Oral history interview with Marilyn Ricci, interviewed by Ben Gammell, CHS Director of Exhibitions, for the Connecticut Historical Society's exhibition, "Common Struggle, Individual Experience: An Exhibition About Mental Health." Interviewed 12 November 2020 at the Connecticut Historical Society.

Marilyn:	00:00	until I don't know when, and I said, "Oh. Well, let me call them, see if I can" It's been so long, and I feel safe going there with her, this particular person. So I'm so looking forward to it this afternoon, but I don't have anything else I have to do.
Interviewer:	00:00	I'll definitely We'll be, like, an hour.
Marilyn:	00:00	That's fine.
Interviewer:	<u>00:16</u>	[crosstalk 00:00:23] for that long. So Marilyn, you have recording on both cameras, and our audio is recording. And if you're comfortable enough to remove the mask, let's do so. Put it on top of your belongings over there. And now, look at the [inaudible 00:00:42].
Marilyn:	<u>00:16</u>	I have to look at her, or you?
Speaker 4:	00:20	I just want to look at the hair, you're good. All right. So eyes on Ben, I'm not here. I'm only going to-
Marilyn:	00:20	Okay, you're not here.
Speaker 4:	00:50	[crosstalk 00:00:52] so my request is, when we're answering questions, Ben's voice is not going to be heard. What that means is that when the video is playing, we're never going to hear him speak. So you want to provide context, but you don't necessarily So imagine Ben says, "Why do you like blue ducks?" Try not to start your sentence with, "I like blue ducks because" Keep it conversational, but build in context.
Marilyn:	<u>01:14</u>	Okay. I'll try.
Speaker 4:	01:14	So if I were answering that same question, then I could say, "You know, there's something about blue feathers that really makes me love everything that is a blue duck. And when I was a child, my mother used to take me to see them." Make it part of the answer, but not, "I like this because" Understood?
Marilyn:	<u>01:34</u>	Yes.

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Speaker 4:	01:40	The other was, sometimes we get ahead of ourselves, and we're trying to answer the question so well that we just keep on speaking. And we don't know when to stop, and we keep connecting it with "and." Just feel free to end your answer and start again, because bite-size really is key for us to be able to cut things apart.
Marilyn:	<u>01:56</u>	I'm always giving my grandson a hard time with that.
Speaker 4:	<u>01:56</u>	Oohs, aahs, ums, ands, run on sentences?
Marilyn:	<u>02:01</u>	And "okay," and all that.
Speaker 4:	<u>02:03</u>	The more [inaudible 00:02:04].
Marilyn:	02:06	Well the kids, too, because they hear it all the time from everywhere, so.
Interviewer:	02:06	And I also will, it feels awkward for me, but I'm going to try not to When you're having a conversation, usually, you're like, "Yeah, right," or, "I understand." I'm going to try to be quiet, try to keep my voice out of the clip.
Marilyn:	<u>02:06</u>	Okay. This is a new experience.
Speaker 4:	<u>02:06</u>	Phones are on silent, for both you guys?
Interviewer:	<u>02:06</u>	Yes.
Speaker 4:	<u>02:06</u>	Excellent. Okay. Well, I'm going to be quiet from here. I'll jump in if I feel as if you need me for something.
Interviewer:	02:14	Okay. So let's just start, if you could just tell us your name, where you're from, and where you live now.
Marilyn:	<u>02:51</u>	My name is Marilyn Ricci, and I'm from Canton, Connecticut. And I was originally from Pennsylvania.
Interviewer:	<u>03:01</u>	So let's maybe start talking about the exhibit a little bit, the exhibit about mental health. What would you When you imagine an exhibit about mental health, friends who are going to the exhibit, what would you want people to learn from this?
Marilyn:	03:22	When I think about mental health, what I want my friends, and family, and professionals in the medical field to learn about mental health, is that it's an illness like any other illness. And they need to show compassion and see the individual, not the

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illness. The thing I've experienced the most is the lack of compassion for people who have mental illness and for their families, being totally, totally alone. Very few physicians have shown the kind of compassion that I think people get when their kids have another illness. Only once in, like, 23 hospitalizations, because my son got ill young.

17, and he's now 45, only once, we had a psychiatrist call us up and say, "I'm going to take good care of your son." And that still just kind of gets to me because most of the time it's nothing like that. You know, I remember once he's talking to us in the hall of the hospital, very early on, and I felt like he didn't care at all or didn't want to know. And that lack of empathy for the family is just so difficult. I don't think that happens in other illnesses, so I want people to see it's an illness. The person didn't ask for this, they got it like you get any other illness.

Interviewer: 05:01

Thank you. That's great. So sort of connecting to that, why do you think there is a lack of [inaudible 00:05:05] or lack of compassion? And why is it difficult for people to talk about mental illness?

Marilyn: 05:09

Mental illness is scary. It's frightening. It's your brain. That, I think, scares people. It's something you don't want to think about, something going on with your brain, because it's just so basic to who you are. So I think it's avoidance of the area that's scary because when your brain goes wrong, it can really do things like hallucinations, and auditory, and psychosis. And that's all scary, and people just want to avoid it.

Interviewer: 05:39

What are some... Let's back up. Was your son's experience, was that your first experience with mental illness, as far as learning about it? Did you know anything about it, or did people talk about it?

Marilyn: 06:01

Before my son became ill, I never thought about mental illness. Although once, when I was in high school, they took us on a field trip to a mental institution. This was in Pennsylvania, which I thought was bizarre, then. And my sister actually took the day off from school because she didn't want to go. And it was very sad, I remember feeling that about it. But I never thought about mental illness, it never entered my mind that anybody in my family could have mental illness. I knew nothing about it, didn't think about it. So when this happened to him, it was like a complete shock.

Interviewer: 06:39

I want to leave it up to you, how much you want to talk about that experience with your son, but would you like to talk about

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it? What are some things you've learned over the years though helping to find the truth for your son, just dealing with the illness?

Marilyn: 07:01

When he became ill, they didn't have early diagnosis back in the late nineties. And that's the one thing, the only thing I can say, that's been great that's happened in mental illness, nothing else. That he had three hospitalizations before they even suggested that he had a mental illness, and all that time we didn't really know. We didn't know what was going on and nobody was really helpful. We were very, very, very alone. At the third hospitalization, a psychiatrist said, "You have to find NAMI, the National Alliance on Mental Illness." So I did, and I was able to cry for an hour on the phone with someone who completely listened.

And I went to a support group, and there were all these other people dealing with the same thing. And it was just... It just made all the difference. And then I took their free education course, and my husband did, and that changed our lives. We learned about the illness. I learned things about how to communicate better. It saved us, which is why I became so active in the organization. I've been national president. I've I've never said no to NAMI when they've asked me to do anything.

Interviewer: 08:19 Can you talk about yo

Can you talk about your experience working with NAMI?

Marilyn: 08:22

Right now, one of the things I do is, I'm still a support group leader every month in Avon. And that's the most rewarding thing I've ever done even though I've been state president, affiliate president, national president. You see that you make a difference because people come in, and they're hurting, and they can see and talk to someone who's been through it, who has. Just the compassion... In a NAMI group, you can say anything that you could not say to anyone else. I mean, I remember telling a social worker something once, and she just reamed me. And I'm like, "I'm trying to tell you what this feels like." But in a NAMI group, somebody else would say, "Yeah, I thought that. Yeah, I've had that feeling." So it's that kind of environment that makes so much difference. I mean, there's no place else. You couldn't even talk to your family with the same kind of feelings because they wouldn't understand.

Interviewer: 09:20

Do you think... I'd like to hear your thoughts about some of the barriers to getting treatment, difficulties. Including discrimination, whether you've experienced that trying to find help for your son?

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Marilyn: 09:46

The hardest thing is sometimes getting someone into the hospital, which it shouldn't be. You should be able to go to the hospital when you're feeling bad and say, "I need help, and I need some place to go." And maybe if it was ideal, it wouldn't be a hospital, there'd be some other facility to take you in. And now it seems like it's difficult, and it's difficult to stay long enough to get back on an even keel. Even, I've seen that different, shorter hospital stays all the time. And in the late nineties, early 2000s, you could have a three-week, four-week hospitalization. Now, I don't think that would happen, or very unusual. You really have to fight, but even then. I mean, I remember fighting with hospitals and saying, "You let him out. He's not well enough, it's your responsibility. I'm going to hold you responsible for doing that."

So oftentimes with mental illness, as a parent, you're fighting. Fighting for care, and you're in the middle of this crisis. You're grieving, your heart's broken, everything's going on. And yet you have to somehow find the stamina to fight to get the kind of care you want, and that is so difficult and so unfair. And that's one thing I feel with NAMI and advocacy, is that... I have a husband and I'm active, but what if your family is not in the same position and you can't do that? Then that young person often ends up in jail because so many people with mental illness are criminalized. I mean, my son's been in trouble with the law, but we had the resources and I had the NAMI understanding to be able to stand up and say, "This is a mental illness."

What he did was not something he would choose to do. He was psychotic, and sometimes those instances happened right in the hospital. And once, we took him emergency room one time, and he was arrested in the emergency room and he went voluntarily. And my husband and my daughter were with him, and a policeman comes in and he says... My husband said to the policeman, "Don't go over to him. He's not violent. There's nothing that... But he is verbally abusive right now because he's psychotic." The next thing you know, he's in handcuffs. [inaudible 00:12:01] how he turned his face.

Now, what other illness do you go to the emergency room for help and end up getting charged with a felony? Which was because they said he spit, so that was a felony. Of course, we got it reduced to misdemeanor, but still there was the whole thing in the... Because that was ridiculous, here he is going to... So, that's something that we have to deal with all the time. And if he didn't have a family, where would he have ended up? So it's not treated like other illnesses. It's just so much more difficult.

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Speaker 4:	<u>12:35</u>	Can we take a small pause and have her move there in the shot? Is that okay with you?
Interviewer:	<u>12:35</u>	Sure.
Speaker 4:	<u>12:42</u>	Okay. It'll only take about 40 seconds.
Marilyn:	<u>12:47</u>	Am I giving you context?
Speaker 4:	12:50	You're giving me a window into a world that I don't know much about, and I appreciate that perspective. And I've always imagined the difficulty, but it's not something I'm familiar with. I've had several family members that work with people that need constant assistance or help, but I've never had that perspective. So this means a lot to me, too.
Marilyn:	<u>13:30</u>	Okay. Thing is, it never ends. And he does fine in between things, when things are going well. He's working part-time and has his own apartment, been through a lot.
Speaker 4:	<u>13:45</u>	Is that count? [inaudible 00:14:08] Yeah. And that last little piece that you said, I got that too. That was good, it's okay. You spoke as though the cameras weren't on, but they certainly were. And it took you 10 seconds, so thank you for that.
Interviewer:	14:44	Okay. We could talk about legislation. Or just in general, you talked about some of the challenges that you faced in getting treatment and getting the truth for your son. Is there important legislation that needs to pass? What things need to be done, do you think, to improve access to treatment? And better treatment of mental illness, in general?
Marilyn:	<u>15:14</u>	For better treatment, I think that we need to decriminalize the illness, for one thing. We have more people in, I think, prison with mental illness than anything else. We need to have other facilities that people can go to and stay for as long as they need to get back. I mean, medicines don't suddenly work in a day or two. It takes time for someone to have a medicine really work where you can start working with them and talking to them about how you can go forward. Instead of taking someone to a police station, there should be someplace else to go to. In some places in the country, there are programs where someone who's mentally ill and psychotic isn't taken right to the police. They're taken to a site. I mean, here in Connecticut, I think you're most often taken to the emergency room. But that doesn't mean they'll keep you, necessarily.

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So if there's some place someone can go to that's safe and can care for them, that would be ideal. One thing that has happened with treatment is early intervention, and here in Connecticut, we have Yale and the Institute of Living doing early intervention. That was not around when my son got ill. And that is, I think, a marvelous thing because they don't... If someone showed any signs, they don't worry about whether it's going to turn into that. They're right there, and they're there for the family and the person that's ill. There's still some work on parity, I guess, that's still out there. There's supposed to be parity, but there definitely isn't. I mean the best mental health system is the state system. You can't get the same care in a private... It's just not available.

Interviewer: <u>17:04</u>

In previous focus groups, people talked a lot about insurance and paying for treatment. Had you found that as a challenge in order to get treatment?

Marilyn: <u>17:16</u>

Well, early on, I just couldn't imagine getting on social security or Medicare, Medicaid, and all those. My husband handles all that, so I'm not as knowledgeable, which I'm lucky. But I could think, "No, no," because you don't think it's going to be all that bad. But I had so many people tell me, "You need to. You're not going to get the care you need to." And after spending tons of money, he was admitted to the schizophrenia rehab, and insurance would pay three weeks. And they said, "You have to get him on Medicare and Medicaid because he needs to be here for..." Well, he was there for two years. First, it's like four days, three days. The program's a long time.

We always got treatment. We were lucky that we could pay for it. Our insurance paid for some. And then now with the state program, he has a FACT team, which is Assertive Community Treatment team. So he has his own insurance through that. And that's a team that's because you've been in the hospital so many times, you get this complete care team. And he's in Florida where there are a lot of those teams. Connecticut, not so much, but that's where he ended up. He used to go missing for months and he ended up in Florida one time, but he's been there now over 10 years.

Interviewer: 18:59 So would you say Florida is ahead of...

Marilyn: 19:02 No. Every state has different things that they're good at, and

not, when it comes to mental illness. I think Connecticut hospitals are much better than I've seen in the other state that I have familiarity, which is Florida. Although, he's been in hospitals, I think, in Washington state, other places. Let's see,

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Colorado, other places. But they have the FACT teams because they had a lawsuit by somebody, and so now they have these FACT teams. And that, we don't seem to have too much in Connecticut.

Interviewer: 19:48

Okay. This is, sort of... We'll circle back to what you said. But if someone was in a similar situation experience, experienced a similar situation that you had experienced with your son, what lessons would you want to impart to them? Advice or lessons?

Marilyn: 20:07

The things that helped me the most was the National Alliance on Mental Illness because it gave me a support group. I have friends that I met there that I can call about anything dealing with mental illness, and I know I will get warmth, and compassion, and understanding. And that would not be available for my family. Other families might be different, but not mine. And friends, they're kind and they know, but they really don't understand. And that's what families need, not just support. They need people who will understand, and then, where to call for resources. And that's one thing that NAMI does, also. You go to a NAMI support group, and you are looking for something... NAMI itself does not tell you, will not say, "Oh, you should go to the psychiatrist." But someone else in the group might, and that's fine. They'll say, "Oh, I did this, and this worked for me." So that sharing of information is so important, because otherwise you're completely alone. And it's never good to be alone no matter what illness you're dealing with.

Interviewer: 21:26

How has COVID-19 affected your experience? You actually talked a little bit about it with travel, difficulty of travel, but how has that affected life for you and for your son as far as his mental illness?

Marilyn: 21:49

Right now, we're in this pandemic of COVID-19, and seeing our son is really a priority. Because again, with mental illness, often the person with the illness doesn't have a lot of friends. Certainly their friends from high school, long gone or even... You know, wherever they've been, they're not available. And we're like his main friendship base. He does have a couple friends, but when we're with him we do a lot of things. We'll take bike rides and walks and go to museums, do things. So with this pandemic and COVID, we haven't stopped going to Florida. We get our COVID tests. We go down to see him every so many weeks because it's just so important to keep him healthy. And we talk, of course, on the phone all the time.

And mainly because I don't want him so isolated. He moved from one apartment to another this past year to be closer to us.

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We have a place in Florida, so to be closer to us and also an opportunity to work in this facility that hires people with mental illness. But he didn't really have a chance... He came there in January, so he definitely didn't have a chance to meet new people. So we really are his friendship base. And I find that with so many families with their loved one who's a young adult, middle aged, their family is pretty much the social life of the person. So COVID, we just haven't let it stop us. He's very careful. He goes to this place that works with people with mental illness, and I know they check regularly. So I'm comfortable being with him. He's pretty concerned about being safe, so. The three of us get together, and I'm comfortable with it. So it hasn't impacted us too much.

Interviewer: 23:51

Sounds like he's doing better than a lot of people. Well, he sees his parents more than I do, gets more recreation that I do. You tell him that he's living [inaudible 00:24:08]. So let's see... Yeah, that actually leads me to this. A nice segue to this question about... You could talk about yourself, obviously this, you are probably prepared to maintain your own mental health. Do you mind telling, what do you do? What are your practices in maintaining your mental health? Whatever you want to talk about. It could be just... Some people have wellness practices, religious practices, medical treatment. Are there things that help you in maintain your mental health?

Marilyn: <u>24:52</u>

When you have someone who has a mental illness, it doesn't just affect him. It affects the whole family, greatly. And one thing I learned pretty early on, was that I had to take care of myself if I was going to help him. And so I did go to a psychologist for a while. He was very, very helpful. And then the NAMI support and... But I spent many, many days and many hours crying, and I can do that anytime. But then I would say, "All right." I'd go for a walk for 10 minutes, cry for 10 minutes, then I'd say, "All right, that's it. You're done for the day. Now you got to move on, because who do you admire? You admire people who can have the resilience and go on with it." So I think about that. I fail a lot because I can get really upset and grieve all the losses.

I mean, he was a state athlete. He was at top of his class. And when that first happens, you grieve like they died because that person died. There's a whole new person, and I don't think people understand the grief with that. And that kind of never goes away, in a way. You think, "Oh, he doesn't have a family, a sister, and he doesn't have this." So you have to take care of yourself, but it's difficult. I do a lot of yoga, barre, try to stay healthy. I'm a dietician, so I eat well. I have a lot of friends, but

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there's just always a little sadness, as with anybody who has a chronic illness.

Interviewer: 26:34

This is, similar question as earlier, but maybe we can just begin. It's a little different. So what would you just say to someone who is struggling with their mental health and doesn't know what to do?

Marilyn: 27:01

When someone is ill, they need to find some help somewhere. Whether they start out... I'd like to say they could start out with their physician, but I don't know that that always works because a lot of physicians don't really understand mental illness. I've even had some psychologists that I've gone to, to check out, and they didn't understand mental illness. There's more support out there today. I think it's more knowledgeable. You have people with bipolar who are famous and talking about it and saying, "Go to this group." And there's things on your phone you can get for illness.

So the important thing is to search out for help, whatever it is. For family members, NAMI's the only resource I really know. There's lots of other things for people with mental illness to go to, to look for information. You just can't stay alone. You have to deal, and you have to face it. You know, there's also a lot of denial that goes on when someone gets sick. And often with families, I have to say this as a woman, the mothers get it before the fathers do. A lot of times, the fathers will stay in denial longer than the mothers who will say, "Nope, something's going on here. We got to do something."

Interviewer: <u>28:33</u>

Let's see. This has been great so far, and a lot of these questions you've already answered.

Speaker 4: <u>28:38</u>

Can I ask something? Just, my mother-in-law that I mentioned, she and a few other family members work a lot in mental illness for people around the state and she works for the state. There's a lot, and if you covered this one, forget it. Does the state provide resources that are adequate? I know that in recent the recent four years, I've heard so much about cuts, cuts, cuts. Reduce staff, more needed with less resource, more needed with less personnel and staff, and the continued to push for privatization. Have you utilized any of those services from the state? Have you noticed a big change in recent years? Anything you want to say to Joe Biden? And if this isn't relevant then-

Marilyn: 29:31

The treatment over the years... I mean, because I've been dealing with now since the late nineties, so it's a long time.

There's no new medications that are significant. They may have

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changed it from being a pill to something that melts in your mouth or maybe even injectable, but nothing remarkably different. Which, if you would've said told me that in 2000, I would've said, "Oh, you got to be kidding. By 2020, there's got to be something that's really great that you can take and not have all these side effects." Because that's one of the reasons people... I mean the side effects are pretty lousy, so you can understand how a 20-something is going to say, "I'm not dealing with all that."

Plus, the idea that this is their illness takes, like anybody, takes time to accept. But the side effects are awful, and there's nothing new there. I mentioned that early interventions, the one good thing that I've seen happen. Then, the other thing is that there just aren't a lot of treatment options. There's not places to go where you can really spend some time in a nice environment to get healthy. If you've ever been in a psychiatric unit, they are not pleasant. I often wonder, why can't they have nice units in a psychiatric part of the hospital? No, they're not colorful. No, they're bad. So there's the long way to go with treatments and aftercare, having enough programs that people get regular visits or have some way for care.

I remember thinking when my son first got ill and they got the diagnosis, I thought there should be somebody coming by my house to check on us and see if we understand because... It's like anything, you go to a doctor and they tell you all this stuff, and you only hear half of it because you're like, "Oh my gosh, what's going on here?" But no, none of that happens and no one checks up on you. So there's just so much better care that needs to be there. I don't even know where to begin. We have a long way to go, a lot more help.

So one of the goals, I guess, in the exhibit that we discussed with focus groups, was trying to destigmatize mental illness. Normalize it, in a sense. How do you feel about this? That the current state of how people see it, do you think it, is it getting better? How could we help? How could we help destigmatize mental illness?

Well, the fact that there's a lot of famous people now saying they have bipolar or depression helps some, certainly schizophrenia. But I would like to see us getting away from those labels. The NINH... I heard the director a few times back, he's not now, say that those labels are misleading and they're meaningless because if they took people from all the illnesses and looked at their symptoms, they're all over the place. They don't fit in those boxes. So I think getting rid of those labels and

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Marilyn: 32:13

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saying, "Oh, you have some kind of gene thing," or "You have a synapse thing here," rather than, "You have this, and this, and this," would help a lot because the labels are stigmatizing. And they're kind of meaningless for how you treat somebody. You treat somebody by what the symptoms are, not by the label. And the labels change.

Families will tell you, "Oh, they gave them this label. Then they gave them that. Then they gave them that," because they're really meaningless, but they stigmatize. Every time someone gets shot and they think it's a person with mental illness, that makes the whole situation, "People scary. Oh, no. Mental illness. They're all violent." Not true, they're more often taken advantage of, and that happens a lot. I know a lot of people have had their loved ones being taken advantage of because they have a mental illness. And that's the fear. You don't want to hear it. You don't want to hear about mental illness because you want to say, "Oh no, I don't want to hear this." So I'd be interested in how many people really want to come to an exhibit about mental illness. They might just say, "Oh no. Why would I want to go there?"

Interviewer: 34:12 That's a question we have in our minds, too. Yes. Is there anything else that you wanted to share that we didn't talk

about?

Marilyn: I don't know. 34:12

34:47

Interviewer: 34:16 Actually I do just have another question, and then if you have

> something else you want to say... What are questions you still have about mental illness that don't understand, that you want

to understand, that's still a mystery?

Marilyn: Oh, I would like to understand about mental illness, what really is happening in the brain? That's not going to happen. I don't think, in my lifetime, that they'll figure out how some of these work. It would be so wonderful, I know there's a lot of brain research going on, if they could pinpoint and get a medicine that pinpoints that. So you don't have these medicines that are

just scatter, shoot, and so many side effects as a result. So better understanding of the brain would be wonderful, but that's the future.

One thing, I'd like people to try to see the individual and not the illness. That's one of our principles of support in NAMI: See the individual, not the illness. And that's with a lot of things, if people could just look at other people and try to see the person, that would help. I would hope that people coming to the exhibit

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Interviewer:	<u>36:06</u>	Is there anything else that you wanted to share?
Marilyn:	<u>36:06</u>	I think that's it.
Interviewer:	<u>36:06</u>	Well, thank you so much. This is wonderful.
Marilyn:	<u>36:16</u>	You're welcome.
Interviewer:	36:19	I have a My printers messed up, so I'm going to email you a release form which would give us permission to use the footage.
Marilyn:	<u>36:28</u>	Okay.
Interviewer:	36:28	If you have second thoughts and you don't want us to use it, you don't need to sign.
Marilyn:	<u>36:29</u>	I'm already with NAMI on YouTube, whatever.
Interviewer:	36:29	[Inaudible 00:36:39] Thank you for sharing all that.
Marilyn:	<u>36:40</u>	Oh, you're welcome. Yeah. I'm willing to help anyway I can.
Interviewer:	<u>36:45</u>	Well, this is You're doing what you want others to do, right. Talking about it is the first and, it's always been, the only way. You're leading by example, so.
Marilyn:	<u>36:56</u>	Yeah, because it's not easy.
Interviewer:	<u>37:00</u>	Thank you, Marilyn.
Marilyn:	<u>37:01</u>	You're welcome.
Interviewer:	<u>37:02</u>	And I'll email you

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