

Adulthood on the Spectrum: The early days of autism advocacy

Andrew: Welcome to Adulthood on the Spectrum episode three. I'm Andrew Komarow, an autistic certified financial planner. I co-run Adulthood on the Spectrum with my host, Eileen Lamb. Hey Eileen!

Eileen: Hey, guys! I am Eileen Lamb, an author and photographer from France. I am autistic and so are my children, Charlie and Jude. And with this podcast, we really wanted to highlight real voices of autistic adults. You know, you hear a lot about inspirational stories in the media, but we wanted to talk about autistic like you, like me, their day-to-day life and what it's like to be autistic even if you don't have a superpower.

Thomas: And I do not. I do not have a superpower.

But you're wearing a superhero shirt. So, I mean...do you want to have a superpower or what would be your superpower?

Thomas: I don't know. I guess that depends on what the superpower is. You know, I don't want to be like bouncing boy of the Legion, but, you know, someone like Captain America, that'd be cool. I'd love to have the shield. Actually, I do. I do have aluminum Captain America shield. But, you know, it's not going to stop bullets or anything.

Andrew: Well, so we would like to introduce Thomas McKean. He was diagnosed with autism and placed in a psychiatric facility that was custom at the time. Back in 1984 to 1983. He studied computer science, Parkland College. He received his GED and graduated high school a year early. And he is the reason why we have a puzzle piece.

Andrew: No, in all seriousness, Thomas has been an advocate for autism before I think many of us, a lot of us were even born, especially me. And I think, Eileen and, you know, I think we can learn a lot from the people who have come before us. He is one of the four original advocates, along with Sean Barron, Donna Williams and Temple Grandin. I don't know how the four were defined.

I guess that could be one of our first questions is, you know, is it like the Fantastic Four?

Thomas: I love the comic reference. I'm not sure how it was defined either. I know that for a while it was well, it started out with Temple and then me then Sean and Donna came along. But for a while it was just the four of us and the four of us did. We did a lot of work that kind of paved the way for the others that came after us. Mind you, we didn't know we were doing that at the time.

Andrew: And sorry, I kind of like jumped right in and kind of skipped your intro/bio. I'm just so excited to talk with you. Is there anything else you would like to add?

Thomas: Well, in relation to the puzzle piece, we're going to be discussing directly related to that, I served two terms nonconsecutive like Grover Cleveland on the national board of

directors of the Autism Society of America from '92 to '94 and then again from '97 to 2000. And that's how I ended up doing the puzzle piece.

Andrew: OK, well, I'd like to hear more about that.

Eileen: And we will soon, and before we start, you know, there's a question we really want to ask all our guests, because there's a lot of, you know, people on the spectrum, autistic people, they like to identify themselves differently. So, we want to ask you, how would you like to identify yourself? Person with autism, autistic?

Thomas: Well, as Andrew mentioned, I've been around a while and I was around before that became an issue, so I'm kind of good either way. I'm not really particular one way or the other as some people are about it.

Andrew: If you had to pick one, would you or would you just be like, nah?

Thomas: You know, there are pros and cons to both. To me, it doesn't really matter. I've always had a little bit of a problem with political language. I mean, some of it's necessary. Some of it's not. A lot of it's not. But, you know, person with autism or individual with autism, that's definitely political. But, you know, I'm really not particular.

I may be in the minority on that as far as people with autism go, but I'm in the minority of a lot of things as far as people with autism go.

Eileen: I'm with you.

Thomas: But I really it doesn't bother you either,

Eileen: No, as long as it's respectful, you know, ASPIE, I even say like I have Asperger's because that was my diagnosis. I have autism. I'm autistic. I really don't care either way. I think they're all fine.

Thomas: I like that. I like knowing I'm not the only one.

Andrew: I think you're probably a little, I think there are probably a lot more like you. And maybe because you don't have a preference, you're not vocal about not having a preference. So it's the people with maybe the very strong preferences who are very vocal, maybe a lot of the people who are just neutral or just the ones like you.

Thomas: Well, yeah, because it doesn't matter to them. So why say anything?

Eileen: **Exactly.**

Andrew: So first question for you. Can you tell us a little bit more about your autism journey? When were you diagnosed? What was it like?

Thomas: Well, as you mentioned, just a little bit ago, I was diagnosed in '79, of course, autism was way, way different, back then. Way different. And then the psychiatric facility came a year later in 1980. I had been seeing doctors and psychologists and therapists and whatever my whole life, which some of it I enjoyed because sometimes it got me out of taking a test at school, which is always kind of nice. I couldn't take the test because I had to see someone who showed me an inkblot.

I had to just kind of make something up about what it looked like, which was never real. I just I it would be years before I would cooperate with those people and I didn't then, which might be why it took me so long to get diagnosed. But you know that that was nice not having to go to school. But eventually someone figured it out. It was it is it the hospitals and the cost of it at the time, even back in the '80s, you know, put him in an institution. So I was there for three years.

Andrew: How old were you?

Thomas: That would be 14 to 17.

Andrew: And so what happened while you were there, what was the experience like? And by the way, you don't have to share, but and you know. And anything you would like to share about where we've been over the past 30, 40 years and how things might have changed?

Thomas: Well, if you have like 30, 40 hours to go through that. Yeah, but it was it was not really, it was not really you know, it wasn't a vacation spot, you know, there was mental illness and suicide attempts and paranoia, and one guy did I think I wrote about this in the book, one guy did try to kill me there. He came very close.

But yeah, it wasn't it wasn't really, that wonderful of an experience and but I did survive, I survived and I'm still here. And you know, I guess when you when you go through something like that, you can either,

I guess you can be bitter about it and let it destroy you or you can find some way to turn it around and channel it into something good. And I am absolutely certain those three years would go on later to make me a better advocate than what I would have been without them.

Andrew: And something else you have in common with me is you got your GED a year early.

Thomas: Oh, did you do that too?

Andrew: I well, I got it a year early, but I, I actually got it two years early because I started kindergarten late for a speech delay, go figure. And so I would have graduated at 19, but I got my GED at 17 actually actually. And I don't even usually publicly disclose this. I beat you. I spent more than three years in institutions from, you know, 13 to 19, give or take some years.

Thomas: Yeah, we were

we were talking about that. So, you know what I mean then. When I talk about how it's not the nicest place to be.

Andrew: But I think what you said really, you know, even for me just to say that right now I talk so much publicly about so many things and, you know, even trying to bring the real side of things. But, you know, even that, you know, I it definitely shaped me into who I am today. I think something you said about how, you know, I can't remember what you said, but it was something good, like, you know, you can choose to move on, have it make you stronger or I can't repeat what you said, but they were good words.

Thomas: So, you know, you really don't have a choice. It made it either makes you stronger or it eats you alive.

Andrew: That that's a that's a great way to put it. So,

Eileen: That makes me sad to hear, because, you know, we talk about it right now and it happened to you many years ago and I'm so sorry that happened to you guys. I didn't have that experience. But in France in 2021, this is still happening. In France, people who have autism or autistic are often put in a psychiatric ward because people there don't know how to deal with that. And I think that's a reality that a lot of people don't know about.

And, you know, as a French person, that's something I would love to shine a light on. You know, I feel like the US and other countries have moved on from that, like autism. You don't usually end up in a psychiatric ward if you have autism. You know, we've come a long way, but in certain countries, this is still a reality, and we can really make a difference and make sure that it doesn't happen to two other autistic anyway.

Thomas: Yeah, I guess I guess one of the things I should be more proud of is keeping as many people as I have out of the institutions over the course of time.

Eileen: Yeah, definitely.

Andrew: How have you done that?

Thomas: You know, I'm not sure people have told me that I've done it. And these are people who would know, so I have to believe them.

My guess is the way my guess is it's happened. A couple of things. First would be my sharing, my own experiences with it. You know, I wrote the book. I meant to hold that up to see if I can find a copy of it around here somewhere. Well, when you see people are the leaders, they've always got like their book in the background. I always thought that was so kind of hokey that I decided not to do that, but I could hold it up. But yeah, there is. There is that I wrote about it in there.

And I think also just the awareness that I've done over the years, just that the conferences and the consulting and all of the all of the advocacy work that I've done, I think has brought a greater awareness to what autism is. I'm not the only one who's done that. I don't mean to say that there are other people who have who have also, you know, sacrificed to do this. But, you know, I think I think that's a part of it.

I think the more we understand, the more we understand what autism is, the more we realize that maybe institutions aren't necessary and could, in fact, be counterproductive.

Eileen: Yeah, that's why awareness is so important right now. There's a big debate about awareness versus acceptance. And I feel like both are important because you don't get acceptance without awareness. We need to talk about these things. Right? I mean, there's so much controversy in the autism world right now.

Thomas: And I know that that's something I've been saying for years. I've been wanting to change Autism Awareness Month to Autism Acceptance Month. This is the first year I've ever been in favor of doing that up until now. You know, I've been against it for that very reason that you say is that acceptance will come with awareness. But this month, this year I've kind of changed my mind about that because the A.S.A., who were the people who created Autism Awareness Month, and I had a part in that, too, just like I did with the puzzle piece.

I could tell you how both of those things happened, if you like.

They're on board with changing it to Acceptance Month. And if they're on board with it, then it's time for me to join the 21st century and be on board with it to

Eileen: Yeah, tell us about it. How, you know, the puzzle symbol is very controversial.

Thomas: It wasn't, it wasn't at the time, you know, this was 22 years ago and it wasn't. Would you like to know how that how that happened, how the puzzle piece actually came to be? I could tell you what, what happened was. The A.S.A. had been kind of given the task to create this worldwide symbol for autism, and I didn't know that apparently.

You know, I miss that somewhere, maybe I missed a page and the little information packet that they send out to board members before the meetings. I had no idea that was going to happen. So when I went into the boardroom that day, I didn't know it was coming. And there's this little table off in the corner of the boardroom that had that had all these different ribbons on it, you know, how like, when you want to have awareness for something, you're always like how these little silk ribbons and have like the different colors and the patterns or whatever they are. And there was like just the whole table was full of them. And they were like all of these different colors and designs and patterns, but they were all kind of quiet, muted, except for one the puzzle piece, which is like all of these big different colors and these interlocking puzzle pieces.

And so that one got everyone's attention and. You know, we thought it was kind of appropriate because, you know, autism is a bit of a puzzle and one of the problems with the controversy right now is, you know, there are people who think it's about the individual, but it's not. It never was. It's not about any person. It's about the condition. It's not that you're missing pieces like they say.

And it's not that you're just a puzzle piece as they claim. It's just the fact that there's things about this this situation of autism that we just don't know. And that's what the puzzle piece represents. And the colors, the different colors represent the diversity of people with autism out of respect for them. So, you know, and for the time 22 years ago, you know, I think I think it was the right thing.

I think it was appropriate for the time. And I will defend my vote because of that. The the only thing that we did not have in the room with us at the time was a crystal ball to see into the future and to see the way the world and autism would change within twenty two years. And there are people who are a little upset with us about that, that we didn't know the future. But we did act, all of us in the room, and we did act on the best information we had at the time, and I think we acted appropriately.

Now, that doesn't mean that that since things have changed, that we can't change the puzzle piece, I would be OK with that. But I do think that for the time it was the right thing.

Eileen: What's your opinion on changing it? Why would you be OK with that? Why do you think it would be a good choice or a good thing?

Thomas: I think, you know, those people who have a problem with it are just wrong in the sense that it's not disparaging to them. They're reading into it things that are not there. But at the same time, because so much has changed the past twenty-two years, I could also sort of understand where they're coming from and why they would think that way. That's why I'm OK with changing. It's obviously, you know, I think some of them are just making noise.

But I do think that there are others who really are actually genuinely traumatized by it. And I don't want that. I don't, I don't, I don't think that's right. So I'd be OK with changing it.

Andrew: That was great. Thank you. And so you've been an advocate for a long time, right? If you could, you know, explain to us. So you mentioned these four people, right? And explain, you know, let's call it the Fantastic Four with your superhero shirt. I don't know if you know, anyone else will appreciate that name. And just, you know, again, what it was like, you know, back then or just and if you could go back in time and change anything, would you even? And if so, why?

Thomas: We were gods. We were gods. We were literal miracles and people, couldn't get enough of us. They hung on our every word and it was very stressful at times to be in that situation. Other times it was fun because, you know, you're like Mr. Popular or with Temple and Donna, Mrs. Popular. But, you know, you you also had this big responsibility since people were listening to you and they were believing everything you said, you had to be sure that you were as truthful and accurate as you could be.

And, you know, I I think I think, you know, all four of us understood that responsibility and we we did the best we could, and that's not the case anymore. You know, nowadays, if you're someone with autism, then you're someone with autism. Autism is a dime a dozen. But back then, there were just four of us who are talking, and it was kind of a big deal. So, you know, I'm glad that that the pressure is off of me that way, and I'm happy about that because there were there were times that it was, you know, the pressure was just a little too much sometimes.

But it was it was different. It was it was very different in that sense. You know, these were parents who were just and I that I guess in that sense, it's no different than now parents who are just looking to do the best they could for their kids because they wanted their kids to be happy and they

wanted their kids to have a higher quality of life. Back then, though, autism meant you were this, you know, nonverbal kid who is banging his head against the wall and screaming all day. And, you know, there was a lot more emphasis on the more severe cases back then because there was no Asperger's back then. That came later. I remember that. And the higher functioning, for lack of a better term, that was quite a bit rarer back then.

Eileen: Yeah, speaking of high functioning, I mean, that's another controversy in the autism world, right, whether we should use functioning labels or not. And right now, the autism community, autistic community is very divided. What do you think about what's going on right now and the divide and what you see on social media?

Thomas: The in terms of the labels of high and low functioning... I never cared for him even in the beginning. All those years ago. But I could never think of anything better. And now I guess they my understanding is that they got these levels, level one, level two, level three. That's not accurate either. I think it's a little more, I think it's moving in the right direction, but I don't think it's an accurate portrayal, accurate portrayal of what autism is I think is so much more complex than just just three levels. So I think we've I think we've got a long, long way to go still before we really understand what it is.

Andrew: Do you think we'll ever get to the point where there is a good way to describe it or to your point, it's just so complex, there's so many different...

Thomas: Maybe, but I don't expect it to happen in my lifetime. Yeah, yeah, all we could do is keep moving forward, find our way there eventually.

Eileen: Yeah, and I mean, we've been trying to find a middle ground because of all those controversies. And like you said earlier, some of the things that define autism, like the puzzle piece happened so many years ago. And it would make sense that some of these things don't fit right now to define autism. And maybe that's why there is so much controversy in the autism world.

And we're seeing a lot of disagreement on social media. Some of it is respectful, and the other side of it is not very respectful in the autism community, just is really divided right now. And I know you've been in the line of fire with that because you spoke about the puzzle piece? What's your take on that?

Thomas: Well, you know, if you unpack everything about the puzzle piece, there's just so many layers to it. There's this layer upon layer upon layer upon layer of complexity to this whole puzzle piece controversy. I do think that the one thing this is not about is the actual puzzle piece. I really think that's got nothing to do with it. I think that the truth is it's just kind of this thing that they're putting there in place of what the real problem is. You know, these are people who have been abused by, uh, by those who are claiming that they wanted to help them. And I don't for a second doubt that's happened. I believe all of their stories. Hello, guys out there. Do you hear me? Do you hear me? I believe you. I believe you. I believe the stories. I believe I believe the the things that happened to them with the ABA, all of it. I believe all of it's true. I know the history of ABA and I believe that, you know, the other the other things that may have happened to them that they've told me about, I believe every word of it. And, you know, if you're going to abuse somebody, find a person with autism because

there's really nothing they can do about it. You know, that whole you've got that you got that whole non-verbal aspect on some, you've got the sensory overload on others. And sometimes, you know, when you when you have autism, there's really nothing you can do but sit there and let it happen. And all of that is just through no fault of your own. So, yeah, that that isn't right. It isn't right that it happened to them. It isn't right that it happened to me.

Andrew, we know things have happened to you because you just said so. That isn't right. So

I think that they're there. They're crying out about the abuse. And I think that they've got some legitimate gripes there. I just think that they're going after the wrong people. Because the parents who are supporting the puzzle piece now or the parents who or people with autism who don't have a problem with it, they're not the ones that did it to them.

Andrew: And I've always, you know, taking a step back as somebody who comes from the legal financial planning realm as well, where, you know, lawyers until recently weren't even required to do continuing education, for example. Right? So, you know, a 60-year-old lawyer, you know, 30, 40 years that, you know, there's a good chance they have no updates and coming from that world in the language that was used and, you know, hearing the logic behind person first language.

Right, and being trained as a professional. Before I knew I had autism, I was a special needs consultant. And ironically, I got through that without knowing I had autism as well. So it goes to show you how little that course can teach you.

Thomas: That and is a little ironic.

Andrew: So it wasn't it was right around that time. In all fairness. But but then, you know, it's if you look at the intent behind the person, first language. Right, it was good intent. It may not be the individual's preference, but it was good intent. And I hear professionals using identity first in that in the way from when they were back in the 1980s, when you were when they were using identity first with you, they weren't using it in a positive way.

And it's kind of like dressing in flare jeans or something, like they're suddenly back in style, although they never changed. Right, or something like that. I don't know. I'm not stylish. I'll see what Eileen says about fashion.

Thomas: Well, you're right. The person first language was, is and is still, you know, at least it supposed to be there to be respectful of the person with autism indicating, hey, I recognize you as a person first, if that's what you're saying. But now there are people with autism who are taking offense at that and saying, well, no, autism is my identity. So I'm not a person with autism.

I'm autistic. And then then you have others who say I'm a person first. And, you know, it's it's enough to ruin your whole day trying to figure it out

Andrew: And, I'm sorry, you go Eileen.

Eileen: Well, I think that the issue is that it's such a personal matter, you know, how you feel about it, that I don't think it should be a community thing. Like you need to ask the autistic person, person with autism how they feel about it, you know, and if they can tell you, well, I like person first language better or the other way. Then their caregiver, are we going to be the person to us just because some people on the spectrum just don't have that ability to express themselves like on social media or to express such like or I like person first language better.

I mean, for a lot of people on the spectrum, their reality is that they can't even communicate beyond basic needs, such as I want water with AAC and I'm speaking from experience because of my son Charlie. And that's like a touchy subject for me, because if one day he's able to tell me, I don't like that you call me autistic or you say I have autism. I would just be like, the happiest mom in the world like you, she comes, you know, if it comes to it and is able to express like these thoughts to me and make his voice heard, whether that's with AAC, or sign language, I really don't care, like, you know, you know what I mean? And all of people on the spectrum just can't express their preference.

And that's something we need to remember. Not everyone can advocate for themselves.

Thomas: And you also, if you can advocate for yourself, you also have to be careful to make sure that you don't claim that you're advocating for everyone. I have spoken for the autism community, but only when I had the authorization from powers that be to do so, such as when I voted on the puzzle piece. But, you know, it's not something that I've done for years. I don't think I ever will again. And you have to you had to be careful that you don't say that the people who are having the problem with a puzzle piece now, they're saying, well, we do speak for everyone with autism. And they're saying, you know, someone someone ran a poll online and 12,000 people with autism responded that they had a problem with a puzzle piece. OK, yeah, maybe that happened. But we also know that there's over five point six million people with autism here in the United States alone. Twelve thousand is just the tiniest, tiniest percentage of that.

So and also the majority of people are not on not on the internet and are not able to vote. So, you know, you can speak for yourself and you could say, I have a problem with it or I kind of like it. I've heard both. But you to you had to be careful when you're being an advocate. You have to be careful about making it clear who you're speaking for. And here today with the two of you, I'm speaking only for Thomas. I'm not speaking for anyone else. I'm not going to claim to you guys or to the people listening to this. I'm speaking for the autism community because I'm not I don't have the right to do that.

Andrew: So question for you and it well a comment first. And that is, I think in the community where that poll was done, you are also banned from talking about the puzzle piece. Or ABA. So I actually and if that's confirmed, then five percent is actually kind of amazing and surprising, given that, you know, you're not even a lot you know, you're not supposed to talk about it.

Thomas: I don't I can't tell you I'm not a part of that community. So I don't know if it's banned or I know that I know that they're not happy about the puzzle piece or ABA. So it wouldn't surprise me if you were banned from talking about it.

Andrew: But, but a question. Why do you think that, you know, the individuals with autism, more so on the internet than anywhere else, seem to feel like they can speak for the entire autism community and that, you know why do you think that is, if you have any guess?

Thomas: I do have a guess. Because again, this is just me talking just a just a wild guess. I can't confirm or deny this, but my take is, you know, they're in they are in a community where they are with like-minded people and all of those people feel the way they do. And so, because they are in a community where everyone feels the same way, maybe they're feeling like everyone feels the same way everywhere, which is, you know, completely different than them. People within your own community feeling a specific way.

Andrew: Do you mean to tell me that individuals who have a diagnosis or a self-diagnosis that includes lack of seeing something from somebody else's perspective have trouble seeing somebody else's perspective? Heavy sarcasm implied with that question there, by the way. And before you answer that, I want to say that something I relate to and correct me if you're wrong, if you think I'm wrong, is I used to think that I could that I didn't have that problem, that I could see things from other perspectives.

And I realized that, no, that that was wrong. I, I don't I can see why somebody might seem that way. Right. I can't see somebody's perspective. I can see anybody's perspective. I can almost, you know, rationalize why anyone might do something and almost benefit of the doubt. So for example, Tom and I just mentioned this because I thought I related to it. And if I'm wrong and you crushed my soul, feel free to tell me.

But it's, you know, where you you didn't you're not denying anybody. Everyone who is advocating you're saying, I have no doubt that there's trauma. I have no doubt the pain. It seems to be like you can absolutely see where everyone is coming from. Right?

Thomas: That's because of 30 years of experience. Yes. They haven't had that. But but I have had, you know, thirty years of experience kind of opens your eyes to other people's points of view. And for those of you who have to answer your question, for those of you who have been around the autism community for a while, those of you listening or watching, Ruth Sullivan once walked up to me and told me that that I do not have a theory of mind and that I was incapable of putting myself in someone else's shoes.

Now, I'm not sure why she said this. If I remember right, it was it was during a break at ASA board meeting and she was there. And something something must have happened. I must have made a comment that she didn't agree with. Somewhere along the line in the boardroom. But Ruth Sullivan once told me that that I don't have a theory of mind and that I'm not capable of putting myself in a position to understand other people's points of view, because that's something that that people with autism have a very difficult time doing.

And she's right. There are some who do have a difficult time doing that. And it was something that that I think really, I had to learn. I don't know if she was right at the time, she might have been. But, you know, over the course of time, I have come to see that. You know, just because I don't agree with somebody like, say, you know, regarding a puzzle piece or ABA, that doesn't mean that their own opinion isn't invalid, and it doesn't mean that they don't have valid reasons for believing the way they do.

If you are abused and you have beliefs based on that, you know, that's a pretty valid reason for believing something that you do. And you have to acknowledge that.

Eileen: You're making a good point, and I think it's really hard sometimes to remember this. I mean, I know it's something I need to work on.

You know, excepting to see it from the other person's perspective, what Andrew was talking about, I mean, that's an issue in my marriage and in my friendships. It's just something hard for a lot of people on the spectrum, you know, and when you're online on social media, interacting with these people who are telling you this, but in a way that is not respectful at all, it makes it even harder to want to put yourself in their shoes and to see it from their perspective.

And I feel like that creates this very difficult communication because they're going at it in a way that is it doesn't make you want to listen when you're being called, you know, abusive and a piece of that type of things. And it just makes it harder for people to want to listen, you know? And so then it just breaks the communication. When I think on a lot of things, we want the same thing. And I posted about this on my social media the beginning of April.

Like in the end, you know, it was a post about whether you like the blue or red or the infinity loop or a puzzle piece. Like in the end, we want the same thing. You know, we want autistic people to be accepted to like the same opportunities as other people. And I think that's true. I think we don't know how to communicate with each other, but deep down, we want the same thing. And I'm sure there is a way to make it that we come together and make this happen.

And that's why I'm really excited about this podcast and talking about talking about you today. I was like, so, so nice because you you're very open to other opinions. And like you say, you have thirty years of experience and it's really nice. I mean, you're one of the Fantastic Four is that what we are calling it now?

Yes. You're open minded.

Thomas: I hope. I hope I'm Reed or Ben. I don't really want to be Johnny. He's a bit of a hothead. Yeah, you're right about that. You know the people who are bullying have told me, you know, the reason that we're doing this is because people aren't going to listen to us unless we're angry. And they're almost right. Not quite.

It would be more accurate to say people are not listening to you because you're angry. And full disclosure here, because I know there are people listening who know me and I don't really want to say this, but I don't want to be accused of hypocrisy either. I understand that. That's another reason I get it, is because I know I know what anger is and I know what rage is. You guys didn't know me a few years ago. Well, I was just as angry as they are. I was angry at a different group, though.

I was angry at the evangelicals because these were people who were claiming to follow and practice a doctrine of love. And yet they and even more so their leadership were going around doing these hateful things like saying, OK, let's just kill all the gays, because that's what God

wants and quoting some obscure scripture to support it. And, you know, I had a problem with that. And you may remember that couple of years ago that really kind of got out of hand.

And every time you turned around, there was another story about some preacher somewhere doing something like that. And I was I was angry about it because, you know, to me to me, it's not right to to treat people that way. And I did come down kind of hard on the evangelicals for that. You know, I didn't I didn't go so far as to do what the people against the puzzle piece or ABA are doing now.

There ,I can give you some examples. There is a there is a lady walking along with her daughter, and they were just they were just out for a walk and she was wearing a puzzle piece. I'm not sure if it was jewelry. I'm not sure if it was like a puzzle piece shirt. Not sure, you know, how it was, how it was. There was something on her that was a puzzle piece. And she was walking with her daughter. And this person came up to her, didn't know her, never met her before, knew nothing about her, and accused her of wanting her child to die because she was wearing a puzzle piece.

And to me, that's just not OK. And then since then, I've heard other stories, there are there are people who have called parents places of employment trying to get them fired over a difference of opinion on the puzzle piece. There are people who have called Child Protective Services trying to get parents, kids taken away from them over a difference on, you're raising your hand. Don't tell me that happened to you?

Eileen: The last two things happened to me. Yeah.

Thomas: That's absolutely unacceptable. You know, it's unacceptable. You don't you don't that's not advocacy. That's not that's not even bullying. That's something beyond bullying.

Eileen: Is there something behind it? I said, well, we'll have to make up a word. We'll to make up word.

Andrew: Abuse?

Thomas: You know, I was angry now I didn't maybe I would have in my rage and anger gone that far. I didn't because, you know, just after those three years in the institution, I came across these two people who,

I'm not exactly sure how to describe it, you know, these my whole life, these doctors and therapists and people were trying to find a way to bring me out of the autism. And even in that place, no one was able to. And then, you know, right after I got out of these two people come along, no kind of mental health or psychiatric training at all. And they managed to do it to the extent that I am out of it anyway.

And the way they did it was just, you know, coming into my world and bringing them out into theirs. And it was really something just that simple that no one else thought to do. And they were they were very devout believers. And they will always have their own kind of place in my heart, you know, because I love them. I love the two of them more than I love anyone else in the world. And we're still friends.

And I did kind of come down rough on both of them. Michael, I apologize to the podcast publicly to the whole world for you to hear and everyone else who was offended. I'm sorry. I shouldn't have been as angry as I was. What I'm saying here, guys, is. I understand I understand the anger and I understand the rage and because I've been there even recently. I also understand that there are things that are just not OK in ways that you express that and it took to be a few years of therapy to get over it.

And people have called me privileged for that, you know, and maybe I am. And one thing all of this together has shown me is that one of the things advocates need to do right now, we need to put a higher emphasis on is making appropriate mental health services available for all people with autism and just people in general. You know, as as cruel as the world is right now, everyone should have easy access to that kind of thing, and they don't.

So they're they're angry because they don't have people to help them. They don't have people to help them because their help isn't there, which just. Makes them even more angry. So it's kind of this vicious circle with no way out.

Andrew: Thank you for that. Now, that's I mean, I am still thinking about it, but I know we could all learn a lot from. You know, from the people who have been there before us and, you know, it's you admit your mistakes, right, and things that you could have done better and that takes a lot. So thank you. Really appreciate it.

Eileen: Shall we move on to the quickfire questions?

Andrew: Eileen, do you want to do it this time?

Eileen: Sure, I'll do I do at this time. Sure.

Andrew: Really? OK.

Eileen: So we're going to ask you some quickfire questions. So you answer,

Thomas: Yes, I have a quickfire fire prop right here. And I'll show it to you at the appropriate moment. I went and I got it and I put it here on the table because I knew you were going to ask. Go ahead.

Eileen: And it's perfect. What is the best piece of advice you've ever been given?

Thomas: I, I don't really know. However, I can tell you a piece of advice, which was a very good piece of advice I got just before this whole thing that we did. I was outside. It was sunny and warm, and I was I was out there, and this neighbor walked up to me and I told him, I said, you know, I'm doing kind of this interview, this podcast's kind of thing, I've never done it before. A little nervous because I have no idea what I'm doing. And he said, you know, you're looking at this wrong way. And, you know, this is for anyone who you guys invite in the future. This is something that I thought that he said to me, and I'll pass on to them. He said you're looking at this wrong way.

He says not that you don't know what you're doing. You know exactly what you're doing. You've had the experience. And you need to go into this thing believing that you know what you're talking about because you do. And he's right. You know, I. I think my record shows that I know what I'm talking about, that I know what I'm doing. And so I tried to I tried to come in here talking to the two of you instead of thinking, you know, oh, no, I'm I am I saying the wrong thing instead believing, OK, Thomas, you know what you're doing.

It's OK to talk. It's OK to have an opinion. Yeah. So that was good. Thank you. Thank you. Joe, if you're out there listening. Thank you for that.

Eileen: Thank you, Joe. What do you like to do to relax?

Thomas: That's the prop. Here it is. I know if you could see this, some of you watching, will recognize this. This is a Kenward THD 74, a handheld amateur radio. I have an extra class of amateur radio license and I talk all over the world. And that's this is this is just one I've got like base stations and antennas all over the place, police scanners and things like that. So that's one thing I do. You could tell by the shirt, read a lot of comics.

You know, the comics were the comics actually turned out to be a big part of the work that I did when I was young, you know, when you're young and artistic, you're in this place where, where the world is, is is is very frightening because you don't understand it, and going into the comics was was kind of an escape because you were you were you were in these other worlds where the good guys won, sometimes there were sacrifices, sometimes they paid a price for winning. But the good guys, the good guys win and, and well, well, the world is kind of a scary place sometimes you want to be where the good guys win and reading those, you know, and I have read literally thousands upon thousands upon thousands upon thousands of comics by now. And a lot of people would say, well, Thomas, you know, that that's a wasted life.

Maybe, but I don't think so because they taught me good from bad, they taught me right from wrong, they taught me how to be a good and decent person and they taught me what being a hero is about. And I took a lot of those lessons later on. I took a lot of that into the work that I did, into the advocacy that I did. So the comics really kind of helped me out with that. And one of the nice things about Facebook, aside from that whole social media thing and being able to talk to people without talking to them, which I think is important for a lot of people with autism, is is that I have been able to tell a lot of those writers and artists who wrote them, you know, thank you for doing that. You didn't just help me, but in helping me, you've helped millions of other people around the world. And I'm really thankful that I've gotten an opportunity to say that to them and I'm thankful that they wrote the stories. So, yeah, Captain America, Fantastic Four, Justice League, Legion of Superheroes, all of it. I've read it all, so I've done that. And there was before you before you ask the next question, there was one more thing. What was it? I don't remember. There was, oh, movies. You'll see it right here where I'm pointing. There's a little shelf and it's got over 2,000 DVDs of movies on it. Most of them are pure crap. We're talking things like just about every 1950s black and white rubber monster suit, sci-fi piece of junk that's ever been made.

The cheesier, the movie is the more I like it because again, it's an escape from reality. You know? And I don't mind spending time in reality. But sometimes you know when you have autism. It's just a good thing to be able to escape it on occasion.

Eileen: What's your favorite crap movie to escape from reality with?

Thomas: I don't I don't know because I've seen so many of them that it's difficult. I think the reason that I mention the 50s, rubber monsters, sci-fi movies is because I just absolutely love those. I like, I like the classics. I like the low budget things, you know, Karloff, Lugosi and Price. I'll see anything with them in it.

You know, they were they were great. Andrew's like, I don't know what that means. Andrew, that look are you like, yeah. Bring it! Are you like man, you're nuts or are you like yeah I love them to?

Andrew: I have no idea what you're talking about.

Thomas: OK, for those who don't know what I'm talking about, I'm talking about Boris Karloff, Bela Lugosi and Vincent Price.

Andrew: That didn't help.

Thomas: Probably best known for the Frankenstein movies back in the '30s. Lugosi, same thing except he was Dracula. [vampire impression] "Listen to the, um, the children of the night, what music they make." Right? And Karloff, just with his hands, you know, supplicating the sun coming down through the barn and not even saying anything that that expressionless guy who was created by this mad scientist who didn't want to live, he just didn't have any choice in his creation or the monster that he became yet none of that is his fault, you know, and he's just kind of this this innocent, tragic figure. You know, he's not really the monster that that that people think he is. So, you know, there was some depth to those movies back then, but they were also low budget. And they were they were cheesy. I love the old movie serials. I got a bunch of those on the shelf. You know, don't dare miss the next chapter at this theater next week. Got a lot of those. So I like I like doing that, too.

Eileen: So good. I'm so glad you came on my podcast today and accepted our invitation. Well, we do at the end of our episode is that we ask our guest you to ask a question to our next guest. So what is your question you would like to ask?

Thomas: I saw that. I saw that on the list when you sent it to me and I,

I wish I could think of something you yeah, autism is just so complex that there's just all of these questions going through my head. It's it's difficult to pick one. How about this, because I'm a writer.

Ask them what their favorite autism biography is? I'm not expecting them to say that it's mine, mine, by the way. Can I plug it? Is that allowed?

Andrew: Absolutely.

Thomas: Because it's a little book. It was written in '94. It's called "Soon Will Come the Light: A View from Inside the Autism Puzzle". It took a literary award, an award for literary excellence. And it got me onto Oprah. And that was kind of cool.

Andrew: And my background isn't like working too well with.

Thomas: That's it!

Andrew: But I do have the book here?

Thomas: You have it.

Thomas: Oh, really? So you haven't had a chance to read it yet, so you don't know if you can recommend it.

Andrew: I don't know. I don't know about that, but I do have it.

Thomas: Well, I appreciate you putting a couple bucks in my pocket.

Andrew: Of course.

Thomas: Well, I that if you guys could sort of see through the through the background there, that's it. At that that that was the first biography written by a guy with autism. Temple beat me. I think Donna Williams might have written somebody somewhere before that one, but I think mine was the first. Sean Barron had, "There's a boy in Here", but he wrote that with his mother. So it's kind of a dual effort. "Soon Will Come the Light," is the first book written by a male with autism as far as autobiographies are concerned. And the way it got that title was I had been reading I had been reading books by professionals in the autism field. This is back in the early '90s, back in the golden age of advocacy before the four of us had really gotten anything accomplished and all of them were hopeless. Put your kid in an institution and forget about them and put and go on with your life. And I really didn't like that. And years ago, before I was an award winning, you know book writer is an award-winning songwriter, written a lot of good songs and one of my favorites I wrote for my nephew Nathan when he was born.

It's called "Soon Will Come the Light". It's a little lullaby that I wrote him. If you if you open the book and the first couple of pages Andrew, you'll see the lyrics to it, the lyrics, the lyrics to the song opened the book. And I wrote I wrote the song for him. And I've always liked the song. I think it's one of my better ones. I like I like the idea of, of just the hope that that sentence can be soon will come to light, and I wanted I I wanted the part of the reason I wrote the book was to say, you know, this is not hopeless. You know, I found my way out. Granted, I just, by dumb luck, happen to come across the probably the only two people in the world that could have done it for me. But, you know, if there's hope for me, then there's hope for others. And no, autism is not the best thing in the world to have, but it's not hopeless either.

And that was really sort of the message I wanted to convey right down to the title of the book. So that's how that's how I got the name, "Soon Will Come the Light".

Andrew: Well, thank you for being like a superhero coming out of retirement, right? You know, to help us so..

Thomas: I don't in any way consider myself a superhero. Others have called me that. I, I you know, I sort of, in a way, had ulterior motives. You know, I, I the reason that I got into doing the advocacy is because I was looking for answers. You know, I was I was looking for answers to what had happened to me and my past. And I was looking for ways to you know, kind of kind of reconcile that and get over, you know, some of my own trauma.

And so it didn't take long, though, before I realized that. You know, in doing that, I was actually making a difference for others, and when I began to realize that when I began to see that, that there were people's lives, you know, just literally all over the world that were being positively affected by the work that I was doing, this cause kind of changed for me. And it kind of got the focus off of me and onto them because I saw that that, you know, this is this is a good purpose to have.

This is a noble purpose. Improving people's lives is a good thing to do if you can do it. And so it kind of. Kind of, became to mean something more to me because of that.

Andrew: So I'm going to take the take away and I'm not going to give you time to correct it in case it's wrong. But it sounds to me like the best way the advocates of today can advocate for for others is by focusing on advocating for themselves.

Thomas: I have said that many times.

Andrew: Well, there you go! That's probably where I heard it before. That was my interpretation of what you said.

Thomas: But, but at the same time, you're doing that, you have to be careful how you're advocating for yourself, because and this ties this whole podcast together. OK, this this ties the whole podcast, this whole interview together. If you're advocating for yourself by bullying others, you're not really advocating for yourself or anyone else. You have to, you have to advocacy is is a matter of of listening to others and and understanding where they're coming from and and seeing the the the problems and the issues that others have and finding a way to fix them.

That's really sort of what advocacy is. It's improving the lives of other people. And and if you improve your own life along the way, then that's really kind of icing on the cake. But it is one way to do whether that's how I started out and it was in improving my own life that I learned that I could improve others.

Eileen: Beautiful.

Andrew: Well, thank you for that. Thank you for listening to "Adulthood on the Spectrum". And thank you so much for joining us and agreeing to be on the podcast. We both really appreciate it.