about, "I
3 wish I had been more involved." I think that many of
4 the interventions that's going to work in elder abuse
5 and neglect are going to be fortification of the social
6 network of the older adult, and I think that's where
7 the education should be directed.

8 There has been some work by Laura Carstensen
9 at Stanford looking for more cognitively intact people,
10 directing educational interventions at them through a
11 telephone intervention, and for certain subsets of
12 older adults, I think those are effective ways of
13 proceeding, but we really need to understand the way in
14 which the brain becomes vulnerable as we age. We live
15 in a society where we assume capacity of older adults
16 until proven otherwise, and we call that preceding
17 guardianship, I've been led to believe, you know, and
18 that is a problem given the fact that you can detect
19 some form of cognitive impairment in 40 to 50 percent
20 of people over the age of 85, the fastest growing
21 segment of society. I don't know if any of my
22 colleagues have any -- you're the preventive medicine

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1 guy, Bob. Do you want to --

2 DR. WALLACE: Okay. So it's a really tough
3 question, and I think one of the problems for us in
4 prevention is we really don't know whether the primary
5 prevention message has reached the people who are
6 already ill, whether it's heart disease or cancer or
7 kidney disease or whatever, and that really is an
8 important question. So when we ask people to stop
9 smoking, it's aimed at people who are not yet sick, and
10 we really don't know whether the smoker who also has
11 had the heart attack is going to respond to those
12 messages.

13 So our public service messages, in my view,
14 aren't targeted well enough, and we don't understand
15 who they reach and how far we can go. And I think it's
16 an open question, as Mark said.

17 DR. LACHS: Yeah. One comment, I was struck
18 earlier -- I believe personally, and I think the
19 literature bears out, that a decaying social network is
20 both a risk factor for elder mistreatment and precludes
21 an older person from responding to existing
22 mistreatment. We heard today about all these internet-

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1 based transactions that make my life easier as a 52-
2 year-old. My first group of 80-year-olds with iPhones
3 are beginning to show up in the practice, and I'm not
4 sure if we're not encouraging a more social isolation
5 by not having that individual go to the post office or
6 to the bank. I mean, those are precious opportunities
7 to interact and intervene, and the convenience for us
8 boomers may be the social isolation of our futures.
9 There is this whole concern about these teenagers who
10 break up through text messages, I'm concerned that
11 we're encouraging isolation with some of these
12 electronic means of transferring funds, as financially
13 secure as they may be.

14 MS. GREENLEE: Laura, can I volunteer you for
15 the last panel? But I actually would like for you to
16 come to a mike. I'm real sensitive about -- but once
17 you're up here, I'm just -- yes, go ahead, Laura moves.

18 Laura, I'll get you in just a second.

19 Yes.

20 DR. YUAN: I'm now totally surrounded by
21 physicians and so I say this with great hesitance.

22 MALE SPEAKER: You just had to say it.

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1 DR. YUAN: Oh, thank you.

2 MALE SPEAKER: You're pretty lucky.

3 (Laughter.)

4 DR. YUAN: I am most fortunate.

5 (Laughter.)

6 MS. GREENLEE: That was a nice cover. That
7 was a nice cover. That was good, yeah.

8 (Laughter.)

9 DR. YUAN: We have often pondered the role of
10 pediatricians, and actually our field starts with
11 pediatrics, noticing the abused child. However,
12 reporting by pediatricians is not increasing. Their
13 role is not very clear. How much training they receive
14 is also not very clear, and yet we know most children
15 do see a pediatrician. We know there are a lot of
16 factors actually stopping pediatricians from really
17 doing a more in-depth interview or finding out more,
18 but I think the analogy is very clear, that
19 geriatricians who work with the elderly also are now
20 confined so tightly to what they can be doing during
21 that time period, they would be an ideal person to be
22 communicating about this issue, but I don't know

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1 whether they will be able to pick that up or not.

2 MS. GREENLEE: Let's ask a geriatrician.

3 Tada!

4 DR. MOSQUEDA: Well, two comments.

5 MS. GREENLEE: Yes.

6 DR. MOSQUEDA: One to pick up on what Ying-
7 Ying just said, and then also to answer David's
8 question. I think the analogy we have regarding people
9 who lack capacity, when you talk to pediatricians on
10 child abuse, are children who are unable to speak for
11 themselves, where you don't know how they got their
12 injury, and they're not good witnesses. And I've spent
13 a lot of time talking to colleagues who are pediatric
14 child abuse experts about this, and I think there's a
15 lot to be learned from them. That's one comment.

16 In response to what Mr. Spiegel asked, I
17 think the other educational opportunity that all these
18 agencies have is to talk to the potential perpetrators
19 and educate them and say, "Guess what, if you do that,
20 that's abuse, and somebody is going to notice, and
21 we're going to come after you."

22 And right now I know we're focusing all of

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1 our education on older adults, I think we need to also
2 focus education on people as to this is not considered
3 appropriate. I think some people either don't realize
4 it or don't quite know the grey areas, and I think we
5 can help people understand when they're beginning to
6 cross into a grey area or even more than that. And a
7 lot of people on this panel have access to the general
8 public of folks who are the perpetrators and potential
9 perpetrators of abuse.

10 MALE SPEAKER: Good point.

11 MS. GREENLEE: David, do you have any follow-
12 up? Because I'm going to open it down here. Go down
13 here? Does anybody -- Skip or anybody?

14 MR. HUMPHREY: I have a question, Dr. Lachs.
15 You heard what -- and I want to make sure I get your
16 name correct. Ying is it?

17 DR. YUAN: Me?

18 MR. HUMPHREY: Yes.

19 DR. YUAN: Ying-Ying.

20 MR. HUMPHREY: You heard what she had to say.
21 How does that fit with the questions that you had about
22 HIPAA and the IRBs, privacy issues, and the parallel

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1 with child abuse reporting and collection of
2 information versus that for older Americans?

3 DR. LACHS: You know, I think that there is a
4 lot we can learn from child abuse. Ying-Ying and I
5 were talking about this earlier. You know, a child is
6 abused and appears at school with a black eye or
7 doesn't appear at school; there is the modern day
8 equivalent of a truant officer who effectively
9 intervenes.

10 MR. HUMPHREY: Right.

11 DR. LACHS: The problem, Skip, is that older
12 adults become isolated. As they age, the social
13 network could come to only involve themselves and the
14 abuser. So to Ying-Ying's earlier point, that annual
15 physical may be the only interaction that that person
16 has effectively with someone outside that dyad.

17 So I think there are some lessons to be
18 learned. I'm a big fan of data collection, to one of
19 Laura's earlier comments, but I'm a big fan of quality
20 data collection.

21 (Laughter.)

22 DR. LACHS: And the problem is that there is

1 tremendous inter-rater variability in the way that data
2 is collected. Certain variation in rates cannot be
3 explained by variations in the phenomena. It has to be
4 an issue around the way the data is collected. So
5 there are some significant methodologic research
6 challenges around standardizing our data collection. I
7 am concerned about the garbage in, garbage out. "Data
8 for the sake of data" I am no fan of.

9 MR. HUMPHREY: Kathy, if I could also just
10 mention the comment about, how do we get to that
11 younger generation and let them know what the
12 responsibilities are that they may be taking on? That's
13 exactly what we're trying to approach with our lay
14 fiduciary guides. It will be very interesting to see
15 the impact of that, is whether or not that's
16 sufficient. But obviously the point is that I
17 recognized early on that Congress may have said, "Okay,
18 Skip, you and your fellow folks over there, you get to
19 work with those who are 62 and older," but if you want
20 to deal with people 62 and older, you better make sure
21 that the ones that are helping them, who are younger,
22 understand what they've got to do.

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1 MS. GREENLEE: Other questions from down
2 here?

3 Stacy, do you have any follow-up?

4 (No audible response.)

5 MS. GREENLEE: All right. I want to just
6 thank you all very much. I don't know that I looked at
7 my notes, I'm just kind of paying attention and trying
8 to figure out -- I'm asking myself questions like,
9 "Where would the data go?" and, "Could we get CMS to do
10 it?"

11 (Laughter.)

12 MS. GREENLEE: Well, you know, I mean, you
13 said it needs to go someplace, and they have a lot of
14 it. So thank you all very much. I want to give a
15 collective thank-you to the rest of the people who are
16 still here who spoke.

17 And can I go ahead and try to just wrap it up
18 and not have you kind of leave the front? But I just
19 want to give a shout-out to my staff, who helped put
20 this together.

21 (Applause.)

22 MS. GREENLEE: We, federal agencies, are a

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1 pesky bunch to schedule, so just getting us all -- we
2 like being here, but this is not easy from the
3 logistical side on the back end, so I just want to
4 thank my colleagues here for coming. And we've learned
5 a lot. It seems like it was yesterday that the
6 Secretary was here with the Attorney General, we've had
7 so many different people speak. I think that for all
8 of us the importance is to continue to maintain the
9 momentum and also to create some focus. We have
10 captured the events for today. We do intend to kind of
11 process the information you've given us, the speakers,
12 the Q&A that we've had, and start to call through and
13 identify -- I mean, obviously there is a whole
14 conversation about data, a conversation about capacity,
15 what do we do for outreach? I mean, there are some
16 things that are starting to cluster that I think we can
17 look at to move forward.

18 We do have an interagency working group. I
19 see my colleagues from Justice there at the back. We
20 have quite a lot of involvement with Skip and his
21 staff, people from the Department of Justice, but also
22 other agencies, and we'll expand this group to make

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1 sure that the whole breadth of the Coordinating Council
2 we signed up your staff to help on this interagency
3 working group. And in that way, we've got some staff
4 support to continue to work forward.

5 I don't have a next date to announce for you.
6 As the Secretary said this morning, we are committed to
7 doing these twice a year, and we'll look for other
8 opportunities to continue to engage with all of you on
9 all of these various issues.

10 So MT quoted me earlier today, "Do one
11 thing." I have different ways of talking about this
12 issue, so if I could end by sharing my favorite way,
13 and we all heard this last week, that the more I work
14 on the issue of elder abuse just personally and
15 professionally, I understand that it's not an add-on to
16 the work that we're doing, it is integral to the work
17 that we're already doing, that if we're working on
18 behalf of older adults in this country, the base of
19 that is really to empower them and their lives, whether
20 it's training them on financial -- if you're doing
21 financial planning with an older adult and someone
22 later steals their money, you have not been successful,

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1 and that we have to work it into everything else that
2 we're doing. If we're doing prevention, and someone
3 beats them up, then the fact that they have their
4 diabetes managed isn't quite as effective, you know,
5 that it needs to be built into the outcomes of the work
6 that we're already doing. We're all tired with extra
7 stuff, that people don't see it as an additional part
8 of aging, but an integral outcome of successful support
9 for older adults and their lives and the programs and
10 the investments that we're making because everything
11 else can be quickly undone with the abuse, and all of
12 the investment, whether it's in personal time or money.
13 And so we have to continue to find a way to have people
14 do one thing but integrate it into work that they're
15 already doing and not ever feel like this is "Elder
16 Abuse Day," but that every day should really
17 incorporate this particular work.

18 And we have much to tackle, but I am very
19 proud to be a part of an administration that really is
20 committed. And I'm glad that we've had members from
21 the Congress here and Senator Blumenthal because it
22 will really take us all to move this forward to have

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1 support of Congress for the changes that we see as well
2 as the funding that we know we need.

3 So thank you all so much. It's been kind of
4 a who's who of people in the field today and it's been
5 wonderful to have you all come together and continue to
6 support what we're doing at the federal level, but this
7 is about our partnership with all of you, and I just
8 want to thank you for everything that you're doing.

9 So safe travels. We'll convene you again.
10 Thank you.

11 (Applause.)

12 (Whereupon, at 4:51 p.m., the Elder Justice
13 Coordinating Council meeting was adjourned.)

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