Matt (host): Parenting a child with autism is hard. Parenting two children on the spectrum while battling your own addiction sounds impossible. Today on Nimble Youth, I'm talking with Jamie Hrobar, autism mom, woman in recovery, and creator of the online community Homebound and Healing. We're gonna talk about severe autism, self injury, systems that fail families, and what it looks like to heal yourself while you're still taking care of everyone else. Please stay with us.

Welcome back to Nimble Youth, the podcast where we explore the real lives of kids and families navigating mental health and developmental challenges. I'm your host, Matt Butterman. My guest today is Jamie Hrobar. Jamie is a mom of two autistic children, a woman in long term recovery from alcoholism, and the creator of Homebound and Healing, a Facebook community where thousands of parents come for raw honesty and hope. Jamie, thank you so much for being here.

Jamie Hrobar: Thank you for having me, Matt. I'm grateful for this opportunity to chat with you.

Matt (host): So when you introduce your family to someone new, how do you describe your kids and what everyday life looks like in your house?

Jamie Hrobar: Sure. You know, I usually start out by saying I'm the mom in the middle. I've got two boys on opposite ends of the autism spectrum. And my younger son is a level one diagnosis. He is extremely creative, so interested in science and history and facts.

He is, we say he's never met a stranger. It doesn't matter if you're six or 60. He's actually extremely social and loves that interaction and really thrives on it because of the life he's had with a brother that is on the very severe end of the spectrum. So he loves community and being with people, which a lot of times you don't hear about. He loves all of that.

My older son, Jim, is level three diagnosis, profound autism, non speaking, and he is very much into routines, structure. We certainly do well with all of that. He's 21 now and he's aged out of services. So life looks very different today. So when people ask me about my kids or invite me to something, do have to explain that pretty much we're home with Jim most of the time now, still looking for services for him now that he's aged out of the education system, which I'm sure he'll get into.

But both boys have had issues with eating. They do have some sensory. Jim has very high sensory needs. Christian, not so much. But I have to say they both are just my greatest teachers.

They really are. They've both taught me so much about what's important and they've both contributed just such unique pieces to my life in their own special way. Our house are, you asked about what every day looks like here. Toy Story is playing on the TV all day long. Jim takes medications that cause him to be hungry all of the time.

So like we have our house looks very different. We have a lock on the refrigerator just to help with with Jim's eating issues. His room looks very different when someone comes into our home and they see the kids bedrooms. Christian's bedroom looks very different than Jim's. Christian has instruments in there and computers and just tons of tons of objects.

Jim, his room, we can only have very minimal furniture in there. He has a bed that was specially built for him by a friend of ours because he had broken so many pieces of furniture. Sometimes in bouts of self injury and aggression and other times just because he's rough, like he doesn't really know his own strength. And so the bouncing and the jumping, we went through more beds than you can imagine. Lost count couches too.

I mean, I even know how many couches we've purchased over the years. So very minimal in there for lots of reasons. Our house looks different. All of our doors and windows have sensors on them. So if any Jim has a history of eloping, not as many as some other kids.

I'm very grateful for that. But you know, one time, one was very severe, one was very serious. We had lost him for a long time and anytime a door or window is open in here, need to know which door, which room, so we can intervene very quickly. A lot of precautions in our Yeah.

Matt (host): So when did you first realize that your kids were developing differently and what do you remember about those early days of getting an autism diagnosis?

Jamie Hrobar: Well, Jim was both boys, I will say, were diagnosed very early. And I'm extremely grateful for that. Jim was diagnosed at about a year and a half. He had stopped speaking. He had stopped imitating.

He had stopped looking at me. I can remember early on there was a day where he wouldn't look me in the eyes for, I think it was fourteen hours straight. And it was gut wrenching and I was terrified. I did not know what to do. I was so grief stricken.

Initially thought that he had lost his hearing because he had stopped responding to my name. So in the beginning with Jim, it was tons of doctor's appointments, audiologists, all of that at first. He had also stopped eating. He was a great eater in the beginning and we got to a point where he stopped eating solid foods for six months straight. I was so concerned.

He was living on Carnation instant breakfast shakes three times a day. He would not eat anything solid. The tantruming was insane, hours and hours of tantruming. And we were very fortunate to get in to see some fabulous doctors. He was accepted to a private school for individuals with autism going there by age two.

And that he received very intensive early intervention services, basically from the jump, almost as soon as we got the diagnosis. There was a very small window waiting. Once we found out that he got accepted to the school, I think they gave us like two weeks to pack up our house and move to another state, we did it. There was a ton of fighting for what these kids needed. Christian was diagnosed, I think at about 11 old, he was diagnosed.

I attribute that truly to having dealt with this already, having dealt with it, having seen having seen what happened with Jim, although they they were different in that Jim had language, Jim had skills, and and then he started losing them. And Christian was just not developing them on schedule because of Jim's placement at private school. I was getting to be around lots of kids with autism. And so I was seeing all of these different symptoms, how it was presenting in different kids. And it was about 11 old.

Christian started, he was banging his head against a wall in the living room. And I don't know, like the light just came on and I thought, uh-oh, you know, here we go again. But I'm grateful for that because I knew who to call. We went to the same doctor, we got the diagnosis and some people had said, I remember to my father, Oh, maybe she's overreacting. Maybe she's a little highly sensitive to all of this.

My father basically just said, you know, she knows what she's looking at.

Matt (host): Sure.

Jamie Hrobar: And so we got that diagnosis and I'm grateful that Christian was afforded the opportunity to go to that school as well. They both had very different outcomes so far because they had varied while they had the same diagnosis of autism, they fell in different places on the spectrum. So Jim was at that school for ten years until we moved to South Carolina to start our own program. And Christian was there, I think just a little bit over a year and then was mainstreamed. He was doing beautifully.

So, you know, the school kind of, we had to meet them where they were.

Matt (host): Right. Yeah. And so you've been very open that this has not been a cute, quirky version of autism neurodivergence. This has been, these have been severe developmental delays in both your children, right?

Jamie Hrobar: More so Jim. Had more issues with some sensory concerns, which, you know, we worked on and the biggest of those really was the eating, eating issues. And so he did therapy, feeding therapy, extensive feeding therapy. He's, he's doing great now, but, it was tough, you know, he wasn't growing. It was, it was scary.

He was getting extremely skinny. You know, I love when people say oh you know just just put the food out and they'll eat it when they're hungry. That is the biggest crock in a household like this one. You know I would never do such a thing because they wouldn't eat if they were hungry. I've been in situations where I had to literally, when Jim was hospitalized for four and a half months in Baltimore, Maryland, I used to get on a plane every week, not only to see him and train with the staff there, I would spend half the week there and half the week home with Christian.

I also went there to feed him because he was not eating. And so I was literally on a plane so that I could feed him. That was also part of the reason so that I knew several days out of the week he was eating.

Matt (host): Right. Yeah. And those are some of the hard realities that people just don't see, right?

Jamie Hrobar: No, they don't. You know, we get judged for that and it's tough because we judge ourselves an awful lot. We're just, we're, we're trying to do our best. With kids like Jim, you know, I always try to protect, protect Jim's dignity, of course, in, in what I'm saying, but it is not easy. It is not easy.

It's a struggle. It's a constant struggle. He is such a bright light in my life and in so many other people's lives, but there are a lot of challenges. I mean, that's just the reality of it. So the judgment is tough.

If there was an easier way to do things, believe me, we'd be doing it. Nobody wants to make it harder than it has to be.

Matt (host): Exactly. Yeah. And so alongside all of this, dealing with two boys who had autism, you were also living with your own struggle with alcohol, right?

Jamie Hrobar: Yes.

Matt (host): And so how did the drinking start out in your life and when did you realize that you shifted from purely a coping mechanism into something that was really taking over your life?

Jamie Hrobar: Say drinking was a problem the minute I put it in my body. It had nothing to do with my kids' autism. The first time I had a drink actually by accident, I took a sip of champagne at a wedding, at a family wedding. I was a young girl, I was a flower girl on that wedding, and I took a sip of that bubbly liquid and it immediately did something for me. I mean, that's just the best way I can say it.

I loved the way it felt. I didn't know what it was, but I loved the way it felt. And I proceeded to go around to all of the glasses at the table while people were on the dance floor and taking sips out of those glasses. And that was from a very young age. I immediately loved what alcohol did for me.

And it also kicked my rear end the first time I ever had it. So even as a young kid, I mean, remember that night I blacked out, I got sick. I woke up with a terrible headache. I was kept on a very tight leash for most of my young years. Thank goodness.

By the time I got to college, I didn't go out a ton because I was interested in my, I was very into my studies, but every time I went out, it was not good. It was not good. And it just got worse and worse over the years. You know, like to say I drank the same at weddings as I do at funerals. And so for me, really had nothing to do with why I drank.

You know, I had a mental obsession with alcohol. And once I put it in my body, I could not stop once I started. So it's not that I didn't necessarily use it to deal with just bad situations. Drank if it was rainy or sunny. It didn't matter.

Matt (host): Right.

Jamie Hrobar: I drank when my marriage was good. I drank when it was bad. I drank when we were in the middle of a snowstorm or if I was on a Caribbean vacation. So, you know, that really didn't have anything to do with it. I always do like to be clear that, you know, having children with autism, you know, did not cause that.

Matt (host): It drive you to drinking, right? It

Jamie Hrobar: certainly did not. No, it did not. Yeah.

Matt (host): Right. Right. Yeah. That's an important point, I think. But you found your way into a 12 step program and into recovery.

Did those first months of sobriety look like while you were still parenting two kids with really high needs and what helped you stay sober when everything around you was still constantly changing and very intense?

Jamie Hrobar: Well, can say that the first time I walked into twelve Step Recovery, I thought I was going to do it my way, which is how I like to, that's how I lived my whole life, just doing everything my way. In some ways, you know, that self reliance, go getter, that I'm gonna figure this out attitude really has served me. You know, it has helped me to get some really great services for my children and to fight for them and make sure that they get what they need and what they're entitled to. But in terms of my drinking, that was failing me miserably. Walked into twelve Step Recovery and I thought, well, I'm going to do it my way and I'll just pick and choose some of these things that you're suggesting that I do and the other stuff that doesn't sound so great to me.

I'm going to skip that. I can tell you that landed me in a horrific relapse. I'm grateful to be alive and to be sitting here having this conversation with you. It's never lost on me. I often say, you know, I should either be dead, I should be locked in a basement somewhere, maybe being tortured, you know, I don't know, or I should be behind bars.

Those are really the three things that should have happened to me. The fact that I get to have this opportunity to sit here with you, it's never lost on me that I get to do this and talk about it. That I had this horrible relapse thinking that enough time had passed since I'd put any alcohol in my body, because it was a good chunk of time and I had no like mental defense against anything and I was presented with a drink. Thought enough time had passed and I'll just I'll have this one and I'll get right back on the horse tomorrow. And that is not what happened.

I like to call that my confirmation drunk, which lasted a year and two months. And it was brutal. It was brutal. So I finally, when I had had enough of that and was white knuckling it again for a minute, I was, my ex husband came to me and said that he had wanted a divorce. Our marriage had been in a tough spot for a good while.

And I knew that if I did not go back to twelve Step Recovery and do everything that was suggested to me and stop trying to do it my way that I was going to drink again. And I couldn't afford that, my kids could not afford that. And so I became willing to basically do whatever anybody told me. It was not easy trying to do all of this while trying to take care of them and also becoming a single mother again. That was very, very hard.

I am grateful for the people in recovery that surrounded me, that helped me get through incredibly challenging times, that encouraged me to develop a relationship with a higher power that I did not have before. I was the only higher power I knew, you know, that reflection in the mirror and, and

Matt (host): that's Let's talk little bit about, let's talk a little bit about that. On your, on your website, you describe yourself as a former atheist who now has a very personal spiritual life. And so how did your view of God or, or heart, higher power shift through your recovery and how does that now show up in your day to day life? Not just in those big dramatic moments that we all encounter.

Jamie Hrobar: Sure. Well, when I finally came back into 12 step recovery and I had avoided the whole, that was the piece I was missing early on, you know, wasn't going to do that. I did not believe in God or a higher power. I say God, because that's what I choose to call my higher power. I mean, I don't care what anybody calls it, you know, and as long as it's not you.

Anyhow, I was told, you know, that I needed to get a higher power and my initial view of God early on, was questioning, you know, was brought up with religion and all of that. I went along with that and I even went to Catholic school for a little while. I would picture as a young kid, God up in the clouds with my relatives that had passed on and all that. And then as I got older, I started questioning things. You know, I was seeing a lot of suffering and people with cancer and all sorts of stuff.

I was like, I don't know about that. And some tough things happened to me also. And I was wondering if God was actually this protector that people were saying. And so I kept questioning, questioning. And then when Jim was diagnosed, that was sort of the nail in the coffin for me.

I was not angry with God. Do like to make that distinction. I was not angry. I just felt that if there actually was a God of some sort that he, she, it would not allow things like this to happen to innocent children and all the other stuff that goes on in the world. I just thought that didn't add up for me.

And so I just thought there wasn't one. I wasn't angry, there just wasn't one. And after not having this higher power in my life that people suggested, I became willing this time to do whatever it took to get one. I looked around these rooms and I saw people that they seemed very peaceful. They seemed to be meeting life very successfully on most days.

And they were experiencing really joyful things and really tough things. And that was important for me to see that because just as I said, I drank the same at weddings as I did at funerals. So I need I need to know you've got something that works in all situations, right? And so I became willing and I didn't know what it was. But I was I was willing to believe that they believed in something.

That's how I got started. Was just well, it was clear to me that they believed in something that was obvious. And so I was like, how am I going to do this? And they said, start by praying. And I didn't really know anything about me.

Knew the prayers of my childhood, but they didn't, I didn't feel anything with respect to them. So I thought I've got to kind of start from scratch here. And, I got a bench and I put it outside and I sat on this bench and I would go out early in the morning when the kids were still asleep and I'd go out there and I would try to just make contact with something out there. I felt foolish and I would wave and I'd say, hey, I don't know if you're out there, but I'm told to pray and I don't if you can hear me. And I just started with simple like, please and thank you.

Please keep me sober. Thank you for keeping me sober. And just as the weeks went by, prayers started to evolve. I started to talk a little more sincerely. There were things that started happening that I just, I started to, I knew, like I knew inside that my higher power was listening, that I had actually like made contact with this thing.

I know it sounds hokey. I know it sounds crazy. But today, for me, I have a direct hotline to my higher power. I spend time in prayer and meditation. I talk to God and I listen.

And I don't argue when my higher power tells me to be helpful to people or try to see who needs something. And he's usually pretty direct about who he is he wants me to help, which is very cool. But I will say having those people in my life, continuing to have those people in my life and this relationship with this higher power has made all the difference during my divorce. Before I got remarried again, things got tough again with Jim. For a while, was on my own and things were getting dangerous again and very serious.

I I was faced with a very tough decision and I had to place Jim in a residential facility. And I could not have done that without a higher power and the friends that I have in recovery. There's just no way. And this is a thing that has worked for me in all situations, in all areas. I mean, I remember my first time in recovery there was a woman with a tattoo on her arm and it said no matter what and people were saying don't drink no matter what and I was like yeah okay you know that makes sense to me.

Mean I could probably like I think I could try to drink no you know not drink no matter what unless two things happened. I had these reservations, unless two things happened, unless something happened in my marriage or if something happened to one of my kids. And the first time during my relapse, again, I mentioned my marriage was kind of on the rocks and we were not in a good place and I didn't like how that felt and I had no solution. I was not working a program. I was in the weeds and I drank, you know, and this time when I came back and was willing to do everything and get a higher power and all of that, you know, I made it through a divorce.

I made it through putting Jim in a residential facility. I have been able to, well, let me back up. Jim was being abused in that facility. We found out that Jim was being abused in that facility and I was able to bring him home. I've been divorced in sobriety.

I've been remarried in sobriety. Great things have happened with my kids and really tough things have happened with my kids. And I have been able to get through those successfully, you know, no matter what and not white knuckling it like, oh my God, I hope I don't, you know, I haven't had the desire. The thought hasn't even entered my mind. And that's a beautiful thing.

That's a miracle for someone that used to obsess about, you know, when am I going to get it? How am going to get it? Do I have enough? I mean, these were the constant. This was the hamster wheel.

Matt (host): Right.

Jamie Hrobar: And I don't live like that today. And that's a beautiful thing.

Matt (host): Yeah. Well, so you mentioned the abuse that Jim had faced in one of the facilities. And so that brings up, I want to zoom in on the system side of raising two boys with autism because the families in situations like yours, they're often fighting on 10 fronts at once. So what have been some of the biggest barriers you've run into trying to get services, and then the right services, and then, you know, the services that won't actually do harm to your kids. It's like, you're trying to put all these pieces together and then sometimes the pieces themselves fall apart, right?

Jamie Hrobar: Yeah. You know, there, there have been times where I have felt like I was fighting a war truthfully. And I would say the biggest barriers are there are such extensive wait lists for doctors, for therapies, for services, for hospitals. The list is so endless. There's only a certain amount of resources, right?

And I often think back to when Jim was first diagnosed, that was around the time that Autism Speaks was founded. So that was twenty years ago. And there was such a huge focus on early intervention services, which is so important. I mean, of my kids benefited so greatly from that. And I think that's so important for every family that is going through this and gets a diagnosis.

I think part of the problem though, you know, all of this funding got poured into early intervention and it's almost like everybody forgot that these kids were going to grow up has grown up. He towers me. He's a man and he towers me. And because of the level of the severity of where he falls on the spectrum and the many deficits that he has, while there are day programs out there, they're not really suitable for Jim. And this is not my opinion.

These are things that have been said to me. He needs a special aid with him, a qualified trained professional. And we have had a hard time finding somebody to be able to go with him. I have had some day programs actually like essentially tell me he's too disabled to go there, which kind of blows my mind because that's what you're there for. Anyway, I'm you know, not telling you how to run your organization.

But anyway, yeah, so the wait list and things that not enough resources, not enough, you know, just families financial capabilities too. I mean, kids are expensive. I mean, Jim is insanely expensive. His food bill alone would blow your mind.

Matt (host): Right.

Jamie Hrobar: But the therapies he's needed and the services, you know, some of them were astronomical. I'm grateful that I've always had a of luck with school districts. I will say sometimes that came as a result of having to get involved in lawsuits, I will say. And that was unfortunate. I was in one that lasted two and a half years with the district.

So that is tough. Doctor getting into doctors, you have to fight. I mean, you know, I've also become an advocate for other families because I know how hard this is. The documentation, the paperwork. I mean, the stacks of paperwork to prove that, you know, your child has these deficits are, I mean, just come over for five minutes.

I mean, it would save us a lot of work.

Matt (host): Yeah.

Jamie Hrobar: So yeah, you know, these, there's a lot of financial barriers. There's a lot of barrier, lot of red tape.

Matt (host): Right.

Jamie Hrobar: So.

Matt (host): And all these fights are going on with a system that's chronically underfunded and seemingly less funded now these days than, than, than before. Yeah. It just makes it so difficult.

Jamie Hrobar: For families like ours that are dealing with such extreme behaviors, mean, Jim is in a very good place right now, but for years it was so, the self injury and aggression and the property destruction was so severe that I said, you know, he needed a four and a half month hospitalization at specialized hospital that only has 16 beds in the unit. The waiting list is insane. We waited over a year for his bed to become available and you have to have very extreme behaviors in order to require or even qualify for a bed there. And so it's like, you know, all of these hoops that you have to jump through in order to get to that, like when you're getting your rear end kicked all over the place and you're literally, I mean, like physically getting your rear end kicked all over the place and trying to keep your child safe and have all of this protocol and safety measures in your house. And you're just like literally trying to make it through the day.

That is extremely hard then to have to constantly be filling out paperwork. And I mean, Jim was engaging in self injury and aggression for hours upon hour. Mean, insane amounts of time throughout the day to put it into perspective at the time of his hospitalization, he was hitting himself on average 40,000 times a month. I mean, that number, you just can't even wrap your head around it.

Matt (host): Right, right. Yeah.

Jamie Hrobar: So the level of what we were dealing with was just unimaginable. And then to be having to be in lawsuits and jumping through hoops and all of this, it's like, you know, how do you do all of that? I mean, we were grateful to have therapists that could help for, you know, part of the day, but sometimes it was all hands on deck. I mean, there were times we had four or five people like restraining. So it's a whole another world that people just a lot of not people a lot of people don't have any idea about.

Matt (host): Right. Yeah. So if a parent is listening and their child has just gotten an autism diagnosis and they're feeling completely overwhelmed as I know you did. What's the first practical step you'd tell them to take now this week?

Jamie Hrobar: Can I give more than one?

Matt (host): Absolutely.

Jamie Hrobar: I would say there's just a couple of things I would say. Life is about to look different and I don't know exactly how different it's going to look because as I said, I'm the mom in the middle. Our beginnings with both of these kids looked a little different in terms of the amounts of therapy they were going need or all of that. But if you have gotten the diagnosis, my biggest piece of advice is start learning what your child's rights are. That is going to be so important, so critical.

I mean, Christian being on the higher functioning side of the spectrum, I mean, I still needed to know his rights. He still needed to go to a specialized school and thank goodness that he did because he's just doing so beautifully today. So that was such a gift. But you've to get educated and find the right schools and the right doctors and learn about what your rights are because these kids are entitled to services. They are entitled to a free and appropriate public education.

And as much as I wish people are going to come to your door with a binder say, here's how you do it and this is what you need to do and this is where you should go and they're entitled to this, that is not what happens. I had to do the research. I was blessed to find these incredible doctors that educated me. I mean, was so, so fortunate. My kids have had unbelievable world renowned doctors and therapists in their lives.

And I'm just so grateful for that. The other thing I would say is, yes, in certain situations, depending on severity, there is grief that is involved here. I did some grieving and I still have moments. Today, joy and sorrow can exist for me at the same time, and I'm grateful for that. But it's been a long road.

Mean, I've been at this for twenty one years. Think, grieve, that's okay. Feel those feelings. My only suggestion would be, as my husband and I like to say, don't put up a mailbox there. Don't move into that because you know, your kids need you and time is of the essence in some of these situations.

You got to get rolling with these therapies and all of that. You don't feel all of that, why not stay there? You know, we've been at this a long time and things change. I mean, there have been times where I thought it was never going to get better. And Jim is in, although we're trying to find the right day program, and he does still need assistance with all daily living skills, he's in a much better place.

He's in a much calmer place. He's more peaceful. He's learning to use a device to communicate. He's more open to life because he's not self injuring so much. He's more present and he's able to participate in things with us.

And so just because you're somewhere now, that doesn't mean that it's always going to be that way. There's going to be a bunch of up and downs, but I would say find, educate yourself, know what your child's rights are and find your community of people because there are people out there that understand. Find those people and lean on them.

Matt (host): Well, and that's a big theme of this podcast. You always talk about not trying to do things by yourself and reaching out to other people. It takes a proverbial village to raise a child and it takes even more of a village to raise a child with autism. So let's talk about Homebound

Healing, which is the community you built online. And so what made you decide to start sharing your family story publicly and what did that very first post feel like?

Jamie Hrobar: It felt like I took the lid off the pot. It was like the steam just came out, you know, we were, we were literally in the thick of it. We were waiting for Jim's bed to become available at Kennedy Krieger Institute. That's the hospital that he went to. And I was just, I was so heartbroken all of the time trying to, I was running a program out of my own home with therapists that the district did help me to create another thing that I was very grateful for because that was what was appropriate for Jim at the time.

But it was, there was so much self injury and aggression and property destruction. Jim didn't sleep for like thirteen years, literally for like thirteen years. He maybe slept two to three hours a night. So I slept maybe two hours a night for many, many years. I was like bouncing off the walls, literally.

I was exhausted. I didn't know if this was going to get better. I was hopeful that bed at this hospital was going to make a difference, but we were just kind of like on eggshells all the time. And I just thought, you know, I need to talk about this. I need, I need to do, I needed an outlet.

And so that's what I did. Also, because it was kind of interesting to have for people to see, because we had a home program, these therapists in our home all of the time and seeing the things we were doing and taking Jim out into the community with them for small periods of time. They would sometimes hop on, do videos and talk about some of the therapies he was getting. And little by slowly, we just started getting these followers and people that were becoming invested in what was going on in our home. I remember when it wasn't so many followers back then, but when he was in the hospital, they would write.

I'd be at the Ronald McDonald House, heartbroken that I had to leave him in that hospital because I would stay there during the week. And people would be reaching out to me, they would help me get through it. And then I started following other people's pages. And so there's all of these families. There is a community out there for all of us parents.

It's just incredible. I mean, people that I've never met in person that are so invested in our life and truly wanting to cheer my kids on and feeling the pain when we're feeling it, not in the same way, but it's just amazing. There are parents, there's educators, grandparents. Mean, we just have such a wide variety of folks on there and it is a, it's a really beautiful thing. I'm so grateful for it.

Matt (host): Absolutely. And when you build a community like that, or I should say when you access a community like that, it makes you feel like you're not alone, which is a feeling I know that so many parents feel like when their child is struggling with something, and in this case, a chronic condition. So I want to end our conversation with a couple of direct messages. So first question for you is if a parent is listening to this in the hospital parking lot or hiding in the bathroom during a meltdown at home and they're thinking, I don't know whether I can do this another day. What would you want to say directly to that person?

Jamie Hrobar: First, I would say that I see you and I understand and I have been there and I want you to have hope that you can move through this and, you know, your kids need you. So lean on, lean on people like us, like myself, you know, other families like mine. You are not alone. And much like I said earlier, there are these ups and downs. I try not to stay there.

Sometimes we have to make some really hard decisions. And I see you in that as well. I've had to make some really, really tough decisions and it doesn't make you a bad person. You do the best you can with what you have, but lean on people that are out there because you're not alone. And there are people like myself that understand.

I mean, one of the things that I love on Homebound and Healing is seeing people just saying, you're giving me hope to keep going. What you're describing you went through, we are, we are in a season like that. And to hear that you're right now that you're on the other side of that, that kids see hope. And that is like the greatest feeling knowing that somehow Jim's story is helping other people.

Matt (host): Absolutely. So if your kids could fully understand this conversation we're having today here someday, what would you want them to know about how you see them and all the things that they've taught you?

Jamie Hrobar: Well, I know Christian for sure understands every bit of this type of a conversation. There's no barrier there for sure. So he's an incredible, brilliant young boy. He's given me a run for my money though because he's a teenager now. But I would say to both of them, and I tell them this all the time, but I would tell them that they are my greatest teachers.

They remind me to stay present and they show me to appreciate the little things in life all the time. They show me how to have gratitude. We are a very special family unit for sure. We lean on each other a tremendous amount they have taught me the most important lessons about life. Christian sometimes he'll get a little frustrated with Jim because life is different.

Sometimes there are things Christian would like to do that he can't because of his brother or whatever but you know if he ever thinks that that his brother is not being treated right by somebody or that somebody looked at him a certain way, I mean you know he almost he all of a sudden assumes the role of big brother and it's very special. They both have taught me so much about compassion and the compassion and the protection that Christian demonstrates for his brother. I mean, I can remember a time in Home Depot one time when Jim had recently come home from the hospital and there was specific protocol we needed to follow when behaviors would occur. And we were doing, Jim started having a self injury burst and a meltdown in the middle of Home Depot. I think Christian was maybe five years old.

And we had these mats out and helmets and all of that. People, I mean, there was a lot going on. They were looking. I mean, there was something to be seen there so they were they were looking and some people were trying to help and Christian was five and he just he was like being the traffic conductor and he he just said it's okay it's all under control there's nothing to see here I mean, was five. He has had to grow up very, very fast.

He was exposed to a lot of things that a lot of five year olds hadn't seen. And I do think about that and I do often tell him that, you know, I realize you had a very different life than some other families, you know, but I think we've always tried to give each of them the best we could. Sometimes one had to have more than the other because, you know, I'm only one person. And so sometimes I feel bad about that, you know, that Christian hasn't always gotten as much time with me. I try to make as much time as I can now on weekends and things like that when Jim's with his father.

But, you know, we've always just done the best we can with what we have.

Matt (host): So final question, if you could just change one thing in our systems, our healthcare school or support systems to better serve families like yours, what would it be?

Jamie Hrobar: I would say resources. And when I say families like mine, I'm speaking most specifically about, you know, families that have a child like Jim, because as I said before, there are some day programs, you know, there day programs out there, there are homes out there, there are residential facilities out there. I'm not saying that there aren't, but number one, there aren't enough of them. Again, all of these kids that got early intervention services that were unable to maybe be mainstreamed or on the more severe end of the spectrum, There's not a whole lot for them. And especially we need more resources.

We need more programs. We need day programs that are specifically designed for individuals like Jim, group homes that are for individuals like Jim. Because parents, as these kids are getting bigger and stronger, I said, he towers me. He's bigger and he's stronger and I'm not getting bigger and stronger. So that is a huge challenge.

Oftentimes those are the families that need the break even more so. And so we need those types of services. I mean, we've got a community here that's being built in our area to help families that have individuals with special needs and to give them more independent living and things like that. My son could never go to a place like that. I mean, it's very specific even in their description of applicants that it is not a place for Jim.

And so there's a shortage of that and also having these places, but having safe places. Not all of them are unsafe. I'm not saying that either, but individuals like Jim are at a huge risk of physical and sexual abuse. I mean, let's just call it what it is. You know, he's nonverbal.

He can't tell anybody. He's at a huge disadvantage. And for parents like me, that is absolutely terrifying. Oftentimes too, the other thing, you know, if they're not just the non speaking is a huge barrier, right? But then you throw self injury or aggression on top of that.

If you've got an individual that engages in those types of behaviors, I mean, I'm just going to call it what it is, right? If your kid all of a sudden has bruises all over them and you go, well, how did that happen? I mean, people are the easy answer is, well, they did it to themselves. I'm being real here. So these are things that a lot of people are not aware of and it's very heavy.

It can weigh very heavy on parents because we just want to keep our, you know, we want to do the best we can. We want to make sure they get what they're entitled to and most of all we want to keep them safe.

Matt (host): Right.

Jamie Hrobar: You know today while Jim is not in a day program and he's not doing some things that I you know I wish that he could, Jim is home and he is safe And after everything that we have been through, that is what's most important to me. And I will say on the days where like if it's a harder day and sometimes there's more messes or whatever to deal with, for lack of a better way to put it at the moment. I just remind myself when I go, Oh my gosh, like this is a lot. Jim is home and he's safe. And that will always be priority number one.

And the rest we'll just deal with. I've been in some tough spots over this with him and that is priority number one, always moving forward.

Matt (host): Well, Jamie, I want to thank you so much for sharing this incredible story with us for all your honesty and all the tremendous work that you're doing to stand alongside other families, and just the love that you're bringing to your own family and to the world at large. And I think we're all better for it. Before we let you go, I want to have you tell listeners where they can find you and your work online.

Jamie Hrobar: Sure. And thank you so much for having me. What an awesome opportunity to talk with you. They can find me on my website, jamiehrobar.com. The spelling is a little different.

It's J A I M E H R B A R dot com. And you can also find me on my Facebook page, Homebound and Healing. And as we said, that's an active and engaged community of parents, caregivers, educators. Come on over and visit with us and become a part of our community. It's really special.

Matt (host): Very good. And we'll link to those in the show notes so that folks can easily find you. And to everyone listening, thank you so much for joining us for this episode of Nimble Youth. If Jamie's story resonated with you, please share this episode with another parent, educator, or clinician who needs to hear it. And if you haven't already rated and reviewed the show, please do so on your podcast app and it really helps other families discover these conversations.

Until next time, I'm Matt Butterman. Take care of yourselves, take care of your kids and remember you don't have to do any of this alone.