ELDER JUSTICE COORDINATING COUNCIL

Panel Four: Advancing Research

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Speakers Panel: Advancing Research

MS. GREENLEE: So welcome to the last panel. It's very good to have you here. Thank all of you for sticking around.

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

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

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

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

DR. LACHS: Correct.

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

(Laughter.)

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

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

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

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

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

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

(Laughter.)

DR. WALLACE: So my assignment was to make

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Thank you very much.

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

(Applause.)

MS. GREENLEE: This is the doctors panel.

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

(Laughter.)

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

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

(Laughter.)

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

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

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

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

HIPAA also assumes beneficence of families.

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

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

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

guidelines, policies preclude us from doing that.

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

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

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

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

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

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

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

the numbers and the expertise involved.

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

Thank you.

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

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

otherwise it's just not going to get conducted.

MS. GREENLEE: Okay. Thank you.

Ying-Ying Yuan. Hi. Welcome.

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

(Laughter.)

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Thank you.

MS. GREENLEE: Thank you very much.

(Applause.)

MS. GREENLEE: Xinqi.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Thank you.

MS. GREENLEE: Thank you very much.

(Applause.)

MS. GREENLEE: David.

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

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

(Laughter.)

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

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

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

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

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

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

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guy, Bob. Do you want to --

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

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

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

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

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

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

Yes.

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

MALE SPEAKER: You just had to say it.

DR. YUAN: Oh, thank you.

MALE SPEAKER: You're pretty lucky.

(Laughter.)

DR. YUAN: I am most fortunate.

(Laughter.)

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

(Laughter.)

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

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

MS. GREENLEE: Let's ask a geriatrician. Tada!

DR. MOSQUEDA: Well, two comments.

MS. GREENLEE: Yes.

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

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

And right now I know we're focusing all of

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

MALE SPEAKER: Good point.

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

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

DR. YUAN: Me?

MR. HUMPHREY: Yes.

DR. YUAN: Ying-Ying.

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

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

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

MR. HUMPHREY: Right.

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

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

(Laughter.)

DR. LACHS: And the problem is that there is

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

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

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MS. GREENLEE: Other questions from down here?

Stacy, do you have any follow-up?

(No audible response.)

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

(Laughter.)

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

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

(Applause.)

MS. GREENLEE: We, federal agencies, are a

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

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

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

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

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

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

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

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

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

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

(Applause.)

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

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