

## **PART II: FACING THE CHALLENGE: INTERVIEWS WITH INDIVIDUALS WHO HAVE BEEN LEADERS OR INNOVATORS IN THE FIGHT TO PROTECT RESIDENTS**

(The following interviews, with individuals who have protected nursing home residents in innovative ways, are part of our larger report on protecting nursing home residents, available at [www.nursinghome411.org](http://www.nursinghome411.org).)

When the Omnibus Reconciliation Act of 1987 (OBRA 87) was signed into law, the legal expectations of nursing home care changed. The Nursing Home Reform Law, which was part of OBRA 87, required that every resident receive care sufficient to enable them to attain and maintain their highest practicable physical, mental, and psycho-social well-being. While OBRA 87 did result in many significant changes for nursing home residents, the problems of nursing home neglect and abuse persist, and too many nursing home residents suffer because neither the word nor the spirit of the law are adequately enforced.

The following interviews were conducted with people who we identified as key leaders in the field of nursing home consumer protection. The purpose is to provide insights into the activities of people whose work has been particularly innovative. Each has made a significant impact in the field of long term care either in their state or nationally, and their work ranges from legal advocacy to policy advocacy to citizen education. We believe that they provide insights that can help others who are working to make the promise of OBRA 87 a reality.

**NAME:** Eric Carlson

**GROUP/FIRM NAME:** National Senior Citizens Law Center, [www.nsclc.org](http://www.nsclc.org)

Eric Carlson is an attorney in the Los Angeles office of the National Senior Citizens Law Center (NSCLC). Mr. Carlson specializes in the law governing long term care facilities, including nursing homes and assisted living facilities. He counsels attorneys from across the country in issues relating to long term care, and also participates in litigation on residents' behalf. He was co-counsel in *Podolsky v. First Healthcare Corp.*, 50 Cal. App. 4th 632, 58 Cal. Rptr. 2d 89 1996 (which established that "guarantee agreements" - requiring a financial guarantee of payment as a condition of admission to the nursing home - that had been used routinely by facilities were illegal and unenforceable).

Mr. Carlson is the author of numerous publications and articles, including "Long Term Care Advocacy," the leading legal treatise on long term care

## Using Law and Regulation to Protect Nursing Home Residents When Their Government Fails Them: A Long Term Care Community Coalition Report

issues. He is the principal author of NSCLC's Nursing Home Law Letter, a comprehensive bimonthly summary of developments in long term care. Mr. Carlson received his B.A. from the University of Minnesota in 1982, and his J.D. from Boalt Hall School of Law at the University of California at Berkeley in 1988.

### Questions

**What was your most important activity that resulted in protection of a nursing home resident(s)?** I would like to think that it is the consumer guide we put out a couple of months ago called "20 common nursing home problems and how to resolve them." I was able to use all the problems I've handled over the years and put them in a 40 page book that can be read by everybody; made to understand what the law is in long term care settings. That is the most effective thing I've done because it allows me to reach thousands of people.

**What is the background/history preceding your action/activity?** I've been doing this kind of work since 1990 and spent 10+ years working with individuals in a legal aid clinic for nursing home issues. I learned many things going through these advocacy battles and noticed that it's the same situation over and over again. There are only so many I can help individually and thought this (a book) would be the best way to reach a large number of people.

**What was the specific incident (if any) that instigated activity?** A few months into my job (the Nursing Home Reform Law was still very new it had been effective for only a few months) and a woman came in because her husband was about to be booted out of his nursing home. I thought to make some kind of appeal, and the nursing facility immediately backed down with a letter from the corporate council. I found that I can actually do something positive about this; where nursing facilities are not doing what they should be doing. There is an element of instinct in this kind of regulation.

**What are the top things that you would want to tell or advise others who would want to replicate your success?** Since I'm a lawyer, I would say you have to understand what the law is and you have to go out and reach people. I would tell them that if you just sit in your office and wait for your phone to ring, that your phone is not going to. You need to do something to get out there to do promotion and education; and so people have belief that there is room for improvement. Especially among LTC residents, it's easy to let things slide and accept the status quo.

**Are you aware of other exceptional instances where an individual or organization was able to improve nursing home resident care/quality of life in a unique or innovative way?** Obviously all sorts of good work are being done, but someone that really stands out from everything else is Allison Hershel. She heads a citizens group in Michigan that strikes me as extremely active. And Michigan has always seemed to have an energized advocacy committee. I attribute a lot of it to Allison.

**Are there any specific resources you would recommend?** This summer I coauthor a book called "Baby-boomer guide to nursing home care" and among some subjects it will cover is Medicare with a focus on problem resolution. This will come out in June. And for advocates I have written a large volume "Long Term Care Advocacy" published by Matthew Bender. Another great resource is the NCCNHR publication "Getting Good Care There." In addition Robert Kane's book is an excellent resource and is based on his consumer experiences trying to find help for his mom. He and his wife have tried to organize an advocacy organization for family members of the LTC community.

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**NAME:** Jeff Crollard

**GROUP/FIRM NAME:** Washington State Long Term Care Ombudsman Program

Jeff Crollard's law practice focuses primarily on elder rights and long term care issues. Since 1990, Mr. Crollard has been the attorney for the Washington State Long Term Care Ombudsman Program. The ombudsman program, with approximately 450 ombudsmen, advocates on behalf of residents living in nursing homes, boarding homes, assisted living facilities, veterans' homes, and adult family homes. In addition, Mr. Crollard represents residents and elders who have been injured, abused, neglected, or exploited.

Jeff Crollard is a frequent speaker and trainer of other advocates, care providers, residents, attorneys, and state licensors and investigators. He serves as an expert witness, is an active member of the elder law section of the state bar association, and participates extensively in state policy, regulatory and legislative issues concerning vulnerable adults and residents of long term care facilities. Mr. Crollard is a 1979 graduate of the University of Washington, and in 1985 received a joint law degree and masters in public policy from the University of California, Berkeley.

In his interview, Mr. Crollard highlights the importance of taking the time to thoroughly examine each complaint, where in most cases damning

## Using Law and Regulation to Protect Nursing Home Residents When Their Government Fails Them: A Long Term Care Community Coalition Report

evidence is recorded and used for a provider's defense. For example, Mr. Crollard recounts a case of a man in an assisted facility who was being evicted on the grounds that careless use of his wheelchair was putting other residents at risk. On closer examination it was the wheelchair's joystick that malfunctioned and to boot the resident's eyeglass prescription was far overdue. Obviously the facility was not performing its task of periodic healthcare management. But most importantly the resident was made to sign a waiver taking responsibility irrespective of any underlying reasons for damages. Mr. Crollard emphasizes a substantive law passed in Washington 1994 that includes a provision prohibiting waivers of potential liability by consumers. He calls this the protector of all other rights because it ensures that providers complete whole care planning. However, Mr. Crollard warns that such provisions are useless unless there is proper enforcement measures put into place.

### Questions

**What was your most important activity that resulted in protection of a nursing home resident(s)?** The most important thing really involved assisted living and adult family homes, or in some places board and care with a spin off effect on nursing home enforcement. Many years ago, in 1994, we essentially cloned a lot of federal laws and passed a statewide resident rights law for assisted living including some protection from discharges transfers. This established a substantive law. For those concerned, non-nursing homes can usually provide care a little less expensively than nursing homes. And at the time, there were egregious examples of people living in these facilities who weren't extended even elementary rights such as receiving mail! Many states have piecemeal laws and confer a lot of discretion on facilities about whom they will take and who they will take out.

The single best provision in the law is a statute that says the facility cannot ask or require that a resident or their representative waive potential liability for any losses or injury or waive any of their rights. And that's a very important provision (the protector of all the other rights). This provision has helped in all sorts of ways; for example, I had a case where a person who used a power wheel chair and occasionally bumped into walls and into other residents facility was told they violated institution rules and had to drive safely. He was made to sign a waiver that basically said he would take responsibility for any damage made to the facility or other residents. Now what that does is that no matter whatever the underlying reasons might be, if I cause damage I waive your potential liability. We told the facility that they cannot have residents sign something like this. Essentially they need to figure out what the problem is, or why is the resident driving

## Using Law and Regulation to Protect Nursing Home Residents When Their Government Fails Them: A Long Term Care Community Coalition Report

a wheelchair like this. It turned out that the joystick was malfunctioning, which caused the wheelchair to accelerate and stall. Furthermore, the resident's eyeglass prescription was out of date. Over time he had developed contractures in his joints affecting his hands obviously making it more difficult to operate a wheelchair. But with physical therapy, eventually, the resident was able to safely use a wheelchair again.

What the facility should have done in the beginning was reassess the patient and do whole care planning. That is exactly the expected procedure of these facilities, set forth in licensing laws: for a facility to take appropriate interventions. Furthermore what the law does is it binds the caretaker to assessment and care planning. This provision is the most important component of our law and applies to all care facilities. So we have a protector provision but what really matters is how and whether it is enforced.

We always hear of bad cases and for a couple years we would go to the enforcement agency and say "do something about this." And depending on the state agency (they vary across the country), you could very easily get a response that says "you always have bad apples" and honestly it gets frustrating yet understandable if there are too few inspectors to thoroughly look into systemic problems. Part of the problem is that most people in a regulatory field do not see themselves as prosecutors but instead see themselves as policemen who get people to follow rules. So even if I had ten times the amount of inspectors, there still would not be enough to be out at different shifts, so there needs to be multiple pressures on the industry to do the right thing. Some areas include training and some are market pressures (i.e., deaths reported in the paper). But we also need watchdogs like ombudsmen and coalitions and an active state agency. So what we did (and this is the only time it's been done in the country) is we devoted time to looking at licensing and complaint investigation files. We opened agency files without anything blacked out and 20 of us read through them over the course of four or five months. We were able to see patterns; we were able to trace a complaint historically across systems. The reason we were able to do this was by a unique interpretation of the law: We convinced the state that the ombudsman has access to these otherwise confidential files under federal law (which was, therefore, applicable to the state). We were able to see names and phone numbers so would call family members and residents, only to find that we were the first to do so even in unsubstantiated cases. We found urgent cases, which hadn't been attended to in months. So we put together a massive report that gave examples of grim and incompetent investigations, terrible things that had

## Using Law and Regulation to Protect Nursing Home Residents When Their Government Fails Them: A Long Term Care Community Coalition Report

happened repeatedly. We took it to the media and did press conferences around the state; eventually we were able to get good laws passed about pursuit of citations and complaints. Ongoing vigilance is a necessary component, as is a government agency with greater enforcement authority.

**What was the specific incident (if any) that instigated activity?** One case that irked us was a group home for developmentally disabled guys. The home was a couple of stories high and had its roof collapsing on about a third of the facility. There was a plastic tarp over the roof, and remember this is in Seattle where it rains nonstop. The tarp was there for three years!!! Meanwhile the ceiling was falling in some rooms, there was mold, and it was cold with water dripping in. Residents were slipping and falling, yet there was no follow-up by the state. We went to the head of enforcement for the state agency and she said, "We're the DOH and we only have so many inspectors so don't come to me with something like this. If you have deaths or rapes, then I have time." This was a proud person whose attitude was we don't need any more help especially with quality of life things. I found that when you look closely at the facts for any specific case, there is some other explanation, mostly to do with bad enforcement.

For example, there was a resident with bad dementia. Her daughter visited at some point and was helping mom get out of bed to the walker and noticed she was wincing regarding one leg and found a bulge on her thigh. It turns out the woman had a fractured femur and it was obviously painful. She was then transferred to a hospital where it was discovered that the fracture had been there at least a week. Which means that in the intervening four or five days, the resident had obviously been showered and it should have been obvious to the bath aid, who had not taken appropriate steps. Now there may have been several causes: she either fell alone or while under supervision, but either way it should have been known to the facility before the daughter discovered it. Records however did show the woman complained of her leg hurting and it's possible that the aid was so incompetent she did not know what was there. On the other hand it could have been lack of staff training or a cover-up. What the DOH focused on was whether the facility took care of the problem when they became aware of it. The answer was yes; the resident was immediately transferred to the hospital, which meant there was no citation leading to an unsubstantiated complaint.

**What are the top things that you would want to tell or advise others who would want to replicate your success?** It is important to pick bullet proof

## Using Law and Regulation to Protect Nursing Home Residents When Their Government Fails Them: A Long Term Care Community Coalition Report

examples because the people you are accusing are going to be defensive and if you overstate the case for rhetorical purposes, someone will always find the two cases out of 10 that are exaggerated. Every example must be scrutinized for it to stand up against skepticism.

**Are you aware of other exceptional instances where an individual or organization was able to improve nursing home resident care/quality of life in a unique or innovative way?** One example that we've done here specific to nursing homes has to do with the issue of mental health services for nursing home residents. Between 20-35 residents have a diagnosable mental illness and nursing homes have an obligation to meet both the physical and mental health needs. For those with serious mental illness, inpatient psychiatric hospitalization becomes an exit from a nursing home. Historically what homes have done is provide little mental health service, with one social worker on staff referring people to community-wide public resources. If more sophisticated intervention is needed, there are limited resources and people go untreated, making them subject to discharge or involuntary commitment.

Every state has a system of mental health professionals that can involuntarily commit a patient. In that body of law, there is a parallel set of laws subject to interpretation, which is that you cannot commit someone if there is a less restrictive alternative. So what I did was I started to train the mental health professionals about what nursing homes' obligations are to provide services. Before you swoop in and take the person out, you should know the following about nursing homes: The obligations to do a reassessment and care planning. So if someone is acting violent suddenly, there may be a medical issue like impacted bowels, electrolyte imbalance or urinary tract infection. Of course, there are really difficult instances when a professional concludes that the nursing home has not completed an obligation and meanwhile this person is a threat to others; in this case, the mental health professional should remove the patient and file a complaint against the nursing home. I knew that the audience I had to reach was the mental health professionals with the power to enforce; it was a way to use the existing nursing home law and hold providers accountable to it. The audience I chose was receptive because these mental health institutions have few beds and each is expensive to occupy, so the training was a success. Advocates need to target key decision points. This system of removing residents to psychiatric units was used as an end run on discharge laws. Again, the approach is how we can use parallel systems to help with enforcement. Unfortunately the obligation to meet mental health needs is not as applicable for assisted living.

## Using Law and Regulation to Protect Nursing Home Residents When Their Government Fails Them: A Long Term Care Community Coalition Report

**Are there any specific resources you would recommend?** National senior citizens law center web site. Eric Carlson's paper on 10 or 20 most common problems in care facilities and how to deal with them from around the country. NCCNHR and also Alzheimer Association have resourceful websites. And one thing family members need to do is become as educated as they can about the condition the resident has and the more they understand the more they can serve as watchdogs. This requires families to be out there frequently because every facility I know will drop the ball on at least small things.

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**NAME:** Toby Edelman

**GROUP/FIRM NAME:** Center for Medicare Advocacy, Inc.

**Website:** [www.medicareadvocacy.org](http://www.medicareadvocacy.org)

Toby Edelman is an attorney at the Washington D.C. office of the Center for Medicare Advocacy. She has been an advocate for nursing home residents since 1977 and was a key author of the Nursing Home Reform Law. She represented plaintiffs in *Valdivia v. California Department of Health Services*, in which California refused to adopt the new Nursing Home Reform Law. She argued successfully that California's position would ultimately harm nursing home residents. This momentous victory prevented other states from doing the same. She is a member of the Board of Directors of the National Citizens Coalition for Nursing Home Reform, where she advocates to improve quality of life for nursing home residents. She received an A.B. from Barnard, an ED. M. from Harvard and a J.D from Georgetown University.

In her interview, Edelman points out that one of the biggest challenges facing advocates is finding residents and families who are willing to endure participation in the battle against providers. She felt the full force of the industry when trying *Valdivia* and remembers the extent of their influence on legislatures at both the national and state levels. She shares the effects of earning the media's sympathy and the impact advocates can have if they join together in one common strategy.

### Questions

#### **What was your most important activity that resulted in protection of a nursing home resident(s)?**

I think the most important work I've done is on *Valdivia v. California Department of Health Services*. California would not implement the Nursing Home Reform Law. The state basically said, "We want federal dollars but we do not want to comply with the law." So we sued the state

## Using Law and Regulation to Protect Nursing Home Residents When Their Government Fails Them: A Long Term Care Community Coalition Report

and a preliminary injunction resulted. Our bottom line was that California's refusal would harm residents.

The case is extremely important because in 1990, if California had gotten away with it, other states would have followed. Their defense was that their law was a model for federal law, which was not true because no one state was the model. And they said it would be extra money to implement the law, but Congress said that the existing waiver authority was just as costly. The industry continued to strong arm legislators asserting that the reimbursement rate was too low. Ultimately California knew that they would either have to face providers or us in court and they chose us. The industry was so powerful everywhere and it was a very big deal at the time.

First media coverage was sympathetic to the state because the federal government said it would disallow reimbursement for surveying nursing homes since an adequate process was not implemented. In an administrative proceeding the night before the hearing, the secretary (of the Department of Health & Human Services) and the state came up with an agreement allowing California to dictate how the survey process would change. It was an amazing experience to go against such a powerful force; we continued to argue that nursing homes residents would suffer if the law was not implemented. Arguing at the injunction was pretty intense for me and the state claimed they were close to settling with the secretary and the secretary claimed the opposite, that they had reached an impasse. The argument that Mr. Valdivia would not get therapy anyway because he was not improving was disputed by our expert who said that even if Valdivia had reached a plateau, it did not mean he was not improving. I argued that therapy allowed him to walk and under California Medicaid law, therapy was revoked and his condition worsened.

**What were the circumstances that impeded your action?** Identifying the people who are willing to come forth publicly with any kind of case is difficult because families are worried about retaliation if there is attention brought to an issue. Advocates were really concerned about this in the summer of 1990; who would be willing to come forth? Out of 100,000 residents in California we only got two people. On the other side we were hit in so many different directions and there was so much press attention to this. What the secretary did was come in and conduct the surveys since California wouldn't do it. And the state appealed to the ideas of "state rights" and "big government"; making it extremely difficult to turn the press around. We painted the industry as being very greedy. There were

## Using Law and Regulation to Protect Nursing Home Residents When Their Government Fails Them: A Long Term Care Community Coalition Report

two substantive issues revolving around the case: 1) Valdavia and the lack of therapy and 2) The use of restraints. We were able to respond to the press by showing how this is about better care for people; and sympathy turned from the state to Medicare advocacy.

**What are the top things that you would want to tell or advise others who would want to replicate your success?** I hope others do not have to go through what I did; where a state is just not following protocol. We're treated as bleeding hearts and not understanding of reality. But it's important for advocates to come together in a common strategy; cooperation in one position really helps and we don't see that a lot in the legislative arena. It is very hard to fight the nursing home industry individually. We had huge numbers of depositions and the industry intervened as a plaintiff in the end. But we were never on the same side on anything.

**Are you aware of other exceptional instances where an individual or organization was able to improve nursing home resident care/quality of life in a unique or innovative way?** I think people have had successes by all kinds of advocacy on the state level, particularly in Texas. The state regulator (in Texas) was being beaten up. A legislator admitted that they acted based on industry promptings, of course the industry denied this. A lot of advocacy groups had been working on legislation independently and AARP came in and made nursing home legislation a priority with the power to change legislation, to give authority to go after industry on a corporate wide basis. We need to take stronger action against corporations rather than individual nursing homes. When I went to Texas, it was tremendously important to have AARP working with other advocacy groups. We need to enlist powerful colleagues. There was one individual who was able to change the law based on a nursing home kicking out Medicaid beneficiaries. Federal law was changed and at the bill signing in the White House, Clinton turned to this man and said "When most people have a problem they walk away but you pursued it and made a difference."

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**NAME:** Deborah Truhowsky

**GROUP/FIRM NAME:** Schwartapfel, Novick, Truhowsky & Marcus

**WEBSITE:** [www.fightingforyou.com](http://www.fightingforyou.com)

Ms. Truhowsky attended New York University where she earned her B.A. degree. She remained on the East coast where, in 1988, she completed her J.D. degree at Hofstra University School of Law. Ms. Truhowsky then

## Using Law and Regulation to Protect Nursing Home Residents When Their Government Fails Them: A Long Term Care Community Coalition Report

completed a Masters of Law degree in Business and Taxation from the University of the Pacific, McGeorge School of Law. She is a pioneer in the field of elder abuse and chairs her law firm's Elder Abuse and Neglect Department.

In her interview, Ms. Truhowsky highlights nuances made in the law between abuse and neglect. She emphasizes the importance of public health law in the context of elder abuse; specifically New York's public health law Section 2801-D, which in addition to other causes of action for nursing home negligence, creates a private cause of action for nursing home abuse. Section 2801-d provides that any residential health care facility that injures a resident by virtue of violating any federal statute or code shall be liable to that resident in damages. Ms. Truhowsky spurns the idea that injuries such as bruises, falling and bedsores are unavoidable consequences of growing older or unavoidable conditions of long term care facilities.

### Questions

#### **What was your most important activity that resulted in protection of a nursing home resident(s)?**

New York State has a fairly new law, Public Health Law (PHL) Section 2801-D, which provides grounds for suing a nursing home for neglect or abuse. It is an excellent piece of legislation; it puts the burden of proof on the facility and not the ones bringing the case.

We are pursuing cases, under PHL Section 2801-d, against nursing homes whose abuse or neglect results in serious injuries or death to a resident. Since this is a new area of law in the State of New York, only one case has gone to verdict holding a nursing home responsible under the PHL Section 2801-d as far as we know. We are currently handling tens of cases and expect several to go to trial this year.

Our goal and expectation is that once we begin to take verdicts against nursing homes that this will create an incentive for the facilities to improve their quality of care. Unfortunately we see over and over again that businesses perform "cost/benefit" analyses. If nursing homes feel that they will have to pay more in the form of jury verdicts or settlements if they continue to engage in poor care, then hopefully they will spend the appropriate money to improve care at their facility.

As this time our adversaries on these cases are using as many delay tactics as they can to prolong our litigation. We are responding to them aggressively each time they do this and will see to it that these cases are

## Using Law and Regulation to Protect Nursing Home Residents When Their Government Fails Them: A Long Term Care Community Coalition Report

tried. We correlate their desire to stall and delay us with their deep concern of these cases getting to a jury and how outraged a jury will be with their behavior. If a jury is outraged, then the jury will hold them financially responsible.

### **What is the background/history preceding your action/activity? (NB: This question might overlap with the next, depending on situation.)**

In New York, there was little precedent for these types of cases. Therefore, we began to bring these types of cases to court (this has been happening over the last 3-4 years). There is a sense of urgency because of an aging demographic. It is a much needed change, but there is so much more that needs to be done. We need to do more, use every tool in the arsenal.

### **What were the circumstances that impeded your action?**

We are always dealing with opposition, i.e., defense firms, insurance companies. Nursing homes are afraid of us bringing these kinds of actions because they don't want a large verdict against them. It is sad to say but, for them, it is often more about the economic bottom line and not the altruistic. They are fighting us bringing these cases. They are trying to limit the use of the Public Health Law. They are also trying to limit what the defense is allowed to bring into court.

### **What facilitated success of your success?**

It is too early to say if we are truly a success. We are certainly moving in the right direction, but still very much in the process. The difference or what has contributed to the success so far has been the strong Public Health Law and the determination (of those) to pursue it.

### **Is there anything that provided strong impetus or support for your action (such as a research study's findings, a court case, news report of abuse, etc...)?**

There are few firms that have handled these cases as negligence and not elder abuse. By using the negligence statute, the burden of proof lies on me, and often I couldn't prove my case. By using the Public Health law, (elder abuse) it puts the burden of proof on the nursing homes.

### **What are the top things that you would want to tell or advise others who would want to replicate your success?**

To other lawyers...well there are two things:

1. First, family/ residents don't always know when they are victims of abuse or neglect (it is up to us to help them realize that they are being wronged) and

## Using Law and Regulation to Protect Nursing Home Residents When Their Government Fails Them: A Long Term Care Community Coalition Report

2. For lawyers, these cases need to be litigated by someone that understands the complexities of the public health law and who is properly trained in identifying what type of wrong is being committed. They need to be able to make the determination of when a case is appropriate to be tried under the public health law and when it should be tried under a negligence statute.

### **Are there any specific resources you would recommend?**

National Association of Trial Lawyers of America ([www.atla.org](http://www.atla.org)): They have a division /subset called the Nursing Home Litigation Group. Very good resources, they keep a database of information.