



# CMS 2012 Tri-Regional PACE CONFERENCE

Programs of All-Inclusive Care for the Elderly

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## TRANSCRIPT

### Elder Abuse: A Local Perspective

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Good afternoon. I hope you are digesting your food now and awake. I'm going to – I was asked to talk about a local perspective, and it's an interesting topic and I know that many of you are from the northeast and on down to Maryland, Virginia, so I wanted – I will talk a little bit about Pennsylvania because that's what I was asked to do, but I also can talk a little more broadly. And I think I have this thing here that's going to help me move on.

First I just wanted to introduce you to my organization, which Mary Jane told you was the Center for Advocacy for the Rights and Interests of the Elderly. We started in 1977 actually as an advocacy organization, and we continue today with our mission to improve the lives, well-being and autonomy of older people through advocacy, education and action. And I wanted to just list a couple of the programs that we have. Our main program is our CARIE line, which is a call-in line and anybody can call at any time about anything from anywhere. And we also have an online contact for that program as well. We also have a long-term care ombudsman program, which I'll talk about in a few minutes.

We do have the SMP program for Pennsylvania. That's the Senior Medicare Patrol for any of you who don't know what that is. It is a program that is – comes out of the administration on aging and is funded in part through CMS. And we have about 75 volunteers across the state of Pennsylvania who do peer education to help beneficiaries know how to look at their Medicare summary notices and they basically be on the lookout. And there are surprisingly a good amount of fraud out there that – that our seniors actually see and report.

We also do elderly victim's assistance in Philadelphia. We do legisla – legislative and policy advocacy and education and training programs. And we do those for both professionals and for the public. And I wanted to say that one of the reasons that I'm here is because of a program that we started back in 1989 which is called Competence With Compassion, An Abuse Prevention Training Program for long-term care staff. And we have trained people in elder abuse prevention from – who work in nursing homes, assisted living, home care, it's adult day centers, and all – all of the basically long-term care programs, and in fact, even in a PACE program. And our program, starting back in 1989, we began the program by doing a – by testing it, and we found that it was – it was successful and effective, and it's still really the only training program that has evidence behind it in the country. And it's been replicated in every state – almost every state in the country.

I do want to say that, you know, we are doing – I was asked to do a local perspective, but CARIE does have – we like to think of ourselves as a local organization that has a national reach because we do have programs that, first of all, are state wide, like our SMP program. I also will say for those of you who aren't familiar with that program, that there is a program in every state in the country and – and territory, so that, you know, that you can talk to those people.

I wanted to talk – I said I would talk more about the ombudsman program, and one of the reasons that I wanted to talk about that, and again, we have a local ombudsman program here in Philadelphia. And so – and I'm sure most of you know about the ombudsman program. In our local program we learn a lot about what's happening. And that's how we make – that's how we develop our policy agenda and our training program. Our elder abuse training program really came out of the experience in that program. And I'm sorry if I'm not looking at you because I'm having a lot of trouble with those lights. They are very, very bright up here.

So – so with that – in the ombudsman program, one of the reasons I wanted to talk about it is because when Andy Penn was talking about the False Claims Act and he mentioned that it started here in Pennsylvania, in the Eastern District, and I have to say that we are very fortunate to have the folks in the Eastern District here because they are very innovative in finding ways to combat fraud through prosecution. But the first False Claims Act actually came out of a complaint from our long-term care ombudsman program. It was actually a Friday afternoon, at 5:00, and the ombudsman came into my office and said, there's a nurse – not a nurse – a doctor on the phone, and this was a doctor in the emergency room at one of the local hospitals. And she said, she's so upset she's crying. This was the doctor in the emergency room. And it was because they had a gentleman in their facility – at the emergency room, he had come from a nursing home, and I don't want to misstate the number of decubitus ulcers he had, but there was a large number, more than ten, decubitus ulcers, and most of them were stage four. And she had never seen anybody look this bad. And so, with that case, and I – the ombudsman came in – and of course, with our ombudsman, and most ombudsmen across the country, we're not an emergency service, we're not on call, so at 5:00 our doors close. And she didn't know what to do. So I said, look, this is what you're going to do. You're going to call protective services because they – they work 24 hours, and they can go out soon. And call the Department of Health, which is a survey agency. And I said call the U.S. Attor – not – don't call – I didn't say call the U. – I said call the Attorney General's office in Pennsylvania. And that's what she did. So the Attorney General's office started to investigate this case. They were out that night, on Friday night. The Department of Health went out Saturday morning to do their investigation, which was quite unusual, I can say, at the time. But because we had had some prosecutions prior to this by the state, they – they – they kind of jumped into action much more quickly than they had before.

So, then the following week, we went out to the facility, and it was – I went, along with a community legal services attorney and two of our ombudsmen. And we walked through this facility and we looked at residents. We basically walked into rooms and we'd say hello and chat a little bit and kind of observe people. So as we were doing this and we saw every resident in the facility, we were kind of making notes about, you know, room 233, bed B. I walked into one room and the lady – the lady that was in the – the bed closest to the window was basically in a fetal position. And non-responsive. And I asked the – the roommate, who was responsive, I said, do you talk to her, is she able to communicate with her, and she said no, we never talk. She can't talk. And so hers was one of the cases I flagged to pull her chart, and so we went back to the nurses' desk and we said, could you pull these charts, and we got a number of them, and I remember pull – looking at that lady's chart. And what it said, I remember it said oriented times three. I had lots of charting, recent charting, about her being involved in activities and so

on. Now this lady was not involved in much at all. So hers was one of the cases that I gave to the U.S. Attorney's Office, which was at the same time interested in this case. And it – she was one of the plaintiffs. She died about two weeks after I saw her, but she was actually one of the named plaintiffs in the case. And that – that's – that was the case that started the use of the False Claims Act against facilities that were – were not providing good care.

So – and it's been applied again and again as Mr. Penn mentioned, but it is primarily, and one of the things you noticed from hearing what he talked about, is it's mostly in – in facilities, in long-term care facilities. You know, I do think that as we move into more and more home and community-based services, we are going to see a change, a shift in that, and one of the things – trends we've seen here in our community is that we have less and less nursing homes, less and less, well, right now, we have something called personal care homes, which is our historically licensed congregate housing for – which is kind of like assisted living. Now we just have a new assisted living licensure, so – so we're seeing less and less, at least of the personal care homes. More of those larger, institutional-type settings of assisted living. But we are seeing more, we have a lot of life programs, PACE programs, here in Pennsylvania, and we also have grown our waiver program, long-term care waiver program, exponentially over the last few years. And so we're going to see, I think, more of that.

One of the cases that I heard about recently happened last summer. This was a case that was in one of counties in the middle part of Pennsylvania, and it was a gentleman who was basically severely neglected, and he was in the waiver program, he was getting home care services, he had a care plan through the area Agency on Aging so there was a waiver, a nurse going out for the waiver program. So – so there were a lot of people in this guy's home, and yet he had, I think they said nine decubitus ulcers, and they were to the point where his muscle and bone were sticking out, so they were very, very serious. And, of course, the question you have to ask is, how long can you see that, you know, the nurse said, you know, it wasn't my job to look at his body because I was there to help with feeding. And is that – is that a good reason not to make a report? Probably not. And I don't know about – I guess, you know, there are probably many clinical people in the room here, but I have been around people who have had those kinds of – those kinds of wounds, and there's usually an odor. There's probably some other evidence in the house that shows that that person is being neglected, and so I don't know if there's a good excuse for not making a report in that case.

So let me just go on, and I'm going to – you have slides. I'm probably going to skip over everything pretty quickly because I don't have a whole lot of time and I certainly would like to talk to people. So I'll talk a little bit about – a little bit about, you know, and you heard a little bit about definitions and stuff. So, and this – this goes back to – and I know Andy talked a little bit about the cases that they handle. It doesn't have to be premeditated. It can be doing something in the heat of the moment. It doesn't – because you did it and didn't intend it doesn't mean that it doesn't constitute abuse. And I think that the other thing that, in our statute here in Pennsylvania, neglect is recognized as abuse. I mean neglect and self-neglect, and I know in some places self-neglect is not part of your statute, but it is – self-neglect is actually the most common form of abuse. And I think it – or neglect. And I think it's something that you, who are in PACE program, probably have to have your eyes on because you have people who are fairly frail, many of them have cognitive impairments, and a surprising number live alone. And so you're providing the services that can help them maintain that independence at home by getting them food and home care and all of the things that can help them maintain a quality of life at home. Nevertheless, things can happen that will cause neglect or self-neglect, if they're not following your advice, I know one of the issues – I'm, by the way, on the advisory committee for two of the PACE programs here in Philadelphia, and I hear a little bit about stories, and, you know, they don't come to the center – to your

center, they're not responding to other, you know, help that you're providing and so on. So it's kind of a difficult situation for some of you to be in at times.

So let me just talk about – the other thing that I think is another issue for all of you is that because you're so well – you're so connected to these people, you're going to see situations where family is abusive or neglectful or financially exploiting the person. I remember a case long ago, I don't remember which program it was or anything, but I do remember a case where it seemed that there was a big problem with the family using all of the resources – this was someone who was in a PACE program – family using all of the resources of that person. They lived with her and they took all of her money, basically, so she had nothing left. And those are things that, again, when you're in a PACE program, you're dealing with abuse by family members, it might be some other person who's coming in and taking advantage of that older person or not providing the care they're supposed to provide. But then you also may have situations where, you know, someone who is a paid caregiver can be abusive. And that can happen with your own staff, with contract staff, and so on. So you've got to have your eyes on a lot of different things.

But just to – to talk a little bit about who the abuser is, the most common abuser is the overwhelmed or impaired abuser. And what we hear is that, you know, I mean, I think we all know that the direct care worker is generally the lowest paid person with a lot of responsibility and often does have multiple stresses in their lives that can affect how they provide care. Similarly, family members have a lot of stress.

And – and then I think the other issue with trying to get – the other issue that we have to think about is sometimes you don't want to get people in trouble because they're doing good. And this is probably the thing we hear most from the elder themselves, who don't want to make complaints about the care they're getting from paid caregivers or family caregivers because it's better than nothing. I can stay in my own home so why would I want to get someone in trouble when, you know, I'm get the best I can. And we deal with this sometimes with – we'll get calls from people and they'll say, well, the home care worker is supposed to be here for two hours to help me get dressed and feed, you know, food, get my meal together and things like that, but they're really – they do it real quickly and they're out in 15 minutes or 20 minutes. But they're, you know, they'd rather put up with that often than make a complaint.

And in terms of incidents, and I think you've probably heard these before, first of all, the incidents of elder abuse is much greater than what we know. We suspect that only one in 25 are actually reported. And actually the statistic coming out of the National Center is that every five seconds an elderly person is abused. And just to show where some of the – where the most incidents of elder abuse is reported at least, and that doesn't mean it's where most of the abuse happens, California is 10.6%, which may not be terribly surprising as it's such a large state. Alaska, again not surprising would have the – the smallest number of cases. And five of the states actually account for one-third of all elder abuse cases. And I know people from Pennsylvania and New York are here, so it's California, Florida, New York, Texas and Pennsylvania. And that's where most of the cases are happening. And again, that's not to say that that's where it happens, but – but that's where it's reported and investigated.

Again, I'll talk a little bit about elder abuse, physical, emotional, financial, sexual mistreatment or neglect of older adults. There are six million cases of elder abuse each year. Thirty – women, older women, are more likely to be abused than men. Thirty-three percent of alleged perpetrators are adult children, and 22% are other than family members. And 16% were strangers. So you see that probably most – most of

the abusers are actually adult children. Oftentimes it isn't recognized because of communication deficits. That person might not be able to tell you what he or she needs or be able to make a complaint for themselves. Physical impairments may make that person more dependent and less likely to make a complaint, and then of course there's cognitive and social impairment where they really can't be involved, and that's – those are the cases where someone needs to step in and help. And then there's cultural biases that promote paternalism and ageism. And I think sometimes those – those interfere with recognition and intervention.

I'm going to skip over that.

And then there are other issues. And these are, I think, big issues. This is something we dealt with in our – our training program pretty heavily because what we – when we talked to staff, what we learned was that, you know, there were – there were – there were direct care workers who would say to us, well, they abuse us, the residents of the nurs- this was in our initial training in nursing homes – they abuse us and what are we supposed to do. So it's sometimes those behavioral problems. And you all know people with the manipulative, repetitive, aggressive behavior, abusive, and those people who can't tell you what they need, and people who are highly dependent because of physical impairment. And, of course, the cognitive impairment is a big factor. And so, when we were doing our training, what we tried to do was to focus on this issue very heavily because we knew from the research that had been done that people were being oftentimes striking back, not just – striking back, two things. Striking back or they were not taking the steps necessary to prevent the abuse in the first place. So if you're – if the – if the worker's response was, I hit them because they hit me first, well, why did they – the resident – hit them to begin with? So we start thinking more about how can we help them assess the situation so they avoid getting into the confrontation that might have caused that.

So that's a big part of what we try to do, is to get people to understand. When we started doing our training program, one of the things I always said was we don't want to train people not to hit people or kick people. What we want to do is to focus more on those subtle – subtle forms of abuse. Because if you're to the point that you're hitting people and you're kicking people and all of those nasty things, it probably is not the right job for you. But if you're, you know, maybe getting into confrontations with people. One of the questions – I'll just tell you one of the questions we asked, because I think this is a real telling question, on our pre- and post-test that we did for our training program, one of the questions we asked was – or it was actually a statement we asked people to agree or disagree with – was older adults are a lot like children, they need to be disciplined from time to time. Well, we had a surprising number of people agree with that statement. And that was the attitude, we really have to – you know, they act like children, they're children, we have to treat them like children.

Well that was something we focused on very heavily because we had to change that attitude in the workers before they could actually address their own behaviors and the behaviors of others. And so we – the fortunate thing is that we brought that percentage of people who agreed with that statement down to almost nothing because of our training. And we found when we did our post-test we – we assessed on those – on the personal behavior we assessed on the observed behavior of others and also we asked their supervisors to evaluate them. And it all – abuse and – abusive and neglectful behaviors went down in all – all cases.

In terms of – I was sent by Mary Jane your – your Level 2 reporting guide, and so I just looked at that very – very quickly, and basically what it says is that if you suspect an incident of elder abuse it must – you must notify the appropriate state agency with oversight for elder affairs, which is great guidance on

a – on a federal level. But I do think that you need to think about what the reporting requirements are in your state also. In Pennsylvania we have varying laws that say you need to – to contact law enforcement, you need to, you know, make sure that the report happens. The other thing that I always tell people and I know some of the providers when I make this presentation kind of look at me funny, but the issue is that, in Pennsylvania, at least, and I suspect in many states, the abuse – if you – if you see abuse and you make a – you need to make a report. Now in many facilities and many program, you would have a policy within your program, so somebody starting to work at the PACE program that says this is what you need to do, as a – as a worker, if you're a direct care worker, a nurse, whatever your position. And so you need to go – generally it says go to your supervisor and make the report. Of course, the trust there is that your supervisor's going to make that report. And so what I try to tell people is that they need to make sure – either they need to make that report themselves or they need to make sure that report was made. And, you know, in Pennsylvania, and nationally and internationally, everybody knows about the Penn State case, which does not deal with elder abuse but child abuse, and if anybody's been following that, which I can't imagine you're not, you've noticed that part – a big part of the problem with that situation is that people saw something, they heard something, but didn't make the report to the proper authorities. They made reports within their own system, but not outside. And that's really what's going to cause the biggest problems for that institution is that they did not – they failed to make those complaints – not the institution but also for those individuals. And that's the problem, that in Pennsylvania, you fail to make that report, you're – you could be prosecuted. And it could be very innocent on your part. And I've heard – I did a presentation at another program a little while ago and they said, well, if I make a report to my supervisor, isn't that enough? Well, it may be enough, because your supervisor's supposed to go on and make the reports. But it may not be enough because you don't know, if you don't know that that report was made and it turns out that it wasn't, then you're going to be at risk.

This is just some statistics from Pennsylvania. I'm going – I'm going to stop soon in case you have questions, but – because I have very little time here. So in Pennsylvania we had fifteen thousand – more than 15,000 reports of need for protective services. Seventy-three percent actually were investigated, and 34% of those were substantiated. And those – I'll give you some idea about where they came from. The victims in Pennsylvania were mostly concentrated among the very old, the most – 54% were actually over 81, which I think is a pretty large percentage of people. So we're not dealing with as much of the younger folks. And I also want to say in Pennsylvania, unlike many other states, and I know some of the states that you're in, our Protective Services Act has focused on people age 60 and over. Last year we had another different bill passed to include people 60 and under, a different system. Hasn't actually been implemented yet and it won't be or when it – even when it does, if it does, we're not going to see all this data together because it's a separate program. But – so what I'm talking about when I use these statistics of over 81, I'm talking about 60 plus. And most people were Caucasian and female, which is really just, I think, almost the exact percentage of the national figures for female.

The perpetrators were 30 to 59 years of age and mostly women. And, you know, again, the data is very similar to the national data.

In Pennsylvania we've had a number of – hold on, where am I? You know, I guess I'm way behind here. Oh, no, I know what I'm doing, I'm pushing the wrong button. I'm sorry. I'm sorry. Anyway, we do have – we – Pennsylvania, when it passed its law back in 1986, 87, I think it was, did not have any form of mandatory reporting. And over the years, because of the kinds of situations that have come up, and some of them were related to the kinds of cases I – that we talked about with the False Claims Act, we did institute some forms of mandatory reporting, and so we have – we actually had something which I

didn't mention here, which is Act 28, which actually codified elder abuse in the criminal statute so that we actually have a criminal statute that – that can be – people can be prosecuted under. And then Act 13 is actually something that was – amended our Protective Services Act and required reporting by employees and administrators of facilities that provide care for dependent persons over 60. So, in Pennsylvania, the PACE program are mandatory reporters.

And I see I have two minutes and 46 seconds. 44. Yes, and so I'm going to stop now because, of course, I've said enough. And if you have any questions I'd really like to – I see one over there. Can you tell us who you are?

\INAUDIBLE\

The female caregiver of one of our member is either emotionally, physically, or, you know, some form of abuse. But yet they're the only caregiver. Without that caregiver our member is in the nursing home.

Right.

So, other than reporting, you know, what are some practical things that we can do, you know, either to educate or, you know, make aware the caregivers what their actions really are.

Right.

Actually bring them around so that we're not losing the caregiver as well as the member.

Yeah, that's an interesting – that's an interesting issue because it seems that, you know, and it's something that you're just giving me some thought about, that, you know, having some support for caregivers also should be part of the PACE program because you are depending on those people. And I, you know, unfortunately sometimes, and you know, I don't know exactly where you are geographically but I do know in some cases that we've had, there really are situations where the abu – the caregiver, regardless of the fact that they're providing some care, they're there overnight and so on, it's just not a good situation and you've got to make that report and get something done about it, or- or, you know, initiate some change in where they live or something. But it does seem, and I will say that the Alzheimer's Association, and if you're talking about people with dementia, the Alzheimer's Association does have programs for caregivers that I would recommend, support groups, and they also have some training programs. Whether or not they have them in your area or not, but I know we have them here and the national office does have them, so whether you use the Alzheimer's Association or you use their materials, that might be helpful. Because particularly, and I do think that I have to say, again, that people with cognitive impairment are probably most at risk.