

# Episode 21: Interview with Mary Giliberti from Mental Health America

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Speakers: Alex Schiwal, Matt Wappett, Mary Giliberti

## **Alex Schiwal 00:00**

\*Music\* Hi and welcome to the Mental Health Crossroads podcast, where we explore the intersection of mental health and developmental disabilities. This week our host, Matt Wappett of the Center for Persons with Disabilities in the MHDD National Training Center, talks to Mary Giliberti of Mental Health America. Make sure to look in the show notes for links to these websites and resources. You can also find a full transcript in English and Spanish. We hope you enjoy this episode. Thanks for listening. \*Music\*

## **Matt Wappett 00:35**

We'd like to welcome everybody to this edition of the Mental Health Crossroads podcast. We're excited today to have Mary Giliberti from Mental Health America with us. Mental Health America is the nation's leading community-based nonprofit dedicated to addressing the needs of those living with mental illness and promoting the overall mental health of all.

## **Matt Wappett 00:57**

Mary Giliberti is the Executive Vice President of Policy with Mental Health America, which focuses on federal policy to promote prevention, early intervention, integration, and recovery. Prior to joining Mental Health America in 2019, she was the CEO of the National Alliance on Mental Illness or NAMI. She's also worked for the Office of Civil Rights in the Department of Health and Human Services, and as Disability Counsel to the US Senate Health, Education and Labor Committee. After graduating from Yale Law School, she clerked for Judge Phyllis Kravitch on the 11th Circuit Court of Appeals and received a Skadden Fellowship to work at the Bazelon Center for Mental Health Law. We're really, really happy to welcome Mary here today. Thank you, Mary, for being here.

## **Mary Giliberti 01:46**

Thank you for having me.

## **Matt Wappett 01:47**

Yeah. Can you tell our listeners a little bit more about Mental Health America?

### **Mary Giliberti 01:51**

Sure. Mental Health America is the oldest advocacy organization for people with mental health conditions founded in 1909 by a gentleman called Clifford Beers. He experienced a lot of abuse and discrimination on the basis of his mental health condition, so he founded the organization. And we still talk about how we "fight in the open" which was his saying. I'm going to fight in the open. I think that also says a lot about the organization, because it comes from the perspective of that lived experience.

### **Mary Giliberti 02:25**

Mental Health America also works very hard at the issues of prevention and early intervention. We like to call it Before Stage 4. When people talk about mental illness, they often are talking about crisis situations, criminal justice, some of the outcomes that are very troubling. But- in all other kind of health conditions, disabilities, we try to talk some about prevention, early intervention. We really focus there and have that tagline of Before Stage 4, so we do a lot of screening on our website. You can come to Mental Health America's website and get screened for any mental health condition. Then we'll offer you choices of following up if what you say reveals any kind of symptoms, or something that you might want to follow up on.

### **Matt Wappett 03:12**

That's great. I have actually spent a bit of time on the Mental Health America website, and I'm really quite pleased with the depth of information. There is a lot of great information. You've done a really good job of getting that out there. This is kind of an added on question... Clifford Beers, I don't know that a whole lot of people know... Tell us a little bit more about his background, and his story, and how that led to Mental Health America.

### **Mary Giliberti 03:39**

Yeah, he's written a book. We can send that along. But people who want to learn more... When he was a young man, he had mental health conditions. He was hospitalized in a series of facilities, and he was abused. In those days and, as many know, continuing today people have really awful experiences sometimes with the mental health treatment system. But unlike many others, Clifford Beers had gone to Yale and had a lot of connections politically. He spoke out. He sent letters. He wrote a lot. He spoke frequently. He was not going to accept how he was being treated. That led to a number of changes. His constant writings of governors got involved, policymakers got involved. He made a difference by speaking out. I think that really set the foundation for Mental Health America, and for our advocacy work, and for recognizing that when you raise your voice you can make a difference.

**Matt Wappett 04:46**

Yeah. I think that's really important, that the founding of the organization was from somebody who was experiencing mental health issues. There's that foundation of advocacy right there at the very beginning and that lived experience, which I think becomes so important.

**Mary Giliberti 05:04**

Mental Health America also has 200 affiliates around the country and associate members. I think that's also really important when you think about our organization, because we're grounded in that experience at the local level. That's one of the things I like best about working in the organization and one of the reasons I've always chosen in my career to work at many organizations that have that local and state presence. Because you're not working in a vacuum. You're not making things up. You're really trying to help people who are telling you what the issues are that they're experiencing in their local communities.

**Matt Wappett 05:39**

Yeah, that's great. That's great. What role does Mental Health America play in shaping policy around mental health?

**Mary Giliberti 05:48**

We play a role at all levels of government. As I mentioned, we're at the local level, talking with counties and local communities raising issues around mental health, and then at the state level, and also at the national level. I tend to do a lot of my work at the national level, which means that I'm working with Congress. I'm working with the administration with coalitions of national groups that are coming together, whether that's a group of health organizations, disability organizations, mental health organizations. There's all different kinds of coalitions and we work together and try to get something done, legislatively and administratively.

**Matt Wappett 06:27**

That's great. We mentioned earlier that you're the executive vice president of policy, so that is your bailiwick, that is your deal. Why is policy so important to you?

**Mary Giliberti 06:41**

Policy is definitely my passion, and it has been now for the over 20, 25 years that I've been doing this. That really comes down to a commitment to justice and seeing from a very early age... When I first started, I was a law student- that's my background, is law. When I was a law student, I represented a number of families, children, adults with mental health conditions. I note over and over again the discrimination, the poor treatment, the lack of dignity. The injustice was just striking. The lack of payment parity, access to care, you name it. It all, I think,

kind of stems from this discrimination and from treating people less than others. I've dedicated my career to trying to address that injustice.

### **Mary Giliberti 07:39**

I really saw it from, as I said, an early age when I was in college. My college roommate, one of my college roommates, had major depression. The way she was treated during a suicide attempt, and she ultimately died by suicide- but seeing how people responded... It was shocking to me and hurtful. And it really... Then when I started representing people, I learned that this was not a one off. This wasn't just about her, it was about a whole system that really denigrated people, called them crazy, awful things like that. I just felt that it needed to change. I'm happy that I think it has changed in some ways. Although, we still have a very, very long way to go.

### **Matt Wappett 08:32**

Yeah. Yeah, I think, especially with COVID and everything else, it's highlighted some of the significant shortcomings in our system. That social isolation has always been an issue for people with disabilities and people with mental health issues. But I think it's now become a little more mainstream. Although, we still, I don't think, aren't terribly effective at addressing it. You have a rich history working at NAMI (National Alliance on Mental Illness) and OCR (Office for Civil Rights) and working in the senate with the Health Committee. What are some of your most memorable experiences in your career working on mental health policy?

### **Mary Giliberti 09:10**

I'll give you one early in my career and one later. Early in my career, I had the incredible privilege to work on the Olmstead case. The Olmstead case, for those of you who may not be familiar with it, was brought by two women who had been institutionalized in a Georgia hospital for many years and were not being released because the state didn't provide the services and supports that they needed. It went all the way to the Supreme Court, whether the Americans with Disabilities Act gave you a right to integrated services. I worked on the breaks. I was part of a team that was doing the research for the brief before the Supreme Court. I helped coordinate a lot of the amicus briefs. We had a whole team of people working on this and it was just an incredible experience. The court ultimately held that indeed, it was discrimination to needlessly segregate people, and that states did have to take action. That suit, I think, really led to a lot of changes. Not just in policy, but also in attitudes and what was expected and how people should be living their life. One of the women who was a plaintiff in that case, Lois Curtis, was an artist. Her work is absolutely magnificent. And I had the privilege to buy some of it, to go visit her in her home when she had moved from the institution and was now making a living from her phenomenal art. I still have many of those pieces, and it just reminds me of the power of who people are and what they can do when they're given that opportunity- which Georgia was denying. But the law changed that and I think continues. It's not perfect, there are many

places where people still are not receiving the services that they need to flourish like she did. Knowing what's happened to her in her life and the beauty that she creates, is really just very moving.

### **Matt Wappett 11:19**

That's great.

### **Mary Giliberti 11:19**

And more recently, I would just say I've been working, you mentioned COVID relief- I've been working to try to increase resources for mental health in the COVID relief packages in the bills that are coming up to Congress. Back in spring, mental health got several hundred millions, a small amount compared to the billions that were spent in other areas. And our CEO at MHA (Mental Health America) said other areas of health are getting billions, mental health should be getting the same because of the increased needs. And while we haven't gotten anything yet over the finish line, the last bill introduced in the House did have a billion dollars in the block grants for mental health and addiction. It was a proposal, we haven't gotten it all the way there. But just the fact that we are getting to the levels that other conditions have gotten as well, and there's a recognition that this COVID pandemic really affects mental health.

### **Matt Wappett 12:15**

That's great. That's actually really exciting to hear, because that has been a huge worry that's come up in various circles that we've been in and just the lack of funding and recognition for mental health issues during the pandemic. But going back to what you mentioned about the Olmstead lawsuit, that's just a remarkable story. I know that the Olmstead lawsuit has shaped the bulk of my career and a lot of the work that we do in our programs here at the Center for Persons with Disabilities at Utah State. I can't even imagine what it must have been like to work on that case. I mean you think about the ADA (Americans with Disabilities Act) and everything else being remarkable land... Why can't I think of this word? \*Laughing\* Landmark lawsuits! Or landmark policy. But Olmstead has such wide ranging implications and continues to define a lot of the work that we do in the disability and the mental health field. So that's just... I appreciate you sharing that story. Thank you.

### **Mary Giliberti 13:24**

Yeah, it was wonderful. As I said, Michael Gottesman argued it and \*inaudible\* and others at the Bazelon Center were just instrumental, and I was a relatively young attorney fresh out of school. It really was an incredible opportunity to work on a case like that.

### **Matt Wappett 13:39**

Yeah, that's great. I think the Olmstead is a good segue into the next question, which is sort of looking at integrating mental health and disability. This podcast is sponsored by the Mental Health and Developmental Disabilities National Training Center, which is looking at how do we deal with issues of dual diagnosis. And so I'm curious on your perspective on how mental health policy and disability policy overlaps, and what are some of the challenges with integrating these two important areas of policy?

### **Mary Giliberti 14:11**

I think we can start with the Americans with Disabilities Act (ADA), because we started talking about that and that's a good frame. Because the Americans with Disabilities Act covered all disabilities, and there was a conversation at the time about whether mental health conditions would be fully covered. And the disability community was adamant. I think this is why they were so successful because they united and said, 'Absolutely, we are covering mental health conditions.' And so mental health conditions are part of the ADA- covered by the ADA is disabilities- and are part of many of the disability policy issues that we are still working on today. With respect to Olmstead, we work on housing, we work on employment, supported employment, all of which are important to the mental health community and the disability community. Then I think there are issues, just as there are with different categories of disabilities, that are unique or different in mental health care. I already talked about the block grant and we were advocating for money in that block grant. That block grant is very specific to mental health treatment or substance use treatment. There's other parity- mental health parity has been a battle for the mental health community, and that has come from insurance companies. In the old days, they used to put direct limits, 20 visits for example. Now they're more subtle, and they come up with medical necessity criteria that render you unable to get services. There was a recent decision called the Wit Decision in Utah that basically found insurance companies to be engaging in those illegal practices. There are lots of issues that are, I think, important to the mental health community as part of the disability community, and then there are some issues that are unique that we also advocate on.

### **Matt Wappett 15:59**

Yeah. That issue of mental health parity, I know this wasn't one of my original questions, but what are- that's been a huge topic for the past 20 years really. What are... I'm trying to think of how to phrase this. Why do you think it's such a challenge to address that issue of parenting? Is it the stigma that is still out there with mental health? Or are there other reasons that maybe insurance companies are less willing to provide the coverage for mental health conditions as opposed to others?

### **Mary Giliberti 16:35**

I think like anything that's persisted for a long time, there's a combination of forces that are continuing to lead to inequity, in terms of access to mental health care. I just will note, since we

haven't really talked about equity, but with respect to access to mental health care, there's great inequity with Black Americans and others having less access to care than others. Parity shows that people with mental health conditions have less access, then even within that we have communities that are disproportionately being affected by that lack of access.

### **Mary Giliberti 17:10**

Back to your question about why it persists, I think stigma is part of it. I think it's part of why it hasn't really changed. I also think that we tend to get caught between different forces. Insurance companies are paying less, there's been studies showing that they are paying specialty mental health providers less than they even pay primary care providers. There is certainly a pay inequity in what insurers are paying, and why is that allowed to persist? I think that's where the stigma and discrimination come in, because in the area of heart disease or cancer care, I just can't imagine that you could get away with having no access to providers. I can tell you, I take a lot of calls from families and from individuals who need help and one of the first things I have to ask them is do you need it covered by insurance? Now, in almost any other area of health or disability, you don't ask that question. Do you need it covered by insurance? But I have to ask that question. I think that is really something that needs to change, still isn't changing, because insurance companies, in my view, continue to underpay.

### **Mary Giliberti 18:25**

Then we have a workforce that we don't have enough. So, many psychiatrists, other mental health professionals that are well trained in evidence based practice, don't take insurance. And that's a problem as well. There's no other area of medicine, really, maybe dermatology, where you see huge numbers not taking insurance. That becomes a real problem. The person in the family is kind of caught between a rock and a hard place in that their providers aren't taking insurance, the insurance companies aren't paying enough, and the family and the individual is left without affordable and accessible care. Then we have, as I was saying before, they're managing the care such that they're denying care, denying aftercare, denying days. One of the issues is that people are getting discharged to nothing. They'll be discharged from the hospital, and there's no services, no supports. One of the things that we really push at Mental Health America and are pushing forward is the idea of peer support. The idea of people with lived experience helping people hopefully avoid going into the hospital in the first place. But also as they're coming out, be that bridge to help that person so they don't go to nothingness which is really what happens now. In so many other health conditions, you get aftercare, you get really good follow up care. We don't see that.

### **Matt Wappett 19:48**

Yeah, that's a huge gap. In addition to mental health parity and inequities and the disproportionality issue that you brought up, what are some of the most important mental health policy issues that people should be paying attention to right now?

### **Mary Giliberti 20:04**

I'll highlight two. I already talked about peer support and that's one. Many healthcare plans don't cover it. On the commercial side, they don't cover it and Medicare doesn't cover it. A lot of people talk about great Medicare is. On the mental health benefits side, Medicare is not so terrific. I'm just saying. \*Laughter\*

### **Mary Giliberti 20:25**

And lack of coverage of peers is something that MHA has been advocating on. We actually have worked on a bill with some other partners to cover it within integrated care settings. In primary care and other kinds of settings there's integrated care. We're starting there. But the ultimate goal is to see peer support covered by Medicare and other insurers. That's one issue. Another issue, and I wanna start at the early intervention stage and the prevention, because we've talked a lot about some of the other areas. And then, the other area of crisis care. I think that's another area where a lot is happening.

### **Mary Giliberti 21:04**

First, early intervention and prevention. I think there's been some statewide developments around mental health education in schools. And, more and more schools that are offering mental health services on-site. The mental health services on-site, in particular I think, is an important equity issue. If you look at the children, about 30% of those getting mental health services only get those services at school, and of that group it is disproportionately children of color. Getting mental health services to where children are rather than expecting children to get to the service is really important. The policy area of mental health K through 12 education in schools, and mental health services in schools is something that we're paying a lot of attention to. With COVID, the recognition is that these issues are really exacerbating. They were there before, really high rates by the way of adolescent depression and anxiety, skyrocketing. So really, the need to get into schools and make sure that students are both educated and have access to care. And the prevention side is some of the social emotional learning that can be part of that, to build resiliency and build skills in our youth. That's one area.

### **Mary Giliberti 22:26**

On the way other end, is crisis care. I do want to mention, there's a new bill that passed just about a month ago, that created a new three digit number for mental health crises. 9-8-8. So, right now if you ask me, and I've been doing this way too many years, if you ask me for the mental health suicide lifeline, I couldn't tell you the 10 numbers. Now, I probably should be able to, but I can't. But I know 9-8-8. That's pretty easy. In two years, by 2022, that will be implemented. There's a real question about what's going to happen, is that just going to be a call number? Or is it going to be part of a larger system that provides more proactive crisis services that people actually want? Things like mobile teams, things like peers, that come to

them and help people get care and get help that they need and support. Rather than, jails and prisons which is where too many people are winding up, or 911 calls where police come out. We have seen most recently, many, many unfortunate, tragic deaths. People like Daniel Prude and others, building on a history of others that have experienced death during one of those mental health crisis calls and a police response. We believe that it's really an opportunity now with the passage of 988. And this is another area where not only is race equity important, but disability equity, because you see many people with developmental disabilities, autism, also having issues when police are called and winding up harmed dead, other bad outcomes. The hope here is that with a crisis number, we really will see a change in how we respond to these. A community response, a mental health response, is what we're saying, instead of a police response.

### **Matt Wappett 24:27**

Yeah.

### **Mary Giliberti 24:28**

We want mental health as the first people out, not the police.

### **Matt Wappett 24:33**

Yeah, that's actually really exciting. As we watched that develop, we have the same concerns. What is this going to look like in the bigger picture? I don't know if you followed the news, just a month ago here in Utah, we had a... It was a young man who was about 13 years old who had an autism spectrum disorder, but also some mental health issues, and was in crisis. His mom called 911. The police came out and they shot him, for no real reason other than they really didn't know how to respond. And it's really elevated the dialogue, at least here locally in Utah, about who should be responding to these situations. That 988 number in the discussion, I think, around this broader response system and community based supports is so, so important to helping protect folks who are already struggling at a significantly increased risk from anybody else. That notion that you brought up about the schools as well, oh! I have kids in high school and the stories that my kids come home and tell me. And the number of students they know over the past four years who have committed suicide, because they've had a lack of support and a lack of education and people just didn't know what to do when their friends were in crisis, are tragic. It's so, so important that we be getting that education down to those early levels, and really getting kids familiar with talking about mental health and being comfortable talking about it like we do with other health concerns.

### **Mary Giliberti 26:09**

Exactly. I think that's really what motivated me in this field. Because when I think back, when I had my own friend who was struggling with depression, I literally said every single thing that all

the mental health organizations would tell you not to say: cheer up, we'll go to a party, it's going to be okay, look on the bright side. I mean, you name it, anything you're not supposed to say, I said it. And that really sent me down this path of recognizing that we need that education so people don't make the same mistakes that I did. And there's no reason for it, it's something that is teachable. We can teach people how to respond compassionately, and how to help people get the help they need, which is very important, as well. So, you're absolutely right. I think the education piece is very important. We also have to link it to the services, because if you go to get help and insurance won't cover it then what have we really accomplished?

### **Matt Wappett 27:05**

Yeah, absolutely. Kind of on that note, how can people be more effective advocates? There's a lot of folks who want to get involved and see the importance of this, but don't know what they can do. What are some tips that you have around individuals who want to be more effective advocates in their community or even at the national level?

### **Mary Giliberti 27:28**

Yeah, I would say get involved at the local level with an organization that resonates with you and that can be... There's a wide variety of organizations. I mentioned mine, I've worked for Mental Health America and I've worked for the National Alliance on Mental Illness. I also work very closely, and I'm actually on their advocacy lists for the American Foundation for Suicide Prevention, the FSP. You can get involved in any of these organizations, depending on where your interests lie. I know there are many others for other disability groups as well. And then when you can do multiple ones, I do a few. And then you want to get involved in talking with legislators, writing to them, tweeting, whatever level of interest you have. I helped my son the other day, he's interested in environmental issues, draft a message to his senator about that.

### **Mary Giliberti 28:28**

You would be surprised, I worked on Capitol Hill and they do look at: What are they hearing about? What is coming in? Where are the voices? Right now, the Affordable Care Act, for example, is up before the Supreme Court. There are lots of people weighing in on that trying to tell their Congressman, depending on what happens with that, what they want to see next. That's very important. In 2016, when Medicaid was threatened, there was a time when we thought Medicaid was going to be converted to a block grant, which would have meant a precipitous decline in Medicaid. The response from people is what made the difference. We went to Capitol Hill with 1,000 people at the time, and they went and sat-in with senators and congressmen and their staff and told their stories. There's nothing more powerful than a story that affects you personally. Putting that story in, whether it's into emails, tweets, social media, or even during meetings- hopefully at some point we'll have meetings again right now we're virtual- but it is important. It is a way to raise your voice and you can do it at all levels. I have been to my county and testified to my county board and said I want the budget for mental

health. My neighbor does coffees with all the candidates. She likes to do that. I go to the coffee, I raised my hand and said what are you going to do for the mental health budget in our county? What's your commitment? And I asked them, so are you committing that you're going to increase it by what? Hold them accountable. Going to those kinds of things, you might think... But if they go to all those coffees and somebody's got their hand up and they're saying, I want to know what you're going to do about this? You see action because they're hearing it, they recognize, 'Wow, this is a problem. This is something I have to be thinking about.' Volume matters. Stories matter. Getting out there at every level of government is important.

### **Matt Wappett 30:32**

Yeah, yeah, absolutely. I think, going back to what you mentioned earlier with Clifford beers in the founding of Mental Health America, those personal stories and those personal experiences can be so incredibly powerful for meeting policymakers and for really illustrating the need for these services.

### **Mary Giliberti 30:53**

Never underestimate the connections that you have. I remember doing advocacy and it turned out that our organization had a librarian in the hometown of the Chair of the Appropriations Committee in that state. He took calls from that librarian and he sure did not want to disappoint her. It's very surprising. People grew up next door, went to high school with... It's amazing how many connections people find, and that's really helpful. I would just say, get involved. You might think 'I don't have any connections' but you have your story. And as time goes on, keep doing the work, you will have those.

### **Matt Wappett 31:31**

Yeah, yeah, absolutely. One of the things that we like to ask all our guests at the end is, what strategies have you found effective in supporting your own mental health?

### **Mary Giliberti 31:43**

That's an excellent question. I will be the first to say that there have been times when I have not been as actively managing of my own mental health, and that is not a good thing. So now, I am very conscious to exercise every day. I also took up meditation. When things got very stressful for me at one point in my career, I took up meditation and it was very, very helpful to me in sort of allowing me to regenerate in the middle of the day or when I was feeling low. It's a very natural and helpful way to get your energy back up. I'm also very cognizant of eating right. I particularly eat a lot of green leafy vegetables. That tends to affect my energy levels. And what I'm not good about, but I recognize I need to get better about, is sleep. I would just advocate for people not to do as I do, but do as I say, in this particular case, and be careful with your sleep.

**Matt Wappett 32:54**

Sleep is really, really important. It's interesting, it's one of the most common experiences and we're only barely starting to understand how important that is for our mental health and cognitive functioning. Thank you for sharing those.

**Mary Giliberti 33:11**

Like I said, I'm working on it. That's all I can say. And I think that's also it. I think that with mental health, we all have mental health, and we just need to work on it. It's not easy to take care of your mental health. Many times, either because of you're busy working or yourself... You know, you're the last one in line sometimes. And it's really important to change that and recognize that you can't give from an empty vessel.

**Matt Wappett 33:35**

Yep, you're absolutely right. Yeah. It's something that we're all... We all keep trying, right? It just takes practice. \*Laughter\* How can people get more involved in supporting your work and Mental Health America?

**Mary Giliberti 33:49**

You can go to our website, and we have an advocacy group, and you can sign up and then you will get our alerts. You will get options to participate in different ways. You also can find an affiliate, by going on our website, that's near you and get involved at the affiliate level. And they too have websites and advocacy and programs and different ways that people can get involved.

**Matt Wappett 34:14**

Perfect. Thank you, Mary. We really appreciate your time and your perspective. This has been a delightful conversation and we hope that our listeners take something away and are committed to getting more involved in advocacy and policy. Thank you.

**Mary Giliberti 34:30**

Thank you for having me.

**Matt Wappett 34:31**

Yeah.

**Mary Giliberti 34:31**

I appreciate it.

## **Alex Schiwal 34:32**

\*Music\* Thanks for listening to this episode of the Mental Health Crossroads podcast, where we explore the intersection of Mental Health and Developmental Disabilities. Visit our project website at [mhddcenter.org](http://mhddcenter.org) or follow us on social media @MHDDcenter. Thanks for listening.

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