



Depression and Bipolar  
Support Alliance

## Jill's Story

*Transcription of a DBSA Podcast*

**Angie:** Welcome to a podcast by the Depression and Bipolar Support Alliance. My name is Angie Day and I am the Chapter and Volunteer Services Director. Today, we are going to be speaking with a parent, Jill, who is going to share her experience as a parent with a child who has a mood disorder. Jill would you mind starting us off with a quick introduction?

**Jill:** Sure: My name is Jill and I am married to a fella named Randy. And, the daughter we are going to talk about today, her name is Anna. She's 15 years old, almost 16. She's the baby of a large family. We have seven kids; she is the only one who is still living at home.

**Angie:** Thank you. And, thank you for being willing and able to share your story and your family's story with us. Maybe we could start off with - before becoming a parent, what was your experience with mental health?

**Jill:** I knew it existed. I really didn't have direct experience with it. I can - once my daughter was diagnosed, we could look back and see other family members that struggled in similar ways, but they hadn't been diagnosed. It wasn't called mental illness for them.

**Angie:** Sure, and I think a lot of individuals would have a similar experience to that. When did you first start noticing symptoms of a mental health or illness occurring with your child?

**Jill:** In our case, it was very early. At four years old, my daughter would have periods where she wouldn't sleep at all for like 72 hours, and then she would crash and she would sleep and we could hardly wake her up for another day or two. And, since she was the youngest of a big family, I - we knew that's not normal. And, so that helped push us to start to ask questions and to try to find help.

**Angie:** And, did you know that these were potential symptoms of a mental health issue when they started occurring?

**Jill:** Not really. One of her older siblings is extreme ADHD. So at first, we were like well, it's probably ADHD. But again, he would be bouncing off walls and a bit out of control, but he would sleep at night once we got him to go to sleep. So we saw it as: well, there is something different, we don't know what it is. Actually, in our case, I kept telling my husband there is something here. He kept saying, oh no your an older mom - you are just not coping as well with normal behavior. And, I knew that wasn't it. But there was an ad on the radio that had all these handful of questions. You know - does your child have this, do they act like this, do they act like this. If so, please call us, we are doing a medication trial. And, it described my daughter perfectly. And, it turns out it was a medication trial for meds to be used in bipolar in children. And so that's really the path on how we got to an initial diagnosis.

**Angie:** Wow, so it was actually when you just happened to hear on a radio that set you towards a path to finding what your daughter needed.

**Jill:** Yeah, yes. Isn't that crazy?



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**Angie:** Wow. Oh, it is incredibly powerful and how fortunate that occurred and you that you had a radio on at that exact moment. When that was happening, before you had kind of discovered what was going on, how did you feel?

**Jill:** I felt overwhelmed. And, like I said, we've got a big family. I'm good at having a bunch of kids and chaos. I enjoy it. This one took me over the top. I felt like it didn't matter what I did. I couldn't find a way to help her deal with life, and I knew that I am normally good at that as a parent.

**Angie:** Yes, absolutely. What kinds of supports were available to you at the time.

**Jill:** There really weren't a whole lot. Because - we would - any of my friends, most of my family, if a I brought up my concerns, it either blown off as either you are either overreacting, she's just a normal active kid or it was blamed on, well, you know, you do have a large family or well, you know, you are homeschooling, why don't you put your kids into school and then you will have plenty of energy for her. At the same time, I knew those things really had nothing to do with what was going on with my daughter.

**Angie:** It sounds like some of your natural instincts were spot on but they were being invalidated by those around you. Is that right?

**Jill:** Yes, that would be a good way to say it.

**Angie:** So you heard this ad on the radio and you called in, you found out more information. What ultimately helped? What started to shift things for your family?

**Jill:** First of all, in the meds trial, it started on a particular med and then it was switched to being whether it would be a placebo or not a placebo. Fortunately, she was kept on the actual med. We saw a night and day difference within a handful of weeks. Suddenly she was not melting down in anger, she was sleeping at night, she was much more regulated in a lot of ways. That's not the experience with most families. The first med she tried worked beautifully. She is still on that medication 11 years later - different dosage obviously - but it still is what keeps her regulated. That's not the experience of most families. Most families I know go through a bunch of different medications that don't work until the finally find the right one for their child. But for us that was just transformative.

**Angie:** That's really incredible. It sounds like for any family who might be facing a similar issue, having some resilience and patience with what maybe be a long process is really important.

**Jill:** I think so, yeah. The other thing for me is I'm a person who anytime we face any new challenge in life, I go find a book or as many different books as I can about that topic. So as soon as we had a diagnosis, I started finding every book - there weren't many out there - but finding what I could about bipolar, specifically in children, because it looks so different in children than it does for adults. Books like that helped reinforce I wasn't crazy, I wasn't overreacting. They would describe things and I was like "oh yeah, that's my daughter". That's what life was before we did the meds or that's what life is like now. That was a help to have books to reinforce that. Eventually, it took me quite a while. But, eventually, I started realizing that I needed to have contact with other families that were facing similar issues.

**Angie:** Was that easy to find other families with similar issues?



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**Jill:** No, it was not easy at all.

**Angie:** I couldn't imagine that it would be. How did you connect?

**Jill:** Partly, It was - ok - I'm very much an extrovert; I will talk to anybody. If we would be out someplace, like maybe the playground, if I would see a parent whose kid look like that maybe they had some similar challenges. I would strike up a conversation and kind of see, you know, just try to be affirming, but try to see would they kind of take the bait. Would they want to talk about their kids, the challenges, etc. And, at that point, I wasn't looking for a parent who had children with mental illness, I was looking for parents whose kids were a big handful. That we could, at least, connect on that level. It was a number of years later that I discovered the parents forum on DBSA and suddenly, it didn't matter if I had - I didn't have to find somebody in my neighborhood or town. That gives access to people internationally who all have similar issues.

**Angie:** That's really incredible. What else helped you? As a parent who has seven children and a lot of responsibility in that area. How did you support yourself during that process?

**Jill:** Part of it was something that I learned as a stay at home parent. To cope with that, I had to become good at saying to my husband, I need a break. I need a couple of hours to just go to the coffee shop, all by myself, with nobody else, no children, and I would take a book or I would take something to doodle on. I would just sit and stare into space, whatever it took. So, I had already gotten good of that because of having a big family and because of homeschooling. Eventually, it took a while for my husband to see that this kid really was different and that I needed more support. And, I didn't need as much from him. He works hard. He is earning the income for all of us. It wasn't that I needed him to jump in and do things as much as I needed him to affirm, yes it was appropriate for me to take breaks. It was appropriate for me to get away. That's what I needed most from him, and I jumped out there to say, "I need this. I am going to make this happen."

**Angie:** Yeah, it sounds like that was a really important part of the process for you, and something that I think that we can all learn from. I know that even though I am not yet a parent, just carving out a little bit of time here and there during stressful times is so important for me.

**Jill:** It really is, and it is something that unfortunately, our culture on a big scale and our friends and family on a small scale, they throw at us that this is selfish. Why would you do that – that's selfish. That's just the word that you hear a lot, and, its no – I know that we all maybe hear the story of, you go on an airplane, and they say put your oxygen on first, before you put it on anybody besides you. We can't help other people if we are totally burnt out, frazzled, and overwhelmed. On the one hand, we hear that, and we hear that in the culture, and on the other hand, we try to do something to get more oxygen, to get more sanity, to get more calm in our lives, then it gets thrown at us that we are more selfish. So, to some extent, you have to be stubborn. To say, no this is what I need, and I am going to do what I need.

**Angie:** That is really terrific, and I wholeheartedly agree with you. When thinking about managing a household with a large number of individuals, how did you find time to support your other children when your daughter was having some challenges?

**Jill:** That one I consider us to be pretty lucky, because I look back and I think if she was – for my first five kids were two years apart. Just two years between each one. They were very close together. If she had been one of those kids, that



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would have just made it really overwhelming. But, then there was a gap to her next older brother – there's actually almost six years between her and the next older one. So, it meant that I really wasn't needing as much moment by moment interaction with the older kids. If they had been toddlers, preschoolers, and young school kids, and I am dealing with her, that would have been really, really difficult. Because, the older kids – I could give them some attention and then they could do things on their own, that made it easier to handle what she needed. In addition, one of the things that, and then of course, then I didn't feel quite as selfish either, one of things that I would sometimes do to get a break for me is my husband would watch the majority of the kids, and I would take one kid at a time with me to run some errands and we would stop and get a treat. And, that way, they got some one on one attention from me. I got a break from all of the kids and from my daughter, I got something done that I needed to get done, but that became a win-win. Occasionally, my husband would have some time and he would take one or two kids on his own. But like I said before, often, most of his effort has been focused on working and then coming home and doing things like mowing the lawn, you know – chores around the house.

**Angie:** Yeah, that makes sense. So, during this journey, when you learning what your family needed and what your daughter needed, what comes to mind about what was not helpful?

**Jill:** One of the biggest things is to politely ignore all the suggestions and advice from people that don't agree that there is mental illness going on or that don't understand mental illness. So, it was really important to tune them out. They would give all of this advice, and it has no bearing, what-so-ever, on my kid and on my family situation. Quite honestly, that also has been applied to – there has been a handful of medical professionals over the years that we have fired, because they just didn't see what life was like in our family. And, what they were saying didn't work and they wouldn't listen to me. So that's a big thing – walk away from anybody who is giving advice that doesn't fit. Another thing that is not helpful is don't read too many parenting books, magazines, blog posts, about parenting neurotypical kids that don't struggle with mental illness, because you will just drive yourself crazy. Most of their suggested parenting styles and ways to deal with things backfire when we use it with our kids.

**Angie:** Sure, I think that is really incredible, and I love your point about making sure that your voice is heard and taking a stand when it is not. I think that's incredibly important as well. I start thinking about the mental health space in general, and think that there are obviously challenges, things that have gotten better over time, and things that have not. Are there any challenges that you see that exist in that mental health space now?

**Jill:** I can think of three things. One is that, and I know that this is something that other families will disagree with me on this – the only way that we are going to change the stigma on mental health is that we have to, as families, we need to be very open about what we are dealing about our child's diagnosis. Be open with them about it, and be open with the larger world. If we don't speak up, if we hide it, the stigma is only going to continue for as long as we hide it. Like I said, a lot of families very much disagree with me on that. They feel a very high need for privacy. I can respect that for them. For us, we are just very open. This is just what we deal with. And, we talk about it. Hopefully, that way, it helps other families see that someone with mental illness is not strange, weird, or different. That is my daughter. They love my kid. She has mental illness. There is not as much stigma for that.

The second thing is that we have a desperate need in this country for more medical providers that have a clue about mental illness. There is a desperate shortage of psychiatrists, and then it takes an additional two years to become a pediatric psychiatrist. That means that shortage is that much worse for them. But, in addition – just pediatricians. It



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would help if they had a better knowledge of mental illness. Nurses. You know, we need a better, we need a better way to get the help that these kids need, and it just, there isn't the man power out there to help the families.

And then the third thing would be – and I guess they're all related – the third thing would be – we need more knowledge in the schools amongst the teachers, amongst, you know, the people at the library. The places where we take out kids. Sometimes I get weary of trying to educate them on what is normal behavior for my kid, and when she does these things, its not bad parenting, its not dangerous. Yes, it's different, but it's normal within the medical illness that she has. It would be helpful if there was some way to better educate our country as to what does this really look like.

**Angie:** Yeah, absolutely. I think those are really important points. Thinking about the fact that you said that you have been on this journey for a little over eleven years, and maybe a little bit more, what do you wish you knew at the beginning of this journey that you know now?

**Jill:** I think the most important thing that I kind of knew what to do, and that was trust your instincts. If you as a parent feel like something is wrong or something a little off, you are right. 9 times out of 10 – you are right. So trust your instincts. And, closely related to that, is the piece of find your voice and use it. Be an advocate for your family, for your child. Keep asking questions, and if somebody isn't listening to you, either just go find someone yourself or ask for a referral. And, it takes a lot of courage, it takes a lot of energy. And, often, when we are dealing with our kids that are in crisis, we don't have much energy to spare. But, once you find people around you – medical professionals, friends, other people around you that are support for you, that listen to you, then suddenly, as issues are resolved, you have far more energy to deal with every aspects of life. So, ask questions and use your voice.

**Angie:** That's incredible. And then, how is your family doing now?

**Jill:** In general, we are doing quite well. All of my older kids are grown and living independently at this point, so we are dealing with just one child at home. And, there have been some adjustments to that. My husband and I really had to take time to recognize that she may or may not ever live independently. We have high hopes that she will, but right now, at almost sixteen, she's not heading to college at a normal age. She's not going to be living independently at a typical age. We hope that will happen a little later. And we had to take time to grieve that. To grieve – to let go of the dreams. To still be supportive and still dream dreams with her, but let them be dreams of her strengths and weaknesses, not the typical parent dream of well, she will go to college and she'll meet a guy and she'll get married and she will have a wonderful job. And, she will have a wonderful family. Having to say, those things may or may not happen; her path is going to be different. So that has been an ongoing challenge – is to find a balance between letting go of unreasonable things and at the same time, holding dreams out there for her. It's also been challenge I expected. We do a good job of raising our kids to be very independent, and the rest of our kids by the time they were this age, I could have had a part time job outside the home; I could have been doing other things. I can't do that. She needs me around. She needs me making sure that she is making safe decisions and so, I have had to let go of some of those things for myself, and say that this is the child that we were given. These are her issues and what she needs from a parent, that parent is going to be me. I just have to step up to doing that. And, it's also a case of having to remember some or a lot of days – things go smoothly, she does the things that she is supposed to be doing. She is homeschooled still, you know, and she steps up and we think, "ah – she has finally got it." But, more than the rest of my kids, she may have everything going fine one day, and then the next day, it's like everything that she has learned, all the coping skills, all the life skills, are just gone. And, I have had to step back and say, hey, she does have them. She had the skills yesterday, she will have them tomorrow. Just ride this day and let it be. Don't panic. They are not gone. She is just not accessing them today. It's a



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whole different style of parenting and my oldest daughter is almost 34 years old, and there are days where I know that I am good parent, I've got this down. Then there I deal with my youngest daughter, laugh, and say, "well, obviously, there is still a lot left to learn."

**Angie:** With that thought, do you have any advice that you would give to parents who are maybe just starting their journey or even in the middle of helping to find what their child needs for wellness?

**Jill:** Probably the biggest thing is don't get locked into just one thing. So, to being with, my daughter took meds. That helped significantly. But, eventually, the time came where, especially right around puberty, that things all derailed, and she was back in crisis. At that point, we finally started doing some therapy. We started looking at, ok what else is going on. We had a really good psychiatrist who figured out it wasn't just mood disorder, it was also extreme anxiety, which was fueling more of the instability. So, we started dealing with that with therapy, with meds. You know, at this point, we also look outside the box. This doesn't seem to make a difference for our family. I know that there are families where diet makes a huge difference, for instance. Or a huge change. For us, my daughter and I take four to six weeks long backpacking trips in the back-country wilderness along the Appalachian Trail. When she is out in nature, she is much more stable and much more settled. I like going out there too. So, we take trips like that. Obviously, I am not suggesting that all families go do that, but the point of bringing it up is to say that keep looking for the all the various different alternatives that are out there. You will find the mix that works best for your child and your entire family. But, its not going to be just one thing, and if you find one thing, it's not going to be that one thing that is the answer all the way along. You are going to have to keep looking for new solutions.

**Angie:** That makes a lot of sense. Well, Jill, thank you for sharing your story and speaking with me this morning. Before we close, did you have any last thoughts that you wanted to share?

**Jill:** I think the most important things to say that I've got a daughter who is almost sixteen. I know that a lot of families who will listen to this have much younger ones. When you are just starting on this journey, it can be overwhelming. And, you think, is this what it is really going to be like forever – in constant crisis. To be honest, it is possible. But, I would say have hope. For most of us, kids become more stable. We figure out as a family ways to support them in the best way possible. Life is unlikely to remain total chaos. There is hope that things will stabilize.

**Angie:** Wonderful; thank you. And, to our listeners, thank you so much for joining us today. To learn more about mood disorders for adults or in children, please join us at our website at [DBSAlliance.org](http://DBSAlliance.org). You can also find the parent forum that Jill mentioned there on our website. And, with that, we are going to go ahead and close the podcast today. Thank you.