

Transcript: Mental health ‘ghost networks’ — and a ghostbuster

Dan: Hey there--

So, one topic we have NOT addressed on this show until now has been mental health. And it's not because it isn't important, right?

Just ask anybody who's lived through a multi-year global pandemic.

And it's not like ACCESS to mental health care -- figuring out how to pay for it, or how to get insurance to pay for it -- isn't a problem.

Actually, pretty much the opposite. It's maybe the biggest problem. It's just notoriously horrible.

We haven't gone there because, well, number one: The horror stories are endless.

And two, I've had absolutely nothing to offer, in terms of what are we gonna do about it. Until now. Because now I've met somebody who has actually won a battle in this awful domain..

Abigail Burman: my name is Abigail Burman and I am an attorney specializing in consumer protection healthcare and technology.

Dan: Abigail's also a policy expert on some of these problems

And she's become a problem-solver for people in her life.

Abigail Burman: it's become a little bit of my superpower to just help friends find an in-network therapist or in-network psychiatrist.

Dan: Or, if there's basically no such thing, to get their insurance to pay for an out-of-network provider.

She sent me a checklist she'd posted to an online forum, with the title, "A broad guide to getting therapy/psych appointments covered when you can't find anyone in network"

It's based on steps Abigail took on behalf of a friend recently, and it's terrific.

It combines the usual unreasonable amount of persistence and grit, and time that not everybody has-- and adds some key legal knowledge.

Now, this legal key won't open every door, of course. It's shape -- and whether it'll work at all for you-- . depends on where you get your insurance, and on where you live.

In fact, even with that legal knowledge on her side, the steps in Abigail's checklist aren't exactly what worked for Abigail in this case. It took more.

Again, more than is reasonable. More than most of us have in us, frankly.

But we'll share what did work — because there ARE insights here that even us non-superheroes can definitely use :

And beyond the mechanics, the specific tips, I find Abigail's approach — the spirit in which she suggests we apply ourselves to these problems-- for ourselves or for others —really refreshing.

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 our job on this show is to take one of the most enraging, terrifying, depressing parts of American life -- and rarely has that word "depressing" carried more weight than in this story about mental health-- and bring you something entertaining, empowering and useful.

Abigail's personal super-powers grow out of her policy research.

Abigail Burman: So as with all good academic work, it started with a grudge. This is my super villain origin story.

Dan: It started during her first semester in law school, when she made an important discovery.

Abigail Burman: law school is uh, a toxic pressure cooker, and so I, like a lot of my classmates realized midway through that talking to someone would be a good idea.

Dan: So she looked up the therapists in her insurance company's directory.

Abigail Burman: I called probably 20 doctors and didn't hear back from anyone. I actually ended up seeing someone out of network.

Dan: And she got mad. And she decided: I'm gonna find out what the hell is going on here. So she spent pretty much the rest of law school researching exactly that.

And her research showed her: This thing she'd experienced? It was a known thing. It had a name.

Researchers and journalists called it a "ghost network."

A "ghost network" is where your insurance company says to you: You need a therapist? Oh sure. Here's a list of therapists who take our insurance-- our "network directory."

And maybe you call a few. Maybe you call twenty, like Abigail. Maybe you call 73, which is what one woman did, according to a recent Washington Post story. Yep. 73.

And they say, "What? No, we don't take that insurance." Or, "We're not taking new clients." Or nobody even answers the phone because it's been disconnected for a long time.

And the problem isn't that you're having bad luck. The problem is: The network itself -- all these providers supposedly waiting to take your call and take your insurance -- is a ghost, a phantasm.

Of course, running into a ghost network can conjure up all the feelings of being ghosted.

Abigail Burman: That can be so isolating when you just think this is a personal annoyance rather than being able to name it as a bigger problem with the entire system.

Dan: I mean, it can also feel like, it can feel like a personal failure, right?

Like, oh, a real adult could do this.

Abigail Burman: Exactly. If I just organized my life better, if I just tried harder, this would be better.

Dan: But Abigail's research showed her: This is not a personal failing. A study of networks in just one city, Washington, DC, found that only half of the phone numbers listed even worked at all.

And Abigail's everyday experience showed her: Those findings in Washington, DC, were not identifying an isolated trouble spot.

Abigail Burman: I realized I was onto something when I would tell people about this and everyone has a story.

Dan: So she let her rage fuel years of academic work. She published some findings in a long article for the Yale Law and Policy Review called [Laying Ghost Networks to Rest](#).

The paper documents the problem's scale -- spoiler alert, it's REALLY big, and not limited to mental health -- and lays out policy prescriptions for fighting them.

Meanwhile, Abigail has graduated from law school, and moved to DC. Now it's late 2022. Abigail's friend needs a therapist, and she's like

Abigail Burman: Put me in. I'm ready.

Dan: This starts with Abigail's friend trying things the "normal" way:

Abigail Burman: They called like 10 or so and just aren't getting any hits either people are not actually taking new patients or they just are not replying. I think we got one or two wrong numbers.

Dan: Again, normal. And not a step you can skip. Going up against this problem — and documenting it — is what gives you standing to tell the insurance company to solve it for you.

Abigail Burman: They had managed to get through to one provider, but they kept saying that their earliest appointment would be in four months, which is unacceptable And so this is where I came in.

Dan: It's unacceptable morally. It's unacceptable as a treatment plan. And because Abigail has studied the law here, she knows it's unacceptable legally. At least in some situations. Including her friend's.

Abigail Burman: Affordable Care Act, marketplace plans, Medicaid plans, and Medicare plans are all subject to rules around network adequacy

Dan: Network adequacy: If you're gonna take away one legal term from this episode that's the big one: Network adequacy. Are there enough doctors in your network to actually provide care?

That's the bedrock for everything else here.

Abigail Burman: Let's say you have like a 500 person directory, two of them will actually pick up if you call, but finding them requires the other 498. That's not what you are entitled to. That is not an adequate network. The key with all of these rules and regulations is that, um, it's meant to make seeking care not a burden.

That when you are already in a place of distress, it should be reasonably easy for you to reach out and get help. And I think that has to be your guidepost. Think about what it is reasonable to expect of someone in your situation.

Dan: So, if you've called, say, ten numbers and are coming up empty, you've got pretty good evidence that the answer is... what's being expected of you isn't reasonable.

You're gonna be telling the insurance company: If you've got an adequate network, prove it.

Abigail Burman: Your stance at that point that you wanna hold firm in is, I have called doctors. I have done my job, I have spent this many hours. Thank you. But no, I will not be doing that anymore. Now the burdens shift to you.

Dan: In other words, if your network really is adequate, you've gotta find me somebody in it. Or pay for me to go outside of it.

And I've gotta acknowledge here: As bedrock goes, it's ... fragmented. And incomplete. For starters, every state makes its own rules for network adequacy.

And within a given state, the rules are different for those three different kinds of plans: Obamacare plans, Medicaid, and Medicare.

And for a lot of us who get insurance from work... we'd be looking at a whole different legal structure.

But beyond the legal specifics the basic idea is: Somewhere, somehow, you've got a *right* to actual care from somebody who takes your insurance.

Insurance is a contract. They're getting something -- money -- and you're supposed to get something: Access to care from somebody for in-network rates.

Abigail Burman: Either you or someone else is paying for you to get this service from your insurer. This is what that money is supposed to cover. And if you can't get that, someone's just getting money for free.

Dan: So, I'm just gonna note a couple of Abigail's broad guidelines here, and we'll post a link to her full checklist wherever you're listening to this.

And we'll supplement it with some of what Abigail told me when we talked.

For now, the gist is:

Her list starts with legal terms like "network adequacy" that you can combine in a Google search-- along with the name of your state-- to see how they apply to your situation.

And it ends with some general purpose advice like, quote "The key is to be a giant asshole." Unquote.

Abigail Burman: I don't mean, you know, screaming at people using swear words, et cetera, but it can feel like you are being a jerk if you stand your ground and say no. But it is worth it. And if nothing else, just remember that. Like you're never gonna talk to any of these people again. Probably. So, worse comes to worse, if you get too stressed out, you can hang up and call again.

Dan: In other words, the key isn't to BE an asshole. It's to tolerate FEELING like you're being an asshole.

But what you're doing is letting the other person know: You know your actual rights.

I tell Abigail, it reminds me of how Jacqueline Fox-- a law professor who used to do this kind of problem-solving as an attorney -- put it: You want the person on the other side to get the feeling, "There's a grown-up here who seems to be getting annoyed."

Abigail Burman: Exactly. I think that's the, the exact vibe you want is kind of, um, I'm disappointed, not angry. And I, that is how I try to go into these is sort of like, here is the rule, here is what you have done. I simply don't understand why you can't comply with the law. Um, also love to you, you always wanna put a specific request at the end.

Uh, say exactly what you want, um, just so it's really clear. Uh, and ideally, you know, say, I, I expect to reply back by this time, just so there's something keeping the conversation moving. If you don't get a response, you can then follow up and say, I thought, you know, I'd ask for a reply by then. Where, where is my reply?

Um, and so, yeah, that's kind of the, the general structure you wanna take in these interactions is like, I have seen that. Like, I know this is what I'm entitled to. This is what happened. How are we collectively working together going to fix this?

Dan: Coming up in a minute: What happened when Abigail actually went into battle for her friend. .

(Midroll)

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So, Abigail's friend had called a bunch of therapists that were supposed to be covered by their insurance-- found bupkis. Abigail steps in.

Her friend happens to be on Medicaid, which is kind of a best-case scenario for this sort of thing: Not only is Medicaid regulated by states, there tend to be detailed rules -- contractual language even -- about things like network adequacy.

Abigail looked up the specific regs that applied in her friend's case, kept them on hand, and started in with the phone calling.

If you've been listening for a while, or if you've done something like this, some of what happened will be familiar.

Once the first few calls didn't get anywhere, Abigail started working her way up.

Abigail Burman: The language that's often used is you wanna ask to have your complaint or your grievance escalated. You want it to go to someone who maybe has a little more power, little more experience.

Dan: She thinks it took maybe five calls to get to anybody at the insurance company whose response went beyond, "Huh? Whatever. Sucks to be you."

Abigail Burman: I finally got a woman who was like, yeah, this is bad. What you want is what we call an administrative grievance. She said, okay, I'm going to with you on the phone. I am gonna call two or three doctors and see if they have an appointment. If not, we will file an administrative grievance.

Dan: The woman dialed a few doctors while Abigail was on the phone, got nowhere, and filed an administrative grievance.

Which, you know, great. But that's not a doctor's appointment. File it under Abigail's general advice of: Do everything. Go on record everywhere. And keep going.

Next, Abigail kept calling, kept asking to talk with someone at the insurance company with more juice. Someone who could actually authorize paying for an appointment with an out-of-network doc, since there weren't in-network docs.

And after another like full day on the phone, she got to that someone.

Abigail made her specific request: I want you to authorize payment for out-of-network provider, as the regulations require. And...

Abigail Burman: They say we have no process for this. This does not exist.

Dan: Like, this thing that the law says they have to do-- get you a provider and cut a check -- this person's saying they have no process for it.

Abigail Burman: I read them the regulation over the phone. It did not, did not change their position.

Dan: I would've really struggled in that conversation to contain my rage. I mean, it's just flabbergasting, right? Like, I spent all day getting on the phone. I mean, all of this reminds me of the Wizard of Oz, and they were like, no one can see Oz.

And you know, she's, she's like, I am going to see him. And, and then she sees him and he's like, go away and come back tomorrow. . I am Oz.

Abigail Burman: exactly. It is a, it is a complete runaround. Um, and so when you get to this place, I think you have to let the rage fuel you, maybe take a break, eat some snacks.

Dan: And keep going with other strategies. Including ones that may seem pretty out of the way at first.

So Abigail called the office of her friend's state representative.

And of all the lessons from Abigail's story, this one may be the MOST important.

Abigail Burman: This is the secret trick for any interaction you are having, largely with government agencies, but also sometimes with private companies. Um, all of your elected representatives from local through to Congress, they have staffers whose only job it is, is to make your interactions with these systems easier.

Dan: Abigail actually worked for a member of Congress once upon a time, so she's seen this all from the other side.

Abigail Burman: your elected representatives, have enormous resources at their disposal. And the good ones know that the way you get reelected is by helping people with their specific problems and will go outta their way to do it.

Dan: you don't have to be a former Congressional aide yourself to call your state representative's office. I mean, [in most cases, a state rep doesn't even have THAT many constituents](#). But they do have staff.

So, Abigail didn't call the state rep's office because she knew someone there. She called because she knew what someone there could DO.

And now you know it too.

Abigail Burman: These staffers have secret phone numbers, they have email addresses, they get things fixed.

Dan: A staffer had given Abigail a direct email to the right person at the state regulator's office--.

Abigail Burman: And so we emailed them, got a reply back almost immediately saying, yeah, you're right, this is bad.

Dan: And then she heard from somebody ELSE altogether.

Abigail Burman: I think within an hour or two, uh, got a phone call from the healthcare plans lobbyists for the state, saying that, yeah, she was personally going to fix this, promising an appointment within the next two days.

Dan: Holy shit. I mean I love that it's the lobbyist

Abigail Burman: Yeah, that was special.

Dan: I mean, it's very interesting, right? That like the official channels did not go anywhere. That what happened was the political actor got involved and a political actor on the insurance side came and made it happen.

Abigail Burman: Exactly. The key is you just, you have to keep moving up and you have to press on all the levers that you can

Dan: In this case, because Abigail's friend was on Medicaid, the state was actually paying the insurance company directly, so getting them involved was probably a more effective lever than in other situations. But it worked! Something actually worked.

And making that happen took an unbelievable amount of work, amount of resources. That is one of the BIG take-aways here, and it's not exactly a cheerful one.

Abigail estimates she put like half a workweek into this. [I mean, holy crap.]

Abigail Burman: I was lucky enough to be in a job where I, I could, you know, my boss was understanding I could be taking these calls at the office for sometimes hours at a time.

Dan: And she's fluent in English. And she's comfortable navigating bureaucracy, to say the least.

Abigail Burman: I am a lawyer who worked in healthcare policy before law school, and I do this work professionally, and it still took me so long. And that was with the added privilege of, getting taken seriously because of my education, because I'm white, because of all these things

Dan: I mean, all of these advantages are among the reasons Abigail's firm charges hundreds of dollars an hour for her time.

So the resources it took to get this individual win are, on that scale, staggering. It absolutely blows.

And yet: The part of Abigail's story that sticks out the most to me-- beyond the specific tips, and beyond the outrage-- is an idea that we've started talking a little more about on this show recently.

We've talked for a long time about self-defense against this awful system. But self defense only gets us so far -- especially when we're actually sick, or needing help. We're not in the best position to engage in a fight.

But we can fight for each other. And you don't always have to be a lawyer.

Abigail Burman: this is a service you can provide for people. If you are the sort of person or you know, someone who really enjoys renegotiating their internet plan, you will probably be great at this.

Dan: Sometimes just showing up is enough. Especially in costume.

Abigail Burman: I have gone and just stood in the corner for people to be the scary person who's wearing a suit.

Dan: And you don't always even need a suit. We talked recently with a professional advocate who said, "When I get on a call with a client and say, 'I'm

her advocate,' I can feel the person on the other end of the line straighten up a little bit."

And as we said then: You don't have to be a professional to say "I'm this person's advocate." The person on the other end of the phone doesn't need to know you're that person's roommate, or just their friend.

The idea is, take what you have -- whatever knowledge you have, whatever skills you have, whatever TIME you have, and yes whatever privilege you have -- and see if you can put it to use.

Abigail Burman: You know, that this, uh, we talk a lot about mutual aid and networks of care and I think this is a huge part of it is just showing up for the bureaucracy side.

Dan: Of course, that's not going to make all the difference we need.

Abigail Burman: Looking out for our friends, helping people in our community is only gonna get us so far, we still need so many more changes from lawmakers to make this a system that works for everyone.

Dan: And yes, of course that's true. So Abigail is out there advocating for policy change. But because none of that is happening tomorrow she's ALSO showing up right now for people in her life, helping fight one battle at a time.

So, just to review, I'm taking three big things from Abigail's fight here.

One is a little basket of possible tools: Think about "network adequacy" as a demand -- your insurance company owes you a doctor. Think about the disappointed-not-angry vibe. Think about your state rep's office as a possible resource. -- and again, we're gonna post some of what Abigail has written so you can find it from wherever you're listening to this.

Two: Jesus Christ, this was a lot of work. Even with Abigail's SIGNIFICANT advantages, and the various pieces of wisdom she shared about hacking through, this is not someone most of us could easily take on.

And three: Let's think about these as fights we take on for each other.

That's something I really want to work toward, something I hope this show can do: How do we become a community -- however big, however loose -- of folks who can help each other HELP EACH OTHER?

It's big. We'll take it one step at a time.

For now, if you haven't already, check out our First Aid Kit newsletter. That's where we've been writing down a lot of the tips and strategies we've been learning about HOW to take on these fights.

You can find everything we've written to date -- more than twenty installments so far -- at [arm and a leg show dot com](http://armandalegshow.com), slash, first aid kit.

I'll catch you soon.

Till then, take care of yourself.

This episode of An Arm and a Leg was produced by me, Dan Weissmann, with help from Emily Pisacreta, and edited by Afi Yellow-Duke and Ellen Weiss -- welcome aboard, Ellen!

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An Arm and a Leg is produced in partnership with KFF Health News--formerly known as Kaiser Health News.

That's a national newsroom producing in-depth journalism about health care in America, and a core program at KFF — an independent source of health policy research, polling, and journalism.

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Thank you!