Death Panel Podcast

TRANSCRIPT: Libby Watson On How Media Get Healthcare Wrong (Medicare for All Week 2021)

SPEAKERS
Libby Watson, Beatrice Adler-Bolton, Artie Vierkant, Philip Rocco

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Beatrice Adler-Bolton 00:00
Welcome to the second annual Medicare for All Week. Today's guest is Libby Watson who is a writer and journalist formerly of the New Republic and Splinter. Libby now helms an independent newsletter about American healthcare called Sick Note, highly recommend that you subscribe to Sick Note which can be found at www.sicknote.co. Thank you for joining us today Libby. It's so nice to have you back on the Panel, and congratulations on launching Sick Note It's been fantastic so far, and I can't wait to see what comes of it.

Libby Watson 00:30
Thank you. That's so nice to hear. It's been very fun and very different to just kind of be able to write about everything to do with healthcare that interests me, regardless of whether or not anyone else thinks it's interesting. So far, that seems to be working out. I am not one of the people who left that job because they didn't like being edited. I do miss having an editor around to tell me, hey, maybe no one cares about this thing that you think is really important. But, we'll see.

Beatrice Adler-Bolton 01:06
Yeah, I mean, you're not making the "crypto fash pivot" to argue why, you know, healthcare is an impediment to canceled culture or something.

Libby Watson 01:15
No, although, the option remains if I ever really need cash quick.

Beatrice Adler-Bolton 01:22
Actually, for people who might not be familiar with your work, do you think you could tell us a little bit about how you came to be doing this independent newsletter?

Libby Watson 01:30
Yeah, sure. So, my last job was at the New Republic and technically, I was hired to write about politics, but I kept kind of just shoehorning healthcare in there instead, because I liked it, I think. I noticed actually, that the Soap Box, which is the New Republic's health, politics, vertical had a healthcare tag.

And I think that was literally just because I kept writing about healthcare on the politics vertical. You know, you can make an argument for it, certainly. But yeah, and so I started this Sub Stack in, I launched it in December, and just started doing it full time in January. The premises just mostly interviews with, I always like to say it's interviews with people about stuff, which is like, very vague on purpose, because I think healthcare touches on pretty much you know, every aspect of human social life. And so, I'm not, I'm not linking it just to what we think of as healthcare topics. It's not just health insurance, or drug coverage or whatever, I'm trying to talk to people whose, whose jobs make them sick, for example, or who are working jobs because they are sick, or I ran an interview in January with a woman whose housing, her DC public housing was making her sick, and things like that. So that the name is Sick Note because it's, it's a newsletter about sickness, just as much as it is about the healthcare system.

Beatrice Adler-Bolton 03:03
Yeah, that's such an important point, because so much coverage of healthcare is kind of acute where you talk about sort of the single bad actor or the one hospital who's overcharging or suing patients, or this one insurance, that's particularly austere. But it ignores so many of the other aspects of just the conception of health and how that's tied into a consumer framing and how that then affects every aspect of your life. I think what Sick Note really does well, is not in an explicit way, but in an implicit way, you really debunk the myth of the "educated healthcare consumer making smart health care choices." I think that's a really important task in the broader fight for health justice, but also in the more short term fight for Medicare for All because this idea of choice and the American right to choice is such a big ideological hurdle to try and push back against in advocating for these types of policies.

Libby Watson 04:11
Yeah, definitely. And, that's a really good point, I think about healthcare coverage focusing on individual hospitals, or insurance companies, or whatever, which from a reporter's point of view for most outlets totally makes sense. You hear about a big bill at a hospital or whatever it makes sense to be like, hey, this hospital overcharged this patient for this procedure or whatever. As a reporter, a lot of the time, that's kind of the only thing you can do. You're limited in how you frame it. And one of the good things about having my own publication and my own thing is that I can link it to the broader fight for health justice, as you say, in a way. I did a story about the — The New York Times and January wrote about this hospital chain in New York that had been suing patients for their unpaid medical bills, even during the pandemic, and someone in my my Twitter mentions was like, "Hey, I wonder how much they spend on lobbying?" So I was like, "That's a good idea!" And so, I spent two days kind of going insane trying to add up all of these, New York State lobbying filings that didn't make any sense. And that were clearly under-reporting how much was really being spent on lobbying. But anyway, I was able to be like, "Hey," in introducing the topic, I was able to say, "all of these numbers are made up, the numbers — the bills that they charge these people — there's no requirement that the 'prices,' that they set for these procedures and services are real in any way." They are not tied to reality in any sense. It's great to have that freedom to be like, okay, here's a specific hospital that did this thing, and then set it in a broader context of, by the way, all of this shit is made up. And also, by the way this is how much they spent on lobbying and how many CT scans or whatever they could have forgiven with that money that they spent on lobbying?

Beatrice Adler-Bolton 06:13
Yeah. I loved, actually from that piece, there was a line that I'll quote really quick. You wrote one hospital in Wisconsin tried to figure out how much a knee surgery should cost and came up with $10,000. They had been charging $50,000.

Libby Watson 06:31
Yeah, that story has stuck in my brain ever since I read it in 2018. And I will say that I kind of go back to the same little data points like that over and over again, the next line in that piece, in that same paragraph was about how the Cleveland Clinic in some regulatory filing, I think they were objecting to the price transparency rules a couple years ago, they claimed that they have like 210 million different prices, because they have 70,000 different lines on the Charge-Master, for 3,000 different [private insurance] plans. And that to me is one of the most illustrative data points that exists. And it was just something that they said, they said that, they told us that! That was like a part of their reasoning for why they shouldn't have to post all of their prices or like, well, we simply have 210 million of them.

Philip Rocco 07:25
There's just too many of them!

Libby Watson 07:26
Yeah, exactly.

Philip Rocco 07:28
People might realize how much choice we have and all the prices! The prices, the prices, the prices! Come on down!

Libby Watson 07:35
Exactly, exactly. But I will say, I think it's important to note that obviously, I love what I'm able to do with Sick Note. And I wish there were one thousand other Sick Note style newsletters doing what I'm doing, in that, there's a lot to complain about in the American media landscape. But stories like the Wisconsin hospital thing, that is really important journalism, and it really does matter to expose these individual cases of insanity, where you have a hospital realizing, "Oh, my God, we have been overcharging by $40,000, for this knee surgery or whatever." So that is one thing that I've gone back to over and over again, but there are countless examples of hospitals arbitrarily making up basically these prices for things. It's systemic.

Beatrice Adler-Bolton 08:24
Oh, for sure. And I think one thing that's always frustrating to me is that often in a lot of the discussion of these outliers of exceptionally cruel charging, you still have this archetype of the "smart consumer," which is kept in mind. It's still this underlying thing that if the patient or if the public had only known in advance, because so often, when these things are called out and talked about in the media, you have the hospital being like, "Whoa-whoa-whoa, just kidding, we're not gonna sue these patients, we promise," or, "we're gonna give up on this." But it still has this idea that if we had only known in advance that they were going to be charging the "healthcare consumer," this ridiculous price, we would have ended up with a different result. And that ultimately, unfortunately, is a false conception of what's

actually going on. And I think what Sick Note does is it sort of shows how, especially with your piece, which was a two-parter, just with people's input on signing up for an ACA plan, how universal the confusion is, and really how fake the idea that there are any "choices" at all involved in healthcare, really is as an idea.

Libby Watson 09:44
Yes, absolutely. And I think one thing I really tried to do is — it's just as important to me the stories where someone could have made a better choice, but for whatever reason, didn't, as the stories where you have the perfect victim of the healthcare system or whatever. If someone was just too overwhelmed by the stupid fucking exchange website, and couldn't pick that plan, and couldn't figure out which one was better... Do you remember that in, around open enrollment time, The New York Times did this story that was like, "Oh, well, you know, actually, people are really bad at picking up plans. And like economists say that people are really stupid at picking their plans." And, and it's just like, "Yeah, because all the choices suck! How the hell are you supposed to know which one?" It is literally! One thing I said in my story about the ACA premiums was, I was picking an ACA plan for the first time, and trying to figure out how much health care I'm going to use... I can't do that, because I'm not a fucking wizard! I don't know how many times I'm going to go to the hospital! Or, how many migraines I'm going to get, or whether I'm going to be taking the same drugs in November that I am in January, or whatever. So I definitely try to tease out those situations where, yes, maybe someone, if they had been perfect, would have done hours of research, and gone to a different hospital, or connected with advocates, who could have helped them sign up for Medicaid. To emphasize how much is stacked against people making those "perfect decisions." And I do actually think that the surprise billing thing is an interesting example of this, because there was a lot of focus in the last couple years on surprise billing, especially, obviously, in Congress and also in the media. I think it totally makes sense, obviously, the existence of surprise billing is really awful. But it does kind of rely on this fiction. I mean, it's [sighs], it's difficult, because the idea with surprise billing is: people did the right thing, and they went to a hospital that's in network, and then, through no fault of their own, got charged X amount by a physician who is out of network. But the implication is almost that — if they hadn't done [the research], then it would have been their fault, and they deserve to pay the bill. Situations where someone is uninsured, for example, and goes to the hospital, surprise billing has nothing to do with that, because they didn't go to an out of network. Every hospital is out of network if you're uninsured, and so with surprise, billing, there's this implication that, like you say, you could be the "perfect consumer," but the system doesn't allow you to be that way. We shouldn't be healthcare consumers at all, you shouldn't be having to do these things at all!

Philip Rocco 12:53
Yeah, that's the argument of the "healthcare consumer" model is that even if people aren't perfect consumers now, we could have a series of fundamentally information based reforms, like nutritional facts effectively, or like "better shopping," for America. And then they could become "perfect consumers." But I think a lot of what you show is that it's not at all about information or the ability to compare and pick and choose, these people don't really have choices at all, because of the fundamental pricing of services on the producer end, but also og insurance plans to begin with. I was thinking about this interview I did with a person who owns a small business, reading this interview was

like, "No, there's no real choices here." This choice is only a sense of like a Hobson's choice. There's not like a real choice.

Libby Watson 13:53
Yeah, no, absolutely. I think that is really important to emphasize. And it's very frustrating, because so much of the coverage does focus on that. And I again, I think it's really important to cover examples of things like surprise bills, and stuff like that. Those are all things that should be covered, but it's harder to cover the situations that are more of a gray area. I understand why reporters gravitate towards things like NPR's Bill of the Month, for example, I think it's a really good thing to do or whatever, it's great. But you do have the sense that as a journalist, you're focusing on the unimpeachable cases where someone "did everything right," quote, unquote. And that is frustrating. So, I'll say like, if you're thinking, "Oh, should I reach out to Libby with my story of my healthcare thing, but like I feel like maybe I did something wrong," like... No! I want to talk to the people who feel like they did something wrong. Absolutely! You don't have to have been the perfect consumer to talk to me.

Beatrice Adler-Bolton 15:05
You're totally right that this idea and the focus of these most extreme cases sets up this binary that is sort of this charity model of like the "deserving consumer" who is a victim versus the "consumer who simply needs some sort of re-education program to bring them up to smart consumer level," because the idea that if you make a mistake, when you're trying to plan for your healthcare, which as you're saying is practically impossible [to plan for], you have to be making that mistake in good faith, I guess it's part of this whole larger individual responsibility dogma that we really ascribe to in the United States, but it ultimately hides the fact that, materially speaking, most people even like "healthy" people on insurance, not people like me, who are heavy utilizers, super utilizers, are having to make some really austere decisions about their own care. It's just so many people are signing up for these plans, where they're like, "Well, I want it in case I get hit by a car. And I know that if I go to the primary care doctor, it's not gonna cost me an arm and a leg. But I have to not ask them about any of the things that are bothering me, because that'll result in extra charges. And I just can't take that risk. I don't have the financial flexibility to even look into things that might be healthcare issues."

Libby Watson 16:37
Yeah, no, totally, I completely agree. One thing I really want to do with Sick Note is try and demonstrate and describe the administrative hurdles that people face. We talked about it with the ACA, I don't blame anyone for looking at all these plans and being like, "Alright, well, these all suck shit, and like, aren't going to help me. So fuck it, I'm not going to sign up or whatever." And around an open enrollment time, you always get these wonks, tweeting things like, "Well, actually, if you earn under X amount of money, you might find that there's a plan that, you know, covers you for a low amount of money or whatever." And again, I just don't blame people for not going through all the steps to find this stuff out, especially if they've done something like that before, and found that the government lets them down, and found that the choices let them down. Things like Medicaid, like signing up for Medicaid. I really want to do more with Sick Note to demonstrate the barriers and burdens that are in the way of getting things that people should be qualified for. I just talked to a woman yesterday, who had this huge, ridiculous bill for her son who was born premature. She was a classic case of like, being in the insurance gap. She was eligible for Medicaid and tried signing up. But the person who had been helping her with it, the advocate that

was paid for by the state, just kind of stopped answering her emails, she thinks, because it's in the middle of the pandemic. And so, she submitted the application herself, and then didn't hear anything. And then when Medicaid did put it through, they got it wrong, and it was covering, like, her other kid and not the kid who was born premature. All these weird little mistakes. There's this assumption, especially among kind of wonky policy types that, if a policy exists, it works perfectly and covers everybody. And there's no kind of barrier to getting it. But actually, Medicaid is like, you know, 60 years old or whatever, and it still sucks! There's still all these situations where people who should be getting it can't get it. And that is just as important to me, you know, it's very important to me to create a picture of why people might not get care that they are qualified for, that they are eligible for, even with the extremely draconian and mean eligibility rules in place. I really want to create a picture of why that might be just too much of a burden.

Artie Vierkant 19:21
I think that's so important because, also, I mean, if you think about, let's take the surprise billing thing, for example, I think when that gets covered in sort of a vacuum, or not even covered, but when we think about that as a vacuum, I feel like it puts this kind of totem, they're like, "Oh, well, if only surprise billing resolved, everything would be fine." If only Trump wasn't attacking the ACA, if only Seema Verma weren't CMS administrator...

Beatrice Adler-Bolton 19:49
"We need to close private private prisons."

Artie Vierkant 19:51
Yeah, exactly. It's that kind of thing. But then, I think, for example, when just you look at what's actually meaningfully happening, it's not even, you know, we could we could talk about the prospective choices of which or whether ACA plan you take — and the worst version of that is when those same pundits you're talking about smugly say, "Well, I really like spending four hours out of a Sunday afternoon, picking my health care plan and looking at all the charts, etc." Like, fuck you, guy. But the...

Philip Rocco 20:22
...there's no treatment for that...

Artie Vierkant 20:24
Yeah. One of my favorites, and I know, Sick Note is still very early on. But one of my favorite things from it currently is this piece where you talk to a social worker who works hospice, and it just lays bare this stuff that I think that we try to talk about all the time, but is actually just gets buried under all this, like, oh, surprise, billing, oh, you know, ACA attacks, etc, which is just the simple stuff of what happens day in and day out? Whether someone's just gotten older, they find out they have an illness, or there's an accident and someone needs long term care. Maybe they find out like, "Oh, wow, I have to do a Medicaid spend down. And this means I basically have to forfeit all my assets." I think it'd be good to get into some of what can actually happen there because it's quite dire. But when that moment where, I guess, I guess what I'm saying is leveraging things. [The idea of] if we had gotten rid of surprise billing, for example, things would be okay, actually reinforces the idea that other than this thing, things are okay. So when people arrive at that point, and they're like, "What do you mean, Medicare doesn't cover

Long Term Care? Medicare doesn't cover a nurse to come to take care of my family member or me?" These things happen all the time. And it just gets, it's like, no one...no one pays attention to it.

Libby Watson 22:04
Yeah. No, absolutely, that stuff that, as you say, kind of happens quietly, is the stuff that I really want to focus on again, because I run my own thing, and because I don't have to be subject to a lot of the assumptions that underpin a lot of reporting, which again, like, you know, this isn't necessarily to fault other healthcare journalists at all, but there is this incentive to only write about stuff, if it's either a new angle, or it's something that is again, someone who did everything, right, or, or whether it's like a new policy or something like that. I don't have to abide by that. I can interview someone whose mom just went into, you know, a nursing home, because they couldn't afford to pay for a home health care aide, or Medicaid wasn't paying for enough hours, or something like that, is just as much a story to me as a surprise bill, or some unintended consequence of the ACA, or some kind of like scandal. There are all these incentives to only cover stuff that is new or sexy or whatever. And I'm like, "No," I really want to cover the mundane stuff that happens to people every day. I said in the interview with the social worker, these are conversations that people are having every single day — like right now as you're reading this — someone is breathing a sigh of despair because they don't have the help that they need to care for their ailing parent. You know? Not not to keep harping on surprise billing, like obviously, we should end surprise billing as a practice, but...something I wrote for a [New Republic] piece in back in 2019 about surprise billing is: it totally doesn't surprise me that Democrats would focus on that and that there would be momentum to fix it because it's this classic thing of focusing on the these perfect victims who they can't imagine anyone would object to helping. It kind of reminded me of the DREAM Act, the Dreamers you know?

Philip Rocco 24:26
Yeah.

Libby Watson 24:27
Back in the Obama years there was this idea that was like, "Okay, well, they're here through no fault of their own" and it was always emphasized and they picked these kids who are like, you know, honor students and like, you know, incredible, like human beings to talk about. "Oh, you really want to kick these people out?" kind of thing and it's like, "We're gonna show how bad the republicans are by picking these, these kids who no one could object to" whatever and it's like, okay, yeah, you can get these perfect cases through, you can. But by doing that you emphasize or accept the premise that, if you're good, then we'll help you. And if you're bad, then sorry. And surprise billing almost does the same thing to me. When you focus on that, it's like saying, if you're uninsured, and you went to the hospital or maybe these imaginary cases where someone looks up, finds out a hospital is out of network and is like, "I'm gonna go to it anyway. I'll try to trick my insurance company into paying for this out of network care," is like, "I don't give a shit." If you do that, you should still have your fucking heart attack paid for! "No one should have a medical bill" is a very important concept to me. Whether it's a surprise or not.

Beatrice Adler-Bolton 25:43
Yeah.

Philip Rocco 25:44
I feel like this surprise billing thing is really emblematic of something that, I don't know if you intended this to come out of your reporting, but it's something that emerged to me. Maybe, because I just wanted to see it? But the surprise billing thing is like, okay, you have this piece of the reform that is just one mole in the whack a mole board, and when you push it down, other things pop up. But it is this perfect case in which professionals who want to make their reputation on something and seem good at addressing these sort of grotesque problems, they find this thing they can peel off, it's actually really politically feasible, because you're not challenging a lot of the way that the system works. You can like, make your bonafides on this little thing. Iit seems like the entire healthcare system — if you want to call it that — seems to be populated by people, some of whom, you know, are, I think, much more cynical, like people with the sort of level of making political decisions. But then there are other people in the system who are forced to do what seems like an almost impossible task of trying to make this completely decrepit and heartless, cruel thing work.

Libby Watson 27:00
Yeah.

Philip Rocco 27:00
And it's interesting, because I feel like I'm always looking for an explanation of why this system, which is so grotesque, endures. That's not just the, "Okay, well, it's powerful interests." Yes, that's a big part of it. Yeah, there's like a hegemonic part of it. But then there are also people within the system who are forced to actually try to make it work and they know what they're doing. And they recognize their role in it, they're doing the best they can — they're actually probably quite virtuous people — I was thinking about this social worker, she understands everything that's wrong about the system. She is trying to help people navigate to do the absolute best that she can. But at the end of the day, she understands how just repulsive the whole thing is. And I keep wondering, I wonder if part of the answer to why this thing endures is that there are also people within the system that are somehow charged with making it almost like, putting their fingers in the various cracks in the hole. And it's, you know, it somehow creates more give than there should be.

Libby Watson 28:16
Yeah, no, that totally makes sense. I think one of the things that stood out to me most with that interview with her was that she often advises people who are dying not to bother signing up for Medicaid, because if they're only going to be alive for a few weeks anyway, she said, the quote that she had was like, "Yeah, it's just a few weeks, just hang out." Yeah, like, if you're gonna die in a few weeks, don't go through all the stress and nightmare of trying to sign up for Medicaid and providing all of this evidence of your income and turning out your pockets and being like, see, there's nothing here. Just to spend, you know, I'd know a week or whatever getting a nursing aide to come or going into a nursing home. That, to me, is so illustrative of the problem. If you have social workers being like, literally, "No, don't don't do this." And I think that you raise a good point, the other thing that I've been thinking about, again, inspired by the interview with Elizabeth is one thing she brought up is that some people are reluctant to sign up for Medicaid because of Medicaid estate recovery, which is when the state will "recover your assets" after you die to pay for the cost of caring for you while you're dying. And some

people don't want to sign up for Medicaid because they don't want that to happen. Basically, they might lose their house. Your house doesn't count towards, up to a certain point, it doesn't count towards your assets when Medicaid is looking at whether or not you deserve to live. And it might be the only thing they have to pass on to the children and so people don't want to sign up for it because they're like, well, I don't want to lose my you know, I don't want my kids to lose the value of my house or whatever?

Artie Vierkant 30:02
Yeah.

Libby Watson 30:05
I've been thinking about that. And I am hoping to write a lot more about it, because I think it's a very under covered as an aspect of Medicaid. But also a lot of the states that are the most aggressive Medicaid estate recovery are all blue states. And I've been thinking about the people who work for the government whose job it is to do Medicaid estate recovery and wondering do they have any idea of how evil what they're doing is? You know, and you have state administrators for these plans that will defend the practice of Medicaid estate recovery being like, well, we need to recover the cost of caring for these people. Because without it, I guess, Medicaid wouldn't be able to function..."we need the funds" or whatever. And it's a very small percent of Medicaid revenues overall, it's like 1%, or something. I would love to talk to someone basically, whose job it is to enact Medicaid estate recovery, as a government administrator, and see, like, do you think this is a good thing? It's baffling to me. There's hundreds of thousands of people in America who do these jobs that are cogs in the machine of this bad system, and actually, I don't know whether it will come out, by the time this episode goes up, but I have done an interview with a person whose job was manning the phones at a health insurer. Talking to people who's a customer service representative for people whose prescriptions cost too much. And she said it was really hard emotionally on her. She did eventually quit, because it was just too hard to constantly tell people, "No, we're not covering your medication." So obviously, there are people out there whose consciences weigh on them, and there are a lot of incentives, on the other hand to keep doing that job, because you need to pay your rent.

Beatrice Adler-Bolton 32:15
Or you need your health insurance...

Libby Watson 32:17
Yeah, well, exactly, exactly. But it does make you wonder about, especially with something like Medicaid estate recovery, where I just, I truly don't know how, what kind of ideology, you would have to have to think that that is good.

Artie Vierkant 32:31
Well, I think to make matters worse, to be to be really explicit about it, if you're listening to this, and you don't know a lot about Medicaid, for example, like Libby, as you mentioned, up to a certain point, for instance, you could you could maybe own a house, and it might not count towards your assets for qualifying for Medicaid, but for the most part, most other assets, that you can have are counted for Medicaid purposes. There are very few things that are not counted. And so, for the most part, most people who are on Medicaid are already extremely destitute or like the idea of a Medicaid spend-down,

if you're not familiar with it, if you're a listener not familiar with it is like, literally, I mean it's really a horrifying thing, but it's basically the idea that, you know, for instance, because, as we've mentioned, Medicare doesn't cover Long Term Care, also Long Term Care through the market is like extremely expensive, paying for it out of pocket or doing some sort of like Long Term Care Insurance is extremely expensive, and covers very little. So people often end up having to spend down their assets just to qualify for Medicaid, and by that point, by the time that they're getting to the point where they could qualify for Medicaid and they've either spent down and sold almost everything that they have, they're extremely destitute.

Beatrice Adler-Bolton 34:03
In most states, it's like a $2,000 total asset cap, and they even consider if you're sleeping on your kid's couch or something, and you've moved in with your child and sold your house, the accommodation could be considered a an asset as well.

Artie Vierkant 34:16
So this process, Medicaid estate recovery, is basically like bleeding a stone. And on top of it, it is all happening, I think it's important to say in this context, where one of the reasons for example, that we advocate for Medicare for All and one thing that we talk about a lot and that we've talked about recently during the pandemic, for example, is all these states, including, as you mentioned, Libby, all these blue states — a good example is everyone's favorite Coronavirus Hero Andrew Cuomo — pledging cuts to Medicaid in the middle of the pandemic. One of the things that we've been saying this whole time is, "Look, if we fucking passed Medicare for All, if we had a single payer system, not only would we not have a hospital where they're they're saying, oh, there are a million different codes, so I don't think we should make that public because no one will get it anyway or, or we'll give up the game or something. Not only do we not have that — we would have one formulary for all of those places." We would also not make it so that states have to pay for poor Medicaid programs, right? We wouldn't, all of that extenuating, all the extenuating circumstances, the extra kicker immiseration that people get with things like Medicaid estate recovery, right, like a bonus torture, or the state does become completely irrelevant because of the whole idea, and they should be anyway, I don't understand why states can't deficit spend or why the federal government can't just pick up the tab for the entirety of state Medicaid programs, but the entire principle of well, this money has to come from somewhere, all that's doing is just driving a stake into the poor. Right?

Beatrice Adler-Bolton 36:09
I mean, as is pointed out, in this interview, that we've been talking about, that you did, for people who are dying, for people who find out suddenly that they're dying, who are entering into hospice, a Medicaid spend down is not even an option for the most extreme cases that you would think just out of sheer compassion, we would take care of people, when they're like, "Oh, you've just been diagnosed with stage four cancer, because maybe you worked for 30 years in a chemical plant. And now you're like super sick," a Medicaid spend down takes on average three to four years to engineer because Medicaid doesn't just look at your immediate financial resources, people have to be diagnosed and that in and of itself, to get diagnosed is a burden, because a lot of people don't have access to regular primary care, don't have access to specialists. So you have to get diagnosed, you have to know that you need Long Term Care, know that you can't afford it. And then make a decision to work towards

long term being able to qualify for Long Term Care under Medicaid, which takes, again, on average between three and four years to spend down assets and then live and demonstrate your need to the state.

Libby Watson 37:22
Yes, exactly. That's one of the things that Elizabeth said is that she doesn't see situations where people do Medicaid, divorce very often, because she's a hospice worker, and so she's talking to people who are already dying, and like you say that stuff, they look back five years, the Medicaid look back is five years. So by the time she's talking to them, that's not really an option. Which is just again, I think that's such a good point about Medicare for All is just I would love to get rid of all like this. Think about just how many people are spending their lives like engineering, these, I mean, even people who are, you know, very heroic, and are advocates for the poor, and the elderly, who should be getting this kind of care. I would love to be able to reassign these people to something else that isn't created by our insane decision to have a separate program for the poor, you know, a separate program to administer health insurance for the poor, they could be doing something else. They could be artists! I talked to the guy, after I spoke to Elizabeth he got in touch with [me], said how meaningful that interview was to him because he is also an advocate for for older adults in Pennsylvania, and I talked to him about his job and his job is helping people again, sign up for Medicaid and get the benefits they're entitled to and he says that he has seen people die waiting to get Medicaid. And yeah, you know, I just...some of the stuff he told me that people have to do to get Medicaid is ridiculous. He said he was helping someone who needed to get statements from his bank, to demonstrate basically that he didn't have too much money and he needed years worth of statements to do that. His credit union wanted to charge him a number of dollars, it was like something like over $100, just to print out the statements going back a number of years. And he didn't have internet access to print out that stuff at home. And so you had to go to the credit union. And so this guy, whose job it is to advocate for these people, was going back and forth with with the credit union like, "No, just just give this guy his fucking bank statements — it's his account. How are you charging him for the paper?" And that guy did die before he got his Medicaid. And it's just, I mean, you know, god bless that guy for doing that job for a nonprofit. These are situations that we have created that we don't have to do. We don't have to have situations like that, we just don't have to do it this way, there are all these people who are employed doing insane things like Medicaid estate recovery, I would love to reassign them to doing actually useful jobs, like picking up trash or whatever, that will be fine with me. At the same time, we have people who are doing very heroic things, and being advocates for people for systems that do not need to exist at all and for situations that we've created that we do not need to have at all. It's just a big waste of time, basically. Going back to a point we made earlier, I do want to focus as much as possible with Sick Note on obviously, the things like bills and high drug costs and high insurance premiums and stuff, that stuff is really important, but I don't want to focus just on money, I want to focus on time as well, that people are having to waste.

Philip Rocco 40:53
Yeah.

Libby Watson 40:54
And, you know, hours is that people spend on the phone, I talked to a guy with a chronic illness from a birth defect, and he was talking about how just the hours and hours you spend on the phone, dealing

with insurance and stuff like that, like that stuff is, again, maybe not as, like, sexy are easy to demonstrate in an article, but, I'm gonna do my best to try and illustrate what that does to a person's life.

Philip Rocco 41:24
I always find it interesting that when the federal government like makes new regulations, one of the things that they have to do is estimate the amount of time businesses will have to spend complying with those regulations, they actually have to do the back of the envelope calculation, they never have to do it for actual human beings living with the consequences of these policies. The reporting, I think, suffers from two problems that are not specific to the reporting. One is just the focus on money. But also, the second thing would just be the inability to go beyond simply talking about one aspect of the, I mean, it's really, really hard to focus on more than like, one aspect [of the healthcare system] at a time. And I think you're, in a lot of these stories, you see how all of these different parts of the system, like, weave together to like, form the trap?

Libby Watson 42:25
Yes, that's actually a really important point. And it's kind of why I decided to structure Sick Note the way that I did, a lot of the time when I get in touch with people, especially at nonprofits, or other advocates, when I talk to them, they're like, how many people are you looking to talk to? Or like, what sort of what sort of story is this going to be? And I have to explain, for good reason, a lot of stories will interview multiple people per story and kind of like pepper that quotes throughout, and use them to illustrate a bigger problem, but I am switching it up with Sick Note. And interview is going to be run just as a whole conversation with that one person. And that is partly because I want to demonstrate all the different things that can go on in a person's life and talk to them about not just, you know, if someone contacts me, because they're like, "Oh, I had this really big hospital bill," or, "My job makes me sick." I want to talk to them about all the different aspects at once. So I want to talk to them about their health insurance, and I want to talk to them about their job and what other situations they have in their life, I want to demonstrate the whole experience that that individual is having, instead of using individuals to demonstrate a bigger story, if that makes sense.

Beatrice Adler-Bolton 43:42
No, totally. And that's so important, too, because I feel like there is such extensive social reproductive work that goes into just the general reinforcement of the idea that illness and sickness are negative or bad states of being, these are stigmatized identities. And in reducing people's experiences, to just the most sensational aspects, you really lose the general material impact of this system on people's whole lives, because it's not just the moment that you're engaging with the one bill or the moment that you're engaging with the one doctor or the one thing that's gone wrong. It's, it's like, for example, in my own Social Security Disability Insurance (SSDI) application, I had to prove to the judge that a significant portion of my time was spent working in order to cover my medical costs because most people who apply for disability can only get approved if you've not been working for two years. So what I showed the judge is that in the year prior, while I was doing my disability appeal, I was in treatment for 138 days. And I spent 84 days on the phone with insurance. And the judge said, "Wow, that's like, that's like a full time job, like, how do you even? How do you even work?" You know? And I said, "Well, if I don't work, then I can't even have the privilege of spending 80 some odd days on the phone with insurance

for multiple hours, because I can't afford my premium. So. And if I can't afford my premium, then I can't get my biologic. And then I will go more blind. So you know, the government has a choice. Do you want to cover me now when I'm sort of blind and really sick? Or do you wanna cover me on Medicaid when I'm like, dying in two years, because I couldn't keep this up?" Yeah. And ultimately that is the only choice that we make in healthcare in the United States, is the choice to make sure that every individual feels the full weight of their care. Everyone has to be aware of just exactly how difficult it is and how special the fact that you can get care is. And I don't think that any of these arguments about "a one size fits all plan" is actually really bad, because then we don't have “choice,” and then we don't have our options. And that “takes away our freedom." To me, it's like, wow, if we all had the same plan, if there was one formulary, could you imagine the freedom that people would have? Because one person's experience of fighting for medication would be universalized. And that would save people time down the line? Because there would be these pathways for approval, for example. It's mind boggling sometimes, to think about how this consumer framing of health at the end of the day is really the issue. It's not about transparency, making Medicaid transparent, making private insurance transparent, making billing transparent, that's not going to fix anything, it's more that we have to completely undo this idea that healthcare as a product, and we need to sever healthcare from work.

Libby Watson 47:15
Yeah, no, I completely agree. And that is a very important point with the hospital price transparency rules as well. It was like one of the things that Trump kind of, I don't want to say accomplished, because it's not, it's barely anything like that, they passed this rule to make hospitals post that price list and I think they're funny to read. I've used them a few times for stories, to compare the costs of various procedures, if you can even understand them, because obviously they are mostly gibberish to a person who is not trained to read hospital billing codes. They can be useful from a journalistic perspective, but they obviously are completely useless from a consumer [perspective] because even if it was very clearly laid out in a in a spreadsheet, like, "Okay, this is how much a heart attack costs this hospital," you're not going to be looking at that in the back of the Uber on the way to the hospital, because you are taking an Uber because an ambulance would cost too much. You know, you're not going to be comparing them like, wait a sec, I'll tell you which hospital I want to go to once I figured out which one is going to cost less — no, that's not how anyone should be making their medical decisions. But also, even if you take a step back, and you say like, "Okay, well, even if they're not going to help consumers, maybe they can help insurance plans pick between hospitals and decide which wants to cover and help them negotiate plans or whatever. It's like, are you fucking stupid, like, come on? Yeah, they're obviously bigger things going on when insurance pays three to five times as much for procedure as Medicare does it's not just because insurance is very stupid, and can't figure out how much these things could cost us it's because they don't, they don't care, they don't care to push prices down that much. Because the more that they are getting in revenue, the more they can charge in premiums, it's actually pretty simple. The incentives for insurance to reduce the cost of American healthcare are very low. Very, very low. So yeah, it's the whole treating patients as consumers thing it's again, very alien to me coming from a country with the NHS. And that's not to say the NHS is perfect in any, to any extent, but it is very alien, I will say.

Artie Vierkant 49:47

Well, and I think, you know, as we were just talking a moment ago, just thinking about the incredible scale of how all these things gum up people's productive energies, right? And how much time? How much aggregate, I don't know, life years or life hours or, or whatever is spent dealing with the absurdities of this system that they call the efficiencies of the market. But there's the energy that we've talked a lot about, for example, framing these things like the consumer framing in media coverage and how people think about it, in general. But I think, one thing that we haven't touched on a lot is I just, I keep thinking about the sort of the productive energies that also get gummed up in — I'm thinking, for example of specifically the "progressives" who have "real" "more realistic" reform goals, if you know what I mean, who do focus on things like hospital trends, like pricing transparency for for insurance companies, and surprise medical billing. And, it occurs to me, that all the energy spent in thinking about trying to get these reasonable reforms, like fighting for these "reasonable reforms" these much smaller tweaks to the overall really, really horrifying health care system. It's another one of these things where that focus gets thrown away even from what some of the big things are, where people just feel the floor come out from under them? I don't know. I'm aware, for example, that prior to and I think even after the Jayapal and Sanders Medicare for All bills, there was a lot of argument between progressives over whether or not Long Term Care should be included in a Medicare for All proposal, which obviously, like it must, it absolutely must be. But if there's so much energy focused on like, well, maybe this one little thing will get us slowly on the road towards a more just health system, and not just saying, "Don't you see how all of these things are related? These aren't little individual issues," these are, as you're saying, you can talk to one of these individuals, and you can hit all of these different aspects of healthcare, right, like you can, or not just healthcare, but you can hit how all of these different aspects of health touch on the political economy, and how how bound up all of these things are, and in a lot of cases, not in every case, because we've never said that, like Medicare for All is gonna solve everything. But in many of the cases, the things that people are really complaining about, and the things that people are complaining about, who were saying, like, "Oh, this is a, this is an 'attainable progressive goal' or whatever," are things that are fundamentally solved through a single payer system.

Beatrice Adler-Bolton 52:52
Mm hmm.

Libby Watson 52:52
Right. Right. I think it's difficult because there's this kind of smugness that comes with choosing the "more pragmatic approach." It's like, "Oh, well, you know, do you realize that, actually, you know, Joe Biden's plan to lower the percent of your income that your ACA plan could cost from 9.5% to 8% is actually going to help a lot of people or whatever?" And it's like, okay, sure, maybe it'll help some people, but the fact is that the health care problem here, it's a many headed Hydra, and you can keep cutting the heads off, you can keep cutting off the heads of surprise billing or drug costs or tweaking with the ACA subsidies or whatever. And it's like, sure then you've got, you've got fewer heads, but you've still got a fucking Hydra! You've still got this major problem, I don't necessarily begrudge people who decide that they want to focus on, you know, they want to dedicate their lives to getting rid of more minor aspects of this terrible system. Because if you can look back and say, alright, well, I got rid of Medicaid estate recovery or whatever, then yeah, you should absolutely pat yourself on the back. And that's great. But to take something like that, and then use it as a reason to oppose Medicare for All, to spend your energies dissing or opposing people who do that, if you want to focus on something like

Medicaid estate recovery, but then your opinion on people who focus on Medicare for All is bad or stupid or whatever, then I just don't have any time for that. If you want to focus on a minor aspect and get and get rid of that, that's fine, but it cannot dissuade you from, you know, like, I think for example, if you know, if Joe Biden turned around tomorrow and managed to get a public option passed, or whatever, like yeah, obviously that would be better than it is right now. But that doesn't mean that you'd like that you can cut you know, if you want to say if you want to dedicate your energies to getting that passed that you then say people who want to dedicate their energies to getting Medicare for All passed or somehow like wrong or idealistic or they just want to pony or whatever any of that stuff, you know it's really frustrating.

Beatrice Adler-Bolton 55:04
No, that's such a good point. Because one thing that when we get that kind of pushback, which we do often on the show — that we are unrealistic, that we're like asking too much...

Artie Vierkant 55:14
"Utopian"

Beatrice Adler-Bolton 55:14
...is that of course you want free healthcare, because you're sick and you need it. So your advocacy is self interested.

Libby Watson 55:23
Is that a real thing people say?

Artie Vierkant 55:27
Oh, yeah. Oh, yeah, those are the best. Those are real, really something special, you know, when Bea gets those.

Libby Watson 55:33
Fucking A.

Artie Vierkant 55:33
Yeah.

Beatrice Adler-Bolton 55:34
I always say like, yeah, you know, a public option would be great. It would be better, it would save lives. But a public option is not a tool that can be used by patients to change the economy of health in the United States. Medicare for All, if it includes long term care is a tool.

Artie Vierkant 55:54
Well, and here's the other problem, though. I mean, a public option. Yeah. Yes. It would help some people. Yeah, it obviously doesn't help everyone. But what does it do? And much like I think about this in the same way as all the hubbub about like, "Oh, my god, Biden might try and reduce the Medicare age to 60." Right? It allows, much like I think the ACA did, for the mainstream Democratic Party to

unfurl the mission accomplished banner, and to take at least the segment of people for whom that helps, right, which I'm not discounting the fact that it would help some people, but the segment of people for whom that helps at least for a short period, you just mollify them. Right?

Beatrice Adler-Bolton 56:43
Right!

Artie Vierkant 56:44
And it kind of, I mean, that's like a minor point, you know, I'm not gonna argue, I wouldn't disparage anyone who fights for these minor tweaks, unless they say that's where it should stop. But I will say that there is a cost to minor reforms. And I think that that cost is the demobilization of some of the people who should help you fight for the good thing.

Beatrice Adler-Bolton 57:09
And you lose the advantage of, of solidarity amongst a much larger population — if everybody's on one plan that's a big bargaining group, you know...

Libby Watson 57:18
Yes, that's exactly it. And that is something a point I made in my last (at time of recording) newsletter — rounding up the healthcare news, I talked about the Trump administration issuing a last minute approval for Tennessee to switch to a Medicaid block grant. And, one thing I noticed, Kaiser health news had an article explaining what block grants are and stuff and it says, for example, a state could offer to cover just one drug class for most conditions. And that that is really scary. And one of the things about block grants, for example, is that they'll be able to do things like that and to renegotiate prices with drug makers and declined to cover drugs, if it deems the price is too high, according to the New York Times, and that is something where you think, "Well, hold on a sec, like — whoa, doesn't Medicare for All empower the government to negotiate drug prices? And don't we want the government to be able to negotiate drug prices, which means declining to cover drugs and stuff?" And it's like, yeah, that is a mechanism that will happen under Medicare for All — obviously, there will be a formulary and the government will decide, because I should also say some drugs are fucking useless, the FDA doesn't say, "Is this drug more cost effective than it's it's comparison drug? Should we approve this drug where they just changed the casing on the outside of the drug and changed the name and slapped the new label on it?" That's a bad thing, obviously, we wouldn't want the government to pay for a more expensive version of a drug that is exactly the same but the difference is between that Medicare for All version and the Medicaid version, where Tennessee can decide, "Alright, we're not going to pay for this type of insulin we're only going to pay for this type of insulin," the reason that's bad is that it's a separate program for the poor and the incentives are completely different when you have the government deciding what it's going to cover for the poor and the disabled versus everybody, when you're cutting drug coverage for rich people and everybody else, and suburban moms and so on, yeah the dynamics for the government are different and the other side of that is you have countries like Britain with the NHS where they make bad decisions about what to cover and you need an energized left to push back on that, you know?

Artie Vierkant 59:38

Yeah.

Libby Watson 59:38
The NHS is always trying to do, and successfully, you're trying to make the local hospital in my hometown worse, the government is rather trying to do that, it's been doing that my entire life. It has been trying to get rid of the obstetrics consultants so that if you give birth in Banbury you got to take an ambulance 45 minutes down the road to Oxford. Which can be devastating and people have died because of those decisions. And that still happens under a single payer. But the difference is that the government is obviously more accountable to the populace than having hundreds of private insurance companies and plans splitting that up across the entire population and taking the population that is the least represented in government and is less likely to vote and putting them on a different plan. It seems very obvious to me why the dynamics would be different.

Beatrice Adler-Bolton 1:00:33
Yeah, absolutely.

Artie Vierkant 1:00:34
Yeah. Would you rather have 10,000 really engaged activists pushing a sustained national campaign against a single entity, or those same people having to fight, I don't know, 20,000 individual companies, from health insurers to hospital networks at the same time, you know,

Beatrice Adler-Bolton 1:00:51
I mean, this is why the mindset of reformism, and it really is this mindset, right? It's a choice and a decision to think about these things in those terms of like, limited imagination — it really is a counter insurgent tactic, because all that we do in the United States with healthcare is create more complicated systems to divide constituencies which demobilizes them and takes away any power that they might have to unify and fight for something that's more equitable. And it's resulting in, I think, worse and worse outcomes for people, that as you're saying Libby, are not represented in government and are not represented in general. And it's, I think, an incredibly powerful idea to just unify the payer, right? And the simple, tiny little one trick, right? What is it one simple trick?

Artie Vierkant 1:01:52
One weird trick.

Philip Rocco 1:01:52
One weird trick, yeah.

Beatrice Adler-Bolton 1:01:53
One weird trick of switching up the payer and unifying the billing codes like, wow, imagine what a difference that would make for long COVID patients who are getting denied supplemental oxygen when they're being discharged from the ICU, because COVID is only coded as a acute diagnosis for 90% of the insurance companies in the United States. If you have one payer, you only need to change one code to accommodate this stuff. And that's a big deal. That's a huge tool.

Libby Watson 1:02:25
Yeah, I mean, to me, I wrote a piece at [the New Republic] not long after I started there about how having — it was called the "Fetishization of Employer Provided Health Care." And I think, at the time, it was still during the primaries, and there was this, all of this just nonsense in the primary about how everyone loves their employer provided plan. But it is true that, it is — all the Medicare for All stuff — it's different. If you've always had everything, if you've always had your employer paying for 90% of your premium, you don't realize how much how much healthcare actually costs, if you pay like, I don't know, 90 bucks or 100 bucks a month for your premium, which a lot of people you know, there are people who pay a ton for employer provided health care, but there are also a lot of people who don't pay a lot for their employer provided health care, and they don't know the cost and they're healthy, they've never had to use that plan. And they're like, Yeah, I don't know, my plan's fine. Because there are these sickos out there who, even if they don't love their insurer, they're like, yeah, that's probably fine. I don't know, because they've never had a chronic health issue, or they've gone to their primary care physician a couple times, they've had a $10 copay, and it's been fine. The work that does to remove solidarity between people who, you know, have these good, I mean, I had great insurance when I was actually at TNR, because it was a union plan, and it was so cheap, like, $25 bucks a month or something insane like that. And it covered everything, those union plans, they're great, but you have these people who have it pretty good. And those are people who vote, and it just completely removes a lot of the incentives of solidarity between people who have it pretty good, who have never expected that they might not know how bad it is, frankly, if you have ACA coverage, and you have to pay a ton for that, or if you have Medicaid or anything like that, or even if you have high healthcare costs. So, you know, the one weird trick of making the like suburban Karens understand, "Oh, actually, the outcomes of my life are indeed tied to everybody else's." Right?

Beatrice Adler-Bolton 1:04:47
Right. And that the cruelty and violence doesn't just occur in these spectacular moments, but it's more banal. It's more every day and if it is part of your life, it's a pretty big part of your life. I think that's what you've been doing so well on Sick Note. And I'm so excited to see where this coverage goes. And I hope that your ACA plan does eventually cover your medications.

Libby Watson 1:05:13
I just put in the refill request this morning. So, we'll see — by the time this comes out, I'll find out.

Beatrice Adler-Bolton 1:05:19
Well, if you need a hand on pushing them until the last final appeal, when they tell you they will not accept another appeal, I am more than happy to help.

Libby Watson 1:05:27
I will absolutely hit you up for that because it is basically inevitable. I had a lot of fun when I called my insurance plan, asking them, to tell them what the name of the drug that I want to cover was and so I had to spell out "dihydroergotamine mesylate" over the phone. She was just, it was really hard. But you know, bless the lady on the phone she did it — she did a good job understanding my accent so...

Artie Vierkant 1:05:48

See all the wonderful life skills that the private market engenders? How could we possibly do without it? You know...

Libby Watson 1:05:54
It was great practice. I've always been really bad at spelling out loud. So um...

Beatrice Adler-Bolton 1:06:00
Yeah, there you go. This is job skills training, you're improving your literacy skills through your engagement with the private health market.

Philip Rocco 1:06:08
Yeah, its Mavis beacon teaches suffering.

Artie Vierkant 1:06:10
Oh god.

Beatrice Adler-Bolton 1:06:14
Before we wrap, are there any final things that we want to hit on before we end?

Libby Watson 1:06:19
Nothing other than subscribe to Sick Note for my perspective, and also, you know, if you know, if you can't afford to subscribe to another thing every month, which I totally understand. At some point, some of my posts will go behind the paywall, but some of them will be free as well. And also, if you have a story about anything we talked about, or anything else, anything that you think involves your health in any way, please get in touch. You can just email sicknotenewsletter@gmail.com. And I'm always happy to let you be anonymous, if you're worried about you know, it being the first result on Google. That's totally fine.

Beatrice Adler-Bolton 1:07:01
Well, I think this has been such a pleasure. Thank you so much for sitting down with us. And I think everybody should at least become a free subscriber to Sick Note.

Artie Vierkant 1:07:09
Yeah. Highly recommended.

Beatrice Adler-Bolton 1:07:10
We encourage supporting Libby's work because as we say, every time Libby's on she is one of the Panel's favorite voices on health care.

Artie Vierkant 1:07:18
Also we gotta get good voices up in the higher ranks of the substack tiers because otherwise, it's just Nazis and Matt Yglesias, you know...

Libby Watson 1:07:28

Yeah.

Beatrice Adler-Bolton 1:07:28
Yeah which is yeah...

Libby Watson 1:07:29
Yes. I agree.

Beatrice Adler-Bolton 1:07:32
Thank you so much, Libby. People can find the newsletter at www.sicknote.co. We will link to that in the episode description, as well as put the email so that you can share your healthcare story with Libby. And definitely if you are hate-listening to this, and you do nothing else, please read the piece that we were talking about with the person who is a social worker with hospice patients, because that, if anything else, people should read that one for sure.

Libby Watson 1:08:05
Thank you. I agree. So far — that is absolutely my favorite Sick Note post. And I would love for everybody to read that.

Beatrice Adler-Bolton 1:08:12
Yeah, we just don't talk about death enough in this country. And as a result, we ignore the incredible cruelty of it for most people. So yeah...

Libby Watson 1:08:20
Absolutely.

Beatrice Adler-Bolton 1:08:20
...very important work. Well, listeners, thank you for joining us for another special interview as part of Medicare for All week. This is our second annual Medicare for All special and we appreciate you checking it out — if you'd like to support the show visit www.patreon.com/deathpanelpod. Medicare for all Now. Solidarity forever. Stay alive another week.

Artie Vierkant 1:08:48
Cool.

Beatrice Adler-Bolton 1:08:48
Yay.

Philip Rocco 1:08:48
Alright.

Beatrice Adler-Bolton 1:08:49
Thank you so much, Libby.

Artie Vierkant 1:08:50
Thank you.

Beatrice Adler-Bolton 1:08:50
Thank you. That was so much fun. I always love coming on. It's always so much fun.