

S6-Ep03: Change comes to New York

An Arm and a Leg transcript published 9/16/2021

Dan: This story starts on a Thursday night in September. Late. Technically Friday.

Reynaldo Prieto: you know, how you get that call at four 30 in the morning and you know, this isn't good

Dan: This call was from Reynaldo Prieto's son, Manny. Manny was 24, living with his folks out on Long Island, east of New York City.

Reynaldo Prieto: I said, what's the matter? He said, I, I passed out.

Dan: A friend had been driving Manny home from work at Wendy's.

Reynaldo Prieto: they stopped at a store and he had a seizure right in their car.

Dan: Manny had woken up in the ER.

Rey heads over right away. The doctor says Manny's got a super-serious brain condition and admits him to the ICU.

The family spends all of the next day in the hospital with Manny.

On their way home, Rey says to Manny's mom Levia that he's a little worried, because Manny doesn't have insurance. [This was 2004, before Obamacare, which did lead to a lot more people having insurance.] Levia says don't be ridiculous. This is America.

And look, I'll just tell you straight up. Manny died because he couldn't get the treatment he needed. Here's Rey.

Reynaldo Prieto: I lost my son because he had no health insurance.

Dan: And you fought for him.

Reynaldo Prieto: And I fought very hard for him.

Dan: Rey won a kind of victory, for a lot of people he'll never meet. With allies he never heard of.

This is *An Arm and a Leg*-- a show about why health care costs so freaking much, and what we can maybe do about it. I'm Dan Weissmann.

I'm a reporter, and I like a challenge, so my job is to take one of the most enraging, terrifying, depressing parts of American life and bring you a show that's entertaining, empowering, and useful.

So we're talking these days about how change happens. And we've arrived at an episode that takes us right to ground level. The nuts and bolts. Ordinary people, pushing and pushing, and finding a way.

The morning after Manny's first day in the ICU, his folks come back to the hospital and Manny's got a surprise, "I'm going home today."

Reynaldo Prieto: Yeah, just like that.

Dan: Rey and Levia don't think this is a good surprise. They go right over to talk to the nurse on duty.

Reynaldo Prieto: It was like, wait a minute. Uh, I spoke with the ER physician. He said, this is serious. It needs to be taken care of. And listen, I worked at a hospital. I know that you don't just get, discharged out of the ICU unit.

Dan: They keep you in the hospital for another couple days.

Reynaldo Prieto: That's the way it's done. That's proper procedure, not right out of the ICU unit. That was ridiculous.

Dan: They call in reinforcements. Levia's sister, the cop.

Reynaldo Prieto: New York city cop.

Dan: And Rey's sister, a pharmacist who has privileges at the hospital, sees Manny's records.

Reynaldo Prieto: She saw everything, you know, And, she showed us and it was like, it was bad. What he had was bad.

Dan: It's a malformed tangle of blood vessels in his brain-- it could kill him. And a rupture could happen any time. Rey's sister confronts the nurses.

Reynaldo Prieto: And she says, aren't you afraid of hemorrhaging? And that's when they started: "Uh, you know, these people are not stupid."

Dan: Suddenly, the hospital has a new plan: Transfer Manny to another hospital. Oh, no, wait. The hospital they're sending him to... doesn't have a bed.

But Later, Rey saw the medical records. Those records said Manny wouldn't be going to the second hospital because he didn't have insurance, and, quote "they have an issue with that."

His family stood their ground, and Manny did go to that second hospital.

And what that hospital does-- what they refuse to do-- is actually worse.

At that hospital, Manny's supposed to get a test called an angiogram.

Reynaldo Prieto: And no, they refuse to do it. You know, they didn't do that at all.

Dan: After NOT doing it for a few days, they discharge Manny, give him a follow-up appointment-- about seven weeks out-- and a prescription for some anti-seizure meds to tide him over.

Except, when Rey fills the scrip, it's only for a three-week supply. Manny's mom Levia calls the hospital, reaches the clinical coordinator. Who says: Look, you want more meds, take him someplace else.

She's not even going to call in a prescription. Levia says, Why does he need to see another doc when you're the ones taking care of him?

The coordinator says, "My kids have insurance. Why doesn't your son have any?"

Manny had just started a new job. Insurance hadn't kicked in yet. At the first hospital, they'd had him apply for Medicaid. That application was still pending.

The coordinator said, "That's not good enough. When you obtain insurance, we'll take care of him."

Reynaldo Prieto: I was in shock. My wife, you know, she has everything on the speaker as I'm listening. And I was in shock listening to some of the I'll never forget her name because she was a real, I don't know if I could say this and you can bleep it out later, but she was a real...

Dan: Yeah, we're not using that word. Or her name. But you get the idea.

A local doc does renew the scrip. Manny gets his test, the angiogram, after six weeks. And it's clear: He needs surgery "like yesterday." His life is on the line.

The hospital schedules a procedure for a week later. Except the night before it's supposed to happen. Rey gets a call. No surgery. The doc's gotta travel out of the country. Call the office to reschedule.

They call. Levia spends most of her time, every day, on the phone, calling, trying to get Manny's treatment scheduled. All they say is "How's the Medicaid application going?" Rey remembers her saying

Reynaldo Prieto: "Listen, we own a house. We'll sell my house. Take care of my son. You know, I mean a house I can replace. I can't replace Manny."

Dan: After three weeks, December 2nd, Levia gets an answer: Yep, we've scheduled Manny's procedure. For February. That's in three months.

Reynaldo Prieto: I remember my wife when they told her that she hung up the phone, he goes, they're going to let him die.

Sure enough. He did.

Manny was a giant Star Wars fan. He wanted to live long enough to see the last prequel, Revenge of the Sith -- he was marking off the days till it was scheduled to come out, in May. He died January 6th.

Reynaldo Prieto: I knew he was in bad shape. Cause I saw him deteriorating from him. He would ask me, dad, is it normal that my hands are shaking like this? And I just couldn't have the heart to say no, Manny.

It's not, you know, it really isn't, you know, you're, you're in bad shape. I couldn't, I couldn't have the heart to tell him that, but he took it like a bit.

Dan: Oh, Rey. I'm so sorry.

Reynaldo Prieto: He's my hero.

I talk about this all these years later,

Dan: Yeah,

Reynaldo Prieto: I still break down.

Dan: of course.

Reynaldo Prieto: You know what? You learn to live with it. But you never forget, and I'll never forget him ever as long as I'm alive.

Dan: Manny's parents went looking for justice. They hired a lawyer. Who dumped them. Proving that Manny wouldn't have died anyway was a heavier lift than she was up for. Over the next bunch of months, six other lawyers declined to take the case.

Rey and Levia filed a complaint with the state health department. After a few months, the department closes the case, without a full investigation. Rey and Levia called elected officials. Nobody bit. They circulated a petition for a U.S. Senate hearing. Rey says they got hundreds of signatures. No go. They try the media.

Reynaldo Prieto: We called a bunch of newspapers and it was like, "Eh, big deal that happened." And I guess nobody really wanted to run this story

Dan: Until: months later, Levia picked up a copy of the New York Post-- the city tabloid with huge headlines-- like MARRIED TO A FAKE. Or... LOVE JUDGE: ACCUSED OF AFFAIR WITH PROSECUTOR. Levia snapped.

Reynaldo Prieto: She called the post and she says, "You know, you have a set of balls running this on the front page of a newspaper. When I got a story that they won't even hear..."

And that's when the ball fell in our direction.

The next day, they got a call from New York Post reporter Sue Edelman.

Sue Edelman: Meeting Levia and talking to her, you know, I was bowled over by her and her husband, Rey. She showed me his room. He had all this Star Wars and sports memorabilia and flags.

I got to know him through the mother. That he was such a wonderful young man— she had had him when she was 16, and he became maybe her best friend. You know, more than a son, but her best friend.

So it was devastating. You know, I'm a mother myself and obviously anyone can sympathize, but as a mother, you could really feel it

Dan: Beyond the emotional pull, there was something else:

Sue Edelman: they had smoking gun evidence that the hospital was withholding care or postponing care because he didn't have Medicaid.

Dan: Yeah. After Manny died, Rey and Levia had gotten his medical records-- without letting the hospital know that Manny was dead. Rey says, They didn't have time to change anything.

Sue Edelman: We printed a copy of a memo and it says “When the patient has his insurance in place (Medicaid) the procedure will be scheduled”

Dan: The story runs on the front page of the Sunday paper. Headline: LEFT TO DIE. Two page spread inside. There's a scan of that memo. A picture of Manny, looking so sweet, it's heartbreaking. A giant photo of Rey and Levia, reading Manny's journal and weeping. And Sue Edelman's meticulously-reported facts.

Once the paper comes out, like that morning, Sue Edelman calls Rey and Levia to ask: A bunch of other media outlets are asking me for your phone number. OK if I give it to them?

They spend the entire rest of the day telling Manny's story over and over again. Rey says they cry every time. A lawyer shows up-- he wants their case, and eventually he wins it for them.

Oh, and the new speaker of the New York City Council called too.

Reynaldo Prieto: That's when the politicians really started getting involved and they passed a law here in New York state.

Dan: The first New York Post story came out in November 2005. New York's Hospital Financial Assistance Act-- also known as Manny's Law-- got signed five months later.

Meanwhile, Rey and Levia were struggling to come up with money to get a proper headstone for Manny's grave. And hospital bills were still coming for Manny's estate: 42 thousand dollars.

Reynaldo Prieto: They wanted their money. Can you imagine? We called the Post. And they ran a story saying, “How dare they?” And they kind of backed off. Bad publicity, you know?

Dan: Yeah. A friend gave them money for Manny's headstone. And in April 2006, Manny's Law became... law. It requires hospitals to have financial aid policies and to tell patients if they're eligible. Like Manny would've been.

Reynaldo Prieto: Me and my wife said, you know what? This has got to change. And we just kept right on pushing, you know, and it was worth it. Somebody that says one person can not make a difference? Well, yes, you can.

Dan: This is one way of telling the story. And it's a true story. Without Rey and Levia's perseverance, without Sue Edelman and the New York Post, there wouldn't be a Manny's Law.

And ... well, Manny's Law-- also called the Hospital Financial Assistance Law-- has things in it that don't map directly on to Manny's case: Like, it says who qualifies for how much financial aid, at different income levels. And it says a repayment plan can't amount to more than 10 percent of a person's gross income. Other stuff too.

And that's because a whole bunch of people had been working hard, for years, to get the state to create a law like this. They played a role too, and they're still at it. That's right after this.

This season of An Arm and a Leg is a co-production with Kaiser Health News. KHN is a non-profit newsroom covering health care in America. It's not affiliated with the giant health care outfit, Kaiser Permanente. We'll have more information about KHN at the end of this episode.

So, here's another version of the story of how Manny's Law came about. We're gonna zoom out, to include more people, and we're gonna start farther back in time.

Twenty years ago, years before Manny called his dad from the emergency room, Elisabeth Benjamin was a legal aid lawyer in New York. And she could see from the stories of her CLIENTS that something was messed up.

Elisabeth Benjamin: it was really clear that patients were eligible for Medicaid and some hospitals were suing patients instead of helping them get insurance. So that's when we started getting grouchy.

Dan: These stories are coming to you because you're a legal aid lawyer. These were, were actually just showing up and being like, Hey, this is my problem. You're like, "What the fuck do you mean, this is your problem? How can this be a problem? Is that Right? Like, can this be a, is this a, is this a thing...

Elisabeth Benjamin: Why is this a thing?

Dan: Especially because NOT ONLY were these hospitals tax exempt because of their non-profit status-- and that tax exemption is worth a LOT of money-- not only that, but: New York state had a fund set up to pay hospitals for uncompensated care.

Not a little fund either. Hundreds of millions of dollars. 700 million, 900 million, up to a BILLION dollars. Individual hospitals got millions and millions from it.

So Elisabeth Benjamin, legal aid lawyer, pulled together a crew of interns-- law students-- and together they called every non-profit hospital in the city, to ask about what kind of charity care they did.

Elisabeth Benjamin: And so when we would call these hospitals and said, Hey, can we have a copy of your charity care policy? They said we don't have them

Dan: So, this wasn't just the people who happened to become her clients. There was no charity care. Even though there was this enormous state fund. She put out a report

Elisabeth Benjamin: This was like nights and weekends, right? Because I'm supposed to be actually helping people with their cases. I'm not supposed to be, you know, moonlighting writing reports.

Dan: She called the report STATE SECRET. As in: New York state gives hospitals hundreds of millions of dollars every year, and what do they do with it? It's a secret.

As an appendix, she published the million-dollar salaries of top hospital executives.

Elisabeth Benjamin: It is unacceptable that all of these hospitals are non-profits and are pulling down a billion dollars a year and couldn't get their acts together to even have a financial aid application. You know? I mean, it just. Is. Not. Okay. The heads of these hospitals were pulling down multi-million dollar salaries. And, you know, that felt really unfair: that these hospitals, which were all supposed to be non-profit, that were getting a billion dollars in charity care funding every single year, were behaving like private businesses.

And that just really got our collective goat, and we weren't going to let it rest until we had some kind of reform. And "we" was a big group of people, right? Like on my hand, I can think of 10 activists that were really involved with this.

For instance...

Rose Guercia: my name is Rosemarie Cantor Guercia. I am a retired physician, formally a deputy commissioner of the Nassau county department of health.

Dan: Rose Guercia retired in 1991-- she's 95 years old-- and spent a lot of the 1990s leading a group on Long Island fighting for a national health plan. A lot of their members worked for social-service agencies... whose clients were getting stuck with giant, un-payable medical bills.

Rose Guercia: That's where we were hearing the stories from. So, as this started to pile up, we got more and more concerned about it.

Dan: And then they heard that there was a little funding available for community groups to research Access to Health care.

Rose Guercia: We got interested and thought this might be a way to find out more about exactly how bad it was on Long Island.

Dan: Rose and her colleague Donna Kass -- a retired occupational therapist-- got one of those little grants-- it paid for things like copy paper-- to compile a report about financial assistance-- or the lack of it-- on Long Island.

... and there were other groups doing the same kinds of things across the state.

Elisabeth Benjamin: And we were very good at working with reporters and we could provide them real people to talk to, so there was a whole series in the Wall Street Journal.

Dan: Yeah, those Wall Street Journal stories made a BUNCH of noise. Like the one about the guy who was paying off his late wife's medical bills. He'd been at it for 20 years, but because of interest on the debt, he owed more than when he started.

And there were local stories. Newsday, a daily newspaper for Long Island, regularly took stories that Rose and Donna fed them. Same with other groups around the state.

Elisabeth Benjamin: We were all working different media outlets. At the same time, I mean, we had regular meetings where we would talk about how to enact a hospital financial assistance law. And then with Manny, it was amazing because finally, the tabloids were really going for it too. And political actors are getting excited.

Dan: And Elisabeth Benjamin, and Rosemarie Guercia, and their colleagues had been cultivating relationships with political actors-- figuring out which legislators on which committees might do something-- for years.

Hospitals knew legislators too, and they had plenty of lobbyists, plenty of money to spread around.

So what Elisabeth Benjamin and her colleagues got--the Hospital Financial Assistance Law-- Manny's Law-- wasn't as strong as what they wanted.

Elisabeth Benjamin: But we did say in exchange for getting that money, you hospitals must have a hospital financial assistance policy, and you can no longer foreclose on people's homes

Dan: YEP. That was an actual thing. Can you believe it?

It took all of them-- Rose and Donna, Elisabeth Benjamin, Manny's parents, Sue Edelman at the Post-- to get Manny's law passed. And it included a ban on foreclosures.

Elisabeth Benjamin: And that's the story of political struggle in America, Right. Of getting change in America. It's so much work by so many people. And I was just really proud to be one of the soldiers in that fight.

Dan: Sue Edelman says the same thing

Sue Edelman: Doing stories like Manny was one of the best stories I've ever done.

Dan: She'd still like to follow up: How much is Manny's Law being enforced?

Elisabeth Benjamin has BEEN following up. Since 2008 she's been doing this as part of her actual job, not moonlighting, working for the Community Service Society of New York.

She's issued reports, and sat on committees, digging into the details of how Manny's Law would get implemented. Like for instance, that billion dollars in state funding that hospitals get for uncompensated care?

It took until 2012-- with a lot of prodding from folks like Elisabeth Benjamin-- before that money started getting distributed to hospitals based on how much they actually DID for uninsured patients.

Then there was a question: Hey, maybe we should AUDIT these hospitals about what they do for this money, not just take their word for it?

And they kept gathering data. Like on hospitals that sue patients. For a recent report, they identified 50 thousand lawsuits against patients. They read a big sample of the court files. Here's some things that stood out:

One: Nobody getting sued had been offered financial aid.

Two: The median amount people were being sued for was 19 hundred dollars. Which is a LOT if you're poor. If you're a hospital, it's ... nothing.

Three: About three quarters of hospitals weren't suing anybody. Those 50 thousand lawsuits came from just a quarter of the state's hospitals.

She met with leaders from those hospitals, including a big-name hospital in New York City.

Elisabeth Benjamin: They were suing a lot of people—super a lot of people. And they also were suing for 9% interest and they are a very, very, very rich hospital. Like their CEO makes \$12 million. And we were like, “Did you know you were suing for these amounts?” At first they said, “Well, they owe it.”

It's \$1,900! You're one of the richest hospitals in the country!

And they're like, "Why are you so angry?" I'm like: I'm angry. Why aren't you angry? I'm angry, I'm angry. This is not right. And you get, you know, \$60 million a year out of this indigent care pool.

Dan: It just feels like, I mean, to have that conversation with them— that the response is "Well they owe it"— really just seems like you've just teleported into a Dickens novel

Elisabeth Benjamin: Right.

She says she had a second meeting, and the hospital agreed: No more 9 percent interest. And she noticed, they didn't file any lawsuits for a while.

Since then, the New York Legislature has passed a new law: Hospitals can't charge 9 percent interest anymore. She's waiting for the governor to sign it.

Next, she wants a bill that says hospitals can't garnish wages or take liens on people's primary homes. Actually, maybe hospital lawsuits just shouldn't be a thing.

Elisabeth Benjamin: If you're a nonprofit charity, you have really no business suing a patient. It's really should be considered a never-event. And if you are that patient better have, you know, a yacht off of Majorca.

Dan: She's not the only one who has kept at it. Reynaldo Prieto doesn't push full-time of course. He has a job, as a mechanic. He was at work when we talked.

Reynaldo Prieto: Right now, uh, I'm putting back a cylinder head on a 2005 Maxima. That's what I'm doing today.

Of course he hasn't forgotten Manny.

Reynaldo Prieto: Every birthday we're at his grave. We go to his grave often, you know, but it was always that pain. We live on, you know: I go to work, my wife does her thing. It's a pain that will never go away.

Dan: Manny's parents pushed their lawsuit all the way to the end-- even though, because of legal limits on these kinds of suits in New York, there was never going to be much money in it.

Reynaldo Prieto: It really wasn't about the money. Because the money's a joke. It was just to give them accountability.

Dan: They kept at it for six years.

And then, Rey made time to write a book. Called *Manny's Law*. Published in 2018, more than a dozen years after Manny died. He says he wanted to spread the word about the law's existence. Do people some good.

Because, he says, people don't know. And they need to.

Reynaldo Prieto: One day we're at the grave and there was another couple there and they were kind of distraught. They had lost somebody, and somebody else in their family was sick. We told them Manny's story. She goes, "Oh my God, we're going through something similar to that," and I go,

**“Really? Did you know about Manny’s law?” And as we found out later on, when we saw them again:
“You saved my son’s life!”**

Dan: So there it is. This is how change happens. A lot of people working for a long time. They may not know each other. All of them pushing, pushing. Pushing that rock uphill.

Getting things to suck a little bit less.

Next time on An Arm and a Leg: We’ll wrap up this little series about how change happens-- how people can come together to make at least some things suck a little bit less. Here and now. Just this spring, the Maryland legislature passed a Medical Debt Protection Act. Now it’s the law. That was THIS year. And a few other states have done the same thing. We’ll take a close up look at Maryland: How did this happen? Why now? And what will it take to make change stick? It’s fascinating.

And there is SO much work to do.

Dan: One note from our inbox this week: Jean, from North Carolina heard our episode from a couple months ago, about how health-care insiders get stupid medical bills too-- where one of them taught us how to write an insurance appeal, like the one that saved her son fourteen thousand dollars.

Jean’s note was short. Subject: Industry insiders.

It just says:

YES!!! [in all caps]

I review and write appeals for others. There is always a way.

THANK YOU, THANK YOU, THANK YOU!!!!

Jean, YES. Thank YOU for writing. We wanna hear from you too. And it doesn’t HAVE to be all super-yes-please all the time. I learn a TON from the horror stories, and the critiques too.

The place to go is <https://armandalegshow.com/contact/>

I’ll catch you in two weeks. Till then, take care of yourself.

An arm and a leg is produced by me, Dan Weissmann, and edited by Marian Wang. Daisy Rosario is our consulting managing producer. Adam Raymonda is our audio wizard. Our music is from Dave Winer and Blue Dot Sessions.

This season of an arm and a leg is a co-production with Kaiser Health News. That’s a nonprofit news service about healthcare in America, an editorially independent program of the Kaiser Family Foundation. Kaiser Health News is not affiliated with Kaiser Permanente, the big healthcare outfit. They share an ancestor. This guy, Henry J Kaiser. He had his hands in a lot of different stuff.

Really different. Smelted aluminum. Owned TV stations. Built ships-- and built one of the first big resorts in Hawaii. When he died more than 50 years ago. He left half his money to the foundation that later created Kaiser Health News. You can learn more about him and kaiser health news at

<https://armandalegshow.com/kaiser>

Diane Webber is national editor for broadcast and Taunya English is senior editor for broadcast innovation at Kaiser Health News. They are editorial liaisons to this show.

Thanks to Public Narrative -- a Chicago-based group that helps journalists and non-profits tell better stories-- for serving as our fiscal sponsor, allowing us to accept tax-exempt donations. You can learn more about Public Narrative at <https://publicnarrative.org>

Thanks to the hundreds of people who donate to make this show happen. We would love for you to join them. You can do that at <https://armandalegshow.com/support/>

Thank you!