Transcript: New lessons from the fight for charity care

Dan: Hey there--

Clara lives in New York City with her husband Remy and their family. And, recently, over the course of a year, they had some ... medical encounters. At hospitals.

Nothing super-dramatic: Remy broke his ankle in August of last year. Hello, emergency room. Hello, ER bill.

They had a second baby in November 2023 — a boy! — who ended up needing to spend a day in neonatal intensive care. He's fine. They named him Isaac.

And one night early this year, Isaac just... wasn't looking good. Lethargic. Had a fever.

Clara: We decided to give him Tylenol. Um, and he spit it all back out.

Dan: They took his temp again. A hundred and three point five.

Clara: We started Googling, um, what is like dangerously high fever for a baby

Dan: And yep. For a baby that little, a hundred three point five is starting to get iffy. Like possible risk of seizure. But it was late at night. No pediatrician, no urgent care. Hello new, unwelcome questions.

Clara: The last thing you want to be thinking about is, Oh shit, this is going to be really expensive. You want to be thinking about, let's go to the ER right now, make sure he doesn't have a seizure.

Dan: So they went. And the folks at the ER gave Isaac more tylenol, he didn't spit it out, his fever went down. They went home, relieved about Isaac and a little anxious about the bills.

After insurance, they were looking at more than eight thousand dollars. Clara didn't think her family could afford anything like that.

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And the billing office didn't offer super-encouraging advice.

Clara: basically every time I've called, they said, why don't you start making small payments now so it doesn't go into collections.

Dan: However. Clara listens to An Arm and a Leg. Where we've been talking about something called charity care for years. This summer, we asked listeners to send us their bills – and tell us about their experience with charity care. Clara was one of the folks who responded.

Just to recap: Federal law requires all nonprofit hospitals to have charity care policies, also called financial assistance.

To reduce people's bills, or even forgive them entirely, if their income falls below a level the hospital sets.

We've been super-interested in charity care here for almost four years, ever since a guy named Jared Walker blew up on TikTok spreading the word and offering to help people apply, through the nonprofit he runs, Dollar For.

Since then, we've learned a LOT about charity care. Dollar For has grown from an infinitesimally tiny organization -- basically Jared, not getting paid much -to a small one, with 15 people on staff.

Jared says they've helped people with thousands of applications and helped to clear millions of dollars in hospital bills.

And in the past year, they've been up to a LOT and they've been learning alot. Before we pick up Clara's story — which ends with her offering a new resource we can share — let's get a big download from Jared.

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 the job we've chosen on this show 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.

In early 2024, Dollar For put out a couple of big research reports documenting how much charity care doesn't get awarded. And why people don't receive it.

Jared: I feel like for a long time we have been looking around at the experts, right? Who are the experts? And where can we find them and what can we ask them?

Dan: Finally, they undertook a major research project of their own. They analyzed thousands of IRS filings from nonprofit hospitals, and compared what they found to a study from the state of Maryland based on even more precise data.

And they hired a firm to survey a sample of more than 11 hundred people. Then ran focus groups to dig in for more detail.

Jared: I think that what these reports have just revealed is like, we are the experts like dollar for actually knows more than everyone else about this.

Dan: The amount of charity care that hospitals do not give to people who qualify for it?

The data analysis produced a number: 14 billion dollars. Which Jared and his colleagues say is a conservative estimate.

The survey showed that more than half of people who qualify for charity care do not get it. About two thirds of those folks do not know that it exists. Some people who know about it just don't apply. And some who do get rejected, even though they qualify.

Their conclusion: "We found that only 29% of patients with hospital bills they cannot afford are able to learn about, apply for, and receive charity care."

None of which surprised Jared.

Jared: It's like, Oh, like our assumptions have been correct on this. Like people don't know about charity care. The process sucks. Um, a lot of people that should get it, don't get it. Um, and hospitals have put all the pain and all of the responsibility on the patient

Dan: Those topline findings put Dollar For's accomplishments in context.

Jared: Like we have submitted over 20, 000 of these financial assistance applications.

Dan: 20, 000 people. That's spectacular. That's I know you're counting the money. How much money is it that you're talking about so far?

Jared: I think we're closing in on 70 million, 70 million in medical debt relief. So

Dan: Right. It's a start.

Jared: there you go.

Dan: It's a start.

Jared: It sounds great, and then you see the 14 billion number and you're like, oh, shoot. What are we doing? What are we doing?

Dan: laugh crying emoji.

Jared: Yeah, yeah, yeah.

Dan: And so, for most of the year, Jared and his team have been testing a strategy to take on a 14 billion dollar problem.

Jared: We have spent the year trying to work with hospitals. We came at this – how do we put a dent in the 14 billion? If it's not going to be through TikTok, and it's not going to be through individual patient advocacy, then what if we moved further upstream, and instead of patients finding out about us one to three months after they get a bill, what if they heard about us at the hospital?

Dan: Jared envisioned patients getting evaluated for charity care, and getting referred to Dollar For for help applying, before they check out. He thought

Jared: Maybe we could make a bigger dent into that 14 billion. And, I think that that was wishful thinking.

Dan: Wishful thinking. That's how Jared now describes his hopes that hospitals would see that they could do better by patients, with his help, and sign right up to work with him.

Jared: Um, well they haven't, Dan. So, we don't have, uh, you know, we've got one hospital.

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We've got one hospital. I don't know if there's a smaller hospital in the United States. It is Catalina Island Health. It is a small hospital on an island off the coast of California

And when patients go in there, they tell them about Dollar For, and they send them over. Um, that was what we were hoping to do with these larger systems.

Dan: Jared talked to a lot of hospitals. He went to conferences for hospital revenue-department administrators. He didn't get a lot of traction

Jared: You know, this is one thing where I'm like, I don't want to be totally unfair to the hospitals.

They're huge entities that you can't just move quickly like that.

it is going to take a lot more on their end than it would on our end, we could spin up one of these partnerships in a week.

And. They're going to need a lot of time and it's going to, you know, how do we implement this? Um, you know, with a small Catalina Island hospital it was easy, but if you're talking to Ascension

Dan: Ascension Healthcare-- a big Catholic hospital system. A hundred thirty-six hospitals. More than a hundred thirty thousand employees. Across 18 states, plus DC. Jared says they might get thousands of charity care applications a month. A deal to steer folks to Jared isn't a simple handshake arrangement.

Jared: How do you, how do you do that? You know, how do you implement that? I mean, it's a pain in the ass. And these hospitals, and more so, hospitals are not motivated to figure this out.

Dan: Yeah. Right.

Jared: Unless you're in North Carolina,

Dan: North Carolina. In 2023, North Carolina expanded Medicaid. In July 2024, Governor Roy Cooper announced a program that would use Medicaid money to reward hospitals for forgiving Medical debt.

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Gov. Roy Cooper: under this program. Hospitals can earn more by forgiving medical debt than trying to collect it. This is a win win win.

Dan: Under the program, hospitals can get more Medicaid dollars if they meet certain conditions. One, forgive a bunch of existing medical debts. Another: Make sure their charity care policies protect patients who meet income threhholds set by the state.

A third: they have to pro-actively identify patients who are eligible for charity care -- and notify those patients before sending a bill, maybe even before they leave the hospital.

Jared: I'm very excited to see how that looks in the future. Because if you remember, the big four, like our shit list, is Texas, Florida, Georgia, North Carolina.

Dan: Jared's shit list. The states where, over the years, he has heard from the greatest number of people who have difficulty getting hospital charity care. Where he often has to fight hardest to help them get it.

Jared's shit list, the big four, were the four biggest states (by population) that had rejected the expansion of Medicaid under the Affordable Care Act.

Because of how the ACA was written, no Medicaid expansion means a lot more people who don't have a lot of money and just don't have ANY insurance at all.

It's a giant problem. And North Carolina was one of those states where it was toughest.

Jared: And in, you know, the span of a year, North Carolina has expanded Medicaid, and created one of the best medical debt charity care policies in the country.

This law essentially says that they have to identify them early. So that's like - on paper, you know, it sounds amazing.

Dan: On paper it sounds amazing. We'll come back to that. But first, let's make clear: This wasn't a sudden transformation. The governor, Roy Cooper, who we heard in that clip? He spent like seven years pushing the state to expand Medicaid.

The legislature finally agreed in 2023. And then Cooper and his team spent months this year figuring out how to bake medical-debt relief into the plan. It took a ton of maneuvering.

Our pals at KFF Health News covered the process. Here's Ames Alexander, who reported that story with Noam Levy, describing the process on a public radio show called "Due South."

Cooper's team started out by trying to quietly bounce their ideas off a few hospitals..

Ames Alexander KFF Health News: But then word got back to the hospital industry's powerful lobbying group. That's the North Carolina Healthcare Association. And the Association was not at all happy about it. .

Dan: They raised a stink. And claimed the whole thing would be illegal, the feds shouldn't approve it.

Cooper and his health secretary Cody Kinsley got kept going-- and they did get the feds to sign off on the plan. So it was legal.

But it wasn't mandatory. They were offering hospitals money, but those hospitals needed to say yes. And that didn't happen right away.

Ames Alexander KFF Health News: When Cooper and Kinsley unveiled this plan on July 1st, there wasn't a single hospital official who would join them there for the press conference. Ultimately, though, all 99 of the state's hospitals signed on. And it's not, it's not really hard to understand why they stood to lose a lot of federal money.

Dan: Lose OUT on a ton of NEW federal money. A ton. According to KFF's reporting, a single hospital system stands to gain like 800 million dollars a year for participating.

And you know, thinking about that -- how much money hospitals were considering turning down -- kind of puts into perspective Jared's experience trying to get them to work with him. He wasn't offering anybody 800 million dollars a year. I said to Jared: Seems like this would be hard to replicate elsewhere. Other states aren't going to be able to put that kind of new federal money on the table. And Jared said:

Jared: I think before like, Oh, can we replicate it? I'm just like, how do we make it? How do we make it work in North Carolina?

Dan: That is: How to make sure when it gets implemented, that it really works? Remember, Jared said before: This all sounds amazing ON PAPER. We'll have some of his caveats after the break. Plus the rest of Clara's story.

An Arm and a Leg is a co-production of Public Road Productions and KFF Health News -- that's a nonprofit newsroom covering health issues in America. KFF's reporters do amazing work -- you just heard one of them breaking down how North Carolina put that deal together. I'm honored to work with them.

Jared loves the idea behind North Carolina's initiative on charity care: Hospitals have to screen people while they're on site, and let them know before they leave the hospital what kind of help they may be eligible for.

Jared: Making sure that a patient knows what is available to them before they leave is very powerful., like, that's where the responsibility should be. Um, but how do you do it? And what happens if you don't? Right?

Dan: In other words, Jared says, the devil is in implementation, and in systems of accountability. He's seen what happens when those systems are pourous.

Jared: In Oregon, they had that law that was like, Oh, you can't sue patients without first checking to see if they're eligible for charity care. And then you find all these people that are being sued that were never screened.

Dan: Yeah, Oregon passed a law in 2019 that required hospitals to evaluate patients for charity care before they could be sued over a bill. Jared's colleague Eli Rushbanks analyzed a sample of hospital-bill lawsuits in one county. He could only see patient's income in a few of them-- but in almost half of those, that income was definitely low enough that the debt should've been forgiven.

He also took a big-picture look: In the years after the law took effect, two thirds of hospitals gave out LESS charity care than they had given before. Probably not what lawmakers had hoped for.

Hospitals in North Carolina will have two years to fully implement the screening requirement, called "presumptive eligibility."

Some hospitals around the country already use automated systems for this: They check your credit, pull other data. Some of them use AI.

Jared says he's seen some hospitals over-rely on the tech.

Jared: Some hospitals that are using presumptive eligibility tools will use that as a way to say, Oh, we already screened you. You can't apply, but the patient is sitting there going, well, I'm eligible.

Your tool must have got it wrong. Cause these things are not a hundred percent accurate, or think of something like this, you lose your job, or maybe you're at the hospital because you just gave birth to another human. So now you're a household of four. It's a four instead of three.

And obviously the presumptive eligibility tool isn't going to be able to know that and calculate that. So if you go to the hospital and say, now I want to apply and they say, well, you don't get to apply because we already screened you and you're not eligible. That's bullshit.

Dan: So, as North Carolina hospitals bring their systems online, Jared wants to push for a process where patients can appeal a machine-made decision.

Jared: I'd love to be able to test that

how does that impact how many people are getting charity care and that 14 billion?

Dan: What do you think is your best shot for the next year of kind of moving towards 14 billion?

Jared: We are trying to figure that out. Um, obviously the election will play into that, but I think that if I had to guess where we would land, um, I think that we will double down on our patient advocacy work.

Dan: Jared says they'll definitely also continue to work with advocates and officials on policy proposals. But...

Jared: The only reason anyone cares about what we have to say about policy is because we know what the patient experiences. So I think that if the, the more people we help, the more opportunity we will have to push policies forward that we want to see happen

November 22, 2024

Dan: So, this is a good place to note: If you or anybody you know has a hospital bill that's scaring you, Dollar For is a great first stop. We'll have a link to their site wherever you're listening to this. They've got a tool that can help you quickly figure out if you might qualify for charity care from your hospital. Plus tons of how-tos. And they've got dedicated staff to help you if you get stuck.

And we just heard Jared say they're not backing away from that work, even as they aim to influence policy.

About policy — Jared does have one other thought about their work in that area

Jared: We think that we're going to get a little bit more feisty, uh, moving forward. So I'm, I'm excited about that.

Dan: I talked with Jared less than a week after the election. We didn't know yet which party would take the House of Representatives, and of course there's still a LOT we don't know about what things look like from here. Jared had just one prediction.

Jared: I think we're going to be needed, you know, that much more.

Dan: I think we're all gonna need each other more than ever. Which is why I'm pleased to bring us back to Clara's story from New York.

You might remember: Her family had three hospital adventures in the space of a year.

The first one, where her husband broke his ankle, got her started. The bill was eighteen hundred dollars, after insurance. A LOT for their family. But she had a few things going for her.

One, she knew charity care existed. Not because the hospital mentioned it.

Clara: No, I know about it from an arm and a leg,

Dan: And two, she had the skills. Because by training, she's a librarian. And —you may already know this but — people come to libraries looking for a lot more than just books.

Clara: People all the time, will come in and bring in a form or need help navigating different systems and, and even just looking and trying to see where to start.

Dan: So, she went and found her hospital's financial assistance policy online. Saw that her family met their income requirements. Found the form. Submitted it. Got offered a discount... that still left her family on the hook for more than they could comfortably pay.

And decided to see if she could ask for more. Was there an appeals process? There was.

But she didn't find all of the information she needed online. The process wasn't quick.

Clara: A lot of phone tag. And I don't know if the bill pay phone lines are staffed better than the financial aid phone lines. But, you know, you get an answering machine a lot. You have to call back. The person doesn't remember you. They're not able to link your account.

All the things that I just feel like they're really greasing the wheels of the paying for the bill option, but actually not making it especially accessible to do the financial aid and appeal process.

Dan: Clara hung in there. Here's what she told my colleague Claire Davenport.

Clara: Being a listener of the podcast, I feel like I'm part of a community of people who are sort of maneuvering through the crazy healthcare system. And I do kind of have Dan's voice in my head, like, this is nuts. This is not your fault. This is crazy and not right.

Dan: Also, when she was angling for more help on her husband's ER bill, she knew anything she learned could come in handy: She was due to give birth at the same hospital pretty soon.

Her persistence paid off. In the end, the hospital reduced that 1800 dollar bill to just 500 dollars.

Two weeks later, Isaac was born. And spent an extra day in the NICU. That, plus the late-night fever that sent them to the ER left Clara's family on the hook for about 6500 dollars.

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Clara used what she'd learned the first time through as a playbook. Apply, then appeal to ask for more help. She says that made it a little simpler. But not simple, and not quick.

Isaac was born in November 2023. His ER visit was in April 2024. When Clara talked with our producer in early August 2024, she was still waiting to hear the hospital's decision about her appeal. Was it gonna be approved?

Clara: In the event that it's not, I think we just put it on like the longest payment plan we can. Maybe we would ask family for help.

Dan: Update: A few days after that conversation, the hospital said yes to Clara's appeal. Her new total, 650 dollars. About a tenth of that initial amount.

Which, yes, is a nice story for Clara and her family. But the reason I'm so pleased to share her story is this:

Clara: Actually, I made a template that you can let your listeners use for making an appeal letter. I'll share it with you.

Dan: Clara thought it might be useful because part of the application and appeal process -- not all of it was just facts and figures and pay stubs. There was also an opportunity to write a letter. Which opened up questions.

Clara: I feel like It's not totally clear what you're supposed to put in the letter and who you're appealing to and how emotional you're supposed to make it versus how technical

Dan: Here's how she approached it.

Clara: I was trying to think about if I was reading the letter, what would help paint the picture of this bill in context of everything else. trying to put myself in their shoes, reading it, what would be useful to kind of add more depth to our story than just the bill. And then also I just tried to be really grateful and express authentic gratitude for the great care we received.

Dan: She also included a realistic estimate of what her family could actually pay. Which the hospital ended up agreeing with.

And yes, Clara shared that template with us. We'll post a link to it wherever you're listening to this. Please copy and paste, and fill in the blanks, and please-tell us if it works for you.

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A big lesson here is, don't take no for a final answer. Don't take "We'll help you this much" for a final answer. Clara discovered one other thing: Don't give up if it looks like you may have missed a deadline. She missed one.

Clara: So I called them and said, I'm really worried. "I didn't send it in time. It might be off by a couple days. Is this going to be a huge problem? And they said, No, don't worry about it.

It's totally fine. Just send it. So I'm thinking, Okay, wait. There are so many people who are going to get cut off or get their bill and realize, Oh, well, I totally missed the window. So let's go for the payment plan option. When actually,

Dan: If you've got the chutzpah, and the time, and the patience to make the next call and ask... you may get a different answer.

It sucks that it's this hard. But I appreciate every clue that it's not impossible. And I appreciate Clara sharing her story -- and her template with us.

I told Jared about it.

Jared: Yeah, that's amazing. I mean, I love, uh, it's so funny. it's just the idea of you have this patient that is going through all of this stuff and is so busy trying to focus on their own health, do their own thing, and they're out here making templates so that other people can, you know, jump through the same hoops because we know We're all going to have to jump through the hoops, uh, is just, man, how frustrating is that?

But how amazing is it that you have, you have built a community of people that are, you know, willing to, uh, take those kind of crappy, not kind of, very terrible experiences and, um, and turn it into something that is helpful for other people. I think that's amazing.

Dan: Me too! So this is where I ask you to help keep a good thing going. We've got so much to do in 2025, and your donations have always been our biggest source of support. After the credits of this episode, you'll hear the names of some folks who have pitched in just in the last few weeks.

And this is The Time to help us build. The place to go is arm and a leg show dot com, slash, support.

That's arm and a leg show dot com, slash, support.

We'll have a link wherever you're listening.

Thank you so much for pitching in if you can.

We'll be back with a brand new episode in a few weeks.

Till then, take care of yourself.

This episode of An Arm and a Leg was produced by Claire Davenport and me, Dan Weissmann, with help from Emily Pisacreta -- and edited by Ellen Weiss.

Adam Raymonda is our audio wizard. Our music is by Dave Weiner and Blue Dot Sessions. Gabrielle Healy is our managing editor for audience. Bea Bosco is our consulting director of operations.

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Zach Dyer is senior audio producer at KFF Health News. He's editorial liaison to this show.

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